

Learning Disabilities

Current Awareness Bulletin

March 2024

Our Current Awareness Bulletins provide details of recently published articles in a given subject. They are a quick and easy way to keep up to date.

Please contact the Academy Library to request any articles:

 ruh-tr.library@nhs.net

 01225 82 4897/4898



Carry out basic searches using the Knowledge and Library Hub.



Sign up to NHS OpenAthens to access our subscriptions.



Contact us to receive our bulletins via email each month.



Get personalised alerts via our KnowledgeShare service.

ruh.nhs.uk/library

1. Exploring the Surge in Paediatric Type 2 Diabetes in an Inner-City London Centre—A Decade-Long Analysis of Incidence, Outcomes, and Transition

Authors: Abdelhameed, Farah;Giuffrida, Anna;Thorp, Ben;Moorthy, Myuri K. and Gevers, Evelien F.

Publication Date: 2024

Journal: Children 11(2), pp. 173

Abstract: The rising prevalence of paediatric type 2 diabetes (T2D) is concerning, particularly with limited medical intervention despite evidence of accelerated disease progression. This study of a Barts Health NHS Trust cohort from 2008 to 2022 aims to elucidate the incidence, clinical outcomes, and complications associated with paediatric T2D. A retrospective analysis utilising electronic and paper records identified 40 patients with T2D. The incidence doubled from 2.6/year in 2008–2013 to 5.4/year in 2014–2018. Sixty-eight percent exhibited co-morbidities, notably learning disabilities. At diagnosis, the mean BMI was 32.4 ± 6.71 kg/m², with no gender-based disparity and no significant change over a two-year follow-up. The initial HbA1c was 75.2 ± 21.0 mmol/mol, decreasing to 55.0 ± 17.4 mmol/mol after three months ($p = 0.001$) and then rising to 63.0 ± 25.5 mmol/mol at one year ($p = 0.07$). While 22/37 patients achieved HbA1c < 48 mmol/mol, only 9 maintained this for a year. Several metabolic and cardiovascular complications were observed at diagnosis and follow-up, with no significant change in frequency. In 2022, 15 patients transitioned to adult services. HbA1c at transition was 74.7 ± 27.6 mmol/mol, showing no change one year post-transition (71.9 ± 26.9 mmol/mol, $p = 0.34$). This study highlights substantial therapeutic failure, with current management falling short in achieving a sustained reduction in BMI or HbA1c. Novel treatment approaches are needed to improve clinical outcomes and address the high burden of co-morbidities and complications.

2. Psychotic illness in people with Prader-Willi syndrome: a systematic review of clinical presentation, course and phenomenology

Authors: Aman, Lucie C. S.;Lester, Suzannah D.;Holland, Anthony J. and Fletcher, Paul C.

Publication Date: 2024

Journal: Orphanet Journal of Rare Diseases 19(1), pp. 69

Abstract: Background: Prader-Willi syndrome (PWS) is a rare and complex neurodevelopmental disorder resulting from absent paternal expression of maternally imprinted genes at chromosomal locus 15q11-13. This absence of expression occurs as a consequence of a deletion on the chromosome 15 of paternal origin (ca. 70%), a chromosome 15 maternal uniparental disomy (mUPD; ca. 25%), or an imprinting centre defect (IC; ca. 1-3%). At birth, individuals with PWS are severely hypotonic and fail to thrive. Hyperphagia and characteristic physical and neuropsychiatric phenotypes become apparent during childhood. The risk for the development of a co-morbid psychotic illness increases during the teenage years, specifically in those with PWS due to the presence of an mUPD. The primary aim of this literature review is to inform clinical practice. To achieve this, we have undertaken a systematic analysis of the clinical research literature on prevalence, presentation, course, characteristics, diagnosis and treatment of psychotic illness in people with PWS. The secondary aim is to identify clinical aspects of psychotic illness in PWS in need of further investigation.; Methods and Findings: A systematic literature review on psychosis in PWS was conducted on the databases Web of Knowledge, PubMed and Scopus, using the terms "((Prader-Willi syndrome) OR (Prader Willi Syndrome)) AND ((psychosis) OR (psychotic illness))". All articles written in English and reporting original human research were reviewed. In all but three of the 16 cohort studies in which the genetic types were known, the authors reported higher rates of psychosis in people with PWS resulting from an mUPD, compared to those with the deletion subtype of PWS. When psychosis was present the presentation was psychosis similar regardless of genetic type and was usually characterised by an acute onset of hallucinations and delusions accompanied by confusion, anxiety and motor symptoms.; Conclusions: The onset of confusion, an affective cyclical pattern with the presence of abnormal mental beliefs and experiences, usually of rapid onset is suggestive of the development of psychotic illness.

Phenomenologically, this psychosis in people with PWS is atypical in comparison to schizophrenia and bipolar disorder in the general population. The relationship to psychosis in the general population and the optimum treatments remain uncertain. (© 2024. The Author(s).)

3. Providing effective care and support for autistic adults with mental health issues

Authors: Barber, Christopher Francis

Publication Date: 2024

Journal: Nursing Standard 39(1), pp. 60-65

Abstract: Why you should read this article: • To enhance your knowledge of co-occurring mental health issues and autism • To recognise the challenges that autistic adults may experience in receiving appropriate care • To understand the role of the nurse in supporting autistic people with mental health issues Autism is a neurodevelopmental condition that is characterised by features such as persistent differences in social interaction and communication, specialised interests and sensory processing issues. It has been identified that autistic people are increasingly likely to experience various mental health issues, and often encounter challenges in accessing appropriate healthcare and a lack of understanding from healthcare professionals. This article explores the co-occurrence of autism and mental health issues in adults, and explains the role of nurses in providing care and support for this population.

4. Dynamic gait stability in children with and without Down syndrome during overground walking

Authors: Beerse, Matthew;Alam, Tasnuva and Wu, Jianhua

Publication Date: 2024

Journal: Clinical Biomechanics 111, pp. N.PAG

Abstract: Challenging children with Down syndrome to walk fast and with external ankle load has demonstrated acute adjustments, such as increased step length and decreased step width, and improved joint stability. However, it is unknown to what extent these task constraints affect gait stability. Assessing dynamic gait stability through margin-of-stability not only quantifies adjustments related to balance control, but also informs safety considerations. Twenty-four children with and without Down syndrome participated in this study. Subjects walked overground at two speed conditions: self-selected (normal) and as fast as possible (fast); and two ankle load conditions: no load and ankle load of 2% body mass. We assessed margin-of-stability in the anteroposterior and mediolateral directions, separately, at three gait events of toe-off, mid-swing, and heel strike. Children with Down syndrome walked with greater mediolateral margin-of-stability than typically developing children. Children with Down syndrome demonstrated less anteroposterior margin-of-stability than typically developing children only before heel-strike at normal speed but increased anteroposterior margin-of-stability at fast speed. The ankle load increased the mediolateral margin-of-stability in both groups but did not impact the anteroposterior margin-of-stability. In addition, children with Down syndrome took shorter and wider steps for more lateral placement of mediolateral margin-of-stability. Children with Down syndrome were capable of adjusting their margin-of-stability for fast walking and ankle-load conditions. However, children with Down syndrome walked with less mediolateral stability and anteroposterior mobility than typically developing children. Children with Down syndrome overcompensate the mediolateral foot placement to recapture their margin-of-stability and maintain gait stability. • Children with Down syndrome walked with a distinct joint pattern compared to peers. • Increased walking speed improved ankle kinematics, but challenged knee kinematics. • Ankle load improved hip and knee kinematics, but challenged ankle plantarflexion. • Intervention design can consider the manipulation of walking speed and ankle load.

