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July 2025

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  Next sessions: 12th August @ 9am, 10th September @ 10am & 2nd October @ 11am

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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: 2025

Journal: Journal of Intellectual & Developmental Disability

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.

2. **The Views of People With Intellectual Disabilities About What Contributes Towards Optimal End-of-Life Care: A Qualitative Evidence Synthesis**

Authors: Bebbington, Corrina Alex and Croot, Elizabeth

Publication Date: 2025

Journal: Journal of Applied Research in Intellectual Disabilities

Abstract: Background: People with intellectual disabilities face inequities in access to end-of-life care and inequalities in its quality and delivery. This review aimed to synthesise qualitative evidence to understand their own perspectives about what contributes to optimal end-of-life care. Methodology: Data from 93 participants in five qualitative studies were thematically synthesised to identify optimal care and inform recommendations. Results: Four overarching and interrelated analytical themes were generated. (1) Optimal care recognises heterogeneity and is person-centred. It aligns with individuals' wishes and preferences which are established through 'active' communication. (2) This enables an individual's holistic support needs to be identified. (3) It fulfils ethical obligations around autonomy, equity and a person's 'right to know'. (4) It involves the necessary people to ensure all needs are met. Conclusion: Optimal end-of-life care is person-centred, holistic, uses 'active' communication, meets ethical obligations and involves the necessary people in care.

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3. **Palliative care communication between patients with intellectual disabilities and hospice staff: a Conversation Analysis pilot study**

Authors: Bruun, Andrea and Tuffrey-Wijne, Irene

Publication Date: 2025

Journal: BMJ Open

Abstract: Competing Interests: Competing interests: None declared.; Introduction: Communication challenges are among the main barriers for people with intellectual disabilities in accessing palliative care. They include inadequate skills among staff and difficulties with confirming understanding and around the presentation and assessment of symptoms. In-depth analysis of interactions between people with an intellectual disability and staff may shed light on these communicative challenges as well as facilitators. However, no studies have closely analysed the interactions between people with an intellectual disability and professionals within palliative care settings.; Methods and Analysis: This protocol describes a pilot study assessing the feasibility and acceptability of conducting a Conversation Analysis study involving video-recording palliative care conversations between people with intellectual disabilities and professionals.Three conversations between patients with an intellectual disability, their companions and palliative care staff will be video recorded in a UK hospice. Recordings will be transcribed and analysed using Conversation Analysis. Communication phenomena of interest and worth further exploration will be identified in collaboration with key stakeholders.; Ethics and Dissemination: The study received a favourable opinion by a UK research ethics committee in February 2025. All participants must provide informed consent to take part in the study. It will be carefully assessed that potential participants with an intellectual disability have capacity to consent to take part. Accessible study information materials for participants with an intellectual disability are available (ie, easy-read and video).Study findings will be disseminated in academic papers and conference presentations. Progress and findings will also be shared via social media and with relevant groups of people with intellectual disabilities, family carers, service providers and academics. (© Author(s) (or their employer(s)) 2025. Re-use permitted under CC BY. Published by BMJ Group.)

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

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

Publication Date: 2025

Journal: Journal of Intellectual Disability Research

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

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5. **Monitoring cognition in people with epilepsy and intellectual disability**

Authors: Catalán-Aguilar, Judit;Witt, Juri-Alexander and Helmstaedter, Christoph

Publication Date: 2025

Journal: Seizure

Abstract: Competing Interests: Declaration of competing interest None.; Monitoring cognition is essential in patients with epilepsy and intellectual disability (ID) to assess the course of the disease and its treatment. Patients with developmental or non-developmental ID are particularly vulnerable, as they more frequently experience severe medical conditions (such as seizures) and cognitive or psychiatric comorbidities than individuals with average intelligence. Given the difficulties in assessing patients with ID, this study aims to contextualise the current field of cognitive screening for patients with epilepsy and moderate or severe ID. To this purpose, this narrative review offers a critique of current approaches and provides a practical framework for individualised patient care. Furthermore, it highlights the challenges in assessing cognitive and behavioural changes in this population and focuses on the need for assessments that adapt to individual patient capabilities. It addresses the specific cognitive domains that should be evaluated and provides an overview of the tools employed, analysing the advantages and limitations of subjective and objective measures. Finally, it examines different procedures for assessing cognitive changes and considers future directions, such as the potential for new technologies, to improve exploration accuracy. In conclusion, objective screening tools to monitor intrasubject short-term changes in this population are necessary. The current approach is eclectic, which combines various age-adjusted and domain-specific tests. Future efforts should incorporate measures based on the WHO International Classification of Functioning, daily living activity scales, and surrogate markers for cognition (e.g., eye-tracking, AI-driven motion analysis, and wearables) to fill diagnostic gaps and improve the precision of cognitive monitoring in these patients. (Copyright © 2025 The Author(s). Published by Elsevier Ltd.. All rights reserved.)

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6. **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

Abstract: 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, client–caregiver models and co-design methodology.

7. **Description of Common Ailments and Nonprescription Medications Found in Medication Reviews for People With Intellectual Disability**

Authors: Felkai, Chelsea;Carew, Jamie-Lee;Newby, David and Croft, Hayley

Publication Date: 2025

Journal: Journal of Intellectual Disability Research

Abstract: Background: People with intellectual disability (ID) are more susceptible to experiencing minor health issues. This research describes the common ailments and nonprescription medications found in people with ID who have had a medication review performed by a credentialed pharmacist in Australia. Aims: The aims of this research were to (i) describe the common ailments found within people with ID and (ii) identify and quantify the nonprescription medications documented in medication reviews for people with ID. Method: This research conducted a retrospective analysis of medication review reports and referrals from credentialed pharmacists who have performed a medication review for a person with ID between January 2020 and January 2024. Results: A total of 80 responses and reports were obtained. The average age of the person with ID was 52 years. On average, each medication review listed 6.6 common ailments and 8.0 nonprescription medications. The highest number of nonprescription medications listed for a single individual was 26. Conclusion: This research is the first to exclusively examine common ailments and nonprescription medications found in people with ID through medication reviews. Further research is needed to confirm study findings revealing a potentially high occurrence of common ailments and nonprescription medication use in this population compared to other similar populations and notable polypharmacy for nonprescription medications.

