

Learning Disabilities

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1. Co-design and pilot of a virtual reality intervention to improve mental and physical healthcare accessibility for people with intellectual disability

Authors: Acton, Daniel James;Arnold, Rosalyn;Williams, Gavin;NG, Nicky;Mackay, Kirstyn and Jaydeokar, Sujeet

Publication Date: /03// ,2024

Journal: Advances in Mental Health & Intellectual Disabilities 18(2), pp. 63-75

Abstract: Purpose: This preliminary study aims to examine the use of a co-designed immersive virtual reality intervention programme in improving access to health care for people with intellectual disability. Design/methodology/approach: A co-production approach was used to design a virtual reality intervention in collaboration with people with intellectual disability, their families and carers. A mixed-method single sample pre-test-post-test design examined using a virtual reality intervention simulating health-care environments to improve access of attending health-care appointments. Qualitative feedback was used to understand participants' experience and opinions of using the digital technology. Findings: The study found that the intervention did help people access health-care appointment and reduced their fear. Improvements were also found in quality-of-life post intervention. Positive feedback was provided from participants on using digital technologies indicating the novelty of the approach and potential further applications. Originality/value: To the best of the authors' knowledge, this is the first study which has used virtual reality to support people with intellectual disability access health care.

2. Comprehensive evaluation of the child with global developmental delays or intellectual disability

Authors: Aldosari, Abdullah and Aldosari, Tahani

Publication Date: /05/29/ ,2024

Journal: Clinical and Experimental Pediatrics

Abstract: Global developmental delay (GDD) and intellectual disability (ID) are relatively common neurodevelopmental disorders that significantly impact affected children, their families, and society. The etiology of GDD/ID is notably diverse, encompassing both genetic and acquired factors. Although the precise cause of most GDD/ID cases remains unclear, an estimated half of all cases can be attributed to genetic factors. Thus, a detailed medical history and comprehensive physical examination remain pivotal for guiding diagnostic investigations into the underlying causes of GDD/ID. Advancements in genetic testing have supplanted traditional methods such as karyotyping and fluorescence in situ hybridization with chromosomal microarrays, which are now the primary genetic tests for children with idiopathic GDD/ID. Moreover, the evaluation of Fragile X and Rett syndrome should be an integral component of initial diagnostic assessments. In recent years, whole-exome sequencing and whole-genome sequencing have emerged as important diagnostic tools for evaluating children with GDD/ID and have substantially enhanced the diagnostic yield rates. Gene therapy has emerged as a promising avenue and is poised to become a cornerstone in addressing various genetic developmental and epilepsy disorders. Early intervention facilitated by a proficient multidisciplinary team can markedly enhance the prognosis and outcomes of GDD/ID, particularly when parents or caregivers are actively engaged in the interventional process. This review discusses risk factors and common underlying causes, explores recent evidence and recommendations for genetic evaluation, and offers management strategies for children with GDD/ID.

3. Efficacy and tolerability of levetiracetam in people with and without intellectual disabilities: A naturalistic case control study

Authors: Allard, Jon;Sellers, Adrian;Henley, William;McLean, Brendan;Parrett, Mary;Rajakulendran, Sanjeev;Watkins, Lance;Maguire, Melissa;Ellawela, Shan;Tittensor, Phil;Bransgrove, Juliet;Sen, Arjune;Mohanraj, Rajiv;Bagary, Many;Ram, Sunil;Vernon, Nathan;Baldwin, Sandy;Gill, Jagdish and

