

Learning Disabilities

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1. Health professionals' education related to people with intellectual and developmental disabilities: A scoping review

Authors: Ailey, Sarah H.;Bathje, Molly;Tichá, Renáta;Abery, Brian;Khuu, Belle K. and Angel, Lisa

Publication Date: 2024

Journal: Journal of Applied Research in Intellectual Disabilities 37(3), pp. 1-24

Abstract: Background: People with intellectual and developmental disabilities are among the most underserved in an inequitable healthcare system. Methods: Using Arksey and O'Malley's methodology and a social determinants of health framework, we conducted a scoping review of literature on the state of practice in education of healthcare professionals in the health and healthcare needs of this population. Results: Searches found 4948 articles, with 182 included in the final review. Themes identified included gaps of not being informed by workforce needs, continued use of the medical model of care, not addressing intersectionality with racial/ethnic and other discriminations, and lack of involvement of the population in developing/evaluating programs and promising trends of development of competency-based interprofessional programs with experiential learning. Conclusion: We provide recommendations for best practices in a concerted effort to educate a healthcare workforce equipped with the knowledge and skills to address the health needs of this population.

2. The impact of rising neurodiversity awareness

Authors: Allkins, Suzannah

Publication Date: 2024

Journal: British Journal of Midwifery 32(4), pp. 169

3. The relationship between clinical presentation and the nature of care in adults with intellectual disability and epilepsy - national comparative cohort study

Authors: Badger, Sarah;Watkins, Lance V.;Bassett, Paul;Roy, Ashok;Eyeoyibo, Mogbeyiteren;Sawhney, Indermeet;Purandare, Kiran;Wood, Laurie;Pugh, Andrea;Hammett, Joanne;Sheehan, Rory;Tromans, Samuel and Shankar, Rohit

Publication Date: 2024

Journal: BJPsych Open 10(3), pp. e94

Abstract: Background: A quarter of People with Intellectual Disabilities (PwID) have epilepsy compared with 1% of the general population. Epilepsy in PwID is a bellwether for premature mortality, multimorbidity and polypharmacy. This group depends on their care provider to give relevant information for management, especially epilepsy. There is no research on care status relationship and clinical characteristics of PwID and epilepsy.; Aim: Explore and compare the

clinical characteristics of PwID with epilepsy across different care settings.; Method: A retrospective multicentre cohort study across England and Wales collected information on seizure characteristics, intellectual disability severity, neurodevelopmental/biological/psychiatric comorbidities, medication including psychotropics/anti-seizure medication, and care status. Clinical characteristics were compared across different care settings, and those aged over and younger than 40 years.; Results: Of 618 adult PwID across six centres (male:female = 61%:39%), 338 (55%) received professional care whereas 258 (42%) lived with family. Significant differences between the care groups existed in intellectual disability severity ($P = 0.01$), autism presence ($P < 0.001$), challenging behaviour ($P < 0.001$) and comorbid physical conditions ($P = 0.008$). The two groups did not vary in intellectual disability severity/genetic conditions/seizure type and frequency/psychiatric disorders. The professional care cohort experienced increased polypharmacy ($P < 0.001$) and antipsychotic/psychotropic use ($P < 0.001/ P = 0.008$).The over-40s cohort had lower autism spectrum disorder (ASD) and attention-deficit hyperactivity disorder (ADHD) comorbidity ($P < 0.001/ P = 0.007$), increased psychiatric comorbidity and challenging behaviour ($P < 0.05$), physical multimorbidity ($P < 0.001$), polypharmacy ($P < 0.001$) and antipsychotic use ($P < 0.001$) but reduced numbers of seizures ($P = 0.007$).; Conclusion: PwID and epilepsy over 40 years in professional care have more complex clinical characteristics, increased polypharmacy and antipsychotic prescribing but fewer seizures.

4. Cancer risks related to intellectual disabilities: A systematic review

Authors: Banda, Amina;Naaldenberg, Jenneken;Timen, Aura;van Eeghen, Agnies;Leusink, Geraline and Cuypers, Maarten

Publication Date: 2024

Journal: Cancer Medicine 13(9), pp. e7210

Abstract: Background: People with intellectual disabilities (ID) face barriers in cancer care contributing to poorer oncological outcomes. Yet, understanding cancer risks in the ID population remains incomplete.; Aim: To provide an overview of cancer incidence and cancer risk assessments in the entire ID population as well as within ID-related disorders.; Methods: This systematic review examined cancer risk in the entire ID population and ID-related disorders. We systematically searched PubMed (MEDLINE) and EMBASE for literature from January 1, 2000 to July 15, 2022 using a search strategy combining terms related to cancer, incidence, and ID.; Results: We found 55 articles assessing cancer risks in the ID population at large groups or in subgroups with ID-related syndromes, indicating that overall cancer risk in the ID population is lower or comparable with that of the general population, while specific disorders (e.g., Down's syndrome) and certain genetic mutations may elevate the risk for particular cancers.; Discussion: The heterogeneity within the ID population challenges precise cancer risk assessment at the population level. Nonetheless, within certain subgroups, such as individuals with specific ID-related disorders or certain genetic mutations, a more distinct pattern of varying cancer risks compared to the general population becomes apparent.; Conclusion: More awareness, and personalized approach in cancer screening within the ID population is necessary. (© 2024 The Authors. Cancer Medicine published by John Wiley & Sons Ltd.)

