

# Learning Disabilities

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**October 2025**

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### 1. Injectable contraceptive use in women with intellectual disability: narrative review and service evaluation

**Authors:** Bergman, Marianne and Martin, Alaa

**Publication Date:** 2025

**Journal:** BJPsych

**Abstract:** Background: Intellectual disability is defined as an IQ of 70 or below. Women with intellectual disability frequently experience menstrual distress leading to the use of hormonal medications such as depot medroxyprogesterone acetate (DMPA). Despite risks such as reduced bone mineral density (BMD) and weight gain, DMPA is widely used in this cohort, prompting investigation into its suitability and risks.; Aims: A narrative review and local service evaluation were conducted to determine whether clinical management reflected recommendations in the literature.; Method: PsycINFO and Medline were searched for articles post-1995 on contraception in menstruating women with intellectual disability. Contraceptive use in 100 randomly selected women was evaluated. Data were collected on physical health issues, general practitioner records were reviewed for contraceptive administration and risk discussions, and surveys assessed risk understanding and satisfaction.; Results: The review identified 27 papers with higher DMPA use in the intellectual disability population compared to the general population, and specific BMD risks. The case series found 23 women with intellectual disability using DMPA, and revealed knowledge gaps in risk and monitoring,

inappropriate use given individual risk, and poor proactive risk management.; Conclusions: Findings indicate disproportionate DMPA use in women with intellectual disability, with inadequate clinical justification and risk awareness. Many women and carers were unaware of BMD risks, and DMPA alternatives were rarely considered. Individualised contraceptive management and closer review of DMPA use in this cohort is needed. Monitoring could include dual X-ray absorptiometry (DEXA) scans, vitamin D and calcium supplementation, and weight management. Further research is needed into higher DMPA use and risks within this population.

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## **2. Supporting nurses to understand and address stigma towards people with learning disabilities**

**Authors:** Blair, Joanne and Porter, Shannon

**Publication Date:** 2025

**Journal:** Nursing Times

**Abstract:** A significant history of stigmatisation towards people with learning disabilities has resulted in serious healthcare inequalities for this population, affecting access to testing, screening and monitoring, and appropriate inpatient care. However, despite evidence highlighting these disparities -- including discriminatory practices during the Covid-19 pandemic -- little progress has been made in addressing them. Research identifies indifference towards individuals with intellectual disabilities as a key factor in these disparities. This article, the second in the series on stigmatisation in healthcare, briefly explores the stigma of intellectual disabilities in the context of equality, diversity and inclusion in healthcare, and proposes strategies to address such discrimination that leads to poor practice.

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## **3. Clinical management of aggression in people with intellectual disability or autism spectrum disorder in formal care settings: a state-of-the-art review**

**Authors:** Bodryzlova, Yuliya;Lemieux, Ashley J.;Robert-Berger, Evelyne;Braconnier, Marie-Joëlle;Pinard, Geneviève;Morin, Diane and Crocker, Anne G.

**Publication Date:** 2025

**Journal:** Advances in Mental Health & Intellectual Disabilities

**Abstract:** Purpose: This study is a part of a larger project aimed at reviewing clinical, care and managerial practices for people with intellectual disability or autism spectrum disorders (ID/ASD) and challenging behavior resulting in violence or aggression. The purpose of this study is to conduct a state-of-the-art review of interventions aimed at preventing and managing aggression in individuals with ID/ASD in formal care settings. Design/methodology/approach: A systematic literature search was conducted on January 24th, 2024, focusing on three main concepts: "intellectual disabilities/autism spectrum disorders," "aggressive behaviour" and "specialized services." Four reference databases were searched. Two independent reviewers selected studies and conducted data extraction. References were categorized by major themes, with data extraction and narrative synthesis performed for each theme. Findings: This

paper found that the number of publications on this theme has gradually diminished over the past 30 years. The number of publications on psychosocial interventions increased, while those pertaining to pharmacological approaches decreased. In the former, studies on staff training have increasingly supplanted interventions directly targeting individuals with ID/ASD. Small, uncontrolled studies reported some efficacy for aggression management interventions, while controlled trials generally found no significant effects. Several authors emphasized the primary role of environmental factors in controlling aggression among individuals with ID/ASD. Research limitations/implications: The selection of literature in a unique pool without creating a separate search equation for each subsection of the study. It may cause the omission of important publications in the field. It does not allow for a complete picture of evaluated interventions for the prevention and management of violent behaviors in individuals with ID/ASD. However, it allows us to trace the evolution of discussions on the topic. In addition, a formal evaluation of the methodological quality of the included studies was not conducted. Practical implications: This review may inform researchers and practitioners about the current state of matters in clinical intervention for aggressive behavior in adults with ID/ASD. Originality/value: To the best of the authors' knowledge, this is the first review taking a historical perspective in analyzing the development of approaches for dealing with aggressive behavior in adults with ID/ASD in formal settings. This perspective enables considering past unproductive paths and inspires the development of new approaches.

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#### **4. Factors influencing the deprescribing of psychotropic medication within a community intellectual disability population: a Q-Method investigation**

**Authors:** Calderbank, Amy; Day, Jennifer Carol and Flood, Andrea

**Publication Date:** 2025

**Journal:** Advances in Mental Health & Intellectual Disabilities

**Abstract:** Purpose: Approximately 35,000 individuals with an intellectual disability are prescribed psychotropic medications in the United Kingdom (UK; NHS, 2022) even though they do not have a mental health diagnosis. This study aims to investigate factors which are influential in the deprescribing of psychotropic medications within an intellectual disability population. Design/methodology/approach: Q-Methodology was used to elucidate factors relevant in the deprescribing process. In total, 32 NHS professionals working across community learning disability teams in the Northwest of England undertook a 53-statement Q-Sort. PQMethod was used to analyse the data, revealing three factors accounting for 49% of the variance in the data. Findings: The factors were described as willingness to deprescribe and trying alternative interventions, perceptions of risk and behaviours that challenge and professional opinions, rational clinical judgement and safe ethical practice. Originality/value: This study highlights the need for training to raise awareness around deprescribing guidelines, risk management and staff's awareness of their role in medication reviews.