Shankar, Rohit

Publication Date: /05/16/ ,2024

Journal: Seizure 120, pp. 25-32

Abstract: Introduction: People with Intellectual Disabilities (PwID) are twenty times more likely than general population to have epilepsy. Guidance for prescribing antiseizure medication (ASM) to PwID is driven by trials excluding them. Levetiracetam (LEV) is a first-line ASM in the UK. Concerns exist regarding LEV's behavioural and psychological adverse effects, particularly in PwID. There is no high-quality evidence comparing effectiveness and adverse effects in PwID to those without, prescribed LEV.; Methods: Pooled casenote data for patients prescribed LEV (2000-2020) at 18 UK NHS Trusts were analysed. Demographics, starting and maximum dose, adverse effects, dropouts and seizure frequency between ID (mild vs. moderate-profound (M/P)) and general population for a 12-month period were compared. Descriptive analysis, Mann-Whitney, Fisher's exact and logistic regression methods were employed.; Results: 173 PwID (mild 53 M/P 120) were compared to 200 without ID. Mean start and maximum dose were similar across all groups. PwID (Mild & M/P) were less likely to withdraw from treatment ($P = 0.036$). No difference was found between ID and non-ID or between ID groups (Mild vs M/P) in LEV's efficacy i.e. $>50\%$ seizure reduction. Significant association emerged between ID severity and psychiatric adverse effects ($P = 0.035$). More irritability (14.2 %) and aggression (10.8 %) were reported in M/P PwID.; Conclusion: PwID and epilepsy have high rates of premature mortality, comorbidities, treatment resistance and polypharmacy but remain poorly researched for ASM use. This is the largest studied cohort of PwID trialled on LEV compared to general population controls. Findings support prescribing of LEV for PwID as a first-line ASM.; Competing Interests: Declaration of competing interest RS has received institutional and research support from LivaNova, UCB, Eisai, Veriton Pharma, Bial, Angelini, UnEEG and Jazz/GW pharma outside the submitted work. He holds grants from NIHR AI, SBRI and other funding bodies all outside this work. No other author has any declared conflict of interest to this paper. (Copyright © 2024 The Author(s). Published by Elsevier Ltd.. All rights reserved.)

4. **Synthesis: International perspectives on healthcare for people with intellectual and developmental disabilities**

Authors: Breuer, Marian E. J.;Pelle, Tim;Leusink, Geraline L.;Linehan, Christine and Naaldenberg, Jenneken

Publication Date: /06// ,2024

Journal: Journal of Policy & Practice in Intellectual Disabilities 21(2), pp. 1-9

Abstract: Background: The organization of healthcare for people with intellectual and developmental disabilities (IDD) varies across countries. Each country has developed unique practices embedded in their historical and organizational context. Understanding and sharing these practices across borders facilitates mutual understanding about healthcare needs of people with IDD and facilitates the adoption of effective strategies in other countries. Aim: To provide a synthesis across the country-specific papers in the JPPID special edition and thereby identify underlying trends, challenges, and best practices in healthcare for people with IDD. Methods: The papers in this special edition, which describe the organization of healthcare for people with IDD in 13 countries, were qualitatively analyzed using thematic content analysis, focusing on general characteristics, history, and context, organization of healthcare for people with IDD, challenges, and best practices. Results: Each paper described a specific national history of evolution of healthcare for people with IDD, but our analysis showed that countries face similar challenges in healthcare for people with IDD. These challenges cover (1) access to healthcare, (2) quality of healthcare, (3) implementation, and (4) visibility of people with IDD. Consequently, people with IDD continue to face significant health disparities. Several best practices have been developed, ranging from making mainstream healthcare more accessible and suitable to providing specialized services, and advocating and raising awareness. Conclusions: This synthesis is the first paper to include perspectives on healthcare for people with IDD across 13 countries. We

identified that, despite differences in context, countries face similar challenges in improving healthcare for people with IDD. International collaboration and networking can provide essential tools in reducing health disparities that people with IDD face, starting with the challenges identified in this synthesis. This will require effort to especially include low- and middle-income countries.

5. What are we planning, exactly? The perspectives of people with intellectual disabilities, their carers and professionals on end-of-life care planning: A focus group study

Authors: Bruun, Andrea;Cresswell, Amanda;Jordan, Leon;Keagan-Bull, Richard;Giles, Jo;Gibson, Sarah L.;Anderson-Kittow, Rebecca and Tuffrey-Wijne, Irene

Publication Date: /06// ,2024

Journal: Palliative Medicine 38(6), pp. 669-678

Abstract: Background: Deaths of people with intellectual disabilities are often unplanned for and poorly managed. Little is known about how to involve people with intellectual disabilities in end-of-life care planning. Aim: To explore the perspectives of people with intellectual disabilities, families, health and social care professionals and policy makers on end-of-life care planning within intellectual disability services. Design: A total of 11 focus groups and 1 semi-structured interview were analysed using qualitative framework and matrix analysis. The analysis was conducted inclusively with co-researchers with intellectual disabilities. Setting/participants: A total of 60 participants (14 people with intellectual disabilities, 9 family carers, 21 intellectual disability professionals, 8 healthcare professionals and 8 policy makers) from the UK. Results: There were differences in how end-of-life care planning was understood by stakeholder groups, covering four areas: funeral planning, illness planning, planning for living and talking about dying. This impacted when end-of-life care planning should happen and with whom. Participants agreed that end-of-life care planning was important, and most wanted to be involved, but in practice discussions were postponed. Barriers included issues with understanding, how or when to initiate the topic and a reluctance to talk about dying. Conclusions: To develop effective interventions and resources aiding end-of-life care planning with people with intellectual disabilities, clarity is needed around what is being planned for, with whom and when. Research and development are needed into supporting intellectual disability staff in end-of-life care planning conversations. Collaboration between intellectual disability staff and palliative care services may facilitate timely end-of-life care planning and thus optimal palliative end-of-life care.