5. Annual health checks for people with intellectual disabilities: An exploration of experiences, follow-up and self-management of health conditions

Authors: Cavanagh, Dawn E.;Northway, Ruth and Todd, Stuart

Publication Date: 2024

Journal: Journal of Applied Research in Intellectual Disabilities : JARID 37(3), pp. e13233

Abstract: Background: Little is known about how health issues identified at the annual health check (AHC) are followed up and addressed, how participants self-manage their health in between AHCs, and what support they receive. This research aimed to explore this.; Methods: People with intellectual disabilities (n = 12), and/or their supporters residing in Wales, were interviewed following their AHC and again at 6 and 11 months. A recurrent cross-sectional thematic analysis was undertaken.; Results: Five main themes emerged from interview one: going for a health check, issues identified, and actions taken, supporting the self-management of health, the personal context, and addressing health inequities. Four main themes emerged from follow-up interviews: follow-up, supporting the self-management of health, the need for reasonably adjusted health services, and going for another health check.; Conclusion: A broader system of support around the AHC is required if people are to achieve or maintain the best possible health. (© 2024 John Wiley & Sons Ltd.)

6. 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: 2024

Journal: Midwifery 133, pp. 104001

Abstract: Problem: Parents with learning disabilities are often disadvantaged and their needs not well understood in maternity services.; Background: 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.; Aim: 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.; Methods: 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.; Findings: 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.; Discussion: 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.; Conclusion: 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.; 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. Published by Elsevier Ltd.)

7. Improvement of palliative care for people with intellectual disabilities: A multi-site evaluation

Authors: De Veer, Anke J. E.;Voss, Hille;Francke, Anneke L. and de Man, Y.

Publication Date: 2024

Journal: Journal of Applied Research in Intellectual Disabilities 37(3), pp. 1-13

Abstract: Background: To improve the quality of palliative care, six evidence-based tools were implemented in 10 care services specialised in care for people with intellectual disabilities. Contextual differences were taken into account by using a participatory action research approach. Method: The RE-AIM framework (Reach, Effectiveness, Adoption, Implementation and Maintenance) structured the evaluation. Data sources were online questionnaires completed by 299 professionals at baseline (response 45.2%) and 250 professionals after 2.5 years (35.1%), 11 semi-structured group interviews with 43 professionals, field notes and implementation plans. Results: A total of 767 professionals and 43 teams were reached. The effectiveness of the intervention was demonstrated in an improved knowledge of palliative care policy and increased competences among professionals. 79% of the professionals adopted tools in the toolbox. The participatory action research method was perceived as valuable in driving change. Conclusions: Improving palliative care needs a context-specific, flexible approach, with involvement of all stakeholders.

8. Who is at risk? Adults with intellectual disability at risk of admission to mental health inpatient care

Authors: Durand, Marianne;Nathan, Rajan;Holt, Sophie;Nall-Evans, Sharleen and Woodrow, Ceri

Publication Date: 2024

Journal: Journal of Applied Research in Intellectual Disabilities 37(3), pp. 1-8

Abstract: Background: NHS England's Transforming Care agenda aims to reduce the number of adults with intellectual disabilities and autistic adults in mental health hospitals. The aim was to understand the demographic and clinical characteristics of those most at risk of admission. Method: A cohort, retrospective study of adults using community intellectual disability services in the North West of England from 2018 to 2022 was undertaken. Results: We compared 211 adults at imminent risk of admission to a mental health hospital and 249 at significant (but not

imminent) risk on a validated risk stratification tool. Individuals at significant risk were more likely to have moderate intellectual disability. Individuals at imminent risk were more likely to have diagnoses of mild intellectual disability, autism, personality disorder, or psychosis. Conclusion: By furthering our understanding of the clinical characteristics of those most at risk of admission, the findings inform more appropriate targeting of resources.

9. Physiotherapy for individuals with intellectual disabilities

Authors: Durlak, Damian

Publication Date: 2024

Journal: Fizjoterapia Polska (1), pp. 78-82

Abstract: Intellectual disability affects 1 to 3% of the population, with a higher percentage among residents of developing countries. Due to the possible occurrence of movement limitations in individuals with intellectual disabilities, physiotherapy can be an invaluable element of patient support for better functioning. However, understanding the key issues in working with patients from this group is necessary. This article is dedicated to introducing the topic of intellectual disability and the issues that physiotherapists should pay attention to when providing health services.; Niepełnosprawność intelektualna dotyka od 1 do 3% społeczeństwa, przy czym wśród mieszkańców krajów rozwijających się ten odsetek jest wyższy. Ze względu na możliwe występowanie ograniczeń w zakresie ruchu u osób niepełnosprawnych intelektualnie fizjoterapia może być nieocenionym elementem wsparcia pacjenta w lepszym funkcjonowaniu. Konieczne jest jednak zrozumienie kluczowych kwestii w pracy z pacjentami z tej grupy. Niniejszy artykuł poświęcony został przybliżeniu tematyki niepełnosprawności intelektualnej oraz kwestii, na jakie fizjoterapeuta powinien zwrócić uwagę przy udzielaniu świadczeń zdrowotnych.

