Learning Disabilities

Current Awareness Bulletin

June 2024

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1. Health literacy in parents of children with Down syndrome

Authors: Akça, Gülfer;Sanri, Aslihan and Akca, Unal

Abstract: Purpose: This study aims to evaluate the health literacy level of the parents of children diagnosed with Down syndrome (DS) within one institution in Turkey. Design/methodology/approach: A cross-sectional survey measuring demographics, information of the child and the parent and health literacy was administered to participants. The health literacy levels in the study were measured with the European Health Literacy Scale (EHLS), which consists of 47 questions. Findings: Of the 65 participants who completed the questionnaire, 56.9% were mothers, 68.1% were diagnosed in the neonatal outpatient clinic examination after birth, and 58.5% stayed in the neonatal intensive care unit after birth. The mean score of the IHLS scale was 25.06 ± 6.59. Of the parents, 63.1% were found to be inadequate, 18.5% problematic-limited, and 18.5% adequate health literate. Any parent with excellent health literacy level was identified. High education level ($p < 0.001$), high income level ($p < 0.001$), living in the city center ($p < 0.05$), planned pregnancy ($p < 0.05$) and being a health worker ($p < 0.001$) were found to be statistically significant with a high EHSL score. Research limitations/implications: The presence of Down syndrome (DS) in a child also necessitates ongoing monitoring for a range of conditions, including eye diseases and heart disease. Some surgical procedures, such as heart or gastrointestinal surgeries, may also be required. Additionally, the child may require the administration of various medications. Finally, due to the potential lifelong need for assistance, the child may require the support of an adult throughout their lifetime. This is because of the child's inability to live independently due to their mental state. Therefore, parent education is the most important issue in the follow-up of the disease. Practical implications: To the best of the authors' knowledge, this is the first study to determine that parents of children diagnosed with DS have very limited knowledge of the disease and health literacy. Explanation of current diseases, treatments and training of parents should also be included in genetic counseling. Social implications: DS is a chromosomal disease that requires multidisciplinary care. Parents have to know the course of the disease and its complications. Originality/value: The findings of this study indicate that parents of children with Down syndrome exhibit a profound lack of knowledge regarding the nature of their child's condition and the available healthcare options. It is therefore imperative that genetic counseling incorporates an explanation of the diagnosed diseases, treatments, and educational resources for parents.

2. How nurses can apply spiritual care to improve the daily lives of people with learning disabilities and their families

Authors: Argles, Ishmay Jessica Slechta and Arrey, Sally

Abstract: Background: Most UK nursing research into spirituality overlooks its daily application in certain specialties, notably learning disability nursing. Aims: Tz explore spirituality over the lifespans of people with learning disabilities and how spiritual care affects their quality of life. To provide practical examples for nurses on how to apply spiritual care in their daily practice. Methods: A literature review conducted between January 2002 and July 2022) following recommendations from the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA). Thomas and Harden's (2008) approach to thematic synthesis was used to structure 10 full-text articles into three key themes. Findings: The three key themes were: the role of the nurse, the impacts on the individual, and family/carer perspectives. Conclusion: The nursing role in using spiritual care encompasses care planning an individual's spiritual activities, facilitating time alone, nurturing values such as self-acceptance, building therapeutic relationships, and advocating for progression in existing social structures and legislation.

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3. Whose voice is it anyway? Adults with intellectual disabilities and future planning: A scoping review of qualitative studies

Authors: Belperio, I.;Walker, R.;Bigby, C.;Wiesel, I.;Rillotta, F. and Hutchinson, C.

Abstract: Future planning is a way of supporting people with intellectual disabilities and their families to think about their support needs as both groups age. Adults with intellectual disabilities, family members, and service providers are often involved in planning processes. However, it is unclear whose perspectives dominate in the literature and how these might vary. A scoping review of qualitative studies (2012–2022) was undertaken to identify which perspectives are present in research on adults with intellectual disabilities and future planning, and to examine key aspects of their future planning experience. The perspectives of parents and siblings predominate in the research. Those of adults with intellectual disabilities and service providers are underrepresented. The views of adults with intellectual disabilities need to be elevated in future planning and they need to be meaningfully involved in planning processes. Focus on the experiences of service providers is likewise needed.

