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Learning Disabilities

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April 2025

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1. **Step back in time: Learning disability nursing faced a major review 50 years ago**

Authors: Ford, Steve

Publication Date: 2025

Journal: Nursing Times

Abstract: March will see the holding of closing statements in the Muckamore Abbey Hospital Public Inquiry, a statutory investigation into the treatment of patients with learning disabilities there. The inquiry and a criminal investigation have been examining the issue of abuse of patients at the hospital in County Antrim to determine why it happened and the circumstances that allowed it to take place.

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2. **A Systematic Review to Explore Antenatal Care From the Perspectives of Women With Intellectual Disabilities and Midwives**

Item Type: Journal Article

Authors: Alhulaibi, Weam;Stockdale, Janine and McAleer, Paul

Publication Date: 2025

Journal: British Journal of Learning Disabilities

Abstract: Background: During pregnancy, some women with an intellectual disability encounter some challenges, and some midwives who provide them with support lack the knowledge to provide the best care. This systematic review explores the experiences of women with intellectual disability during pregnancy and midwives' experiences of providing care. Method: Four databases were searched (PubMed, CINHAL, PsycINFO and Web of Science) and the resultant studies were appraised for quality using CASP. The selected papers were published between January 2012 and December 2022 and originated from the United Kingdom, Sweden, Canada and Ireland. Results: Eight studies were included: five examined the experiences of pregnant women with intellectual disability, one investigated the midwives' experiences of caring and two analysed both groups. The primary themes amongst women included pregnancy announcements, involvement in their care and fear of losing their baby custody. The midwives expressed their lack of readiness and need for additional support. Both groups recognised the necessity for improved education and accessible communication. Conclusion: Women with intellectual disabilities who are in the context of this review revealed their requirement for improved education and assistance in understanding antenatal information. The midwives within the included studies felt inadequately prepared to support women with intellectual disabilities: they lacked specialist training and required additional support in health education and communication skills. Summary: This review provides an up-to-date summary of the evidence related to what women with intellectual disabilities require in terms of best antenatal care; and what the experiences are of midwives who aim to provide this care.Some challenges experienced by pregnant women with intellectual disability include sharing their pregnancy news, involvement in their care and fear of not being allowed to keep their baby.Some challenges have been experienced by midwives, including feeling ill-prepared for their supportive role.

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3. **Effectiveness of Oral Health Interventions Among Intellectually Disabled Children-A Systematic Review**

Authors: Alwin, Roshni Maria Irwina and Ragavane, Priyadharshini

Publication Date: 2025

Journal: Special Care in Dentistry : Official Publication of the American Association of Hospital Dentists, the Academy of Dentistry for the Handicapped, and the American Society for Geriatric Dentistry

Abstract: Aim: This review aims to compare the effectiveness of various oral health interventions to improve the oral hygiene and oral health status of intellectually disabled children.; Methods: A comprehensive literature search was performed and screened for articles in PubMed, Cochrane-CENTRAL, Google Scholar, EMBASE databases, and gray literature databases from January 2013 to December 2023. The search focused on randomized and clinical trials aimed at improving oral health status in children with intellectual disabilities were included. The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines were followed. Data extraction was performed independently by two authors, involving 11 studies that met the inclusion criteria. The studies were assessed using the Cochrane Rob Tool. A descriptive summary of the significant findings was reported.; Results: The studies used various oral health promotion strategies such as supervised tooth brushing, fluoride application, and oral health education interventions in reducing dental caries, gingival disease, and improving oral health among intellectually disabled children. All the included studies were of level 2 evidence.; Conclusion: This review highlights the effectiveness of fluoride applications, specialized toothbrushes, and caregiver training in improving the oral health of children with intellectual disabilities. (© 2025 Special Care Dentistry Association and Wiley Periodicals LLC.)

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4. **Prevalence of psychiatric conditions in people with intellectual disability: A record linkage study in New South Wales, Australia**

Authors: Arnold, Samuel Rc;Huang, Yunhe;Srasuebkul, Preeyaporn;Cvejic, Rachael C.;Michalski, Stefan C. and Trollor, Julian N.

Publication Date: 2025

Journal: The Australian and New Zealand Journal of Psychiatry

Abstract: Objective: To compare the prevalence of psychiatric conditions in a population-based cohort of people with intellectual disability and matched comparators in New South Wales, Australia.; Method: The study cohort included 97,644 people with intellectual disability and 451,502 comparators aged ⩾ 5 between 1 July 2001 to 30 June 2018. We used linked records of hospital admissions, emergency department presentations, ambulatory mental health service contacts, and Medicare rebates to identify any, serious, and specific psychiatric conditions.; Results: People with intellectual disability showed greatly elevated period prevalence of any psychiatric condition (76.0% vs 38.3%), serious mental illness (16.2% vs 5.1%), and all specific psychiatric conditions compared to comparators. Among people with intellectual disability and congenital/developmental conditions, people with Down syndrome showed reduced risk of most psychiatric conditions while people with attention-deficit hyperactivity disorder and people with learning disorders showed increased risk. Age-specific analysis showed earlier onset of dementia and heightened prevalence of self-injury/suicidality in adulthood among people with intellectual disability. Annualised prevalence trends showed increases in 2006-2007 for most psychiatric conditions and decreases in 2014-2015 to 2017-2018.; Conclusions: The higher prevalence of psychiatric conditions in people with intellectual disability indicates the importance of systemic responses to address the mental health needs of this population. Our findings highlight the importance of considering the psychiatric profiles of specific congenital/developmental conditions among people with intellectual disability, and the need to provide targeted services to high-risk groups such as those with co-occurring attention-deficit hyperactivity disorder.

5. **Views and Experiences of Dementia in People With Intellectual Disabilities: A Systematic Review of Qualitative Research**

Authors: Carter, Joanna;Spector, Aimee;Ali, Afia;McFeeters, Amelia;Butt, Sarah and Charlesworth, Georgina

Publication Date: 2025

Journal: Journal of Intellectual Disability Research : JIDR
Abstract: Background: It is important to hear the perspectives of people with intellectual disabilities on dementia. This review aimed to explore views and experiences of dementia from the perspective of people with intellectual disabilities and methodologies enabling people with intellectual disabilities and dementia to participate in qualitative research.; Methods: Studies were identified in database searches, along with reference and citation searches. Qualitative data were reviewed using thematic synthesis and risk of bias assessed using the Critical Appraisal Skills Programme (2018). Methodologies used to include participants with intellectual disabilities and dementia were reviewed.; Results: Findings from 11 studies, with a total of 47 participants, highlighted loss of ability, relationships and connection associated with dementia, counteracted by support from others, and maintenance of a sense of self through choice, relational connection and competence. A range of methodologies were identified to enable participants with intellectual disabilities and dementia to participate in research.; Conclusions: This review highlights emerging, albeit demographically limited, qualitative research in this field. It suggests ways to build on this including methodologies to facilitate inclusion of people with intellectual disabilities and dementia in further research. (© 2025 The Author(s). Journal of Intellectual Disability Research published by John Wiley & Sons Ltd and MENCAP.)