10. Contribution of static and dynamic balance skills to activities of daily living in children with intellectual disabilities

Authors: Endo, Soma; Asano, Daiki and Asai, Hitoshi

Publication Date: 2024

Journal: Journal of Applied Research in Intellectual Disabilities 37(3), pp. 1-10

Abstract: Background: Static and dynamic balance skills can be related to the activities of daily living (ADL) in children with non-syndromic intellectual disabilities, and the type of balance skills affecting ADL can differ depending on the domain of ADL (self-care, mobility, and social function). Methods: The ADL capabilities of 66 children with intellectual disabilities were assessed using the Pediatric Evaluation of Disability Inventory (PEDI) and were examined in relation to static and dynamic balance skills. Results: Significant positive correlations were found between the one-leg standing and PEDI ($r = .841$ for self-care, $r = .700$ for mobility, and $r = .760$ for social function). Our analysis showed that static balance skills affected self-care, dynamic balance skills affected mobility, and intelligence quotient affected

social function. Conclusions: Improving balance skills is important for enhancing ADL capabilities, and the type of balance skills that need enhancement vary based on the domain of ADL.

11. Prader–Willi syndrome in a large sample from Spain: general features, obesity and regular use of psychotropic medication

Authors: González-Domenech, P. J.;Gurpegui, M.;González-Domenech, C. M.;Gómez-González, S.;Rustarazo, A.;Ruiz-Nieto, V.;Carretero, M. D. and Gutiérrez-Rojas, L.

Publication Date: 2024

Journal: Journal of Intellectual Disability Research 68(5), pp. 446-463

Abstract: Background: Prader–Willi syndrome (PWS), a genetically determined disorder, the most frequent cause of early onset obesity, is associated with physical and cognitive dysfunctions and behavioural disturbances; these disturbances are frequently treated with psychotropic medication. The aim of this cross-sectional study was to describe the characteristics of the first large national sample of persons with PWS in Spain and analyse the relationships of those characteristics with key demographic and clinical factors, particularly with obesity and the regular use of psychotropic medication. Methods: Participants were recruited among all members of the Spanish Prader–Willi Association who agreed to take part in the study and fulfilled its inclusion criteria. Family and patient demographic features, family size and birth order, intelligence quotient (IQ), anthropometric measures, lifestyle habits, behavioural disturbances (with the Aberrant Behavior Checklist) and clinical data, as well as use of psychotropic drugs and their side effects (with the UKU scale), were collected in genetically confirmed cases of PWS. Bivariate and logistic regression analyses were used for determining the associations of demographic and clinical factors with both obesity and the regular use of psychotropic medication. Results: The cohort included 177 participants (aged 6–48 years), that is, 90 (50.8%) males and 87 (49.2%) females. Behavioural disturbances were present in a range of 75% to 93% of participants; psychotropic medication was prescribed to 81 (45.8%) of them. Number of siblings showed a direct correlation with IQ, especially among males, and inappropriate speech was more intense in only-child females. Obesity was, in parallel, strongly associated with ascending age and with not being currently under growth hormone (GH) treatment. Participants taking any psychotropic medication were characterised by more frequent age ≥ 30 years, high level of hyperactivity and a psychiatric diagnosis. Conclusions: Characterisation of persons with PWS in Spain confirms their physical and behavioural phenotype and supports the long-term application of GH therapy and the rational use of psychotropic medication.

12. Chewing difficulties, oral health, and nutritional status in adults with intellectual disabilities: A cross-sectional study

Authors: İslamoğlu, Ayşe Hümeýra;Berkel, Gülcan;Yildirim, Hatice Selin;Aktaç, Şule;Bayram, Ferit;Sabuncular, Güleren and Güneş, Fatma Esra

Publication Date: 2024

Journal: Journal of Applied Research in Intellectual Disabilities 37(3), pp. 1-12

Abstract: Background: Chewing difficulty, poor oral health, inadequate and imbalanced nutrition are serious health problems in individuals with intellectual disabilities. The participants' chewing abilities, oral health and nutritional status were analysed in this study. Methods: Forty-five adult participants with intellectual disabilities were included. Anthropometric measurements, oral health assessments, chewing ability evaluations and dietary intake analyses were conducted. Results: A 56.8% of the participants were classified as overweight or obese. Teeth grinding was reported in 33.3% of the participants, while 40.0% experienced drooling. All participants with Down syndrome and 58.6% of the participants with developmental delay had chewing difficulties. Inadequate nutrient intake was observed and the fibre, vitamins B1, B3, B9, sodium, phosphorus and iron intakes were significantly lower than reference values in those with chewing difficulty ($p < .05$). Conclusions: Chewing difficulties were associated with lower intake of certain nutrients, highlighting the importance of addressing oral health and dietary counselling in this population.