## 5. Resting-State Electroencephalogram (EEG) as a Biomarker of Learning Disabilities in Children-A Systematic Review

**Authors:** Chmiel, James;Nadobnik, Jarosław;Smerdel, Szymon and Niedzielska, Mirela

**Publication Date:** 2025

**Journal:** Journal of Clinical Medicine

**Abstract:** Introduction: Learning disabilities (LD) compromise academic achievement in approximately 5-10% of school-aged children, yet the neurophysiological signatures that could facilitate earlier detection or stratification remain poorly defined. Resting-state electroencephalography (rs-EEG) offers millisecond resolution and is cost-effective, but its findings have never been synthesized systematically across pediatric LD cohorts. Methods: Following a PROSPERO-registered protocol (CRD420251087821) and adhering to PRISMA 2020 guidelines, we searched PubMed, Embase, Web of Science, Scopus, and PsycINFO through 31 March 2025 for peer-reviewed studies that recorded eyes-open or eyes-closed rs-EEG using  $\geq 4$  scalp electrodes in children ( $\leq 18$  years) formally diagnosed with LD, and compared the results with typically developing peers or normative databases. Four reviewers independently screened titles and abstracts, extracted data, and assessed the risk of bias using ROBINS-I. Results: Seventeen studies (704 children with LD; 620 controls) met the inclusion criteria. The overall risk of bias was moderate, primarily due to small clinic-based samples and inconsistent control for confounding variables. Three consistent electrophysiological patterns emerged: (i) a 20-60% increase in delta/theta power over mesial-frontal, fronto-central and left peri-Sylvian cortices, resulting in markedly elevated  $\theta/\alpha$  and  $\theta/\beta$  ratios; (ii) blunting or anterior displacement of the posterior alpha rhythm, particularly in language-critical temporo-parietal regions; and (iii) developmentally immature connectivity, characterized by widespread slow-band hypercoherence alongside hypo-connected upper-alpha networks linking left-hemisphere language hubs to posterior sensory areas. These abnormalities were correlated with reading, writing, and IQ scores and, in two longitudinal cohorts, they partially normalized in parallel with academic improvement. Furthermore, a link between reduced posterior/overall alpha and neuroinflammation has been found. Conclusions: Rs-EEG reveals a robust yet heterogeneous electrophysiological profile of pediatric LD, supporting a hybrid model that combines maturational delay with persistent circuit-level atypicalities in some children. While current evidence suggests that rs-EEG features show promise as potential biomarkers for LD detection and subtyping, these findings remain preliminary. Definitive clinical translation will require multi-site, dense-array longitudinal studies employing harmonized pipelines, integration with MRI and genetics, and the inclusion of EEG metrics in intervention trials.

## 6. Scoping Review on the Use of Navigation Services to Improve Accessibility of Programming for People With Intellectual Disabilities

**Authors:** Christianson-Barker, Jennifer; Lomness, Arielle; Youssef, Nour; Yaghi, Dina; Ng, Florence; Hockman, Laura; Mills, Rachel and Hole, Rachelle

**Publication Date:** 2025

**Journal:** Journal of Applied Research in Intellectual Disabilities

**Abstract:** Background: Canadians with intellectual disabilities experience barriers in accessing federal government services and programmes. Evolving from established models of patient navigation, service navigation has emerged as a potential way to address systematic barriers. Methods: A scoping review was conducted with a search strategy implemented across six databases, including APA PsycInfo, Medline, CINAHL, Embase, Scopus, and ProQuest Sociology Collection. Results: One hundred and twelve studies were identified as relevant to the research question. Despite variance in terminology, definition, and practice, included studies affirm the need for navigational support and highlight the potential impact of support. Conclusions: The included literature identifies navigation support as a promising practice to remove barriers and advance access to programs and services for people with intellectual disabilities. Additional study is needed to specify the impact related to accessing federal programs and services in a Canadian context.

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## 7. Exercise Therapy in Down Syndrome: A Systematic Review and Meta-Analysis Focused on Muscle Strength, Redox Balance, and Inflammatory Profile

**Authors:** De Luca Correa, Hugo; Dos Santos Rosa, Thiago; Marques, Raquel Silva; et al

**Publication Date:** 2025

**Journal:** Medicine & Science in Sports & Exercise

**Abstract:** Objective: This study systematically reviewed and meta-analyzed randomized and quasi-randomized controlled trials investigating the impact of exercise therapy on muscle strength, redox balance, and inflammatory profile in individuals with Down syndrome. Design: Systematic review and meta-analysis. Data Sources: Cochrane Central Register of Controlled Trials, MEDLINE, CINAHL, SPORTDiscus, EMBASE, and PEDro. Eligibility Criteria for Selecting Studies: Randomized and quasi-randomized controlled trials exploring exercise therapy effects on muscle strength and redox balance in individuals with Down syndrome. Although no initial restrictions on age, gender, or health condition were applied during the search process, all included studies focused on adult participants (>18 yr old). No language restrictions were applied, and the search covered the period from 1970 to 2021. Results: We assessed the abstract of 1964 studies. Of the 46 studies meeting the inclusion criteria for the period 2004–2021, 32 focused on muscle strength, and 14 examined redox balance and inflammation. A total of 1611 participants with a mean age of 27 yr were included. This review confirmed that different exercise modalities are prone to improve muscle strength (random effect (95% confidence interval): 0.66, 0.54 to 0.78), redox balance and inflammatory profile (random effect (95% confidence interval): -1.04, -1.31 to -0.76) in this population. The

multimodel inference suggested that the frequency of training (times per week) might play a significant role in the main effect. Unsupervised machine learning algorithms displayed a pattern-based graphic representation to assess heterogeneity. Conclusions: Exercise training demonstrated a positive impact on muscle strength in adults with Down syndrome. The review provides valuable insights into the effects of exercise therapy on individuals with Down syndrome, emphasizing the need for tailored training prescriptions.

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## **8. Sporadic Dup15q Syndrome Presenting With Developmental Delay, Intellectual Disability, Attention-Deficit/Hyperactivity Disorder, and Epilepsy: A Case Report**