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8. **Science and Practice of Identifying Specific Learning Disabilities: Kind Conversations About a Wicked Problem**

Authors: Hajovsky, Daniel B.;Maki, Kathrin E.;Niileksela, Christopher R. and McGill, Ryan J.

Publication Date: 2025

Journal: Journal of Psychoeducational Assessment

Abstract: Although specific learning disabilities (SLD) represent the largest category for which school-age children receive special education services, the science and practice of SLD identification continues to evade consensus. Our goal is to bring together trainers and researchers with different perspectives on SLD identification to help spur a move toward a potential consensus, discuss agreements and disagreements on SLD identification in the field including amongst ourselves, and work toward productive discussion that may help move the field forward. We review essential conceptual questions that require greater scrutiny and thought to build a stronger understanding of SLD. We then discuss current assessment and identification practices, focusing on the not-so-controversial and the controversial issues in the field. Finally, we conclude with questions and considerations that challenge many of the established assumptions and systems currently in place. The aim of this article is to support constructive discussion on the topic of SLD that may have profound effects on the perennial issues the field continues to face.

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9. **Why your input is vital for our learning disability nursing study**

Authors: Heaslip, Vanessa

Publication Date: 2025

Journal: Learning Disability Practice

Abstract: There were 622,897 nurses, midwives and nursing associates on the Nursing and Midwifery Council (NMC) register in England in September 2023. However, the proportion of registered learning disability nurses has declined over the past five years.

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10. **Prediction of amyloid and tau brain deposition and cognitive decline in people with Down syndrome using plasma biomarkers: a longitudinal cohort study**

Authors: Janelidze, Shorena;Collij, Lyduine E.;Mattsson-Carlgren, Niklas;Antill, Alex;Laymon, Charles M.;Lott, Ira;Rosas, H. D.;Minhas, Davneet S.;Luo, Weiquan;Zaman, Shahid;Mapstone, Mark;Head, Elizabeth;Lai, Florence;Hartley, Sigan L.;Ances, Beau M.;Krinsky-McHale, Sharon;Lee, Joseph H.;Ossenkoppele, Rik;Christian, Bradley T.;Handen, Benjamin L., et al

Publication Date: 2025

Journal: The Lancet.Neurology

Abstract: Competing Interests: Declaration of interests LEC has received research support from GE Healthcare, Life Molecular Imaging, and Springer Healthcare (funded by Eli Lilly), both paid to their institution. LEC's salary is supported by the MSCA postdoctoral fellowship research grant (grant number 101108819) and the Alzheimer Association Research Fellowship grant (grant number 23AARF-1029663). NM-C has received consultancy fees from Biogen, Eli Lilly, Merck, and Owkin in the past 2 years. SJ reports grants from Swedish Alzheimer Foundation, Kockska Foundations, and Foundation for Gamla Tjänarinnor. BMA, CML, and EH report funding from the NIH. EH reports funding from the Brightfocus and consulting fees from Cyclo Therapeutics, Alzheon, and Elsevier. SLH reports consulting from Ionis Pharmauticals and being a Chair of Alzheimer's Association Down Syndrome Professional Interest Area. SHZ reports funding from Cambridgeshire & Peterborough Foundation NHS Trust, UK and support for attending meetings and travel. MM reports royalties from University of Rochester, consulting fees from NovoGlia and Ireneo Health, and several US patents. BDC reports support from Alzheimer's Disease Research Centers Program, Eunice Kennedy Shriver Intellectual and Developmental Disabilities Research Centers Program, National Center for Advancing Translational Sciences, National Centralized Repository for Alzheimer Disease and Related Dementias, DS-Connect (The Down Syndrome Registry), NIHR Cambridge Biomedical Research Centre, Windsor Research Unit, CPFT, and Fulbourn Hospital Cambridge, UK and consulting fees from Alnylam. SLH reports consulting from Ionis