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6. **Caregiver burden and familial impact in Down Syndrome Regression Disorder**

Authors: Chow, Katherine;Rezvan, Panteha Hayati;Kazerooni, Lilia;Nguyen, Lina;Boyd, Natalie K.;Vogel, Benjamin N.;Lucas, Maeve C.;Brown, Ruth;Quinn, Eileen A.;Jafarpour, Saba and Santoro, Jonathan D.

Publication Date: 2025

Journal: Orphanet Journal of Rare Diseases

Abstract: Competing Interests: Declarations. Ethical approval: This study was approved by the institutional review board at Children’s Hospital Los Angeles and the University of Southern California (IRB number: CHLA-24-00184). Virtual consent was obtained by caregivers or guardians. Consent for publication: Not applicable. Competing interests: The authors declare that they have no competing interest.; Background: Down Syndrome Regression Disorder (DSRD) is an acute or subacute neurocognitive regression in individuals with Down syndrome (DS), characterized by a loss of previously acquired cognitive, adaptive, and social skills. DSRD profoundly affects individuals' ability to engage in activities of daily living, making them highly dependent on their caregivers who must provide significantly more support than before the DSRD diagnosis. This study aimed to examine caregiver burden, quality of life, and depression among caregivers of individuals with DSRD versus caregivers of those with DS

and other neurological disorders (DSN).; Design/methods: In this cross-sectional study, caregivers of individuals with DSRD (n = 228) and DSN (n = 137) were recruited through Children's Hospital Los Angeles neurology clinic and a Facebook DSRD support group. Participants completed standardized questionnaires assessing quality of life (PedsQL Family Impact Module), caregiver burden (Zarit Caregiver Burden Assessment, ZCB), and depression (Glasgow Depression Scale, GDS), along with additional items addressing other factors of caregiver well-being. Data were analyzed using bivariate comparisons and univariate regression models to assess differences between groups.; Results: Caregivers of individuals with DSRD were more likely than caregivers of those with DSN to report increased financial burden ($p = 0.003$), housing changes ($p = 0.02$), disrupted sleep ($p < 0.001$), negative impacts on social networks ($p < 0.001$), and worsened mental health ($p < 0.001$). Furthermore, DSRD caregivers reported significantly higher levels of burden (mean difference 95% CI]: 8.3 6.3, 9.7]) and depression symptoms (2 0.7, 3.4]), reflecting greater perceived stress and burden. They also had lower quality of life scores (-27.9 -30.2, -25.5]), indicating a more substantial impact on overall well-being and daily functioning compared to DSN caregivers. Additionally, caregivers in the DSRD group had higher odds (odds ratio 95% CI]: 4.7 2.9, 7.7)] of meeting clinical depression criteria (GDS score ≥ 13) than caregivers in the DSN group.; Conclusions: Caregivers of individuals with DSRD experience significantly greater distress and burden compared to those caring for individuals with DSN. The elevated risk of depression, combined with reduced quality of life and increased burden, underscores the multimodal nature of the challenges faced by this population. (© 2025. The Author(s).)

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7. **The Effects of Single Bouts of Physical Activity on Cognition in Adolescents and Young Adults With Intellectual Disabilities: A Systematic Review**

Authors: Chueh, Ting-Yu;Wu, Jia-Hao;Hung, Wei-Kang;Pan, Cheng-Chen;Chou, Chien-Chih;Huang, Chung-Ju and Wu, Chien-Ting

Publication Date: 2025

Journal: Journal of Applied Research in Intellectual Disabilities : JARID

Abstract: Background: Individuals with intellectual disabilities (ID) typically exhibit cognitive deficits. While single bouts of physical activity (PA) have shown cognitive benefits in typically developing individuals, the effects on those with ID are unclear. This study aimed to investigate the effectiveness of single bouts of PA on cognition in individuals with ID.; Method: This registered review followed the PRISMA guidelines and searched for eligible studies on PubMed and Scopus.; Results: Eight studies were included, showing that participants demonstrated transient improvements in cognition, including information processing speed, inhibition and working memory, following moderate aerobic-based intensity PA. However, findings regarding the optimal intensity or types of PA for enhancing specific cognitions, and the effects on higher-level cognition (e.g., planning), are limited.; Conclusions: Single bouts of PA may transiently enhance cognition in adolescents and young adults with mild to moderate ID, but more rigorous research with a feasible protocol is required to refine exercise prescriptions for maximal cognitive benefits. (© 2025 John Wiley & Sons Ltd.)

8. "We're all in this together": patient and public involvement and engagement in developing a new psychosocial intervention for adults with an intellectual disability who display aggressive challenging behaviour

Authors: Clarke, Connor;Kouroupa, Athanasia;Royston, Rachel;Hassiotis, Angela;Jin, Yufei;Cooper, Vivien;Daniels, Robert;Grimley, Lisa;Hay, Sue;Marston, Louise;Odeyemi, Olawole;Penfold, Ian;Pullar, Claire;Rapaport, Penny;Sanger, Kate;Southworth, Adam;Taggart, Laurence and Ali, Afia

Publication Date: 2025

Journal: Research Involvement and Engagement

Abstract: Competing Interests: Declarations. Ethics approval and consent to participate: The PETAL trial received ethical approval from the Wales 7 REC committee on 31/10/2022 (REC reference: 22/WA/0267). The trial is ISRCTN registered (ISRCTN71781827), but ethical approval was not required for the PETAL PPI impact study specifically. The contributors provided verbal consent to take part in the interviews and focus groups. Consent for publication: Not applicable. Competing interests: The authors declare no competing interests.; Background: Although there is consensus regarding the added value of adults with an intellectual disability and family carers as Patient and Public Involvement and Engagement (PPIE) members in research studies, there is limited reporting on the practice and impact of their involvement.; Methods: PPIE input was integral to the application process and subsequent research activities in the NIHR-funded PETAL (PErsonalised Treatment packages for Adults With Learning disabilities) programme. We also conducted semi-structured interviews with five researchers/PPIE facilitators and four family carers, and a focus group with three adults with an intellectual disability who are members of the programme advisory groups. The GRIPP2 checklist guided the reporting of PPIE activities.; Results: Thematic analysis identified four overarching themes: (a) Motivation for being a PPIE member, (b) Added value of PPIE input into research (c) Logistics and practicalities of PPIE activities, and (d) Insights and reflections. Family carers highlighted the benefit of giving a voice to adults with an intellectual disability in PPIE activities within research. Both PPIE groups were positive about being able to share their thoughts and feelings with the PETAL research team and making valued contributions to research activities. All stakeholders highlighted the importance of accessible meeting formats to facilitate PPIE activities. They also reflected on how meaningful collaboration could enhance research in the field of intellectual disability. Researchers raised the need for greater diversity within PPIE groups.; Conclusions: Future work should aim to further develop PPIE processes and identify strategies to maximise the diversity and inclusion of adults with an intellectual disability and family carers in research advisory groups. (© 2025. Crown.)

