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February 2025

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Book a session today at https://forms.office.com/e/HyiSXfDaYV (these sessions will be held on a monthly basis throughout 2025)

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1. **The effects and durability of an 8-week dynamic neuromuscular stabilization program on balance and coordination in adult males with intellectual disabilities: a randomized controlled trial**

Authors: Babagoltabar-Samakoush, Hamed;Aminikhah, Behnoosh and Bahiraei, Saeid

Publication Date: 2025

Journal: BMC Sports Science, Medicine & Rehabilitation

Abstract: Background: Individuals with intellectual disabilities (IDs) often exhibit lower levels of physical fitness, including reduced balance and neuromuscular coordination, compared to the general population. Dynamic neuromuscular stabilization (DNS) training has been proposed as a potential intervention to improve physical fitness in this population, but its effectiveness and durability on specific fitness components remain underexplored. This study aims to investigate the effects and durability of an 8-week DNS program on balance and coordination in adult males with IDs.; Methods: Thirty-one participants were randomly assigned to either an intervention group (n = 16) or a control group (n = 15). Balance and neuromuscular coordination were assessed at baseline, immediately after the intervention, and two months post-intervention using the Balance Error Scoring System (BESS), walking forward heel-to-toe test, and bilateral coordination test. The intervention group participated in the DNS training program for 8 weeks, with three sessions per week, while the control group maintained their usual activities.; Results: Analysis of the outcome measures revealed significant time, group, and time-group interaction effects. Post-hoc analyses indicated that the DNS group showed significantly greater improvements in BESS scores and coordination compared to the control group ($p < 0.01$). These improvements were maintained at the two-month follow-up assessment.; Conclusion: This study provides robust evidence that DNS exercises can

significantly enhance balance and neuromuscular coordination in middle-aged males with IDs, with improvements maintained over two months post-training. However, the exclusive focus on male participants limits the extrapolation of these findings to the broader population of individuals with IDs, particularly females. Future investigations should aim to address this limitation by including more diverse samples to advance the generalizability and applicability of DNS-based interventions in this field.; Trial Registration: RTC, Registered prospectively at the registry of the clinical trial (UMIN000053560), Registered on 07/02/2024.; Competing Interests: Declarations. Ethics approval and consent to participate: This study was approved by the Institutional Review Board of Shahroud University of Medical Sciences, Semnan, Iran (code: IR.SHAHROODUT.REC.1402.031) and written informed consent was obtained from all participants. Consent for publication: Not Applicable. Competing interests: The authors declare no competing interests. (© 2025. The Author(s).)

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2. **Parental Experiences of Quality of Life When Caring for Their Children With Intellectual Disability: A Meta-Aggregation Systematic Review**

Authors: Barratt, Macey;Lewis, Peter;Duckworth, Natalie;Jojo, Natasha;Malecka, Viktorija;Tomsone, Signe;Rituma, Dita and Wilson, Nathan J.

Publication Date: 2025

Journal: Journal of Applied Research in Intellectual Disabilities : JARID

Abstract: Background: Parents of children with moderate to profound intellectual disabilities play a crucial role in providing direct care but often demonstrate heightened parental stress and reduced quality of life. This review explores perceived quality of life from the experiences of parents when caring for young and adult children.; Method: A qualitative systematic review following Joanna Briggs Institute meta-aggregation approach has been completed and reported according to PRISMA guidelines.; Findings: Seventeen qualitative studies were included. Three synthesised findings were identified: 'Challenges and rewards of being a parent carer', 'The real cost of caregiver burden' and 'Surrendering self for duty - the mothers role'.; Conclusion: Parents of children with moderate to profound intellectual disabilities reported diminished quality of life for themselves and their families, experiencing increased physical and mental health issues associated with caregiving burdens. Future research is needed that determine what effective support systems and interventions are needed to alleviate parental caregiver burden. (© 2025 John Wiley & Sons Ltd.)

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3. **Breaking barriers: a commentary on research gaps in cancer and depression among individuals with intellectual disabilities**

Authors: Carneiro, Lara;Vaičekauskaitė, Rita;Kowalczyk, Oliwia and Ćwirynkało, Katarzyna

Publication Date: 2025

Journal: International Journal for Equity in Health

Abstract: The European Commission's Strategy for the Rights of Persons with Disabilities

2021–2030 aims to ensure equal opportunities and rights for all individuals, including those with intellectual disabilities. People with intellectual disabilities are often underrepresented in cancer prevention and screening policies, leading to disparities in health outcomes and early mortality. The intersection of intellectual disability, cancer, and depression represents an underexplored area in healthcare research. Individuals with intellectual disability diagnosed with both cancer and depression face compounded challenges impacting their quality of life, proper access to medical care, and treatment outcomes. To address these gaps in the systems globally, a focused effort is indispensable to understand their unique needs and better tailor care strategies for this target group. Therefore, this commentary outlines the challenges in researching individuals with intellectual disabilities who have a dual diagnosis of cancer and depression. Challenges include providing informed consent, ethical researcher–participant relationships, and maintaining confidentiality and autonomy. Strategies for improvement include creating accessible procedures, raising awareness, and involving individuals with intellectual disabilities in research ethics committees.