Pharmauticals. BLH reports receipt of speaker's fees, royalties from two books. RO received research funding and support from Avid Radiopharmaceuticals, Janssen Research & Development, Roche, Quanterix, and Optina Diagnostics; has given lectures in symposia sponsored by GE Healthcare; received speaker fees from Springer; is an advisory board member for Asceneuron; and is a steering committee member for Biogen and Bristol Myers Squibb; all the aforementioned funding has been paid to his institutions. OH is an employee of Lund University and Eli Lilly. All other authors declare no competing interests.; Background: Plasma biomarkers associated with Alzheimer's disease could improve prognostic assessment for people with Down syndrome in both clinical practice and research settings. We aimed to identify the plasma biomarkers that most accurately predict longitudinal changes in Alzheimer's disease-related pathology and cognitive functioning in individuals with Down syndrome.; Methods: This longitudinal cohort study included data from 258 adults (aged ≥25 years) with Down syndrome who were followed up prospectively every 16 months as part of the longitudinal Alzheimer's Biomarker Consortium-Down Syndrome study (recruited from seven university sites in the USA and UK between July 13, 2016, and Jan 15, 2019). Participants had baseline and longitudinal assessments of plasma tau phosphorylated at threonine 217 (p-tau217), glial fibrillary acidic protein (GFAP), amyloid β (Aβ) 42/40 , neurofilament light (NfL), or total tau (t-tau). Associations of baseline plasma biomarkers and longitudinal changes in plasma biomarkers with changes in global cognitive functioning (Down Syndrome Mental Status Examination DS-MSE] scores), Aβ-PET, and tau-PET were examined using linear regression models. Plasma biomarker-associated risk of progression to dementia was assessed using Cox regression analysis.; Findings: Baseline p-tau217, as well as GFAP, NfL, or t-tau, were individually associated with longitudinal changes in DS-MSE, Aβ-PET, and tau-PET, and with progression to dementia. However, in combined models, only baseline p-tau217 remained associated with changes in DS-MSE (β -0·30 95% CI -0·45 to -0·15], p=0·0001, n=220), tau-PET (0·42 0·14 to 0·70], p=0·0039, n=88), and progression to dementia (hazard ratio 3·51 95% CI 1·76-7·00], p=0·0004, n=194), whereas baseline p-tau217 (0·29 0·14-0·45], p=0·0003) and GFAP (0·37 0·18-0·56], p=0·0003) were associated with changes in Aβ-PET (n=106 for both). Similar associations were shown between longitudinal p-tau217 or GFAP and changes in DS-MSE (p-tau217: β -0·33 95% CI-0·52 to -0·13], p=0·0015, n=133), tau-PET (p-tau217: 0·61 0·40 to 0·83], p<0·0001, n=87), and Aβ-PET (p-tau217: 0·35 0·19 to 0·50], p<0·0001; GFAP: 0·49 0·27 to 0·70], p<0·0001, n=88).; Interpretation: Baseline and longitudinal plasma p-tau217 were associated with subsequent decline in global cognition, progression to dementia, and increased tau burden, whereas baseline p-tau217 and GFAP were associated with Aβ accumulation. These findings suggest that plasma p-tau217 and GFAP might be valuable for prognostic assessment of Alzheimer's disease in people with Down syndrome in both clinical and research contexts. The results further support evaluation of these biomarkers for monitoring disease progression in clinical trials of Down syndrome-related Alzheimer's disease.; Funding: The European Research Council and National Institute on Aging (National Institute of Health). (Copyright © Published by Elsevier Ltd. This is an Open Access article under the CC BY-NC-ND license.)

11. **Cognitive Impairment as A Vulnerability for Exploitation: A Scoping Review**

Authors: Lambert, Imogen;Wright, Nicola;Gardner, Alison;Fyson, Rachel;Abubakar, Aisha and Clawson, Rachael

Publication Date: 2025

Journal: Trauma, Violence & Abuse

Abstract: Exploitation is a form of abuse that occurs when one person unfairly manipulates another for profit or personal gain. Various individual and social characteristics have the potential to increase an individual's risk of being exploited. Cognitive impairment is one potential vulnerability factor that has received minimal research attention. This scoping review aimed to investigate cognitive impairment as a factor that may increase an individual's vulnerability to exploitation. Study inclusion criteria were: (a) empirical studies; (b) studies presenting extractable data related to cognitive impairment and exploitation; (c) studies exploring cognitive impairment as a vulnerability factor for exploitation; (d) studies published after 1998; and (e) studies available in English. A six-step search strategy was employed: (a) electronic searches of bibliographic databases; (b) screening reference lists of included studies; (c) forward citation tracking in Google Scholar; (d) expert recommendations; (e) website searches of relevant Non-Governmental Organizations (NGOs); and (f) a call for evidence. Twenty studies met the inclusion criteria. Three types of exploitation were reported: sexual (n = 10), financial (n = 8), and criminal (n = 2). Intellectual disability (n = 8) and mental health (n = 8) were the most frequently described forms of cognitive impairment. The results indicate that cognitive impairment is a factor that increases vulnerability to exploitation. However, the limited number and disparate nature of the studies means that it is impossible to disentangle all the complexities in the relationship between cognitive impairment and exploitation. Further research is needed to understand if cognitive impairment increases vulnerability to all types of exploitation or if it results in varying levels of susceptibility to different types of exploitation.

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12. **Body appreciation mediates the association between satisfaction with autistic identity and flourishing in autistic adults**

Authors: Longhurst, Phaedra;Aspell, Jane E.;Todd, Jennifer and Swami, Viren

Publication Date: 2025

Journal: Body Image

Abstract: Underpinned by the neurodiversity paradigm, scholars are increasingly interested in relationships between positive autistic identity (i.e., feeling satisfaction and pride with being autistic) and states of flourishing (i.e., where numerous aspects of a person's life and well-being are good) in autistic people. However, possible mediational pathways between these constructs remain relatively under-researched. Here, we propose a conceptual model wherein positive autistic identity is associated with flourishing in autistic adults via positive body image. To test this model, we recruited an online sample of 384 autistic adults (189 women, 195 men; M = 34.66 years , SD = 10.77) from the United Kingdom. Participants were asked to complete measures of satisfaction with autistic identity, body appreciation, and flourishing, and provide their demographic information. Structural equation modelling showed that body appreciation mediated the association between satisfaction with autistic identity and flourishing. The mediational triangle remained significantly robust after controlling for participant demographics. Future research should consider promoting positive autistic identity as a means of developing more positive body image and capacities to flourish in autistic adults. • Body appreciation mediates the link between satisfaction with autistic identity and flourishing. • Model remains robust after controlling for participant socio-demographics. • Satisfaction with autistic identity may be beneficial for body appreciation.