6. The Children's Corner: Perspectives on Supportive Care. Caring for Children Who Use Augmentative and Alternative Communication

Authors: Cole, Allison J. and Lutwak, Al

Publication Date: /05//May/Jun ,2024

Journal: Pediatric Nursing 50(3), pp. 147-150

Abstract: Addressing communication needs of individuals with intellectual and developmental disabilities who rely on augmentative and alternative communication (AAC) is crucial, particularly in health care settings where these needs often go unmet. Despite the potential of AAC to improve patient/provider interactions, health care professionals frequently lack adequate training and experience in AAC, leading to overlooked patient needs and suboptimal care delivery. Negative attitudes toward AAC users further hinder effective communication and care provision. This article highlights the urgent need for enhanced AAC support in health care settings and proposes strategies to address these challenges, including comprehensive training programs for health care professionals and fostering a supportive environment for AAC users. By prioritizing communication access, health care systems can ensure equitable and person-centered care for all patients, regardless of their communication abilities.

7. Limits on quality of life: Who has the answer?

Authors: Coppus, Antonia and van Berkel, Jannemeis

Publication Date: /06// ,2024

Journal: Journal of Policy & Practice in Intellectual Disabilities 21(2), pp. 1-4

Abstract: Taking care of persons with intellectual and multiple disabilities (IMD), especially when vulnerability and medical intervention increase, can lead to the question: to what extent is there still quality of life? In the search for answers, caretakers and families are confronted with unsolvable dilemmas such as how can we identify the meaning of this life or recognise when there is suffering? How does one understand and give meaning to quality of life where fragility is present? Society, on the other hand, which rates successful living as the standard, avoids the discussion on limits to quality of life by labelling it as a medical ethical issue. It has recently been argued that the medical perspective is leading in this discussion and is the deciding factor in giving meaning to quality of life. Such statements worry IMD healthcare professionals and caregivers. This article therefore aims to offer an insight into the professional, practical and personal care experience of both authors, to explore the issue in more depth and start a nuanced dialogue without losing sight of the immense complexity of the subject. To do this, we first outline the social context in which the healthcare practice has to take place, explaining the reality of it and the difficulties faced

8. Implementing and evaluating resources to support good maternity care for parents with learning disabilities: A qualitative feasibility study in England

Authors: Cox, Anna;Ip, Athena;Watkin, Scott;Matuska, George;Bunford, Sharon;Gallagher, Ann and Taylor, Cath

Publication Date: /06// ,2024

Journal: Midwifery 133, pp. N.PAG

Abstract: Parents with learning disabilities are often disadvantaged and their needs not well understood in maternity services. Despite a global vision to improve maternity care, current evidence confirms poor pre- and post-natal care for parents with learning disabilities and their families. Midwives have expressed a need for support in the delivery of good care to this population of parents. To test the feasibility of implementing and evaluating two evidence-based and values-based resources – the Together Toolkit and Maternity Passport - to support good maternity care for people with learning disabilities. A qualitative feasibility study employing semi-structured interviews with 17 midwives and 6 parents who had used the resources in practice in four NHS Trusts in the south of England. Midwives and parents described how the resources positively impacted maternity care by enabling midwives, connecting networks and empowering parents. Factors affecting effective implementation of the resources were reported at an individual and setting level. Staff training to raise awareness and confidence in supporting parents with learning disabilities, and improved systems for recording parent's individual needs are required to enable the delivery of personalised care. Reasonable adjustments need to be prioritised to facilitate implementation of resources to support personalised maternity care and to address inequity for parents with learning disabilities. Aspirations for equity suggested commitment from midwives to challenge and overcome barriers to implementation. Recommendations were made to improve the resources and their implementation. These resources are free and accessible for use www.surrey.ac.uk/togetherproject].

9. 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: /05// ,2024

Journal: BMJ Quality & Safety 33(5), pp. 277-279

10. A review of the evidence that people with learning disabilities experience eye health inequalities: What policies can better ensure an equal right to sight?

