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1. **Awareness of down syndrome screening among educated Muslim women is associated with a favorable attitude toward testing**

Authors: Arab, Kholoud and Halawani, Lujain

Publication Date: 2024

Journal: BMC Women's Health 24(1), pp. 508

Abstract: Objective: There is a general assumption that Muslim women refuse Down syndrome screening, and therefore, many health practitioners do not offer it or briefly discuss it with their participants. This study aims to objectively assess women's awareness, knowledge, and attitudes toward Down Syndrome screening (D.S.S) in a Muslim-majority population.; Methods: We conducted a cross-sectional study among attendees of antenatal clinics at a major university hospital in Saudi Arabia, aiming for a sample size of at least 385 Muslim women. A semi-structured questionnaire assessed awareness of different D.S.S. options and the source of that information (2 items), specific knowledge of D.S.S. (14 items), and attitudes (4 items). The knowledge and attitudes scores were calculated using a five-level agreement Likert-type scale.; Results: Among 434 participants, with an even distribution among all age groups and a majority of a college degree holder or higher (71%), 178 (41.0%) reported awareness of D.S.S. Factors associated with increased awareness were maternal age above 40 or those under 30, nulliparity, and extended family history of fetal congenital anomalies (P-value = 0.03,0.015, and 0.017, respectively). Recognized tests were ultrasound measurement of nuchal translucency (71.9%) and first-trimester serum screening (58.4%). The sources of knowledge were obstetricians (53.9%), followed by family and friends (27.0%). The overall mean ± SD knowledge score was 53.9 ± 8.7 out of 70, and the mean attitude score was 17.4 ± 2.9 out of 20. Having 1 or 2 children is associated with a higher knowledge score, and most participants who reported awareness of D.S.S. (51.7%) had a favorable attitude toward screening.; Conclusion: Awareness of D.S.S. among Muslim women is associated with favorable attitudes towards testing, contradicting the general assumption and highlighting the need for systematic education to increase awareness and subsequent testing uptake. (© 2024. The Author(s).)

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2. **Autism in ICU**

Authors: Baruah, Rosaleen

Publication Date: 2024

Journal: Journal of the Intensive Care Society 25(3), pp. 319–325

Abstract: Autism is a lifelong neurodevelopmental condition. Autistic people face challenges as patients in the intensive care unit (ICU) and as providers of healthcare in the ICU. This article describes the experience of autistic people using a neurodiversity-affirming approach. Using the 'Autistic SPACE' framework, the needs of autistic people are described in terms of sensory needs, need for predictability, need for autistic acceptance, communication differences and how to approach them, and the benefits of a person-centred empathy-based approach to autistic people. The approach to autistic patients is described in terms of

reasonable adjustments within a framework of positive risk taking. For supervisors and managers of autistic healthcare professionals, autism-friendly adjustments to training and working practice, with rationales, are suggested.; Competing Interests: The author declared the following potential conflicts of interest with respect to the research, authorship, and/or publication of this article: The author is autistic and is the ICU lead of Autistic Doctors International, a not-for-profit peer support and advocacy network. (© The Intensive Care Society 2024.)

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3. **Developmental Milestones for Children With Down Syndrome**

Authors: Baumer, Nicole;DePillis, Rafael;Pawlowski, Katherine;Zhang, Bo and Mazumdar, Maitreyi

Publication Date: 2024

Journal: Pediatrics 154(4)

Abstract: Objectives: The American Academy of Pediatrics recommends that children and adolescents with Down syndrome receive anticipatory guidance regarding development and behavior. However, few tools provide specific guidance on developmental norms for children with Down syndrome. Our objective was to estimate age ranges at which children and adolescents with Down syndrome achieve developmental milestones to facilitate developmental screening by pediatric practitioners.; Methods: We used standardized questionnaires to obtain information from clinicians and caregivers of children with Down syndrome who received care at the Boston Children's Hospital Down Syndrome Program between March 2018 and March 2023. Data included information from 2599 visits for 842 individuals with Down syndrome ages 2 months to 24 years. We used mixed-effects logistic regressions to predict the probability of achieving 25 specific developmental milestones with 15%, 30%, 45%, 60%, 75%, and 90% probability as a function of age. We further stratified results by individuals' sex.; Results: We present age norms for our study's population of people with Down syndrome for key milestones in academic, adaptive, language, and motor domains by calculating the ages at which milestone achievement was 75% probable. We then compare these norms to published norms for the general population.; Conclusions: This study provides clinicians and families with age-based norms for achievement of key developmental milestones for children and adolescents with Down syndrome. (Copyright © 2024 by the American Academy of Pediatrics.)

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4. **Parkinsonism in people with intellectual disability**

Authors: Boot, Erik;van Eeghen, Agnies,M.;Bloem, Bas R.;van de Warrenburg, Bart,P. and Cuypers, Maarten

Publication Date: 2024

Journal: Parkinsonism & Related Disorders 128, pp. 107079

Abstract: Competing Interests: Declaration of competing interest The authors declare that they have no known competing financial interests or personal relationships that could have

appeared to influence the work reported in this paper.

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5. **Specialized medical care for people with intellectual disabilities: A retrospective cohort study in an outpatient ID practice**

Authors: Breuer, Marian E. J.;Naaldenberg, Jenneken;Schalk, Bianca W. M.;Heutmekers, Marloes;Pelle, Tim;Bakker-van Gijssel, Esther J. and Leusink, Geraline L.

Publication Date: 2024

Journal: Journal of Policy & Practice in Intellectual Disabilities 21(3), pp. 1–10

Abstract: People with intellectual disabilities (ID) experience complex medical care needs and high levels of multimorbidity. In mainstream healthcare, these needs might remain undetected leading to unmanaged health problems and avoidable deaths. In the Netherlands, general practitioners (GPs) can refer to specialized ID physicians when ID-specific expertise is required. Little is known about the characteristics of specialized medical care for people with ID. This study explores the characteristics of specialized medical care for people with ID, including the interplay between medical-, psychological-, and context-related problems. A retrospective cohort study using medical records of patients with ID who had visited the outpatient ID practice in Nijmegen, the Netherlands. Medical records (n = 128) were analyzed using descriptive statistics, focusing on (1) reasons for initial consultation, (2) health-related problems identified during initial consultation, and (3) disciplines involved following initial consultation. Analyses were performed separately for patients who were referred by a medical professional and patients who visited the practice for proactive health checks related to the etiological diagnosis. Patients often initially visit the outpatient ID practice for one type of complaint, most often psychological. Diverse, multiple, and interconnected problems were identified during specialized medical ID consultation. A range of specialist professionals (n = 25) were involved by the ID physician. The health-related problems of people with ID seen at the outpatient ID practice are diverse and interconnected, and originate from an interplay between medical-, psychological-, and context-related problems. This complexity is not mirrored in the reasons for referring to the outpatient ID practice. It is essential to go beyond medical views and assess health complaints in an integrated way, including the way ID can influence all levels (physical, mental, contextual) of the experienced health issue within the context of everyday life.

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6. **The All Together Group: Co-Designing a Toolkit of Approaches and Resources for End-of-Life Care Planning With People With Intellectual Disabilities in Social Care Settings**

Authors: Bruun, Andrea;Cresswell, Amanda;Jeffrey, David;Jordan, Leon;Keagan-Bull, Richard;Giles, Jo;Swindells, Sarah;Wilding, Meg;Payne, Nicola;Gibson, Sarah L.;Anderson-Kittow, Rebecca and Tuffrey-Wijne, Irene

