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Learning Disabilities

Current Awareness Bulletin

July 2026

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- **Quickfire health literacy: communicating with patients more effectively**
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1. **Menopause as a factor in psychological, behavioural and cognitive changes in women with learning disabilities**

Authors: Adams, Danielle;Sawhney, Inder and Shah, Chetan

Publication Date: 2026

Journal: Learning Disability Practice 29(3), pp. 32–42

Abstract: Why you should read this article: • To refresh your knowledge of the unique healthcare challenges posed by the menopause for women with learning disabilities • To appreciate the risk of diagnostic overshadowing, incomplete differential diagnosis and inadequate support in women with learning disabilities • To contribute towards revalidation as part of your 35 hours of CPD (UK readers) • To contribute towards your professional development and local registration renewal requirements (non-UK readers). The menopause presents unique challenges for women with learning disabilities but it is often overlooked or misdiagnosed in this population. Unrecognised and untreated menopausal symptoms can trigger behaviour that challenges, potentially leading to the inappropriate prescribing of psychotropics. Diagnostic overshadowing must be avoided, but it is also important to

recognise that psychological, behavioural and cognitive changes in women with learning disabilities from their late thirties or early forties onwards do not necessarily stem from hormonal fluctuations. This article explores the menopause in women with learning disabilities, highlighting the risks of diagnostic overshadowing, incomplete differential diagnosis and inadequate support. Learning disability nurses have a pivotal role in helping service users and their families and carers to recognise and manage menopausal symptoms. Useful strategies include developing a proactive and individualised care plan for each woman approaching perimenopausal age, providing information in accessible formats, and educating families, carers and other health and social care professionals.

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2. **Novel Variants in PUS7 Associated With Intellectual Disability and Growth Retardation: Expanding the Clinical Spectrum in 13 Patients**

Authors: Bergès, Camille;Sauvestre, Clément;Naudion, Sophie;Delorme, Catherine Vincent;Smol, Thomas;Rama, Mélanie;Moortgat, Stephanie;Maystadt, Isabelle;Kersseboom, Rogier;Wilke, Martina;Barakat, Tahsin Stefan;Vial, Yoann;Perrin, Laurence;Passemard, Sandrine;Ahmad, Farooq;Umair, Muhammad;Haack, Tobias;Grimmel, Mona;Kuechler, Alma;Slavotinek, Anne, et al

Publication Date: 2026

Journal: Clinical Genetics 110(3), pp. 379–388

Abstract: Pseudouridylation is a frequent post-transcriptional modification resulting in uridine isomerization in 5-ribosyluracil, also called pseudouridine. This mechanism leads to RNA stability with an increase in base-stacking and the creation of hydrogen bonds. Recently, papers reported that variants in PUS7 in 16 patients were involved in marked growth retardation with microcephaly, associated with intellectual disability and behavioral issues such as self-injurious and aggressive behavior. Through Genematcher, we initiated a collaboration to describe a new cohort of PUS7 patients. In total, we report 13 new cases carrying 15 new variants. This cohort further expands the phenotypic spectrum associated with PUS7-related syndromes, allowing for improved genotype-phenotype correlations and ultimately better healthcare for affected individuals and their families.

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3. **Understanding Obesity in Individuals with Down Syndrome: Caregiver Perceptions, Awareness, and Motivation**

Authors: Cahill, Thomas;Nalesso, Valerie;Clarke, Pat;Martinez de Lagran, Maria;Strydom, Andre;Chan, Li;Potier, Marie-Claude;Beckers, Johannes;Langohr, Klaus;Liò, Pietro;de La Torre, Rafael;Forcano, Laura;Hiance-Delahaye, Anne;Hérault, Yann and Dierssen, Mara

Publication Date: 2026

Journal: Nutrients 18(11), pp. 1727

Abstract: Background: Individuals with Down syndrome (DS) are at an increased risk of obesity and, subsequently, its cardiometabolic and cognitive impacts. Caregivers play a critical role in managing health, yet their perceptions and behaviors have been poorly characterized.