13. A holistic approach to fragile X syndrome integrated guidance for person-centred care

Authors: Johnson, Kirsten; Stanfield, Andrew C.; Scerif, Gaia; McKechnie, Andrew; Clarke, Angus; Herring, Jonathan; Smith, Kayla and Crawford, Hayley

Publication Date: 2024

Journal: Journal of Applied Research in Intellectual Disabilities 37(3), pp. 1-11

Abstract: Background: The Fragile X community has expressed a desire for centralised, national guidelines in the form of integrated guidance for Fragile X Syndrome (FXS). Methods: This article draws on existing literature reviews, primary research and clinical trials on FXS, a Fragile X Society conference workshop and first-hand experience of clinicians who have worked with those living with FXS over many years. Results: The article scopes proposed integrated guidance over the life course, including appendices of symptoms, comorbidities and referral options for FXS and Fragile X Premutation Associated Conditions. Conclusion: Integrated guidance would provide an authoritative source for doctors, health professionals, therapists, care workers, social workers, educators, employers, families and those living with FXS, so that a holistic, person-centred approach can be taken across the United Kingdom to garner the best outcomes for those with FXS.

14. Cancer Risk in Patients with Down Syndrome—A Retrospective Cohort Study from Germany

Authors: Krieg, Sarah; Krieg, Andreas; Loosen, Sven H.; Roderburg, Christoph and Kostev, Karel

Publication Date: 2024

Journal: Cancers 16(6), pp. 1103

Abstract: Simple Summary: Individuals with Down syndrome (DS) are thought to have a unique tumor profile. This study retrospectively compared patients with DS aged ≥ 18 years from primary care practices with patients without DS between 2005 and 2021 for cancer incidence after matching for age, sex, average annual visit frequency, and comorbidity. The 5-year cumulative incidence of cancer overall and specific cancers was analyzed using Kaplan–Meier curves and compared using the log-rank test. In addition, univariable Cox regression analysis was performed. A total of 2438 patients with DS and 12,190 patients without DS were included. Regression analysis showed no significant association between DS and subsequent cancer in the overall population. Analyses by cancer type and sex showed a strong but non-significant negative association between DS and breast cancer in women. Our results may provide the basis for future studies to clarify whether and to what extent an adapted screening program needs to be modified for individuals with Down syndrome due to the particular cancer distribution pattern. Background: Individuals with Down syndrome are thought to have a unique tumor profile. Methods: Using the IQVIA Disease Analyzer database, patients aged ≥ 18 years diagnosed with Down syndrome in German general practices between 2005 and 2021 were compared with patients without Down syndrome for cancer incidence, adjusting for age, sex, average annual visit frequency, and comorbidity. The 5-year cumulative incidence of cancer overall and specific cancers was analyzed using Kaplan–Meier curves and compared using the log-rank test. In addition, univariable Cox regression analysis was performed. Results: A total of 2438 patients with Down syndrome and 12,190 patients without Down syndrome were included; 3.9% of patients without Down syndrome and 3.1% of patients with Down syndrome were diagnosed with cancer ($p = 0.143$). Regression analysis showed no significant association between Down syndrome and subsequent cancer in the total population (HR: 0.79; 95% CI: 0.57–1.09), in women (HR: 0.89; 95% CI: 0.56–1.37), or in men (HR: 0.69; 95% CI: 0.43–1.11). Analyses by cancer type and sex showed a strong but not significant negative association between Down syndrome and breast cancer in women (HR: 0.33; 95% CI: 0.12–0.93). Conclusions: Our results could form the basis for future studies to clarify whether and to what extent an adapted screening program needs to be modified for individuals with Down syndrome due to the particular cancer distribution pattern.

15. Ultrasonography is an effective tool for breast cancer screening in individuals with severe motor and intellectual disabilities

Authors: Miyashita, Yusuke; Yanagida, Kumi; Shirafuji, Naoki; Hoshide, Ryuji; Sato, Katsuyuki; Taku, Keiichi and Nakamura, Kimitoshi

Publication Date: 2024

Journal: Journal of Applied Research in Intellectual Disabilities 37(3), pp. 1-6

Abstract: Background: Individuals with severe motor and intellectual disabilities have become an aging population, and high cancer morbidity and mortality are critical issues affecting their survival. Cancer screening is a crucial method of resolving this issue; however, a suitable screening method for them has not been established. Methods: We used ultrasonography alone and performed breast cancer screening for women over 30 years old in our facility from 2016 to 2023. We observed the outcomes and calculated the recall/detection rate in this screening. Results: Three cases among 379 tested positive in this screening, all of which underwent radical surgery. They are alive and well without relapse present. We detected these

breast cancer cases with a low recall rate. Conclusion: We were able to successfully detect breast cancer cases using ultrasonography alone. Ultrasonography is an effective and feasible tool for breast cancer screening in individuals with severe motor and intellectual disabilities.

16. Navigating the outcome maze: a scoping review of outcomes and instruments in clinical trials in genetic neurodevelopmental disorders and intellectual disability

Authors: Müller, Annelieke,R.;van Silfhout, Nadia,Y.;den Hollander, Bibiche;Kampman, Dick H. C.;Bakkum, Lianne;Brands, Marion M. M. G.;Haverman, Lotte;Terwee, Caroline B.;Schuengel, Carlo;Daams, Joost;Hessl, David;Wijburg, Frits A.;Boot, Erik and van Eeghen, Agnies,M.

