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Learning Disabilities

Current Awareness Bulletin

June 2025

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  Next sessions: 7th July @ 4pm, 12th August @ 9am & 10th September @ 10am

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

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1. **Identified Gaps in Nutrition Research and Practice Related to Trisomy 21 and Future Considerations: A Rapid Review**

Authors: Baranowski, Maria S,M.Sc, R.D. and Shooshtari, Shahin, PhD.

Publication Date: 2025

Journal: Canadian Journal of Dietetic Practice and Research : A Publication of Dietitians of Canada = Revue Canadienne De La Pratique Et De La Recherche En Dietetique : Une Publication Des Dietetistes Du Canada 86(2), pp. 90–95

Abstract: Individuals born with Trisomy 21 may be more susceptible to experiencing nutrition-related conditions and diseases throughout their lifespan. Seven studies conducted outside of Canada that investigated the impact of nutrition interventions in individuals of different ages (mostly children and youth) born with Trisomy 21 reported mixed results. Furthermore, Canadian clinical nutrition practice guidelines for the provision of care to individuals born with Trisomy 21 tend to be general in nature and may be based on a body of evidence that was not representative of this population. There is a need for well-designed inclusive nutrition research studies to determine the nutritional needs of individuals born with Trisomy 21 and to better understand how to provide person-centred nutrition and healthcare services that achieve nutrition and health equity for these individuals and improve their overall nutritional status and health.

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2. **Nonfatal injury emergency department visits and inpatient hospitalizations among persons under age 65 with an intellectual and developmental disability or deaf or hard of hearing disability**

Authors: Bunn, Terry L.;Seals, Jacqueline;Quesinberry, Dana;Murphy, Alaina and Costich, Julia F.

Publication Date: 2025

Journal: Injury Epidemiology 12(1), pp. 1–9

Abstract: Background: Vulnerable populations at risk of injury include persons with intellectual and developmental disabilities (IDD), and persons who are deaf or hard of hearing (DHH). The purpose of this study was to describe and compare emergency department and inpatient hospitalization (ED + IP) injury rates and rate ratios by injury type among persons under age 65 with IDD or with DHH to those without IDD or DHH. Methods: This is a descriptive population-based retrospective cross-sectional study of injuries among patients under the age of 65 with an IDD disability or a DHH disability using Kentucky ED + IP discharge datasets from 2019 to 2023. Injury rates and injury rate ratios were calculated for those under the age of 65 with an IDD or a DHH disability and without an IDD or a DHH disability, using number of persons under age 65 with or without the related disability as the denominator. Results: The overall injury rate was lower for persons under age 65 with an IDD or DHH compared to those without those disabilities in 2023 (1 and 3 per 100,000 population, respectively). IDD or DHH disability types had significantly lower overall ED + IP injury rate ratios compared to those without those disabilities (IDD: 0.667 95% CI: 0.640–0.694], DHH: 0.658 95% CI: 0.633–0.683]). When ED + IP injury type rate ratios were compared, IDD or DHH persons had higher injury rate ratios for self-harm (IDD: 8.740 95% CI: 7.783–9.815], DHH: 1.7846 95% CI: 1.402–2.272]), assault (IDD: 1.386 95% CI: 1.173–1.637], DHH: 1.310 95% CI: 1.115–1.540]), unintentional falls (IDD: 1.540 95% CI: 1.436–1.633], DHH: 1.283 95% CI: 1.201–1.372]), and drug poisonings (IDD: 2.401 95% CI: 2.103–2.740], DHH:1.620 95% CI: 1.391–1.886]) compared to those without such disabilities. Those with IHH or DHH who were treated for injuries incurred triple the charges of patients without these conditions (~$17,086 IDD; $19,550 DHH; and $5,216 no IDD or DHH disabilities). Conclusions: These findings have implications for health policy at the state and federal level. Clinical care interventions to reduce assault, self-harm, drug poisonings and unintentional injuries and healthcare utilization in persons with IDD or DHH should be publicly funded or covered by health insurance.

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3. **Radiological Screening of Atlantoaxial Instability in Children with Trisomy 21: A Systematic Review and Evidence-Based Recommendations**

Authors: Cattarinussi, Leo;Bregou, Aline;Newman, Christopher J. and Merckaert, Sophie R.