Methods: We performed a cross-sectional online survey of caregivers (n = 764) taking care of 48% females and 52% males with DS, conducted across European populations, predominantly in Spain and France. We assessed perceived obesity, perceived harmfulness of current weight, professional consultation, and confidence in promoting healthy behaviors. Associations were examined using chi-square tests, correlation analysis, and ordinal and logistic regression models. Results: Around one-third (32%) of caregivers perceived their family member with DS with obesity. Perceived obesity changed with age and was more frequently reported in female family members with DS. Awareness of general metabolic risk factors was high among caregivers, but half of respondents were unaware that abdominal fat affects brain health. Consultation with healthcare professionals was uncommon (57% "Never/Rarely/Sometimes") even among those perceived with obesity. Conclusions: Caregivers demonstrate good general awareness about high energy food risks but limited knowledge of the link between obesity and brain health. Enhancing caregiver education and supporting behavioral change could promote healthier lifestyles in families with individuals with DS.

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4. **Communicative Dilemmas for Practitioners in Service Encounters With People With Intellectual Disabilities: Insights From a Systematic Review of Conversation Analytic Research**

Authors: Chinn, Deborah;Bruun, Andrea;Worrall, Deborah;Buell, Susan and La, Jessica

Publication Date: 2026

Journal: Journal of Applied Research in Intellectual Disabilities 39(3), pp. 1–32

Abstract: Background: How do practitioners in service settings respond to communication support needs of people with intellectual disabilities? Conversation Analysis (CA) uses recordings of everyday encounters to understand the challenges practitioners face. Method: Following specialist guidance on systematically reviewing CA research, we reviewed 65 CA research articles examining staff communication in healthcare, education, social care and the police. Results: We identified five themes in the synthesis. Two were categories of interactional practices (Questions and Answers; Decision-Making), one examined non-verbal communication (Embodied and Non-Verbal Communication) and two considered contributions of other material and human agents (Communication Aids and Supports; Involvement of Companions). In each theme, we saw examples of competency-enhancing and competency-inhibiting practices. Conclusions: Practitioners face interactional dilemmas: (1) Orienting to the Person's Self-determination versus Getting the Job Done; (2) Adapting Communication versus Downplaying Difference. Future research should build on this review to develop and evaluate communication training for staff. Lay Summary: Need for communication support: People with intellectual disabilities often need communication support in order to present their views, make decisions and engage in activities, but there is not much research that shows how this support is delivered by practitioners in real life.Using Conversation Analysis research to understand everyday interactions: We reviewed existing research that used a method called Conversation Analysis (CA) to understand how ordinary ways that staff ask questions, offer choices, use communication aids and respond to body language strongly shape whether people with intellectual disabilities are heard, understood and treated as competent decision-makers.Support can both help and hinder: The research demonstrated that strategies intended to help—such as simplifying language, guiding decisions or speaking on someone's behalf—

can unintentionally limit autonomy and participation if they prioritise efficiency or control over listening and choice.Implications for practice and research: Practitioners can improve their practice by being aware of the implications of offering support in different ways. This review provides information that can underpin evidence-based communication training at a level of detail beyond what is currently available.

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5. **The Mental Health Impacts of the COVID-19 Pandemic on Adults With Intellectual and Developmental Disabilities: A Qualitative Study**

Authors: Cvitanovic, Megan;Steinberg, Justin;Seay-Morrison, Timothy;Hui, Felicia;Young, Amanda;Respicio, Kobie;Margetts, Bradley;Digre, Sue;Vega, Colleen;Taylor, Sarah;Clarke, Lauren;Walls, Sydney C.;Rosas, Lisa G.;Barton, Krysta S. and Tabor, Holly K.

Publication Date: 2026

Journal: Journal of Applied Research in Intellectual Disabilities 39(3), pp. 1–13