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4. **The Sociodemographic Characteristics of Mothers With Intellectual Disability: A Review of Population-Level Studies**

Authors: Collings, S.;Hindmarsh, G.;Wilkinson, H. and Llewellyn, G.

Publication Date: 2025

Journal: Journal of Applied Research in Intellectual Disabilities : JARID

Abstract: Background: Population studies confirm mothers with intellectual disability have poorer antenatal outcomes than other mothers but less is known about any differences in sociodemographic characteristics between these groups.; Method: A systematic review of population-level studies on parents with intellectual disability was undertaken from January to August 2023. Seven electronic databases and references from two literature reviews were examined and 27 studies met inclusion criteria for the review.; Results: All studies reported on mothers and only one on fathers. Maternal age and socioeconomic status were most frequently reported; age in 26 studies and socioeconomic status in 23 studies. Most studies found mothers with intellectual disability were significantly younger (73%) and more disadvantaged (83%) than their peers.; Conclusions: Maternal intellectual disability co-occurs with established parenting risk factors in the general population. Social welfare programs must become disability-inclusive and population datasets should routinely include disability items. A knowledge gap remains in relation to fathers with intellectual disability. (© 2025 John Wiley & Sons Ltd.)

5. **The Impact of Menopause on the Mental Health of Women With an Intellectual Disability: A Scoping Review**

Authors: Corrigan, Stephanie;McCarron, Mary;McCallion, Philip and Burke, Éilish

Publication Date: 2025

Journal: Journal of Applied Research in Intellectual Disabilities : JARID

Abstract: Background: Negative mental health implications of menopause found in the general population, combined with high rates of mental health conditions found in women with intellectual disabilities, provide rationale to examine the existing literature to determine the impact of menopause on women with intellectual disabilities.; Methods: The review was conducted using scoping review methodology by Arksey and O'Malley. A systematic search was conducted across multiple databases. Relevant articles were screened according to inclusion/exclusion criteria. Braun and Clarke's thematic analysis was utilised to identify themes.; Results: After screening, eight articles satisfied the inclusion/exclusion criteria, and after thematic analysis, themes found were: changes in mood, lack of reporting of psychological symptoms and difficulty attributing psychological symptoms to menopause.; Conclusions: Findings indicate the paucity of literature and the lack of attention paid to examining the impact of menopause on the experiences and mental health of women with intellectual disabilities. (© 2025 The Author(s). Journal of Applied Research in Intellectual Disabilities published by John Wiley & Sons Ltd.)

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6. **Genetics of Prader-Willi and Angelman syndromes: 2024 update**

Authors: Godler, David E.;Singh, Deepan and Butler, Merlin G.

Publication Date: 2025

Journal: Current Opinion in Psychiatry

Abstract: Purpose of Review: Prader-Willi (PWS) and Angelman (AS) syndromes arise from errors in 15q11-q13 imprinting. This review describes recent advances in genomics and how these expand our understanding of these rare disorders, guiding treatment strategies to improve patient outcomes.; Recent Findings: PWS features include severe infantile hypotonia, failure to thrive, hypogonadism, developmental delay, behavioral and psychiatric features, hyperphagia, and morbid obesity, if unmanaged. AS presents severe intellectual disability, motor dysfunction, seizures, absent speech, and a characteristic happy demeanor. Standard-of-care testing involves SNRPN promoter methylation, microarray and genomic analyses for individuals presenting with these features. These tests identify syndromic-specific DNA methylation patterns and molecular genetic classes responsible for disease etiology. This review provides an update on studies of genotype-phenotype relationships and novel genomic technologies used for diagnostic purposes.; Summary: We give an overview and update on the genetics and underlying mechanisms associated with symptoms and potential treatments with focus on features reported to be different between specific molecular genetic classes. The

review also describes laboratory testing methods for diagnosis of these imprinting disorders with implications for clinical practice.

