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Learning Disabilities

Current Awareness Bulletin

September 2025

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1. Equitable hospital length of stay prediction for patients with learning disabilities and multiple long-term conditions using machine learning

Authors: Abakasanga, Emeka;Kousovista, Rania;Cosma, Georgina;Akbari, Ashley;Zaccardi, Francesco;Kaur, Navjot;Fitt, Danielle;Jun, Gyuchan Thomas;Kiani, Reza and Gangadharan, Satheesh

Publication Date: 2025

Journal: Frontiers in Digital Health

Abstract: Competing Interests: The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.; Purpose: Individuals with learning disabilities (LD) often face higher rates of premature mortality and prolonged hospital stays compared to the general population. Predicting the length of stay (LOS) for patients with LD and multiple long-term conditions (MLTCs) is critical for improving patient care and optimising medical resource allocation. However, there is limited research on the application of machine learning (ML) models to this population. Furthermore, approaches designed for the general population often lack generalisability and fairness, particularly when applied across sensitive groups within their cohort.; Method: This study analyses hospitalisations of 9,618 patients with LD in Wales using electronic health records (EHR) from the SAIL Databank. A Random Forest (RF) ML model

was developed to predict hospital LOS, incorporating demographics, medication history, lifestyle factors, and 39 long-term conditions. To address fairness concerns, two bias mitigation techniques were applied: a post-processing threshold optimiser and an in-processing reductions method using an exponentiated gradient. These methods aimed to minimise performance discrepancies across ethnic groups while ensuring robust model performance.; Results: The RF model outperformed other state-of-the-art models, achieving an area under the curve of 0.759 for males and 0.756 for females, a false negative rate of 0.224 for males and 0.229 for females, and a balanced accuracy of 0.690 for males and 0.689 for females. Bias mitigation algorithms reduced disparities in prediction performance across ethnic groups, with the threshold optimiser yielding the most notable improvements. Performance metrics, including false positive rate and balanced accuracy, showed significant enhancements in fairness for the male cohort.; Conclusion: This study demonstrates the feasibility of applying ML models to predict LOS for patients with LD and MLTCs, while addressing fairness through bias mitigation techniques. The findings highlight the potential for equitable healthcare predictions using EHR data, paving the way for improved clinical decision-making and resource management. (© 2025 Abakasanga, Kousovista, Cosma, Akbari, Zaccardi, Kaur, Fitt, Jun, Kiani and Gangadharan.)

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2. **The Ten-Point Treatment Programme: developing and evaluating an easy-read version for people with intellectual disabilities**

Authors: Amiola, Ayomipo Jeremiah;Wilson, Hollyanna;Patteril, Elizabeth;Chester, Verity and Alexander, Regi

Publication Date: 2025

Journal: Advances in Mental Health & Intellectual Disabilities

Abstract: Purpose: People with intellectual disabilities (IDs) typically present with co-occurring communication difficulties. Research indicates that cognitive-linguistic impairment is predictive of poor health literacy, which can preclude individuals from developing a comprehensive understanding of their health, care and treatment needs. People accessing forensic intellectual and developmental disability (FIDD) services are more likely to engage meaningfully in treatment and rehabilitation only if they feel empowered to play active roles in their own care. Delivering proposed treatment programmes in an accessible format, which meets their language needs, is likely to promote this. Design/methodology/approach: This paper aims to describe the development and evaluation of an easy read version of the "Ten point treatment programme" within an inpatient FIDD service. An expert panel comprising speech and language therapists and education professionals utilised a quality improvement method to develop this. Patients and staff evaluated this resource and gave feedback through surveys or meetings. The resource was refined based on responses, and a final version produced. Findings: The easy-read Ten-Point Treatment programme resource was considered valuable by patients and staff from this service. Research limitations/implications: Future research should seek to pilot this resource, to explore alternative multi-modal means of accessible

information provision coproduced at every level and to examine ways in which this resource could be incorporated within health-care consultations. Another research direction will be to assess the impact of this resource on comprehension, drawing upon objective, previously validated measures. Practical implications: Provision of an easy-read version of the Ten-Point Treatment Programme may support individuals with communication difficulties to understand health and care information relevant to their inpatient admission and may empower them to take more active roles in their treatment pathway. It is important to acknowledge, however, that easy read is not an accessible means of information provision for all individuals with ID and that the empirical evidence for its impact is limited. Originality/value: This is the first published attempt to evaluate the acceptability of an easy-read version of the Ten-Point Treatment Programme within an inpatient FIDD service in the UK.

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3. **Access to healthcare for people with intellectual disability: a scoping review**

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

Publication Date: 2025

Journal: Scandinavian Journal of Public Health

Abstract: Competing Interests: Declaration of conflicting interestsThe authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.; Aims: People with intellectual disability experience stark health inequalities, often because of poor access to mainstream healthcare. This scoping review aimed to identify factors that influence access to healthcare for people with intellectual disability using Levesque and colleagues' comprehensive framework of healthcare access.; Method: This review followed Joanna Briggs Institute guidelines. Articles were identified and retrieved from CINAHL, PsycINFO, PubMed and EMBASE. Two reviewers completed abstract and full-text screening, addressing any conflicts at each stage. Data was extracted and coded deductively, according to the supply (healthcare provider) and demand (healthcare seeker) dimensions of Levesque and colleagues' framework.; Results: Following search and screening, 66 references were included for review. Barriers to healthcare were more frequently identified in the literature compared to facilitators, with most information relating to supply-side dimensions. Barriers were related to inaccessible health information, low health literacy, stigma and discrimination by healthcare providers, and lack of organisational support, training and resourcing in both healthcare and support sectors. Facilitators often involved specialist workforces, strong interpersonal skills among healthcare providers, and advocacy from supporters. Importantly, findings indicated that both sociohistorical processes and support networks are necessary to understanding access experiences for people with intellectual disability.; Conclusions: Greater efforts are required internationally to ensure the health rights of people with intellectual disability, to eliminate discrimination, and provide the support and resources necessary for all stakeholders to facilitate healthcare access. Models of healthcare access for people with intellectual disability should consider both the role of supporters and the sociohistorical context within which healthcare access occurs.