9. **Pattern of psychotropic prescribing in adults with intellectual disabilities in the community settings in the UK: A cross-sectional view**

Authors: Deb, S.;Limbu, B. and Allgar, V.

Publication Date: 2025

Journal: Research in Developmental Disabilities

Abstract: Competing Interests: Conflict of interest None declared.; Background: A high proportion of adults with intellectual disabilities receive psychotropic medicines, often in the absence of a mental illness but primarily off-licence for behaviours that challenge.; Aim: To provide a cross-sectional view of the pattern of psychotropic medicine prescriptions with the reasons for their use among adults with intellectual disabilities in community settings in the UK.; Method: We collected psychotropic prescription data on 112 adults with intellectual disabilities who lived in community homes or supported accommodations in the UK. This was done in the context of a feasibility RCT involving a staff training programme, SPECTROM, designed to help reduce the overmedication of adults with intellectual disabilities.; Results: The most commonly prescribed psychotropics were antipsychotics (47 %) followed by antidepressants (23 %), anti-epileptics (13 %) and benzodiazepines (7 %). In 45 % of cases, there was a polypharmacy of more than one psychotropic class of medicines, and in 20 %, a combination of antipsychotics and antidepressants. Antipsychotics were used for severe mental illness only in 19 % but for behaviours that challenge in 40 %, and 17 % of the time for anxiety. Antidepressants were prescribed 47.7 % of the time for depression, 11.4 % for anxiety, and 9 % for behaviours that challenge. Antiepileptics were prescribed more often for behaviours that challenge (40 %) than epilepsy (32 %). In the SPECTROM training group, the antipsychotic dose was reduced in 18.6 % of prescriptions compared with 6.5 % in the non-training group at six months follow-up.; Conclusion: Psychotropic medicines are still prescribed in a high proportion of cases off-licence for behaviours that challenge than mental illness. (Copyright © 2025 The Authors. Published by Elsevier Ltd.. All rights reserved.)

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10. **Exploring the transformative power of dance: A scoping review of dance interventions for adults with intellectual disabilities**

Authors: Dumitru, Cristina

Publication Date: 2025

Journal: Journal of Intellectual Disabilities

Abstract: The aim of this scoping literature review (SCR) was to analyze the impact of dance on adults with intellectual disabilities, specifically examining its influence on their mobility, interpersonal relationships, well-being, and overall quality of life. A total of 15 papers were reviewed in order to explore the effects of dance on the well-being and quality of life of adults with intellectual disabilities. The findings indicated significant improvements in body awareness, increased engagement in physical activity, and enhanced mental health. This SCR demonstrates that dance is an effective means of facilitating social interaction among adults with intellectual disabilities, both with their therapists and family members. Additionally, the review uncovered valuable data on dance therapy programs designed for adults with intellectual disabilities, highlighting their potential to promote physical activity and reduce stress levels.

11. **Out of Sight, Out of Mind—Explaining and Challenging the Re-Institutionalisation of People With Learning Disabilities and/or Autistic People**

Authors: Glasby, Jon;Waring, Justin;Miller, Robin;Glasby, Anne-Marie and Ince, Rebecca

Publication Date: 2025

Journal: Sociology of Health & Illness

Abstract: During the twentieth century, many countries underwent processes of 'de-institutionalisation'—closing 'asylums' for people with mental health problems, learning disabilities and dementia. Despite this, the UK has witnessed a subsequent process of 're-institutionalisation' with the creation of new public/private sector facilities providing 'secure' care to large numbers of people, who can be residents for many years with no sense of when they may leave. In 2023, 2035 people with learning disabilities and/or autistic people were receiving inpatient hospital care in England, with 54% in hospital for over two years. Drawing on the lived experience of people in hospital/families, and the practice knowledge of front-line staff, this paper critically analyses why this process of re-institutionalisation may be taking place. Our argument is that institutional forms of care have gradually been re-introduced—despite the influence of neoliberal health policies that have previously aimed at deinstitutionalisation and self-care—because some people are viewed as 'too difficult' to govern through the prevailing dispositive of self-care, and therefore become the subjects of more disciplinary forms of power. Once in hospital, the primary routes to 'escape' require performative acts of 'good conduct' that give confidence to professionals of a person's capacity for self-government.

12. **A Systematic Review of Community-Based Exercise Interventions for Adults with Intellectual Disabilities**

Authors: Greene, Teresa;Taggart, Laurence and Breslin, Gavin

Publication Date: 2025

Journal: Healthcare

13. **Modifying quantitative sensory testing to investigate tactile sensory function and behavioral reactivity in children with intellectual and developmental disabilities: establishing feasibility and testing sex, autism, and self-injury effects**

Authors: Gunderson, Jaclyn;Worthley, Emma;Byiers, Breanne;Merbler, Alyssa;Huebner, Andrea;Hofschulte, Deanna;Lee, Jasmine;Riodique, Catherine and Symons, Frank

Publication Date: 2025

Journal: Journal of Neurodevelopmental Disorders

Abstract: Competing Interests: Declarations. Ethics approval and consent to participate: Ethics approval was obtained from Mayo Clinic and Fairview Health internal review boards. Written informed consent was obtained for all participants. Consent for publication: Not applicable. Competing interests: The authors declare no competing interests.; Background: Sensory reactivity differences are common across neurodevelopmental disorders (NDDs), however very few studies specifically examine tactile or pain responses in children with NNDs, especially those with communication challenges. The current study aimed to (a) replicate the feasibility of a modified quantitative sensory test (mQST) with a sample of children with NDDs, (b) assess validity evidence based on behavioral reactivity during mQST application and the corresponding behavioral measurement coding system, and (c) explore group differences in behavioral reactivity to mQST stimuli by demographic (sex), clinical (autism status), and behavioral pathology (self-injury) variables.; Methods: The mQST protocol was implemented and blindly coded across 47 participants aged 2-12 years (M age = 6.7 years, SD = 2.6; 70% male) with NDDs. Feasibility was measured by completion of the mQST protocol and interobserver agreement. Validity was assessed using paired t-tests investigating differences between behavioral reactivity to active stimuli compared to a sham trial. Boxplots were used to visually explore differences in group characteristics (sex, autism status, and self-injurious behavior), with two-sample t-tests used to further characterize differences in SIB group characteristics in behavioral reactivity to mQST stimuli.; Results: The mQST provided codable data across 91% of stimuli applications with high IOA (84.7% 76.7-95%]). Behavioral reactivity was significantly higher for active vs. sham stimuli. Children reported to engage in self-injurious behavior showed significantly more reactivity to the second half of the repeated von Frey stimulus application compared to children without caregiver-reported self-injurious behavior (M = 6.14, SD = 3.44), t (40)= -2.247, p =.04).; Conclusion: The mQST is a feasible approach to investigate tactile reactivity in children with NDDs and complex communication needs. The mQST may be useful in understanding sensory variables in relation to developmental and behavioral outcomes such as self-injurious behavior. (© 2025. The Author(s).)