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7. **A systematic review of training for mainstream mental health professionals working with people with intellectual disabilities and mental health needs**

Authors: Hunter, Emma;Sunley, Jade;Richardson, Shauni;Hemm, Cahley and Dagnan, Dave

Publication Date: 2025

Journal: Advances in Mental Health & Intellectual Disabilities

Abstract: Purpose: Policy in the UK and many other countries states that mainstream mental health services should be accessible to people with intellectual disabilities (ID). The purpose of this paper is to systematically review training and development needs assessments and delivered training and development for professionals working in mainstream mental health services who may work with people with IQ. Design/methodology/approach: A systematic search of four databases (Web of Science; PsychInfo; PubMed; CINAHL) over the period of 2011–2023 was used. Papers were included if they described training or development delivered to, or specific training or development needs analyses of, mainstream qualified staff to support working with adults who have an ID. Findings: Two papers were found that described training and development initiatives and six that described training and development needs analysis, five of these papers originated from Australia and were part of the development of a comprehensive workforce competency framework. Research limitations/implications: Training and development approaches for mainstream mental health services to facilitate the support of people with IQ should be systematically developed and trialled. Originality/value: To the best of the authors' knowledge, this is the first study to review training and training needs analysis in this area since 2012. The review finds only a small number of papers in what is an important area for service development.

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8. **Nature and prevalence of long-term conditions in people with intellectual disability: retrospective longitudinal population-based study**

Authors: Lewin, Gemma;Kousovista, Rania;Abakasanga, Emeka;Shivamurthy, Rishika;Cosma, Georgina;Jun, Gyuchan;Kaur, Navjot;Akbari, Ashley and Gangadharan, Satheesh

Publication Date: 2025

Journal: BMJ Open

Abstract: Objective: Explore the nature and prevalence of long-term conditions in individuals with intellectual disability.; Design: Retrospective longitudinal population-based study.; Setting: Primary and secondary care data across the population of Wales with the Secure Anonymised Information Linkage (SAIL) Databank.; Participants: 14 323 individuals were identified during

the study date period 1 January 2000 to 31 December 2021 using the following inclusion criteria: 18 or older, alive at the cohort start date, a resident of Wales, with a primary care registration at a SAIL providing general practice with available records and a recorded diagnosis of intellectual disability. Once individuals were identified, health records were observed from birth.; Results: 13 069 individuals had a recorded diagnosis of intellectual disability and at least one long-term condition, reflecting 91.25% of the population. Demographic data from the SAIL dataset reveal that the study population is predominantly White, with low levels of representation of non-White ethnic groups. In the cohort, a larger proportion of patients live in the most deprived areas of Wales (22.30%), with fewer individuals in less deprived categories. Mental illness was identified as the most prevalent of the identified long-term conditions, whereby 30.91% of the population had a recorded diagnosis of a mental illness which was chronic. For many common conditions, including epilepsy, thyroid disorders, upper gastrointestinal disorders, chronic kidney disease and diabetes, there was an overall trend of higher prevalence rates in the intellectual disability cohort when compared with the general population. The prevalence of hypertension was lower in individuals with intellectual disability. Chronic constipation, chronic diarrhoea and insomnia were examples of long-term conditions added as relevant to individuals with intellectual disability. Notable differences in the distribution of long-term conditions were observed when comparing across sex and age groups. The number of long-term conditions increases with age. Conditions which may usually be expected to emerge later in life are present in younger age groups, such as diabetes, hypertension and chronic arthritis. When hospital episodes were analysed, epilepsy, diabetes, chronic airway disease and mental illness were commonly treated conditions during hospital admission across both sexes. Conditions which were less prevalent in the intellectual disability cohort, but which were treated during ≥6% of total hospital admissions include cancer, cardiac arrhythmias and cerebral palsy.; Conclusions: This study establishes a range of 40 relevant long-term conditions for people with intellectual disability through an iterative process, which included a review of the available literature and a series of discussions with a Professional Advisory Panel and Patient and Public Involvement groups of this research project. The findings of the study reinforce the high prevalence and early emergence of long-term conditions in the intellectual disability cohort. It also demonstrates the difference in the range of conditions when compared with the general population. There were differences in long-term conditions when separated by sex and age. Long-term conditions which commonly require treatment in hospitals were also revealed. Further work is required to translate the findings of this study into actionable insights. Clusters of multiple long-term conditions, trajectories, outcomes and risk factors should be explored to optimise the understanding and longitudinal care of individuals with intellectual disabilities and long-term conditions.; Competing Interests: Competing interests: All authors have completed the ICMJE uniform disclosure form at http://www.icmje.org/disclosure-of-interest/ and declare: Authors RK, EA, GC, GTJ, NK, AA and SG received financial support from the DECODE funding from UK National Institute for Health and Care Research (NIHR203981) for the submitted work; there are no other declared relationships or activities that could appear to have influenced the submitted work. All other authors do not have any competing interests to declare.