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4. **Implementation of Annual Health Assessments for Adults With Intellectual Disabilities: An Integrative Review**

Authors: Breau, Genevieve;Tiwari, Ritika;Ravindran, Shaiyini and Gijssel, Esther Bakker-van

Publication Date: 2025

Journal: Journal of Policy & Practice in Intellectual Disabilities

Abstract: People with intellectual disabilities (ID) face health inequalities, often arising from undiagnosed health conditions. An annual health assessment (or health check) administered by a primary care provider can be a systematic method of identifying these health conditions and initiating treatment and management, leading to better health outcomes. While these health checks are recommended in many countries, including the United Kingdom (UK), they have not been administered to all adults with ID. In light of this, the barriers and facilitators to systematic implementation have not been systematically studied. The aim of this Integrative review was to identify the barriers and facilitators to the systematic implementation of health checks, using the Consolidated Framework for Implementation Research (CFIR). This model has been used in implementation research and is useful in determining the levels of healthcare interaction that are involved in the delivery of this intervention. We identified 35 peer-reviewed primary research articles that met inclusion criteria. The barriers and facilitators to health check implementation were extracted and coded according to the individual involved, whether it was a barrier or facilitator, and the domains and constructs of the CFIR model. We concluded that most factors related to the physician's role, as well as many factors related to the intervention itself. Some of these facilitators included the perceived efficacy of the health check intervention and the belief that it provides more comprehensive care. Some of the barriers include additional time that is necessary to implement the intervention and a lack of resources. Future interventions could train physicians and target some structural health system barriers to implementing health checks, and further research with physicians, patients, and carers is needed. This research may confirm the barriers and facilitators to health check implementation and explore methods to promote health checks.

5. **Effects of learning disability and autism training on healthcare professionals' perspectives and practice: a scoping review**

Authors: Butler, India and Marsden, Daniel

Publication Date: 2025

Journal: Learning Disability Practice

Abstract: Why you should read this article: • To acknowledge that healthcare professionals' knowledge, attitudes and behaviour are factors in the health inequalities experienced by people with learning disabilities and autistic people • To enhance your awareness of how learning disability and autism education and training for healthcare professionals can influence their perspectives and practice • To recognise the need for further research into the effects of learning disability and autism education on nurses' practice. It has been identified that healthcare professionals' knowledge, attitudes and behaviour in practice are significant factors in the health inequalities experienced by people with learning disabilities and autistic people. Lack of awareness of the adjustments that may be required in communication and to support autonomous decision-making can lead to suboptimal treatment outcomes and avoidable deaths. This article presents a scoping review that aimed to examine the research on learning disability and autism education and training for healthcare professionals and how this may affect their perspectives and practice. The review highlighted the benefits of such education and training, finding that it could improve healthcare professionals' knowledge, confidence and screening behaviours. The findings could aid future research and support the development of a contemporary evidence base that would inform learning disabilities and autism mandatory training for healthcare staff in England and Wales.

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6. **Serious Games for constipation management for people with intellectual disabilities: A scoping review and narrative synthesis**

Authors: Daniel, Serena;Bishop, Ruth;Killner, Ellie;Whight, Alison;Lennard, Sarah;Howard, Stephen;Laugharne, Richard and Shankar, Rohit

Publication Date: 2025

Journal: International Journal of Medical Informatics

Abstract: Competing Interests: Declaration of competing interest The authors declare the following financial interests/personal relationships which may be considered as potential competing interests: RS has received institutional and research support from LivaNova, UCB, Eisai, Veriton Pharma, Neuraxpharm, Bial, Angelini, UnEEG and Jazz/GW pharma outside the submitted work. He holds grants from NIHR AI, SBRI and other funding bodies all outside this work. RL has been Chief Investigator for clinical trials sponsored by Janssen and Boehringer Ingelheim outside the submitted work. No other author has any declared conflict of interest related to this paper.; Introduction: People with intellectual disability (PwID) are 2% of the UK population. Constipation and bowel movement (BM) problems (diarrhoea/faecal incontinence etc.) affects over a third of PwID and is a serious cause of morbidity and mortality. Pw ID rely heavily on outside support (family/professional carers/healthcare professionals), many of whom are ignorant to bowel related harms. There is significant stigma to discuss BM particularly constipation. Serious Games (SG) are increasingly used for education of health needs. This review examines if game-based technology can assist improving knowledge and reducing stigma of BM problems particularly constipation.; Objective: To identify and gain evidence of SGs aimed at improving knowledge of BM management particularly constipation.; Methods: A systematic search of publications between 2010 and 2024 was conducted following the PRISMA ScR statement for scoping reviews. The search inclusion/exclusion criteria were designed and overseen by an information specialist. PUBMED, EMBASE and PsychINFO databases were searched. Extracted variables included SG title, co-production and expert involvement, target outcome, evaluation methodology, effectiveness, sustainability and game platform. Results were narratively synthesised.; Results: Of 2966 papers retrieved, three were selected for inclusion, none RCTs. All three included SGs aimed to teach BM management or recognition to healthcare workers/ professionals. Two studies evaluated game efficacy. No SGs were assessed after initial trials, none were implemented in clinical practice. Only one game successfully improved participant knowledge. All game creators consulted experts during game design, but none consulted patients. None discussed reducing stigma amongst their audience.; Conclusion: Only one of three SGs identified improved BM knowledge in healthcare workers/professionals and was not specific to PwID. There is potential to co-produce with PwID and their carers a SG to support BM problems particularly constipation to reduce stigma, improve outcomes and be a templar for other similarly vulnerable groups like those with dementia. (Copyright © 2025 The Author(s). Published by Elsevier B.V. All rights reserved.)

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7. **Understanding how including ‘experts by experience’ in nurse education can improve care quality**

Authors: Davies, Sarah

Publication Date: 2025

Journal: Learning Disability Practice

Abstract: Why you should read this article: • To refresh your understanding of the role of the ‘expert by experience’ • To understand the importance of nurses learning from people with lived experience • To appreciate the challenges involved in incorporating the experience of people with learning disabilities into nursing education. ‘Experts by experience’ (EBEs) have a valuable role in education and improving healthcare, while collaborative working with professionals is of increasing importance for people with learning disabilities. This literature review examines the impact that EBEs have in nurse education and learning disability care. Four themes emerged through a review of the literature – partnership, benefits, challenges and support. This review collates knowledge of how to effectively collaborate with EBEs; build partnerships based on empowerment; maximise benefits in relation to education, practice and personal development; and overcome any challenges encountered. The author also details some areas where further research is needed.