Publication Date: 2024

Journal: Therapeutic Advances in Rare Disease 5, pp. 26330040241245721

Abstract: Background: Individuals with genetic neurodevelopmental disorders (GNDs) or intellectual disability (ID) are often affected by complex neuropsychiatric comorbidities. Targeted treatments are increasingly available, but due to the heterogeneity of these patient populations, choosing a key outcome and corresponding outcome measurement instrument remains challenging.; Objectives: The aim of this scoping review was to describe the research on outcomes and instruments used in clinical trials in GNDs and ID.; Eligibility Criteria: Clinical trials in individuals with GNDs and ID for any intervention over the past 10 years were included in the review.; Sources of Evidence: MEDLINE, PsycINFO, and Cochrane CENTRAL were searched. Titles and abstracts were independently screened for eligibility with a subsample of 10% double-screening for interrater reliability. Data from full texts were independently reviewed. Discrepancies were discussed until consensus was reached.; Charting Methods: Information was recorded on patient populations, interventions, designs, outcomes, measurement instruments, and type of reporter when applicable. Qualitative and descriptive analyses were performed.; Results: We included 312 studies reporting 91 different outcomes, with cognitive function most frequently measured (28%). Various outcome measurement instruments (n = 457) were used, with 288 in only a single clinical trial. There were 18 genetic condition-specific instruments and 16 measures were designed ad-hoc for one particular trial. Types of report included proxy-report (39%), self-report (22%), clinician-report (16%), observer-report (6%), self-assisted report (1%), or unknown (16%).; Conclusion: This scoping review of current practice reveals a myriad of outcomes and outcome measurement instruments for clinical trials in GNDs and ID. This complicates generalization, evidence synthesis, and evaluation. It underlines the need for consensus on suitability, validity, and relevancy of instruments, ultimately resulting in a core outcome set. A series of steps is proposed to move from the myriad of measures to a more unified approach.; Competing Interests: The authors declare that there is no conflict of interest. (© The Author(s), 2024.)

17. Adapting the EQ-5D-3L for adults with mild to moderate learning disabilities

Authors: O'Dwyer, John,L.;Bryant, Louise D.;Hulme, Claire;Kind, Paul and Meads, David M.

Publication Date: 2024

Journal: Health and Quality of Life Outcomes 22(1), pp. 37

Abstract: Background: Approximately 1.5 million adults in the UK have a learning disability. The difference between age at death for this group and the general population is 26 years for females and 22 years for males. The NHS Long Term Plan (January 2019) recognises learning disabilities as a clinical priority area. People with a learning disability are often excluded from research by design or lack of reasonable adjustments, and self-reported health status/health-related quality of life questionnaires such as the EQ-5D are often not appropriate for this population. Here, we systematically examine the EQ-5D-3L (its wording, content, and format) using qualitative methods to inform the adaption of the measure for use with adults with mild to moderate learning disabilities.; Methods: Think-aloud interviews with carers/advocates of learning-disabled adults were undertaken to explore the difficulties with completing the EQ-5D-3L. Alternative wording, language, structure, and images were developed using focus groups, stakeholder reference groups, and an expert panel. Data analysis followed a framework method.; Results: The dimensions and levels within the EQ-5D-3L were deemed appropriate for adults with mild to moderate learning disabilities. Consensus on wording, structure, and images was reached through an iterative process, and an adapted version of the EQ-5D-3L was finalised.; Conclusion: The EQ-5D-3L adapted for adults with mild to moderate intellectual/learning disabilities can facilitate measurement of self-reported health status. Research is underway to assess the potential use of the adaptation for economic evaluation. (© 2024. The Author(s).)

18. Prolonged exposure treatment for post-traumatic stress disorder: Single case studies in a sample of adults with mild intellectual disabilities

Authors: Prins, Paul and Nijhof, Karin

Publication Date: 2024

Journal: Journal of Applied Research in Intellectual Disabilities 37(3), pp. 1-11

Abstract: Background: Post-traumatic stress disorder (PTSD) is common in adults with intellectual disabilities. Often there are additional disorders such as substance use, mood and anxiety disorders. The current study focuses on the feasibility and initial efficacy of prolonged exposure (PE) for PTSD in adults with mild intellectual disabilities. The secondary effect of PE on additional mood, anxiety and substance use disorders is also examined. Methods: A single case experimental design (N = 12) with an A (baseline)-B (intervention) phase including a follow-up measurement after 3 months was conducted. Time series and single time points measurements were performed. Results: Six participants dropped-out. The results showed a significant decrease in PTSD symptoms and a significant decrease in additional symptoms (social avoidance, anxiety and stress), among participants who completed treatment. Conclusion: PE appears to be a feasible and effective treatment for PTSD in some adults with mild intellectual disabilities. Suggestions emerge from this study to make standard PE treatment more appropriate for adults with mild intellectual disabilities. Further research is needed to reduce drop-out in trauma treatment. Some suggestions for this are made in this study. Treatment of PTSD with PE did not appear to affect comorbid mood disorders. Further research is needed.