5. The oral health of adults with learning disabilities: A secondary analysis of the Adult Dental Health Survey 2009

Authors: Bird, J.; Marshman, Z.; Jones, K. and Baker, S. R.

Publication Date: 2024

Journal: Community Dental Health

Abstract: Objectives: Adults who have learning disabilities are a vulnerable group, little is known about their oral health and how this affects their quality of life. The aims of this secondary analysis of data from the 2009 Adult Dental Health Survey (ADHS) were to describe the oral health status of adults with learning disabilities, determine if severity of learning disability is associated with oral health and identify some of the methodological complexities of working with this population. The survey yields the most recent representative data on the oral health of adults with learning disabilities in England and importantly, contains information about oral health related quality of life (OHRQoL).; Basic Research Design: Secondary analysis of data from a supplemental survey of adults with learning disabilities collected alongside the 2009 ADHS.; Participants: 607 participants with a diagnosed learning disability aged 18 years and over.; Results: Adults with learning disabilities had similar levels of active dental caries, fewer natural teeth, and fewer fillings than comparable participants from the general population. Self-reported oral and general health were worse for adults with learning disabilities than the general population. Possible associations between the severity of learning disability and the numbers of decayed, missing or filled teeth were identified. However, large amounts of missing data limited the analysis.; Conclusions: There are important questions relating to the accessibility of existing self-reported oral health questionnaires and the reliability of proxy-reported questions about OHRQoL that should be addressed to give a fuller picture of the oral health of adults with learning disabilities. (Copyright© 2024 Dennis Barber Ltd.)

6. The inclusion of adults with intellectual disabilities in health research – challenges, barriers and opportunities: a mixed-method study among stakeholders in England

Authors: Bishop, R.; Laugharne, R.; Shaw, N.; Russell, A. M.; Goodley, D.; Banerjee, S.; Clack, E. and Shankar, R.

Publication Date: 2024

Journal: Journal of Intellectual Disability Research 68(2), pp. 140-149

Abstract: Background: The study aims to understand system barriers to research participation for people with intellectual disabilities. Methods: A mixed-methods approach examined the inclusivity of people with intellectual disabilities (IDs) in a random sample of National Institute for Health and Care Research (NIHR) studies conducted in 2019–2020. An online questionnaire (stage 1) was sent to the selected studies lead investigators. An expert by experience panel of 25 people with intellectual disabilities (IDs, stage 2), discussed the stage 1 feedback. Descriptive statistics for quantitative data and thematic analysis for qualitative data was conducted. Results: Of 180 studies reviewed, 131 studies (78%) excluded people with IDs. Of these, 45 (34.3%) study researchers provided feedback. Seven (20%) of the 34 studies which included people with IDs gave feedback. Of all respondents over half felt their study had some relevance to people with IDs. A minority (7.6%) stated their study had no relevance. For a quarter of respondents (23.5%), resource issues were a challenge. Qualitative analysis of both stages produced four overarching themes of Research design and delivery, Informed consent, Resource allocation, and Knowledge and skills. Conclusion: Health research continues to exclude people with IDs. Researchers and experts by experience identified non-accessible research design, lack of confidence with capacity and consent processes, limited resources such as time and a need for training as barriers. Ethics committees appear reluctant to include people with cognitive deficits to 'protect' them. People with IDs want to be included in research, not only as participants but also through coproduction.

7. Beyond Silence: A Scoping Review of Provided Support for Grieving Children With Intellectual Disabilities or Autism Spectrum Disorder

Authors: Bonin, Maria;Augustine, Lilly and Meng, Qi

Publication Date: 2024

Journal: Omega , pp. 302228231226343

Abstract: Children with intellectual disabilities (ID) or autism spectrum disorder (ASD) are considered unable to grieve or understand the concept of death and might not receive grief support after the death of a beloved person; hence, they are at risk of developing complicated grief. This scoping review identified existing grief support for children with ID or ASD. Searching seven databases yielded 514 records; six studies met the predefined inclusion criteria. The six studies identified grief support, including discussions, participation in death rituals, family support, stories, and professional interventions. The support could be organized into three levels, micro, meso, and exo, overlooking the macro level completely, indicating that grief support for these children tends to be irregular and inconsistent.; Competing Interests: Declaration of Conflicting InterestsThe author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

8. How to support an adult with a learning disability to undergo an electrocardiogram

Authors: Brown, Michael and McKenna, Niall

Publication Date: 2024

Journal: Learning Disability Practice 27(1), pp. 22-25

Abstract: Why you should read this article: • To enhance your ability to support an adult with a learning disability to undergo an electrocardiogram (ECG) • To recognise the importance of comprehensive preparation to ensure the procedure is successful • To be aware of the various clinical reasons why an adult with a learning disability may require an ECG. Rationale and key points: An electrocardiogram (ECG) is a routine clinical investigation undertaken to diagnose and monitor heart conditions. ECGs are needed for the identification and ongoing management of a range of health issues commonly experienced by people with learning disabilities. Additionally, some people with learning disabilities will have been prescribed antipsychotics and will therefore require cardiac monitoring. People with learning disabilities may require additional support before, during and after undergoing an ECG. This article explains how to support an adult with a learning disability to undergo an ECG. • The individual needs of the person should be investigated and reasonable adjustments put in place ahead of the procedure. • Working with the person, their relative or carer and the clinician conducting the ECG increases the chances of a successful procedure. • The ECG results should be shared with the person in a way that involves them in decision-making about their care. Reflective activity: 'How to' articles can help you to update your practice and ensure it remains evidence-based. Apply this article to your practice. Reflect on, and write a short account of: • How this article might improve your practice when supporting an adult with a learning disability to undergo an ECG. • How you could use this information to educate nursing students or colleagues on the appropriate steps to follow when supporting an adult with a learning disability to undergo an ECG and the relevant evidence base.