Publication Date: 2024

Journal: Health Expectations 27(4), pp. 1–11

Abstract: Introduction: Support staff within social care settings have expressed a need for resources to facilitate end-of-life care planning with people with intellectual disabilities. This study aimed to co-design a preliminary toolkit of end-of-life care planning approaches and resources that can be implemented in adult social care services for people with intellectual disabilities. Methods: An adapted Experience-Based Co-Design process was applied to develop a toolkit for end-of-life care planning with people with intellectual disabilities. A co-design group (the 'All Together Group') met six times from January to October 2023. The group comprised nine people with intellectual disabilities (including four researchers with intellectual disabilities, who also co-facilitated the workshops), five family members, five intellectual disability support staff including two intellectual disability service managers, and five healthcare professionals. Results: The All Together Group tested resources for and approaches to end-of-life care planning with people with intellectual disabilities, based on findings from a scoping review and a focus group study. Easy-read end-of-life care planning forms were deemed overwhelming and complicated, whilst visual and creative approaches were welcomed. Three new visual resources to support illness planning and funeral planning with people with intellectual disabilities were developed: (i) 'When I'm ill' thinking cards; (ii) 'Let's Talk About Funerals' conversation-starter pictures; and (iii) 'My funeral' planning cards. These three resources, alongside three positively evaluated existing resources, were included in a new toolkit for end-of-life care planning with people with intellectual disabilities. Conclusion: Through an iterative, flexible, inclusive, and comprehensive co-design process, a toolkit of three newly developed and three existing resources was created to facilitate support staff in doing end-of-life care planning with people with intellectual disabilities. Following a trialling process with support staff, the final toolkit was made freely available online. Patient or Public Contribution: The research team included four researchers with intellectual disabilities (A.C., D.J., L.J., and R.K.-B). Researchers with intellectual disability have been part of every step of the research process; from study design to data collection and analysis to dissemination of study findings.Intellectual disability service provider representatives (M.W., N.P., and S.S.) were part of the co-design group as well. Two of these representatives were also co-applicants in the overall project (N.P. and S.S.). The co-design group included people with intellectual disabilities, families, intellectual disability support staff and health and social care professionals. The study was supported by a Research Advisory Group comprising a variety of stakeholders, including people with intellectual disabilities families, intellectual disability researchers, representatives from intellectual disability organisations, and policymakers. Practitioner Points: To facilitate proper and timely end-of-life care planning, resources and approaches should be developed together with people with intellectual disabilities and support staff to make sure they are relevant, accessible, and workable in social care practice.People with intellectual disabilities prefer visual and creative approaches to end-of-life care planning rather than easy-read plans and forms.Co-producing an end-of-life care planning toolkit is an iterative, time-consuming, and complex process, which requires a flexible approach, adapting to the feedback from and needs of co-design group members.

7. **Prescription Medication Use in Pregnancy in People with Disabilities: A Population-Based Cohort Study**

Authors: Camden, Andi;Grandi, Sonia M.;Lunsky, Yona;Ray, Joel G.;Sharpe, Isobel;Lu, Hong;Guttmann, Astrid;Tailor, Lauren;Vigod, Simone;De Vera, Mary A. and Brown, Hilary K.

Publication Date: 2024

Journal: Journal of Women's Health (15409996) 33(9), pp. 1224–1232

Abstract: Background: Individuals with disabilities may require specific medications in pregnancy. The prevalence and patterns of medication use, overall and for medications with known teratogenic risks, are largely unknown. Methods: This population-based cohort study in Ontario, Canada, 2004–2021, comprised all recognized pregnancies among individuals eligible for public drug plan coverage. Included were those with a physical (n = 44,136), sensory (n = 13,633), intellectual or developmental (n = 2,446) disability, or multiple disabilities (n = 5,064), compared with those without a disability (n = 299,944). Prescription medication use in pregnancy, overall and by type, was described. Modified Poisson regression generated relative risks (aRR) for the use of medications with known teratogenic risks and use of ≥2 and ≥5 medications concurrently in pregnancy, comparing those with versus without a disability, adjusting for sociodemographic and clinical factors. Results: Medication use in pregnancy was more common in people with intellectual or developmental (82.1%), multiple (80.4%), physical (73.9%), and sensory (71.9%) disabilities, than in those with no known disability (67.4%). Compared with those without a disability (5.7%), teratogenic medication use in pregnancy was especially higher in people with multiple disabilities (14.2%; aRR 2.03, 95% confidence interval CI]: 1.88–2.20). Furthermore, compared with people without a disability (3.2%), the use of ≥5 medications concurrently was more common in those with multiple disabilities (13.4%; aRR 2.21, 95% CI: 2.02–2.41) and an intellectual or developmental disability (9.3%; aRR 2.13, 95% CI: 1.86–2.45). Interpretation: Among people with disabilities, medication use in pregnancy is prevalent, especially for potentially teratogenic medications and polypharmacy, highlighting the need for preconception counseling/monitoring to reduce medication-related harm in pregnancy.

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8. **Quality of life of children and young adults with Down syndrome from caregivers' perspective: A systematic review and meta-analysis**

Authors: Chan, Yu Yi;Wong, Bryan Wei Zhi;Cheok, Fergus Edward;Tan, Natania Rae Xiangqin;Kong, Gwyneth;Amin, Zubair and Ng, Yvonne Peng Mei

Publication Date: 2024

Journal: Annals of the Academy of Medicine, Singapore 53(8), pp. 502–513

Abstract: Introduction: Down syndrome (DS) negatively impacts the well-being of affected individuals. This study aimed to summarise the evidence on quality of life (QOL) of children and young adults with DS using quantitative measures from caregivers' perspective and identify factors that affected their QOL.; Method: Database search was conducted on PubMed,

Embase, Web of Science and CINAHL on 24 April 2024. Meta-analysis using random effects model was conducted where feasible. All studies underwent qualitative synthesis. The study protocol was registered with PROSPERO (CRD42023413532).; Results: Seventeen studies involving 3038 children with DS using various QOL measures were included: Pediatric Quality of Life Inventory (PedsQL) (8 studies), KIDSCREEN (4 studies), KidsLife (2 studies), The Netherlands Organization for Applied Scientific Research Academic Medical Center Children's QOL (2 studies) and Personal Outcome Scale (1 study). Meta-analysis on PedsQL studies compared scores between children with DS and typically developing (TD) children. Total scale score was lower in children with DS (mean 70.28, 95% confidence interval CI] 64.31-76.24) compared to TD children (mean 88.17, 95% CI 80.50-95.83). All subdomains of PedsQL were also lower in children with DS. Within the domain of psychosocial health, children with DS had statistically significant lower social functioning (standardised mean difference -1.40, 95% CI -2.27 to -0.53) and school functioning (standardised mean difference -1.09, 95% CI -1.55 to -0.62) scores, but similar emotional functioning scores. Qualitative synthesis revealed poorer subdomain QOL compared to TD children, especially in social functioning and cognitive functioning. QOL worsened during adolescent years. Family variables (parental education and occupation) did not affect parental perception of children's QOL. Children with DS who had higher intelligent quotient had better QOL.; Conclusion: Children with DS have lower caregiver-reported QOL than TD children, especially in social functioning and school functioning subdomains.

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9. **Quality of life of family caregivers of children and young adults with Down syndrome: A systematic review and meta-analysis**

Authors: Cheok, Fergus Edward;Tan, Natania Rae Xiangqin;Chan, Yu Yi;Wong, Bryan Wei Zhi;Kong, Gwyneth;Amin, Zubair and Ng, Yvonne Peng Mei

Publication Date: 2024

Journal: Annals of the Academy of Medicine, Singapore 53(8), pp. 490–501

Abstract: Introduction: The aims of this systematic review and meta-analysis are to synthesise quality of life (QOL) of family caregivers of children and young adults with Down syndrome (DS) and determine factors affecting their QOL.; Method: This review was conducted as per Preferred Reporting Items for Systematic Reviews and Meta-Analyses guideline. Key search terms were "quality of life", "down syndrome" and "trisomy 21". Meta-analysis using random effect model was conducted where feasible. All studies underwent qualitative synthesis. The study protocol was registered with PROSPERO (CRD42023413532).; Results: Eighteen studies with 1956 caregivers were included. Of the 10 studies utilising the World Health Organization Quality of Life Instrument-Brief Version, 5 were included in the meta-analysis. Psychosocial domain had the highest score with mean (95% confidence interval CI]) of 63.18 (39.10-87.25). Scores were poorer in physical, environmental and social domains: 59.36 (28.24-90.48), 59.82 (19.57-100.07) and 59.83 (44.24-75.41), respectively. Studies were heterogenous with I 2 values ranging from 99-100% (P <0.01). The remaining 8 studies used 6 other instruments. Qualitative synthesis revealed that caregivers' QOL was adversely affected by child-related factors, such as level of functional independence, developmental delay, presence of multiple comorbidities, impaired activities of daily living and poor sleep quality. Environmental factors that adversely affected caregivers' QOL included number of

children, housing and support from the family. Personal factors that affected caregivers' QOL included age, being a single mother, low education and low income.; Conclusion: QOL of caregivers of children with DS was lower than population reference data. Understand-ing the factors that influence family caregivers' QOL is an essential step towards improving the QOL of caregivers and their children with DS.