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

Authors: Daw Srdanovic, Bojana

Publication Date: 2025

Journal: Sociology of Health & Illness

Abstract: There is a dearth of literature focusing on how allyship in health may be enacted in relation to people with learning disabilities (LD). This is concerning, because people with LD are vulnerable to health inequalities and forms of medical dehumanisation including do-not-resuscitate orders, diagnostic overshadowing and overprescription of psychotropic drugs. Deploying critical disability studies as a lens through which to understand disability, this paper reviews models of disability allyship developed in healthcare, research and theatre. In doing so it advocates transformative allyship as a model that can both animate action in support of people with learning disabilities and accommodate the involvement of others, including clinicians, carers and relatives, without compromising the all-important commitment to supporting disability cultures. The paper presents and analyses ethnographic data gained through observations of eleven healthcare appointments between seven clinicians and five patients with LD, undertaken as part of the ESRC-funded study Humanising Healthcare. It documents the potential of transformative allyship in healthcare to transform harmful disablist practices through emphasising respect, attention and collaborative action while also noting that broader structural conditions and diagnostic technologies limit the extent to which clinicians can enact transformative allyship. (© 2025 The Author(s). Sociology of Health & Illness published by John Wiley & Sons Ltd on behalf of Foundation for the Sociology of Health & Illness.)

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9. **Accessible leaflets on psychotropic medication for people with mild intellectual disabilities developed in a coproduction method**

Authors: de Kuijper, Gerda;Heringa, Mette and Deb, Shoumitro

Publication Date: 2025

Journal: Advances in Mental Health & Intellectual Disabilities

Abstract: Purpose: In intellectual disability healtcare, providing accessible information on treatment proposals is a necessary part of shared decision-making. However, although the medication use of especially psychotropic drugs is high, people with intellectual disability often lack knowledge about these prescriptions. Accessible written medication information is often not available. The authors aimed to fill this gap. Design/methodology/approach: Four individuals with intellectual disability (the panel), their coach, pharmacists and intellectual disability healthcare professionals/researchers collaborated in this inclusive research project. A coproduction method was used. The healthcare professionals/researchers developed a set of 64 Dutch leaflets on psychotropic drugs for use in people with intellectual disability based on 29 accessible English leaflets. A checklist for the panel was developed to review each leaflet draft. The drafts were adapted according to the panel's recommendations. The final drafts were presented in a meeting of the project group and stakeholders. Findings: The main adaptations in the drafts were textual changes, including adding headings and frequent side effects and layout changes in photos and colours. The results of the checklists and stakeholders' feedback revealed that the quality and accessibility of the leaflets overall were very clear. Research limitations/implications: More (inclusive) studies are needed to investigate whether the use of the leaflets is effective in improving the patients' medication knowledge and shared decision-making. Originality/value: Stakeholders welcomed the availability of accessible leaflets on psychotropic medication. This methodology could be used by other professionals to develop similar accessible information for their own populations.

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10. **Cardiovascular Disease Incidence and Risk Factors in Older Adults With Intellectual Disabilities: Results of the Healthy Ageing and Intellectual Disabilities Study**

Authors: de Leeuw, Marleen,J.;Böhmer, Mylène,N.;Bindels, Patrick J. E.;Maes-Festen, Dederieke and Oppewal, Alyt

Publication Date: 2025

Journal: Journal of Intellectual Disability Research : JIDR

Abstract: Background: Previous research has shown that older adults with intellectual disabilities are at increased risk of cardiovascular diseases (CVD). However, longitudinal studies investigating the actual incidence of CVD and its associated risk factors in this population are limited. Such research is essential for optimising healthcare delivery and informing effective resource allocation. Therefore, this study aimed to examine CVD incidence in older adults with intellectual disabilities and explore its associations with participant characteristics and risk factors.; Method: A prospective longitudinal study was conducted in older adults (≥ 50 years) with intellectual disabilities as part of the Healthy Ageing and Intellectual Disabilities study. Baseline measurements were performed in 2009-2010, with follow-up assessments, including medical record reviews, in 2020-2023. Incidence rates for myocardial infarction (MI), heart failure (HF) and stroke were calculated by sex and 10-year age categories. Competing risk analysis was performed to examine the associations between CVD diagnoses during follow-up and baseline participant characteristics/CVD risk factors, accounting for mortality as a competing risk.; Results: Among 598 participants (62.0 ± 8.5 year; 49.3% female), with a mean follow-up of 8.6 years, incidence rates were 2.3 per 1000 person years for MI, 7.2 for HF, and 5.3 for stroke. Hypertension (HR 3.17; $p < 0.001$), Down syndrome (HR 2.66; $p < 0.01$) and antipsychotic use (HR 1.98; $p = 0.04$) were associated with an increased CVD risk during follow-up.; Conclusions: A lower incidence of MI and similar to higher incidence of HF and stroke were found in older adults with intellectual disabilities than in the general population. Further research, including a focus on the association of CVD incidence with Down syndrome, is needed. Meanwhile, proactive assessment and management of CVD risk factors, such as hypertension and antipsychotic use, are important for improving cardiovascular health in older adults with intellectual disabilities. (© 2025 The Author(s). Journal of Intellectual Disability Research published by MENCAP and John Wiley & Sons Ltd.)