Publication Date: 2025

Journal: Children 12(4), pp. 421

Abstract: Background/Objectives: Atlantoaxial instability (AAI) affects approximately 20% of individuals with Trisomy 21. Radiological screening has been debated for decades due to its unclear clinical utility and lack of standardized diagnostic criteria. This systematic review evaluates the indications, efficacy, and clinical implications of radiological screening for AAI in children with Trisomy 21. Methods: Following the PRISMA guidelines, we conducted a systematic search in PubMed, Embase, and Google Scholar for studies published between 1990 and May 2024. Studies were included if they assessed AAI screening in pediatric Trisomy 21 populations, defined AAI radiologically, and reported at least two cases. We extracted the demographic data, study design, radiological criteria, screening recommendations, and biases from these studies. Results: Of the 537 identified studies, 8 met the inclusion criteria, encompassing 2536 children (mean age: 7 years). Five studies supported routine screening, while three opposed it. Studies varied significantly in their AAI definitions, using atlanto-dental interval (ADI) thresholds of 4 mm to 6 mm, the space available for cord (SAC), and the basion-axial interval (BAI). No study demonstrated a definitive correlation between radiological findings and neurological symptoms. Conclusions: Routine radiological screening for AAI in asymptomatic children with Trisomy 21 is not supported by consistent evidence. A selective screening approach, focusing on symptomatic patients or those engaging in high-risk activities, may be more appropriate. The standardization of radiological criteria and prospective studies are needed to refine screening recommendations.

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4. **Barriers to Healthcare for People With a Learning Disability From Ethnic Minorities: Perspectives of Self-Advocates and Carers**

Authors: Cooper-Moss, Nicola;Umpleby, Katie;Roberts, Christina;Garner, Christie;Edwards, Aisha

Hazel;Ditzel, Nicola;Butt, Jabeer;Clark, Samantha;Hatton, Christopher and Chauhan, Umesh

Publication Date: 2025

Journal: British Journal of Learning Disabilities 53(2), pp. 301–311

Abstract: Background: People with a learning disability from ethnic minorities experience barriers in their access to healthcare services and poorer health outcomes. This study aimed to explore the factors that contribute to these barriers and to better understand how they can be reduced. Methods: Twenty 'experts by experience' took part in experience-based co-design workshops to ascertain how lived experiences related to findings from a co-designed scoping review. Audio recordings were transcribed and analysed using framework analysis. Findings: Self-advocates and carers experienced discrimination within a range of healthcare settings; however, recognising and understanding the source was difficult. Many people reported a lack of reasonable adjustments or support services that considered their ethnic identities. Participants also experienced isolation and stigma within their own family and community networks. Access to healthcare was adversely affected by COVID-19. Many people were unaware of the Learning Disability Register and there was insufficient support when transitioning between healthcare services. Conclusions: Services can be improved by effective communication, continuity of care and an enhanced understanding of the experiences of learning disability across different ethnic groups. Understanding an individual's needs and preferences from the first point of contact is important for the allocation of resources. Summary: People with a learning disability from ethnic minorities have problems using healthcare services.We call these problems barriers because they stop people from getting help. This means their health gets worse.We had three meetings with people from ethnic minorities with a learning disability and carers. We asked them to tell us what barriers they have when using healthcare services.People were treated unfairly in healthcare. It was difficult to know if this was because of their disability or ethnicity. They were also treated differently by their families and communities.Healthcare workers should learn how people from different ethnic groups experience learning disabilities to give better care.

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5. **Digital motor intervention effects on physical activity performance of individuals with developmental disabilities: a systematic review**

Authors: Corey, J.;Tsai, J. M.;Mhadeshwar, A.;Srinivasan, S. and Bhat, A.

Publication Date: 2025

Journal: Disability & Rehabilitation 47(10), pp. 2475–2490

Abstract: Purpose: Post-pandemic, use of digital technologies (e.g., mobile app, Zoom, virtual reality, and videogaming) to promote physical activity (PA) in populations with intellectual and developmental disabilities (IDD) has increased. The efficacy of various digital technologies in promoting PA in individuals with IDD varies. We conducted a systematic review to examine current literature findings on the efficacy of digital PA interventions on PA outcomes in individuals with IDD. Methods: Articles published between 1900 and 2024 that examined effects of technology-based PA interventions on PA levels/fitness of individuals with IDD using experimental or quasi-experimental study designs were included. Sixteen articles were retrieved from four health databases PubMed (914), PsycInfo (1201), SCOPUS (1910), and CINAHL (948). Results: Findings based on 604 participants (Autism: 383; Down Syndrome: 106; Developmental Disability: 83, Developmental Coordination Disorder: 37) provide the most support for exergaming/digital PA intervention benefits for populations with ID, Down Syndrome, and Autism; however, there was limited support for its use in those without ID (e.g., DCD). Conclusion: Digital technology is an effective tool to promote improvements in PA/fitness, motor, cardiovascular performance in individuals with ID. Future studies need to build on this evidence to support the use of PA outcomes in individuals with different IDD diagnoses. IMPLICATIONS FOR REHABILITATION: Individuals with intellectual and developmental disabilities (IDD) are more physically inactive compared to peers without IDD. Exercise and physical activity are effective modalities to improve health and well-being of individuals with IDD. Exergaming/digital technologies are a promising option to promote physical activity in individuals with IDD, specifically, in children with Down Syndrome and Autism

Spectrum Disorder. This is the first review comparing effects of exergaming/digital technologies on physical activity outcomes of individuals with and without intellectual disabilities.