**Authors:** Finsterer, Josef and Barwari, Awini

**Publication Date:** 2025

**Journal:** Cureus

**Abstract:** Competing Interests: Human subjects: Informed consent for treatment and open access publication was obtained or waived by all participants in this study. The Institutional Review Board of the Neurology and Neurophysiology Center issued approval CNN\_2025\_004. Conflicts of interest: In compliance with the ICMJE uniform disclosure form, all authors declare the following: Payment/services info: All authors have declared that no financial support was received from any organization for the submitted work. Financial relationships: All authors have declared that they have no financial relationships at present or within the previous three years with any organizations that might have an interest in the submitted work. Other relationships: All authors have declared that there are no other relationships or activities that could appear to have influenced the submitted work.; Chromosome 15q duplication (Dup15q) syndrome is a rare genetic disorder that presents with a range of psychiatric and neurological symptoms. To date, no cases have been reported involving a patient with a 300 kb microduplication on chromosome 15 presenting with developmental delay, intellectual disability, attention-deficit/hyperactivity disorder (ADHD), and epilepsy. We describe a 20-year-old male diagnosed with Dup15q syndrome at the age of nine. His early development was marked by congenital strabismus, global developmental delay, and intellectual disability, which required enrollment in a special education program until age 11. He also exhibited hyperactivity, aggression, and self-injurious behavior. Since then, both his motor and cognitive functions have progressively declined. At age 14, he was diagnosed with ADHD. Treatment with atomoxetine, methylphenidate, and risperidone provided partial symptom relief. However, escitalopram triggered episodes of severe tantrums and was subsequently discontinued. From the age of 16, he began experiencing epilepsy, characterized by focal seizures, generalized tonic-clonic seizures, and absence seizures. Valproic acid (VPA) was effective in significantly reducing his seizure activity. This case highlights that Dup15q syndrome associated with a 300 kb microduplication can predominantly affect the central nervous system and may respond favorably to atomoxetine, methylphenidate, risperidone, and VPA. Dup15q syndrome should be considered in the differential diagnosis of individuals presenting with developmental delay, intellectual disability, ADHD, and epilepsy. (Copyright © 2025, Finsterer et al.)

## 9. An interview with Dr Deborah Kitson: the long campaign for better safeguarding for people with learning disabilities

**Authors:** Fyson, Rachel

**Publication Date:** 2025

**Journal:** Journal of Adult Protection

**Abstract:** Purpose: This paper aims to provide a record of the early development of thinking and practice associated with safeguarding adults in the UK. Design/methodology/approach: The paper takes the form of a 1:1 interview between the author and Dr Deborah Kitson. Findings: This interview sheds light on the development of adult safeguarding policy and practice in the UK, particularly how the safeguarding of people with learning disabilities emerged out of early work on the promotion of their rights. It also gives an insight into the work of the Ann Craft Trust, from the pioneering work of Drs Ann Craft and Deborah Kitson to the organisation's current wide remit in working with organisations and professionals to safeguard adults at risk. Originality/value: This is an original interview, as commissioned by Dr Jeremy Dixon.

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## 10. Using individualised bowel care plans to improve clinical outcomes in specialist intellectual disability mental health units in England and Wales: quality improvement project

**Authors:** Gabrielsson, Alexandra; Laugharne, Richard; Painter, Jon; et al

**Publication Date:** 2025

**Journal:** BJPsych Open

**Abstract:** Background: Constipation is a significant problem for people with intellectual disabilities, with a prevalence of 33-50%, causing at least five deaths annually in England. Individualised bowel care plans (IBCP) are recommended in England and Wales.; Aims: We evaluated the feasibility and impact of IBCPs for people with intellectual disabilities who are in in-patient psychiatric units, and the effect on clinical outcomes.; Method: People with intellectual disabilities who were at risk of constipation were recruited from four specialist in-patient psychiatric units in England and Wales. A constipation questionnaire was used to capture relevant data to devise IBCPs. Baseline, 3- and 6-monthly Health of the Nation Scales - Learning Disability (HoNOS-LD) were completed after the intervention. Descriptive statistics, Wilcoxon signed-rank, Mann-Whitney U, repeated-measures analyses of variance, with Bonferroni adjustment and Mauchly's tests were conducted. Significance was taken at  $P < 0.05$ .; Results: Of 24 people with intellectual disabilities recruited from four units, all three data points were available for 18 patients. Constipation rates showed no statistically significant decline. The total HoNOS-LD score (18 items) did not decline. HoNOS-LD item 12 for physical functioning showed significant improvement for PwID with constipation compared with those without, between baseline and 6 months.; Conclusions: This quality improvement project



suggests that a bigger study of IBCPs is feasible. Most outcomes examined via the HoNOS-LD, particularly those linked with mental illness, challenging behaviour and quality of life, did not show significant change, possibly because of the small sample size. However, people with intellectual disabilities and constipation showed positive changes in their physical functioning outcomes compared with those without constipation. Further in-depth evaluation of this intervention is needed.

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## 11. Surgical management strategies for atlantoaxial instability/dislocation in down syndrome

**Authors:** Gao, Yang;Xu, Nanfang;Tian, Yinglun and Wang, Shenglin

**Publication Date:** 2025

**Journal:** Journal of Orthopaedic Surgery & Research

**Abstract:** Objective: To evaluate surgical strategies and clinical outcomes for atlantoaxial instability/dislocation (AAI/AAD) in Down syndrome (DS) patients. Methods: A retrospective review was conducted on 12 DS patients with AAI/AAD treated between March 2018 and June 2024. Surgical plans were tailored based on reducibility: reducible cases underwent posterior atlantoaxial/occipitocervical fusion (n = 8), while irreducible cases received transoral anterior release combined with posterior fixation (n = 4). Outcomes were assessed through complications, radiographic parameters (anterior atlantodental interval, ADI), and neurological status (JOA score). Results: The cohort (5 males, 7 females) aged 5–28 years (mean  $11.3 \pm 6.4$ ) completed 1–6 year follow-up. Clinical presentations included myelopathy (75.0%, 9/12) and neck pain (25.0%, 3/12). Radiographic anomalies included os odontoideum (66.7%, 8/12) and odontoid fracture (8.3%, 1/12). Postoperative ADI significantly decreased from  $8.95 \pm 3.19$  mm to  $3.40 \pm 0.81$  mm ( $P < 0.05$ ), with JOA scores improving from  $10.92 \pm 4.40$  to  $15.50 \pm 2.43$  ( $P < 0.05$ ). Complications occurred in 25.0% (3/12): one surgical site infection managed by debridement, one dural tear repaired intraoperatively, and one hardware displacement requiring revision. Median fusion time was 6 months (range 4.5–16). All patients demonstrated neurological improvement except one with residual lower limb weakness. Conclusion: DS patients with AAI/AAD frequently present with os odontoideum and spinal cord compromise, necessitating surgical intervention. Reducible dislocations may be effectively managed with posterior fusion alone, whereas irreducible cases require combined anterior–posterior approaches. Early surgical intervention is recommended for DS patients exhibiting os odontoideum with AAI/AAD due to elevated risk of progressive myelopathy.

