

Learning Disabilities

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April 2026

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1. Active ageing in people with intellectual disability: a qualitative evidence synthesis of the experiences, challenges, and pathways to support

Authors: Acton, Daniel; Talbot, Grace; Mogan, Caroline and Jaydeokar, Sujeet

Publication Date: 2026

Journal: Journal of Intellectual & Developmental Disability 51(1), pp. 1–13

Abstract:

Background: Improved life expectancy, among individuals with intellectual disability, highlights unique health, social, and emotional challenges in ageing, including premature ageing, comorbidities, and access barriers to accessing care. This review explores whether current systems adequately address the holistic needs of ageing individuals with intellectual disability, emphasising the importance of person-centred support. Method: A qualitative evidence synthesis was undertaken using thematic synthesis to identify and analyse patterns across studies. A systematic search of eight databases was conducted, and 15 qualitative studies, published between 2010 and 2023, were included. Results: Five key themes were identified: challenges in managing physical health declines, reduction in personal autonomy and control, increased social isolation, uncertainty about future care, and age-related stigma, and discrimination. Conclusion: This review underscores the importance of a holistic, person-centred approach to supporting ageing individuals with intellectual disability. Addressing health and psychosocial needs, and advocating for inclusive service planning remains essential. Access or request item here:

2. Applying the World Health Organization's International Classification of Functioning, Disability and Health to speech-language pathology social communication interventions for autistic children and youth: A scoping review

Authors: Albin, Maya;Phoenix, Michelle and Rosenbaum, Peter

Publication Date: 2026

Journal: *Autism: The International Journal of Research & Practice* 30(4), pp. 847–865

Abstract:

The World Health Organization's International Classification of Functioning, Disability and Health (ICF) aligns with the neurodiversity paradigm in viewing autistic people's social communication holistically and in a strength-based manner. In this scoping review, we explored how social communication interventions for autistic children and youth map onto the domains of the International Classification of Functioning, Disability and Health in the field of speech-language pathology. OVID Medline, OVID Embase, OVID PsycINFO and Web of Science databases were searched to identify relevant articles. Population, intervention and study data were extracted, as well as data on each of the International Classification of Functioning, Disability and Health domains related to the social communication interventions. In total, 21 articles were included in our analysis. No studies explicitly mentioned the International Classification of Functioning, Disability and Health. All the studies focused on participation and environmental factors (e.g., people's attitudes, physical environment), and some studies discussed other International Classification of Functioning, Disability and Health domains such as body structures and functions, personal factors and activities. The examples provided for each International Classification of Functioning, Disability and Health domain may be helpful for clinicians and researchers looking to understand how components of social communication interventions link to International Classification of Functioning, Disability and Health categories. Future work could analyse how social communication interventions in other fields (e.g., psychology, occupational therapy) map onto the International Classification of Functioning, Disability and Health. This review article investigates how the World Health Organization's International Classification of Functioning, Disability and Health can be applied to better understand speech-language pathology social communication interventions. In recent years, academic articles have supported thinking differently about how autistic people communicate, including the many strengths autistic people have and how other people and the environment influence communication. The International Classification of Functioning, Disability and Health is a holistic, widely used framework that provides a neurodiversity-affirming perspective on social communication interventions for autistic children. We did not find any published literature applying the International Classification of Functioning, Disability and Health to speech-language pathology social communication interventions for autistic children and youth and therefore wanted to explore whether and how social communication interventions reflect International Classification of Functioning, Disability and Health concepts. To answer this question, we searched the academic literature using several databases using a methodology called a scoping review. We included articles that had autistic children and youth as participants and focused on social communication interventions in the field of speech-language pathology. We found 21 articles that met our inclusion criteria. No studies talked explicitly about the International Classification of Functioning, Disability and Health. All the studies focused on participation and environmental factors (e.g., people's attitudes, physical environment), and some studies discussed other International Classification of Functioning, Disability and Health domains such as body structures and functions, personal factors and

activities. It is important for speech-language pathology social communication interventions to consider how the physical environment, social environment and personal factors impact social communication. Clinicians and researchers may find our application of the International Classification of Functioning, Disability and Health to social communication interventions useful to shape how they think about interventions. Access or request item here:

3. Experiences of health professionals conducting cancer screening of individuals with intellectual disabilities: A phenomenological study

Authors: Aydın, Mesiya;Aydın, Ruveyde and Avcı, İlknur Aydın

Publication Date: 2026

Journal: Research in Developmental Disabilities 171, pp. 105271

Abstract:

Background: Cancer, with its increasing incidence and mortality rates, remains one of today's top global public health concerns. People with intellectual disabilities, a vulnerable population group, are at increased risk of developing cancer due to their high prevalence of behavioral risk factors. This study aims to examine the experiences of health professionals who perform cancer screening on individuals with intellectual disabilities.; Method: The research is a phenomenological study. Data were collected from 13 healthcare professionals working in Cancer Early Diagnosis, Screening, and Education Centers between May and August 2025. A semi-structured interview form based on the literature was used to collect data. The data were analyzed using thematic analysis.; Results: Participants' experiences were examined under four themes and eleven subthemes: the meaning of caring for an individual with intellectual disabilities, difficulties experienced, coping with difficulties, and encouragement for cancer screening.; Conclusion: It has been determined that healthcare professionals experience professional satisfaction when providing care to individuals with intellectual disabilities, but at the same time, they face challenges during this process. Healthcare professionals and managers working in screening units should collaborate to restructure services aimed at increasing the participation of individuals with intellectual disabilities in cancer screening programmes. (Copyright © 2026 Elsevier Ltd. All rights reserved.) Access or request item here:

4. Distributed Health Literacy Among People With Intellectual Disability, Their Supporters and Healthcare Professionals: A Scoping Review

Authors: Barrington, Maryann;Fisher, Karen R.;Harris-Roxas, Ben;Trollor, Julian N.;Spooner, Catherine;Christensen, Julie M. and Weise, Janelle

Publication Date: 2026

Journal: Health Expectations : An International Journal of Public Participation in Health Care and Health Policy 29(2), pp. e70548

Abstract:

Background: Health literacy is associated with improved healthcare experiences and health outcomes and is influenced by the social context in which it occurs. People with intellectual

disability face stark health inequalities, yet the health literacy concept is underexplored for this group. Little is known about how health literacy is co-constructed between people with intellectual disability, supporters and healthcare professionals.; Objective: The aim is to understand the experiences of people with intellectual disability accessing, understanding, appraising and applying health information together with their supporters and healthcare professionals.; Search Strategy: This scoping review followed Joanna Briggs Institute guidelines. Articles were identified and retrieved from CINAHL, PsycINFO, PubMed and EMBASE. Articles were included if they were published between 2000 and the present and focussed on aspects of how people with intellectual disability accessed, understood, appraised or used information or the role that socio-environmental influences, including support networks and healthcare professionals, have in this process.; Data Extraction and Synthesis: Two reviewers completed abstract and full-text screening, addressing any conflicts at each stage. Data were extracted and coded deductively, according to the integrated model of health literacy.; Main Result: Following search and screening, 90 articles were included for review. Interpretation of the evidence suggests that health literacy is a relational process between people with intellectual disability, support networks and healthcare professionals. Each group experiences particular barriers and facilitators to this process and is impacted by its wider social and environmental contexts. There was limited evidence about how personal characteristics might shape health literacy, particularly intersectional experiences.; Discussion and Conclusions: Health literacy is a social practice, with roles and responsibilities shared among people and systems. Healthcare and disability sectors can facilitate health literacy by creating environments that support shared access and use of health information, as well as facilitate choice and decision-making.; Patient or Public Contribution: Collaboration with people with intellectual disability in scoping reviews is an emerging area. We gained the perspectives and feedback of colleagues with lived experience of intellectual disability for the design of the review and interpretation of the evidence. This included meeting with a Lived Experience Reference Group of seven people with intellectual disability to discuss our process and findings and receive their guidance. Their contributions supported how we interpreted the findings and reported the review. (© 2026 The Author(s). Health Expectations published by John Wiley & Sons Ltd.) Access or request item here:

5. Tier 1 evaluating the implementation of the Oliver McGowan Mandatory Training in learning disabilities and autism across interdisciplinarity health-related courses at Aston University

Authors: Bashir, Amreen;Rana, Karan Singh;Murphy, Jayne and Drozd, Mary

Publication Date: 2026

Journal: Frontiers in Medicine 13, pp. 1672094

Abstract:

Introduction: The Oliver McGowan Mandatory Training (OMMT) on Learning Disability and Autism was developed to address recognized gaps in healthcare professionals' education and training. Under the Health and Care Act, 2022, healthcare providers are required to ensure staff receive role-appropriate training in autism and learning disabilities. In response, NHS England introduced OMMT as a standardized national programme to support the development of a skilled and inclusive healthcare workforce, aligned with the NHS Long Term Workforce Plan (2023). This study reports on the first pilot implementation of Tier 1 OMMT within a higher

education institution, involving students enrolled in Nursing, Biomedical Science, Physician Associate, Optometry, and Pharmacy programmes at Aston University, UK.; Materials and Methods: The interdisciplinary Tier 1 training consisted of a 90-min e-learning module and a 1-h interactive webinar featuring experts by experience and facilitators. This study evaluated healthcare students' understanding pre-and post-training. Data on autism and learning disabilities awareness was collected via Jisc Online Surveys. Likert scale data were analyzed quantitatively, and free-text responses examined using thematic analysis to evaluate training effectiveness.; Results: Post-OMMT training results showed significant improvements in students' confidence in verbal communication and using various methods to communicate with autistic individuals and those with learning disabilities ($p < 0.0001$). Students reported enhanced understanding and awareness of autism and mild, moderate, severe and profound learning disabilities ($p < 0.0001$). Thematic analysis highlighted those students valued learning from experts by experience. Post-training participants recognized the benefits of individualized healthcare, the need for reasonable adjustments, and the importance of multidisciplinary team approaches in providing equitable care for autistic people and people with learning/intellectual disabilities.; Discussion: This interdisciplinary training enhanced healthcare students' understanding of autism and learning disabilities, equipping them with key skills for future NHS roles and supporting improved outcomes for neurodivergent populations. Embedding such training across all HEIs is essential to prepare professionals to not only treat, but also understand, respect, and advocate for autistic and learning-disabled individuals. (Copyright © 2026 Bashir, Rana, Murphy and Drozd.) Access or request item here:

6. Antipsychotic Use Among Intellectually Disabled Individuals With Rare Genetic Variants That Confer Risk for Schizophrenia

Authors: Colijn, Mark Ainsley

Publication Date: 2026

Journal: Journal of Intellectual Disability Research 70(4), pp. 440–445

Abstract:

Background: Rare genetic variation can predispose individuals to the development of schizophrenia, with certain genes and copy number variants (CNVs) conferring risk at the exome/genome-wide level. Despite this strong association, little is known about antipsychotic effectiveness and tolerability among individuals with most of these disorders. As such, this retrospective chart review sought to gather more data regarding the real-world use of antipsychotics in this context. Methods: This largely descriptive, cross-sectional and retrospective chart review took place at a developmental disabilities mental health clinic. Clinical information was primarily derived from electronic medical records. Individuals with a history of psychosis and antipsychotic exposure identified as having a genetic variant known to confer exome/genome-wide risk for schizophrenia were included in the study. Results: Of the 1196 charts reviewed, 24 individuals with a relevant genetic variant were identified, 11 of whom had experienced psychotic symptoms that were treated with antipsychotic medication. Six have 22q11.2 deletion syndrome, two have 15q11-q13 duplication syndrome and one individual each has a 16p11.2 duplication, a 7q11.23 duplication and a missense variant in TRIO. Overall, antipsychotic therapy tended to be reasonably effective and well tolerated (particularly among those individuals who do not have 22q11.2 deletion syndrome), despite side effects of some kind occurring in most cases. Conclusion: While this study had numerous

limitations that prevent firm conclusions from being drawn, it provides preliminary evidence that antipsychotics may be relatively safe and effective in at least some of the genetic disorders most strongly associated with schizophrenia. Access or request item here:

7. Using Network Analysis to Understand the Associations Between Menopausal Symptoms and Mental Health in Women With Intellectual Disabilities

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

Publication Date: 2026

Journal: Journal of Applied Research in Intellectual Disabilities : JARID 39(2), pp. e70216

Abstract:

Background: Women with intellectual disabilities typically face high rates of mental health and communication difficulties. Given associations between menopause and mental health in the general population and the lack of research on this topic in women with intellectual disabilities, it is critical to investigate associations between menopause and mental health in this population.; Method: Cross-sectional data were drawn from a cohort study in Ireland (n = 104). Measures included data on menopause, challenging behaviours and psychotropic medication. Associations between menopausal symptoms and mental health were examined through regression and network analysis.; Results: Vasomotor symptoms, fatigue, and mood changes were associated with menopause-specific anxiety, which was further linked to challenging behaviour and psychotropic medication use.; Conclusions: Menopausal symptoms were associated with mental health challenges, which, in turn, could influence challenging behaviour and psychotropic medication use in this population; implying that menopause-specific mental health symptoms may be overlooked and incorrectly treated. (© 2026 The Author(s). Journal of Applied Research in Intellectual Disabilities published by John Wiley & Sons Ltd.) Access or request item here:

8. Connecting in the time of COVID: exploring digital communication in an intellectual disability service

Authors: Darrant, Joanne;Lewington, Tim and Dobel-Ober, David

Publication Date: 2026

Journal: Advances in Mental Health & Intellectual Disabilities 20(1), pp. 1–12

Abstract:

Purpose: The COVID-19 pandemic created a rapid move to digital delivery of services within the NHS. Reduced face-to-face contact for the general population meant accessing services through video or telephone calls; this was not possible for some service users with intellectual disabilities. Technology, originally designed for use with older adults to reduce isolation, was trialled by the learning disability (LD) service in an NHS Trust. The pilot was exploratory, giving staff and service users the opportunity to experiment and find potential uses for equipment initially designed for a different client group. This evaluation aims to review how staff utilised the equipment, its benefits and drawbacks. Design/methodology/approach: Semi-structured interviews were carried out with staff and service users to explore the possibilities of remote

service delivery with this patient group. Interview data was coded, themed and analysed. Findings: Devices were well received once technical issues were resolved. The trial was successful in reducing isolation and delivering some services in a new way at a time of mandatory social isolation. The move to digital service delivery has not stopped post-pandemic and has enhanced choices available for clinicians. This may improve service access for vulnerable communities with limited access to mainstream IT. Originality/value: This study highlights how technology can be used to support access to services amongst vulnerable groups. Further research into patient experience of using devices should be considered to develop evidence of their usefulness in delivering services and reducing isolation across services.

9. Baseline cognitive and adaptive functioning assessments for people who have Down's syndrome: survey of practice in the UK

Authors: Dodd, Karen

Publication Date: 2026

Journal: *Advances in Mental Health & Intellectual Disabilities* 20(1), pp. 24–37

Abstract:

Purpose: This study aims to explore the prevalence of baseline assessment services for people who have Down's syndrome in the UK. It aimed to collate information on the types of assessment offered and information about additional interventions offered after the completion of the baseline assessment. **Design/methodology/approach:** A short survey form was developed and distributed via the British Psychological Society Faculty for People with Intellectual Disabilities. **Findings:** Responses were received representing 73 services across all four nations of the UK. About 47 (64%) of services currently offer baseline assessments to people who have Down's syndrome, mostly at age 30. Also, 34 (72%) of these services offer both direct cognitive assessment and informant assessment. Direct cognitive assessments were primarily conducted by members of the psychology team, and informant assessments by psychologists and other members of the Community Learning Disability Team (CLDT). Services that only offered informant assessments tended to be nurse-led and involve other members of the CLDT. In total, 23 (49%) services offered a variety of post baseline interventions. Comments reflected issues with resources; commissioning; transformation; expertise; terminology. **Practical implications:** Baseline assessments for people who have Down's syndrome are an important part of service provision, and there needs to be further work to ensure that people are not subject to a post-code lottery on whether they can receive this service. The recommendations from the BPS/RCPsych guidance (BPS, 2025) should be implemented in full. **Originality/value:** This is the first survey of services across the UK to establish information about baseline assessments for people who have Down's syndrome.

10. The Experiences of Autistic Healthcare Students in a Clinical Learning Environment: A Scoping Review

Authors: Edwards, Emilie;Porter, Nicolette;Handley-Stone, Ruby;Hingley-Jones, Helen and Reynolds, Gemma

Publication Date: 2026

Abstract:

Autism is increasingly understood from a neurodiversity-affirmative perspective recognising the unique contributions of autistic individuals. Despite this shift, the specific experiences of autistic healthcare students in clinical placements remain underexplored. This scoping review aims to map existing literature on this topic, identifying both barriers and enablers to learning in clinical environments. Using Arksey and O'Malley's framework, with methodological updates, a comprehensive search was conducted across databases including CINAHL, Medline, APA PsychInfo, Education Research Complete PubMed, Google Scholar, ProQuest and grey literature. Studies were included if they focused on the perspectives of autistic undergraduate healthcare students in clinical practice. Six studies met the inclusion criteria, which were synthesised into four overarching analytical categories: autistic profiles, sensory environments, disclosure and support and belonging and inclusion. Students reported strengths including empathy and attention to detail, alongside challenges like sensory sensitivities and social communication difficulties. Disclosure experiences varied, and a strong sense of belonging was linked to improved mental health and academic success. This review highlights the urgent need for inclusive educational practices, including tailored support, autism training for educators and a culture of acceptance. It also reveals a significant gap in the literature, underscoring the need for further research in this area.

Lay Abstract This study explores what it is like to be an autistic student training in healthcare, particularly during clinical placements. While we know autistic people are entering higher education and healthcare professions, there is still very little research about their specific experiences in clinical learning environments. These placements are a key part of training for careers like nursing, midwifery and medicine, but they can be especially challenging for autistic students. To better understand this, a scoping review was carried out. This means the researcher searched for and reviewed existing studies and articles on the topic. Only six relevant articles were found, all written in the UK, and were based on personal experiences shared by autistic students themselves. The review grouped findings into four main areas: the unique strengths and challenges of autistic students, the impact of sensory environments, the difficulties around disclosing an autism diagnosis and the importance of feeling included and supported. The findings show that while autistic students bring valuable qualities to healthcare, like empathy and attention to detail, they often face barriers such as sensory overload, stigma and a lack of tailored support. Many students feel they must mask their autism to fit in, which can affect their mental health and sense of belonging. This study highlights the urgent need for more inclusive and supportive clinical learning environments. It calls for better training for educators and supervisors, more awareness of autism and practical changes to help autistic students thrive. More research is needed to fully understand and support this group of students. Access or request item here:

11. Emphasising Learning in Health Promotion Targeting Individuals With Intellectual Disabilities

Authors: Fägerstam, Elin;Ågren, Kristin Alfredsson;Kvarnström, Maria;Törnqvist, Tove;Dahlgren, Madeleine Abrandt and Müssener, Ulrika

Publication Date: 2026

Journal: Journal of Intellectual Disability Research : JIDR 70(5), pp. 529–540

Abstract:

Background: Individuals with intellectual disabilities (ID) face disproportionately poor health profiles, underscoring the need for targeted and tailored health promotion strategies. Increasing health-related knowledge is essential for making lifestyle changes. However, difficulties associated with ID can affect the learning processes within health promotion, challenging professionals to apply various strategies to promote health. There is a lack of research exploring strategies perceived as meaningful and helpful in everyday health promotion informed by the lived experiences of individuals with ID and the insights of those who support them. The aim of this study is to explore strategies and organisational prerequisites for health promotion targeting individuals with ID by including the perspectives of individuals with ID, their significant others and professionals within healthcare, social services and educational systems.; Methods: The study was conducted in the southeast of Sweden. Data collection included eight workshops involving 30 participants in total. Individuals with ID (n = 14) participated in two constellations: one group attended a series of three workshops, whereas the other group attended a single workshop. Support persons, including significant others and professionals (n = 16), were divided into four separate groups, attending one workshop each. All workshops were audio-recorded and transcribed verbatim. The data were analysed using qualitative content analysis.; Results: Three categories emerged during analysis: enabling informed decision-making for health promotion, promoting health and well-being through encouraging relations, and organisational factors influencing prerequisites for health promotion.; Conclusions: Learning about health among individuals with ID appears to constitute a vital component of healthy decision-making, and support persons play a central role in facilitating health-related learning in everyday contexts. Prominent strategies for health promotion targeting individuals with ID include enabling informed decision-making and fostering encouraging relationships. These strategies must be responsive to individual needs, grounded in everyday relationships and supported by organisational structures. Hindering organisational structures and limited health promotion knowledge among professionals may constrain these efforts. Strengthening professional capacity and organisational responsibility within health, social care and educational systems could enhance the conditions for equitable health promotion in this population. (© 2026 The Author(s). Journal of Intellectual Disability Research published by MENCAP and John Wiley & Sons Ltd.) Access or request item here:

12. Personal and Environmental Factors Influencing Self-Determination of People With Intellectual Disabilities and Epilepsy: A Scoping Review

Authors: Haenen, Alexandra I.;Frielink, Noud;van Ool, Jans S.;Snoeijen-Schouwenaars, Francesca M. and Embregts, Petri J. C. M.

Publication Date: 2026

Journal: Journal of Intellectual Disability Research 70(4), pp. 345–363

Abstract:

Background: Epilepsy is a chronic neurological disorder that is prevalent among people with intellectual disabilities, profoundly affecting various aspects of life. Understanding the association between epilepsy and reduced quality of life in this population may benefit from exploring self-determination, a key dimension of quality of life. Self-determination evolves throughout life, shaped by personal and environmental factors, including intellectual disabilities

and access to supportive interventions. This review aims to map existing research to identify the personal and environmental factors that affect self-determination among people with intellectual disabilities and epilepsy. Methods: Eight electronic databases (Embase, MEDLINE ALL, PsycINFO, CINAHL, Cochrane Central Register of Controlled Trials, Web of Science, ERIC and Google Scholar) were systematically searched in December 2022 and again on 2 October 2024 to update the previous search. All English-language studies presenting original research data on self-determination among people (above age 10) with intellectual disabilities and epilepsy were included, without date restrictions. The methodological quality of included studies was assessed using the Mixed Methods Appraisal Tool (MMAT). To extract the data, we used the PCC (population, concept and context) framework. To analyse the data, we employed descriptive thematic analysis. Results: Of the 1485 records identified, nine studies were eligible. These studies employed a qualitative design (n = 7) or were quantitative case studies (n = 2). Together, the studies included 68 participants with varying levels of intellectual disabilities and types of epilepsy and 115 caregivers. Five overarching themes were identified: (1) different approaches to managing epilepsy (n = 4); (2) information sharing and a trust in the collaboration with health care professionals (n = 5); (3) the need for recognition and autonomy in health care and support (n = 5); (4) the tendency of parents and professionals to take over decision making and associated concerns, responsibilities and emotions (n = 6); (5) the importance of considering personal preferences in care and support (n = 5). Discussion: This review reveals the complex interplay between personal factors (i.e., individual coping strategies) and environmental factors (i.e., characteristics of the relationships with parents and professionals) in shaping self-determination among people with intellectual disabilities and epilepsy. These insights stress the importance of developing interventions to enhance self-efficacy and of specific training to equip caregivers and professionals with autonomy supportive skills to improve well-being at the individual level. This review also highlights a need for quantitative studies to enhance generalisability of findings. Access or request item here:

13. Key Factors for Quality End-of-Life Care for People With Intellectual Disabilities. A Critical Interpretive Synthesis Review Using a 'Best-Fit' Framework Approach

Authors: Haigh, Margaret;McCallion, Philip;McCarron, Mary;Pavithra, Pavithra and McMahon, Martin

Publication Date: 2026

Journal: Journal of Applied Research in Intellectual Disabilities : JARID 39(2), pp. e70208

Abstract:

Background: The aim of this review was to develop a theoretical framework to guide understanding of the key factors in quality end-of-life care for people with intellectual disabilities.; Method: A systematic review was conducted using a critical interpretive synthesis methodology and a 'best-fit' framework approach to develop a new theoretical framework. Databases were searched using a wide-ranging search strategy. Broad eligibility criteria were applied. Data were extracted from a purposive sample of relevant papers for the synthesis.; Results: Of 1270 retrieved records, 40 papers were selected for inclusion in the synthesis. From this, a new theoretical framework was developed comprising three themes-'a personal approach to care', 'an involved network' and 'an enabling infrastructure'.; Conclusion: The theoretical framework presented reflects the integration of a range of perspectives and provides a more developed understanding of the key factors in quality end-of-life care for

14. The overlooked burden: anti-seizure medications, laxatives, and antipsychotics prescribed in primary care for people with intellectual disability