9. The physician's role in reducing health disparities for persons with epilepsy and intellectual disability: "it's not just epilepsy...you really have to take a deeper dive."

Authors: Casey, Emma and Linehan, Christine

Publication Date: 2024

Journal: Epilepsy & Behavior : E&B 151, pp. 109646

Abstract: Epilepsy affects approximately 25 % of people with intellectual disability (ID). Despite this high prevalence, evidence of health disparity exists in healthcare access and health outcomes for this population. Patients with ID experience additional challenges in accessing appropriate epilepsy care, and are at greater risk of experiencing inappropriate prescribing, polypharmacy and misdiagnosis compared with the general population. The expectations, attitudes and actions of physicians are key in addressing health inequalities, particularly those which disproportionately impact a specific group of patients, such as patients with ID and epilepsy. This qualitative study aimed to explore the views of specialist physicians as to why they believe this patient group are at a disadvantage when it comes to accessing appropriate epilepsy care, and how physicians can intervene to ensure that patients with ID are given equal access to suitable epilepsy care, and equal opportunity to achieve the best possible treatment outcomes. Semi-structured interviews were carried out with six physicians, located in six countries, who specialise in the care of persons with ID who have epilepsy. Interviews sought views on prognostic expectations, experiences of disparities in epilepsy care, and suggestions for advocacy interventions. Interviews were analysed using reflexive thematic analysis. Three core themes and nine subthemes were identified. Core themes included (1) 'Nervousness in care and treatment,' which reflected participants' descriptions of a nervousness by colleagues when treating epilepsy in patients with ID. (2) 'Taking a deeper dive' captured the harmful effects of accepting "common dogma," as well as the issue of a lack of clarity around treatment pathways for patients with epilepsy and ID. (3) 'Teach me' illustrated the importance of shared expertise, reflective practice and continued research and advocacy. Findings reflected participants' recommendations to address disparities in epilepsy care for patients with ID. These recommendations highlighted education and training, taking time to learn how to communicate in different ways, and regular reflection on personal assumptions and biases as important contributors to addressing inequalities in epilepsy care for patients with ID. It is hoped that findings will prompt those providing epilepsy care to reflect on their own practice and identify ways in which they might intervene to minimise inadvertent harm and reduce health disparities in epilepsy care for patients with ID.; Competing Interests: Declaration of competing interest The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper. (Copyright © 2024 Elsevier Inc. All rights reserved.)

10. Posterior Hypothalamic Region Deep Brain Stimulation for the Treatment of Aggression Disorders in Patients with Intellectual Disability: A Systematic Review

Authors: Cojazzi, Vittoria;Innocenti, Niccolò;Castelli, Nicolò;Levi, Vincenzo;Nazzi, Vittoria;Lozano, Andres and Rizzi, Michele

Publication Date: 2024

Journal: Stereotactic and Functional Neurosurgery , pp. 1-9

Abstract: Introduction: Aggressive disorders, in patients with intellectual disability, are satisfactorily managed with an educational, psychological, and pharmacological approach. Posterior hypothalamic region deep brain stimulation emerged in the last two decades as a promising treatment for patients with severe aggressive disorders. However, limited experiences are reported in the literature.; Methods: A systematic review was performed following PRISMA guidelines and recommendations by querying PubMed and Embase on August 24th, 2022, with the ensuing string parameters: (deep brain stimulation] OR DBS]) AND (aggressiv*] OR disruptive). Cochrane Library, DynaMed, and ClinicalTrials.gov were consulted using the combination of keywords "deep brain stimulation" and "aggressive" or "aggression". The clinical outcome at the last follow-up and the rate of complications were considered primary and secondary outcomes of interest.; Results: The initial search identified 1,080 records, but only 10 studies met the inclusion criteria and were considered. The analysis of clinical outcome and complications was therefore performed on a total of 60 patients. Quality of all selected studies was classified as high, but one. Mean Overt Aggression Scale (OAS) improvement was 68%, while Inventory for Client Agency Planning (ICAP) improvement ranged between 38.3% and 80%. Complications occurred in 4 patients (6.7%).; Conclusion: Posterior hypothalamic region deep brain stimulation may be considered a valuable option for patients with severe aggression disorders and ID. This review can represent a mainstay for those who will be engaged in the surgical treatment of these patients. (© 2024 S. Karger AG, Basel.)

11. Associations Among Sex, Cognitive Ability, and Autism Symptoms in Individuals with Down Syndrome

Authors: del Hoyo Soriano, Laura;Sterling, Audra;Edgin, Jamie;Hamilton, Debra R.;Berry-Kravis, Elizabeth;Dimachkie Nunnally, Amanda;Thurman, Angela John and Abbeduto, Leonard

Publication Date: 2024

Journal: Journal of Autism & Developmental Disorders 54(1), pp. 301-311

Abstract: This study explores sex-differences in (a) rates and profiles of autism symptoms as well as in (b) the contribution of intellectual quotient (IQ) to autism symptom presentation in Down syndrome (DS). Participants were 40 males and 38 females with DS, aged 6 to 23 years. Autism symptoms were rated through the Autism Diagnostic Observation Schedule-Second Edition (ADOS-2). Results show no sex differences in the ADOS-2 Calibrated Severity Scores (CSS). However, only females with DS who are classified as DS-Only have higher scores on verbal IQ than those classified as DS + autism. Furthermore, associations between IQ and all CSSs are found for females, but not for males. Findings suggest that verbal cognition may play differential roles for females and males with DS.

12. It is up to healthcare professionals to talk to us in a way that we can understand: informed consent processes in people with an intellectual disability

Authors: Ding, Jonathon;Keagan-Bull, Richard and Tuffrey-Wijne, Irene

Publication Date: 2024

Journal: BMJ Quality & Safety

Abstract: Competing Interests: Competing interests: None declared.

13. Longitudinal Associations Between Relationship Quality and Depression Among Youth with Intellectual Disabilities: A Latent Change Perspective

Authors: Dubé, Céleste;Morin, Alexandre J. S.;Olivier, Elizabeth;Tóth-Király, István;Tracey, Danielle;Craven, Rhonda G. and Maïano, Christophe

Publication Date: 2024

Journal: Journal of Autism & Developmental Disorders 54(2), pp. 673-690

Abstract: This study investigates associations between initial levels and change in the quality of the relationships youth with intellectual disabilities (ID) share with their parents and teachers, and changes in their levels of depression over time. A sample of 395 youth with mild (48.3%) and moderate (51.7%) ID, aged between 11 and 22 ($M = 15.69$), were recruited in Canada ($n = 142$) and Australia ($n = 253$). Youth completed self-report measures of relationship quality and depression twice over a one-year period. Initial levels of warmth ($\beta = -.109$) and conflict ($\beta = -.302$) predicted decreases in depression. Increases in warmth predicted decreases in depression ($\beta = -.179$), while increases in conflict predicted increases in depression ($\beta = .268$). Discrepancies between youth relationships with their parents and teachers predicted decreases in depression ($\beta_{\text{warmth}} = -.732$; $\beta_{\text{conflict}} = -.608$).