14. **Family factors associated with physical activity in children with intellectual disability: A systematic review**

Authors: Hao, Yaru and Razman, Rizal

Publication Date: 2025

Journal: Journal of Intellectual Disabilities

Abstract: This systematic review aimed to explore the influence of family factors on physical activity in children with intellectual disability. How and what family factors that specifically influence physical activity has not been compiled and reviewed previously. In accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines, a systematic search was performed for articles published in English and Chinese without any year limits in six databases. Ten studies met the eligibility criteria and were included in the review. All studies were qualitatively integrated to identify and compare positive and negative family factors. A total of 1135 participants, of which 497 were children with intellectual disability while the other 638 participants were family members (parents, siblings and caregivers). The family factors of 6 themes and 18 sub-themes (10 positive, 7 negative and 1 inconclusive factors) were extracted. Overall, these results highlight the importance of encouragement, support and involvement by family members, concurrently it points out that parental psychological factors, socioeconomic status, responsibilities and electronic devices could both promote and hinder engagement in physical activity for children with intellectual disability. The findings accentuate the role of the family unit in helping determine the activity levels of children with intellectual disability. Future studies should include a wider range of participants and be longitudinal in nature, utilizing more accurate monitoring tools.

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15. **Weight-loss interventions for adolescents with Down syndrome: a systematic review**

Authors: Hilgenkamp, Thessa I. M.;Davidson, Emily;Diaz, Keith M.;Fleming, Richard;Foster Kirk, Rachel;Hastert, Mary;Kim, Judy;Mann, Sarah;Usseglio, John;Videlefsky, Andrea and Ptomey, Lauren

Publication Date: 2025

Journal: Obesity (Silver Spring, Md.)

Abstract: Objective: Youth with Down syndrome (DS) experience high rates of overweight and obesity; therefore, weight-loss interventions are warranted. We aimed to systematically review weight-loss interventions for adolescents with DS to better understand the most effective strategies and identify the current gaps in the literature.; Methods: This systematic review followed Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines (International Prospective Register of Systematic Reviews PROSPERO] #CRD42022303781). Databases were searched through July 28, 2023, and screening, evaluation, and data extraction were performed by two independent reviewers. Change scores for weight or BMI were presented by study design and intervention components.; Results: The 26 included papers describing 24 unique studies included a total of n = 1171 participants, of whom n = 393 were participants with DS. Eleven studies focused on physical activity, one on diet, and two on physical activity and diet; seven studies used multicomponent interventions; and three studies investigated laparoscopic sleeve gastrectomy. Thirteen studies using either a multicomponent intervention, a physical activity intervention, or surgery resulted in weight loss or a decrease in BMI in adolescents with DS.; Conclusions: Weight-loss interventions can be effective for adolescents with DS and could benefit from increasing duration/intensity to meet the existing weight-loss intervention recommendations. More research on surgery and weight-loss medications is needed. (© 2025 The Author(s). Obesity published by Wiley Periodicals LLC on behalf of The Obesity Society.)

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16. **Healthcare for People With Intellectual Disabilities: An Exploration of Intellectual Disability Service Providers' Experiences of Joint Working With Acute Service Providers When People With Intellectual Disabilities Access Healthcare in Acute Services**

Authors: Kelleher, Eileen;Caples, Maria;Wills, Teresa and Martin, Anne-Marie

Publication Date: 2025

Journal: British Journal of Learning Disabilities

Abstract: Background: Individuals with intellectual disabilities often require various supports in their everyday lives. Many access both acute and intellectual disability services depending on their needs. Previous research has highlighted suboptimal experiences of care provided in acute services. Joint working between both services has been recognised as a measure of improving healthcare for this group. Although there is some evidence regarding this issue from the perspective of acute service providers, further research is required to understand the perspective of intellectual disability service providers. Methods: Ten nurses working in various roles in intellectual disability services across Ireland took part in semistructured interviews. The data were analysed using thematic analysis. Findings: Issues with inter-service communication and insufficient policies, protocols and pathways were found to negatively impact joint working. Acute services seemed to have a limited understanding of the role and capacity of intellectual disability services. Acute services do not always identify the individual needs of the people in their care. Despite this, there were examples of joint working taking place that benefited those with intellectual disabilities. Conclusions: Joint working needs to include improving communication between both services, co-developing policies, protocols and pathways and appointing acute care liaison nurses. Summary: People with intellectual disabilities access different services such as hospitals and intellectual disability services.We wanted to understand the experiences of people working in intellectual disability services when they support people with intellectual disabilities in hospitals. Those who took part talked about what worked well and problems they had when supporting someone in hospitals.There needs to be better communication between services. Policies are important in helping staff support people with intellectual disabilities in hospitals. Having intellectual disability nurses present in hospitals can help the people during their hospital stay.

17. **'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 and Van Eeghen, Agnies,M.

Publication Date: 2025

Journal: Journal of Intellectual Disability Research : JIDR

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. (© 2025 The Author(s). Journal of Intellectual Disability Research published by John Wiley & Sons Ltd and MENCAP.)

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18. **Analysis of the European Union's National Cancer Control Programs: Meeting the Needs of People with Intellectual Disabilities**

Authors: Kowalczyk, Oliwia;Ambrocio, Rainer Pier Paolo M.;Vuković, Vladimir;Denieffe, Suzanne and Denny, Margaret

Publication Date: 2025

Journal: Healthcare (Basel, Switzerland)

Abstract: Background/Objectives : People with intellectual disabilities (IDs), representing approximately 200 million individuals globally (3% of the world's population), face significant disparities in cancer prevention and care. While cancer remains one of the leading causes of mortality worldwide, the intersection of cancer care and intellectual disability presents unique challenges that demand specialized attention within healthcare systems. This study evaluates the current status and effectiveness of National Cancer Control Programs (NCCPs) for individuals with intellectual disabilities across the European Union. Methods : A systematic analysis was conducted of 27 European Union member states' National Cancer Control Programs between August 2023 and August 2024. The study utilized the International Cancer Control Partnership (ICCP) framework, examining English-language documents and official translations to ensure analytical consistency. Results : Our analysis reveals that while all 27 EU member states have established NCCPs, significant variations exist in their approach to ID-specific provisions, with implementation scores ranging from 1 (basic) to 3 (comprehensive). Key findings indicate that only 15% of programs have comprehensive ID-specific provisions, while 60% maintain moderate adaptations and 25% offer basic provisions. Specific gaps identified include limited specialized healthcare provider training (present in only 7.5% of programs) and inadequate screening program adaptations. Conclusions : Based on a quantitative assessment of implementation status and program components, we propose evidence-based recommendations emphasizing the urgent need for enhanced ID-specific provisions in NCCPs.