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6. **Allyship in Healthcare for People With Learning Disabilities as a Praxis of Respect, Attention and Collaborative Action**

Authors: Daw Srdanovic, Bojana

Publication Date: 2025

Journal: Sociology of Health & Illness 47(4), pp. 1–12

Abstract: There is a dearth of literature focusing on how allyship in health may be enacted in relation to people with learning disabilities (LD). This is concerning, because people with LD are vulnerable to health inequalities and forms of medical dehumanisation including do-not-resuscitate orders, diagnostic overshadowing and overprescription of psychotropic drugs. Deploying critical disability studies as a lens through which to understand disability, this paper reviews models of disability allyship developed in healthcare, research and theatre. In doing so it advocates transformative allyship as a model that can both animate action in support of people with learning disabilities and accommodate the involvement of others, including clinicians, carers and relatives, without compromising the all-important commitment to supporting disability cultures. The paper presents and analyses ethnographic data gained through observations of eleven healthcare appointments between seven clinicians and five patients with LD, undertaken as part of the ESRC-funded study Humanising Healthcare. It documents the potential of transformative allyship in healthcare to transform harmful disablist practices through emphasising respect, attention and collaborative action while also noting that broader structural conditions and diagnostic technologies limit the extent to which clinicians can enact transformative allyship.

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7. **Prevalence and Incidence of Cardiovascular Disease in Adults With Intellectual Disabilities: A Systematic Review**

Authors: de Leeuw, Marleen,J.;Hilgenkamp, Thessa I. M.;Maes-Festen, Dederieke;Bindels, Patrick J. E.;Elbers, Roy G. and Oppewal, Alyt

Publication Date: 2025

Journal: Journal of Intellectual Disability Research : JIDR

Abstract: Background: Given the high risk of cardiovascular diseases (CVD) in adults with intellectual disabilities (ID), there is a strong need for accurate understanding on CVD prevalence and incidence in this population. This information is important to ensure optimal care and resource allocation. However, systematic reviews on this topic are limited. Therefore, this systematic review aimed to provide a comprehensive synthesis of studies on the prevalence and incidence of CVD in adults with ID, including subgroup data.; Method: We performed a systematic search in Embase, Medline ALL, Web of Science, Cochrane Central, PsycINFO and Google Scholar up to 21 January 2025, including peer-reviewed articles on CVD prevalence or incidence in adults with ID. Article screening and data extraction were independently performed by two researchers. Data were synthesised by CVD diagnosis. When available, data were reported separately for different subgroups. The methodological quality was assessed by two independent researchers. This review followed the PRISMA guidelines.; Results: In 55 articles, prevalence and incidence rates were identified for coronary artery disease (prev 0%-12.9%; inc 2.0-2.8 per 1000py), myocardial infarction (prev 0%-7.9%; inc 0.3-2.8 per 1000py), heart failure (prev 0.8%-18.6%; inc 12.5 per 1000py), cerebrovascular disease (prev 0.7%-15.0%; inc 2.55 per 1000py), stroke (prev 1.3%-17.2%; inc 2.7-3.2 per 1000py), peripheral arterial disease (prev 0.4%-20.7%; inc 1.1 per 1000py), venous thrombosis (prev 0.6%-12.4%; inc 0.8-4.1 per 1000py) and atrial fibrillation (prev 0.8%-6.3%). Subgroup data have been reported based on age, sex, level of ID, aetiology of ID, living circumstances, CVD risk factors, data collection methods and source populations. Overall, higher prevalence and incidence rates were reported in older people and in studies that used physical measurements for diagnosis.; Conclusions: Due to variability in methodological quality, clinical characteristics and high statistical heterogeneity, drawing conclusions about CVD prevalence and incidence in adults with ID is challenging. Therefore, the subgroup data presented in this review are valuable for identifying rates within specific subgroups. Longitudinal studies along with research employing valid and reliable data collection methods (preferably objective measurements) aligned with studies in the general population, clear reporting of individual CVD diagnoses and subgroup analyses will offer valuable additional insights in future research. (© 2025 The Author(s). Journal of Intellectual Disability Research published by MENCAP and John Wiley & Sons Ltd.)

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8. **Understanding Music Participation for Adults With Down Syndrome**

Authors: Dorris, Jennie L.;Rodakowski, Juleen and Caldwell, Angela

Publication Date: 2025

Journal: Journal of Intellectual Disability Research 69(6), pp. 527–532

Abstract: Background: Adults with Down syndrome are living longer and have high risk of experiencing Alzheimer's disease as they age. With few services available, music is a promising modality that has been shown to support cognitive functioning. This study reported on the frequency of music participation for adults with Down syndrome and explored associations of age, race and level of intellectual disability with music participation. Methods: The research team administered a survey to care partners of adults with Down syndrome (n = 27) that measured music participation in terms of 'listening' and 'playing' using the Guernsey Community Participation and Leisure Assessment. Results: 44.4% of care partners reported providing over 50 h of care a week. 92.6% of adults with Down syndrome listened to music, and 33.3% played music either weekly or daily. 74.1% of care partners reported that adults with Down syndrome could listen to music unaccompanied, and 48.2% of care partners reported that adults with Down syndrome could play music unaccompanied. A statistically significant association was found between race and playing music. Conclusions: Knowing that multiracial adults with Down syndrome had a higher frequency in playing music, a potent future research direction is better understanding the musical needs and preferences of these diverse adults. Broadly, those developing services and supports could consider utilizing music as a meaningful activity that does not add care partner burden. Trial Registration: University of Pittsburgh's Institutional Review Board: 22080146