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4. Improving annual health checks based on the health consultation experiences of people with learning disabilities

Authors: Chapman, Hazel Margaret

Abstract: Why you should read this article: • To recognise the importance of annual health checks in identifying health conditions and reducing health disparities • To learn about the experiences of health consultations involving people with learning disabilities, including potential barriers to care • To consider how to promote engagement with annual health checks.

Annual health checks in primary care improve the detection of health issues in people with learning disabilities. The NHS has set a target for at least 75% of people with learning disabilities aged 14 years or over to receive a health check every year by 2023-2024. However, not all primary care professionals are trained adequately in communicating with people with learning disabilities and the number of learning disability nurses in the NHS continues to decline. This article draws on the findings of a constructivist grounded theory study and other relevant literature to discuss the experiences of people with learning disabilities of interacting with healthcare professionals and what can be learned from these experiences to improve annual health checks.

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5. **Perceptions of the use of restraint with children and young adults with disabilities and mental health disorders: A review of the literature**

Authors: Cramer, Allie M.;Virgin, Ashley S. and Barnard-Brak, Lucy

Publication Date: /06// ,2024

Journal: Children & Youth Services Review 161, pp. N.PAG

Abstract: • Policy reform is needed to provide appropriate guidance for implementation. • Practitioners must create positive relationships with individuals prior to crisis. • Consent and positive communication may lead to more positive experiences. • Debriefing helps individuals process their emotions after a crisis event. • Culture and the climate must be addressed for implications to be successful. Physical and mechanical restraint are reactive procedures implemented to maintain the safety of individuals. Physical and mechanical restraint are most frequently used on children and young adults with disabilities and mental health disorders who exhibit an imminent threat of physical harm to themselves or others. However, the current body of research on the use of restraint is limited, especially when examining the synthesis of perceptions of the use of restraint. There has only been one review conducted within the past three decades examining attitudes on the use of restraint on individuals with intellectual disabilities. The current review synthesizes the body of literature by investigating the attitudes, perceptions, and experiences of those receiving and implementing physical and mechanical restraint, including caregivers, service providers, medical professionals, and children and young adults with disabilities and mental health disorders. We also examine attitudes, perceptions, and experiences of the use of restraint across time and barriers to eliminating the use of restraint. Recommendations for future research and practitioners are discussed.

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6. **A survey on service users' perspectives about information and shared decision-making in psychotropic drug prescriptions in people with intellectual disabilities**

Authors: de Kuijper, Gerda;Jonker, Josien;Sheehan, Rory and Hassiotis, Angela

Publication Date: /06// ,2024

Journal: British Journal of Learning Disabilities 52(2), pp. 350-361

Abstract: Background: In people with intellectual disabilities and mental disorders and/or

challenging behaviours, rates of psychotropic drug prescription are high. In clinical treatments and evaluations, all stakeholders should be involved in a process of shared decision-making (SDM). We aimed to investigate the perspectives of clients and their carers on clients' treatments with psychotropic drugs. Methods: We conducted a survey among adults with intellectual disabilities in a Dutch mental healthcare centre providing community, outpatient and inpatient care. Data were collected between January and June 2022. Questions focused on experiences with the provision of information, treatment involvement and SDM and participants' wishes in this regard. Findings: Respondents (57 clients and 21 carers) were largely satisfied with the overall care from their clinicians, and with how information on the pharmacological treatment was provided verbally, but written information was insufficient or not provided. Seventy per cent of clients and 60% of carers reported being involved in medication decision-making. However, over 75% of participants desired greater involvement in SDM and over 60% in medication reviews. Conclusions: Service users and representatives were satisfied about the treatment and verbal information on their psychotropic drug use. The provision of written information, the SDM process and ongoing evaluation of psychotropic medication use could be improved. Accessible summaries: People with intellectual disabilities are often prescribed medication for mental or behavioural disorders.It is important that healthcare professionals listen to the views of people who are prescribed this medication.However, people may not be involved enough when decisions are made about their medication. They might not have enough information about their medication in a way that they understand. We wanted to know the views of clients with intellectual disability about their psychotropic medication use. We invited clients, their representatives and paid carers of a specialist mental healthcare centre to take part in a survey. Questions were about: (1)The relationship with their doctor.(2)If they were given the right information.(3)Involvement in medication evaluations.(4)Involvement in decisions regarding their medications. Seventy-eight service users (57 clients and 21 carers) completed the questionnaire. Answers were that: (1)Service users were satisfied with the overall care from their doctor.(2)Service users were satisfied with the information about the prescription of medication that was provided verbally.They were less satisfied about written information that they received about their psychotropic medication.(3)Most service users reported being involved in medication decision-making, but fewer than half were completely satisfied with this.(4)Most service users wanted to be more involved in decisions about their medication. Our findings mean that healthcare professionals need to do more to involve service users with learning disabilities in decisions about their medication.