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11. **Mental health outcomes across the reproductive life course among women with disabilities: a systematic review**

Authors: Deierlein, Andrea Lauren;Park, Curie;Patel, Nishtha;Gagnier, Robin and Thorpe, Michele

Publication Date: 2025

Journal: Archives of Women's Mental Health

Abstract: Purpose: This systematic review examined literature on mental health outcomes among women with disabilities living in high-income countries within the context of reproductive health, spanning menstruation through menopause. Methods: Following the Preferred Reporting Items for Systematic Reviews and Meta-Analyses guidelines, we searched MEDLINE, CINAHL, and PsycINFO databases for studies published through June 2023. Eligible studies were observational, quantitative, and included a comparison group without disabilities. Results: A total of 2,520 studies were evaluated and 27 studies met inclusion criteria. These studies assessed mental health during prepregnancy, pregnancy, postpartum, and parenting among women with and without disabilities. None of the studies examined reproductive health time periods related to menstruation, fertility, or menopause. Women of reproductive age with disabilities were more likely to have poor mental health outcomes compared to women without disabilities. During pregnancy and the postpartum, women with disabilities were at greater risk of diagnosed perinatal mental disorders and psychiatric-related healthcare visits. Findings also suggested mental distress and inadequate emotional and social support related to parenting among women with disabilities. The greatest risks of poor mental health outcomes were often observed among women with intellectual and developmental disabilities and among women with multiple types of disabilities, compared to women without disabilities. Conclusions: Routine reproductive healthcare visits provide significant prevention and treatment opportunities for poor mental health among women with disabilities. Further research examining mental health outcomes within the context of reproductive health, especially understudied areas of menstruation, fertility, parenting, and menopause, among women with disabilities is needed.

12. **The burden of illness in Prader-Willi syndrome: a systematic literature review**

Authors: Dempsey, Dairine;Hall, Maria;Lanning, Ben;Barron-Millar, Ben;Huang, Michael;Cowen, Neil;Nagao, Mitch;Gandhi, Raj and Bhatnagar, Anish

Publication Date: 2025

Journal: Orphanet Journal of Rare Diseases

Abstract: Competing Interests: Declarations. Ethics approval and consent to participate: Not applicable. Consent for publication: Not applicable. Competing interests: Dairine DEMPSEY is an employee of Soleno Therapeutics Europe Ltd. Michael HUANG, Neil COWEN, Mitch NAGAO, Raj GANDHI and Anish BHATNAGAR are employees of Soleno Therapeutics Inc, USA. Maria HALL is a contractor for Soleno Therapeutics Europe Ltd. Kintiga was commissioned to undertake the systematic literature review. Ben LANNING and Ben BARRON-MILLAR are employees of Kintiga.; Background: Prader-Willi syndrome (PWS) is a rare, genetic neurobehavioral and metabolic disorder marked by hyperphagia, behavioral challenges, and significant comorbidities, requiring a multidisciplinary approach for effective management. This systematic review aimed to comprehensively evaluate the burden of disease associated with PWS, focusing on mortality, healthcare resource utilization, economic burden, and quality of life.; Methods: The literature search, conducted on August 13, 2024, included the MEDLINE, Embase, and Cochrane Library databases, as well as conference proceedings. Original studies published since 2014 were selected based on relevance to PWS patient burden, covering mortality, humanistic and economic impacts. Data from the selected studies were extracted, and currency conversions were standardized.; Results: For the topics of mortality, humanistic burden and economic burden, a total of 11 studies, 95 studies, and 33 studies were included, respectively. Individuals with PWS faced significantly reduced life expectancy compared to the general population, with leading causes of death including respiratory failure, consequences of uncontrolled hyperphagia, and cardiovascular complications. Hyperphagia contributed substantially to the disease burden, necessitating constant food security measures to prevent life-threatening complications. Primary caregivers, predominantly parents of individuals with PWS, experienced significant emotional and psychological strain. The time-intensive responsibilities of implementing food security measures heavily impacted their daily lives, social and family dynamics, as well as their financial health. Quality of life for patients was less frequently reported but markedly impaired, driven by physical health challenges, behavioral issues, and social isolation. Wider family dynamics were also often impacted, with siblings reporting increased psychosocial stress and feelings of neglect. The direct costs of managing PWS, including frequent hospitalizations and specialized care, were consistently reported to exceed those of matched controls without PWS, highlighting the substantial economic burden associated with the condition.; Conclusion: This systematic literature review highlights the profound burden of PWS on patients, caregivers, payers of care, and healthcare systems. Complications of PWS reduce life expectancy, impair quality of life, and impose considerable financial strain. The findings underscore an urgent need for comprehensive support and innovative treatments that address the complex manifestations and consequences of PWS, particularly hyperphagia, to improve outcomes for patients and their families. (© 2025. The Author(s).)

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13. **Using Virtual Care to Assess the Health Needs of People With Intellectual Disabilities: A Scoping Review**

Authors: Devitt, Alison;Nott, Melissa;Nelson, Stephanie;Sgarlata, Julia;Gray, Michelle;Balachandran, Srilaxmi and Taskin, Asma

Publication Date: 2025

Journal: Journal of Applied Research in Intellectual Disabilities

Abstract: Background: The COVID-19 pandemic precipitated a rapid roll-out of virtual health care services to people with intellectual disabilities. Limited evidence is available for clinicians to guide virtual care delivery. Method: Twenty-three studies were identified through systematic searching of 16 databases. Extracted data were mapped to the NSW Virtual Health Strategy. Results: Evidence exists to support the use of virtual care for screening, diagnosis, assessment, and review of people with intellectual disabilities, with benefits for clients, carers, and clinicians. Evidence mapped well to the priority areas of the NSW Virtual Health Strategy, highlighting the need for clinician training and specific supports and adaptations to ensure accessibility for people with intellectual disabilities. Conclusions: The use of virtual care to assess the health needs of people with intellectual disabilities across the lifespan is nascent. An opportunity exists for co-design with people with intellectual disabilities to reduce barriers to accessing and engaging in virtual care.

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14. **A Scoping Review of Health-Related Self-Management Approaches for Adults With Intellectual Disabilities**

Authors: Devitt, Alison;Nott, Melissa and Rossiter, Rachel

Publication Date: 2025

Journal: Journal of Applied Research in Intellectual Disabilities : JARID

A**bstract:** Background: The global rise in chronic health conditions highlights the importance of self-management in empowering people to actively participate in their healthcare. People with intellectual disabilities are disproportionately affected by these conditions and face barriers in accessing self-management interventions.; Method: This scoping review mapped literature on self-management approaches for adults with intellectual disabilities. A three-step search strategy was employed, involving electronic databases, reference lists, and advocacy organisation websites. Data on study design, intervention characteristics and outcomes were synthesised.; Results: The review included 38 articles from 34 studies, focusing on adults with intellectual disabilities. Studies with varied designs and interventions reported successful engagement and positive health outcomes when self-management interventions were adapted for adults with intellectual disabilities and featured caregiver support.; Main Conclusions: Adapted self-management interventions are feasible and yield positive outcomes for adults with intellectual disabilities. Future research should focus on long-term outcomes, clientcaregiver models and co-design methodology. (© 2025 The Author(s). Journal of Applied Research in Intellectual Disabilities published by John Wiley & Sons Ltd.)