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9. **The effect of exercise on improving cognitive function in people with Down's syndrome: a systematic review and meta-analysis**

Authors: Duan, Xing-Liang and Li, Meng-Meng

Publication Date: 2025

Journal: European Journal of Pediatrics 184(6), pp. 349

Abstract: Competing Interests: Declarations. Ethical approval: The current study is a systematic review and does not involve clinical trials, and all original data are from previous studies that have been published, so no ethical approval statement is required. Conflict of interest: The authors declare no competing interests.; This study aims to systematically evaluate the effects of exercise on cognitive function in individuals with Down syndrome (DS) through a comprehensive systematic review and meta-analysis. Five electronic databases (PubMed, Embase, Cochrane Library, Web of Science, and SPORTDiscus) were systematically searched from inception to February 10, 2025. Additional studies were identified through manual reference screening. Meta-analyses were performed using Stata 17.0. Exercise interventions were associated with significant improvements in cognitive function among individuals with DS (standardized mean difference = 0.50; 95% CI: 0.33,0.67; $P < 0.01$). Subgroup analyses revealed consistent benefits across cognitive domains, age groups, exercise intensities, and sample sizes. However, no significant effects were observed for interventions involving treadmill walking or single-session exercise. No substantial heterogeneity was detected within any subgroup, supporting the robustness of the findings. Conclusion: This systematic review and meta-analysis provide strong evidence that exercise is an effective strategy for enhancing cognitive function in individuals with DS. The consistency of the results across subgroups supports their generalizability. Future studies should focus on the long-term effectiveness and methodological quality of interventions to refine exercise-based strategies for cognitive rehabilitation in this population. (© 2025. The Author(s), under exclusive licence to Springer-Verlag GmbH Germany, part of Springer Nature.)

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10. **The desire for parenthood among individuals with intellectual disabilities : systematic review**

Authors: Guénoun, Tamara;Essadek, Aziz;Clesse, Christophe;Mauran-Mignorat, Marion;Veyron-Lacroix, Estelle;Ciccone, Albert and Smaniotto, Barbara

Publication Date: 2025

Journal: Journal of Intellectual Disabilities 29(2), pp. 423–446

Abstract: Background: This qualitative systematic review provides an overview of existing studies on the desire for parenthood of people with intellectual disabilities. Method: The scientific studies were identified following the Prisma protocol on 18 databases using keywords relating to sexuality and parenting. Results: Sixteen studies have been included and three categories identified: the obstacles and motivations to becoming a parent; parents' decision making during pregnancy; and the social construction of a parental identity. The results from these studies show that people with intellectual disabilities have a genuine desire for children, which is repressed because of an unfavorable social context. Conclusion: Further clinical and participatory research is needed to better understand the singular modes of expression of people's intimate desires and how to better accompany them on this issue.

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11. **The Alzheimer's Biomarker Consortium-Down Syndrome (ABC-DS): A 10-year report**

Authors: Handen, Benjamin L.;Mapstone, Mark;Hartley, Sigan;Andrews, Howard;Christian, Brad;Lee, Joseph H.;Tudorascu, Dana;Hom, Christy;Ances, Beau M.;Zaman, Shahid;Krinsky-McHale, Sharon;Brickman, Adam M.;Rosas, H. D.;Cohen, Annie;Petersen, Melissa;O'Bryant, Sid;Harp, Jordan P.;Schmitt, Frederick;Ptomey, Lauren;Burns, Jeffrey, et al

Publication Date: 2025

Journal: Alzheimer's & Dementia : The Journal of the Alzheimer's Association 21(5), pp. e70294