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7. **Perspectives on the essential skills of healthcare decision making in children and adolescents with intellectual disability**

Authors: Downs, Jenny;Keeley, Jessica;Skoss, Rachel;Mills, Jaquie;Nevill, Thom;Schippers, Alice;Lindly, Olivia and Thompson, Sandra

Abstract: Background: Involvement in healthcare decisions is associated with better health outcomes for patients. For children and adolescents with intellectual disability, parents and healthcare professionals need to balance listening to a child's wishes with the responsibility of

keeping them safe. However, there is a scarcity of literature evaluating how to effectively involve them in decision making. In this context, we review the concept of health literacy, focusing on the skills of healthcare decision making for children and adolescents with intellectual disability.; Methods: We describe the concept of health literacy and models explaining shared decision making (individuals and healthcare professionals collaborate in decision making process) and supported decision making (when a trusted person supports the individual to collaborate with the healthcare professional in the decision-making process), and a rapid review of the literature evaluating their efficacy. We discuss healthcare decision making for children and adolescents with intellectual disability in the context of relevant recommendations from the recent Disability Royal Commission into Violence, Abuse, Neglect, and Exploitation of People with Disability in Australia.; Results: Health literacy skills enable individuals to access, understand, appraise, remember and use health information and services. Shared decision making has been described for children with chronic conditions and supported decision making for adults with intellectual disability. Decision-making contributes to how individuals appraise and use healthcare. The rapid review found very limited evidence of outcomes where children and adolescents with intellectual disability have been supported to contribute to their healthcare decisions. Recommendations from the Disability Royal Commission highlight current needs for greater efforts to support and build the capacity of individuals with disability to be involved in the decisions that affect their life, including healthcare decision making.; Conclusions: Existing rights frameworks and healthcare standards confirm the importance of providing all people with the opportunities to learn and practise health literacy skills including decision making. There is little literature examining interventions for healthcare decision making for children with intellectual disability. Childhood is a critical time for the development of skills and autonomy. Evidence for how children and adolescents with intellectual disability can learn and practice healthcare decision-making skills in preparation for adulthood is needed to reduce inequities in their autonomy. (© 2024. The Author(s).)

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8. **Equitable and accessible informed healthcare consent process for people with intellectual disability: a systematic literature review**

Authors: Dunn, Manjekah;Strnadová, Iva;Scully, Jackie Leach;Hansen, Jennifer;Loblinzk, Julie;Sarfaraz, Skie;Molnar, Chloe and Palmer, Elizabeth Emma