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10. **Living longer and stronger: Are children and young adults with Down syndrome experiencing healthier and better lives?**

Authors: Chow, Cristelle

Publication Date: 2024

Journal: Annals of the Academy of Medicine, Singapore 53(8), pp. 466–467

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11. **Antipsychotic medication in people with intellectual disability and schizophrenia: A 25-year updated systematic review and cross-sectional study**

Authors: Courtial, Elsa;Pouchon, Arnaud;Polosan, Mircea and Dondé, Clément

Publication Date: 2024

Journal: Journal of Psychopharmacology (Oxford, England) , pp. 2698811241276787

Abstract: Objectives: To determine the efficacy and safety of antipsychotic medication for treating individuals with a dual diagnosis of intellectual disability (ID) and schizophrenia.; Methods: We systematically reviewed the literature to explore the risks and benefits of antipsychotics for schizophrenia in ID. In addition, a cross-sectional retrospective study on the tolerance profiles of a representative ID and schizophrenia cohort was conducted.; Results: From the systematic search, we retained 18 articles detailing information on 24 cases. In almost all cases, the antipsychotic improved psychotic symptoms (e.g., hallucinations, delusions, disorganization). Negative manifestations were also improved (blunted affects, amotivation, poor rapport), as were challenging behaviors in a few cases. The most commonly reported side effects were neurological (extra-pyramidal, movement disorder, epilepsy) and metabolic manifestations. In the retrospective cross-sectional study, we reported data on 112 participants with comorbid ID and schizophrenia. In all, 103 participants were antipsychotic-treated, of which 39% were on antipsychotic monotherapy. Of these, 35% were in the obesity range, 25% in the hyperglycemic range, and 25% in the dyslipidemia range. The body mass index did not differ between the groups.; Conclusions: This study provides an initial evidence base underpinning the efficacy of antipsychotic drugs on schizophrenia in the ID population. Nevertheless, there may be an increased risk of metabolic side effects, hence, close monitoring of blood glucose, lipids, and weight should be implemented when prescribing antipsychotics to this population.; Competing Interests: Declaration of conflicting interestsThe author(s) declared the following potential conflicts of interest with respect to the research, authorship, and/or publication of this article: Clément Dondé and Mircea Polosan have received travel awards or financial compensation from Lundbeck and Otsuka. Arnaud Pouchon has received financial compensation from Lundbeck. Elsa Courtial declares that she has no

conflicts of interest pertaining to this submission.

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12. **Factors Influencing Palliative and End-of-Life Care for Adults with Intellectual Disabilities: A Scoping Review of Health and Care Workers' Experiences**

Authors: Couvrette, Romane;Milot, É and Fortin, G.

Publication Date: Jul ,2024

Journal: Journal of Social Work in End-of-Life & Palliative Care 20(3), pp. 292–310

Abstract: In developed countries, there has been an increase in the longevity of adults with intellectual disabilities. In the later stages of their lives, people with intellectual disability have specific needs in terms of palliative and end-of-life care that need to be better understood in order to offer appropriate care. This scoping review aimed to identify the main factors influencing the provision of palliative and end-of-life care from the perspective of health and care workers involved with adults with an intellectual disability at the end of life. Seven databases were systematically searched for relevant articles published between 2002 and 2022. NVivo qualitative research analysis software was used to conduct a thematic analysis of the 50 included studies. Three main factors were identified: the location of care and death, the involvement of the person with intellectual disability, and collaborative practices.

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13. **Supports Provided to People with Intellectual Disability and Dysphagia to Assist with Participation in Eating and Drinking: A Scoping Review**

Authors: Cox, Gillian;Wylie, Karen;Leitão, Suze;Cocks, Naomi and Shweta Kalyani, Kumari

Publication Date: 2024

Journal: Health & Social Care in the Community 2024, pp. 1–17

Abstract: Many people with intellectual disability live with swallowing, eating, and drinking difficulties (dysphagia). People living with both intellectual disability and dysphagia may require a range of supports in order to have the opportunity to participate in different eating and drinking environments of their choice. Understanding the nature of those supports is important to ensure that people with intellectual disability living with dysphagia can continue to create a good life for themselves at home and in their community. This study aimed to identify the nature of supports provided to people with intellectual disability and dysphagia when eating and drinking in different environments, as described in the published literature. A scoping review, underpinned by an a priori protocol, was conducted by a team of four reviewers. Four databases were searched. Sixteen papers were included for full-text review. The review identified that studies most frequently reported support in the form of safety strategies to prevent the ill-health consequences of dysphagia and training carers in those safety strategies by speech-language pathologists. To a much lesser extent, studies identified the psychosocial needs of people with intellectual disability and dysphagia and how these were being considered in the design of training support. Overall, this review identified a significant need for future research into supports for eating outside the home and collaboration with people with

intellectual disability and dysphagia about dysphagia training content which reflects the experience of living with dysphagia in social community environments.

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14. **The influence of therapy quality on outcomes from behavioural activation and guided self-help treatments for depression in adults with intellectual disabilities**

Authors: Dagnan, Dave;Thompson, Paul;Hastings, Richard P.;Hatton, Chris;Melville, Chris;Cooper, Sally-Ann;McMeekin, Nicola;Fulton, Lauren;Jones, Rob S. P.;McConnachie, Alex and Jahoda, Andrew

Publication Date: 2024

Journal: The British Journal of Clinical Psychology

Abstract: Objectives: We report the effect of quality of therapy delivery on outcomes in a randomized, controlled trial of behavioural activation (BA) and guided self-help (GSH) for depression in adults with intellectual disabilities.; Methods: A study specific measure of quality was used in a linear mixed effect model to determine the effects therapy and therapy quality on therapy outcome.; Results: There was a significant interaction between quality and treatment type, with lower quality therapy associated with better outcome for GSH but poorer outcome for BA, with little difference in outcomes at higher levels of therapy quality.; Conclusions: Factors suggesting high quality in individualized BA may indicate problematic engagement for GSH. More research into processes in therapy for people with intellectual disabilities is required. (© 2024 The Author(s). British Journal of Clinical Psychology published by John Wiley & Sons Ltd on behalf of British Psychological Society.)

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15. **Barriers to healthcare predict reduced health-related quality of life in autistic adults without intellectual disability**

Authors: David, Nicole;Rahlff, Pascal;König, Hannah;Dückert, Sophia;Gewohn, Petia;Erik, Frank;Vogeley, Kai;Schöttle, Daniel;Konnopka, Alexander;Schulz, Holger and Peth, Judith

Publication Date: 2024

Journal: Autism : The International Journal of Research and Practice , pp. 13623613241275406

Abstract: Lay Abstract: Health-related quality of life reflects a person's perspective on their well-being in physical, mental, social, work-related, and other aspects of health or life. Autistic adults typically report difficulties in many or all of these domains and, thus, often experience their health-related quality of life being reduced. Nonetheless, they do not obtain the professional support they need and report barriers to accessing or receiving appropriate healthcare. We know little about the impact of barriers to healthcare on health-related quality of life in autistic adults. In the present study, 311 autistic adults without intellectual disability in Germany completed an online survey on their current health-related quality of life and the number of barriers to healthcare they experience. In addition, they were asked about their personal and clinical background as well as about the amount of healthcare and support they recently received. We investigated how this information and, particularly, barriers to healthcare

explained variations in individual levels of health-related quality of life. We found that barriers to healthcare, compared to most other variables, were a strong predictor of health-related quality of life: The more barriers autistic adults reported, the lower their experienced psychological and physical well-being. To our knowledge, this is the first paper to examine the relationship between barriers to healthcare and health-related quality of life in autism. Our results suggest that healthcare providers need to become aware of the barriers individuals with autism have in seeking and getting healthcare. Improved access to services might contribute to better health-related quality of life in autistic adults.; Competing Interests: Declaration of conflicting interestsThe author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

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16. **Capturing Staff Perspectives on Quality Interaction With Clients With Intellectual Disability: A Diary Study**

Authors: Droogmans, Gilles;Nijs, Sara and Maes, Bea

Publication Date: 2024

Journal: Intellectual and Developmental Disabilities 62(5), pp. 376–391

Abstract: For people with severe or profound intellectual disability (ID), support staff are important interaction partners. The quality of their interactions, a multidimensional construct, is well documented, but the staff perspective remains underexposed. This study aims to capture the behaviors, thoughts, and emotions of staff when interacting with their clients, and their views on what constitutes quality. Thirty-four support staff completed a 5-day diary about a daily interaction with a specific client. A thematic analysis was carried out. The diary entries depicted behaviors and thoughts with different foci, and emotions with positive and negative valences. The pursuit of Harmonization and the experience of Return emerged as overarching dimensions central to staff's views on quality interaction. Limitations and directions for future research are discussed. (©AAIDD.)