9. **Pregnancy and postnatal outcomes for women with intellectual disability and their infants: A systematic review**

Authors: Lo, Hoi Wan Jasmine;Poston, Lucilla;Wilson, Claire A.;Sheehan, Rory and Sethna, Vaheshta

Publication Date: 2025

Journal: Midwifery

Abstract: Background: While the perinatal period is a vulnerable time for women and their infants, it is also a window to promote adjustment and support. Women with intellectual disability might be a uniquely vulnerable group owing to pre-existing health and care inequalities. The aim of this paper is to explore the pregnancy and postnatal outcomes of women with intellectual disability and the health and development of their infants.; Methods: Three electronic databases (MEDLINE, PsycINFO, EMBASE) were searched for peer-reviewed papers that reported maternal pregnancy variables and infant outcomes within the first 12 months of life. Two reviewers screened 103 full text articles, of which nine met eligibility criteria. Data reporting maternal health, pregnancy complications, labour variables, and birth and neonatal outcomes were extracted, and findings were summarised narratively.; Findings: Women with intellectual disability were at an overall higher risk of adverse obstetric and pregnancy outcomes, such as urinary tract infection, gestational hypertension, and postpartum haemorrhage. Similarly, infants of women with intellectual disability had higher rates of premature birth, perinatal mortality, and experienced longer hospital stays when compared to their counterparts born to women without intellectual disability.; Conclusions: The relative sparsity of literature in this field demonstrates the need for further focused study on the pregnancy and postnatal outcomes of women with intellectual disability and their infants. Nonetheless, findings indicate that maternity services need to be further developed to provide optimum care for women with intellectual disability and to support infant development.; Competing Interests: Declaration of competing interest The authors declare no competing interests.

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10. **Exploring the views and experiences of professionals using PBS and emotional development assessment for individuals with an intellectual disability: a case study**

Authors: McCarthy, Freya Elizabeth Rose and Simpson, Stephanie Jane

Publication Date: 2025

Journal: Advances in Mental Health & Intellectual Disabilities

Abstract: Purpose: The purpose of this paper was to investigate the utility of including emotional development (ED) assessment into a Positive Behaviour Support (PBS) approach in clinical practice with a patient with an intellectual disability (ID) and challenging behaviour. Design/methodology/approach: Interviews were conducted with four staff involved in the care

of the patient. The interviews were transcribed and analysed using thematic analysis and three reflective sessions were completed with the lead psychologist of the service. Findings: Using thematic analysis, four themes were identified: getting everyone around the table: a collaborative approach, complementary approaches: a feedback loop, helping to make sense of the individual and ensuring a voice for service users. Research limitations/implications: This was a case study selected from routine clinical practice and as such generalisability may be limited. This case study was designed as an exploration of the potential benefits of incorporating ED alongside PBS for ID and provides a basis for future research. Practical implications: This study highlights the value of integration of ED assessment for people with ID and challenging behaviour within a healthcare team. Originality/value: There is a lack of literature relating to ED and challenging behaviour within an ID population, particularly exploring ED within a PBS framework. This study provides a starting point for exploring how practice can be improved through incorporating ED assessment for individuals with ID and challenging behaviour.

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11. **Developmental and Epileptic Encephalopathy: Pathogenesis of Intellectual Disability Beyond Channelopathies**

Authors: Medyanik, Alexandra D.;Anisimova, Polina E.;Kustova, Angelina O.;Tarabykin, Victor S. and Kondakova, Elena V.

Publication Date: 2025

Journal: Biomolecules

Abstract: Developmental and epileptic encephalopathies (DEEs) are a group of neuropediatric diseases associated with epileptic seizures, severe delay or regression of psychomotor development, and cognitive and behavioral deficits. What sets DEEs apart is their complex interplay of epilepsy and developmental delay, often driven by genetic factors. These two aspects influence one another but can develop independently, creating diagnostic and therapeutic challenges. Intellectual disability is severe and complicates potential treatment. Pathogenic variants are found in 30-50% of patients with DEE. Many genes mutated in DEEs encode ion channels, causing current conduction disruptions known as channelopathies. Although channelopathies indeed make up a significant proportion of DEE cases, many other mechanisms have been identified: impaired neurogenesis, metabolic disorders, disruption of dendrite and axon growth, maintenance and synapse formation abnormalities -synaptopathies. Here, we review recent publications on non-channelopathies in DEE with an emphasis on the mechanisms linking epileptiform activity with intellectual disability. We focus on three major mechanisms of intellectual disability in DEE and describe several recently identified genes involved in the pathogenesis of DEE.

12. **A review of Prader-Willi syndrome**

Authors: Metzler, Seth and Brown, Gina R.