Abstract: Introduction: Virtually all adults with Down syndrome (DS) will accumulate the neuropathologies associated with Alzheimer's disease (AD) by age 40, with the majority having a clinical dementia diagnosis by their middle 50s.; Methods: This paper complements a 2020 publication describing the Alzheimer's Biomarker Consortium-Down Syndrome (ABC-DS) methodology by highlighting protocol changes since initial funding in 2015. It describes available clinical, neuropsychological, neuroimaging, and biofluid data and bio-specimen repository. Ten years of accomplishments are summarized.; Results: Over 500 adults with DS and 59 sibling controls have been enrolled since 2015 with nearly 800 follow-up visits. More than 900 magnetic resonance imaging (MRI), 800 amyloid positron emission tomography (PET), and 600 tau PET scans have been conducted; multiple omics data have been generated using over 1100 blood and 100 cerebrospinal fluid (CSF) samples.; Discussion: ABC-DS is the largest U.S.-based, multi-site (including the United Kingdom and Puerto Rico), longitudinal biomarker initiative to target adults with DS at risk for AD.; Highlights: The Alzheimer's Biomarker Consortium-Down Syndrome (ABC-DS) is entering its 10th year. Over 500 adults with Down syndrome (DS) and 59 sibling controls have been enrolled. More than 900 magnetic resonance imaging (MRI), 800 amyloid positron emission tomography (PET), and 600 tau PET scans have been conducted. Multiple omics data have been generated using over 1100 blood and 100 cerebrospinal fluid (CSF) samples. It is positioned to continue to make substantial contributions to the DS field. (© 2025 The Author(s). Alzheimer's & Dementia published by Wiley Periodicals LLC on behalf of Alzheimer's Association.)

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12. **Sedation for transthoracic echocardiography in children with Down syndrome: a propensity score-weighted retrospective cohort study**

Authors: Hu, Jie;Wang, Lu;Xue, Bing;Zhang, Ying and Zhang, Ruidong

Publication Date: 2025

Journal: European Journal of Medical Research 30(1), pp. 387

Abstract: Competing Interests: Declarations. Ethics approval and consent to participate: This study was approved by the Ethics Committee of Shanghai Children’s Medical Center in China (approval number: SCMCIRB-K2022087-1; July 1, 2022). The requirement for informed consent was waived by institutional review board of Shanghai Children’s Medical Center, as the data used were anonymized. Consent for publication: Not applicable. Competing interests: The authors declare no competing interests.; Background: Transthoracic echocardiography can be performed under sedation in children with Down syndrome who have neurological or behavioral problems. This study aimed to compare the efficacy and safety of intranasal dexmedetomidine and oral chloral hydrate in children with Down syndrome who are undergoing transthoracic echocardiography.; Methods: This retrospective cohort study reviewed the electronic medical records of patients with Down syndrome who underwent transthoracic echocardiography under oral chloral hydrate or intranasal dexmedetomidine sedation between June 2014 and September 2021. The patients were divided into oral chloral hydrate and intranasal dexmedetomidine groups according to the main agents used for sedation. The primary endpoint was the outcome of single-dose sedative agents, and the groups were compared using a propensity score weighting analysis.; Results: In total, 149 patients (chloral hydrate group, n = 75; dexmedetomidine group, n = 74) were included in the final analysis. After propensity score weighting, 150 and 148 patients were included in the chloral hydrate and dexmedetomidine groups, respectively. The success rate of the initial sedative medication was significantly higher in the dexmedetomidine group than in the chloral hydrate group (89.1% vs. 80.7%, p = 0.0412) after adjustment for propensity score weighting. The success rate of the final sedative medication was higher in the dexmedetomidine group than in the chloral hydrate group (before propensity score weighting, 98.7% vs. 86.7%; after propensity score weighting, 98.5% vs. 86.8%; both p values < 0.01). Before and after propensity score weighting, the incidence of bradycardia during sleep was significantly higher in the dexmedetomidine group than in the chloral hydrate group. Sedation with dexmedetomidine or chloral hydrate was not associated with severe oxygen desaturation in children with Down syndrome.; Conclusions: Compared with oral 50 mg/kg chloral hydrate, the use of a single intranasal dose of 2 µg/kg dexmedetomidine was related to a significantly higher success rate of sedation without increasing severe hypoxic events in children with Down syndrome undergoing transthoracic echocardiography, except for the incidence of bradycardia. (© 2025. The Author(s).)

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13. **'Mind the Gap'—A Survey on Care Gaps and Priorities for the Transition to Adult Healthcare According to Caregivers of Young People With Rare Conditions Associated With Intellectual Disability**

Authors: Klein Haneveld, Mirthe J.;Vyshka, Klea;Gaasterland, Charlotte M. W.;Grybek, Tomasz;Świeczkowska, Katarzyna;Van Staa, AnneLoes;Van Eeghen, Agnies M.;van Amelsvoort, Thérese A. M.,J.;Bedeschi, Maria F.;Behan, Claire;Dufke, Andreas;Dupont, Juliette;Garavelli, Livia;Helverschou, Sissel Berge;Labunets, Kinga;McAnallen, Susan;Milska-Musa, Katarzyna A.;van Staa, AnneLoes;Streată, Ioana and Stumpel, Connie T. R. M.