Abstract: Abstract Background: While COVID-19 had a devastating impact on mental health worldwide, little is known about its effects on adults with intellectual and developmental disabilities. We used a community-based participatory approach to study this population's mental health experiences. Methods: Six focus groups were conducted: four with adults with intellectual and developmental disabilities (n = 21) and two with caregivers (n = 13). Conventional content analysis and thematic network analysis were utilised. Results: We identified cascading impacts of the pandemic on the mental health of this population. Sub-themes included: (1) environmental effects, (2) emotional effects and (3) physical and behavioural effects of COVID-19. Five modifying factors were identified. Conclusions: The COVID-19 pandemic, while specific in its restrictions and timing, illustrated and exacerbated unmet mental health needs of adults with intellectual and developmental disabilities. These results suggest opportunities for empirical research and policy development, relevant for future emergencies and ongoing medical and non-medical support of this population. Summary: The COVID-19 pandemic impacted the mental health of people with intellectual and developmental disabilities in several different ways.People with intellectual and developmental disabilities felt sad and lonely because they could no longer participate in their normal in-person activities. They also felt scared of getting COVID-19.Some people with intellectual and developmental disabilities experienced physical aggression and challenging behaviours.People with intellectual and developmental disabilities participated in several activities to help their mental health during the pandemic.Researchers and doctors should develop and test models of mental healthcare delivery that meet the specific needs of individuals with intellectual and developmental disabilities.

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6. **Intergenerational Change in Health, Well-Being and Social Inclusion for Two Groups of Adults With Intellectual Disability Aged 40-49: Findings From a National Longitudinal Study**

Authors: de Lima, Kálya,Yasmine Nunes;McCausland, Darren;McCallion, Philip and McCarron, Mary

Publication Date: 2026

Journal: Journal of Applied Research in Intellectual Disabilities : JARID 39(3), pp. e70254

Abstract: Background This paper examines differences in health, well-being and social inclusion between two generations of adults with intellectual disability in their 40s, measured 12 years apart. Method Data was drawn from Waves 1 and 5 of the Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing. Descriptive statistics were calculated at Waves 1 and 5 and outcomes were analysed using CHAID (Chi Squared Automatic Interaction Detection) decision tree. Results Wave was the main predictor of increased weekly contact with friends ($p < 0.001$), internet use ($p < 0.001$) and alcohol consumption ($p < 0.001$). Mild exercise ($p < 0.001$) and moderate exercise decreased ($p < 0.001$). Self-rated health ($p < 0.001$) and mental health ratings ($p = 0.006$) improved, while loneliness declined ($p = 0.041$). Use of general practitioners ($p < 0.001$), social work ($p < 0.001$) and home help ($p = 0.020$) declined, whereas optician ($p = 0.001$) and dermatological services ($p = 0.048$) increased. Conclusion Intergenerational changes were observed, with improved social inclusion and health perceptions, alongside shifts in behaviour and healthcare use.

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7. **Psychological Practitioners' Perceived Barriers and Solutions for Facilitating Access to Mental Health Services for Adults With Intellectual Disabilities**

Authors: Doherty, Joanna;Knight-Davies, Maisie and Gomes, Freya

Publication Date: 2026

Journal: Journal of Applied Research in Intellectual Disabilities 39(3), pp. 1–13

Abstract: Background: People with intellectual disabilities have the right to access mainstream healthcare services. However, research highlights barriers to accessing services and recommends reasonable adjustments to improve this. Method: Focus groups were held with 21 staff from adult mental health services, including the intellectual disability service in Somerset, UK, to identify barriers and solutions to improve access. Reflexive thematic analysis was used, and change ideas were generated. Results: Four themes were identified: service barriers to making reasonable adjustments, the need for adequate training, the need for joint working, and reasonable adjustments in practice. Staff reported awareness of adjustments but variable knowledge and confidence in implementing them. Participants highlighted service constraints and wanted increased flexibility, joint working, and clearer record keeping. Conclusions: From the identified barriers, change ideas were developed and solutions proposed to improve service access. Future service improvements and research need to meaningfully involve people with intellectual disabilities. Lay Summary: Adults with intellectual disabilities do not always get the help they need for their mental health.Mental Health staff in Somerset, UK, were asked what works well, what does not work well, and ideas for making it better.Staff said they tried to make small changes (reasonable adjustments) like having longer appointments and easy read letters but want more training and support to do this. Staff also want services to work better together and keep clearer records.Future research and changes to services need to involve people with intellectual disabilities.

8. **Equipping a Health System for Care of Persons with Intellectual and Developmental Disabilities | OJIN: The Online Journal of Issues in Nursing**

Authors: Eng, Elizabeth and Bourne, Melissa J.