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17. **Trends in Body Mass Index Among Individuals With Neurodevelopmental Disorders**

Authors: Garcia-Argibay, Miguel;Lundström, Sebastian;Cortese, Samuele and Larsson, Henrik

Publication Date: 2024

Journal: JAMA Network Open 7(9), pp. e2431543

Abstract: This repeated cross-sectional study compares changes in body mass index over time among Swedish youths with vs without neurodevelopmental disorders from 2004 to 2020. Key Points: Question: Has there been a change in body mass index (BMI) over time among youths with neurodevelopmental disorders (NDDs) compared with youths without NDDs? Findings: This repeated cross-sectional study of 24 969 Swedish youths aged 9 or 12 years found significantly steeper increases in BMI over time between 2004 and 2020 at the upper end of the BMI distribution among individuals with NDDs compared with those without NDDs. Meaning: Results from this study suggest a need to address an increasing risk of overweight in

youths with NDDs through targeted prevention and treatment. Importance: Neurodevelopmental disorders (NDDs) such as autism spectrum disorder (ASD) and attention-deficit/hyperactivity disorder (ADHD) are increasingly common. Individuals with NDDs have heightened obesity risks, but long-term data on body mass index (BMI) trends over time in this population are lacking. Objective: To assess secular BMI changes from 2004 to 2020 among children with NDDs compared with those without NDDs. Design, Setting, and Participants: This repeated cross-sectional study used data from the Child and Adolescent Twin Study in Sweden. Children born between January 1, 1992, and December 31, 2010, were screened for neurodevelopmental symptoms using the Autism-Tics, ADHD, and Other Comorbidities inventory between July 2004 and April 2020 when they were 9 or 12 years of age. Data analysis was conducted between September 27, 2023, and January 30, 2024. Main Outcomes and Measures: BMI percentiles (15th, 50th, and 85th) were modeled using quantile regression and compared between youths with and without NDDs. Secular changes in BMI percentiles over time spanning 2004 to 2020 were evaluated and stratified by NDD subtype. Results: The cohort included 24 969 Swedish twins (12 681 51%] boys) born between 1992 and 2010, with mean (SD) age of 9 (0.6) years. Of these, 1103 (4%) screened positive for 1 or more NDDs, including ADHD, ASD, and/or learning disability. Results indicated that at the 85th BMI percentile, there was a greater increase in BMI from 2004 to 2020 among youths with NDDs compared with those without NDDs (β for interaction βint] between NDD status and time, 1.67; 95% CI, 0.39-2.90). The greatest divergence was seen for ASD (βint, 2.12; 95% CI, 1.26-3.70) and learning disability (βint, 1.92; 95% CI, 0.65-3.82). Within the latest cohort (2016-2020), the 85th BMI percentile was 1.99 (95% CI, 1.08-2.89) points higher among children with NDDs compared with those without NDDs. Conclusions and Relevance: In this repeated cross-sectional study, at the higher end of the BMI distribution, children with NDDs had significantly greater increases in BMI compared with peers without NDDs over a 16-year period, highlighting an increasing risk of overweight over time in youths with NDDs compared with those without NDDs. Targeted obesity prevention efforts for this high-risk population are needed.

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18. **Concurrent Validity of Abbreviated Walk Tests Among Adults With Mild to Moderate Intellectual Disability**

Authors: Goh, Rena Wen Yi;Chan, Gideon Ji Yan;Mohammad Hanip, Lynn Amelia and Kwok, Boon Chong

Publication Date: 2024

Journal: Journal of Applied Research in Intellectual Disabilities : JARID 37(6), pp. e13304

Abstract: Background: Walk tests are common gait speed and endurance assessments. Shorter test versions could benefit adults with intellectual disability. Thus, the concurrent validity of shorter tests was studied.; Methods: Thirty-five adults with mild to moderate intellectual disability, aged 21-64 years, were assessed with the 4-m walk test, 10-m walk test for gait speed, 2-min walk test, and 6-min walk test for endurance. Correlation and Bland-Altman plots analyses were used to establish concurrent validity between shorter and standard tests.; Results: Strong positive relationships were found for gait speed tests, $r = 0.94$, $p < 0.001$, and endurance tests, $r = 0.83$, $p < 0.001$, and differences between shorter and standard tests were within limits of agreement.; Conclusions: The concurrent validity of shorter

walk tests was established in this study. This would mean that adults with intellectual disability with lower levels of fitness could be assessed.; Trial Registration: Australian New Zealand Clinical Trial Registry: ACTRN12624000203550. (© 2024 John Wiley & Sons Ltd.)

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19. **Turner syndrome and neuropsychological abnormalities: a review and case series**

Authors: Guaraná, Bruna Baierle;Nunes, Marcela Rodrigues;Muniz, Victória Feitosa;Diniz, Bruna Lixinski;Nunes, Maurício Rouvel;Böttcher, Ana Kalise;Rosa, Rafael Fabiano Machado;Mergener, Rafaella and Zen, Paulo Ricardo Gazzola

Publication Date: 2024

Journal: Revista Paulista De Pediatria : Orgao Oficial Da Sociedade De Pediatria De Sao Paulo 43, pp. e2023199

Abstract: Objective: The objective of this study was to establish the genotype-phenotype correlation between karyotype results and the neurological and psychiatric alterations presented in patients with Turner syndrome (TS).; Methods: A retrospective study was conducted on the medical records of 10/140 patients with TS and neurophysiological abnormalities seen at a university hospital in southern Brazil. In addition, a literature review spanning the period from January 1, 2012 to January 1, 2023 was carried out using the PubMed and Virtual Health Library databases.; Results: Our study showed a potential correlation between neurological and psychiatric alterations in patients with TS. These findings are in accordance with those described in literature such as a high prevalence of learning or intellectual disabilities. However, our sample found more seizure episodes than those reported in other studies.; Conclusions: The correlation established could be due to X chromosome dose-effect, as the review suggests that sex chromosome number and hormonal development can be associated with verbal, social, and cognitive skills or impairments.

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20. **Transitional challenges: Psychotropic medication and residential setting among young adults with intellectual disabilities**

Authors: Houseworth, James;Tichá, Renáta;Pettingell, Sandra L.;Stancliffe, Roger J. and Bershadsky, Julie

Publication Date: 2024

Journal: Journal of Policy & Practice in Intellectual Disabilities 21(3), pp. 1–12

Abstract: As youth with intellectual and developmental disabilities (IDD) are transitioning from the school systems and special education supports, many of them are moving into the adult service system (e.g., Vocational Rehabilitation, Home and Community-Based Services). Thus, in addition to adolescence being a source of many psychological and behavioral needs, the change in service systems often leads to uncertainty and anxiety. Psychotropic medications tend to be used to treat challenging behavior and psychological conditions (e.g., depression, anxiety, psychosis). This study used National Core Indicators-In-Person Survey 2020–2021 data to explore the prevalence of psychotropic medication use among two groups of people

with IDD: disability service users of transition age (18–25 years) and disability service users of adult age (26–45 years) and the role of residential settings (where one lives) as related to psychotropic medication use. The results indicated that adults (aged 26–45 years) are more likely to be prescribed psychotropic medications. This appears to be driven by the larger number of transition-aged adults who still live with family, where prescription rates are much lower. Psychotropic drug use is an important issue due to its potential to lead to unintended negative consequences that affect health, social inclusion, and self-determination if not carefully and effectively administered.

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21. **An overview of the effects of physical exercise programs on individuals with Intellectual and Developmental Disabilities**

Authors: Jacinto, Miguel;Ferreira, José Pedro;Monteiro, Diogo;Antunes, Raul;Campos, Maria João and Matos, Rui

Publication Date: 2024

Journal: Motricidade 20(2), pp. 85–98

Abstract: Being aware of the relevance of physical exercise in individuals with Intellectual and Developmental Disabilities (IDD), we intend to conduct a brief review on the importance of regular physical exercise for this population. An approach will be taken in order to acknowledge the barriers to the high rates of sedentary lifestyles in this population, the potential benefits of physical exercise, and the essential aspects for a correct assessment, prescription, and implementation of these programs in the population with IDD, through a reflection supported by scientific evidence. The current overview aims to provide relevant information regarding the health benefits of physical exercise in individuals with IDD, as the basis for QoL promoting more active and healthier lifestyles, namely through structured physical exercise. In addition, it is also a useful tool for consultation by exercise professionals since adjusted indoor and outdoor exercise programs are listed.