14. Ensuring effective communication when undertaking a systematic health assessment

Authors: Fleming, Sandra;Burke, Éilish;Doyle, Carmel;Henderson, Karen;Horan, Paul;Byrne, Kathleen and Keenan, Paul

Publication Date: 2024

Journal: Learning Disability Practice 27(1), pp. 34-42

Abstract: Why you should read this article: • To understand the importance of the early recognition of health issues in people with learning disabilities • To enhance your knowledge of the range of communication skills nurses may use to engage service users in a systematic health assessment • 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). An important element of the role of the learning disability nurse is to support service users to maintain their health, particularly in relation to the early detection of health issues and timely access to appropriate treatments. One way of achieving this is by undertaking a systematic health assessment, of which effective communication is a central component in terms of identifying the person's communication needs and using appropriate communication methods to meet those needs. Effective communication can engage the person in the assessment process as well as identifying their own experience of their health. This article explains the importance of using a systematic approach to health assessment and describes various elements of communication involved in this process. The authors include a fictional case study to outline how a systematic health assessment works in practice and the range of communication skills nurses may use to engage service users in the process.

15. Enhancing the nursing profession's awareness of neurodiversity

Authors: Frawley, Timmy;Gavin, Blánaid;Valeur, Charlotte and Morin, Karen

Publication Date: 2024

Journal: Journal of Clinical Nursing (John Wiley & Sons, Inc.) 33(2), pp. 419-421

16. Differentiation of the body build and posture in the population of people with intellectual disabilities and Down Syndrome: a systematic review

Authors: Gawęł, Eliza;Celebańska, Diana and Zwierzchowska, Anna

Publication Date: 2024

Journal: BMC Public Health 24(1), pp. 406

Abstract: Background: The aim of the study was to identify the variables of the internal compensatory mechanisms that differentiate the body build and posture of people with Down syndrome (DS) from the intellectual disability (ID) population. It was assumed that gaining knowledge in the abovementioned aspect will allow for a better understanding of the limitation of the kinesthetic abilities of people with ID and DS and simultaneously enable to optimize the process of planning and interventions to improve physical activity in this population with the adequate use of their strengths in the biomechanical and morphofunctional systems.; Methods: The methodology of this systematic review was developed according to the PRISMA guidelines. A search of PubMed, EBSCO, Scopus databases was conducted to identify all studies on DS/ID and the body build and posture from 2003 to 2023.; Results: 395 articles were assessed to determine eligibility, while 22 studies met the inclusion criteria and were subjected to detailed analysis and assessment of their methodological quality. The differentiation of the body build and posture in DS population can be induced by both internal and external compensatory mechanisms. It is difficult to confirm the direct effect of the intrinsic variables that impact the body build and posture in the ID population, excluding people with DS.; Conclusions: Compared to other ID, the intrinsic differences in the body build and posture in DS individuals were induced by gender, age, and level of ID. The tendency for diversity between DS and other ID populations in body build and posture may be determined by the presence of the third copy of chromosome 21 in DS group. Internal compensatory processes may be induced mainly by abnormalities in the structure of the cervical vertebrae and feet. IQ should not be used as the only variable that identifies the population of people with ID.

17. Recurrent Respiratory Infections in Children with Down Syndrome: A Review

Authors: Ghezzi, Michele;Garancini, Nicolò;De Santis, Raffaella;Gianolio, Laura;Zirpoli, Salvatore;Mandelli, Anna;Farolfi, Andrea;D'Auria, Enza and Zuccotti, Gian Vincenzo

Publication Date: 2024

Journal: Children 11(2), pp. 246

Abstract: Down Syndrome (DS) is the most common chromosomal abnormality compatible with life. The life of patients suffering from DS can be strongly impacted by Recurrent Respiratory tract Infections (RRIs), leading to an increased rate of hospitalisation, a higher need for intensive care and fatality. With a literature review, we summarise here the main etiological factors for RRI in this category of patients, particularly focusing on airway malformations such as tracheomalacia, tracheal bronchus and bronchomalacia, comorbidities associated with the syndrome, like congenital heart diseases, dysphagia, gastroesophageal reflux, musculoskeletal involvement and obesity, and immunologic impairments, involving both innate and adaptive immunity. For these patients, a multidisciplinary approach is imperative as well as some preventive strategies, in particular vaccinations in accordance with their national schedule for immunization.

18. 'Why are we stuck in hospital?' Barriers to people with learning disabilities/autistic people leaving 'long-stay' hospital: a mixed methods study

Authors: Glasby, Jon;Miller, Robin;Glasby, Anne-Marie;Ince, Rebecca and Konteh, Frederick

Publication Date: 2024

Journal: Health and Social Care Delivery Research 12(3), pp. 1-119

Abstract: Background: Transforming care so that people with learning disabilities and/or autistic people can receive support at home rather than in hospital settings is a key priority, but progress has been slow. Despite significant national debate, little previous research has engaged directly with people in hospital, their families or front-line staff to understand the issues from their perspectives.; Objectives: This research seeks to better understand the experiences of people with learning disabilities and/or autistic people in long-stay hospital settings, their families and front-line staff - using this knowledge to create practice guides and training materials to support new understandings and ways of working.; Design: Following a structured review of the literature, we sought to work with up to 10 people with learning disabilities and/or autistic people in three case-study sites (2021-22), supplementing this with interviews with family members and commissioners; interviews/focus groups with hospital staff, social workers, advocates and care providers; information from case files; and observations of multidisciplinary meetings.; Setting: Three 'long-stay' hospital settings in England.; Participants: Twenty-seven people in hospital, together with families, health and social care staff and commissioners.; Results: • People in hospital report widespread frustration, feel that hospital environments are not conducive to getting/staying well, and face multiple barriers to leaving hospital. Without someone to fight for them, people struggle to overcome the inertia built into our current systems and processes. • Front-line staff are equally frustrated and describe a complex and seemingly dysfunctional system which they find almost impossible to navigate. • Hospital staff from different professional backgrounds do not have a shared sense of how many people really need to be in hospital or how many people could be cared for in different settings - suggesting that different definitions, world views and professional judgements might be at play. • Hospital staff are frustrated about what they see as the difficulty of discharging people into community services, while community services are equally frustrated about what they see as a risk-averse approach which they feel can lack an up-to-date knowledge of what is possible to achieve in the community. • Despite over a decade of policy attempts to resolve these issues, very significant barriers remain.; Limitations: This research explored the experiences of a small number of people, but has done so in significant depth. The research was undertaken in secure settings, during COVID and in a difficult external policy and practice context, and so has had to be very flexible and empathetic in order to build relationships and make the research