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19. **Outcome Measures in intellectual disability: A Review and narrative synthesis of validated instruments**

Authors: Kumar, Mrityunjai;Sawhney, Indermeet;Chester, Verity;Alexander, Regi;Mitchell, James and Shankar, Rohit

Publication Date: 2025

Journal: International Journal of Social Psychiatry

Abstract: Background: Outcome measurement is essential to determine the effectiveness of health interventions and improve the quality of services. The interplay of social, individual, and biological factors makes this a complex process in the psychiatry of people with intellectual disability (PwID). Aim: Review of outcome measures which are validated in PwID Methods: A PRISMA-guided review was conducted, using a predefined criteria and a relevant word combination on four databases: EMBASE, Medline, CINAHL and PsycINFO. Each included study was examined for relevance to intellectual disability psychiatry. The psychometric data of each tool was critically assessed. Findings were narratively synthesised. Results: Of 1,548 articles, 35 met the inclusion criteria. Several outcome measures were identified relevant to intellectual disability psychiatry, including tools for challenging/offending behavior, specific neurodevelopmental/clinical conditions such as ADHD, epilepsy, and dementia however, psychometric properties, validity and reliability varied considerably. The tools identified were largely clinician rated, with a dearth of measures suitable for completion by patients or their family carers. Conclusion: Most outcome measures used for PwID lack suitable psychometric properties including validity or reliability for use within the ID population. Of importance, those with alternative expression or are non-verbal have been excluded from the research developing and reporting on measurement instruments. There is an underserved population who risk being left behind in the era of value-based medicine and increasing use of outcome measurement when assessing the effectiveness of healthcare interventions on individual and population levels. This is the first of its kind review in this area.

20. **Congenital Anomalies of the Kidney and Urinary Tract in Down Syndrome: Prevalence, Phenotypes, Genetics and Clinical Management**

Authors: Leskur, Mirela;Leskur, Dario;Marijan, Sandra;Minarik, Luka and Lozić, Bernarda

Publication Date: 2025

Journal: Genes

Abstract: Down syndrome (DS), the most common survivable autosomal aneuploidy, is associated with a high prevalence of congenital anomalies of the kidney and urinary tract (CAKUT), significantly increasing the risk of chronic kidney disease (CKD). This review examines the diversity of CAKUT phenotypes reported in individuals with DS, focusing on anomalies affecting the kidney, ureter, bladder, and urethra. According to available literature, hydronephrosis is the most common renal anomaly, often secondary to other CAKUT phenotypes, followed by renal hypoplasia and glomerulocystic disease. Furthermore, obstructive uropathies are also frequent but usually lack detailed characterization in the literature. Key features of CAKUT in DS, including reduced kidney size, renal cystic diseases, acquired glomerulopathies, reduced nephron number, and immature glomeruli heighten the risk of CKD. Also, early detection of lower urinary tract dysfunction (LUTD) is critical to prevent progressive upper urinary tract damage and CKD. Despite the prevalence of CAKUT in DS, reported between 0.22% and 21.16%, there is a lack of standardized diagnostic criteria, consistent terminology, and extended follow-up studies. Systematic screening from infancy, including regular renal monitoring via urinalysis and ultrasound, plays a critical role in the timely diagnosis and intervention of CAKUT. To further enhance diagnostic accuracy and develop effective therapeutic strategies, increased awareness and focused research into the genetic factors underlying these anomalies are essential. Moreover, a multidisciplinary approach is indispensable for managing CAKUT and its associated complications, ultimately ensuring better long-term outcomes and an improved quality of life for individuals with DS.

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21. **The Effect of SPECTROM Training on Support Staff Knowledge of Psychotropic Medicine and Attitude Towards Behaviours That Challenge in Adults With Intellectual Disabilities to Help Implement the STOMP Initiative**

Authors: Limbu, B.;Deb, S.;Bradshaw, J. and Cooper, V.

Publication Date: 2025

Journal: Journal of Intellectual Disability Research : JIDR

Abstract: Background: Overmedication of adults with intellectual (learning) disabilities, particularly the off-licence use of psychotropic medicines for behaviours that challenge in the absence of a psychiatric disorder, is a major public health concern and an example of health inequalities. In the United Kingdom, we coproduced online training resources backed up by face-to-face training for support staff (direct care workers) called SPECTROM involving all stakeholders, including adults with intellectual disabilities and their families, to help reduce the overmedication and implement NHS England's STOMP initiative.; Method: In a feasibility cluster randomised controlled trial, we trained service managers and support staff using two

core modules of SPECTROM, namely, (a) Medicine/STOMP and (b) Alternatives to Medicine (ATM) using an online platform. These two core modules introduced 12 other modules and other online resources. We assessed trainees' knowledge of psychotropic medicines using the Psychotropic Knowledge Questionnaire-Revised (PKQ-R) and their attitude to behaviours that challenge using the Management of Aggression and Violence Attitude Scale-Revised-Intellectual Disabilities (MAVAS-R-ID) using a pre-post training design.; Results: The research team delivered SPECTROM training to 18 service managers and 122 support staff. Of the 140 trainees, 126 completed PKQ-R at baseline before and within 4 weeks after the training. There was a post-training improvement in PKQ-R scores in 42 of the 43 questions (97.7%), 22 of which were statistically significant differences ($p < 0.001$). The MAVAS-R-ID was completed at baseline and within 4 weeks of training by 125 trainees. The MAVAS-R-ID total score showed statistically significant post-training improvements ($p < 0.01$). Individual domain score analysis showed a statistically significant improvement in one of the five domains related to attitude regarding the use of medicine for behaviours that challenge.; Conclusions: The SPECTROM training seems to improve staff knowledge of psychotropic medicine, at least in the short-term, and attitude towards behaviours that challenge, particularly concerning the use of psychotropic medicine. (© 2025 The Author(s). Journal of Intellectual Disability Research published by John Wiley & Sons Ltd and MENCAP.)