19. 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.;Germeni, 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 68(5), pp. 387-445

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.

20. Augmentative and alternative communication with children with severe/profound intellectual and multiple disabilities: speech language pathologists' clinical practices and reasoning

Authors: Rensfeld Flink, Anna;Thunberg, Gunilla;Nyman, Anna;Broberg, Malin and Åsberg Johnels, Jakob

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Journal: Disability & Rehabilitation: Assistive Technology 19(3), pp. 962-974

Abstract: Augmentative and alternative communication (AAC) is recommended to be included in communication interventions directed at children/youth with severe/profound intellectual and multiple disabilities (S/PIMD). Even so, the evidence base for AAC practices with children with S/PIMD is limited. Also, little is known about how frequently AAC is implemented with this target group, which AAC tools and methods are applied, and the related clinical reasoning of speech-language pathologists (SLPs). This study aimed to explore SLPs' beliefs, clinical reasoning and practices in relation to AAC implementation with children/youth with S/PIMD. In this sequential, mixed-methods study, 90 SLPs working with children with disabilities within habilitation services in Sweden participated in an online survey. The survey answers were statistically analysed. Subsequently, focus group data were collected from seven SLPs and analysed using thematic analysis. Despite AAC being highly prioritized, SLPs found it challenging and complex to implement with this target group. A wide variety of AAC methods and tools were considered and implemented. Clinical decision-making was a balancing act between competing considerations and was mainly guided by the SLPs' individual, clinical experiences. The resources, engagement and wishes of the social network surrounding the child were considered crucial for clinical decision-making on AAC. Implications for research and practice are discussed. Speech-language pathologists (SLPs) seemingly find a wide variety of Augmentative and Alternative Communication (AAC), ranging from unaided methods to assistive technology of various complexity, to be potentially suitable for children/youth with severe/profound intellectual and multiple disabilities (S/PIMD). The motivation and preferences of the social network surrounding the child with S/PIMD seem to influence SLPs' clinical decision-making on AAC to a high degree. Sometimes this may be considered an even more important factor than the abilities of the child. SLPs' clinical decision-making on AAC for children/youth is guided by their individual, clinical experience to a high degree. An increase in family oriented AAC intervention research targeting individuals with S/PIMD could potentially

strengthen the association between research and the current, experience-based clinical practice.

21. 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: 2024

Journal: Italian Journal of Pediatrics 50(1), pp. 79

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. (© 2024. The Author(s).)

22. Prevalence of swallowing difficulties and associated factors in older people with intellectual disabilities

Authors: Sanders, Kim J. V.; Elbers, Roy G.; Bastiaanse, Luc P.; Echteld, Michael A.; Evenhuis, Heleen M. and Festen, Dederieke A. M.

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Journal: Journal of Applied Research in Intellectual Disabilities 37(3), pp. 1-9

Abstract: Background: We investigated the prevalence of swallowing difficulties and associated factors in people with intellectual disability. Methods: We included people aged 50+ receiving care for people with intellectual disabilities. The Dysphagia Disorder Survey (DDS) was used to assess swallowing difficulties. We determined the agreement between the DDS and swallowing difficulties in medical records. We used logistic regression analyses to explore associated factors. Results: One thousand and fifty people were included. The prevalence of swallowing difficulties was 43.8%. Swallowing difficulties were not reported in the medical

records of 83.3% of these cases. Frailty (odds ratio (OR) = 4.22, 95% CI = 2.05–8.71), mobility impairment (OR = 2.50, 95% CI = 1.01–6.19), and mealtime dependency (OR = 3.05, 95% CI = 1.10–8.47) were independently associated with swallowing difficulties. Conclusion: Swallowing difficulties are prevalent in older people with intellectual disability but may be under-recognised. Frailty may be a good indicator for population-based screening for swallowing difficulties.

23. Physical Activity for Persons with Intellectual and Developmental Disabilities: A Support Guide for Health Care Professionals

Authors: Santos, Flavia H.;Sood, Pallavi;Gan, Dan R. Y.;Lansang, Noemi;Devos, Hannes and Heyn, Patricia C.

Publication Date: 2024

Journal: Archives of Physical Medicine & Rehabilitation 105(5), pp. 1025-1028

24. Fiberoptic Endoscopic Evaluation of Swallowing Findings in Children With Rett Syndrome

Authors: Sideris, Giorgos;Panagoulis, Evangelos;Grigoropoulos, Christos;Mermiri, Despina;Nikolopoulos, Thomas and Delides, Alexander

Publication Date: 2024

Journal: Clinical Pediatrics 63(4), pp. 551-556

Abstract: Feeding abnormalities, swallowing dysfunction, and gastrointestinal issues cause poor weight gain, oral motor dysfunction, and air swallowing in children with Rett syndrome (RTT). Pneumonia is the leading cause of death. Our study describes fiberoptic endoscopic swallowing findings in 11 female RTT children. Each patient was evaluated using the 8-point Penetration/Aspiration Scale (PAS). The average age was 7 years. All patients had tongue dyskinesia and prolonged oral stage. Eight girls exhibited liquid entering the airway without coughing, whereas 6 did well with pureed meal. Three girls had pneumonia. Age was not correlated with pneumonia episodes ($P = .18$). Pureed material was related with pneumonia ($P = .006$), whereas liquids were not. Pureed PAS was positively correlated with Liquid PAS ($P = .008$) and age ($P = .004$). All aspiration/penetration incidents occurred before the pharyngeal phase. No patient under 7 years experienced pneumonia episodes. Silent aspiration can occur early in infancy, although pneumonia episodes can occur later.