Abstract: Objective To identify factors acting as barriers or enablers to the process of healthcare consent for people with intellectual disability and to understand how to make this process equitable and accessible. Data sources Databases: Embase, MEDLINE, PsychINFO, PubMed, SCOPUS, Web of Science and CINAHL. Additional articles were obtained from an ancestral search and hand- searching three journals. Eligibility criteria Peer- reviewed original research about the consent process for healthcare interventions, published after 1990, involving adult participants with intellectual disability. Synthesis of results Inductive thematic analysis was used to identify factors affecting informed consent. The findings were reviewed by co- researchers with intellectual disability to ensure they reflected lived experiences, and an easy read summary was created. Results Twenty- three studies were included (1999 to 2020),

with a mix of qualitative (n=14), quantitative (n=6) and mixed- methods (n=3) studies. Participant numbers ranged from 9 to 604 people (median 21) and included people with intellectual disability, health professionals, carers and support people, and others working with people with intellectual disability. Six themes were identified: (1) health professionals' attitudes and lack of education, (2) inadequate accessible health information, (3) involvement of support people, (4) systemic constraints, (5) person- centred informed consent and (6) effective communication between health professionals and patients. Themes were barriers (themes 1, 2 and 4), enablers (themes 5 and 6) or both (theme 3). Conclusions Multiple reasons contribute to poor consent practices for people with intellectual disability in current health systems. Recommendations include addressing health professionals' attitudes and lack of education in informed consent with clinician training, the coproduction of accessible information resources and further inclusive research into informed consent for people with intellectual disability. PROSPERO registration CRD42021290548.

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9. A systematic review and meta-analysis of serum lipid concentrations in people with Down syndrome

Authors: Guerrero, Carolina Gastelum;Cháidez Fernández, Yuridia Lizet;Ordorica, Dalia Magaña;Berger, Heidi;Landrove, Marilyn Vazquez;Llanos, Alma Guadrón;Rojo, Carla Angulo and Gómez, Javier Magaña

Abstract: Background Down syndrome (DS) is the most prevalent chromosomal disorder, being the leading cause of intellectual disability. The increased life expectancy of individuals with DS has led to a shift in the incidence of non-communicable chronic diseases, resulting in new concerns, particularly cardiovascular disease (CVD) and Alzheimer's disease. This study aimed to analyse the blood lipid profile of a large DS cohort to establish a baseline for evaluating health risk parameters. Methods A comprehensive literature search was conducted on PubMed and Virtual Health Library databases to identify original articles published before July 2022. Selected studies were included in the meta-analysis. Results Fifteen studies reporting serum lipid levels in individuals with DS were incorporated into the analysis. The meta-analysis used the means and standard deviations extracted from the selected studies. The analysis encompassed 671 participants in the DS group and 898 euploid controls. The results indicated significant differences in total cholesterol C] (mean difference MD]: -3.34; CI: 95%: -4.94 to -1.73; $P < 0.0001$), HDL-C (MD: -3.39; CI: 95%: -6.72 to -0.06; $P = 0.05$) and triglycerides (MD: 21.48; CI: 95%: 9.32 to 33.65; $P = 0.0005$) levels between individuals with DS and their control counterparts. Conclusions Individuals with DS have less favourable blood lipid concentrations than their controls, particularly HDL-C, triglycerides, and total-C, even when grouped by age. These findings underscore the importance of closer monitoring of lipid profiles in people with DS and the necessity for specific cut-offs for this population, considering the risk for ischemic heart and Alzheimer's diseases.

10. Health and healthcare of people with learning disabilities in the United Kingdom through the COVID-19 pandemic

Authors: Hatton, Chris;Hastings, Richard P.;Caton, Sue;Bradshaw, Jill;Jahoda, Andrew;Kelly, Rosemary;Maguire, Roseann;Oloidi, Edward;Taggart, Laurence and Todd, Stuart