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22. **Inclusive healthcare for people with intellectual disabilities: The impact of labelling and biomedical causal beliefs**

Authors: Lucassen, Laurie;Rinaldi, Romina and Batsele, Elise

Publication Date: 2025

Journal: Research in Developmental Disabilities

Abstract: Competing Interests: Declaration of Competing Interest We have no conflicts of interest to declare.; Background: People with intellectual disabilities often face inequalities in healthcare, including a lack of sensitivity on the part of healthcare professionals who are less able to identify and recognise these people's health needs despite the desire to make healthcare accessible.; Aims: This study examined the links between variables related to intellectual disability literacy and variables related to stigma which may be related to healthcare professionals' sensitivity to the health needs of people with intellectual disabilities.; Method and Procedure: An online cross-sectional survey was conducted with 163 healthcare professionals. Participants were randomly assigned to one of the following vignettes, with two presentation conditions (labelled or unlabelled) and two gender conditions (male or female), and the participants were asked to complete an intellectual disability literacy scale (IDLS, Scior & Furnham, 2011).; Results: Only 31 % of healthcare professionals in the unlabelled condition recognise a neurodevelopmental disorder. Furthermore, the label predicts an attribution of biomedical causal beliefs and fewer environmental causal beliefs than the unlabelled condition. Moreover, the belief in a biomedical cause predicts a reduction in social distance. Finally, gender and label seem to affect social distance.; Conclusions and Implications: Healthcare professionals are not sufficiently aware of intellectual disability (i.e., recognition of symptoms, causes of the disorder). These findings seem all the more important given that our results indicate that attributing a biomedical cause to a person's situation helps reduce social distance, which is an essential element in caring for people. It therefore seems essential to promote practices aimed at improving access to inclusive healthcare. (Copyright © 2025 Elsevier Ltd. All rights reserved.)

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23. **Physical health effects of sedentary behaviour on adults with an intellectual disability: A scoping review**

Authors: Lynch, Louise;McCarron, Mary;Eustace-Cook, Jessica;Burke, Éilish and McCallion, Phillip

Publication Date: 2025

Journal: Journal of Intellectual Disabilities

Abstract: This literature review was designed to establish the effects of sedentary behaviour on the physical health of adults with an intellectual disability. Sedentary behaviour is defined as any waking behaviour characterized by an energy expenditure of ≤1.5 METs while in a sitting, lying or reclining posture. An extensive search was executed in six databases: EMBASE, Medline, CINAHL, PsycINFO, ASSIA and Web of Science. Following screening, 18 articles remained for inclusion in the review. A thematic analysis using the Braun and Clarke six step process resulted in the identification of seven broad health areas. Studies showed a prevalence of obesity, multimorbidity and metabolic syndrome as well as elevated levels of sedentary behaviour in adults with an intellectual disability. This literature review demonstrated that sedentary behaviour could be a contributor to the poor health which is common in adults with an intellectual disability. However to date the body of evidence does not confirm a cause-and-effect relationship.

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24. **Bridging the digital divide for individuals with intellectual disabilities: Implications for well-being and inclusion**

Authors: Murphy, Esther;Shiels, Orla;Fiori, Sara;McCausland, Darren;Bergström, Helena;Koster, Raphael;Noorlandt, Hanna;Korfage, Ida and Wallén, Eva Flygare

Publication Date: 2025

Journal: British Journal of Learning Disabilities

Abstract: Background: Developments in digital technologies have transformed how people interact with the world, offering employment, education, communication, health benefits and entertainment. Research has shown that not everyone can easily access digital content, particularly people with intellectual disabilities. Despite internet access being recognised as a human right in the United Nations' Conventions on the Rights of Persons with Disabilities, this group faces significant disadvantages. Methods: A thematic analysis of quantitative and qualitative findings was conducted with data from focus groups and interviews with 200+ participants across Ireland, Sweden, France, and the Netherlands on how people with intellectual disabilities are using technology at this time and access facilitators and barriers. Findings: The pandemic exacerbated the digital divide between people with intellectual disabilities and their neurotypical peers, impacting physical and mental well-being. Growing demand for accessible digital skills training underscores the need to bridge this gap. Conclusion: Addressing these digital access disparities is crucial to ensure that individuals with intellectual disabilities can enjoy the benefits of the digital age and maintain their well-being. By identifying priority topics in our interview data, researchers also pinpointed critical accessibility barriers and facilitators to support codesigning activities for future digital skills education content within the Digi-ID project. Accessible summaries: Digital technology has changed the way we live, but not everyone can use it easily, especially people with intellectual disabilities.Digital technology is used in every part of life, for example, keeping in contact with friends and family and connecting with all types of services. It is used in education and in workplaces.Our Digi-ID project was based in Ireland, Sweden, France and the Netherlands. The researchers from these countries listened to people with intellectual disabilities to learn how we can better support them to access and use technology.Our platform DigiAcademy has been designed with and for people with intellectual disabilities. Our teachers with intellectual disabilities have learnt the skills to show others how to build skills with confidence.If you would like to learn more, you can watch a short video cocreated with our teachers: https://vimeo.com/783266517 or send us an email: digi-id@tcd.ie.

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25. Shifting participatory approach when ideology meets reality: a grounded theory study based on project leaders' experiences with peer-led sex education programs for and by persons with intellectual disabilities and/or autism

Item Type: Journal Article

Authors: Nelson, B.;Emmelin, M.;Agardh, A.;Löfgren, L. and Stafström, M.

Publication Date: 2025

Journal: Reproductive Health

Abstract: Competing Interests: Declarations. Ethics approval and consent to participate: The study was approved by the Swedish Ethical Review Authority, reference number 2020–04440. All research participants were informed about the study purpose and how the data would be handled, that participation was voluntary and signed a consent form. Consent for publication: Research participants were informed that the material would be used in scientific articles and consented to publication of the material. Competing interests: The authors declare no competing interests.; Background: This study explored peer-led sex education for individuals with intellectual disabilities and/or autism (ID/ASD) from the perspective of project leaders within Swedish non-governmental organizations (NGOs). The purpose of this Grounded Theory study was to develop a conceptual model that characterizes the ways in which peer-led sex education is implemented by Swedish NGOs. This was done by exploring what the concept of peer-led sex education means to NGO project leaders, and how they experience, explain and reason about the application of peer education in their daily operations.; Methods: This study conducted 12 qualitative in-depth interviews with project leaders working with peer-led sex education initiatives. Grounded Theory enabled the construction of a conceptual model.; Results: The study identified the core category, "Shifting participatory approach when ideology meets reality," encapsulating project leaders' experiences in managing peer-led sex education programs. Three distinct approaches were discerned: (1) The Radical approach, where project leaders prioritize empowerment and norm criticism, striving to create an inclusive and equitable environment for individuals with ID/ASD. This approach resonates with Paulo Freire's pedagogy of the oppressed, emphasizing liberation through education. (2) The Pragmatic approach, which navigates the tension between ideology and pragmatism, recognizing the co-dependency between project leaders and persons with ID/ASD. External pressures from funders and the requirements to achieve tangible project outcomes inform this approach. (3) The Skeptical approach, which exhibits caution, doubting the capabilities and willingness of individuals with ID/ASD to challenge societal norms and work equally with people without ID/ASD.; Conclusions: The findings underscore the complexity of peer-led sex education programs and highlight the need for a balanced approach that addresses both ideological aspirations and practical constraints. Empowerment and norm criticism are central to fostering agency and challenging oppressive systems. However, the pragmatic realities of project management and external pressures necessitate a delicate balance. Understanding these diverse approaches can inform the design of more effective initiatives, ultimately contributing to sexual and reproductive health and rights of individuals with ID/ASD. (© 2025. The Author(s).)