Authors: Donaldson, Lisa; O'Brien, Donna and Karas, Marek

Publication Date: /06// ,2024

Journal: British Journal of Learning Disabilities 52(2), pp. 302-311

Abstract: Background: People with a learning disability experience challenges accessing primary health care services, including eye care services. Methods: Eye care needs of people with a learning disability, and how well they are met by existing services in England, were explored. Barriers and enablers to accessing these services were investigated. This was informed by a scoping review of the literature and a historic literature library. Findings: Adults with a learning disability are 10 times more likely than other adults to have a serious sight problem and children with learning disabilities are 28 times more likely. There is good evidence of high levels of unmet eye care need special schools in England with over 4 in 10 children attending having no history of any eye care. Conclusion: The authors discuss possible systemic changes to address these inequalities in England. These include automatic entitlement to an NHS sight test annually, specialist pathways in community opticians, eye care services in special schools, and peer to peer and peer to professional promotion of services by people with lived experience. Dedicated care pathways have improved uptake of services in other areas of primary care. Research into the effectiveness of lived experience eye health advocacy is needed. Accessible summaries: People with learning disabilities are much more likely to have sight problems but much less likely to get the eye care they need. Everyone should be able to access good eye care. Not getting good eye care puts eyesight at risk and existing problems might not be discovered. We look at what helps people get better eye care and what stops people from getting it. We found that improving awareness, better staff training and good communication are important. Special eye care services for people with learning disabilities have been designed but are not available in much of the UK. Having these specialist services across nations would help more people get the eye care they need.

11. Assessing adherence to National Institute for Health and Care Excellence dementia assessment and diagnosis guidelines in adults with intellectual disability: a retrospective cohort study

Authors: Duncan, Caroline; Wilkinson, Ewan; Jaydeokar, Sujeet and Acton, Daniel James

Publication Date: /01// ,2024

Journal: Advances in Mental Health & Intellectual Disabilities 18(1), pp. 12-21

Abstract: Purpose: This study aims to evaluate the dementia assessment and diagnosis care provided to adults with intellectual disability. The authors selected recommendations from the National Institute for Health and Care Excellence (NICE) standards which could be evidenced in clinical notes and aimed to identify characteristics which may be associated with improved adherence to these recommendations. Design/methodology/approach: The study population was adults with an intellectual disability who were diagnosed with dementia between January 2019 and December 2022 by a UK-based intellectual disability service. Data to demonstrate adherence to selected recommendations and demographic and clinical characteristics were extracted from electronic patient records. Findings: The authors identified 41 individuals. A mean of six of the eight recommendations were adhered to. There was low adherence with structural imaging to support dementia subtype diagnosis (9 individuals, 22%). This may be linked with the low percentage of people diagnosed with vascular dementia (1 individual, 2%) despite a national figure of 20%. No demographic or clinical characteristics were associated with level of adherence recorded. The authors found incomplete recording of diagnostic clinical coding in electronic patient records. This may disadvantage this population, as they cannot be readily identified for post diagnostic support or resource allocation. Originality/value: To the best of the authors'

knowledge, this is the first study to examine adherence to these NICE guidelines in this population.

12. Collective effort to enhance the quality of research evidence in intellectual and developmental disabilities: a case study of an academic-practice network

Authors: Grindle, Corinna;Denne, Louise D.;Roberts-Tyler, Emily;Sapiets, Suzi Jayne;Apanasionok, Magda M.;Hughes, J. C.;Hastings, Richard P.;Gore, Nick;Baker, Peter and McDowell, Claire

Publication Date: /01// ,2024

Journal: Tizard Learning Disability Review 29(1), pp. 5-13

Abstract: Purpose: With a historic lack of attention to synthesis methods such as systematic review and meta-analysis and a lack of randomised controlled trials, the evidence base for behavioural interventions for children and adults who are autistic or are diagnosed with developmental disabilities is patchy. The Sharland Foundation Developmental Disabilities Applied Behavioural Research and Impact Network (SF-DDARIN), a network of like-minded researchers and practitioners across the UK, aims to address this. The purpose of this paper is to describe the network's work and provide the context for the remaining articles in the special issue that exemplify network projects.

Design/methodology/approach: In this case study paper, the authors describe how the SF-DDARIN works and is resourced, detailing the process used to maximise research opportunities by facilitating network members working together. The authors outline the progressive research steps that the SF-DDARIN has identified are needed to develop and improve the evidence base for behavioural interventions systematically and, with examples, describe how the network delivers these steps.