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22. **Effects of visual and auditory cognitive tasks on postural balance in adolescents with intellectual disability: A comparative analysis of trained versus non-trained individuals**

Authors: Jouira, Ghada;Iulian Alexe, Dan;Rekik, Ghazi;Ioana Alexe, Cristina;Čaušević, Denis;Setiawan, Edi and Sahli, Sonia

Publication Date: 2024

Journal: Neuroscience Letters 842, pp. 137968

Abstract: This study aimed to investigate the influence of visual and auditory cognitive tasks on postural balance in adolescents with intellectual disabilities (ID). Participants included two groups: a trained group (n = 11) with experience in athletic activities and a sedentary group (n = 14). The experiment used a comparative cross-sectional design, with data collection involving single-task (ST) and Visual dual-task (VDT), and auditory dual-task (ADT) conditions

in both firm and foam surface conditions. Cognitive tests included the Working Memory Test (WMT) and the Selective Attention Test (SAT). Results revealed that the trained group demonstrated significantly superior balance performance ($p < 0.05$). During the SAT, VDT conditions had lower center of pressure (CoP) values than ADT conditions in the sedentary group ($p < 0.01$), this result was observed in the training group only in the WMT, suggesting greater postural instability during ADT. These findings highlight the complex relationship between cognitive function and motor control in adolescents with ID, highlighting the potential benefits of regular physical activity interventions to improve postural balance abilities in this population.; Competing Interests: Declaration of Competing Interest The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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23. **Perspectives of Adults with Intellectual Disabilities on Quality of Life: A Qualitative Study**

Authors: Kapsalakis, Pavlos and Nteropoulou-Nterou, Evdoxia

Publication Date: 2024

Journal: International Journal of Environmental Research and Public Health 21(9)
Abstract: Experiences of occupational participation of adults with Intellectual Disabilities (IDs) were explored through the lens of the Model of Occupational Justice (MOJ) and Critical Theory in order to shape and develop an occupation-centered model of quality of life (QoL). This qualitative study involved thirteen adults with IDs (N = 13). A semi-structured interview, constructed based on MOJ and Critical Theory principles, was administered to explore perspectives on QoL, as well as injustices regarding occupational participation. The interviews were analyzed using QSR NVivo8 and followed a content analysis methodology. A preliminary model of Occupational Quality of Life (O-QoL), with an everyday occupations core component, has been formed. The model includes three core O-QoL domains: (i) social well-being, (ii) emotional-physical well-being, and (iii) material adequacy. Key indicators of O-QoL were identified as leisure and social activities, while socioenvironmental factors such as occupational deprivation were noted as aggravating. Specific occupations, including leisure activities, physical exercise/sports, art, video games, and vocational training, were found to be beneficial for O-QoL. Moreover, the importance of promoting and supporting the rights of people with IDs for employment, independent living, and sexual expression was highlighted. The model of O-QoL (version 1) could be a valuable alternative conceptual framework of QoL in the field of IDs; however, further research is needed to validate and refine the model.

24. **Good mental health in people with intellectual disabilities: a systematic review**

Authors: Komenda-Schned, Sophie;Landskron, Sarah Jasmin;Moritz, Paula;Brunevskaya, Nadine;Santambrogio, Jacopo;Salvador-Carulla, Luis;Lueger-Schuster, Brigitte and Zeilinger, Elisabeth Lucia

Publication Date: 2024

Journal: Health Psychology Review , pp. 1–23

Abstract: While mental disorders have been broadly researched in people with intellectual disabilities (ID), comparatively less attention has been given to the conceptualisation of good mental health for this population. To capture existing concepts, definitions and measurement approaches of good mental health a systematic literature review was conducted following PRISMA guidelines. The search was carried out in eleven databases, using various synonyms of (i) intellectual disability, (ii) mental health, (iii) wellbeing, (iv) definition, and (v) assessment. A total of 2,046 datasets were identified, of which 37 met the inclusion criteria and were analysed using reflexive thematic analysis and content analysis. Results show four main themes: (1) environment, (2) absence of mental illness, (3) physical health, and (4) psychosocial functioning. The fourth was the most dominant theme and was further divided into five sub-themes: (1) emotionality, (2) interpersonal relations, (3) realise own potential, (4) personal resources, and (5) overall appraisal of life. Our findings reveal different conceptualisations of wellbeing, which is a vital part of good mental health, but highlight a notable research gap in the actual definition and conceptualisation of good mental health for people with ID.

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25. **‘Shocking’ gap in acute services may be raising risk for vulnerable group: Almost one in three acute NHS hospital trusts in England may not have an acute learning disability liaison service with an LD nurse, a Nursing Standard investigation suggests**

Authors: Kowalczyk, Anita

Publication Date: 2024

Journal: Nursing Standard 39(9), pp. 8–10

Abstract: Nearly one in three acute NHS trusts in England (30%) do not have a specific acute learning disability liaison service with a learning disability registered nurse, a Nursing Standard investigation suggests.

26. **Gabapentin treatment for challenging behaviors in autism spectrum disorder and coexisting intellectual disability: a case report**

Authors: Marini, Stefano;D'Agostino, Lucia;Ciamarra, Carla;De Berardis, Domenico and Gentile, Alessandro

Publication Date: 2024

Journal: Advances in Mental Health & Intellectual Disabilities 18(3), pp. 101–109

Abstract: Purpose: The purpose of this case report is to report the clinical experience of the use of gabapentin in the management of problem behaviors in a person with autism spectrum disorder and comorbid intellectual disability. Autism spectrum disorder is a neurodevelopmental disorder with a high prevalence of intellectual disability. Challenging behaviors in autism spectrum disorder are very common. In recent years, the hypothesis that the symptoms of autism derive from a deficiency of the inhibitory neurotransmission of gamma-aminobutyric acid is gaining considerable weight. Design/methodology/approach: Exploring behavioral symptoms improvement in an adult man with ASD and severe intellectual disability taking gabapentin. Findings: The rating scales used show improvement in challenging behaviors and aggressions. No side effects were observed. Originality/value: Currently, there are no authorized drugs for the treatment of the symptomatic features of autism spectrum disorder, but drugs are used for comorbid psychopathological aspects. The authors want to speculate on a hypothetical function of gabapentin in remodeling the expression of alpha-2-delta subunits in people with autism and the processing of neural information.

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27. **Nurses' experiences on the use of Positive Behaviour Support in the management of challenging behaviour in adults with a dual diagnosis of a mental health disorder and an intellectual disability**

Authors: Meggs, Joseph and O'Reilly, Professor Pauline

Publication Date: 2024

Journal: Archives of Psychiatric Nursing 52, pp. 76–82

Abstract: Individuals who have a dual diagnosis of both a psychiatric disorder and an intellectual disability (ID) are more likely to exhibit challenging behaviour than the general population. Clinicians globally have been encouraged to use positive approaches such as Positive Behaviour Support (PBS) when managing challenging behaviour. To explore nurses' views, opinions and perceptions on the use of positive behaviour support, as an adjunctive therapy, in the management of challenging behaviour in adults with a dual diagnosis of a mental health disorder and an intellectual disability within a mental health setting. A descriptive qualitative study was undertaken to identify registered nurses' experiences of using PBS in managing challenging behaviour. Data were collected from ten participants via semi-structured interviews and analysed using thematic analysis. Two themes were constructed; 1) Being involved from the beginning and 2) Impact on adults with a dual diagnosis. Nurses' involvement from the onset was fundamental in maximising the potential of PBS. Benefits of

PBS were identified. Having a meaningful relationship with clients and a good knowledge of their behaviours was integral to the success of PBS. Participants emphasised the importance of continuous education around PBS. Nurses should be included in the formulation of PBS plans. • Nurses identified the need for continuous education around PBS, highlighting the potential benefits of practical workshops, where nurses could be afforded an opportunity to enhance their PBS skills. • Nurses held the belief that their inclusion in PBS formulation from the outset was imperative to help aid the success of the intervention. • This paper focuses on the views of nurses on the use of PBS in the management of challenging behaviour, in adults with a dual diagnosis of a mental health disorder and an intellectual disability. There has been an international focus on reducing restrictive practices in the management of challenging behaviours. Consequently, there is an increased use of PBS. It is important nurses use PBS from the onset to ensure the consistent management of challenging behaviours. Having a good rapport and relationship with clients has a positive impact on PBS outcomes.