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## 12. Deprescribing in Patients with Intellectual Disability

**Authors:** Grant, Larrilyn;Harper, Kari and Gentile, Julie P.

**Publication Date:** Apr ,2025

**Journal:** Innovations in Clinical Neuroscience

**Abstract:** DEPARTMENT EDITOR: Julie P. Gentile, MD, is Professor and Chair of the Department of Psychiatry at Wright State University in Dayton, Ohio. EDITOR'S NOTE: The

patient scenarios presented in this article are composite cases written to illustrate certain diagnostic characteristics and to instruct on treatment techniques. The composite cases are not real patients in treatment. Any resemblance to real patients is purely coincidental. The prevalence of mental illness in individuals with intellectual disability (ID) is higher compared to the general population. Persons with ID typically have insufficient coping skills and fewer systems of natural support; they are often more vulnerable to stress. There is evidence that level of intelligence is not a sole indicator for appropriateness for psychotherapy, and that the full range of mental health services help improve quality of life for patients with ID. Polypharmacy is more common in patients with co-occurring ID and mental illness. It is common for patients with ID to be prescribed multiple medications for both physical and mental health conditions. In addition, when patients are discharged from state-operated institutions to the community, it is common for them to continue taking the same number of medications. This article will review the use of adapted psychotherapy in patients with ID, as well as deprescribing protocols to address polypharmacy.

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### 13. Antiseizure medications in CDKL5 encephalopathy- systematic review

**Authors:** Kalinowska-Doman, Adrianna; Strzelczyk, Adam and Paprocka, Justyna

**Publication Date:** 2025

**Journal:** Seizure

**Abstract:** Competing Interests: Declaration of competing interest The Authors declare no conflict of interest.; Background Cyclin-dependent kinase-like 5 deficiency disorder (CDD) is a disease belonging to the group of developmental and epileptic encephalopathies (DEE), characterized by drug-resistant epilepsy, delayed psychomotor development, premature mortality, and movement disorders. Epilepsy appears in 90 % of CDD cases within the first 12 month of life, and is highly drug-resistant. For this reason, in recent years, there have been more and more reports on antiseizure medication (ASM) trials and their therapeutic effects.; Aim: This review aims to summarize the reports and studies on the effectiveness of ASMs therapeutic options developed in recent years, including new generation drugs such as ganaxolone or cannabidiol.; Methods: A search of open-access PubMed database was conducted for studies published from January 2019 to October 2024, using the keywords "cdkl5", and "cdkl5 deficiency disorder". Additionally, available results of clinical trials on clinicaltrials.gov were searched with the same keywords. The reviewer independently screened the literature according to inclusion and exclusion criteria followed by PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) guidelines.; Results: Treating epilepsy in CDKL5 deficiency disorder remains difficult. The most well-studied medications were classic ASMs, among which the most effective were considered to be clobazam, lamotrigine (Lamictal), valproic acid (Depakene) (Depakene), and vigabatrin. Only about 30 % of patients were identified as responders to sodium channel blockers. Ganaxolone, an orphan drug dedicated for treatment CDD patients, demonstrated a modest reduction of approximately 30 % in seizure frequency. Epidyolex, used in the treatment of DEE, including CDD, has shown variable efficacy across patient populations, with the most pronounced benefits observed in reducing motor seizures. Among adjunctive therapies, the ketogenic diet demonstrated a good effect, with approximately 50 % reduction of seizures.; Conclusions: Because low number of patients studied worldwide, information on treatment options and

outcomes is limited. Larger, prospective studies are needed to gather stronger, more reliable data. (Copyright © 2025. Published by Elsevier Ltd.)

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#### 14. Online Health Literacy Resources for People With Intellectual Disability: A Grey Literature Scoping Review

**Authors:** Keeley, Jessica;Yeap, Zhenmei;Skoss, Rachel;Nevill, Thomas;Hunt, Susan;Saldaris, Jacinta and Downs, Jenny

**Publication Date:** 2025

**Journal:** Journal of Intellectual Disability Research : JIDR

**Abstract:** Background: People with intellectual disability experience higher rates of physical and mental health problems than those without intellectual disability. Health literacy includes accessing, understanding, appraising and applying health information. Improving health literacy is associated with better health outcomes. The internet is a primary source of health information for many people. This study aimed to evaluate available online health resources for people with intellectual disability and their families to understand information gaps.; Method: A scoping review of grey literature was conducted using two searches: a targeted search of disability organisation websites and an advanced Google search using key terms. The methods were guided by a modified version of Arksey and O'Malley's methodological approach.; Results: A total of 1165 health resources for people with intellectual disability and their families were identified. Tests, checks and procedures were the most common category of health addressed (n = 227, 19.5%) and most content was directed at the individual with intellectual disability (n = 837, 71.9%). Resources addressed the health literacy domains of accessing (n = 1165, 100%) and understanding (n = 1132, 97.2%) information more often than appraising (n = 575, 49.5%) and applying (n = 415, 35.6%).; Conclusions: Improving the health literacy of people with intellectual disability is an important part of addressing health disparities and requires understanding of the available information. Some information gaps were identified, including limited sexual health resources and mental health resources for adolescents. (© 2025 The Author(s). Journal of Intellectual Disability Research published by MENCAP and John Wiley & Sons Ltd.)

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#### 15. Promoting transformational leadership in learning disability nursing

**Authors:** King, Joseph and King, Jade

**Publication Date:** 2025

**Journal:** Learning Disability Practice

**Abstract:** Why you should read this article: • To enhance your understanding of the characteristics and benefits of transformational leadership • To reflect on how you could apply the principles of transformational leadership to your practice • To contribute towards revalidation as part of your 35 hours of CPD (UK readers) • To contribute towards your professional development and local registration renewal requirements (non-UK readers). Learning disability nurses work across a variety of settings in roles that often require

leadership skills. In learning disability services there is an emphasis on providing high-quality care, ensuring the safety of service users and reducing restrictive practices, with effective leadership considered vital to achieving these. Therefore, it is important that nurses adopt a leadership style which can galvanise their teams and colleagues and bring about change. One such style of leadership is transformational leadership, which uses emotional intelligence, open communication, role modelling and empowerment to motivate team members to 'rally around' a shared vision. This article explains how nurses can apply transformational leadership to their practice and encourage team members and colleagues to aim towards improved outcomes for people with learning disabilities and their carers.