Findings: Since its establishment in 2016, the SF-DDARIN network members have collectively worked on more than 53 projects involving over 50 researchers, had over 120 special schools contribute to projects and have recruited over 500 participants. This has been achieved through funding from the Sharland Foundation, primarily to cover the staffing costs of a small support team and internship partnerships with external organisations. Some projects have attracted external funding.

Originality/value: SF-DDARIN may provide an innovative, effective and resource-efficient model for other groups seeking to develop and extend their evidence base in developmental disability research.

13. Measuring healthcare experiences among people with intellectual disability: a rapid evidence synthesis of tools and methods

Authors: Harrison, Reema;Adams, Corey;Newman, Bronwyn;Mimmo, Laurel;Mitchell, Rebecca;Manias, Elizabeth;Alston, Megan and Hadley, Anne-Marie

Publication Date: /06/04/ ,2024

Journal: Value in Health : The Journal of the International Society for Pharmacoeconomics and Outcomes Research

Abstract: Objectives: Patient-reported experience measures (PREMs) collect essential data for service and system-wide quality improvement and performance monitoring towards value-based care.

However, the experiences of people with intellectual disability, who have high healthcare utilisation couple with poorer outcomes, are often omitted from system-wide PREMs and service-wide PREMs data. The use of PREMs instruments for data collection among people with intellectual disability has not been explored. This review aimed to identify and synthesise measurement tools and approaches that have been used to gather patient-reported experience data from people with intellectual disability.;

Methods: Rapid Evidence Assessment (REA) was employed in which comprehensive search strategies were applied to electronic databases and grey literature. Narrative synthesis was employed with the included articles to address the review aim.;

Results: A total of 48 documents were included; 26 peer-reviewed journal articles and 22 articles from grey literature. Patient-reported experiences have been gathered from people with intellectual disabilities in relation to specific services or encounters, predominantly using qualitative methods. To date, there is an absence of targeted service- or system-wide surveys. Existing clinic- and condition-specific instruments provide insight for broader application.;

Conclusions: Patient experience assessment among people with intellectual disability requires consideration of a) how individuals are identified and approached, b) the content, design and structure of measurement instruments and c) the process by which data are collected and d) how it may be applied to create change. Despite the collection of patient experience data from people with intellectual disability, there is little research available about how this information is later used to support health service improvement. Applying PREMs for quality improvement is critical to realise the improvements to healthcare provision required for people with intellectual disability towards equitable care quality. (Copyright © 2024. Published by Elsevier Inc.)

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

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

Publication Date: /06// ,2024

Journal: Journal of Intellectual & Developmental Disability 49(2), pp. 134-145

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

15. Supporting self-determination of individuals with severe or profound intellectual and multiple disabilities according to relatives and healthcare professionals: A concept mapping study

Authors: Kúld, P. B.;Frielink, N.;Schuengel, C. and Embregts, P. J. C. M.

Publication Date: /07// ,2024

Journal: Journal of Applied Research in Intellectual Disabilities : JARID 37(4), pp. e13267

Abstract: Background: This study aimed to identify perspectives of relatives and healthcare professionals regarding self-determination support for people with severe or profound intellectual and multiple disabilities, highlighting agreements and differences in their viewpoints.; Method: Following a concept mapping study, online focus group meetings yielded statements on self-determination support from relatives (residential facilities: n = 6, family homes: n = 7) and healthcare professionals (residential facilities: n = 9, family home: n = 5). Participants clustered and rated statements, resulting in four concept maps interpreted by experts (N = 6).; Results: The 285 statements were categorised into 5-7 clusters per map, revealing key strategies for self-determination support: communication and choice making (facilitated by aids), sensitivity, familiarity, and collaboration among involved parties.; Conclusion: Each group placed different emphasis on these strategies, highlighting importance of continuous support in their implementation. Future research should prioritise practical implementations of these strategies to enhance self-determination. (© 2024 The Author(s). Journal of Applied Research in Intellectual Disabilities published by John Wiley & Sons Ltd.)

16. Conducting mental health assessments of people with learning disabilities

Authors: Kupara, Dorothy and Woodward, Peter

Publication Date: /04// ,2024

Journal: Learning Disability Practice 27(2), pp. 34-42

Abstract: Why you should read this article: • To recognise the challenges that may be involved in undertaking mental health assessments of people with learning disabilities • To identify appropriate communication skills, strategies and approaches that can be used when conducting mental health assessments of people with learning disabilities • To contribute towards revalidation as part of your 35 hours of CPD (UK readers) • To contribute towards your professional development and local registration renewal requirements (non-UK readers). Mental health issues are not only more prevalent in people with learning disabilities compared with the general population, but they are also more challenging to assess and diagnose. Reasons for this may include the communication issues and cognitive impairments often experienced by people with learning disabilities. This article describes some of the challenges that nurses and other healthcare professionals may encounter when assessing mental health issues in people with learning disabilities. It provides practical advice on how to conduct an effective mental health assessment and outlines a range of communication strategies that can be used to overcome any issues that occur.