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13. **Factors influencing physical healthcare quality for people with intellectual disabilities: psychiatry multidisciplinary team perspective**

Authors: Majid, Madiha;Rennick-Egglestone, Stefan;Harris, Bronwyn;Roy, Ashok and Crawford, Hayley

Publication Date: 2025

Journal: BJPsych Open

Abstract: Background: There is a need for better collaborative care between services to improve healthcare provision for people with intellectual disabilities. In the UK, the learning disability psychiatry multidisciplinary team (MDT) is a specialist team responsible for providing and coordinating care for people with intellectual disabilities.; Aims: To document learning disability MDT perspectives on factors influencing healthcare quality for people with intellectual disabilities.; Method: Healthcare professionals who were members of a learning disability MDT within a National Health Service Trust in the West Midlands were purposively sampled for interview (n = 11). Participants included psychiatrists, nurses, occupational therapists and speech and language therapists. Data were analysed thematically using Braun and Clarke's six-stage approach.; Results: Factors influencing the quality of healthcare provision included: the learning disability MDT working to overcome systemic barriers; the consequences of specific failures within mainstream healthcare services, such as diagnostic overshadowing; inadequate use of information collated in health passports; and inadequate capacity assessments of people with intellectual disabilities. Improvements in healthcare provision for people with intellectual disabilities require better accessibility to healthcare and better training for healthcare professionals so they can understand the health needs of people with intellectual disabilities.; Conclusions: A rapid review of practices around health passports for people with intellectual disabilities should be conducted. Healthcare professionals working in mainstream healthcare services need an increased awareness of the harms of diagnostic overshadowing and inadequate capacity assessments. Conclusions are based on findings from MDTs within one health board; future work may focus on understanding perspectives from different teams.

14. **The history of Down syndrome-associated Alzheimer's disease; past, present, and future**

Authors: Maure-Blesa, Lucia;Carmona-Iragui, Mar;Lott, Ira;Head, Elizabeth;Wisniewski, Thomas;Rafii, Michael S.;Espinosa, Joaquín;Flórez, Jesús;Mobley, William C.;Holland, Anthony;Strydom, André;Zaman, Shahid and Fortea, Juan

Publication Date: 2025

Journal: Alzheimer's & Dementia : The Journal of the Alzheimer's Association

Abstract: The landscape of Down syndrome-associated Alzheimer's disease (DSAD) research reflects decades of scientific endeavor and collaborative effort, charting a remarkable journey from initial observations to the elucidation of complex genetic and molecular mechanisms. This perspective article chronicles key milestones and breakthroughs, paying homage to the pioneering scientists and advancements that have shaped the field. A thorough review of historical and contemporary literature offers a comprehensive narrative, highlighting the evolution of knowledge surrounding DSAD, from early recognition to the characterization of clinical presentation and natural history. The unique challenges and ethical considerations associated with DSAD populations are also examined, underscoring the importance of tailoring research and clinical approaches. By reflecting on the field's trajectory, this work celebrates past achievements while emphasizing the critical need for sustained research efforts. As part of a special issue, this article provides a foundation for appreciating the challenges and opportunities that lie ahead in advancing DSAD understanding and care. HIGHLIGHTS: This article provides a comprehensive overview of Down syndrome-associated Alzheimer's disease (DSAD) history, from early descriptions to its recognition as a genetic form of AD. It reflects on historical challenges faced by individuals with intellectual disabilities in achieving inclusion in scientific research. This historical perspective highlights the critical contributions of individuals with DS in advancing understanding of AD natural history. It explores pivotal milestones and efforts that have driven progress in DSAD research. Finally, it provides context to understand challenges and opportunities in DSAD research and its future directions. (© 2025 The Author(s). Alzheimer's & Dementia published by Wiley Periodicals LLC on behalf of Alzheimer's Association.)

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15. **The Role of Reproductive Injustice in the Access of Motherhood for Women With Intellectual Disabilities: A Narrative Literature Review**

Authors: Mercerat, Coralie;Pacheco, Laura;Aunos, Marjorie;Cousineau, Marie-Marthe;Goulden, Ami;Swab, Michelle;Brenton, Bethany and Moyo, Sibusiso

Publication Date: 2025

Journal: Journal of Applied Research in Intellectual Disabilities : JARID

Abstract: Background: Even though becoming a parent and forming meaningful relationships are considered fundamental rights, research shows that there are significant barriers for people with intellectual disabilities within these social roles, as they are still seen as unfit for parenthood. Given limited research knowledge about the reproductive trajectories of women with intellectual disabilities, this paper presents the results of a narrative literature review on reproductive injustices against women with intellectual disabilities.; Methods: We conducted in-depth research within the scientific literature to better understand the reproductive injustice experienced by women with intellectual disabilities.; Results: Thirty-two publications were included in this narrative literature review. The main results are related to the nature and actors involved in the reproductive injustice and six types of discourses underpinning the non-consensual contraception, including sterilisation.; Conclusion: The findings have implications for future community-based research and intersectoral policies and practices that promote agency and relational autonomy of women with intellectual disabilities. (© 2025 The Author(s). Journal of Applied Research in Intellectual Disabilities published by John Wiley & Sons Ltd.)

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16. **Specialist Psychiatric Bed Utilisation by People With Intellectual Disabilities and Autistic People: A Time-Series Analysis Using the English Assuring Transformation Dataset**

Authors: Nisar, Atiyya;Thompson, Paul A.;Boer, Harm;Al-Delfi, Haider and Langdon, Peter E.