Authors: Laugharne, Richard;Wilson, Ian;Wilcock, Mike and Shankar, Rohit

Publication Date: 2026

Journal: Frontiers in Psychiatry 17, pp. 1714524

Abstract:

Objectives: People with intellectual disabilities (PwID) have higher prevalences of epilepsy and constipation than the general population. Constipation is having fewer than three bowel movements or requiring laxatives three or more times weekly. Both epilepsy and constipation contribute significantly to premature mortality. To manage constipation, many individuals are prescribed long-term laxatives, which serve as a surrogate indicator of constipation. PwID and epilepsy also have a high prevalence of multimorbidity and polypharmacy, particularly involving antiseizure medications (ASMs) and antipsychotics. This study aimed to explore associations between ASM use, antipsychotics, and laxative prescribing.; Method: The primary care dataset in Cornwall, England (population 572,000), was used to examine patient prescribing records for laxatives, ASMs, and antipsychotics using SNOMED diagnosis codes for PwID. Age and sex were recorded. Results are reported as the prevalence of study cohorts.; Results: Of 3,189 PwID in Cornwall's GP registers, 2,799 (88%) were over 18, and 1,881 (59%) were men. Among them, 725 (23%) were prescribed laxatives and 467 (15%) ASMs. Of these, 209 were on both laxatives and ASMs (28.8% of all laxative users, 44.8% of all ASM users). Older PwID (> 40 years) were more likely to be on both ASMs and laxatives. Among the 209, 72 (34.4%) were on antipsychotics, with overrepresentation in those over 40.; Conclusion: Nearly half of PwID on ASMs are prescribed laxatives, and over a third of them were also found to be taking antipsychotics. Given the significant links among epilepsy, constipation, and antipsychotic use to premature mortality in PwID, it is imperative to consider these factors collectively rather than individually. (Copyright © 2026 Laugharne, Wilson, Wilcock and Shankar.) Access or request item here:

15. Suicide and Self-Harm in Intellectual Disability: A Systematic Review and Meta-Analysis

Authors: Lindstedt, Sara;Rück, Christian;Hirvikoski, Tatja;Hintze, Emma;Lundin Kleberg, Johan;Grossmann, Leoni;Wallert, John;Bjureberg, Johan and Flygare, Oskar

Publication Date: 2026

Journal: Journal of Intellectual Disability Research 70(4), pp. 364–374

Abstract:

Background: Individuals with intellectual disabilities (ID) are disproportionately exposed to several risk factors for suicidality. However, no meta-analysis has yet quantified the relative risk of suicide and self-harm, including suicide attempts, within this population. The aim of this

project was to bring together and synthesise the research on suicidality among individuals with ID. Methods: A systematic review and meta-analysis was carried out. Medline, Embase, Web of Science and PsycInfo were searched from inception through 4 August 2025. Observational studies with a quantitative design, evaluating the relative risk of suicide or self-harm, including suicide attempts, in individuals with and without ID, were included. Risk of bias was assessed using a shortened version of the Risk Of Bias In Non-randomized Studies–of Exposure (ROBINS-E) checklist. A random effects model was used to synthesise the results. Results: Eleven primary studies were included in the review (n = 241 438). The level of ID severity was only presented in two articles. Compared to the general population, the pooled relative risk for death by suicide was 0.54 (95% CI 0.33 to 0.89, k = 6, I² = 77%) and the relative risk for self-harm was 3.16, (95% CI 2.3 to 4.35, k = 6, I² = 89%). Conclusion: The findings suggest that individuals with ID have an elevated risk of self-harm but a lower risk of dying by suicide compared to the general population. However, these results should be interpreted with caution due to the limited number of primary studies and substantial between-study heterogeneity. Further, separate analyses of mild versus moderate-to-profound ID are warranted. Access or request item here:

16. Understanding perimenopause and menopause treatment in women with intellectual disability: a retrospective cohort study

Authors: Mackay, Kirstyn;Wee, Christine and Acton, Danny

Publication Date: 2026

Journal: Tizard Learning Disability Review 31(1), pp. 11–21

Abstract:

Purpose: This study aims to explore how menopause is recognised, recorded and treated in women with intellectual disability receiving care from community learning disability services. It sought to identify gaps in diagnosis, treatment provision and access to routine health checks, as well as regional disparities across a NHS Trust in the Northwest of England.

Design/methodology/approach: A retrospective cohort study was conducted using routinely collected clinical data from 555 women aged 40–60 with intellectual disability, obtained from electronic health records across multiple community learning disability teams. Descriptive and comparative analyses were performed to examine menopause diagnosis rates, treatment patterns and annual health check (AHC) participation. Findings: Only 4% of women had a recorded diagnosis of menopause or perimenopause. However, a greater proportion received menopause-related interventions, indicating a potential gap in formal recognition. The use of Hormone Replacement Therapy varied significantly across regions, with less than half of eligible women having had an AHC. Practical implications: Findings support the need for accessible screening tools, workforce education and equitable service commissioning.

Originality/value: To the best of the authors' knowledge, this is one of the first studies to audit menopause care for women with intellectual disability at scale using data from electronic patient records. The findings highlight systemic under-recognition, inconsistent documentation and inequities in access to care, calling for improved screening, professional training and inclusive policy responses.

17. Usability and effect of immersive simulation on empathy: A pilot study in nursing education

Authors: Martin, Anne-Marie;Saab, Mohamad M.;Henn, Patrick;McAuliffe, Ann;Cotter, Patrick;Drohan, Damien;McGuire, Kevin;Murphy, David;Chakraborty, Shelly;Goodwin, John and Noonan, Brendan

Publication Date: 2026

Journal: Teaching & Learning in Nursing 21(2), pp. e733–e739

Abstract:

• Empathy is essential in nursing, yet challenging when supporting people with disabilities. • Immersive simulation significantly improved empathy and was rated highly usable by students. • Findings support integrating immersive simulation into nursing curricula to enhance empathic care. Empathy is a core nursing skill essential for therapeutic relationships. Some healthcare professionals struggle to empathize with people with intellectual and multiple disabilities. This study examined the usability and effect of immersive simulation as a teaching and learning strategy on empathy among students in an intellectual disability nursing programme. To examine the usability and effect of immersive simulation on empathy among intellectual disability nursing students. A 1-group pre-post pilot study was conducted with students enrolled in an intellectual disability nursing programme at an Irish university. Participants experienced an immersive simulation of travelling on a bus in a wheelchair. Pre-and post-simulation questionnaires assessed usability and empathy. Fifty-five students participated. Empathy scores significantly increased post-simulation. Usability was rated highly (system usability scale (SUS) $M = 92.8$), with most participants finding the simulation easy to use and confidence-enhancing. Satisfaction was high, with nearly all students agreeing that immersive simulation was a valuable learning method. Immersive simulation shows promise for enhancing empathy and engagement in nursing education. Further research should explore long-term impacts and integration into curricula. Access or request item here:

18. Exploring influences on infant-feeding decisions among mothers with learning disabilities: A scoping review

Authors: Mitchell, Vicky;McFadden, Alison and Buell, Susan

Publication Date: 2026

Journal: Midwifery 156, pp. N.PAG

Abstract:

During the transition to motherhood, women need to make decisions about infant-feeding. For women with learning disabilities, making such decisions is impacted by their capacity to interpret information. Understanding the influences on infant-feeding decisions can improve support for mothers with learning disabilities. Our review explores broad intersecting influences, including autonomy, formal and informal support systems, and information delivery, by synthesising both peer-reviewed and grey literature. It aimed to understand these aspects in relation to infant-feeding decisions for mothers with learning disabilities and to identify evidence research gaps. We conducted a scoping review following the Joanna Briggs Institute methods. Three electronic databases, Medline, CINAHL and PubMed were searched for peer-

reviewed literature, and Google, Google Scholar and Ethos for grey literature in March 2023 and updated in March 2025. Articles were eligible for inclusion if the participants were mothers with learning disabilities and they included data on infant-feeding decisions. The peer-reviewed literature was analysed thematically, and the grey literature is summarised narratively. Six peer-reviewed papers and seven sources of grey literature were included. The findings suggested that mothers want autonomy regarding their infant-feeding decisions but are influenced by those around them, including family, friends, and professionals. Mothers can only make informed choices if timely information is tailored to the right level. We found limited research on the influences on infant-feeding decisions for mothers with learning disabilities; more research is needed. Our review suggests that mothers with learning disabilities' infant-feeding decisions are influenced by their support networks. Effective accessible information on infant-feeding targeted to women with learning disabilities is needed. Maternity service policies should include guidance for supporting mothers with learning disabilities. Access or request item here:

19. Examining Education Models for Clinical Staff Working with People with Intellectual and Developmental Disabilities in Hospice and Palliative Care: A Narrative Literature Review

Authors: Moore, Caitlyn M.

Publication Date: 2026

Journal: American Journal of Hospice & Palliative Medicine 43(5), pp. 553–563

Abstract:

Background: Education and training are essential for providing quality hospice and palliative care (HAPC). Despite individuals with intellectual and developmental disabilities (IDD) living longer with serious illness, healthcare professionals report inadequate training in this area. Additionally, IDD specialists consistently express discomfort and limited knowledge regarding HAPC. Objective: This narrative review evaluates existing education and training models for hospice and palliative care (HAPC) professionals working with individuals with IDD, emphasizing the reciprocal educational needs between these two specialties. Methods: A comprehensive literature search was conducted in March 2024 across multiple databases, including Embase, PubMed, and CINAHL, using terms related to IDD, training, and palliative care. Inclusion and exclusion criteria were applied, resulting in seven relevant studies providing insight into educational interventions for IDD and palliative care professionals. Results: Findings indicate that while several studies demonstrate positive outcomes regarding knowledge, self-efficacy, and satisfaction among participants, there is a lack of standardized training and patient-centered metrics. Existing interventions largely focused on improving the knowledge of IDD staff regarding HAPC, with limited attention given to educating HAPC professionals on the nuances and complexities needs of people with IDD. Conclusion: This review underscores the importance of developing and implementing evidence-based and standardized training programs that encompass the needs of both HAPC and IDD specialists. Future research should prioritize inclusive educational frameworks that involve individuals with IDD and their families in the development process. Attention to exploring metrics beyond self-reported outcomes to enhance the quality of HAPC provided to this vulnerable population should be prioritized. Access or request item here:

20. Personality disorder diagnoses in UK Autistic people: Evidence from a matched cohort study

Authors: O'Nions, Elizabeth;Brown, Jude;Buckman, Joshua E. J.;Charlton, Rebecca;Cooper, Claudia;El Baou, Céline;Happé, Francesca;Hoare, Sarah;Lewer, Dan;Long, Cathie;Manthorpe, Jill;McKechnie, Douglas G. J.;Richards, Marcus;Saunders, Rob;Mandy, Will and Stott, Joshua

Publication Date: 2026

Journal: *Autism: The International Journal of Research & Practice* 30(4), pp. 901–913

Abstract:

Clinical accounts and cohort studies suggest that Autistic people are disproportionately likely to be diagnosed with personality disorder. We conducted a cohort study of adults diagnosed Autistic drawn from the IQVIA Medical Research Database, with follow-up from 1 January 2000 to 16 January 2019. We included a comparison group without diagnosed autism, matched (1:10) by age, sex and primary care practice. We included 22,112 Autistic adults, of whom 6437 (29.1%) had a diagnosis of intellectual disability. Median age was 20.36 (interquartile range: 18.0–28.5), and 16,881 (76.3%) were men. The rate of new personality disorder diagnosis in Autistic people without intellectual disability was 4.8 (3.5–6.7) times higher for Autistic versus comparison men, and 4.6 (3.1–6.8) times higher for Autistic versus comparison women. For Autistic participants with intellectual disability, the rate was 2.0 (1.0–3.7) times higher for Autistic versus comparison men and 8.3 (4.0–17.2) times higher for Autistic versus comparison women. The estimated rate of new personality disorder diagnosis for Autistic people aged 20 increased from 14.67 (95% confidence interval: 10.4–20.8) per 10,000 person-years in 2009 to 22.43 (95% confidence interval: 13.9–36.3) in 2019. The findings indicate that personality disorder diagnoses are more common in Autistic people and increased overall in women from 2000 to 2019. Several research studies have suggested that Autistic people are more likely to be diagnosed with personality disorder than people who are not Autistic. We compared rates of personality disorder diagnoses between Autistic people and a comparison group of people not diagnosed Autistic using anonymised data collected by UK primary care practitioners for participants registered at a primary care (general practitioner) practice sometime between 1 January 2000 to 16 January 2019. The comparison group of people in the community who did not have an autism diagnosis were of the same age, sex and registered at the same primary care practice as their matched Autistic participant, with 10 times as many matched participants as Autistic participants. We included 22,112 Autistic adults, of whom 6437 (29.1%) had a diagnosis of intellectual disability. Median age was 20.36 years, and most, 16,881 (76.3%), were men. We included 221,120 comparison adults. New personality disorder diagnoses were more than four times as common for Autistic men and women without an intellectual disability compared to men and women in the comparison group. For Autistic participants with an intellectual disability, the rate was twice as high for Autistic versus comparison men and 8 times higher for Autistic versus comparison women. Between 2000 and 2019, there was an increase in the rate of new personality disorder diagnoses among Autistic people, and in women. The findings highlight the need for further investigation into reasons for this increase. Access or request item here:

21. Restricted and Repetitive Behaviors in Intellectual Disabilities: A Scoping Review with a Systematic Search of the Literature

Authors: Payne, Emily;Sarasua, Sara;Rogers, Curtis;Martin, Rebekah;Phelan, Katy and Boccuto, Luigi

Publication Date: 2026

Journal: Reviews on Recent Clinical Trials

Abstract:

Background: Restricted and Repetitive Behaviors (RRBs) are a core feature of autism and are present in numerous neurodevelopmental disorders and Intellectual Disabilities (ID). These behaviors include repetitive movements, restricted interests, and insistence on sameness, among others. RRBs can cause distress, self-injury, and affect development. The proper assessment of RRBs is critical for the design of clinical trials and the identification of outcome measures for patients with ID, but unfortunately, the scientific literature lacks a deeper characterization of RRBs, particularly in individuals with ID. The goal of this study is to review the current literature to describe the RRB profile in ID (mild, moderate, severe, and profound).; Methods: A systematic search of the literature in PubMed, Web of Science, and the Cumulative Index to Nursing and Allied Health Literature (CINAHL) was performed for articles in the past 10 years.; Results: Following de-duplication and screening, a total of 20 articles met the inclusion criteria for this review. Various repetitive behaviors were described across all levels of ID. The most common behaviors included broad repetitive movements, hand-and finger-stereotypies, restricted interests, and self-injury. No major differences were observed between individuals across all levels of ID.; Discussion: This review explores the relationship between RRBs and different levels of ID, highlighting the different assessment approaches utilized in various studies. A similar RRB profile across all levels of ID could be beneficial for diagnosis and, potentially, for standardized treatment of RRBs.; Conclusion: Standardized assessment tools for RRB profiles are recommended for proper evaluations of the complex behavioral profiles in individuals with ID. (Copyright© Bentham Science Publishers; For any queries, please email at epub@benthamscience.net.) Access or request item here:

22. Can the P-C-P quality framework be used to understand service quality from the perspective of service users and their significant others accessing specialist community teams for people with learning disabilities? A framework analysis

Authors: Richardson, Shauni;Lewis, Dani and Dagnan, Dave

Publication Date: 2026

Journal: Journal of Intellectual Disabilities : JOID , pp. 17446295261434776

Abstract:

There is no research that considers service user perspectives on the quality of Community Teams for People with Learning Disabilities (CTPLDs) from within standard quality assessment frameworks. Two hundred and sixty-seven people with intellectual disabilities and 226 significant others completed an online survey detailing their experiences of six specialist CTPLDs in the North of England. Data were analysed using framework analysis. The data from service users and significant others were coded into the attributes of the Peripheral-Core-

Pivotal (P-C-P) framework. Responses emphasised the Core attribute which describes service processes (78.0% of responses from people with intellectual disabilities and 73.8% of responses from significant others) and include aspects of empathy, assurance, reliability, and responsiveness, over Peripheral (service structure) and Pivotal (service outcome) attributes. We discuss the advantages of using a quality framework such as the P-C-P and the important aspects of service quality identified by people with intellectual disabilities and their significant others. Access or request item here:

23. 'Tired of spinning plates': Synopsis of mixed methods exploration of mental health experiences of adult/older carers of adults with learning disabilities

Authors: Runswick-Cole, Katherine; Ryan, Sara; Smith, Martina; Hatton, Chris; Douglas, Patty; Kassa, Clare; Cisneros, Rosemary and Croot, Liz

Publication Date: 2026

Journal: Health and Social Care Delivery Research 14(6), pp. 1–35

Abstract:

Background: This research addresses the mental health of family carers of adults with learning disabilities. We investigated participants' perceptions of their mental health and views on the accessibility and quality of support.; **Design and Methods:** The research involved seven work packages which included public involvement, a rapid scoping review of evidence about family carers' mental health and support, an online exhibition, interviews with parent and sibling carers, digital storytelling workshops, key stakeholder discussions and the creation of learning and teaching materials.; **Results:** Caregiving driven by love is often exploited by health and social care services which deny basic support, information and kindness. Enduring struggle for support and worries about the future are often the cause of mental distress. Participants know what supports mental well-being but have little time to look after themselves due to the lack of support. Social services were described as 'hostile' or absent and participants viewed themselves as exhausted by the lack of support, rather than depressed. Medication can help but can be offered without consideration of their caring role or because there are no alternatives. Participants ask for their statutory entitlements for health and social care support to be met with kindness.; **Outputs and Dissemination:** We delivered: (1) an expansive public engagement model; (2) an innovative and creative participatory approach to generate stories of care; (3) a dissemination strategy to raise awareness of the mental health of family carers and (4) the development of general practitioner resources. We published journal articles, blogs, magazine articles, an online exhibition, films and presented findings at international conferences.; **Public and Stakeholder Involvement and Engagement:** Family carers and people with learning disabilities were involved across the study, and in the Study Steering Group.; **Limitations:** Recruitment was slower than expected. Carers were unable to use care replacement costs because of a lack of alternative care. There were challenges involving marginalised communities. We engaged with fewer respondents through the Exhibition than the planned survey; however, it was important to respond to participants' views.; **Conclusions:** Health and care services often fail to recognise or adjust support for family carers despite provision under the Equality Act. The role of love in caring relationships, the absence of consideration of this in research, and the exploitation of this love by service systems which rely heavily on family carers were highlighted. Provisions in The Care Act and The Equalities Act are not always upheld, family carers struggle to gain support over years and even the 'feeblest'