17. Neighbourhood deprivation and access to early intervention and support for families of children with intellectual and developmental disabilities

Authors: Laxton, Sophie;Moriarty, Caitlin;Sapiets, Suzi J.;Hastings, Richard P. and Totsika, Vasiliki

Publication Date: /06// ,2024

Journal: Journal of Policy & Practice in Intellectual Disabilities 21(2), pp. 1-10

Abstract: Ensuring families of children with intellectual and/or developmental disabilities (e.g., developmental delay, intellectual disability, autism) can access early intervention and support is important. Current research indicates there are family-level socioeconomic disparities of access to early intervention and support, however, there is limited evidence on the relationship between neighbourhood-level socioeconomic deprivation and access to support. Therefore, the aim of this study was to examine the relationship between neighbourhood deprivation and families' access to and unmet need for early intervention and support. We collected cross-sectional data using a survey of 673 parental caregivers of young children with suspected or diagnosed intellectual and/or developmental disabilities in the UK. Multiple regression models were fitted for three early intervention and support outcome variables: access to early intervention; access to services across education, health, social care, and other sectors; and unmet need for services. Each regression model included a neighbourhood deprivation variable based on the index of multiple deprivation and five control variables: family-level economic deprivation, country, caregivers' educational level, developmental disability diagnosis, and informal support sources. Neighbourhood deprivation was a significant independent predictor of access to services, but neighbourhood deprivation was not a significant predictor of access to early intervention or unmet need for services. Families living in the most deprived neighbourhoods accessed fewer services than other families. Socioeconomic disparities of access to early intervention and support, at both a neighbourhood and family level, exist for families of young children with suspected or diagnosed intellectual and/or developmental disabilities in the UK. Future research should focus on policy and other interventions aimed at addressing socioeconomic disparities at the neighbourhood and family level, to ensure equitable access to early intervention and support.

18. What do we know about sex education of people with intellectual disabilities? An umbrella review

Authors: Pérez-Curiel, Patricia;Vicente, Eva;Morán, M^a Lucía and Gómez, Laura E.

Publication Date: /06// ,2024

Journal: British Journal of Learning Disabilities 52(2), pp. 272-290

Abstract: Background: Special attention is required when considering any educational intervention aimed at its promotion and development. Our objective is to conduct an umbrella review of systematic reviews that gather evidence from relationships and sex education programmes tailored for individuals with intellectual disabilities. Methods: The protocol was developed in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-analyses Protocol. Systematic reviews were identified through a search in Web of Science, SCOPUS and PsychINFO, using the descriptors: 'intellectual disab*' AND 'sex*'AND 'systematic'. Findings: The results of the nine reviews included in the meta-review yield relevant outcomes related to 50 sex education interventions carried out with people with intellectual disabilities. This provided the opportunity to delve into the characteristics of these interventions to ascertain the accomplishments achieved to date. Conclusions: The findings serve as foundation to propose and promote new research on this important area of life, addressing the inequalities identified concerning the sexuality and affective-sexual education of people with intellectual disabilities. It offers valuable information for the educational, social and healthcare fields, facilitating the design of more effective and rights-respecting initiatives. Accessible summary: What we wanted to do: We wanted to see what different studies say about teaching people with intellectual disabilities about relationships and sex education and how well these lessons are working. What we found: Our discoveries can help us think of new ideas to help people with intellectual disabilities understand love, relationships, hygiene and body changes and get better at making friends. Educative, social and health centres can use this information to find better ways to support sexuality and rights.

19. Making clinical consultations inclusive for people with learning disabilities

Authors: Roberts, Rachel;Parfitt, Lou;Green, Nathan;Hilliar, Kate;Watkins, Olivia;Coleman, Lucy;Martin, Peter;Kane, Tom;Avery, Shaun;Martin, Linda;Powell, Chloe;Clarke, Terri;Moreno-Chamorro, Deborah;Maunder-Buller, Frances and Berrou, Ilhem

Publication Date: /05// ,2024

Journal: Journal of Prescribing Practice 6(5), pp. 202-209

Abstract: People with learning disabilities, autism or both (PWLDA) are severely impacted by health inequalities. Health professionals report a lack of confidence and competence when communicating with PWLDA, often leading to over-prescribing medicines and poor-quality care. This article describes a collaboration between a university and the Adventurers, a group of PWLDA, to co-produce communication training as part of a prescribing training programme. Over 800 prescribers reported improved communication skills with PWLDA. The project increased the group's understanding of the healthcare system and appreciation of the power of their voice in shaping their care. The co-production model is now being adopted wider within the university. The Adventurers went on to co-design services and research studies with other organisations and, as a result, won a regional south-west co-production award.