Publication Date: 2025

Journal: Journal of Intellectual Disability Research 69(6), pp. 480–488

Abstract: Background: For young people with rare conditions associated with intellectual disability, the transfer from paediatric to adult healthcare providers is often complicated. European Reference

Network ERN-ITHACA (Intellectual disability, TeleHealth, Autism and Congenital Anomalies) on Rare Congenital Malformations and Rare Intellectual Disability aims to develop a clinical practice guideline to improve this transition. The aim of this study was to identify which aspects of the transition to adult care matter most and to describe the current care gap as experienced by European caregivers to inform the guideline scope. Methods: An international web-based survey was conducted by ERN-ITHACA in January–February 2023. Priorities for a good transition process and current care gaps in Europe were identified using the 'Mind the Gap' scale. The surveys were created in plain and easy-to-read language and available in nine European languages. Results: One hundred fifty-seven caregivers from 15 European countries completed the survey, representing over 40 conditions, including the Phelan–McDermid, Rubinstein–Taybi, 22q11.2 deletion and Kleefstra syndromes. Care gaps were identified, particularly related to process issues such as the preparation for and adaptation to adult healthcare, supporting independence and planning for the future. Items considered essential for optimal healthcare were related to individualised approaches, information provision and coordination of care. Discussion: Coordinated, specialised, individualised and multidisciplinary care is required to support youth with rare conditions and intellectual disability in the transitional age. Supporting young people's independence, orchestrating multidisciplinary care and ensuring effective communication are particularly challenging in the transition to adult healthcare for this population.

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14. **Factors Associated With Length of Hospital Stay for Forensic Psychiatric Inpatients With Intellectual Disabilities**

Authors: McKenna, Penelope;England, Rosie;Fadzelmulla-Moreno, Carmen;Thompson, Paul A.;Boer, Harm and Langdon, Peter E.

Publication Date: 2025

Journal: Journal of Applied Research in Intellectual Disabilities : JARID 38(3), pp. e70065

Abstract: Introduction: The aim of this study was to examine factors associated with length of stay within a psychiatric hospital for patients with intellectual disabilities who have a forensic history.; Methods: Data about 111 patients were gathered retrospectively from historical records for the period of February 2011 to March 2021. Negative binomial regression was then used to examine the relationship between selected predictor variables and length of stay.; Results: Patients who were older upon admission and those who had received psychological therapies or positive behavioural support (PBS) had a significantly longer length of stay. Those with a diagnosis of a neurodevelopmental disorder had a significantly shorter length of stay. All other predictors were not statistically significant.; Conclusions: There was evidence of a clinical improvement at discharge and those with autism or ADHD had a shorter length of stay. Similar studies with larger sample sizes should be completed across England. (© 2025 The Author(s). Journal of Applied Research in Intellectual Disabilities published by John Wiley & Sons Ltd.)

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

Authors: Metzler, Seth and Brown, Gina R.

Publication Date: 2025

Journal: JAAPA: Journal of the American Academy of Physician Assistants (Lippincott Williams & Wilkins) 38(2), pp. e1–e6

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.

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16. **Inpatient Child and Adolescent Psychiatry Youth with Autism and/or Intellectual Disabilities: Clinical Characteristics and Considerations**

Authors: Morris, Arielle M.;Lynch, Sean;Kasdin, Rachel G.;Hill, Isabela;Shah, Salonee;Shanker, Parul;Becker, Timothy D.;Staudenmaier, Paige;Leong, Alicia W.;Martin, Dalton and Rice, Timothy

Publication Date: 2025

Journal: Journal of Autism and Developmental Disorders

Abstract: Competing Interests: Declarations. Conflict of interest: The authors have no conflicts of interest to report. Ethical Approval: All procedures were approved by the Icahn School of Medicine at Mount Sinai Institutional Review Board (STUDY-21-01676).; Children and adolescents with autism spectrum disorder and/or an intellectual disability (ASD/ID) are psychiatrically hospitalized at disproportionately higher rates than youth without ASD/ID. Despite this, few studies have compared the clinical courses of youth with and without ASD/ID in inpatient (IP) child and adolescent psychiatry (CAP) settings. This study used a cross-sectional design of all youth (M = 14.0 years, SD = 2.6 years) admitted to an urban IP unit between 2018 and 2021 to examine differences between ASD/ID and non-ASD/ID youth across dimensions of sociodemographic and psychiatric history and clinical course. 1101 Patients were included in the study and 170 (15.4%) had a history of ASD/ID. ASD/ID youth were more likely to be younger, be male, have histories of violence, and on average have more prior hospitalizations and existing psychotropic prescriptions than their non-ASD/ID counterparts. ASD/ID youth were less likely than their non-ASD/ID peers to be admitted for suicidality and more likely to be admitted for aggression; they had longer average lengths of stay, received more IP emergency medications for agitation, and experienced greater polypharmacy at discharge. The IP psychiatric clinical course of ASD/ID youth differs from that of non-ASD/ID youth, suggesting that ASD/ID youth often present to IP settings with externalizing symptoms. Findings highlight the importance of clinical strategies tailored to the unique needs of ASD/ID youth to improve their care in general IP CAP settings. (© 2025. The Author(s), under exclusive licence to Springer Science+Business Media, LLC, part of Springer Nature.)