possible. Future research could helpfully consider the needs of people from black and minority ethnic communities, the extent to which the experiences of people on forensic pathways are similar to/different from other people's experiences (including perspectives from the criminal justice system), and what happens to people in the long term after they leave hospital.; Conclusions: Working to make the voices of people with learning disabilities and/or autistic people (as well as the staff who support them) centre stage is complex and sensitive. However, this lived experience/practice knowledge is a crucial resource if we are going to develop better policy and practice solutions in the longer term.; Study Registration: This study is registered at www.researchregistry.com (researchregistry6124).; Funding: This award was funded by the National Institute for Health and Care Research (NIHR) Health and Social Care Delivery Research programme (NIHR award ref: NIHR130298) and is published in full in Health and Social Care Delivery Research ; Vol. 12, No. 3. See the NIHR Funding and Awards website for further award information.

19. Factors influencing communication partners of persons with severe/profound intellectual disability use of augmentative and alternative communication: an integrative review

Authors: Hanley, Edina;Lehane, Elaine;Martin, Anne-Marie and Dalton, Caroline

Publication Date: 2024

Journal: Disability and Rehabilitation.Assistive Technology , pp. 1-17

Abstract: Purpose: To present a synthesis of evidence related to the factors influencing communication partners' use of augmentative and alternative communication with persons with severe/profound intellectual disability.; Materials and Methods: An integrative review guided by five steps; problem identification, literature search, data evaluation, data analysis and presentation was undertaken. In accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses statement, nine databases were searched, 1,342 studies were screened against the eligibility criteria, and 15 studies underwent thematic analysis.; Results: Two themes emerged; (1) Achieving Meaningful Communication and (2) Communication Partners' Preparedness to Use Augmentative and Alternative Communication. Achieving meaningful communication was central to communication partners' use of augmentative and alternative communication and was two-fold. It involved identifying the persons' communication methods and encouraging them to communicate. Communication partners' preparedness also influenced their use of augmentative and alternative communication. This preparedness was impacted by communication partners' preconceived thoughts about and knowledge of augmentative and alternative communication, nurturing their belief in augmentative and alternative communication, and the interpersonal dynamic between network members.; Conclusion: Communication partners' use of augmentative and alternative communication is influenced by multiple and complex factors. The findings contribute to the knowledge of the potential factors to be considered to prepare communication partners to use augmentative and alternative communication.

20. The experiences of caring for someone with dementia and a learning disability: A qualitative systematic review

Authors: Hughes, Michelle;Hanna, Kerry;Wiles, Akpewwohene;Taylor, Ellie and Giebel, Clarissa

Publication Date: 2024

Journal: Dementia (London, England) , pp. 14713012231225797

Abstract: Background: The life expectancy of people with a learning disability is increasing and with this comes a greater risk of developing dementia. Dementia poses new challenges for both family and formal learning disability carers as they try to support dementia's progressive nature and quality of life for their care recipient. This qualitative systematic review explores the evidence base of family and formal carers' experiences and needs of caring for someone with both a learning disability and dementia.; Methods: Six electronic databases (PubMed, PsycINFO, Cochrane Library, Prospero,

Scopus, CINAHL), were searched in May 2022, utilising a predefined search strategy. Thirteen papers fulfilled inclusion criteria and were included in the review.; Results: Thematic synthesis was used to explore and synthesise the qualitative findings of the studies. Four conceptual themes were identified following analysis: Knowledge and skills, Accessing support, Repercussions of dementia for carers, Influences of continuity of caring role .; Conclusion: There are significant training and educational needs for all carers who support the dual diagnosis of dementia and learning disability. Differences between family and formal carers relate to the organisational support and process available to formal carers. Parity across services combined with sufficiently trained carers may support dementia diagnosis and improve quality of care provided. Further research is needed to address environmental, and economic barriers carers face to facilitate ageing in place for their care recipients.; Competing Interests: Declaration of conflicting interestsThe author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

21. Latent Class Analysis Identifies Distinctive Behavioral Subtypes in Children with Fragile X Syndrome

Authors: Kaufmann, Walter E.; Raspa, Melissa; Bann, Carla M.; Gable, Julia M.; Harris, Holly K.; Budimirovic, Dejan B.; Lozano, Reymundo; Berry-Kravis, Elizabeth; Velinov, Milen; Talboy, Amy L.; Sherman, Stephanie L.; Kaufmann, Walter E.; Schuster, Marcy; Tartaglia, Nicole; Filipink, Robyn A.; Budimirovic, Dejan B.; Barbouth, Deborah; Lightbody, Amy; Reiss, Allan and Delahunty, Carol M.

Publication Date: 2024

Journal: Journal of Autism & Developmental Disorders 54(2), pp. 725-737

Abstract: Fragile X syndrome (FXS) is characterized by variable neurobehavioral abnormalities, which leads to difficulties in developing and evaluating treatments and in determining accurate prognosis. We employed a pediatric cross-sectional sample (1,072 males, 338 females) from FORWARD, a clinic-based natural history study, to identify behavioral subtypes by latent class analysis. Input included co-occurring behavioral conditions, sleep and sensory problems, autistic behavior scales (SCQ, SRS-2), and the Aberrant Behavior Checklist revised for FXS (ABCFX). A 5-class solution yielded the most clinically meaningful, pharmacotherapy independent behavioral groups with distinctive SCQ, SRS-2, and ABCFX profiles, and adequate non-overlap ($\geq 71\%$): "Mild" (31%), "Moderate without Social Impairment" (32%), "Moderate with Social Impairment" (7%), "Moderate with Disruptive Behavior" (20%), and "Severe" (9%). Our findings support FXS subtyping, for improving clinical management and therapeutic development.