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15. **Effectiveness of psychological therapies for depression or anxiety in adults with intellectual disabilities: retrospective, matched, observational cohort study of primary care electronic healthcare records in England**

Authors: El Baou, Céline;Saunders, Rob;Buckman, Joshua E. J.;Dagnan, Dave;Mandy, William;O'Nions, Elizabeth;Scior, Katrina;Pender, Richard;Hoare, Sarah;Richards, Marcus;Clements, Henry;Pilling, Stephen;John, Amber and Stott, Joshua

Publication Date: 2025

Journal: The British Journal of Psychiatry : The Journal of Mental Science

Abstract: Background: Treatment guidelines recommend evidence-based psychological therapies for adults with intellectual disabilities with co-occurring anxiety or depression. No previous research has explored the effectiveness of these therapies in mainstream psychological therapy settings or outside specialist settings.; Aims: To evaluate the effectiveness of psychological therapies delivered in routine primary care settings for people with intellectual disability who are experiencing co-occurring depression or anxiety.; Method: This study used linked electronic healthcare records of 2 048 542 adults who received a course of NHS Talking Therapies for anxiety and depression in England between 2012 and 2019 to build a retrospective, observational cohort of individuals with intellectual disability, matched 1:2 with individuals without intellectual disability. Logistic regressions were used to compare metrics of symptom improvement and deterioration used in the national programme, on the basis of depression and anxiety measures collected before and at the last attended therapy session.; Results: The study included 6870 adults with intellectual disability and 2 041 672 adults without intellectual disability. In unadjusted analyses, symptoms improved on average for people with intellectual disability after a course of therapy, but these individuals experienced poorer outcomes compared with those without intellectual disability (reliable improvement 60.2% for people with intellectual disability v . 69.2% for people without intellectual disability, odds ratio 0.66, 95% CI 0.63-0.70; reliable deterioration 10.3% for people with intellectual disability v . 5.7% for those without intellectual disability, odds ratio 1.89, 95% CI 1.75-2.04). After propensity score matching, some differences were attenuated (reliable improvement, adjusted odds ratio 0.97, 95% CI 1.91-1.04), but some outcomes remained poorer for people with intellectual disability (reliable deterioration, adjusted odds ratio 1.28, 95% CI 1.16-1.42).; Conclusions: Evidence-based psychological therapies may be effective for adults with intellectual disability, but their outcomes may be similar to (for improvement and recovery) or poorer than (for deterioration) those for adults without intellectual disability. Future work should investigate the impact of adaptations of therapies for those with intelectual disability to make such interventions more effective and accessible for this population.

16. **"I felt belittled and ridiculed for being in pain": An online survey of Autistic people's experience of care for pregnancy loss (perinatal loss) in the United Kingdom☆**

Authors: Grant, Aimee;Griffiths, Catrin;Williams, Kathryn and Brown, Amy E.

Publication Date: 2025

Journal: Midwifery

Abstract: Around 3 % of people are Autistic; women may be under-diagnosed. Autistic people report lack of staff understanding, stigma and environmental barriers to using midwifery services. It is not known if these issues are present in perinatal loss services. To understand Autistic people's experiences of care for perinatal loss. An online survey for Autistic adults in the United Kingdom who had been pregnant, using closed and open questions. Data were analysed descriptively, using Kruskal-Wallis tests and thematically. The majority of losses appeared to be early in pregnancy. Among 67 participants, over half (58.2 %, n = 39) always sought healthcare during a perinatal loss, but 28.4 % (n = 19) never accessed care. Of those who received healthcare (n = 48; 71.6 %), over half (n = 27; 56.3 %) did not know they were Autistic at the time, and just one person told health professionals that they were Autistic. Four participants identified instances where staff were supportive or kind, but the majority of experiences were negative, with reported issues focused on communication, the way support was provided, inadequate pain relief and the hospital environment. We generated one overarching theme: "trauma". Autistic people from the UK identified significant Disability-related access issues with perinatal loss care in addition to issues reported by a general population. UK Perinatal loss services need urgent investment to be able to provide person-centred care to all. Staff supporting perinatal loss should receive neurodiversity-affirming Autism training and be aware that many Autistic people experiencing perinatal loss may not have or share a diagnosis.

17. **'We are the engine': a focus group study on clinical practice guideline development with European patient advocates for rare congenital malformations and/or intellectual disability**

Authors: Klein Haneveld, Mirthe Jasmijn;de Mortier, Chloé Aymée;Hugon, Anne;Cornel, Martina Cornelia;Gaasterland, Charlotte Maria Wilhelmina and van Eeghen, Agnies Marguerite

Publication Date: 2025

Journal: Orphanet Journal of Rare Diseases

Abstract: Competing Interests: Declarations. Ethics approval and consent to participate: On 8 December 2022, the Medical Ethics Review Committee AMC declared that the Dutch Medical Research Involving Human Subjects Act (WMO) does not apply to this study and that official ethical approval is not required. All participants provided oral informed consent. Consent for publication: Not applicable. Competing interests: The authors declare that they have no competing interests.; Background: Individuals living with rare congenital malformations and/or intellectual disability often face challenges in accessing appropriate healthcare. Clinical practice guidelines (CPGs) may serve as a tool to provide evidence-based care for rare diseases, but their development is complex, and the views of affected individuals and families often remain unknown.; Methods: Patient advocates of the European Reference Network ITHACA (Intellectual disability, TeleHealth, Autism and Congenital Anomalies) participated in focus groups in which their experiences with and perspectives on CPG use and development were discussed.; Results: Patient advocates considered CPGs relevant to address information and care needs and support advocacy efforts. Important characteristics included representation of heterogeneity within conditions, a holistic approach in which and how topics are addressed, user-friendly availability for individuals and families, and reliability of information. Guideline development and implementation were described as challenging, iterative processes in which effective partnership between clinicians, patient advocates, and other stakeholders is essential.; Conclusions: Understanding the perspectives of patient advocates is essential to develop CPGs that meet the life-long and complex care needs of individuals and families living with rare conditions. Identified challenges include balancing the urgency of information needs with thorough guideline development processes, as well as the integration and interpretation of different types of knowledge. (© 2025. The Author(s).