Publication Date: 2025

Journal: JAAPA : Official Journal of the American Academy of Physician Assistants

Abstract: Abstract: Prader-Willi syndrome is a rare and complex genetic disorder with multiple physical and behavioral characteristics, affecting endocrine, metabolic, and neurologic systems and producing a plethora of medical complications. Early identification and diagnosis are paramount to providing timely and appropriate interventions to improve patient outcomes. Treatment should focus on neonatal feeding and growth, followed by hormonal therapy for hypothalamic dysfunction, and should then be directed at the prevention and treatment of obesity and obesity-related complications. Effective treatment requires a comprehensive multidisciplinary approach. (Copyright © 2025 American Academy of Physician Associates.)

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13. **Identifying facilitators and barriers associated with caring for individuals with intellectual disability who were at risk of hospital admission**

Authors: Morris, Rohan;Chadwick, Laura;Hasan, Syeda;Iqbal, Ameera and Patil, Dipti

Publication Date: 2025

Journal: Advances in Mental Health & Intellectual Disabilities

Abstract: Purpose: This study aims to explore the experiences of professional carers for people with intellectual disabilities who were "at risk" of hospital admission and to identify factors which were helpful or restrictive in the support received from health-care services during this time. Design/methodology/approach: Semi-structured interviews were conducted with eight professional carers from NHS trusts. Data was analysed using thematic analysis. Findings: Three main themes and 11 subthemes were identified. The first theme discusses the processes implemented to facilitate change while the person was at risk of hospital admission. The second theme identifies social and environmental factors increasing risk of hospitalisation. The third theme was the support received by staff. Originality/value: To the best of the authors' knowledge, this study was the first to gather and analyse data on carer's experiences in supporting an individual with intellectual disability who is at risk of hospital admission within the locality of Greater Manchester.

14. **What I Wish I Had Known: Examining Parent Accounts of Managing the Health of Their Child With Intellectual Disability**

Authors: Nevill, Thom;Keely, Jessica;Skoss, Rachel;Collins, Rachel;Langdon, Katherine;Mills, Jaquie and Downs, Jenny

Publication Date: 2025

Journal: Health Expectations : An International Journal of Public Participation in Health Care and Health Policy

Abstract: Background: Appropriate support for the health of children with an intellectual disability by parents and healthcare professionals is pivotal, given the high risk of chronic conditions. However, there is limited research that has collected important insights from parents on their learnings for supporting their child's evolving healthcare needs.; Aim: This study focuses on parents' experiences and learnings from managing and supporting the health of their child with intellectual disability. It aims to understand what parents wish they had known earlier, the essential knowledge and skills they needed to manage their child's health.; Method: A qualitative study was carried out using semi-structured interviews with 21 parents of adolescents and young people with intellectual disability. The children had chronic health conditions that fell into six health domains, including (1) difficulties with movement and physical activity, (2) epilepsy, (3) dental care, (4) respiratory health and infection, (5) behaviour, mental health or sleep and (6) gastrointestinal health.; Results: Thematic analysis yielded five themes: (1) optimising mutual engagement between healthcare professionals and families; (2) planning and practising effective healthcare; (3) having the right information at the right time; (4) finding the support that was needed and (5) navigating healthcare and disability systems. Over time, parents developed specific skills and knowledge for managing their child's health effectively. Some parents expressed regret for not seeking support and information about their child's health conditions earlier. Parents described how mutual engagement between healthcare professionals and parents optimised the management of their child's healthcare.; Conclusion: The study found that managing the health of a child with intellectual disability is complex. The themes were consistent across health comorbidities, indicating important common experiences. The themes aligned with conceptualisations of health literacy, suggesting that improving health literacy skills can help parents better manage their children's health conditions.; Patient or Public Contribution: We developed the project in consultation with members of the public who have lived experience of parenting a child with intellectual disability. They commented on the study aims, interview schedule, participant recruitment and provided feedback on the analysis and discussion.

15. **Use of the Adaptive Behaviour Dementia Questionnaire in a Down Syndrome Specialty Clinic**

Authors: Oreskovic, Nicolas M.;Harisinghani, Ayesha;Bregman, Caroline;Cottrell, Clorinda;Pulsifer, Margaret;Skotko, Brian G.;Torres, Amy;Spognardi, Alexa Gozdiff and Santoro, Stephanie L.