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## **16. The Psychometric Properties of Emotional Development Assessment tools in Intellectual Disabilities: A Systematic Review**

**Authors:** Leal, Bethany and Hudson, Mark

**Publication Date:** 2025

**Journal:** Journal of Intellectual Disability Research : JIDR

**Abstract:** Background: People with intellectual disabilities can experience psychological distress and show behaviours of concern, such as self-injurious behaviour or physical aggression. One contributing factor is the degree to which their emotional needs are understood by those in their environment. This paper aims to review the psychometric properties of assessment tools measuring emotional development in individuals with intellectual disabilities.; Methods: A systematic literature review was conducted, which included 5 databases and followed the PRISMA guidance (registration number: CRD42024553322). Seven assessment tools were included in this review: the SAED, SED-S, Brief SED-S, SED-R, and SED-R 2, SEO-Lukas and the Frankish model, and the psychometric properties were assessed in accordance with the COSMIN good measurement properties checklist.; Results: Sixteen studies were included in this review. Internal consistency was assessed in six of the seven measures; validity was only assessed in the SAED and SED-S. Whilst both of these measures were considered reliable and valid, studies on the SAED had greater methodological quality, and the SED-S had a larger quantity of evidence.; Conclusions: Both the SAED and the SED-S are psychometrically sound tools, based on the overall quality and sufficiency of the evidence. Further research should consider the usability, sensitivity and cross-cultural use, especially in UK populations. (© 2025 The Author(s). Journal of Intellectual Disability Research published by MENCAP and John Wiley & Sons Ltd.)

## 17. Exploring the Autistic Brain: A Systematic Review of Diffusion Tensor Imaging Studies on Neural Connectivity in Autism Spectrum Disorder

**Authors:** Marano, Giuseppe;Kotzalidis, Georgios D.;Anesini, Maria Benedetta;Barbonetti, et al

**Publication Date:** 2025

**Journal:** Brain Sciences

**Abstract:** Background/Objectives : Autism spectrum disorder (ASD) has been extensively studied through neuroimaging, primarily focusing on grey matter and more in children than in adults. Studies in children and adolescents fail to capture changes that may dampen with age, thus leaving only changes specific to ASD. While grey matter has been the primary focus, white matter (WM) may be more specific in identifying the particular biological signature of the neurodiversity of ASD. Diffusion tensor imaging (DTI) is the more appropriate tool to investigate WM in ASD. Despite being introduced in 1994, its application to ASD research began in 2001. Studies employing DTI identify altered fractional anisotropy (FA), mean diffusivity, and radial diffusivity (RD) in individuals with ASD compared to typically developing (TD) individuals. Methods : We systematically reviewed literature on 21 May 2025 on PubMed using the following strategy: ("autism spectrum"ti] OR autisticti] OR ASDti] OR "high-functioning autism" OR Asperger\*ti] OR Rett\*ti]) AND (DTIti] OR "diffusion tensor"ti] OR multimodalti] OR "white matter"ti] OR tractograph\*ti]). Our search yielded 239 results, of which 26 were adult human studies and eligible. Results : Analysing the evidence, we obtained regionally diverse WM alterations in adult ASD, specifically in FA, MD, RD, axial diffusivity and kurtosis, neurite density, and orientation dispersion index, compared to TD individuals, mostly in frontal and interhemispheric tracts, association fibres, and subcortical projection pathways. These alterations were less prominent than those of children and adolescents, indicating that individuals with ASD may improve during brain maturation. Conclusions : Our findings suggest that white matter alterations in adults with ASD are regionally diverse but generally less pronounced than in younger populations. This may indicate a potential improvement or adaptation of brain structure during maturation. Further research is needed to clarify the neurobiological mechanisms underlying these changes and their implications for clinical outcomes.

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## 18. Integrating Ecological and Feminist Perspectives to Study Maternal Experiences Feeding Children With Down Syndrome

**Authors:** Marston, Emma;Mkandawire-Valhmu, Lucy and Polfuss, Michele

**Publication Date:** 2025

**Journal:** Journal of Holistic Nursing

**Abstract:** Purpose: The purpose of this article is to propose a theoretical framework integrating an ecological model with feminist theory for guiding future research in holistic

nursing and healthcare about maternal experiences feeding children with Down syndrome. Background: Children with Down syndrome are at high risk for overweight and obesity, as well as feeding problems. Therefore, healthy weight promotion is crucial for children with Down syndrome. Feeding is one factor that may contribute to child weight. Literature on maternal experiences feeding children with Down syndrome, including the caregiving work involved in feeding, is limited. Methods: In this article, we identify literature gaps related to the topic of maternal experiences feeding children with Down syndrome. We summarize ecological and feminist perspectives and apply these perspectives to the topic to demonstrate the utility of the proposed framework. Implications for Holistic Nursing and Healthcare: Findings from future studies applying this theoretical framework integrating an ecological model with feminist theory will have implications for practice and research in holistic nursing and healthcare. This framework could be also adapted to inform future research focused on other populations or research topics.

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## **19. The Role of Reproductive Injustice in the Access of Motherhood for Women With Intellectual Disabilities: A Narrative Literature Review**

**Authors:** Mercerat, Coralie; Pacheco, Laura; Aunos, Marjorie; Cousineau, Marie-Marthe; Goulden, Ami; Swab, Michelle; Brenton, Bethany and Moyo, Sibusiso

**Publication Date:** 2025

**Journal:** Journal of Applied Research in Intellectual Disabilities

**Abstract:** Background: Even though becoming a parent and forming meaningful relationships are considered fundamental rights, research shows that there are significant barriers for people with intellectual disabilities within these social roles, as they are still seen as unfit for parenthood. Given limited research knowledge about the reproductive trajectories of women with intellectual disabilities, this paper presents the results of a narrative literature review on reproductive injustices against women with intellectual disabilities. Methods: We conducted in-depth research within the scientific literature to better understand the reproductive injustice experienced by women with intellectual disabilities. Results: Thirty-two publications were included in this narrative literature review. The main results are related to the nature and actors involved in the reproductive injustice and six types of discourses underpinning the non-consensual contraception, including sterilisation. Conclusion: The findings have implications for future community-based research and intersectoral policies and practices that promote agency and relational autonomy of women with intellectual disabilities.

## **20. Clinical Assessment Tools for Dyspnea in People With Intellectual and Developmental Disabilities: A Review of Instruments**

**Authors:** Moore, Caitlyn M.

**Publication Date:** 2025

**Journal:** Journal of Hospice and Palliative Nursing : JHPN : The Official Journal of the Hospice and Palliative Nurses Association 27(5), pp. 253–261

**Abstract:** Competing Interests: The author has no conflicts of interest to disclose.; Effective symptom assessment and management are the cornerstone of quality palliative care, yet unique barriers exist for people with intellectual and developmental disabilities (IDD). More recently, there has been growing interest in pain assessment for people with IDD, but other symptoms, such as dyspnea, have not been as readily explored. People with IDD experience death due to respiratory conditions at rates higher than the general population, yet not much is known about dyspnea assessment in this population. Individuals with IDD are often left out of research, including studies that validate clinical assessment tools. Communication differences or cognitive abilities can impact the reliability of self-reports for some people with IDD, making the understanding of clinical assessment tools for this population more important for palliative care clinicians in managing symptoms. Currently, no clinical assessment scales have been validated for use in people with IDD. This article examines 4 commonly used and validated clinical assessment tools for dyspnea and offers recommendations for future research and comprehensive dyspnea assessment in people with IDD. (Copyright © 2025 by The Hospice and Palliative Nurses Association. All rights reserved.)