25. Encounters with public and professional understandings of Down syndrome: A qualitative study of parents' experiences

Authors: Steffensen, Ellen H.;Santoro, Stephanie L.;Pedersen, Lars H.;Vogel, Ida and Lou, Stina

Publication Date: 2024

Journal: Journal of Applied Research in Intellectual Disabilities 37(3), pp. 1-9

Abstract: Background: The meanings of neurodevelopmental conditions are socially and culturally defined. We explored how parents of a child with Down syndrome experienced public and professional understandings of Down syndrome. Method: Qualitative interviews with 25 parents of a child with Down syndrome living in Denmark. From a reflexive thematic analysis, we developed themes describing understandings (i.e., attitudes or perceptions) of Down syndrome. Results: The parents experienced that the Down syndrome diagnosis acted as a 'label'; this had perceived positive and negative consequences for the child. The parents felt others understood Down syndrome as severe and undesirable. This attitude was tied to the existence of prenatal screening. Finally, to the parents, professional support for their child expressed an understanding of children with Down syndrome as valued individuals. Conclusions: Parents encountered ambiguous understandings of Down syndrome. This should be recognised by professionals who may shape such understandings.

26. Suicidal and Nonsuicidal Self-Injury Behaviors: A Primer for Rehabilitation Counselors

Authors: Tseng, Yen Chun and Ditchman, Nicole

Publication Date: 2024

Journal: Journal of Applied Rehabilitation Counseling 55(1), pp. 16-34

Abstract: Rehabilitation counselors have a unique role in addressing suicidal and self-injury thoughts and behaviors in people with disabilities. Adults and adolescents with disabilities are at increased risk of suicide and nonsuicidal self-injury (NSSI), necessitating that rehabilitation counselors possess the knowledge and skills to respond systematically and effectively. To address this need, rehabilitation counselors should have access to sufficient education and ongoing training on self-injury terminology, prominent theories, ethical and legal issues related to research and practice, risk/protective factors, and risk assessment processes and instruments. The objective of this article is to provide rehabilitation counseling professionals with an overview of research on suicidality and NSSI, including a review of existing literature related to specific disability groups. Key issues and recommended considerations for rehabilitation counselors are highlighted, including training, risk assessment, evidence-based practice, ethical considerations, self-awareness, and supervision and support.

27. Making physical activity fun and accessible to adults with intellectual disabilities: A pilot study of a gamification intervention

Authors: Turgeon, Stéphanie;MacKenzie, Alexandra;Batcho, Charles Sebiyo and D'Amour, Jason

Publication Date: 2024

Journal: Journal of Applied Research in Intellectual Disabilities 37(3), pp. 1-21

Abstract: Background: Only about 9% of individuals with intellectual disabilities reach the

government's physical activity (PA) recommendations. Combining gamification and technology seems particularly promising in overcoming personal and environmental barriers to PA participation. Method: Eighteen adults with varying levels of intellectual disabilities completed a pilot study to assess the initial effects of a cycling gamification intervention on levels of PA, fitness, psychosocial outcomes, and challenging behaviours. The study comprised three designs: pre-post single group, AB single-case, and qualitative. Social validity, implementation barriers and facilitators were also explored. Results: Nearly all 18 participants cycled daily. Time and distance cycled daily increase during the intervention while a decrease in stereotyped behaviours was observed. Participants and staff found the intervention enjoyable and socially valid. Conclusions: Results of the multiple-design study suggest that gamification interventions may be a suitable, enjoyable, and promising way to contribute to PA participation of adults with intellectual disabilities.

28. Emerging therapies for childhood-onset movement disorders

Authors: Vogt, Lindsey; Quiroz, Vicente and Ebrahimi-Fakhari, Darius

Publication Date: 2024

Journal: Current Opinion in Pediatrics 36(3), pp. 331-341

Abstract: Purpose of Review: We highlight novel and emerging therapies in the treatment of childhood-onset movement disorders. We structured this review by therapeutic entity (small molecule drugs, RNA-targeted therapeutics, gene replacement therapy, and neuromodulation), recognizing that there are two main approaches to treatment: symptomatic (based on phenomenology) and molecular mechanism-based therapy or 'precision medicine' (which is disease-modifying).; Recent Findings: We highlight reports of new small molecule drugs for Tourette syndrome, Friedreich's ataxia and Rett syndrome. We also discuss developments in gene therapy for aromatic L-amino acid decarboxylase deficiency and hereditary spastic paraplegia, as well as current work exploring optimization of deep brain stimulation and lesioning with focused ultrasound.; Summary: Childhood-onset movement disorders have traditionally been treated symptomatically based on phenomenology, but focus has recently shifted toward targeted molecular mechanism-based therapeutics. The development of precision therapies is driven by increasing capabilities for genetic testing and a better delineation of the underlying disease mechanisms. We highlight novel and exciting approaches to the treatment of genetic childhood-onset movement disorders while also discussing general challenges in therapy development for rare diseases. We provide a framework for molecular mechanism-based treatment approaches, a summary of specific treatments for various movement disorders, and a clinical trial readiness framework. (Copyright © 2024 Wolters Kluwer Health, Inc. All rights reserved.)