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28. **"It does change the narrative for health and social care" views of clinical and homeless service staff about the use of intellectual disability screening tools within homeless support pathways in the north of England**

Authors: Metcalfe, Dale;McKenzie, Karen;Murray, George and Shirley, Alex

Publication Date: 2024

Journal: Journal of Policy & Practice in Intellectual Disabilities 21(3), pp. 1–11

Abstract: Homelessness is a worldwide health inequality. People with intellectual disability represent a relatively high proportion of homeless people, and for many their intellectual disability is not recognised. The study intended to obtain stakeholder views about how intellectual disability screening can be integrated into the support pathway for people who are homeless. A qualitative approach was taken using Thematic Analysis. Nine staff, who work with homeless people or are involved in the intellectual disability assessment pathway, were interviewed. Analysis produced three themes, each containing two subthemes. 'Current routes to support' investigates experiences of the existing pathway; 'Labels', explores views about making intellectual disability visible; 'Creating a pathway,' outlines ideas about developing and implementing a screening pathway between services. The results help inform how current practices of identifying people with intellectual disability might be improved and the role of screening in this. These results, when combined with other research around screening tools, provide insight into how intellectual disability screening can be integrated within services.

29. **Perspectives of practitioners on support for caregivers of children with intellectual disability**

Authors: Molefe, Lebogang L.;Sehularo, Leepile A. and Koen, Daleen M.

Publication Date: 2024

Journal: Curationis 47(1), pp. e1–e11

Abstract: Background: Children with profound intellectual disabilities are unable to do anything for themselves and require full-time care in healthcare facilities. While caring for children, secondary caregivers become overwhelmed. Coupled with little or no support, the overwhelming work affects their psychological, social and financial well-being. Mental healthcare practitioners have perspectives on conditions under which secondary caregivers work and how can they be supported. Little is known about such perspectives.; Objectives: This study aims to explore and describe the perspectives of mental healthcare practitioners regarding the conditions under which secondary caregivers of children with profound intellectual disabilities work and how can they be supported.; Method: A qualitative-exploratory-descriptive and contextual research design was adopted using a non-probability purposive sampling technique. This study was conducted in Gauteng province. Semi-structured individual interviews were performed to collect data. Content data analysis and ATLAS.ti were used to analyse the data.; Results: Knowledge and skills development, stress reduction, resources and motivation were themes that emerged.; Conclusion: This study explored and described the perspectives of mental healthcare practitioners regarding the conditions under which secondary caregivers of children with profound intellectual disabilities work and how can they be supported. If implemented, perspectives can improve the holistic well-being of secondary caregivers.Contribution: This study broadened an understanding of how secondary caregivers can be supported. Future researchers can use study results to develop programmes, intervention strategies and frameworks to support secondary caregivers.

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30. **Adapting Complicated Grief Therapy for Use With People With Intellectual Disabilities: An Action Research Study**

Authors: O'Riordan, Damien;Conway, Emma;Dodd, Philip and Guerin, Suzanne

Publication Date: 2024

Journal: Journal of Applied Research in Intellectual Disabilities : JARID 37(6), pp. e13296

Abstract: Background: There is established evidence of complicated grief among people with an intellectual disability. This paper describes the process of adapting complicated grief therapy (CGT) for this population.; Method: Action research documented the adaptation of CGT. Qualitative methods included analysing meeting notes, reflective interviews with two members of the team involved in adapting the materials, and interviews with six professionals working in disability settings who reviewed the adapted materials.; Results: Key processes included adapting the standardised tools that form part of CGT and developing adapted approaches to abstract concepts related to death, dying and bereavement. Key therapeutic components such as imaginal revisiting and the role of significant others required adaptation

for implementation with people with intellectual disabilities.; Conclusion: The importance of adapting evidence-based therapies for people with intellectual disabilities is emphasised. This research provides an adapted form of an established therapy for piloting with this population. (© 2024 The Author(s). Journal of Applied Research in Intellectual Disabilities published by John Wiley & Sons Ltd.)

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31. **Rett Syndrome: The Emerging Landscape of Treatment Strategies**

Authors: Percy, Alan K.;Ananth, Amitha and Neul, Jeffrey L.

Publication Date: 2024

Journal: CNS Drugs 38(11), pp. 851–867

Abstract: Rett syndrome (RTT) has enjoyed remarkable progress in achieving specific therapies. RTT, a unique neurodevelopmental disorder first described in 1966, progressed slowly until the landmark paper of Hagberg and colleagues in 1983. Thereafter, rapid advances were achieved including the development of specific diagnostic criteria and the active search for a genetic etiology, resulting 16 years later in identification of variants in the methyl-CpG-binding protein (MECP2) gene located at Xq28. Shortly thereafter, the NIH Office of Rare Diseases funded the RTT Natural History Study (NHS) in 2003, initiating the acquisition of natural history data on clinical features from a large population of individuals with RTT. This information was essential for advancement of clinical trials to provide specific therapies for this disorder. In the process, the International Rett Syndrome Association (IRSA) was formed (now the International Rett Syndrome Foundation-IRSF), which participated directly in encouraging and expanding enrollment in the NHS and, subsequently, in developing the SCOUT program to facilitate testing of potential therapeutic agents in a mouse model of RTT. The overall objective was to review clinical characteristics developed from the NHS and to discuss the status of specific therapies for this progressive neurodevelopmental disorder. The NHS study provided critical information on RTT: growth, anthropometrics, longevity, key comorbidities including epilepsy, breath abnormalities, gastroesophageal dysfunction, scoliosis and other orthopedic issues, puberty, behavior and anxiety, and progressive motor deterioration including the appearance of parkinsonian features. Phenotype-genotype correlations were noted including the role of X chromosome inactivation. Development of clinical severity and quality of life measures also proved critical for subsequent clinical trials. Further, development of biochemical and neurophysiologic biomarkers offered further endpoints for clinical trials. Initial clinical trials prior to the NHS were ineffective, but advances resulting from the NHS and other studies worldwide promoted significant interest from pharmaceutical firms resulting in several clinical trials. While some of these have been unrewarding such as sarizotan, others have been quite promising including the approval of trofinetide by the FDA in 2023 as the first agent available for specific treatment of RTT. Blarcamesine has been trialed in phase 3 trials, 14 agents have been studied in phase 2 trials, and 7 agents are being evaluated in preclinical/translational studies. A landmark study in 2007 by Guy et al. demonstrated that activation of a normal MECP2 gene in a null mouse model resulted in significant improvement. Gene replacement therapy has advanced through translational studies to two current phase 1/2 clinical trials (Taysha102 and Neurogene-401). Additional genetic therapies are also under study including gene editing, RNA editing, and X-chromosome reactivation. Taken together, progress in understanding and treating RTT over

the past 40 years has been remarkable. This suggests that further advances can be expected. (© 2024. The Author(s).)

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32. **Moving Toward Neurodiversity-Affirming Integrated Psychotherapy With Autistic Clients**

Authors: Pliskin, Ariel E. and Crehan, Eileen T.

Publication Date: 2024

Journal: Journal of Psychotherapy Integration 34(3), pp. 338–350

Abstract: As mental health providers often do not know how to work with autistic clients in a way that respects autistic experience, many autistic adults are left with unmet mental health needs. Developing neurocultural competence and humility involves questioning antiautistic bias and innovating affirming methods. This article explores how therapy sessions may look when informed by Henriques' character adaptation systems theory. The suggested approach can inform treatment stages and provide mental health professionals with ways to improve their practice. Public Health Significance Statement: Autistic people are systematically harmed by living in a world that is not designed to include them. Pathology-based methods of intervention have harmed autistic people, and the neurodiversity-affirming approach outlined in this article can benefit autistic people around the world.

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33. **Alzheimer Dementia Among Individuals With Down Syndrome**

Authors: Rubenstein, Eric;Tewolde, Salina;Michals, Amy;Weuve, Jennifer;Fortea, Juan;Fox, Matthew P.;Pescador Jimenez, Marcia;Scott, Ashley;Tripodis, Yorghos and Skotko, Brian G.