22. Differences in Telemedicine Use Between People With and Without an Intellectual or Other Developmental Disability During the COVID-19 Pandemic

Authors: Kim, Jaewhan; Roy, Indrakshi; Sanchez, Joseph; Weir, Peter; Nelson, Richard and Jones, Kyle

Publication Date: 2024

Journal: Inquiry (00469580) , pp. 1-7

Abstract: Telemedicine utilization of people with an Intellectual or Other Developmental Disability (IDD) during the COVID-19 Pandemic is not well known. This study compares telemedicine utilization of those with and without IDD prior to the pandemic to after it began. Using the Utah All Payers Claims Database from 2019 to 2021, the study identified telemedicine utilization of adults aged 18 to 62 years old in 2019. Propensity score matching was used to minimize observed confounders of subjects with and without IDD in 2019. Negative binomial regression was used to identify factors that were associated with telemedicine utilization. The final number of subjects in the analysis was 18 204 (IDD: n = 6068, non-IDD: n = 12 136 based on 1:2 propensity score matching). The average (SD) age of the subjects was 31 (11.3) years old in 2019. Forty percent of the subjects were female, about 70% of subjects were covered by Medicaid in 2019. Average (SD) number of telemedicine use in 2020 (IDD:

1.96 (5.97), non-IDD: 1.18 (4.90); $P < .01$) and 2021 (IDD: 2.24 (6.78) vs 1.37 (5.13); $P < .01$) were higher for the IDD group than the non-IDD group. The regression results showed that the subjects with IDD had 56% more telemedicine encounters than those in the non-IDD group (Incidence Rate Ratio (IRR) = 1.56, $P < .01$). The growth of telemedicine during the COVID-19 pandemic has the potential to reduce persistent healthcare disparities in individuals with IDD. However, quality of telemedicine should be considered when it is provided to improve health of subjects with IDD.

23. Health inequalities for people with learning disabilities: why it matters and what emergency physicians need to know

Authors: Lee, Andrew Ck;Herrieven, Elizabeth and Harrower, Neil A.

Publication Date: 2024

Journal: British Journal of Hospital Medicine (London, England : 2005) 85(2), pp. 1-7

Abstract: People with learning disabilities die on average 16 years earlier than the general population in England. They are a vulnerable group and may have unhealthy lifestyles and multimorbidity that lead to poor health outcomes. Worryingly, premature deaths are also more common and these often have contributory healthcare causes. This may be a result of staff lacking awareness, expertise and experience managing people with learning disabilities, the lack of reasonable adjustments, or discriminatory attitudes. Other issues include polypharmacy and inappropriate prescribing of sedatives, inappropriate use of do not resuscitate orders, and diagnostic overshadowing leading to delayed or misdiagnoses. Emergency physicians need to be aware of subtle or atypical presentations of illnesses such as sepsis. Carers and family can be vital informants, helping clinicians to interpret subtle signs and aid communication with people with learning disabilities. One simple approach to reasonable adjustments, as required by law, is the TEACH mnemonic: people with learning disabilities need more time (T), in a conducive environment (E), with clinicians approaching them with the right attitude (A) and an open mind. Good communication (C) is essential and clinicians must make every attempt to understand their patients and to be understood by their patients. Finally clinicians need to consider what 'help' (H) the patient and their carers or family needs. With the right approach, time and environment, emergency physicians can optimise the care delivered to people with learning disabilities to address their needs.

24. Understanding the contribution of intellectual disabilities nurses. Paper 4 of 4 - Impacts of intellectual disability nursing interventions

Authors: Mafuba, Kay;Chapman, Hazel M.;Chester, Rebecca;Kiernan, Joann;Kudita, Chiedza and Kupara, Dorothy

Publication Date: 2024

Journal: Journal of Intellectual Disabilities : JOID , pp. 17446295241228044

Abstract: Internationally, there is a wide variety of roles and expectations for intellectual disabilities nurses, and the range of nursing interventions they undertake in this field has not been clearly identified. In this paper we report the impacts of intellectual nursing interventions from an online survey of intellectual disability nurses. An online survey, using voluntary response sampling was used to collect case study examples from 230 participants from seven countries. We identified 13 themes of the impacts, and 23 broad groups of case examples of intellectual disability nursing interventions with, pregnant women, children, adults, older adults, and people at the end of life. Awareness of the roles of intellectual disability nurses and their importance in addressing health inequalities and facilitating the use of mainstream services for people with intellectual disabilities will enable improved healthcare experience and healthcare outcomes for people with intellectual disabilities.; Competing Interests: Declaration of conflicting interestsThe author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

25. The need for co-educators to drive a new model of inclusive, person-centred and respectful co-healthcare with people with intellectual disability

Authors: Molnar, Chloe;Strnadová, Iva;Dunn, Manjekah;Loblinzk, Julie;Sarfaraz, Skie;Cathcart-King, Yasmin;Tso, Michelle;Danker, Joanne;Hayes, Sarah;Willow, Sierra Angelina;Hansen, Jennifer;Lim, Tiffany Qing;Boyle, Jackie;Terrill, Bronwyn;Scully, Jackie Leach and Palmer, Elizabeth Emma

Publication Date: 2024

Journal: *Frontiers in Psychiatry* 15, pp. 1346423

Abstract: Competing Interests: EP has received funding from the NHMRC and NSW Health. She is a clinical geneticist at Sydney Children's Hospitals Network-Randwick and a member of the medical and scientific advisory committee for Rare Voices Australia, the national peak body for Australians living with a rare condition. IS has received funding from the NHMRC and the NSW Department of Health. She is also a Board member of Self Advocacy Sydney, an organisation run by and for people with intellectual disability. JS is Director of the Disability Innovation Institute, which has received funding from the NHMRC and the NSW Department of Health. JL, OAM has received funding from the NHMRC and the NSW Department of Health. She is also a Board member of Self Advocacy Sydney, an organisation run by and for people with intellectual disability. SS has received funding from the NHMRC and the NSW Department of Health. She is also an employee at Self-Advocacy Sydney, an organisation run by and for people with intellectual disability. JB and BT have received funding from the NHMRC. The remaining 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.

26. Impact of Physical Activity on Autonomy and Quality of Life in Individuals with Down Syndrome: A Systematic Review

Authors: Muñoz-Llerena, Antonio;Ladrón-de-Guevara, Laura;Medina-Rebollo, Daniel and Alcaraz-Rodríguez, Virginia

Publication Date: 2024

Journal: *Healthcare* (2227-9032) 12(2), pp. 181

27. What do parents think about the quality and safety of care provided by hospitals to children and young people with an intellectual disability? A qualitative study using thematic analysis

Authors: Ong, Natalie;Lucien, Abbie;Long, Janet;Weise, Janelle;Burgess, Annette and Walton, Merrilyn