29. Expectant parents with intellectual disabilities in child protection: Risk factors for child safety

Authors: Zijlstra, Annick; Sterenborg, Tessel; van Nieuwenhuijzen, Maroesjka and de Castro, Bram O.

Publication Date: 2024

Journal: Journal of Applied Research in Intellectual Disabilities 37(3), pp. 1-13

Abstract: Background: Newborns of parents with intellectual disabilities face higher risks in their environment for child unsafety, despite parents' good intentions. To help parents prevent unsafe circumstances, a good understanding of the risk factors faced by these parents is needed. Methods: This casefile study examined (1) which risk factors were present for expectant parents with intellectual disabilities in child protection, (2) which domains of risk factors, and (3) whether a cumulation of risk factors was related to child safety. Results: Expectant parents with intellectual disabilities in child protection before the child was born often experienced a cumulation of risk factors. Child, family, and care factors best predicted child safety. A cumulation of risk factors over multiple life domains increased the risks for child unsafety. Conclusions: To reduce the risks of unsafe parenting conditions for newborns, preventive interventions for expectant parents with intellectual disabilities should address their needs from an ecological perspective.

30. A systematic review of auditory processing abilities in children with non-syndromic cleft lip and/or palate

Authors: Banumathi and Jain, Chandni

Publication Date: Jan ,2023

Journal: Journal of the all India Institute of Speech & Hearing 42(1), pp. 5-14

Abstract: Purpose: The present systematic review aims to understand auditory processing abilities in children with nonsyndromic cleft lip and/or palate (NSCL/P). The review summarizes questionnaire, behavioral, and electrophysiological findings of auditory processing abilities in children with NSCL/P. Method: The study used a literature search of electronic databases (e.g., Pub Med, Google Scholar, J Stage, Research Gate, ScienceDirect) and the AIISH repository from 2000 to 2021. The retrieved articles were assessed in two stages: title and abstract screening, followed by a full-length article review. About 13 articles were selected after the full-length review of 17 shortlisted articles. All selected studies used cohort design. Result: The review showed that speech perception in noise and temporal processing were the majorly affected processing abilities in children with NSCL/P. The review also showed that cleft palate children are more prone to auditory processing deficits than other cleft subgroups. These auditory processing deficits in NSCL/P children may cause delayed speech and language skills, reading, and learning disabilities, which are highly reported in these children. Conclusion: Auditory processing evaluation should be a part of the audiological test battery for these children to promote early diagnosis and management.

31. A scoping systematic review of dance application as a rehabilitation tool in adults and older individuals with neurological diseases

Authors: Zuliani, Flávia Guirro;Fonseca, Bruno Henrique de Souza;Miranda, Jéssica Mariana de Aquino;Sande de Souza, Luciane,Aparecida Pascucci and Luvizutto, Gustavo José

Publication Date: Aug ,2023

Journal: Physical Therapy Reviews 28(4-6), pp. 291-302

Abstract: The implementation of dance during rehabilitation can generate motivation and patient engagement. The compilation about dance style, type of neurological disease, functional profile, and outcomes may facilitate the understanding of dance applications in neurofunctional rehabilitation scenario. Therefore, this review mapped the studies on dance in neurological rehabilitation. Based on Joanna Briggs Institute methodology, this scoping review addressed dance in rehabilitation in various in- and out-of-hospital environments. The search was conducted between December 2021 and July 2022 on MEDLINE/PubMed®, Cochrane Library, PEDro, Scopus, CINAHL, Web of Science, Science Direct, and Springer, with a three-step analysis and categorization of the studies: pre-analysis, exploration of the material, and data processing. On a total of 2,256 studies identified, 62 were included. The number of publications in the last two decades were: 1980–1989 (n = 2 studies); 1990–1999 (n = 1); 2000–2009 (n = 4); 2010–2019 (n = 41), and from 2020 (n = 16). Dancers were predominant in older (n = 42) and female (n = 599) individuals, compared to younger (n = 20) and male (n = 589) individuals, respectively. They included ballroom dancing (n = 24), Argentine or Adapted Tango (n = 20), aerobic dance (n = 9), and ballet (n = 8). The predominant neurological conditions were Parkinson's disease (n = 40), stroke (n = 7), intellectual disability (n = 4), multiple sclerosis (n = 4), dementia or cognitive disabilities (n = 3). The predominant outcomes were balance and gait analysis, cognitive functions, motor coordination, psychological symptoms, and quality of life. The application of dance in neurological rehabilitation has increased over the last two decades, with an emphasis on ballroom dancing, Argentine tango, and classical ballet in Parkinson's disease (PD).

Sources Used:

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

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