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17. **Borderline Intellectual Functioning: A Scoping Review**

Authors: Orío-Aparicio, Cristina;López-Escribano, Carmen and Bel-Fenellós, Cristina

Publication Date: 2025

Journal: Journal of Intellectual Disability Research 69(6), pp. 437–456

Abstract: Background: Borderline intellectual functioning (BIF) is a condition that involves limitations in cognitive skills that affect the daily functioning of people who present it. BIF has lost visibility in diagnostic manuals such as the DSM-5-TR and ICD-11, which relegate it to complementary categories of aspects requiring attention, rather than recognising it as a category of its own. This lack of recognition as well as unclear criteria for diagnosis underscores the need for a deeper understanding of BIF. Method: The study conducted a scoping review to map the available evidence in the field of BIF. Following the PRISMA-ScR framework, ProQuest, WoS, SCOPUS and EBSCOhost databases were searched. Documents were selected based on inclusion criteria: date of publication (since 2012), study of BIF as a specific group and language (English or Spanish). A total of 138 documents were included, both academic and grey literature. Results: The review mapped the literature into key categories: intellectual functioning, adaptive functioning and additions for a comprehensive evaluation. Most research focused on comorbid psychiatric, emotional and behavioural disorders associated with BIF, as well as cognitive aspects. Very few addressed adaptive functioning explicitly, a crucial area for diagnosing and supporting individuals with BIF, though many covered its domains (conceptual, social and practical). Studies predominantly used quantitative methodologies, with only a few incorporating qualitative methods and directly involving people with BIF. Conclusions: The review emphasises the need for a clearer definition of BIF. Future studies should incorporate the perspectives of individuals with BIF to fully understand their needs and challenges across various life domains.

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18. **Alternative Diagnoses in the Work Up of Down Syndrome Regression Disorder**

Authors: Santoro, Jonathan D.;Khoshnood, Mellad M.;Nguyen, Lina;Vogel, Benjamin N.;Boyd, Natalie K.;Paulsen, Kelli C. and Rafii, Michael S.

Publication Date: 2025

Journal: Journal of Autism & Developmental Disorders 55(6), pp. 2085–2091

Abstract: Purpose: Down Syndrome Regression Disorder (DSRD) is a diagnosis of exclusion. Psychiatric and neuroimmunologic etiologies have been proposed although the exact etiology remains unknown. This study sought to review non-DSRD diagnoses at a large quaternary medical center specializing in the diagnosis of DSRD and compare clinical characteristics between those diagnosed with DSRD and those with non-DSRD diagnoses. Methods: The authors performed a single-center retrospective, chart-based, review of referrals for developmental regression in individuals with Down syndrome. Results: Two hundred and sixty-six individuals were evaluated for DSRD and of these, 54 (20%) ultimately had alternative diagnoses. Individuals with DSRD were more likely to have shorter nadir to clinical symptoms ($p = 0.01$, 95% CI: 0.36–0.47) and have preceding triggers (p 12 months) and earlier onset (median 8 years, IQR: 6–11). Other diagnoses included epilepsy (5/54, 9%), Celiac disease (5/54, 9%), cerebrovascular disease (3/54, 6%). Conclusions: This study identifies that 20% of individuals referred with concerns for DSRD have alternative diagnoses. The majority of these diagnoses were autism, but rare treatable conditions were also identified, highlighting the importance of a thorough neurodiagnostic assessment.

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19. **Neurodiversity-Affirming Clinical Care: Principles and Pearls**

Authors: Shear, Talia;Ayoub, Maya;Cejas, Diana;Christy, Alison;Holler-Managan, Yolanda;Labrie, Uloma;King, Hannah and Kim, Young-Min

Publication Date: 2025

Journal: Journal of Child Neurology , pp. 8830738251340268

Abstract: To provide the best possible care, neurologists must have a thorough understanding of the social and historical context of disability. Knowledge of the biology of neurologic conditions alone is insufficient. Currently, there is a scarcity of explicit education and training on disability beyond the traditional medical lens. Additionally, neurologists may be unfamiliar with the neurodiversity movement and its principles. This lack of awareness may inadvertently perpetuate ableist perspectives and practices, resulting in harm for our patients. In this article, we provide an overview of ableism and language-use considerations. We also discuss the history and current context of the neurodiversity movement and review neurodiversity-affirming core principles and clinical practices. This article offers perspective on an important shift in paradigms of the brain, as well as tools that can be used for a career-long commitment to excellent and equitable neurologic care

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20. **The association of cognitive functioning and substance use disorders with adaptive impairments of inpatients in forensic addiction treatment**

Authors: Suelmann, Rianne and Blaauw, Eric

Publication Date: 2025

Journal: Journal of Intellectual & Developmental Disability 50(2), pp. 165–173

Abstract: Background: Addiction medicine still largely neglects the topic of mild and borderline intellectual disabilities (MBID), although patients with MBID are considered a risk group for substance-related problems and offending behaviour. This study aimed to explore the cognitive and adaptive impairments of inpatients in forensic addiction mental health care. Method: Participants included a total of 50 consecutive referrals who had a substance use disorder. Results: 74% of the patients had a total IQ-score lower than 85, and 78% had an adaptive impairment in one or more domains of functioning. Only 10% had no cognitive or adaptive impairments. The total IQ-score significantly predicted the total number of impaired domains of adaptive functioning and the severity of substance use disorder did not predict adaptive functioning at all. Conclusions: It can be concluded that in forensic addiction care the prevalence of cognitive and adaptive impairments is high, with 62% having cognitive as well as adaptive impairments.