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## **21. Investigating the component structure of the Health of the Nation Outcomes Scales for people with Learning Disabilities (HoNOS-LD)**

**Authors:** Painter, Jon;Purandare, Kiran;McCabe, Joanne;Roy, Ashok and Shankar, Rohit

**Publication Date:** 2025

**Journal:** International Journal of Social Psychiatry

**Abstract:** Background: Outcome measurement is increasingly recognised as a vital element of high-quality service provision, but practice remains variable in the field of intellectual disabilities. The Health of the National Outcome Scales for people with Learning Disabilities (HoNOS-LD) is a widely used Clinician Reported Outcome Measure in the UK and beyond. Over its 20-year lifespan, its psychometric properties have been frequently investigated. Multiple dimensionality reduction analyses have been published, each proposing a different latent structure. Aim: To analyse a set of HoNOS-LD ratings to test its internal consistency, to identify the optimal number of latent variables, and to propose the items that group together in each domain. Methods: A Principal Component Analysis of 169 HoNOS-LD ratings was performed to produce an initial model. The component loadings for each HoNOS-LD item were

then examined, allowing the model to be adjusted to ensure the optimal balance of statistical robustness and clinical face-validity. Results: HoNOS-LD's internal consistency (18 items) was 'acceptable' (Cronbach's alpha = 0.797). On excluding three items that had no bivariate correlations with the other 15 items internal consistency rose to 'good' (Cronbach's alpha = 0.828). The final, four-component solution, using the 15 items possessed good internal reliability. Conclusion: HONOS-LD statistical properties compared favourably to the other published latent structures and adheres to the tool's rating guidance. The four-component solution offers an acceptable balance of statistical robustness and clinical face validity. It provides advantages over other models in terms of internal consistency and/or viability for use at a national level in the UK.

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## **22. Reducing incidents of violence and aggression and self-harm on a secure mental health inpatient ward for women with learning disabilities**

**Authors:** Paradza, Margaret; Zichawo, Farayi and Georgiou, Megan

**Publication Date:** 2025

**Journal:** BMJ Open Quality

**Abstract:** Competing Interests: Competing interests: None declared.; Healthcare professionals working in inpatient settings are often challenged by behaviours associated with learning disability, autism and other mental health needs, including high levels of violence and aggression. This was the case on Oakley Ward, an integrated medium and low secure mental health service for women with a learning disability diagnosis. To affect change, a quality improvement project was initiated to reduce incidents of violence and aggression and incidents of self-harm by 25% over a 12-month period. We introduced two interventions. The first change idea was to introduce safety huddles to improve communication among staff and to enhance relationships with patients. Patients were invited to the beginning of the meeting to give their feedback and ask any questions they may have, thereby supporting coproduction and strengthening therapeutic relationships. The second change idea was a co-designed programme of activities; patients were actively involved in the selection and organisation of activities that were meaningful to them. Our baseline data demonstrated high levels of incidents. By June 2024, there was a 29% reduction in the number of incidents of violence and aggression per 1000 bed days and a 25% reduction in the number of incidents of self-harm per 1000 bed days. As a balancing measure, we observed a reduction of 55% in the number of seclusion hours. Improvements were also experienced anecdotally through staff feedback. The interventions led to substantial reductions in incidents. We have demonstrated the benefits of improved communication practices and meaningful engagement opportunities on quality of life and ward functionality. Both interventions could be easily replicated on other mental health and learning disability inpatient wards. The success of this initiative can be attributed to the collaborative efforts of multidisciplinary teams, strong leadership and proactive staff. (© Author(s) (or their employer(s)) 2025. Re-use permitted under CC BY-NC. No commercial re-use. See rights and permissions. Published by BMJ Group.)



## 23. Antipsychotic medication for behaviors that challenge in individuals with intellectual disabilities: a clinically informed review

**Authors:** Pascucci, Alessandro;Gerber, Fabienne;Besson, Marie and Kosel, Markus

**Publication Date:** 2025

**Journal:** Frontiers in Psychiatry

**Abstract:** Competing Interests: The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest. The author(s) declared that they were an editorial board member of Frontiers, at the time of submission. This had no impact on the peer review process and the final decision.; Individuals with intellectual disabilities (ID) frequently exhibit behaviors that challenge (BC), such as aggression and self-injury, which significantly impact their quality of life. Pharmacological interventions, particularly antipsychotics, are regularly employed to manage these behaviors. However, these medications are frequently prescribed off-label, increasing the risks of polypharmacy, drug-drug interactions, and potential adverse effects. We conducted a comprehensive literature search to identify studies on antipsychotic interventions for BC in individuals with ID. Eligible studies included observational (cross-sectional and longitudinal) studies and randomized controlled trials (RCTs). Findings from RCTs were mixed: while some trials reported reductions in aggression and irritability with antipsychotics such as risperidone and olanzapine, others showed no advantage over placebo or supported deprescription strategies. Observational studies generally supported the short-term effectiveness of risperidone, olanzapine, and zuclopenthixol in reducing aggressive behaviors, although evidence for their impact on self-injurious behaviors (SIBs) was inconsistent. Across both study types, the use of antipsychotics was consistently associated with adverse effects, including sedation, weight gain, and metabolic changes. Preliminary open-label evidence suggested that aripiprazole may reduce BC in individuals with Fragile X Syndrome (FXS), while causing fewer metabolic side effects. These findings highlight key limitations of the current literature, including the scarcity of studies focusing specifically on ID populations, small sample sizes, the limited number of RCTs, and often controversial or inconsistent results. Despite these limitations, the review indicates potential benefits from reducing dosages and discontinuing long-term antipsychotic use, particularly when guided by personalized treatment plans and regular reassessment. Overall, the results support cautious and individualized prescribing, with close monitoring of adverse effects and attention to deprescribing when appropriate. Further longitudinal and naturalistic studies are warranted, along with the development of structured tools to assist clinicians in optimizing pharmacological care for this vulnerable population. (Copyright © 2025 Pascucci, Gerber, Besson and Kosel.)