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

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

Publication Date: 2025

Journal: The International Journal of Social Psychiatry

Abstract: Background: Outcome measurement is increasingly recognised as a vital element of high-quality service provision, but practice remains variable in the field of intellectual disabilities. The Health of the National Outcome Scales for people with Learning Disabilities (HoNOS-LD) is a widely used Clinician Reported Outcome Measure in the UK and beyond. Over its 20-year lifespan, its psychometric properties have been frequently investigated. Multiple dimensionality reduction analyses have been published, each proposing a different latent structure.; Aim: To analyse a set of HoNOS-LD ratings to test its internal consistency, to identify the optimal number of latent variables, and to propose the items that group together in each domain.; Methods: A Principal Component Analysis of 169 HoNOS-LD ratings was performed to produce an initial model. The component loadings for each HoNOS-LD item were then examined, allowing the model to be adjusted to ensure the optimal balance of statistical robustness and clinical face-validity.; Results: HoNOS-LD's internal consistency (18 items) was 'acceptable' (Cronbach's alpha = 0.797). On excluding three items that had no bivariate correlations with the other 15 items internal consistency rose to 'good' (Cronbach's alpha = 0.828). The final, four-component solution, using the 15 items possessed good internal reliability.; Conclusion: HONOS-LD statistical properties compared favourably to the other published latent structures and adheres to the tool's rating guidance. The four-component solution offers an acceptable balance of statistical robustness and clinical face validity. It provides advantages over other models in terms of internal consistency and/or viability for use at a national level in the UK.

27. **Culturally adaptive healthcare for people with a learning disability from an ethnic minority background: A qualitative synthesis**

Authors: Roberts, Christina;Ditzel, Nicola;Cooper-Moss, Nicola;Umbleby, Katie and Chauhan, Umesh

Publication Date: 2025

Journal: British Journal of Learning Disabilities

Abstract: Background: People with a learning disability face health inequality. Those from ethnic minority backgrounds with a learning disability face 'double discrimination' as members of two marginalised groups. Methods: This codesigned review consolidated the evidence on the healthcare experiences of individuals and their carers from ethnic minority backgrounds with a learning disability. Three electronic databases were searched for UK studies from January 1990 to June 2022. Qualitative data from 28 studies were analysed using thematic framework analysis. Findings: There was an overarching theme of 'culture, choice and conflicts of control', which related to the variable preferences for involvement in healthcare decisions. Cultural and individual factors impacted upon experience, with themes relating to 'misunderstanding and mistrust', 'discrimination and stigma', 'isolation', 'feelings of shame and blame', 'burdens of care' and 'carer wellbeing'. Factors associated with healthcare-seeking and care provision are described in the themes 'triangles of care', 'community networks' and 'adaptive communication'. Conclusions: People from ethnic minority backgrounds with learning disability experience complex barriers which influence their healthcare experiences. Recognising and understanding discrimination can be difficult for people with a learning disability. Carers face challenges which influence their own wellbeing. Services need to be responsive to individual cultural contexts, while addressing potential conflicts of control. Accessible summary: People with a learning disability from ethnic minority backgrounds experience problems using healthcare services and poorer health.This review compared findings from 28 UK studies which explored the healthcare experiences of people with a learning disability from ethnic minority backgrounds, and their carers.Patients and carers had different preferences in how they wanted to be involved in their healthcare, which were often unmet by healthcare services.Services should be responsive to the needs of individuals from different ethnic minority backgrounds with a learning disability, and their carers.

28. **Between epistemic injustice and therapeutic jurisprudence: Coronial processes involving families of autistic people, people with learning disabilities and/or mental ill health**

Authors: Ryan, Sara;Ribenfors, Francesca;Mikulak, Magdalena and Coles, Deborah

Publication Date: 2025

Journal: Sociology of Health & Illness

Abstract: Understanding how and why someone dies unexpectedly is key to bereaved family members. The coronial process in England investigates instances where the cause of death is unknown, violent or unnatural and/or occurred in state detention. Families are held to be at the centre of this process and the coroner's role has extended to concern about therapeutic jurisprudence, that is, how legal processes can minimise negative consequences for participants without jeopardising due process. Therapeutic jurisprudence involves unresolved tensions, however, and an epistemic power imbalance. Within the inquest, knowledge is produced, evaluated and contested, and epistemic privilege may be unevenly distributed. The inquest is also a process that, as we demonstrate, requires epistemic courage and resistance on the part of families. Families with relatives who are autistic, have learning disabilities and/or mental ill health can experience epistemic and structural injustice before an unexpected death which makes the distinctiveness of their experiences important to understand. Here, we report on a qualitative interview project which focused on how bereaved families experience the coronial process after their relative died in receipt of health and/or social care support.

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29. **Evaluation Methods of Dysphagia in Adults With Intellectual Disability: A Scoping Review**

Authors: Sauna-Aho, Minttu;Tuomiranta, Leena;Geneid, Ahmed and Launonen, Kaisa

Publication Date: 2025

Journal: Intellectual and Developmental Disabilities

Abstract: Dysphagia is a serious but underdiagnosed health-related condition in people with intellectual disability (ID). In this scoping review, we provide an overview of dysphagia evaluation methods used in adults with ID. The data from 31 studies were analyzed qualitatively by identifying the evaluation methods and the validity and reliability of the methods. To summarize, dysphagia has been evaluated in many ways and for different purposes. The most common evaluation method was a videofluorographic swallowing study (VFSS). Four of the reviewed methods were found to be valid and reliable in detecting swallowing problems in adults with ID. (©AAIDD.)

30. **Associations between neurodivergence, learning disabilities and metabolic syndrome risk: evidence from the Health Survey for England**

Authors: Shelton, Nicola;Abdinor, Sofia and Lodder, Annemarie

Publication Date: 2025

Journal: Journal of Public Health (Oxford, England)

Abstract: Background: A higher prevalence of metabolic syndrome conditions amongst individuals with learning disabilities is well established; however, there is mixed evidence for neurodivergent adults.; Methods: Health Survey for England data 2016-19 were analysed. N = 32 390, 728 with neurodivergent conditions and 1419 with learning disabilities. Diabetes was self-reported and physician-diagnosed. Hypertension was assessed through blood pressure readings or reported medication use. Obesity and overweight were measured objectively. Covariates included age, sex and ethnicity and physical activity (2017-18 subsample).; Results: An association between obesity and neurodivergence was found relative risk ratio (RRR) = 1.64 95% CI = 1.54-1.76, P < 0.001]. The association with overweight was weaker. An association was found for diabetes (OR = 4.18, 95% CI = 3.82-4.57, P < 0.001) and hypertension (OR = 1.51, 95% CI = 1.40-1.64, P = < 0.001).An association was found between obesity and learning disabilities (RRR = 1.70, 95% CI = 1.42-2.04, P = < 0.001) but not overweight. An association was found for diabetes (OR = 2.39, 95% CI = 2.01-2.85, P < 0.001) and hypertension (OR = 1.24, 95% CI = 1.02-1.50, P < 0.001).; Conclusion: To mitigate metabolic syndrome risk, both adapting annual health checks available to adults with learning disabilities and adapting National Health Service weight management plans, to include neurodivergent adults is recommended. (© The Author(s) 2025. Published by Oxford University Press on behalf of Faculty of Public Health.)