Publication Date: 2025

Journal: Journal of Intellectual Disability Research : JIDR

Abstract: Background: Using nationally available anonymised and aggregated English data, we examined specialist and nonspecialist psychiatric bed utilisation by people with intellectual disabilities and/or autism.; Methods: Using data about specialist psychiatric bed utilisation from the Assuring Transformation Dataset, from March 2015 to January 2024, we applied linear regression (with moving average or autoregressive errors) to explore the relationships between a set of outcome variables (e.g., number of inpatients and length of stay) and a set of sociodemographic, clinical and service-related predictor variables (e.g., age, ethnicity, admission source, legal status, admission source, discharge destination, Care (Education) and Treatment Reviews) over time. Comparisons were made with data from the Mental Health Services Data Set about nonspecialist psychiatric bed utilisation.; Results: Over time, there was an average reduction of 8.07 inpatients per month. This reduction was due to a reduction in the number with a length of stay longer than 2 years, and fewer inpatients with intellectual disabilities without autism over time, rather than fewer autistic inpatients without intellectual disabilities; instead, the number of autistic inpatients increased by 6.02 per month. However, overall, there were fewer inpatients in specialist psychiatric beds than in nonspecialist beds by an average of 877 patients, and the number in specialist beds reduced faster than the number in nonspecialist beds over time. We found that more hospital spells were associated with more inpatients older than 18, more detentions under Part III of the Mental Health Act, more inpatients not known to the local authority, and an increased number of White inpatients. More admissions were associated with fewer discharges, while those with a hospital stay longer than 2 years were less likely to have had a postadmission Care (Education) and Treatment Reviews and were more likely to use advocacy.; Conclusions: The number of inpatients with intellectual disabilities in specialist psychiatric beds continues to decline over time, while the number of autistic inpatients without intellectual disabilities is increasing. Future research should utilise participant-level data to explore patient long-term trajectories. (© 2025 The

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

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17. **Developing a practice template for communicating with families of people with learning disabilities**

Authors: Price, Bob

Publication Date: 2025

Journal: Learning Disability Practice

Abstract: Why you should read this article: • To refresh your knowledge of the importance of effective communication with families of service users • To understand how to develop a practice template for communicating with families of service users • 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). Practice templates are a way to empower nurses by providing guidance on nursing techniques that have proved to be effective in practice. However, there is a paucity of literature on the development of practice templates and, at the time of writing, none relating to learning disability care. This means there is an opportunity for learning disability nurses to draw on their clinical experience of collaborating with clients to develop useful practice templates. This article uses the example of how to communicate with the families of service users with learning disabilities to describe the process of developing a practice template and what nurses can include. The author argues that practice templates can assist nurses to outline care standards and help to develop a rapport between themselves and the families of service users.

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18. **Supporting autistic refugees in the UK using the HOPE(S) model**

Authors: Read, Max and Quinn, Alexis

Publication Date: 2025

Journal: Learning Disability Practice

Abstract: Why you should read this article: • To better understand the adverse conditions that autistic refugees are likely to experience in the UK • To appreciate how solitary confinement exposes autistic refugees to additional trauma or re-traumatisation • To find out how healthcare professionals can use the HOPE(S) model to support autistic refugees. Refugees are likely to have experienced considerable trauma in their life, even more so if they are autistic. The ‘hostile environment’ created in the UK to reduce the number of refugees claiming asylum is likely to have exacerbated the difficulties experienced by refugees, including in terms of access to healthcare services. Refugees detained under the Mental Health Act 1983 may experience restrictive practices and therefore be exposed to additional trauma or re-traumatisation. This article focuses in particular on the harmful effects of solitary confinement on autistic refugees and discusses how healthcare professionals can use the HOPE(S) model to support this population.

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19. **Inclusion of Individuals with Autism and Co-Occurring Intellectual Disability or Language Impairment as Research Participants**

Authors: Reuben, Katherine E.;Arias, Jalayne J.;Self-Brown, Shannon and Vinoski Thomas, Erin

Publication Date: 2025

Journal: Journal of Autism and Developmental Disorders

Abstract: Competing Interests: Declarations. Conflict of Interest: The authors have no conflicts of interest to report for this manuscript.; Autistic individuals with higher support needs, including those with co-occurring intellectual disability (ID) and language impairment (LI), are underrepresented in research. Researchers who attempt to include this population face unique challenges regarding participant recruitment, informed consent, accurate measurement, and protecting privacy and confidentiality. This leads to gaps in understanding as well as a lack of evidence-based support for clinical and public health practice. Careful consideration is needed to ensure that autism research is appropriately inclusive and does not unduly burden vulnerable populations. This commentary uses the Kass framework as an example scaffold for navigating complex ethical challenges and improving accessibility and fairness in autism research. It reviews existing literature on the topic, and the resulting recommendations are informed by autistic individuals with substantial support needs. Increased representation of the full autism spectrum in research is necessary to ensure equitable health outcomes for all autistic individuals. Ethical analysis, guidance from autism research organizations, and recommendations from autistic adults can assist with this process. (© 2025. The Author(s), under exclusive licence to Springer Science+Business Media, LLC, part of Springer Nature.)

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20. **An exploratory analysis of the physical health DIALOG outcome measure within a UK Mental Health and Learning Disability NHS Trust**

Authors: Shah, Chetan;Anstee, Lottie;Kimpton, Ben;Magon, Rakesh;Kelly, Brid and Zia, Asif

Publication Date: 2025

Journal: Mental Health Review Journal

Abstract: Purpose: This study aims to explore and investigate the patient-reported outcome and experience measure (DIALOG) with respect to physical health of service users under the care of a Mental Health and Learning Disabilities National Health Service trust. Design/methodology/approach: Three exploratory statistical analyses (paired samples t-test, a logistic regression on changing from unsatisfied to satisfied and a logistic regression on improving by at least one DIALOG score) were conducted on physical health DIALOG scores (n = 3,077). Findings: The mean score for the DIALOG physical health question increased from 3.28 to 3.43 whilst under the care of secondary care mental health services. Service users living in deprived areas were 35% (OR 0.65, CI 0.45, 0.95]) less likely to be satisfied with their physical health. Service users recorded as long-term sick or disabled were 60% (OR 0.40, CI 0.25, 0.63]) less likely to be satisfied with their physical health. Service users who had not had a physical health assessment were 57% (OR 0.43, CI 0.23, 0.79]) less likely to be satisfied with their physical health. Originality/value: The routine collection of patient-reported outcome measures and patient-reported experience measures in the UK mental health setting is in its infancy with currently little analysis of data taking place; therefore, this exploratory study generates several discussion points.