Publication Date: 2026

Journal: Online Journal of Issues in Nursing 31(1), pp. N.PAG

Abstract: Individuals with intellectual and developmental disabilities (IDD) are more likely than the general population to experience health inequities. While a number of factors contribute to these health inequities, a major modifiable factor is inadequate healthcare provider knowledge and comfort in caring for individuals with IDD. Education has been effective to improve patient outcomes, yet no regulatory or licensing bodies require IDD training for nurses. Educational content must be delivered voluntarily by educational institutions and healthcare employers. Change leadership can be useful to support the voluntary addition of IDD education. This article shares an example of creating change in a health system, guided by Kotter's model, by adding IDD education to institutional library offerings. Topics within the newly developed education module included IDD awareness, patient rights, caregiver empathy, health inequities, communication skills, and de-escalation techniques. Using a pre- and post-survey design, improvements were noted by those completing the education model, specifically in the areas of comfort and perceived knowledge levels related to care for individuals with IDD. In the article, we also discuss implications for nurse clinicians, educators, researchers, and administrators.

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9. **Unmet healthcare needs in adults with childhood-onset neurodisabilities: a systematic review and narrative synthesis**

Authors: Gallagher, Aoife L.;Meehan, Elaine;Kerr, Claire;Manikandan, Manjula;O'Sullivan, Rory;Whiston, Aoife;Galvin, Rose and Robinson, Katie

Publication Date: 2026

Journal: Disability & Rehabilitation 48(13), pp. 3959–3983

Abstract: Purpose: To synthesise the literature regarding prevalence and types of unmet healthcare needs amongst adults with neurodevelopmental disabilities (NDDs) and to summarise the reasons for, and factors associated with these needs. Materials and Methods: Searches of electronic databases (n = 5) were completed in November 2024. Papers were included if they had an observational study design and focused on unmet health needs of adults with NDDs. Screening of papers was undertaken independently by two reviewers, initially by title and abstract (n = 7802), and then full text (n = 55). Included papers (n = 17) were independently appraised for quality. Data were synthesised using narrative analysis. Results: The prevalence of unmet needs appears higher for adults with NDDs than the general population across the pooled sample (n = 17,385). Unmet psychological needs were most frequently reported, followed by unmet therapy needs. Disability type, and the co-occurrence of psychiatric conditions increased the odds of having unmet needs, particularly for those from minority groups. Reasons for unmet needs related primarily to barriers at the practitioner level.

Conclusion: The need to enhance the health literacy competencies of practitioners is highlighted. The use of implementation science theories can advance the development and uptake of health literacy interventions in medical education and healthcare practice. IMPLICATIONS FOR REHABILITATION: Adults with childhood-onset neurodevelopmental disabilities report greater unmet healthcare needs than the general adult population. Unmet healthcare needs amongst adults with neurodevelopmental disabilities vary by disability type, the presence of additional mental health conditions, and ethnicity. Healthcare practitioners need opportunities to develop health literacy competencies as part of their prequalification training and their continuing professional development.

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10. **Values of Individuals With Rare Genetic Neurodevelopmental Disorders and Their Family/Caregivers in Healthcare: A Scoping Review to Inform Guideline Development**

Authors: Klein Haneveld, Mirthe J.;Cox, Louise;Embregts, Petri J. C. M.;Niemeijer, Alistair R.;Cornel, Martina C.;Gaasterland, Charlotte M. W. and van Eeghen, Agnies M.

Publication Date: 2026

Journal: Journal of Intellectual Disability Research 70(6), pp. 608–652

Abstract: Background: Healthcare decision-making for individuals with rare genetic neurodevelopmental disorders (RGNDs) associated with intellectual disabilities (ID) can be complex due to the intersection of lifelong care needs, limited medical expertise and communication barriers. Clinical practice guideline recommendations for managing RGNDs should align with the values of individuals and their families/caregivers; this requires the use of an appropriate Evidence-to-Decision framework in guideline development. This review aims to describe what individuals with RGNDs associated with ID and their family/caregivers value in healthcare and healthcare decision-making. Methods: This scoping review aimed to map the available evidence on individual and family/caregiver values in healthcare for RGNDs to inform guideline development. MEDLINE, Embase, PsycINFO and CINAHL were systematically searched for literature published from 2000 to 2025, with the final search conducted on 1 June 2025. Studies reporting primary qualitative data on individuals with RGNDs and/or their family/caregivers in the context of healthcare were eligible for inclusion. Inductive content analysis was conducted to map values in healthcare and healthcare decision-making. Results: One hundred twenty-five articles were included. Most studies reported on the perspectives of families/caregivers and on relatively more common conditions, in particular Down syndrome. Important values included autonomy, person-centredness, feasibility, competence of and connection with the healthcare professional and accessibility, coordination and absence of stigma on the level of the healthcare system and society. In healthcare decision-making, benefits and harms both on an individual and on the family level were balanced alongside uncertainty, priority of health issues and identity-related considerations. Discussion: Guideline developers should address issues that matter to individuals with RGNDs and their families/caregivers during Evidence-to-Decision processes, such as family-level impact and identity-related considerations. Further research is needed to capture perspectives of individuals with ID, which are underrepresented compared to family/caregivers.