20. Kidney and urogenital abnormalities in Down syndrome: a meta-analysis

Authors: Rossetti, Caterina Maria;Simonetti, Giacomo D.;Bianchetti, Mario G.;Lava, Sebastiano A. G.;Treglia, Giorgio;Agostoni, Carlo;Milani, Gregorio P. and de Winter, J. Peter

Publication Date: /04/20/ ,2024

Journal: Italian Journal of Pediatrics 50, pp. 1-7

Abstract: Background: Reviews on Down syndrome do not or only marginally address the issue of kidney and urogenital tract abnormalities, and lower urinary tract dysfunctions. Hence, we performed a meta-analysis of the literature. Methods: A literature search was undertaken in the Library of Medicine, Web of Science and Excerpta Medica. The search algorithm combined various keywords: (Down

syndrome OR trisomy 21 OR mongolism) AND (kidney OR urinary tract OR bladder) AND (malformation OR dysfunction OR anomaly OR abnormality OR size). The Preferred Reporting Items for Systematic Reviews and Meta-Analyses statement was used. Results: Eight case-control studies were retained for the final analysis. Three studies addressed the prevalence of kidney and urogenital tract abnormalities: an increased pooled relative risk of 5.49 (95%-CI: 1.78–16.93) was observed in Down syndrome. Penile malformations, obstructive malformations (including urethral valves), dilated urinary tract system, and kidney hypodysplasia were especially common. Three reports addressed the prevalence of lower urinary tract dysfunction: an increased pooled relative risk of 2.95 (95%-CI: 1.15–7.56) was observed. Finally, an autoptic study and an ultrasound study disclosed a reduced kidney size in Down syndrome. Conclusions: This meta-analysis indicates that abnormalities of the kidney and urogenital tract, lower urinary tract dysfunctions, and a reduced kidney size present with an increased frequency in individuals with Down syndrome.

21. Self-reported explanations for self-injury by people with intellectual disabilities: a systematic review of qualitative studies

Authors: Samways, Beverley;Heslop, Pauline and Dowling, Sandra

Publication Date: /05// ,2024

Journal: International Journal of Developmental Disabilities 70(3), pp. 382-396

Abstract: Emotional distress has received less attention as an explanatory factor for self-injury in people with intellectual disabilities, with research and practice primarily focusing on biobehavioural factors. This systematic review examines the self-reported explanations for self-injury by people with mild or moderate intellectual disabilities, and discusses how the findings contrast with those from self-reported studies of people within the general population who self-harm. Five databases (PsychINFO, IBSS, CINAHL, Web of Science and Medline) were systematically searched to find qualitative, empirical research since 2000 about self-reported reasons for self-injury. Four studies were found which conducted research with people with intellectual disabilities. Three primary themes are discussed: relief from overwhelming emotions; trauma and loss; and difficulty in articulating emotions. This review found a paucity of research asking people with intellectual disabilities about their own self-injury. However, the research available suggests that explanatory factors for self-injury typically reported in the general population should be considered for those with mild or moderate intellectual disabilities.

22. Aphasia subsequent to stroke in adults with Williams syndrome or autism: A review

Authors: Silva, Sierra;Phillips, Rhiannon;Bloss, Jamie E. and Walenski, Matthew

Publication Date: /08// ,2024

Journal: Aphasiology 38(8), pp. 1390-1396

Abstract: Aphasia is an acquired neurogenic language disorder that is often caused by stroke in adulthood. However, how does aphasia present, and how can it be effectively treated, in a neurodivergent adult with pre-existing differences in language or cognition? To confirm our intuitions that there are few published cases of aphasia resulting from stroke in adults with either Williams syndrome or autism, we searched for articles from 1990 to 2022 across multiple publication databases. For Williams syndrome, the search revealed two cases of aphasia, but few details were provided. No clear adult cases of autism with aphasia were found, though two potential cases were discovered. Despite the paucity of cases, we discuss how researchers and clinicians might meet the specific needs of these populations in relation to the assessment and treatment of aphasia.