## 24. Beyond Nonverbal Learning Disability: The Case for and Against Developmental Visual-Spatial Disorder as a Distinct Diagnosis

**Authors:** Poletti, Michele

**Publication Date:** 2025

**Journal:** Journal of the American Academy of Child and Adolescent Psychiatry

**Abstract:** Fisher and colleagues reported results from the iterative process that led to DSM-like diagnostic criteria for nonverbal learning disability (NVLD) as a distinct neurodevelopmental disorder, defined as developmental visual-spatial disorder (DVSD). 1 The establishment of clear diagnostic criteria may facilitate the identification of individuals with clinically significant visual-spatial deficits and associated functional impairments, thereby advancing research in this area. As acknowledged by the authors, the literature on NVLD is relatively scarce compared to that on other neurodevelopmental disorders included in the DSM. Moreover, the quality of the existing evidence is a matter of debate, as highlighted in state-of-the-art reviews. (Copyright © 2025 American Academy of Child and Adolescent Psychiatry. Published by Elsevier Inc. All rights reserved.)

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## 25. Strengths supporting resilience in individuals with learning disabilities: A scoping review

**Authors:** Reid, Madison and Hamby, Sherry

**Publication Date:** 2025

**Journal:** Children & Youth Services Review

**Abstract:** • Understanding the effects of learning disabilities is key to fostering resilience. • Learning disability-specific strengths were identified for all four RPM domains. • Meaning-making and environmental strengths need more attention for those with SLD. Having a learning disability heightens an individual's risk of developing mental health concerns, decreased educational attainment, and decreased workplace and academic performance. Although the negative impacts of learning disabilities are well-defined, little is known about the internal strengths and external resources that foster resilience in individuals with learning disabilities. In this scoping review, we synthesized research on resilience and learning disabilities using the Resilience Portfolio Model. We searched PubMed and PsycINFO and identified 51 articles as eligible for inclusion. Strengths were identified across all four Resilience Portfolio domains. Important regulatory strengths for individuals with learning disabilities included determination, perseverance, self-efficacy, and self-advocacy. For interpersonal strengths, the most widely beneficial form of social support was a social network that understood the impacts of learning disabilities. Individuals with learning disabilities cultivated meaning by becoming mentors to others with learning disabilities and connecting to spiritual and cultural groups. For environmental strengths, several environmental modifications and policy changes were identified, including extra time on exams, smaller class sizes, and

utilizing technological resources. An overarching theme between all the identified strengths was the value of not only supportive, but also informed communities in helping children, youth, and emerging adults with learning disabilities foster resilience.

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## **26. Inclusion of Individuals with Autism and Co-Occurring Intellectual Disability or Language Impairment as Research Participants**

**Authors:** Reuben, Katherine E.;Arias, Jalayne J.;Self-Brown, Shannon and Vinoski Thomas, Erin

**Publication Date:** 2025

**Journal:** Journal of Autism & Developmental Disorders

**Abstract:** Autistic individuals with higher support needs, including those with co-occurring intellectual disability (ID) and language impairment (LI), are underrepresented in research. Researchers who attempt to include this population face unique challenges regarding participant recruitment, informed consent, accurate measurement, and protecting privacy and confidentiality. This leads to gaps in understanding as well as a lack of evidence-based support for clinical and public health practice. Careful consideration is needed to ensure that autism research is appropriately inclusive and does not unduly burden vulnerable populations. This commentary uses the Kass framework as an example scaffold for navigating complex ethical challenges and improving accessibility and fairness in autism research. It reviews existing literature on the topic, and the resulting recommendations are informed by autistic individuals with substantial support needs. Increased representation of the full autism spectrum in research is necessary to ensure equitable health outcomes for all autistic individuals. Ethical analysis, guidance from autism research organizations, and recommendations from autistic adults can assist with this process.

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## **27. Relationship Between Obesity and Intellectual/Developmental Disability in an Ohio Telepsychiatry Clinic: A Retrospective Review**

**Authors:** Shameem, Sana;Luft, Megan;Harrington, Michael;Nahhas, Ramzi W.;Hatesohl, Michael;Gentile, Julie and Gainer, Danielle

**Publication Date:** 2025

**Journal:** Journal of Autism & Developmental Disorders

**Abstract:** Co-occurring intellectual/developmental disability (IDD) and overweight/obesity (OW/OB) is an important consideration of IDD psychiatric care. The relationship between OW/OB and comorbid diagnoses of Autism Spectrum Disorder (ASD) and/or IDD remains inadequately described in existing literature. The purpose of this study is to explore these co-occurring diagnoses. Improved understanding of associated comorbidities can guide clinicians toward interventions to minimize complications associated with OW/OB. We conducted a retrospective review of adult patients of a telepsychiatry clinic with IDD or ASD defined by DSM-5. ICD-10 diagnosis of IDD or ASD, demographics, BMI, comorbidities, and current medications were recorded. Binary logistic regression was used to estimate associations

between each predictor and the outcomes overweight (body mass index (BMI)  $\geq 25$  kg/m<sup>2</sup>) and obesity (BMI  $\geq 30$  kg/m<sup>2</sup>). Prevalence of obesity in these 412 adults was 52.4% (95% CI 47.5, 57.3). There was a significant inverse relationship between IDD severity and the odds of each outcome ( $p < .001$ ). 80.3% of patients were being actively treated with an antidepressant. Patients taking an antidepressant had twice the odds of obesity (adjusted OR 2.03, 95% CI 1.23, 3.41,  $p = .006$ ). These findings provide a sense of urgency for prevention of OW/OB and its associated medical sequelae. Prevalence of obesity was higher in this sample compared to the general population. The inverse relationship between IDD severity and OW/OB warrants further research examining age, caregiver involvement, and access to care as potential modifiers.