11. **Perinatal mental health research: priorities from a neurodiverse sample in the United Kingdom**

Authors: Lautarescu, Alexandra;Heraty, Siofra;Johnson, Chloe;Ruigrok, Amber;Eaton, Eliza;Bazelmans, Tessel;Sigurdardottir, Julie;Ratti, Victoria;Stone, Holly;Anderson, Jenna;Javed, Ayesha;Mahtani, Shivali;Lau-Zhu, Alex and Smith, Debbie M.

Publication Date: 2026

Journal: Archives of Women's Mental Health 29(4)

Abstract: Purpose The aim of this study is to better understand perinatal mental health research priorities of neurotypical and neurodivergent people. Methods A co-designed mixed-methods survey was conducted as part of the Wellbeing Across Neurotypes: Depression and Anxiety (WANDA) study. 709 participants in the United Kingdom (UK) quantitatively rated and ranked research topics within perinatal mental health, with 253 also providing qualitative data. Results The top research priorities were (1) interventions and (2) diagnosis for perinatal mental health problems for birthing people and (3) how these impact parent-infant relationships. Qualitative data revealed additional topics of importance including healthcare experiences, trauma, and neurodiversity. Conslusions These results suggest complex, multilevel barriers to accessing diagnosis and support in the UK.

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12. **Hearing Impairments in People With Intellectual Disabilities: A Prospective Cohort Study on Prevalence and Healthcare Utilization**

Authors: Mathmann, Philipp;Gietmann, Corinna;Jankovic, Vincent;Brannath, Werner;Naghipour, Awa;Matulat, Peter;Diekmann, Sandra;Hesping, Amélie;Neumann, Anja;Prein, Lukas;Schäfer, Karolin;Schlierenkamp, Sarah;Schwalen, Anna Sophie;Schwarze, Katharina;Wasmuth, Susanne;Weiler-David, Heike;Wiegand, Anna;Zielonkowski, Susanna;Scharpenberg, Martin and Neumann, Katrin

Publication Date: 2026

Journal: Deutsches Arzteblatt International 123(18)

Abstract: Background People with intellectual disabilities (ID, prevalence ca. 1.04%) have an elevated risk of hearing impairments, which, if untreated, can hinder communication, cognitive development, and social participation. In a project called "HörGeist," we studied the prevalence of hearing impairments and the feasibility and utility of an outreach auditory screening, diagnosis, and intervention program for people with ID in their living and working environments. Methods In an age-stratified cohort study with a total of 1194 subjects, 1053 people with ID (outreach cohort, aged 1-90 years) underwent auditory screening in their living or working environment twice one year apart, and, if indicated, a diagnostic evaluation for a hearing impairment and either an intervention or a referral for outside treatment. To compare utilization, a control cohort of people with ID (141 subjects) was offered screening and auditory diagnostic testing in a clinical setting. Results Clinically relevant hearing impairments were diagnosed in 44.0% of patients in the outreach cohort; 69.8% of these impairments had not been identified previously. Cerumen obturans affecting hearing was present in 9.9% of the

impairments. Approximately one-third of the subjects or their carers overestimated their hearing ability. Screening and diagnostic evaluation yielded a conclusive result in 96.7% of cases. Screening had an estimated 92.3% specificity (95% confidence interval: 89.6; 94.3]) and 96.4% sensitivity (94.1; 97.8]). None of the subjects in the invited control cohort made use of the auditory screening program. The prevalence of hearing impairments varied depending on sex, age, and type of institution. Conclusion The prevalence of hearing impairments in people with ID is high, and most cases are unrecognized. A comprehensive outreach program of auditory screening, diagnostic evaluation, and intervention for people with ID appears feasible and justified and would reach more of the affected persons than a simple invitation. It could improve their social participation as well.