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21. **Molecular Insights into Neurological Regression with a Focus on Rett Syndrome-A Narrative Review**

Authors: Singh, Jatinder and Santosh, Paramala

Publication Date: 2025

Journal: International Journal of Molecular Sciences

Abstract: Rett syndrome (RTT) is a multisystem neurological disorder. Pathogenic changes in the MECP2 gene that codes for methyl-CpG-binding protein 2 (MeCP2) in RTT lead to a loss of previously established motor and cognitive skills. Unravelling the mechanisms of neurological regression in RTT is complex, due to multiple components of the neural epigenome being affected. Most evidence has primarily focused on deciphering the complexity of transcriptional machinery at the molecular level. Little attention has been paid to how epigenetic changes across the neural epigenome in RTT lead to neurological regression. In this narrative review, we examine how pathogenic changes in MECP2 can disrupt the balance of the RTT neural epigenome and lead to neurological regression. Environmental and genetic factors can disturb the balance of the neural epigenome in RTT, modifying the onset of neurological regression. Methylation changes across the RTT neural epigenome and the consequent genotoxic stress cause neurons to regress into a senescent state. These changes influence the brain as it matures and lead to the emergence of specific symptoms at different developmental periods. Future work could focus on epidrugs or epi-editing approaches that may theoretically help to restore the epigenetic imbalance and thereby minimise the impact of genotoxic stress on the RTT neural epigenome.

22. **The effects of resistance training on health-related physical fitness of people with down syndrome – A systematic review and meta-analysis**

Authors: Stojanović, Stefan;Rančić, Doroteja;Ilić, Tamara;Aleksandrović, Marko;Đorđević, Stefan;Hadžović, Miljan and Jorgić, Bojan

Publication Date: 2025

Journal: Disability & Rehabilitation

Abstract: Purpose: This overview of systematic reviews with meta-analysis aimed to summarize the effects of resistance training (RT) on physical fitness of people with Down syndrom (DS). Material and methods: A comprehensive search was conducted across multiple databases, including PubMed, Google Scholar, Cochrane, MEDLINE, Web of Science, and SPORTDiscus, up until January 30th, 2024. The search included key terms like resistance training, strength training, weight training, intellectual disability, and Down syndrome. The quality of the included studies was assessed using the Cochrane Collaboration assessment tool. Eighteen articles were reviewed, with nine included in the meta-analysis. Results: The results demonstrated that RT interventions positively impacted physical fitness in individuals with DS, with significant improvements in both upper and lower limb strength and cardiorespiratory endurance, as indicated by VO2peak ($p = 0.000$). Eleven studies were classified as high quality with low risk of bias, four had some methodological concerns, and three non-randomized studies exhibited a high risk of bias. Conclusion: RT interventions appear to significantly enhance physical fitness, including muscle strength, functional abilities, cardiorespiratory fitness, and balance, among individuals with DS, regardless of variations in training methods or program designs. IMPLICATION FOR REHABILITATION: People with Down syndrome display lower physical fitness levels and participate in fewer physical activities compared to their typically developing peers. This reduced participation and fitness level contribute to a pattern of heightened sedentary behavior, which is evident across all age groups. Resistance training interventions exhibit the potential to significantly enhance physical fitness, encompassing improvements in body composition, muscle strength, functional abilities, cardiorespiratory fitness, and balance among individuals with down syndrome.

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23. **Acoustics-Derived Home-Based Sleep Study for the Diagnosis of Obstructive Sleep Apnoea in Adults With Intellectual Disabilities: A Feasibility Study**

Authors: Stranks, Lachlan;Abdulsalam, Mohammad;O'Regan, David;Steier, Joerg and Hare, Alanna

Publication Date: 2025

Journal: Journal of Intellectual Disability Research : JIDR

Abstract: Background: Adults with intellectual disabilities (IDs) face significant health inequalities and reduced life expectancy compared to the general population. Sleep disorders, including obstructive sleep apnoea (OSA), are highly prevalent in this population; however, standard diagnostic modalities may be poorly tolerated and many people may remain undiagnosed. The aim of this study was to assess the feasibility of using an acoustic-derived home-based sleep study to diagnose OSA in adults with ID who were unable to tolerate standard inpatient or home sleep studies.; Method: This was a prospective feasibility study (GSTT/2024/15803). Participants were identified from two tertiary outpatient sleep departments in London, UK. Eligible participants were aged ≥ 17 years with a diagnosed ID. Inpatient or existing home studies had not been tolerated or had been declined. Participants wore a small diagnostic sensor, the AcuPebble SA100 (Acurable Ltd., London, UK) for one to two nights in their own home. Baseline symptom screening and quality of life questionnaires were administered. Semiqualitative and qualitative feedback was obtained from participants. The primary outcome was successful completion of testing, defined as ≥ 240 min of recording on at least one night. Quantitative diagnostic parameters were reviewed in a multidisciplinary team (MDT) meeting to formulate a management plan. Data are presented as mean (standard deviation), unless otherwise specified.; Results: Seventeen people were screened, and 10 agreed to participate in the study (3F/7M). Eight participants (80%) successfully completed testing (2F/6M, 4 severe ID, age 29.7 15.4] years, body mass index, BMI 27.1 5.9] kg/m 2 , apnoea hypopnoea index, median AHI 5.5 IQR 7.8] ev/h). Of these, five participants (63%) were found to have OSA. Feedback was favourable with an average total satisfaction score of 14.0 (4.8) out of 20 points.; Conclusion: In a cohort of participants with ID who were unable to tolerate standard sleep diagnostics to assess OSA, an acoustic-derived home-based sleep study may provide a solution to achieve clinically diagnostic recordings. (© 2025 MENCAP and John Wiley & Sons Ltd.)