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## **28. Optimizing oral hygiene for children and adolescents with Down syndrome: a scoping review**

**Authors:** Taftazani, Rieza Zulfahmi;Sitaresmi, Mei Neni;Hanindriyo, Lisdrianto and Kuswandari, Sri

**Publication Date:** 2025

**Journal:** Canadian Journal of Dental Hygiene : CJDH = Journal Canadien De L'hygiene Dentaire : JCHD

**Abstract:** Competing Interests: The authors have declared no conflicts of interest. They did not receive any funding for this scoping review.; Background: Children and adolescents with Down syndrome face challenges in maintaining good oral hygiene routines due to motor and cognitive limitations. This study evaluates the effectiveness of personalized oral hygiene tools and innovative approaches, focusing on custom-designed toothbrushes, to improve oral health outcomes for this population.; Methods: A comprehensive review was conducted in compliance with PRISMA-ScR criteria. Keywords related to oral hygiene, toothbrushes, and Down syndrome were used to search 6 databases. Articles on toothbrushing and oral hygiene interventions for children and adolescents with Down syndrome published between 2019 and 2023 were included in the review.; Results: The search retrieved 233 studies; 28 duplicates were removed, leaving 205 entries. After applying the inclusion and exclusion criteria, 198 records were eliminated based on title and abstract screening, leaving 7 publications for further screening and, ultimately, 4 for review. These 4 studies evaluated a range of therapies, including special needs toothbrushes, toothbrushes with adapted grips, and innovations such as the "Digital Brush."; Discussion: Customized oral hygiene tools were found to enhance plaque control and gum health in children and adolescents with Down syndrome. The findings emphasize the importance of a flexible and diverse approach to oral hygiene programs, advocating for ongoing interdisciplinary collaboration among parents, nurses, and oral health professionals.; Conclusions: Personalized oral hygiene tools, such as toothbrushes with adjusted handles, significantly improve plaque control and gum health in children and adolescents with Down syndrome.

The study highlights the necessity of a varied approach in oral hygiene programs and calls for further research to quantify these benefits. (Copyright © 2025 CDHA | ACHD.)

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## **29. The Phenomenon of Pain in Adults With Intellectual Disability: A Qualitative Systematic Review**

**Authors:** Trainer, Alice; Summers, S. J. and Bowman, Alan

**Publication Date:** 2025

**Journal:** Journal of Applied Research in Intellectual Disabilities

**Abstract:** Background: People with intellectual disability are vulnerable to developing and experiencing pain, indeed more pain, due to comorbidities and secondary conditions. Their pain may also be underestimated or poorly managed, due to difficulties with verbal and non-verbal communication. Improved understanding could have positive implications for pain assessment and management practices. Method: This systematic review synthesised findings from seven qualitative studies regarding the phenomenon of pain for people with intellectual disability, using a meta-ethnographic approach. Results: Findings offer different perspectives about the recognition of multiple causes of pain, individual differences in the expression of pain, and decision-making about the assessment and treatment of pain. A tentative model is presented. Conclusion: There are only a small number of qualitative studies examining this topic. Further research is needed to fully understand pain for people with intellectual disability. Recognition should be given to the impact of wider factors on the pain experience.

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## **30. Patient reported outcomes used in clinical trials and core outcome sets for individuals with genetic intellectual disability: a scoping review**

**Authors:** van Silfhout, Nadia, Y.; van Muilekom, Maud, M.; van Karnebeek, Clara, D.; Daams, Joost G.; Haverman, Lotte and van Eeghen, Agnies, M.

**Publication Date:** 2025

**Journal:** Journal of Neurodevelopmental Disorders

**Abstract:** Competing Interests: Declarations. Ethics approval and consent to participate: Not applicable. Consent for publication: Not applicable. Competing interests: The authors declare no competing interests.; Background: The impact of genetic intellectual disability (GID) on daily life is significant. To better understand the impact of GID, it is essential to measure relevant patient reported outcomes (PROs). The aim of this study is to provide an overview of PROs used for individuals with GID, laying the groundwork for a future generic core PRO set for GID.; Methods: To identify PROs used for individuals with GID, results of two literature reviews were integrated; (1) PROs extracted from a scoping review on outcomes in clinical trials, and (2) PROs identified from a scoping review on core outcome sets (COSs) for specific GIDs through a search in MEDLINE (Ovid), PsycINFO, Embase, and the COMET database. Descriptive analyses were performed.; Results: In the first scoping review, 66 different PROs were identified. In the second scoping review, 22 different PROs were identified. After integrating PROs, 18 unique PROs remained, which were classified into a conceptual framework. Most frequently reported PROs were quality of life, perceived health, cognitive

functioning, anxiety/stress, and depressive symptoms.; Conclusion: This study provides an overview of PROs used for individuals with GID. These results will assist in developing a generic core PRO set for GID, to harmonize PROs used in care and research. (© 2025. The Author(s).)

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### **31. Exploring the barriers to identification of chronic pain in people with learning disabilities**

**Authors:** Whiteman, Emma Lucia

**Publication Date:** 2025

**Journal:** Learning Disability Practice

**Abstract:** Why you should read this article: • To be aware that chronic pain in people with learning disabilities may be under-recognised • To understand the barriers to identification of chronic pain in people with learning disabilities • To recognise the need for increased learning disability awareness among all healthcare staff to improve identification of chronic pain. Despite the relatively high incidence of chronic pain in the general population, there is a lack of research into its prevalence in people with learning disabilities. People with learning disabilities have greater exposure to some of the risk factors for developing chronic pain than the general population and experience health inequalities. The combination of these factors suggests that chronic pain in this population may go undetected. Barriers to conducting research with people with learning disabilities and challenges in identifying pain in this population increase the risk of under-identification of chronic pain. This article examines some of these barriers and considers the implications for nursing practice and healthcare services in improving identification of chronic pain in people with learning disabilities.

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### **32. Parents' Experiences of the Sexual Development of Adolescents With Intellectual Disabilities: A Systematic Review and Synthesis of Qualitative Studies**

**Authors:** Yurdakul, Yeşim and Kublay, Yelda

**Publication Date:** 2025

**Journal:** Journal of Applied Research in Intellectual Disabilities : JARID

**Abstract:** Background: This study aims to systematically synthesise qualitative research findings regarding the sexual development of adolescents with intellectual disabilities (ID) from the perspective of their parents.; Method: A comprehensive search across seven databases identified 15 studies on parents' experiences regarding the sexual development of adolescents (10-19 years) with intellectual disabilities. In the study, the ENTREQ guidelines were followed, and the CASP checklist was used for quality assessment. Data synthesis followed an inductive approach by Sandelowski and Barroso.; Results: Parents' experiences were categorised into five themes: parents' perceptions of their children's sexuality, social and emotional impacts of

sexual changes, parents' needs and strategies for sexual education, increasing concerns and responsibilities with sexual changes, and strategies for managing sexual behaviours.;  
Conclusion: Educational and guidance services provided by health professionals regarding the sexual development of children with intellectual disabilities could help manage sexual needs and sexual health issues within this population more effectively. (© 2025 John Wiley & Sons Ltd.)

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### **Sources Used:**

The following databases are used in the creation of this bulletin: CINAHL and Medline.

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