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21. **Facilitators, barriers, and strategies for supporting shared decision-making with people with intellectual disability: A West Australian primary healthcare professional perspective**

Authors: Teale, Kathryn;Lewis, Abigail and Skoss, Rachel

Publication Date: 2025

Journal: Journal of Intellectual & Developmental Disability 50(2), pp. 127–138

Abstract: Background: Shared decision-making between patients and primary healthcare professionals positively impacts health outcomes. However, people with intellectual disability face additional barriers and require supported shared decision-making (SSDM) to participate. Little is known about how healthcare professionals use SSDM with this population. This paper explores the facilitators and barriers experienced, and strategies/resources employed by healthcare professionals working with people with intellectual disability. Method: Ten purposively sampled primary healthcare professionals participated in semi-structured interviews. This descriptive qualitative study used content analysis. Findings were compared with a proposed model of factors influencing triadic (the person with intellectual disability, their caregiver and the healthcare professional) SSDM. Results: Five factor categories emerged: previous training/experience; engagement and trust; effective collaboration with caregivers; organisational culture and contexts; and familiarity/confidence with communication support strategies and resources. Conclusions: Healthcare professionals can leverage pre-existing skills and knowledge, but provision of targeted professional development may reduce anxiety and increase successful SSDM.

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22. **A systematic review of studies on the association between physiological parameters and self-harm**

Authors: van Swieten, Marlieke;Nijman, Inge;de Looff, Peter;VanDerNagel, Joanneke and Didden, Robert

Publication Date: 2025

Journal: Research in Developmental Disabilities 162, pp. 105010

Abstract: Competing Interests: Declaration of Competing Interest None of the authors have potential conflicts of interest to disclose.; Background: Self-harm is common in people with intellectual disabilities and is associated with multiple adverse consequences for the client engaging in self-harm, other clients and caregivers. Self-harm is related to emotional dysregulation according to both observational and self-report data. Measures of the autonomic nervous system might provide additional insight in this relationship.; Methods: The current systematic review systematically summarized a broad spectrum of studies on the association between self-harm and physiological parameters. The search identified 2400 articles, 46 were included.; Results: In most studies, which compared electrodermal activity and heart rate in people with and without self-harm, no clear indications for a relation between physiology and self-harm was found. Studies on heart rate variability showed indications for lower heart rate variability during recovery, which could imply emotion dysregulation, findings which were supported by results from imagery studies (heart rate and skin conductance). No consistent findings were found when self-harm was studied before, during or after actual occurrences of self-harm, although this was examined by very few studies.; Conclusions: Although wearable technology has improved, the majority of studies to date are lab-studies. Future research should focus on measuring physiology in daily life before, during and after self-harm, in people with intellectual disabilities, study different types and functions of self-harm separately, and test multimodal prediction models. This knowledge could improve the understanding, prevention and assessment of this debilitating behaviour. (Copyright © 2025 The Authors. Published by Elsevier Ltd.. All rights reserved.)

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23. **Sensory approaches for adults with severe or profound and multiple learning disabilities: A systematic literature review**

Authors: Humpheson, Jennifer

Publication Date: 2024

Journal: The British Journal of Occupational Therapy 87(3), pp. 129–142

Abstract: Competing Interests: The author declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.; Introduction: Sensory approaches are often used by Occupational Therapists working with clients with a severe or profound and multiple learning disabilities (SLD/PMLD). The aims of this review were to synthesise the outcomes of sensory approaches for adults with an SLD/PMLD and describe the key intervention components.; Method: A mixed methods literature review of three databases was completed to identify studies where sensory approaches were used for clients with an SLD/PMLD. Peer-reviewed research articles published between January 1990 and April 2021 were included. Data quality was assessed using the Mixed Methods Appraisal Tool. A convergent-segregated approach to synthesis was taken, including thematic analysis of qualitative data and a narrative review of quantitative data.; Results: Eighteen studies were included. Positive outcomes were reductions in challenging behaviour, stress and improved engagement, attention and communication. Three themes emerged, suggesting important components of sensory approaches for clients with an SLD/PMLD: matching sensory stimuli to the needs of the individual, sensory integration therapists and caregivers as facilitators and increased intervention duration and frequency.; Conclusion: Evidence suggests that sensory approaches support positive social, emotional and cognitive outcomes for individuals with an SLD/PMLD. Essential features of sensory approaches for this client group are sensitive use of sensory stimuli, skilled facilitators and more intensive intervention protocols. (© The Author(s) 2024.)

Sources Used:

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

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