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31. **Care-giving experiences of parents of young people with PMLD and complex healthcare needs in the transition to adulthood years: a qualitative poetic synthesis**

Authors: Slade, Katharine;Shaw, Rachel L.;Larkin, Michael and Heath, Gemma

Publication Date: 2025

Journal: Arts & Health: International Journal for Research, Policy & Practice 17(1), pp. 39–56

Abstract: Objective: To synthesise qualitative research exploring the care-giving experiences of parents of young people with profound and multiple learning disabilities (PMLD) and complex healthcare needs, in the transition to adulthood years. Method: Four databases were systematically searched: Scopus, WoS Core Collection, Medline and SciELO. Included papers were assessed for quality and thematically synthesised. Findings are presented in the form of free-verse poems. Results: Nineteen papers from eight countries were included. Analysis generated three themes: interdependency of parent and child, where parents retained responsibility for their child's care; apprehension regarding sharing and shifting responsibility between parents and professionals; an uncertain future in terms of care provision. Conclusions: Parents are concerned about the future care of their children. Training professionals in alternative and effective communication is fundamental to successful transition. Encouraging discussions about advanced care planning may also alleviate parental concerns and ensure good outcomes for young people with PMLD.

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32. **Best Practices for Supporting Social--Emotional Development in Children With Developmental Language Disorder and Attention-Deficit/Hyperactivity Disorder**

Authors: Timler, Geralyn R.;Zane, Emily;Decker, Alyssa L.;Ritter, Rachel and Stewart, Anne

Publication Date: 2025

Journal: Perspectives of the ASHA Special Interest Groups

Abstract: Purpose: Children with developmental language disorder (DLD) and/or attention-deficit/hyperactivity disorder (ADHD) are at an elevated risk of social--emotional difficulties, including low self-esteem and anxiety, related to school achievement and peer interactions. This clinical focus article provides best practice guidelines, shaped by a neurodiversity-affirming lens, to support children's social--emotional development. Method: The guidelines were developed through interprofessional discussions among the authors, which included three communication specialists and two mental health specialists, and supported by review of the scholarly literature on neurodiversity, DLD, and ADHD, with a focus on first-person perspectives of children and adults with these conditions and their parents and teachers. Results: The practice guidelines include recommendations for the interprofessional assessment of DLD and/or ADHD and suggestions for neurodiversity-affirming supports to promote acceptance of students with DLD and/or ADHD by teachers and peers. Intervention recommendations for social communication skills, self-regulation supports, and self-advocacy are described. A hypothetical case study is provided to illustrate implementation of the recommended practices. Conclusions: First-person and family perspectives studies provide compelling evidence that having DLD and/or ADHD, coupled with the negative reactions of others to children's differences related to these conditions, have adverse effects on children's social--emotional development. Speech-language pathologists and their interprofessional team members have an important role to play in preventing these effects by providing social--emotional supports for children with DLD and/or ADHD.

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33. **Prevalence of Psychotropic Medication Use and Psychotropic Polypharmacy in Autistic Adults With or Without Intellectual Disability**

Authors: Yoshida, Kazunari;Lunsky, Yona;Müller, Daniel J. and Desarkar, Pushpal

Publication Date: 2025

Journal: Journal of Autism & Developmental Disorders

Abstract: The aim of this study was to compare the rates of psychotropic medication use and psychotropic polypharmacy between autistic adults with and without intellectual disability (ID) and to examine factors associated with psychotropic medication use and psychotropic polypharmacy in autistic adults, stratified by the presence of ID. We conducted a retrospective medical chart review of outpatients with an autism diagnosis aged 18 years and older. The rates of psychotropic medication use and psychotropic polypharmacy were compared between autistic adults with and without ID. Subsequently, logistic regression analyses were performed to identify factors associated with psychotropic medication use and psychotropic polypharmacy in autistic adults with ID and those without ID, respectively. The rates of prevalence of psychotropic medication use and polypharmacy were significantly higher in participants with ID than those without ID (78.6% vs. 58.8% and 49.3% vs. 31.2%; p-values < 0.05). Age, gender, race, residence, presence of mood disorders, presence of schizophrenia, absence of anxiety disorder, number of psychiatric comorbidities, and presence of behaviors that challenge were significantly associated with these outcomes, depending on the presence/absence of ID. The need to optimize pharmacotherapy in autistic adults, stratifying by the presence of ID, is highlighted.

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34. **The use of control group in research design: the ethical challenge in the population with intellectual and developmental disabilities**

Authors: Diz, Susana;Jacinto, Miguel;Monteiro, Diogo;Matos, Rui;Esteves, Dulce;Costa, Aldo,M. and Antunes, Raul

Publication Date: 2024

Journal: Motricidade

Abstract: Ethics studies moral values and defines good and bad conduct in research and researchers. In research with human beings, it plays a crucial role in imposing limits, reducing abuses, and providing fair lines of research. The use of control groups in this type of research has been addressed and seems to be an effective method to assess the effects of an intervention, but it has raised doubts about the ethical challenges it involves. Therefore, this narrative review aims to address the ethical challenges in the use of control groups in research projects. In the analysed studies on populations with intellectual and developmental disabilities (IDD), it was found that most researchers favoured the use of control groups, which, during the research period, did not engage in any activity other than the usual activities in their daily lives. However, they should ensure that the control group has the opportunity to perform an intervention equal to the one performed by the experimental group after the end of the research. In addition, it was possible to verify that, for the most part, the authors ensure the follow-up of ethical standards in studies with human subjects.

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35. **Case study: Newly diagnosed type 1 diabetes education given to families with learning disabilities**

Authors: Hama, Zilan

Publication Date: 2024

Journal: Journal of Diabetes Nursing

Abstract: A child diagnosed with type 1 diabetes will rely on their parents to be able to effectively manage their condition, with the level of dependence gradually decreasing with advancing age and maturity. Treatment requires insulin administration, carbohydrate counting, regular blood glucose monitoring, a balanced diet and regular exercise. This can be especially challenging for a parent with a learning disability who may need additional support and has the legal right to reasonable adjustments when accessing healthcare services. This case study highlights the crucial role of the multidisciplinary team in supporting a parent with a learning disability. It details the reasonable adjustments made to ensure their child's safety and provide optimised diabetes management. The tailored education for the mother and the rationale for selecting the hybrid closed-loop system are also discussed. Pseudonyms are used throughout.

Sources Used:

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

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