acts of kindness make a difference in health and care delivery. There is a need for policy-makers and practitioners to review and develop robust monitoring of the provision set out in legislation to ensure family carers and people with learning disabilities' entitlements are met. Small acts of kindness on the part of health and social care providers have a big impact on the well-being of family carers.; Future Work: Further exploration of care as a relational activity. The development of ways of monitoring compliance and adherence to legal frameworks. Bringing together the perceptions, views and experiences of people with learning disabilities, siblings and parent carers to generate a comprehensive understanding of the support needs of these groups. An exploration of the mental health experiences of LGBTQI+ family carers and family carers of autistic adults without learning disabilities.; Funding: This synopsis presents independent research funded by the National Institute for Health and Care Research (NIHR) Health and Social Care Delivery Research programme as award number NIHR135080. Access or request item here:

24. A literature review of cancer diagnostic tests and treatments in adults with intellectual disability

Authors: Smihula, Kennedy;Danon, Mikayla;Walsh, Shauna;McMahon, Martin and Lynch, Louise

Publication Date: 2026

Journal: HRB Open Research 8, pp. 66

Abstract:

Background: Adults with intellectual disabilities have significantly lower rates of routine cancer screening and cancer is often diagnosed at more advanced stages. Some studies highlight gaps that exist in national screening programmes for cancers such as breast, cervical and colorectal. Evidence in the intellectual disability population points towards factors such as limited screening education, distrust in healthcare providers, and challenges in providing consent, leading to limited uptake of screening programmes. While there are many contributing factors to these inequalities, changes in individuals' health status may go unrecognised for longer because of their intellectual disability. The aim of this literature review is to explore cancer diagnostic approaches and treatment options for adults with intellectual disability and examine barriers to accessing diagnostic procedures and treatments.; Methods: Five electronic databases were systematically searched: Cinahl Ultimate, Medline, PsycINFO, PubMed, and Web of Science. Thematic analysis was completed using the Braun and Clark Six Step process.; Results: Four main themes emerged from 28 included studies: Prevention, education, adaptation, and ethical practice. Prevention encompassed individuals receiving regular screening and barriers that prevented access. Educational tools that explained the importance of screening reduced feelings of stress and anxiety. Case studies illustrated how specific treatment plans were adapted for patients with intellectual disability. Autonomy and honesty were themes throughout many studies, in terms of treatment, education, and diagnostics. It was determined that patients should be involved in decision making and be aware of their cancer diagnosis unless there are contra-indications.; Conclusion: Adults with intellectual disability face considerable barriers when accessing cancer diagnosis and treatment. Barriers, including living conditions, communication difficulties and age, contributed to later cancer diagnosis and worse outcomes, compared to the general population. The

successful use of education and tailored treatments were enabling factors. (Copyright: © 2026 Smihula K et al.) Access or request item here:

25. Clinical Diagnostics After Failed Hearing Screening in People With Intellectual Disabilities Do Not Often Take Place

Authors: Wiegand, Anna;Mathmann, Philipp;Wasmuth, Susanne;Prein, Lukas;Parfitt, Ross;Scharpenberg, Martin;Jankovic, Vincent;Schwarze, Katharina;Neumann, Anja;Schäfer, Karolin;Speckemeier, Christian;Baessler, Sven;Schlierenkamp, Sarah;Diekmann, Sandra;Stuhrmann, Nicole;Lang-Roth, Ruth;Demir, Muhittin;Brannath, Werner;Naghypour, Awa and Zielonkowski, Susanna Marie

Publication Date: 2026

Journal: Journal of Intellectual Disability Research 70(4), pp. 384–394

Abstract:

Background: Individuals with intellectual disabilities are at higher risk of undiagnosed or inadequately treated hearing loss. This situation requires easily accessible hearing screening, diagnostics and intervention programmes in the living environment, i.e., in nurseries, schools, workplaces and homes. However, a full audiometric assessment is not always possible in nonclinical settings. The multicentre cohort study HörGeist investigated the effectiveness, feasibility and costs of an outreach programme of repeated hearing screening, diagnostics, intervention and monitoring of children, adolescents and adults with intellectual disabilities in their living environment in comparison with an invitation-only programme comprising a control cohort in a clinical setting and with standard care. This paper reports on the HörGeist substudy of the outreach cohort, focusing on participants referred for 'external' diagnostics in clinical settings after failing on-site screening, and evaluating both referral uptake and outcomes. Methods: Because none of the 141 individuals in the control cohort provided informed consent to attend the programme in a clinical setting, our results pertain solely to the outcomes and feasibility within the outreach cohort. All of the 1053 participants in the outreach cohort who failed the hearing screening tests underwent full on-site audiometric assessment. Where on-site screening and/or diagnostics were not feasible, referrals to external medical institutions were provided. Participants who were referred to external diagnostics were tracked via telephone interviews using a questionnaire and asked about their utilisation and the outcome of diagnostics. In cases where referrals were not pursued, reasons for non-compliance were recorded. Results: A referral for external diagnostics was received by 262 of the 1053 participants of the outreach cohort. Of these, 19 dropped out of the study. Of the 248 referrals received by the remaining 243 participants, 93 (37.5%) were attended and 155 (62.5%) were not. The main reasons for non-attendance were 'no attempt to arrange an appointment' (32.9%), 'refusal by caregivers' (23.2%) and 'refusal by participants' (18.1%). Approximately 4% did not receive an appointment for external diagnostics. Referral uptake declined with age, with uptake rates of 50.8% in young children, 41.3% in school-aged participants and 24.7% in adults. Telephone tracking of a subsample of 48 participants who primarily did not attend for external assessment led to further clinical diagnostics in eight cases (16.7%). Conclusions: In order to achieve an improvement in the hearing situation of people with intellectual disabilities, a screening, diagnostic and intervention programme in their living environment seems both feasible and beneficial. However, reliable assessment of the hearing status of the participants of such a programme requires education of participants, caregivers and medical professionals

regarding its necessity and fostering of close collaboration with healthcare providers in outpatient and clinical settings. Trial Registration: German Clinical Trials Register (DRKS-ID: DRKS00024804) Access or request item here:

Sources:

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

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