Publication Date: 2025

Journal: Journal of Integrative Neuroscience

Abstract: Objective: To study the use of a dementia screening tool in our clinic cohort of adults with Down syndrome.; Study Design: A retrospective chart review of patients with Down syndrome was conducted to follow the use of the Adaptive Behaviour Dementia Questionnaire (ABDQ) in a dementia screening protocol. The ABDQ results for patients aged 40 years and older at a Down syndrome specialty clinic program were assessed. Based on caregiver feedback, an ABDQ with modified instructions was piloted and the impact assessed.; Results: As part of our clinic's initiative to implement a new clinical protocol to screen for dementia, the ABDQ was completed by 47 caregivers of adults with Down syndrome, aged 39 years and above, from December, 2021 to April, 2023. Based on clinical impressions at the same timepoint, the ABDQ had a sensitivity of 0%, specificity of 97.4%, positive predictive value of 0%, and negative predictive value of 80.4%. Nine patients were deemed to have mild cognitive impairment and/or dementia by clinical impressions, but they did not identify as positive on the ABDQ. The Down syndrome clinic team modified the ABDQ in an effort to provide clearer language and increased sensitivity. The modified ABDQ showed a sensitivity of 0%, specificity of 93.8%, positive predictive value of 0% and negative predictive value of 75%.; Conclusion: Neither the original ABDQ nor a modified version adequately identified patients with cognitive impairment and/or dementia within the Down syndrome clinical program. The inability to replicate findings from the initial ABDQ validation may be due to differences in setting and format. (© 2025 The Author(s). Published by IMR Press.)

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16. **Autistic adults' perspectives and experiences of diagnostic assessments that include play across the lifespan**

Authors: Pritchard-Rowe, Emma;de Lemos, Carmen;Howard, Katie and Gibson, Jenny

Publication Date: 2025

Journal: Autism: The International Journal of Research & Practice

Abstract: Play is often included in autism diagnostic assessments. These tend to focus on 'deficits' and non-autistic interpretation of observable behaviours. In contrast, a neurodiversity-affirmative assessment approach involves centring autistic perspectives and focusing on strengths, differences and needs. Accordingly, this study was designed to focus on autistic perspectives of diagnostic assessments that incorporate play. Autism community stakeholders were consulted on the design of the study. Semi-structured interviews were conducted with 22 autistic adults aged 18–57 years who live in the United Kingdom. Interpretative phenomenological analysis was used to identify themes. Autistic adults highlighted the varying ways in which play was included in their diagnostic assessments, such as via the Autism

Diagnostic Observation Schedule. Our findings highlight the importance of better adapting assessment to the heterogeneity of autism. For example, our findings question the extent to which play is useful for assessing autistic women and girls who mask. Our findings also suggest that holistic, neurodiversity-affirmative assessment practices should be adopted. Our findings support the importance of adopting a personalised approach to diagnostic assessments that use play, in addition to assessing strengths and differences as well as needs. Play is often included in autism diagnostic assessments. These assessments tend to focus on negatives and how people who are not autistic interpret observable behaviours. It is important to take a neurodiversity-affirmative assessment approach. This involves focusing on what autistic people say and looking at strengths and needs. We wanted to find out how autistic adults experience diagnostic assessments that include play. We asked autistic and non-autistic people to help us design our study and interview questions. We then interviewed 22 autistic adults to find out what they think about the use of play in assessments. We used a qualitative method called interpretative phenomenological analysis to analyse the data. Autistic adults told us about the different ways play was included in their diagnostic assessments. For example, some completed a diagnostic tool called the Autism Diagnostic Observation Schedule. Autistic adults also talked about the importance of considering how autistic people are different to each other. For example, we found that play may not be useful for assessing women or girls who mask. This suggests that professionals should adopt a personalised approach to diagnostic assessments that use play catering to each person's needs. Our findings also suggested that professionals should assess strengths and differences as well as needs.

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17. **Exploring the Intersection of Gender Diversity and Intellectual Disability: A Scoping Review With a Focus on Clinical Care**

Authors: Sternberg, Kady F.;Cloutier, Joanna G.;Ahlers, Kaitlyn;Moore, Christina;Koth, Kathleen A.;Soda, Takahiro;Malhi, Narpinder Kaur;Verma, Shikha;Yeh, Lisa C. and McLaren, Jennifer L.

Publication Date: 2025

Journal: Journal of Applied Research in Intellectual Disabilities : JARID

Abstract: Background: Little research has been conducted solely exploring gender diversity in people with intellectual disabilities. This review explores the literature, discusses the prevalence, and identifies clinical best practices for people at the intersection of gender diversity and intellectual disability.; Method: A scoping review was conducted utilising PRISMA methodology of the following databases: PubMed, CINAHL Complete (EBSCO), Cochrane Library (Wiley), Dissertations & Theses Global (ProQuest), PsycInfo (EBSCO), Scopus and Web of Science.; Results: Five hundred seventy five titles and abstracts were screened, 61 full-text articles were reviewed and 17 met inclusion criteria. Four major themes were identified: prevalence, trauma and co-occurring mental health disorders, barriers to care and best practices.; Conclusion: This review highlights the lack of research and provides valuable insight into the experiences of people with gender diversity and intellectual disability. Further research is needed to understand the prevalence and explore the intersection and experience of gender-diverse people with intellectual disabilities. (© 2025 John Wiley & Sons Ltd.)