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13. **Adults with Intellectual Disability and Consent to Precision Medicine Research: Using Supported Decision-Making to Facilitate First-Person Consent**

Authors: McDonald, Katherine;Olick, Robert;Dinerstein, Robert;Mulcahy, David;Cooley, Mark;Banzer, Eulena and Sabatello, Maya

Publication Date: 2026

Journal: Journal of Law, Medicine & Ethics 54(2), pp. 45–55

Abstract: Scientific discoveries and precision medicine research, especially efforts to identify individually tailored approaches to healthcare considering individual variability in genetics, environmental, and lifestyle factors, have the potential to transform health. This goal is especially critical for those who experience social injustices and substantial health disparities. Yet the inclusion of adults with intellectual disability in precision medicine research, a growing field in clinical and translational genomic research, raises ethical, social, and legal concerns about their ability to make informed decisions to participate, and subsequently whether this population should be excluded altogether or enrolled only via proxy consent. Both practices demand scrutiny and are sometimes without legal or ethical justification. Supported decision-making, a reasonable accommodation and relatively recent legal and ethical construct, can facilitate first-person consent and maintain the prospective participant's position as the decision-maker. As such, supported decision-making is a promising development with critical implications for consent to precision medicine research. Using findings from our national survey with adults with intellectual disability and a legal analysis, our academic-community research partnership developed recommendations and a tool for using supported decision-making for enrollment in precision medicine research. We conclude with persistent challenges that need resolving to ensure the responsible inclusion of adults with intellectual disability in precision medicine research, and clinical research more generally.

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14. **Healthcare Utilisation in Ageing Adults With Intellectual Disability: Longitudinal Evidence From Five Waves of IDS-TILDA**

Authors: McMahon, Martin;Paul, Aviejay;Ryan, Catriona;Lynch, Louise;McCallion, Philip;McCarron, Mary and Burke, Eilish

Publication Date: 2026

Journal: Journal of Applied Research in Intellectual Disabilities 39(3), pp. 1–9

Abstract: Background: Adults with intellectual disability are living longer and ageing with more illness. This impacts healthcare utilisation. Yet little is known about how healthcare utilisation changes over time as this population ages. Methods: Five waves of longitudinal data of people ≥ 40 years with intellectual disability from 2009 to 2023 were analysed. Generalised linear multilevel models examined associations between sociodemographic characteristics and multimorbidity with patterns of General Practitioner (GP), outpatient and emergency department use. Results: GP use was consistently high across all waves. Outpatient use increased as people aged, while emergency department use was associated with age greater than 65, multimorbidity and conditions such as neurological, joint, gastrointestinal, endocrine and heart disease. Residence was a significant factor influencing healthcare utilisation. Conclusion: Our findings demonstrate that multimorbidity, residence and age were associated with healthcare utilisation. These are important insights to help support the planning of accessible and preventative health services for this population. Summary: GP use was consistently high, with outpatient use increasing as people aged. Emergency department use was associated with multimorbidity and older age.Where people live had an impact on how much healthcare they used.These findings point to gaps in access that need attention as people get older.This study provides evidence that can help improve how services are planned and delivered for ageing adults with intellectual disability.

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15. **Context, Mechanisms and Outcomes of Reasonable Adjustments Across Acute Hospital Settings for People With Intellectual Disabilities: A Scoping Review Protocol**