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24. **More Parents With Intellectual Disabilities than we Thought: A Short Report from England**

Authors: Tarleton, Beth and Burch, Katy

Publication Date: 2025

Journal: Journal of Applied Research in Intellectual Disabilities

Abstract: Background: This paper recognises that there has been a long history of research into support for parents with intellectual disabilities in England and a helpful approach to integrating adults with intellectual disabilities in society called ‘Valuing People’. This focus has now faded. Method: The paper draws together findings from three recent English studies. Results: One third of the cases involving babies in the child protection system involved parents with diagnosed intellectual disability or a borderline or specific learning disability. The other two studies found that general adult social services were not set up to work with these parents, that social workers wanted more or better training and support and there was variable awareness of the Good Practice Guidance document. Conclusions: Parents with intellectual disabilities need to be on this Government's agenda; their need for tailored, on-going support should also be acknowledged.

25. **Virtual Acceptance and Commitment Training to Promote Wellbeing of Staff Supporting Adults With Intellectual Disabilities: A Feasibility Study**

Authors: Thomson, Kendra;Davis, Sarah;Bernier, Sarah Ludmilla;Magnacca, Carly;Noone, teve and Lunsky, Yona

Publication Date: 2025

Journal: Journal of Applied Research in Intellectual Disabilities

Abstract: Background: Staff supporting people with intellectual disabilities may experience work-related stress that adversely impacts their wellbeing and capacity to provide support. Acceptance and Commitment Training interventions like Promotion of Acceptance in Carers and Teachers (PACT) have been shown to be effective for reducing stress and promoting psychological flexibility in direct staff in the United Kingdom. Aims: We evaluated the feasibility of a virtual adaptation of PACT for staff in Canada. Methods: Within a single-arm feasibility trial, we assessed five categories of feasibility: acceptability, demand, implementation, adaptation and limited efficacy testing. Between 2021 and 2023, 149 staff consented to participate and 81 completed all measures. Results: The intervention was a feasible and acceptable method of supporting staff wellbeing with promising outcomes in terms of improved psychological flexibility and decreased stress, anxiety and depression. Discussion/Conclusion:

Future research should explore the benefits of this intervention relative to other staff wellbeing interventions in randomised controlled trials.

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26. **Safer Online Lives: Internet Use and Online Experiences of Adults With Intellectual Disabilities—A Survey Study**

Authors: Triantafyllopoulou, Paraskevi;Newsome, Jessie;Tsang, Winnie;McCarthy, Michelle and Jones, Karen

Publication Date: 2025

Journal: Journal of Applied Research in Intellectual Disabilities

Abstract: Background and Aims: The internet and social media are increasingly accessible to people with intellectual disabilities, offering significant benefits but also posing unique challenges and risks. This study aimed to explore the online experiences of adults with intellectual disabilities in England. Methods: An accessible survey was conducted from July 2021 to July 2022 collecting data on online risks, perceived benefits and barriers to internet use. Results: Amongst 115 participants, 74% reported using the internet daily, and 48% used social media every day. Participants who reported more frequent engagement in cyber-aggression were significantly more likely to also report experiences of cyber-victimisation. Conclusions: The findings highlight the evolving use of the internet for adults with intellectual disabilities and the factors that influence their online experiences. They emphasise the need for strategies to enhance safe internet use and inform social care practices aimed at fostering positive online experiences whilst mitigating risks.

27. **Understanding the current provisions of support for people with an intellectual disabilities and/or autism in crisis: A mixed methods study**

Authors: Tromans, Samuel;Summers, Ian;Abdullah, Shahbaz;Ledger, Joanne;Lennard, Sarah;Bassett, Paul;Colledge, Remie;Bilkey, Danielle;Staples, Chloe;Edwards, Samuel;Carr, Grahame;Laugharne, Richard and Shankar, Rohit

Publication Date: 2025

Journal: International Journal of Social Psychiatry

Abstract: Background: There has been significant reduction in inpatient beds for people with intellectual disability and/or autism (PwID/A) in the UK in the last decade following high profile national scandals in specialist psychiatric hospitals. To reduce inappropriate admissions a new strategy (Blue-Light, an emergency multi-disciplinary meeting to prevent admission to hospital) was introduced. However, there is no research on the influence of Blue-Light on crisis management for PwID/A. Aim: To assess Blue-Light's impact on PwID/A's crisis presentations Methods: Co-produced with experts-by-experience, a mixed methods approach using a 13 question Likert based survey of health and social-care professionals along with semi-structured interviews of carers involved with consecutive Blue-Light patient reviews was undertaken in Cornwall UK (population: 538,000). Patient data was accessed to understand the patient journey. All data analysis was descriptive in nature. Semi-structured interviews were transcribed and thematically analysed using Braun and Clarke's six-step process. Results: Ten patient journeys were examined. Staff interviewed had a good understanding of the Blue-Light process, Blue-Light activation practical challenges and considered Blue-Light reactive. Nearly half wanted ID/A specialist beds recommissioned. A majority wanted improved supervision and standards for third sector providers. Semi-structured interviews of 10 patient-carers identified a lack of consistency from professionals, limited infrastructure provision, the prolongation of crises and a lack of definition of crisis as carers did not feel supported by services. Conclusions: Current crisis support systems are not standardised and often leave carers feeling unsupported in crises. An evidence-based debate of crisis support and the inpatient role for PwID/A is required.