18. **Down syndrome with cryptorchidism and retroperitoneal mixed germ cell tumour in an adult patient: a case report and literature review**

Authors: Wang, Qiang;Zhou, Hai-Bin;Ao, Li;Jiang, Yi and Zhou, Xiao-Cong

Publication Date: 2025

Journal: World Journal of Surgical Oncology

Abstract: Background: An association between testicular cancer and Down syndrome has been reported by several studies. Down syndrome with cryptorchidism and retroperitoneal mixed germ cell tumours is rare, and yolk sac tumours are often considered secondary components of mixed germ cell tumours. Herein, we present a rare case of retroperitoneal mixed germ cell tumour with cryptorchidism accompanied by yolk sac tumour and seminoma in a patient with Down syndrome, along with its imaging features.; Case Presentation: A 42-year-old man was admitted to the hospital for 6 months due to a worsening abdominal pain that was followed by syncope for 8 h. There was a significant increase in AFP and β-HCG levels. An enhanced computed tomography (CT) scan of the entire abdomen showed a mixed cystic solid mass in the retroperitoneal space. Fluorine-2-fluoro-2-deoxy-d-glucose (18 F-FDG) positron emission tomography/CT examination showed an abnormal increase in the FDG uptake in the parenchymal part of the mass, with a maximum standardised uptake value of approximately 10.5. The pathological diagnosis was retroperitoneal mixed germ cell tumour (yolk sac tumour + seminoma). One and a half months postoperatively, the tumour recurred. Consequently, the patient underwent chemotherapy, and after one course of treatment, the patient developed bone marrow suppression. Finally, he died due to complications.; Conclusions: Yolk sac tumours, the main components of mixed germ cell tumours, are rare in adults and exhibit rapid growth, heightened malignancy, and poor prognoses. CT features play a crucial role in diagnosis. Down syndrome is a high-risk factor for malignant testicular germ cell tumours. Therefore, comprehensive examinations for gonadal and germ cell tumours in patients with Down syndrome are imperative and should be prioritised by clinicians.; Competing Interests: Declarations. Ethics approval and consent to participate: The study was approved by the ethics committee of Wenzhou Central Hospital. Written informed consent was obtained from the participants for publication of the details of their medical case and any accompanying images. Consent for publication: not applicable. Competing interests: The authors declare no competing interests. (© 2024. The Author(s).)

19. **Treatment of Seizures in People with Intellectual Disability**

Authors: Watkins, Lance Vincent;Kinney, Michael and Shankar, Rohit

Publication Date: 2025

Journal: CNS Drugs

Abstract: There is a synergistic relationship between epilepsy and intellectual disability (ID), and the approach to managing people with these conditions needs to be holistic. Epilepsy is the main co-morbidity associated with ID, and clinical presentation tends to be complex, associated with higher rates of treatment resistance, multi-morbidity and premature mortality. Despite this relationship, there is limited level 1 evidence to inform treatment choice for this vulnerable population. This review updates the current evidence base for anti-seizure medication (ASM) prescribing for people with ID. Recommendations are made on the basis of evidence and expert clinical opinion and summarised into a Traffic Light System for accessibility. This review builds on work developed through UK's Royal College of Psychiatrists, Faculty of Intellectual Disability Psychiatry and includes newer pragmatic data from the Cornwall UK Ep-ID Research Register, a national research register for England and Wales that has been in existence for the last 10 years. The Register acts as a source for an in-depth exploration of the evidence base for prescribing 'newer' (third generation, specifically post-2004) ASMs. Its findings are discussed and compared. A practical approach to prescribing and choosing ASMs is recommended on the based evidence. This approach considers the drug profile, including adverse effects and clinical characteristics. The review also details newer specialist ASMs restricted to certain epilepsy syndromes, and potential future ASMs that may be available soon. For completeness, we also explore non-pharmacological interventions, including surgeries, to support epilepsy management.; Competing Interests: Declarations. Funding: No funding was received for the preparation of this article. Conflicts of Interest: L.W. has received honoraria from the pharmaceutical companies of UCB and Veriton Pharma to provide talks to peer audiences. M.K. has received honoraria to provide talks to peer audiences and for conference travel from UCB, Eisai and Angelini Pharma. R.S. is the chief investigator of the NIHR adopted national Ep-ID register (which is described in the paper and evidence from it used). The Register is supported and monitored by the National Institute of Health Research UK. The funding for each molecule examined by the Register is via an Investigator Initiated Support grant from each of the molecule’s parent company. The funding is to RSs’ NHS institution and goes towards the salary of the research co-ordinator and the institution’s project oversight costs. The contributing companies to date include Eisai, UCB, Bial and Jazz Pharmaceuticals (previously GW pharma). In addition to the above, R.S. has received institutional research, travel support and/or honorarium for talks and expert advisory boards from LivaNova, UCB, Eisai, Veriton Pharma, Bial, Angelini, UnEEG and Jazz/GW Pharma outside the submitted work. He holds or has held competitive grants from various national grant bodies including Innovate, Economic and Social Research Council (ESRC), Engineering and Physical Sciences Research Council (ESPRC), National Institute of Health Research (NIHR), NHS Small Business Research Initiative (SBRI) and other funding bodies including charities, all outside this work. Ethics Approval: Not applicable. Consent to Participate: Not applicable. Consent for Publication: Not applicable. Availability of Data and Material: Not applicable. Code Availability: Not applicable. Author Contributions: L.W.: initial draft of manuscript and outline, initial literature search and