Authors: Moloney, Mairead;Taggart, Laurence and Doody, Owen

Publication Date: 2026

Journal: Campbell Systematic Reviews 22(2), pp. 18911803261453950

Abstract: This is a protocol for a Campbell scoping review. The objective is to map the existing evidence on the implementation of reasonable adjustments in acute hospital settings for people with intellectual disabilities, using a realist lens. This involves examining how contextual factors interact with underlying mechanisms to influence outcomes related to equitable access, quality of care, and health experiences. In the context of healthcare for people with intellectual disabilities, reasonable adjustments can help bridge health inequities. There is a strong evidence base in the literature for reasonable adjustments, however there is little evidence of implementation across acute hospitals. Exploring this topic using a realist lens of context, mechanism and outcomes may help identify the underlying factors influencing implementation of reasonable adjustments in clinical practice. The review will follow the JBI scoping review methodology and will be reported in line with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews. Evidence sources examining reasonable adjustments implemented by healthcare staff to support people with intellectual disabilities in acute hospital settings will be included. A comprehensive search strategy will be applied across the following information sources: MEDLINE, CINAHL, Academic Search Complete, Embase, Scopus, Web of Science Core Collection, PsycINFO, JBI Evidence Synthesis, and The Cochrane Database of Systematic Review. Additionally, a rigorous search of grey literature will be conducted across defined databases, search engines

and repositories. Sources will be limited to the English language, with no time limit imposed. Data will be extracted using a table designed for the review and following qualitative content analysis, results will be presented in tabular form with narrative summaries.

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16. **Exploring perceived usefulness and perceived ease of use of patient-led recording for adults with Down syndrome and their support people: A qualitative study**

Authors: Ryan, Laura;Ellem, Kathy;Le Brocque, Robyne;Mitchell, Claire and Langdon, Luka

Publication Date: 2026

Journal: Journal of Intellectual & Developmental Disability 51(2), pp. 127–138

Abstract: Background: People with Down syndrome often face communication barriers, cognitive limitations, and inadequate service responses during hospital clinical encounters, leading to poorer health outcomes. Patient-led recordings, where individuals use their own smart devices to capture clinical encounters, show promise in helping to address these issues. However, their use in this population remains unexplored. Method: Semi-structured interviews were conducted with 12 adults with Down syndrome and 12 nominated support people. Interviews were transcribed and analysed using a critical realist approach to thematic analysis. Results: Participants identified several benefits of patient-led recordings, including improved communication, enhanced comprehension, supported decision-making, increased empowerment, and positive emotional impacts. However, barriers such as awareness, accessibility, digital literacy, consent, and confidentiality concerns were noted. Conclusion: Patient-led recordings could improve healthcare experiences for some people with Down syndrome, but addressing key barriers is necessary for successful implementation.

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17. **Developing community mental healthcare services for adults with intellectual disability can reduce involuntary hospital admissions and improve patient experience**

Authors: Sheehan, Rory

Publication Date: 2026

Journal: Evidence-Based Nursing

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18. **Illness experiences of people with intellectual disabilities facing cancer: A qualitative study**

Authors: Soffer, Michal;Cohen, Miri;Hijazi, Ashraf and Arbel-Alon, Sagit

Publication Date: 2026

Journal: Disability and Health Journal , pp. 102109

Abstract: Background People with intellectual disabilities (PWID) experience substantial disparities across the cancer care continuum, including delayed diagnosis, communication

barriers, and unequal access to information and support. Little is known about the illness experiences of PWID facing cancer. Objectives This study explored the illness experience of PWID and cancer and elicited their illness narratives, with particular attention to their perceptions of cancer, communication about the disease, and the support they received from healthcare professionals, residential staff, and family. Methods Semistructured, linguistically adapted interviews were conducted with 18 PWID diagnosed with cancer. Reflexive thematic analysis was applied. Interviews were adapted to remove communicative barriers and structured at a pace that minimized anxiety. Results Four themes emerged: (a) perceptions of cancer-participants seldom used the word "cancer," describing illness through bodily sensations, treatments, or vague terms; (b) emotional responses to cancer-dominated by fear of death, yet participants reported few opportunities to express or discuss these emotions; (c) Impact of cancer on life after treatment -participants reported changes in body, functioning, and dependence, with varied life disruptions; and (d) social reactions-support from family and others was meaningful, but concealment of the illness was often encouraged, reinforcing silence and isolation. Conclusions Across these accounts, a lack of accessible information and limited emotional dialogue shaped experiences of loneliness and silence. The findings underscore the need for cancer care practices that prioritize accessible communication, emotional engagement, and inclusion of PWID as active participants in their care.