18. **Temporal patterns of multiple long-term conditions in individuals with intellectual disability living in Wales: an unsupervised clustering approach to disease trajectories**

Authors: Kousovista, Rania;Cosma, Georgina;Abakasanga, Emeka;Akbari, Ashley;Zaccardi, Francesco;Jun, Gyuchan Thomas;Kiani, Reza and Gangadharan, Satheesh

Publication Date: 2025

Journal: Frontiers in Digital Health

Abstract: Competing Interests: The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.; Introduction: Identifying and understanding the co-occurrence of multiple long-term conditions (MLTCs) in individuals with intellectual disability (ID) is crucial for effective healthcare management. Individuals with ID often experience earlier onset and higher prevalence of MLTCs compared to the general population, however, the specific patterns of co-occurrence and temporal progression of these conditions remain largely unexplored. This study presents an innovative unsupervised approach for examining and characterising clusters of MLTC in individuals with ID, based on their shared disease trajectories.; Methods: Using a dataset of electronic health records (EHRs) from 13,069 individuals with ID, encompassing primary and secondary care data in Wales from 2000 to 2021, this study analysed the time sequences of disease diagnoses. Significant pairwise disease associations were identified, and their temporal directionality assessed. Subsequently, an unsupervised clustering algorithm-spectral clustering-was applied to the shared disease trajectories, grouping them based on common temporal patterns.; Results: The study population comprised 52.3% males and 47.7% females, with a mean of 4.5 INLINEMATH 3 long-term conditions (LTCs) per patient. Distinct MLTC clusters were identified in both males and females, stratified by age groups (<45 and INLINEMATH 45 years). For males under 45, a single cluster dominated by neurological conditions (32.4%), while three clusters were identified for older males, with the largest characterised by circulatory (51.8%). In females under 45, one cluster was found with digestive system conditions (24.6%) being most prevalent. For females INLINEMATH 45 years, two clusters were identified: the first cluster was predominantly defined by circulatory (34.1%), while the second cluster by digestive (25.9%) and musculoskeletal (21.9%) system conditions. Mental illness, epilepsy, and reflux disorders were prevalent across all groups.; Discussion: This study reveals complex multimorbidity patterns in individuals with ID, highlighting age and sex differences. The identified clusters provide new insights into disease progression and co-occurrence in this population. These findings can inform the development of targeted interventions and risk stratification strategies, potentially improving personalised healthcare for individuals with ID and MLTCs with the aim of improving health outcome for this vulnerable group of patients i.e. reducing frequency and length of hospital admissions and premature mortality. (© 2025 Kousovista, Cosma, Abakasanga, Akbari, Zaccardi, Jun, Kiani and Gangadharan.)

19. **Recognising and assessing for dementia in people with learning disabilities**

Authors: Lyons, Victoria;Nickels, Jane and Dening, KarenHarrison

Publication Date: 2025

Journal: Learning Disability Practice

Abstract: Why you should read this article: • To enhance your ability to spot early signs and symptoms of dementia in people with learning disabilities • To think about what an ‘ideal’ dementia diagnostic pathway for people with learning disabilities may look like • 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). People with learning disabilities are living longer and are therefore at risk of developing age-related conditions such as dementia. They also tend to develop dementia at a younger age than the general population. However, people with learning disabilities experience a range of health inequalities and barriers to accessing healthcare services, including dementia assessment and diagnostic services. Furthermore, the early signs and symptoms of dementia in this group tend to differ from those in the general population. It is vital, therefore, that those working with people with learning disabilities are able to recognise the early signs and symptoms of dementia in this population and know how to refer the person for assessment. This article discusses dementia in people with learning disabilities, including early signs and symptoms, and uses a case study to explore an ‘ideal’ dementia diagnostic pathway for this population.

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20. **Exploring Barriers to Mammography Access for Women With Intellectual Disabilities: A Meta-Synthesis of the Perspectives of Four Stakeholder Groups**

Authors: Pitt, Adam and Hodge, Suzanne

Publication Date: 2025

Journal: Journal of Applied Research in Intellectual Disabilities : JARID

Abstract: Background: Breast cancer is as frequent in women with intellectual disabilities as the general population, but the mammography uptake rate for women with intellectual disabilities is almost a third lower. This meta-synthesis aimed to explore physical and psychosocial barriers to mammography access for women with intellectual disabilities from the perspectives of the women themselves, healthcare professionals, paid carers and family members.; Method: A systematic search of six databases yielded 12 papers for thematic synthesis review.; Results: Three analytic themes were developed: (i) knowing what to expect; (ii) knowing who will assume responsibility and (iii) making adjustments.; Conclusions: Mammography screening elicits anxiety from both women with intellectual disabilities and their supporters (whether paid, family or healthcare professional). A formulation-based approach to mammography attendance may help to provide tailored information to women with intellectual disabilities, whilst easing the pressures placed upon their support network and healthcare professionals. (© 2025 John Wiley & Sons Ltd.)