Publication Date: 2024

Journal: JAMA Network Open 7(9), pp. e2435018

Abstract: Importance: With the advancement in administrative data as a research tool and the reliance on public health insurance for individuals with Down syndrome, population-level trends in Alzheimer dementia in this population are beginning to be understood.; Objective: To comprehensively describe the epidemiology of Alzheimer dementia in adults with Down syndrome in a full US Medicare and Medicaid sample.; Design, Setting, and Participants: This cohort study included 132 720 adults aged 18 years or older with Medicaid and/or Medicare claims data with an International Statistical Classification of Diseases and Related Health Problems code for Down syndrome. Data were collected from January 1, 2011, to December 31, 2019, and analyzed from August 2023 to May 2024.; Main Outcomes and Measures: The main outcome was prevalence of Alzheimer dementia in each calendar year and during the 9-year period. Alzheimer dementia incidence rates by calendar year and age and stratified for race or ethnicity as well as time to death after Alzheimer dementia diagnosis were also assessed.; Results: There were 132 720 unique adults with Down syndrome from 2011 to 2019: 79 578 (53.2%) were male, 17 090 (11.7%) were non-Hispanic Black, 20 777 (15.7%) were Hispanic, 101 120 (68.8%) were non-Hispanic White, and 47 692 (23.3%) had ever had an Alzheimer dementia diagnosis. Incidence was 22.4 cases per 1000 person-years. The

probability of an incident Alzheimer dementia diagnosis over 8 years was 0.63 (95% CI, 0.62-0.64) for those entering the study between ages 55 to 64 years. Mean (SD) age at incident diagnosis was 54.5 (7.4) years and median (IQR) age was 54.6 (9.3) years. Mean (SD) age at death among those with Alzheimer dementia was 59.2 (6.9) years (median IQR], 59.0 8.0] years). The mean (SD) age at onset for the Hispanic group was 54.2 (9.2) years, 52.4 (7.8) years for the American Indian or Alaska Native group, and 52.8 (8.2) years for the mixed race groups compared with 55.0 (7.8) years for the White non-Hispanic group. For age at death, there were no differences by sex. The mean (SD) age at death was later for the White non-Hispanic group (59.3 6.8] years) compared with the Hispanic group (58.5 7.8] years), Native American group (57.8 7.1] years), and mixed race group (58.2 7.0] years).; Conclusions and Relevance: In this cohort study of adults with Down syndrome who were enrolled in Medicaid and Medicare, Alzheimer dementia occurred at high rates. Consistency with clinical studies of dementia in Down syndrome supports the use of administrative data in Down syndrome-Alzheimer dementia research.

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34. **Technology-Based Physical Health Interventions for Adults with Intellectual Disability: A Scoping Review**

Authors: Savage, Melissa N.;Clark, Tina A.;Baffoe, Edward;Candelaria, Alexandra E.;Aneke, Lola;Gonzalez, Renee;Al Enizi, Ali;Anguita-Otero, Marisol;Edwards-Adams, Keita;Grandberry, Lilliesha and Reed, Stella

Publication Date: 2024

Journal: Journal of Developmental & Physical Disabilities 36(5), pp. 757–792

Abstract: Physical health habits including physical activity and nutrition are essential for numerous health benefits. However, beginning in childhood, individuals with intellectual disability engage in lower levels of physical activity and healthy nutrition habits compared to individuals without intellectual disability, a trend that carries on into adulthood. Researchers continue to examine the effectiveness of interventions to increase engagement in physical health habits and improve health outcomes for individuals with intellectual disability, with an increased focus on technology-based interventions. This scoping review aimed to describe how technology was being utilized within interventions to improve health-related outcomes for adults with intellectual disability. We described the technology being used, who used the technology, and the feasibility of the interventions. Forty-one studies met criteria, with a total of 698 adult participants with an intellectual disability. While no studies on nutrition were located, technology was used in various physical activity interventions, with the most common being preferred stimulus access, exergaming, and video-based instruction. Most studies took place at day or rehabilitation centers, were implemented by research teams, and either did not discuss cost or were vague in their description related to cost. Implications, limitations, and future research directions are discussed.

35. **Hormonal Imbalance as a Prognostic Factor of Physical Development of Children with Intellectual Disability**

Authors: Smirnova, Olga V.;Ovcharenko, Elizaveta S. and Kasparov, Edward V.

Publication Date: 2024

Journal: Children 11(8), pp. 913

Abstract: Introduction: The purpose was to study the indicators of physical development of primary-school-aged children with intellectual disability by observing the type of autonomic nervous regulation and their levels of catecholamines and serotonin. Methods: A total of 168 primary school age children were examined, of which 54 had intellectual disability. The autonomic nervous system was assessed using cardiointervalography; anthropometric parameters were applied in accordance with recommendations. The contents of serotonin and catecholamines in blood plasma and lymphocytes were assessed using enzyme immunoassay and luminescent histochemical methods. Results and conclusions: Delayed physical and mental development in children with intellectual disability were associated with low serotonin levels in this group of children. The optimal option for the physical development of children with intellectual disability is a sympathetic type of autonomic nervous regulation, while negative-type vagotonic nervous regulation was associated with the maximum delay in physical development. The hypersympathetic type of nervous regulation was accompanied by minimal changes in physical development, despite the hormonal imbalance in the ratio of catecholamines and serotonin. The level of the neurotransmitter serotonin is a prognostic marker of the physical development of children of primary school age. The total amount of catecholamines and serotonin in blood plasma has a direct relationship with the amount of these neurotransmitters in blood lymphocytes; the more hormones in plasma, the more of them in lymphocytes. Therefore, the determination of the contents of catecholamines and serotonin in lymphocytes can be used as a model for studying neurotransmitters in humans.

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36. **Aging Well With a Lifelong Disability: A Scoping Review**

Authors: Smith, Kimberley J.;Gupta, Saahil;Fortune, Jennifer;Lowton, Karen;Victor, Christina;Burke, Eilish;Carew, Mark T.;Livingstone, Emma;Creeger, Miriam;Shanahan, Paul;Walsh, Michael and Ryan, Jennifer M.

Publication Date: 2024

Journal: Gerontologist 64(9), pp. 1–14

Abstract: Background and Objectives Existing literature highlights notable health and social inequalities for people aging with a lifelong disability and the need for research to better understand how we can support this group to age well. This scoping review mapped existing literature related to "aging well" in people with lifelong disabilities. Research Design and Methods Five scientific databases and gray literature sources were searched for studies related to "aging well" and "lifelong disability" (defined as a disability that a person had lived with since birth or early childhood). Results We identified 81 studies that discussed aging well with a lifelong disability, with most (70%) focusing on intellectual disabilities. Two themes

captured existing research on aging well with a lifelong disability: (1) framing aging well with a lifelong disability, which included the ways that people with lifelong disability, their supporters, and existing research frame aging well for this group and (2) supporting people to age well with a lifelong disability, which involves the micro-, meso-, and macro-level factors where research suggests interventions to facilitate aging well could be situated. Discussion and Implications This synthesis highlights how aging well is currently framed in the literature and where interventions to improve aging well in this group could be situated. Literature highlights the importance of considering multilevel interventions to improve aging well. Evidence gaps include the lack of research conducted with groups other than those with intellectual disabilities and the need for more research examining aging well interventions.