review, and revision of work based upon feedback comments from author team and reviewer. M.K.: literature review and draft of Novel Drugs and Non-Pharmacological interventions. R.S.: corresponding author, development of idea and core outline, review of draft editions and revision, and final overview of manuscript prior to submission. All authors have read and approve the final submitted manuscript, and agree to be accountable for the work. (© 2025. The Author(s), under exclusive licence to Springer Nature Switzerland AG.)

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20. **Systematic review: Correlates of depression in adults with an intellectual disability: A systematic review of quantitative studies**

Authors: Kerry, Emily

Publication Date: 2024

Journal: FPID Bulletin: The Bulletin of the Faculty for People with Intellectual Disabilities

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21. **Effect of Physical Activity Interventions on Health Parameters in Children and Adolescents with Intellectual Disabilities: A Systematic Review**

Authors: Maicas-Pérez, Luis;Hernández-Lougedo, Juan;Maté-Muñoz, José Luis;Villagra-Astudillo, Ariel;García-Fernández, Pablo;Suárez-Villadat, Borja and Jiménez-Rojo, Blanca

Publication Date: 2024

Journal: Healthcare

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22. **Intellectual disability nurses' challenges in medication management in primary health care: A qualitative study**

Authors: Måløy, Elfrid;Aasen- Stensvold, Maria Therese;Vatne, Solfrid and Julnes, Signe Gunn

Publication Date: 2024

Journal: Journal of Intellectual Disabilities
Abstract: This study examines how intellectual disability nurses employed in residential living services for persons with intellectual disabilities, in Norway, deal with medication management for these individuals. Using a qualitative study, a total of 18 intellectual disability nurses were interviewed as part of four focus groups. The results demonstrate six main challenges: First, Being alone with the responsibility of medication management - a challenge; Second, The need for further competence development; Third, Teaching and supervising unskilled colleagues in safe medication management; Fourth, Interpreting residents with little or only nonverbal communication; Fifth, The need to act as advocates when residents require hospitalization; Sixth, Deficient systems for medication management on several levels. The findings point to several major flaws in the system of medication management, which necessitates the need for highly qualified intellectual disability nurses. Managers must ensure that there is a secure system to mitigate errors and promote patient safety.

23. **"She just makes it easier..." The impact of having a dedicated nursing role in supporting people with intellectual disability when accessing acute hospitals, from the perspective of their support staff, the Irish context**

Authors: Ní Riain, Muireann and Wickham, Sheelagh

Publication Date: 2024

Journal: Journal of Intellectual Disabilities

Abstract: Learning Disability Liaison Nurses have been shown to improve hospital experiences and this is an emerging role in Ireland. This research qualitatively explored the impact of a Clinical Nurse Specialist Acute Hospital Liaison from the perspective of staff in an intellectual disability community organisation. Participants identified significant challenges with supporting people attending hospitals including accessing and understanding information, anxieties and not being prepared for transitions through the hospital. The findings demonstrate the introduction of this role is a supportive, positive step with reports of improved information sharing, feeling better prepared and alleviating anxieties related to supporting someone in hospital. The findings clearly identify that this role has considerable benefits when set in a community organisation. This role has had a positive impact on service users and staff when interacting with hospitals, providing evidence of the value of this role in Ireland and also of they having a specialist qualification in the role.

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24. **Systematic review: Exploring the experiences of caring for a family member with intellectual disabilities displaying behaviours that challenge and/or mental health difficulties: A meta-ethnography review**

Authors: Yates, Lucy

Publication Date: 2024

Journal: FPID Bulletin: The Bulletin of the Faculty for People with Intellectual Disabilities

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Sources Used:

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

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interpretation or application of these results, which are not intended to provide advice or recommendations on patient care.