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21. **Parental Perspectives on Oral Health and Access to Care in Children with Down Syndrome: A Narrative Review**

Authors: Saitos, Petra;Iurcov, Raluca;Moca, Abel Emanuel;Bota, Teofana;Marton, Rebeca Daniela and Juncar, Mihai

Publication Date: 2025

Journal: Children

Abstract: Background/Objectives: Children with Down syndrome are predisposed to various oro-dental conditions, which can impact their oral-health-related quality of life (OHRQoL) and overall well-being. Given their critical role, parents' and caregivers' perceptions are essential for understanding the challenges in oral care access and quality. This narrative review aimed to synthesise the available evidence on parental and caregiver perceptions regarding oral health, OHRQoL, and dental care access for children with Down syndrome. Methods: A literature search was conducted in PubMed, Web of Science, and Scopus, covering studies published between January 2015 and January 2025. The search included the keywords "Down syndrome", "oral health", "oral health-related quality of life", "caregivers", "parents", "dental care access", and "special needs children". Thirteen studies were included after applying eligibility criteria, which selected original research focusing on the target population and themes. Results: The findings highlighted that oral health significantly affects the quality of life of children with Down syndrome, influencing their functional, emotional, and social well-being. Caregivers often reported a gap between perceived and clinically observed oral health. Barriers to dental care access included insufficient training of dental professionals, financial constraints, systemic limitations, and perceived biases. Variations across different countries also revealed the influence of cultural and healthcare system factors. Conclusions: Oral health plays a critical role in the lives of children with Down syndrome and their families. Strengthening caregiver education, improving communication, validating adapted OHRQoL instruments, and enhancing dental professionals' training in special needs care are crucial steps to ensure equitable and family-centred oral healthcare.

22. **Introduction and outcomes from an enhanced physical health clinic for people with intellectual disabilities prescribed psychotropic medication**

Authors: Sawhney, Indermeet;Patteril, Elizabeth;Alexander, Regi;Sathick, Mohamed;Gale, Tim M.;Zia, Asif and Chester, Verity

Publication Date: 2025

Journal: Advances in Mental Health & Intellectual Disabilities

Abstract: Purpose: This study aims to explore an intervention that addresses the physical health inequalities and premature mortality experienced by people with intellectual disabilities and comorbid mental health difficulties. In the UK, physical health care has traditionally been coordinated and delivered through primary health-care settings. There is a case that physical health inequalities for those with intellectual disabilities and mental health difficulties can be reduced further if primary care interventions are supplemented by Enhanced Physical Health Clinics (EPHCs) co-located in mental health outpatient settings.
Design/methodology/approach: This paper describes the structure and setting up of an EPHC for people with intellectual disabilities and mental disorders and an evaluation of its first two years. The EPHC database, which contains patient demographics and process data for the clinic regarding tests and interventions completed, was used for this study. This includes sociodemographic, psychiatric and physical health diagnoses, prescribed medication, physical health assessments and interventions. Findings: During its first two years, the clinic saw 463 patients. The mean age was 44 years, and 62% were male. There was considerable developmental and psychiatric comorbidity, with high rates of autism and major mental illness. The most common physical health diagnoses were epilepsy, hypothyroidism, diabetes, hypertension and asthma. A range of previously unidentified unmet health-care needs that warrant further assessment and treatment was identified. Originality/value: The EPHC was effective in promoting physical health monitoring and screening in a population that experiences significant health barriers. Recommendations regarding clinical practice and future research are provided.

23. **Hospitalisation rates for epilepsy, asthma and insulin-dependent diabetes in 796 190 school-aged children and young people with and without intellectual disabilities: a record-linkage cohort study**

Authors: Smith, Gillian S.;Fleming, Michael;Cooper, Sally-Ann;Henderson, Angela;Pell, Jill;Melville, Craig and Cairns, Deborah

Publication Date: 2025

Journal: BMJ Open

Abstract: Competing Interests: Competing interests: None declared.; Objectives: To investigate hospitalisation rates for the ambulatory care-sensitive conditions of epilepsy, asthma and insulin-dependent diabetes in school-aged children and young people with intellectual disabilities in comparison with their peers.; Design: Record-linkage cohort study. Scotland's Pupil Census, 2008-2013, was used to identify pupils with and without intellectual disabilities and was linked with the Prescribing Information Service to identify pupils with epilepsy, asthma and insulin-dependent diabetes, and the Scottish Morbidity Records-01 to identify hospital admissions.; Setting: The general child population of Scotland.; Participants: School pupils aged 4-19 years; 18 278 with intellectual disabilities and 777 912 without intellectual disabilities.; Outcomes: Overall, emergency and non-emergency hospitalisations for epilepsy, asthma and/or diabetes; and length of stay.; Results: Epilepsy and asthma were more prevalent in pupils with intellectual disabilities (8.8% and 8.9%, respectively, compared with 0.8% and 6.9% among pupils without intellectual disabilities, $p<0.001$), whereas insulin-dependent diabetes was not (0.5% prevalence). After adjusting for prevalence, pupils with intellectual disabilities and epilepsy had more epilepsy-related admissions than their peers (adjusted Hazard Ratio (aHR) 2.24, 95% CI 1.97, 2.55). For emergency admissions, these stays were longer compared with controls (adjusted incidence rate ratio (aIRR) 2.77, 95% CI 2.13, 3.59). Pupils with intellectual disabilities and asthma had similar admission rates due to asthma as control pupils with asthma (aHR 0.81, 95% CI 0.62, 1.06), but emergency admissions were longer (aIRR 2.72, 95% CI 1.49, 4.96). Pupils with intellectual disabilities and insulin-dependent diabetes had similar admission rates to controls (aHR 0.94, 95% CI 0.63, 1.41) but with shorter admissions (aIRR 0.71, 95% CI 0.51, 0.99).; Conclusions: Our findings suggest pupils with intellectual disabilities may receive poorer community healthcare than their peers for the common conditions of epilepsy and asthma. Hospital admissions are disruptive for both the child and their family. Epilepsy and asthma are associated with avoidable deaths; hence, a better understanding of these hospitalisations is important. (© Author(s) (or their employer(s)) 2025. Re-use permitted under CC BY. Published by BMJ Group.)