23. A Systematic Review of Digital Interventions to Promote Physical Activity in People With Intellectual Disabilities and/or Autism

Authors: Van Biesen, Debbie;Van Damme, Tine;Morgulec-Adamowicz, Natalia;Buchholz, Aleksandra;Anjum, Momna and Healy, Séan

Publication Date: /04// ,2024

Journal: Adapted Physical Activity Quarterly 41(2), pp. 330-350

Abstract: This systematic review synthesized the literature on digital health interventions for the promotion of physical activity (PA) among people with intellectual disabilities and/or autism. From an initial screening of 553 records, 10 studies underwent full-text review. Data were extracted relating to study, intervention, and sample characteristics and PA-related findings. Methodological quality was evaluated using the Crowe Critical Appraisal Tool. There were mixed findings pertaining to the effectiveness of digital health interventions for promoting PA among these populations. Positive results were reported for three of five active-video-game interventions, two of three social-media-based interventions, and one of two e-learning/multicomponent interventions. Digital health interventions can potentially be effective for promoting PA among people with intellectual disabilities and/or autism. However, the large variation in the samples and intervention types and a reliance on pre- and quasi-experimental research designs suggest that inferences should be made with caution and additional research is needed.

24. Strategies for Accessible Breast Screening for People With Intellectual Disability

Authors: Weise, Janelle;Cvejic, Rachael and Trollor, Julian

Publication Date: /05/06/ ,2024

Journal: Journal of Primary Care & Community Health , pp. 1-9

Abstract: Introduction: People with intellectual disability are less likely to participate in breast screening than people without intellectual disability. They experience a range of barriers to accessing breast screening, however, there is no consensus on strategies to overcome these barriers. Our objective was to reach consensus on the strategies required for accessible breast screening for people with intellectual disability. Methods: Fourteen experts participated in a modified on-line Delphi that used Levesque's model of health care access as the theoretical framework. At the end of each round descriptive and thematic analyses were completed. Data was then triangulated to determine if consensus was reached. Results: After 3 rounds, 9 strategies were modified, 24 strategies were added and consensus was reached for 52 strategies across the 5 dimensions of access. Key areas of action related to (i) decision making and consent, (ii) accessible information, (iii) engagement of peer mentors, (iv) service navigators, and (v) equipping key stakeholders. Conclusions: The resulting strategies are the first to articulate how to make breast screening accessible and can be used to inform health policy and quality improvement practices.

25. Snoezelen in people with intellectual disability or dementia: A systematic review

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Publication Date: /08/25/ ,2023

Journal: International Journal of Nursing Studies Advances 5, pp. 100152

Abstract: Background: Snoezelen focuses on multisensory stimulation in an adapted environment and was originally developed for people with severe and profound intellectual (and multiple) disabilities. Snoezelen has been used for many years with various target groups and for different purposes. Variation in its application has resulted in a lack of understanding of snoezelen's application characteristics and of how they may relate to effects.; Objective: The aim of this review was to provide an overview of the application and effects of snoezelen in people with intellectual disability or dementia in order to analyse the relationship between application characteristics and effects.; Design: A

systematic review.; Methods: Five databases were searched for snoezelen studies that took place in a specially adapted environment. The methodological quality of the included studies was assessed using the Mixed Methods Appraisal Tool. The application characteristics (that is, the stimuli used, environment, and support given) and the effects were extracted. Reported effects were categorized into different human functioning dimensions using the model of intellectual disabilities of the American Association on Intellectual and Developmental Disabilities.; Results: In total, 62 studies involving people with intellectual disability (n = 30) or dementia (n = 32) were included. An overview of snoezelen used in other target groups (n = 24) is provided as supplementary material. Details on the application of snoezelen were often lacking. A total of 10 application characteristics (for example, frequency, role of the support person) were extracted. All studies reported the presence of a support person (n = 62; 100%). Effects were found in all five human functioning dimensions. The most-reported effects (61.3% overall) related to mental health, such as a reduction in challenging behaviour and improved mood. In a minority of studies (n = 10, 16.1%), effects on the support person were also reported. Due to limited details about the application of snoezelen and the large variation in measured effects, analysing the relationship between these was impossible.; Conclusions: The majority of studies lacked details on application characteristics during snoezelen. Reported effects varied, although most related to mental health. Future research should analyse in detail the relationship between application and effects.; Competing Interests: 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. (© 2023 The Authors. Published by Elsevier Ltd.)

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