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37. **Causes of Hospitalization in Children with Down Syndrome**

Authors: Takita, Stefanie Yaemi;Sé, Ana,Beatriz Silva;Hoffmann, Giovanna Michelin;Bunduki, William;Carvalho, Lidia Raquel and Fonseca, Cátia Regina Branco

Publication Date: 2024

Journal: Medicina (Kaunas, Lithuania) 60(9)

Abstract: Background and Objectives : Down syndrome (DS) is the most common chromosomal disorder in the world. It is caused by the imbalance of the chromosomal constitution of 21 by free trisomy, translocation or mosaicism. Children and adolescents with Down syndrome have immune dysregulation and are more susceptible to infections. This study aims to evaluate hospitalizations of children and adolescents with DS in the pediatric ward of Botucatu Clinics Hospital (HCFMB) and to classify the population of children included in the study according to age, diagnosis, outpatient follow-up, length of stay and need for the intensive care unit (ICU). Thus, it will be possible to improve care for these children, aiming to reduce these hospitalizations. Materials and Methods : This study was an observational, cross-sectional study, with retrospective data collected from the last nine years of hospitalization, from January 2013 to December 2021, from children and adolescents with DS in the pediatric ward, emergency room, and the ICU of HCFMB. Children hospitalized in this period in the pediatric ward and ICU, in the age range of 30 days to 15 years, were included in this study. The evaluation of comorbidities that culminated in the need for hospitalization in this population can be the focus of actions to improve the diagnoses and conducts for this population, which can prevent worsening illness and hospitalizations in future populations. Results : In this analysis, 80 children with DS were evaluated, with a total of 283 hospitalizations. The most prevalent age group was 1 to 3 years, and the main cause was due to problems in the respiratory system (99 cases). Among the respiratory causes, the main cause of hospitalization was due to pneumonia in 50% of cases, followed by acute respiratory failure in 14%. The average hospitalization time was 8 days, and in 49 hospitalizations, the children required the ICU. The main cause of hospitalization in the ICU was due to respiratory causes (36%), followed by cardiac malformations (14%). During the ICU hospitalizations, there were 13 deaths, and we observed a higher prevalence of heart conditions and, in some cases, positive urine cultures in these children. Conclusions: The Hospital serves as a reference for pediatric hospitalizations within its region and beyond, owing to its specialized capabilities. The main causes of hospitalization were those related to the respiratory system and cardiac

malformations. Roughly one-third of the children required admission to the intensive care unit.

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38. **Learning disability advanced practitioners in primary care**

Authors: Thompson, Kerry

Publication Date: 2024

Journal: British Journal of Nursing (Mark Allen Publishing) 33(16), pp. 752

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39. **Screening Instrument for Dysphagia in People with an Intellectual Disability (SD-ID): Quick and Reliable Screening by Caregivers**

Authors: van der Woude, T. S.;Schüller-Korevaar, R. M.;Ulgiati, A. M.;Pavlis-Maldonado, G.;Hovenkamp-Hermelink, J. and Dekker, A. D.

Publication Date: 2024

Journal: Journal of Developmental & Physical Disabilities 36(5), pp. 821–841

Abstract: Background and Aim: Timely diagnosis of dysphagia is important for people with an intellectual disability. Periodic screening of each individual by speech-language therapists is barely feasible with respect to limited resources. Therefore, preselection of individuals with an increased dysphagia risk through screening by caregivers is crucial. Objective: This study aimed to develop the novel Screening instrument for Dysphagia for people with an Intellectual Disability (SD-ID). Methods: The SD-ID was developed, validated and optimised in two rounds. Version 3, consisting of nine risk factors and 20 items concerning eating/drinking behaviour, was thoroughly studied for feasibility, concurrent validity and reliability, and then optimised. Outcomes and Results: The SD-ID (version 3) was filled out in an average of four minutes (feasibility). A strong positive association was found between scores on SD-ID and Dysphagia Disorder Survey (concurrent validity). Test-retest and interrater reliability were very good. Two additional risk factors were added and two items removed to yield the final version 4. The most optimal cut-off score appeared to be either 4 or 5. Conclusions and Implications: The SD-ID is a reliable instrument to screen for an increased risk of dysphagia in people with an intellectual disability. Ideally it is part of a cyclic work process: Screening with SD-ID (step 1), diagnostic work-up if necessary (step 2), recommendations (step 3), and evaluation (step 4).

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40. **Mortality risk among Autistic children and young people: A nationwide birth cohort study**

Authors: Vu, Hien;Bowden, Nicholas;Gibb, Sheree;Audas, Richard;Dacombe, Joanne;McLay, Laurie;Sporle, Andrew;Stace, Hilary;Taylor, Barry;Thabrew, Hiran;Theodore, Reremoana;Tupou, Jessica and Schluter, Philip J.

Publication Date: 2024

Journal: Autism: The International Journal of Research & Practice 28(9), pp. 2244–2253

Abstract: Autism has been associated with increased mortality risk among adult populations, but little is known about the mortality risk among children and young people (0–24 years). We used a 15-year nationwide birth cohort study using linked health and non-health administrative data to estimate the mortality risk among Autistic children and young people in Aotearoa/New Zealand. Time-to-event analysis was used to determine the association between autism and mortality, controlling for sex, age, ethnicity, deprivation and rurality of residence. The participant population included 895,707 children of whom 11,919 (1.4%) were identified as Autistic. Autism was associated with a significantly higher mortality risk (hazard ratio = 2.35; 95% confidence interval = 1.80–3.06) compared to the general population. In addition, using stratified analyses, we found that this risk was significantly higher among females (hazard ratio = 5.40; 95% confidence interval = 3.42–8.52) compared to males (hazard ratio = 1.82; 95% confidence interval = 1.32–2.52). We also determined that among Autistic young people, mortality risk was significantly higher for those with a co-occurring intellectual disability (hazard ratio = 2.02; 95% confidence interval = 1.17–3.46). In this study, autism was associated with higher mortality in children and young people compared to the non-Autistic population. Increased efforts are required to better meet the health needs of this population. Existing literature indicates that Autistic people have shorter life expectancy, but little is known about the mortality risk among Autistic children and young people (0–24 years). We used a 15-year nationwide birth cohort study to estimate the mortality risk among Autistic children and young people in Aotearoa/New Zealand. The study included 895,707 children and 11,919 (1.4%) were Autistic. We found that autism was associated with a significantly higher mortality risk compared to the non-Autistic population. In addition, we found that this risk was significantly higher among females compared to males and for those with a co-occurring intellectual disability. Increased efforts are required to better meet the health needs of this population.

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41. **Remote consultation: The experiences of community intellectual disability teams**

Authors: Welsh, Heather;Farquharson, Alistair and Nicholson, Laura

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Journal: Journal of Policy & Practice in Intellectual Disabilities 21(3), pp. 1–8

Abstract: The use of remote technology, via telephone and video, was rapidly introduced across health services at the outset of the COVID-19 pandemic and is likely to future. This study investigated the experience and opinions of staff working in Specialist Intellectual Disability Community Teams, with the aim of clarifying the advantages and disadvantages of remote technology in this setting and helping to guide service development. Fourteen members of staff from seven different health disciplines across seven NHS Greater Glasgow and Clyde Community Intellectual Disability Teams were interviewed using a semi-structured format. Thematic analysis identified three overarching themes: use of remote technology; efficiency and limitations. Participants reported clear efficiency advantages using remote technology but some challenges with communication and completing comprehensive patient assessments. There was support for the ongoing use of remote technology in the assessment and treatment of people with intellectual disability, particularly for multidisciplinary meetings. However, participants also described a need for face to face assessments, particularly for people with more severe intellectual disability, with complex care needs or when particular

assessments are required (such as a new patient appointment or physical assessment).

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42. **Clinical Characteristics, Genetic Analysis, and Literature Review of Cornelia de Lange Syndrome Type 4 Associated With a RAD21 Variant**

Authors: Yue, Xinyu;Chen, Meiping;Ke, Xiaoan;Yang, Hongbo;Gong, Fengying;Wang, Linjie;Duan, Lian;Pan, Hui and Zhu, Huijuan

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Journal: Molecular Genetics & Genomic Medicine 12(9), pp. e70009

Abstract: Background: Cornelia de Lange syndrome (CdLS) is an uncommon congenital developmental disorder distinguished by intellectual disorder and distinctive facial characteristics, with a minority of cases attributed to RAD21 variants.; Methods: A patient was admitted to the endocrinology department at Peking Union Medical College Hospital, where 2 mL of peripheral venous blood was collected from the patient and his parents. DNA was extracted for whole-exome sequencing (WES) analysis, and the genetic variation of the parents was confirmed through Sanger sequencing.; Results: A 13.3-year-old male patient with a height of 136.5 cm (-3.5 SDS) and a weight of 28.4 kg (-3.1 SDS) was found to have typical craniofacial features. WES revealed a pathogenic variant c.1143G>A (p.Trp381*) in the RAD21 gene. He was diagnosed with CdLS type 4 (OMIM #614701). We reviewed 36 patients with CdLS related to RAD21 gene variants reported worldwide from May 2012 to March 2024. Patient's variant status, clinical characteristics, and rhGH treatment response were summarized. Frameshift variants constituted the predominant variant type, representing 36% (13/36) of cases. Clinical features included verbal developmental delay and intellectual disorder observed in 94% of patients.; Conclusion: This study reported the third case of CdLS type 4 in China caused by a RAD21 gene variant, enriching the genetic mutational spectrum.

Sources Used:

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

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