24. **The Forgotten Voices: Enabling Children and Young People With Intellectual Disability to Express Their Views on Their Inpatient Hospital Experience**

Authors: Wray, Jo;Russell, Jessica;Gibson, Faith;Kenten, Charlotte and Oulton, Kate

Publication Date: 2025

Journal: Health Expectations

Abstract: Background: The importance of enabling patients to provide feedback on their experience of healthcare is widely accepted but there are few appropriate measures to enable children and young people to directly provide feedback, particularly those with intellectual disability or younger children. Our primary aim was to develop and test patient-reported experience measures for children and young people with intellectual disability who use inpatient hospital services. A secondary aim was to test these measures with younger children aged 4–7 years without intellectual disability. Methods: A hospital inpatient patient-reported experience measure previously developed for children aged 8–11 years was revised iteratively in conjunction with a parent advisory group (comprising five parents of children and young people with and without intellectual disability) and children and young people with intellectual disability. The final patient-reported experience measure was tested in children's inpatient wards at seven hospitals in England over a 3-month period. Results: Parents suggested a need for a single patient-reported experience measure for all children with intellectual disability which contained simpler language, fewer questions and response options, and images to illustrate each question. The final patient-reported experience measure had 22 questions, each with a corresponding image, and a free text box in which children could add anything further. Questions addressed environment, people, care and treatment and safety. During testing at seven children's hospitals, 52 children and young people with intellectual disability (4–18 years) and 76 children without intellectual disability (4–7 years), all of whom received inpatient care, completed the patient-reported experience measure. Two percent of data were missing; in 16 instances respondents either ticked two responses or placed a tick between two response categories. Half the respondents added comments and/or drew a picture. Conclusion: The development of a patient-reported experience measure for children and young people with intellectual disability provides a previously unavailable opportunity for them to report on their experiences of inpatient care and have their voices heard. Future work to extend testing to a wider group is underway and will enable us to clarify whether one patient-reported experience measure is valid and reliable for all children and young people with intellectual disability. Patient or Public Contribution: A parent advisory group, comprising parents/carers of young people with or without a learning disability, advised on all aspects of the wider study design and specifically on revisions to the measure reported in this manuscript. The parent advisory group met twice a year during the study with email contact between meetings for specific requests and study updates. Representatives of the advisory group also attended the study steering group.

25. **Identifying challenges in meeting the unmet health care needs of children with intellectual disabilities: a scoping review**

Authors: Zare, Zahra;Sarpourian, Fatemeh;Jalali, Faride Sadat and Bahrami, Mohammad Amin

Publication Date: 2025

Journal: BMC Health Services Research

Abstract: Competing Interests: Declarations. Ethics approval and consent to participate: This study received ethical approval from the Ethics Committee of ShirazUniversity of Medical Sciences (ID: IR.SUMS.NUMIMG.REC.1404.041). Consent for publication: Not applicable. Competing interests: The authors declare no competing interests.; Background: Children with intellectual disability have significantly below-average intellectual functioning and adaptive behavior, experience more challenges in a lifetime, and are at higher risks of physical illness, mental health problems, and mortality compared to the unmet health care needs of others. Thus, this scoping review aimed to identify challenges in meeting the unmet healthcare needs of children with intellectual disabilities.; Method: This was a scoping review applying the JBI framework. Five databases of Scopus, PubMed, WOS, Embase, and ProQuest were systematically searched, applying related keywords up to 23.1.2024. All the retrieved studies in English, which determine the challenges in meeting the unmet healthcare needs of children with intellectual disabilities, were included regardless of their methodological designs. Microsoft Power BI was used for descriptive quantitative Analysis, and MAXQDA version 10 was applied for qualitative thematic Analysis.; Results: The number of 639 articles was retrieved systematically based on the search strategy. After excluding duplications and appraising the eligibility, 16 articles were included. According to the descriptive results, most studies were conducted in the US (37%). The results of the thematic Analysis also revealed six main themes: "Governance," "Care process," "Social challenges," "Information and education," "Infrastructure constraints," and "Personal challenges."; Conclusion: The findings comprehensively understand the challenges in meeting the unmet healthcare needs of children with intellectual disabilities. This synthesized knowledge could pave the way for policymakers to conduct related interventions better to improve unmet health care and, as a result, increase the children's health status. (© 2025. The Author(s).)

26. **Educating the educated: The impact of educational interventions on knowledge, attitudes and confidence of healthcare professionals in caring for patients with intellectual disability: A systematic review**

Authors: Hay, Gracie;Wilson, Nathan J.;Ong, Natalie;Benson, Patrick and Gallego, Gisselle

Publication Date: 2024

Journal: Journal of Intellectual & Developmental Disability

Abstract: Background: The attitudes, perceptions and inherent biases of healthcare professionals (HCPs) have the potential to influence and inform health outcomes of people with intellectual disability. This review aimed to identify what educational interventions have been conducted to improve the attitude, knowledge, and confidence of HCPs in caring for people with intellectual disability.; Method: A systematic literature review was conducted using Medline, ERIC and PsycINFO. Inclusion criteria included: articles published after 1980 in English, quantitative and mixed methods studies.; Results: Of 1444 articles yielded, 10 met the inclusion criteria. Studies predominantly included doctors and nurses. Almost half (40%) of the studies reported interventions that were effective in changing perceived confidence and attitudes, while 60% achieved improvement in knowledge or skills based on Kirkpatrick classification.; Conclusions: Training is valuable in improving knowledge, broadening perspectives, and increasing confidence in managing people with intellectual disability but there are limited studies in this area.

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27. **A comparative analysis of the prevalence and predictors of chronic pain in older adults with and without intellectual disability in Australia**

Authors: Wark, Stuart;Hussain, Rafat;Janicki, Matthew P.;Knox, Marie and Parmenter, Trevor

Publication Date: 2024

Journal: Journal of Intellectual & Developmental Disability

Abstract: Background: There is little research comparatively assessing prevalence of pain between older people either with or without intellectual disability. This paper explores health and social factors associated with chronic pain in these two groups.; Method: A cross-sectional survey was undertaken in New South Wales and Queensland, Australia. Inclusion criteria were adults either with or without intellectual disability, aged 60 years and older, and currently living in community-settings. Univariate and multivariable analyses were undertaken on a sample of 391 adults with intellectual disability and 920 adults without intellectual disability.; Results: Key findings included higher prevalence of pain in the intellectual disability group, along with higher rates of osteoarthritis, falls, oral health problems, and mood disorders.; Conclusions: Mitigating risk factors for conditions that cause chronic pain in older adults is crucial. As longevity increases, the healthcare sector needs to prioritise chronic pain management for people with intellectual disabilities through appropriate treatment strategies.

Sources Used:

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

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