Publication Date: 2024

Journal: *Health Expectations* 27(1), pp. 1-16

Abstract: Objectives: Children with intellectual disability experience patient safety issues resulting in poor care experiences and health outcomes. This study sought to identify patient safety issues that pertain to children aged 0–16 years with intellectual disability admitted to two tertiary state-wide children's hospitals and a children's palliative care centre; to describe and understand these factors to modify the Australian Patient Safety Education Framework to meet the particular needs for children and young people with intellectual disability. Design, Setting and Participants: Parents of children with intellectual disability from two paediatric hospitals and a palliative care unit participated in semi-structured interviews to elicit their experiences of their child's care in the context of patient safety. Thirteen interviews were conducted with parents from various backgrounds with children with intellectual, developmental and medical diagnoses. Results: Eight themes about safety in hospital care for children and young people with intellectual disability emerged from thematic analyses: Safety is not

only being safe but feeling safe; Negative dismissive attitudes compromise safety, quality and care experience; Parental roles as safety advocates involve being heard, included and empowered; Need for purposeful and planned communication and care coordination to build trust and improve care; Systems, processes and environments require adjustments to prevent patient safety events; Inequity in care due to lack of resources and skills, Need for training in disability-specific safety and quality issues and Core staff attributes: Kindness, Patience, Flexibility and Responsiveness. Parents highlighted the dilemma of being dismissed when raising concerns with staff and being required to provide care with little support. Parents also reported a lack of comprehensive care coordination services. They noted limitations within the healthcare system in accommodating reasonable adjustments for a family and child-centred context. Conclusions: The development of an adapted Patient Safety Education Framework for children with intellectual disability should consider ways for staff to transform attitudes and reduce bias which leads to adaptations for safer and better care. In addition, issues that apply to quality and safety for these children can be generalised to all children in the hospital. Patient and Public Contribution: Parent advocates in the project advisory team were shown the questions to determine their appropriateness for the interviews.

28. Lifestyle modification interventions for adults with intellectual disabilities: systematic review and meta-analysis at intervention and component levels

Authors: Rana, D.;Westrop, S.;Jaiswal, N.;Germini, E.;McGarty, A.;Ells, L.;Lally, P.;McEwan, M.;Melville, C.;Harris, L. and Wu, O.

Publication Date: 2024

Journal: Journal of Intellectual Disability Research : JIDR

Abstract: Background: Adults with intellectual disabilities (IDs) are susceptible to multiple health risk behaviours such as alcohol consumption, smoking, low physical activity, sedentary behaviour and poor diet. Lifestyle modification interventions can prevent or reduce negative health consequences caused by these behaviours. We aim to determine the effectiveness of lifestyle modification interventions and their components in targeting health risk behaviours in adults with IDs.; Methods: A systematic review and meta-analysis were conducted. Electronic databases, clinical trial registries, grey literature and citations of systematic reviews and included studies were searched in January 2021 (updated February 2022). Randomised controlled trials and non-randomised controlled trials targeting alcohol consumption, smoking, low physical activity, sedentary behaviours and poor diet in adults (aged ≥ 18 years) with ID were included. Meta-analysis was conducted at the intervention level (pairwise and network meta-analysis) and the component-level (component network meta-analysis). Studies were coded using Michie's 19-item theory coding scheme and 94-item behaviour change taxonomies. Risk of bias was assessed using the Cochrane Risk of Bias (ROB) Version 2 and Risk of Bias in Non-randomised Studies of Interventions (ROBINS-I). The study involved a patient and public involvement (PPI) group, including people with lived experience, who contributed extensively by shaping the methodology, providing valuable insights in interpreting results and organising of dissemination events.; Results: Our literature search identified 12 180 articles, of which 80 studies with 4805 participants were included in the review. The complexity of lifestyle modification intervention was dismantled by identifying six core components that influenced outcomes. Interventions targeting single or multiple health risk behaviours could have a single or combination of multiple core-components. Interventions (2 RCTs; 4 non-RCTs; 228 participants) targeting alcohol consumption and smoking behaviour were effective but based on limited evidence. Similarly, interventions targeting low physical activity only (16 RCTs; 17 non-RCTs; 1413 participants) or multiple behaviours (low physical activity only, sedentary behaviours and poor diet) (17 RCTs; 24 non-RCTs; 3164 participants) yielded mixed effectiveness in outcomes. Most interventions targeting low physical activity only or multiple behaviours generated positive effects on various outcomes while some interventions led to no change or worsened outcomes, which could be attributed to the presence of a single core-component or a combination of similar core components in interventions. The intervention-level meta-analysis for weight management outcomes showed that none of the interventions were associated with a statistically significant change in outcomes when compared with treatment-as-usual and each other. Interventions with core-components combination of energy deficit diet, aerobic exercise and behaviour change techniques showed the

highest weight loss mean difference (MD) = -3.61, 95% credible interval (CrI) -9.68 to 1.95] and those with core-components combination dietary advice and aerobic exercise showed a weight gain (MD 0.94, 95% CrI -3.93 to 4.91). Similar findings were found with the component network meta-analysis for which additional components were identified. Most studies had a high and moderate risk of bias. Various theories and behaviour change techniques were used in intervention development and adaptation.; Conclusion: Our systematic review is the first to comprehensively explore lifestyle modification interventions targeting a range of single and multiple health risk behaviours in adults with ID, co-produced with people with lived experience. It has practical implications for future research as it highlights the importance of mixed-methods research in understanding lifestyle modification interventions and the need for population-specific improvements in the field (e.g., tailored interventions, development of evaluation instruments or tools, use of rigorous research methodologies and comprehensive reporting frameworks). Wide dissemination of related knowledge and the involvement of PPI groups, including people with lived experience, will help future researchers design interventions that consider the unique needs, desires and abilities of people with ID. (© 2024 The Authors. Journal of Intellectual Disability Research published by John Wiley & Sons and MENCAP.)

29. Efficacy of cannabinoids in neurodevelopmental and neuropsychiatric disorders among children and adolescents: a systematic review

Authors: Rice, Lauren J.;Cannon, Lisa;Dadlani, Navin;Cheung, Melissa Mei Yin;Einfeld, Stewart L.;Efron, Daryl;Dossetor, David R. and Elliott, Elizabeth J.

Publication Date: 2024

Journal: European Child & Adolescent Psychiatry 33(2), pp. 505-526

Abstract: A better understanding of the endocannabinoid system and a relaxation in regulatory control of cannabis globally has increased interest in the medicinal use of cannabinoid-based products (CBP). We provide a systematic review of the rationale and current clinical trial evidence for CBP in the treatment of neuropsychiatric and neurodevelopmental disorders in children and adolescents. A systematic search of MEDLINE, Embase, PsycINFO, and the Cochrane Central Register of Trials was performed to identify articles published after 1980 about CBP for medical purposes in individuals aged 18 years or younger with selected neuropsychiatric or neurodevelopmental conditions. Risk of bias and quality of evidence was assessed for each article. Of 4466 articles screened, 18 were eligible for inclusion, addressing eight conditions (anxiety disorders (n = 1); autism spectrum disorder (n = 5); foetal alcohol spectrum disorder (n = 1); fragile X syndrome (n = 2); intellectual disability (n = 1); mood disorders (n = 2); post-traumatic stress disorder (n = 3); and Tourette syndrome (n = 3)). Only one randomised controlled trial (RCT) was identified. The remaining seventeen articles included one open-label trial, three uncontrolled before-and-after trials, two case series and 11 case reports, thus the risk of bias was high. Despite growing community and scientific interest, our systematic review identified limited and generally poor-quality evidence for the efficacy of CBP in neuropsychiatric and neurodevelopmental disorders in children and adolescents. Large rigorous RCTs are required to inform clinical care. In the meantime, clinicians must balance patient expectations with the limited evidence available.