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28. **A conceptual framework for self-advocacy by people with intellectual disabilities**

Authors: Tyabashe-Phume, Babalwa and Kleintjes, Sharon R.

Publication Date: 2025

Journal: African Journal of Disability

Abstract: Competing Interests: The authors reported that they received funding from the National Research Foundation (NRF), the South African Medical Research Council (SAMRC) and the Vera Grover scholarship, which may be affected by the research reported in the enclosed publication. The authors have disclosed those interests fully and have implemented an approved plan for managing any potential conflicts arising from their involvement. The terms of these funding arrangements have been reviewed and approved by the affiliated university in accordance with its policy on objectivity in research.; Background: People with intellectual disabilities are generally not consulted in the development of public policies, which impact their lives, and little is known about how to best empower people with intellectual disabilities to enable them to participate in public policy processes.; Objectives: Our article reports on developing a conceptual framework to support self-advocacy by people with intellectual disabilities in social and health-related policy development in South Africa.; Method: Our qualitative study was conducted using empowerment theory and integrated the concept of Ubuntu as a guide and was underpinned by a phenomenological approach. Data were collected through a scoping review, semi-structured interviews and focus groups. The scoping review was conducted using the Joanna Briggs Institute (JBI) scoping review protocol. Semi-structured interviews and focus groups were analysed using framework analysis. Data sources were triangulated to develop the conceptual framework, using a process adapted from three approaches used to develop similar conceptual frameworks.; Results: Data triangulation identified three core elements for self-advocacy: (1) personal development; (2) creating a supportive environment to facilitate the empowerment of people with intellectual disability; and (3) improved policy participation opportunities.; Conclusion: Participation of people with intellectual disabilities in public policy decisions, which can improve their quality of life, can be supported by developing their capacity for participation and increasing policymakers' understanding as well as facilitation of what is needed to support their participation.; Contribution: Our study offers a framework for a comprehensive approach to supporting people with intellectual disabilities in participating in and influencing public policy processes that impact their lives. (© 2025. The Authors.)

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29. **Hear Our Voice: A Photo-Elicitation Study to Explore the Social Participation of Older People With Mild/Moderate Intellectual Disability**

Authors: Wang, Zuyu;Sommerlad, Andrew;Monin, Joan K.;Hassiotis, Angela and Livingston, Gill

Publication Date: 2025

Journal: Journal of Applied Research in Intellectual Disabilities : JARID

Abstract: Background: People with intellectual disability are more socially isolated than the general population.; Aims: To explore the social participation experiences and enablers and barriers of older people with mild/moderate intellectual disability.; Methods: Following co-production of the research with an advocacy group, we purposively recruited people aged over 50 with mild/moderate intellectual disability, using photo-elicitation methods and qualitative interviews, analysed thematically.; Results: We recruited 14 participants (5 women) from London, UK. Themes were (1) negotiating social belonging in a world of barriers, (2) obstacles go beyond intellectual disability, (3) support must be tailored and personalised. Their experiences of discrimination made them afraid to go out and often to mix with people without disabilities. However, they enjoyed socialising, appreciating variety, social connection and learning.; Conclusion: People with intellectual disability wished to socialise but encountered multiple obstacles. Such barriers limit meaningful community engagement and inclusivity, underscoring the need for interventions to combat isolation. (© 2025 The Author(s). Journal of Applied Research in Intellectual Disabilities published by John Wiley & Sons Ltd.)

30. **Developing the allied health professionals workforce within mental health, learning disability and autism inpatient services: rapid review of learning from quality and safety incidents**

Authors: Wilson, Ceri;Wakefield, Rachel;Prothero, Louise;Janes, Gillian;Nolan, Fiona and Fowler-Davis, Sally

Publication Date: 2025

Journal: BMJ Quality & Safety

Abstract: Background Allied health professionals (AHPs) in inpatient mental health, learning disability and autism services work in cultures dominated by other professions who often poorly understand their roles. Furthermore, identified learning from safety incidents often lacks focus on AHPs and research is needed to understand how AHPs contribute to safe care in these services. Methods A rapid literature review was conducted on material published from February 2014 to February 2024, reporting safety incidents within adult inpatient mental health, learning disability and autism services in England, with identifiable learning for AHPs. 115 reports/ publications were included, predominantly consisting of independent investigations by NHS England, prevent future deaths reports and Care Quality Commission reports. Findings Misunderstanding of AHP roles, from senior leadership to frontline staff, led to AHPs being disempowered and excluded from conversations/ decisions, and patients not getting sufficient access to AHPs, contributing to safety incidents. A central thread 'organisational culture' ran through five subthemes: (1) (lack of) effective multidisciplinary team (MDT) working, evidenced by poor communication, siloed working, marginalisation of AHPs and a lack of psychological safety; (2) (lack of) AHP involvement in patient care including care and discharge planning, and risk assessment/management. Some MDTs had no AHPs, some recommendations by AHPs were not actioned and referrals to AHPs were not always made when indicated; (3) training needs were identified for AHPs and other professions; (4) staffing issues included understaffing of AHPs and (5) senior management and leadership were found to not value/understand AHP roles, and instil a blame culture. A need for cohesive, well-led and nurturing MDTs was emphasised. Conclusion Understanding and recognition of AHP roles is lacking at all levels of healthcare organisations. AHPs can be marginalised in MDTs, presenting risks to patients and missed opportunities for quality improvement. Raising awareness of the essential roles of AHPs is critical for improving quality and safety in inpatient mental health, learning disability and autism services.

Sources Used:

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

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interpretation or application of these results, which are not intended to provide advice or recommendations on patient care.