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19. **Broad perspective on socio-economic disadvantages in youth with mild to borderline intellectual disabilities in mental health care**

Authors: Storm, Maxine M. C.;van Eldik, Willemijn M.;Kasius, Marianne C.;Vermeiren, Robert R. J. M. and Giltay, Erik J.

Publication Date: 2026

Journal: European Child & Adolescent Psychiatry 35(4), pp. 1235–1246

Abstract: The objective of this study was to understand how socio-economic disadvantages relate to mental health problems (MHP) among children with mild intellectual disability or borderline intellectual functioning (MID-BIF) in outpatient care by extending beyond traditional economic measures, incorporating cumulative risks, and analyzing variations across clinical subgroups. Using a population-based case-control design, data from Statistics Netherlands and mental health records were analyzed for 1,742 children with MID-BIF receiving mental health care (M_{age} = 9.6, 33.1% girls) and 8,710 age- and sex-matched controls aged 0–17. Logistic regression revealed that children with MID-BIF and MHP were significantly more likely than controls to come from families facing socio-economic disadvantages, such as single parenthood, lower parental education, reliance on social benefits, low income, and subsidized housing. Socio-economic risks were more likely to cluster in the case group, with 15.3% of children exposed to five risk categories and 6.7% to all six, compared to 6.7% and 3.6% in controls, respectively. Children in the internalizing and externalizing symptom-based groups faced more pronounced socio-economic disadvantages than those in the developmental group. Additionally, more extensive care was unexpectedly linked to more favorable socio-economic conditions, suggesting a complex interplay between care needs and socio-economic conditions. Taken together, this study showed that children with MID-BIF receiving outpatient care for their MHP often face greater and more clustered socio-economic disadvantages. Simultaneously, children from socio-economically disadvantaged backgrounds received less

specialized mental health care. This underscores the importance of addressing barriers in mental health care and promoting family- and community-based care.

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20. **Views and experiences of weight management for people living with mobility-limiting conditions, intellectual disabilities or severe mental illness: a qualitative evidence synthesis**

Authors: Sutcliffe, Katy;Kneale, Dylan;Dimitrova, Velichka;Mathew, Silvy;Stansfield, Claire;Schucan Bird, Karen;Rivas, Carol;Hunter, Rachael and O'Mara-Eves, Alison

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Journal: The Cochrane Database of Systematic Reviews 6

Abstract: Objectives This is a protocol for a Cochrane Review (qualitative). The objectives are as follows: This qualitative evidence synthesis (QES) aims to address the question: What is known from qualitative evidence about behavioural weight management for people living with mobility-limiting conditions, intellectual disabilities, or severe mental illness? The five review objectives are as follows. To explore individuals' experiences with weight and behavioural weight-management programmes. This includes understanding how individuals living with mobility-limiting conditions, intellectual disabilities, severe mental illness and their carers experience managing their weight and how they perceive and engage with behavioural weight-management programmes, including how accessible, supportive, and relevant they find the programme elements. To identify barriers to and facilitators of managing a healthy weight and accessing behavioural weight-management programmes. Focusing on the unique obstacles encountered by each population group, we will examine issues such as physical accessibility, communication challenges, financial constraints, and gaps in tailored support that may prevent equitable participation. We will also include people's perspectives on structural and system-level barriers, as well as the influence of intersectional factors (e.g. gender and ethnicity), on the challenges of maintaining weight and accessing and benefiting from support. To understand the impact of stigma and discrimination on programme engagement and outcomes. This objective seeks to uncover how stigma related to weight, disability, or mental health influences individuals' willingness to participate, their inclusion and sense of belonging with others within the programmes, and overall programme satisfaction. It also examines the role of stigma as a potential barrier to success. To capture the perspectives of programme providers and healthcare practitioners. Gathering insights from healthcare providers and programme facilitators, this objective assesses which programme elements are considered successful and which present ongoing challenges. This includes evaluating aspects like accessibility, engagement strategies, and support mechanisms that may require improvement. To produce an inclusive piece of research through incorporating the insight of people with lived experience and professional expertise in interpreting and considering the implications of the evidence. By synthesising this qualitative evidence, the review aims to provide a comprehensive understanding of how to design and implement behavioural weight-management programmes that are more inclusive, effective, and responsive to the needs of these populations.

The following databases are used in the creation of this bulletin:

CINAHL and Medline.

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