30. Buspirone for the treatment of anxiety in Williams syndrome: a retrospective chart review study

Authors: Shin, Eva;Renzi, Danielle;Canales, Camila;Ravichandran, Caitlin;McDougle, Christopher J. and Thom, Robyn P.

Publication Date: 2024

Journal: Expert Opinion on Pharmacotherapy 25(1), pp. 113-120

Abstract: Background: Williams syndrome (WS) is a rare genetic disorder associated with a high

prevalence of anxiety disorders. Evidence-based pharmacologic treatments for anxiety in WS are lacking. The purpose of this study is to provide naturalistic data on the use of buspirone for the treatment of anxiety in WS.; Research Design and Methods: Medical records of 24 individuals with Williams syndrome (ages 7-47 years) and anxiety who received treatment with buspirone were reviewed. Treatment response to buspirone was rated by assigning a retrospective Clinical Global Impression Improvement subscale (CGI-I) score.; Results: Twenty-three of 24 (96%) patients completed at least a 16-week treatment course with buspirone. Sixteen patients (67%; 95% CI 47%, 82%) were treatment responders (CGI-I \leq 2). Only 1 (4%) patient discontinued buspirone due to a treatment-emergent side effect (nausea and vomiting). The most common side effect was nausea (13%). Twenty (84%) patients remained on buspirone at the time of their most recent follow-up visit.; Conclusions: In this retrospective study, the majority of patients responded to a 16-week course of buspirone. Prospective studies are warranted to further assess the efficacy and tolerability of buspirone for anxiety in WS.

31. Surveying views of an accessible Covid-19 vaccination clinic

Authors: Stewart, Kitty;Hawkins-Drew, Alex;Roos, Alida and Mackelworth, Mandy

Publication Date: 2024

Journal: Nursing Times 120(2), pp. 50-53

Abstract: People with learning disabilities experience health inequalities. This has been clearly evidenced during the Covid-19 pandemic as they have had worse outcomes than other population groups. This article focuses on the methods of gaining feedback about the experience of attending accessible vaccination clinics for people with learning disabilities. Survey methodology is considered and relevant learning from this process. We summarise what people told us about their experiences and what matters to them when accessing healthcare.

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

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

Publication Date: 2024

Journal: Journal of Autism and Developmental Disorders

Abstract: The aim of this study was to compare the rates of psychotropic medication use and psychotropic polypharmacy between autistic adults with and without intellectual disability (ID) and to examine factors associated with psychotropic medication use and psychotropic polypharmacy in autistic adults, stratified by the presence of ID. We conducted a retrospective medical chart review of outpatients with an autism diagnosis aged 18 years and older. The rates of psychotropic medication use and psychotropic polypharmacy were compared between autistic adults with and without ID. Subsequently, logistic regression analyses were performed to identify factors associated with psychotropic medication use and psychotropic polypharmacy in autistic adults with ID and those without ID, respectively. The rates of prevalence of psychotropic medication use and polypharmacy were significantly higher in participants with ID than those without ID (78.6% vs. 58.8% and 49.3% vs. 31.2%; p-values < 0.05). Age, gender, race, residence, presence of mood disorders, presence of schizophrenia, absence of anxiety disorder, number of psychiatric comorbidities, and presence of behaviors that challenge were significantly associated with these outcomes, depending on the presence/absence of ID. The need to optimize pharmacotherapy in autistic adults, stratifying by the presence of ID, is highlighted. (© 2024. The Author(s), under exclusive licence to Springer Science+Business Media, LLC, part of Springer Nature.)

33. Effects of exercise training programs on motor skills of individuals with intellectual disabilities: a systematic review and meta-analysis

Authors: Zarei, Hamed;Norasteh, Ali Asghar;Dehghani, Nastaran;Lieberman, Lauren J.;Ertel, Michael W. and Brian, Ali

Publication Date: 2024

Journal: Disability and Rehabilitation , pp. 1-10

Abstract: Purpose: Motor skills are involved in many physical activities and are prerequisites for the performance of sport skills. The purpose of this systematic review was to examine the effects of exercise training programs (ETP) on the motor skills of individuals with intellectual disabilities (IwID).; Methods: Primary sources were obtained from four databases including PubMed, SCOPUS, CENTRAL, and Web of Science. The search period covered years from inception to October 26 th , 2023. Inclusion criteria were as follows: Population: IwID; Intervention: ETP; Comparator: motor skills vs. nontraining control; Outcomes: motor skills outcomes. Standardized mean differences, weighted mean differences, and 95% confidence intervals (CI) were calculated using both random and fixed-effect models for outcomes.; Results: A total of 14 studies involving 586 participants were included in the systematic review. The results of the present meta-analysis showed that ETP improved composite motor skills (1.28 95% CI: 0.86, 1.70], p = 0.001), gross motor skills (0.91, 95% CI: 0.62,1.19], p = 0.001), fine motor skills (0.74, 95% CI: 0.21,1.27], p = 0.01) and fine-gross motor skills (0.64, 95% CI: 0.29, 1.00], p = 0.001).; Conclusion: The results meta-analysis demonstrated that ETP improves the motor skills of IwID. Therefore, it is recommended to apply ETP to improve the motor skills of the IwID.

34. Learning disability and autism: best practice tips: Advice for non-specialist nurses on adapting practice for people with a learning disability and autistic people

Authors: Anderson, Allie

Publication Date: 2023

Journal: Mental Health Practice 26(6), pp. 10-11

Abstract: About 2.5% of the population in England has a learning disability, while latest estimates suggest that as many as 1.2 million people are autistic. People with learning disabilities and/or autism face health inequalities throughout their lives and often have complex needs. Nurses in all settings will provide care for people with learning disabilities and/or autism, who will have a range of needs.

Sources Used:

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

Disclaimer:

The results of your literature search are based on the request that you made, and consist of a list of references, some with abstracts. Royal United Hospital Bath Healthcare Library will endeavour to use the best, most appropriate and most recent sources available to it, but accepts no liability for the information retrieved, which is subject to the content and accuracy of databases, and the limitations of the search process. The library assumes no liability for the interpretation or application of these results, which are not intended to provide advice or recommendations on patient care.