Abstract: Background: During the COVID-19 pandemic in the United Kingdom, many health services were withdrawn from people with learning disabilities, with negative impacts on people's health. What has happened to people's health and healthcare as we move beyond the pandemic? Methods: Access to health services and health status were tracked for 550 UK adults with learning disabilities, using structured online interviews with people with learning disabilities and online surveys with family members or paid carers. Information was provided four times, from Wave 1 (in the winter 2020/2021 'lockdown') to Wave 4 (autumn 2022, over a year after public health protections stopped). Findings: By Wave 4, most people with learning disabilities had had COVID-19, although high vaccination rates limited the number of people hospitalised. There was little evidence that use of GP services, community nurses, other therapists or annual health checks had increased over time, and at Wave 4 more people were having difficulty getting their medicines. People's health did not substantially improve over time. People with profound and multiple learning disabilities had poorer health and were less likely to be accessing health services. Conclusions: Improvements in access to health services for people with learning disabilities after the pandemic have not yet happened. Accessible Summaries: Many health services stopped for people with learning disabilities in the COVID-19 pandemic, with a bad impact on people's health. What has happened to people's health and how they use health services through the COVID-19 pandemic and beyond?People and families told us about the health of over 500 people with learning disabilities living in the United Kingdom four times, from the national lockdown in winter 2020/2021 through to autumn 2022.A lot of people were still not getting the health services they needed after the end of the pandemic, and people's health was not getting better.People with profound and multiple learning disabilities had worse health but were not in contact with health services as much as other people with learning disabilities.

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11. Strategies to prevent or reduce inequalities in specific avoidable causes of death for adults with intellectual disability: A systematic review

Authors: Heslop, Pauline and Lauer, Emily

Abstract: Background: We now have sufficient evidence demonstrating inequalities in specific avoidable causes of death for adults with intellectual disability compared to their peers without intellectual disability. Apart from covid-19, the largest differentials that disadvantage people with intellectual disability are in relation to pneumonia, aspiration pneumonia, epilepsy,

cerebrovascular disease, ischaemic heart disease, deep vein thrombosis, diabetes and sepsis. The aim of this systematic review is to report on strategies at the individual, population or policy levels aimed at preventing these conditions that are applicable to adults with intellectual disability and that have been based on or recommended by research. Methods: Systematic review of PUBMED, EMBASE, CINAHL, PsychInfo, Social Care Online, International Bibliography of the Social Sciences (IBSS), Web of Science, Scopus, Overton, the Cochrane Library and Google Scholar databases was carried out. Searches were completed on 30 June 2023. Quantitative, qualitative and mixed-methods research; systematic, scoping or evidence-based reviews; and audit and reports of mortality reviews were included. Publications included in the review were about preventing the eight potentially avoidable causes of death. Findings: Ninety-four papers were included in the review (9 in relation to pneumonia; 11 for aspiration pneumonia; 18 for sudden unexpected death in epilepsy; 7 for cerebrovascular disease; 8 for ischaemic heart disease; 4 for deep vein thrombosis; 31 for diabetes; 6 for sepsis). The eight most frequently occurring potentially avoidable causes of death in people with intellectual disability are very different medical conditions, but they shared striking similarities in how they could be prevented. The literature overwhelmingly implicated the need to make lifestyle changes to address obesity, lack of exercise and poor nutrition, and to have regular medical reviews. In addition, 'whole-population' approaches are required that look beyond the individual to the social determinants of health. Conclusions: We found little peer-reviewed evidence specifically about preventing these conditions in people with intellectual disability. However, most of the literature about preventative strategies pertaining to the general population was applicable to people with intellectual disability, albeit that some 'reasonable adjustments' would be required. Accessible Summaries: People with intellectual disability die from some illnesses that could be avoided. This is a bigger problem in people with intellectual disability than in people without intellectual disability.We searched for evidence about what we could do to prevent these illnesses.We found that although the most common illnesses are very different, there are things we can do that will prevent them. Some things will prevent a few illnesses.The best things that we can do are to eat a healthy diet with lots of fruit and vegetables, to do lots of exercise and to lose weight if we are overweight. Changing our lifestyle like this can make a big difference to how long we live.The government also needs to do things, like making sure that healthy food is easy to get and that there are safe places to exercise.

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12. 'It wasn't the strategies on their own': Exploring caregivers' experiences of accessing services in the development of interventions for autistic people with intellectual disability

Authors: Hughes, Jessica;Roberts, Ruth;Tarver, Joanne;Warters-Louth, Cheryl;Zhang, Betty;Southward, Emma;Shaw, Rachel;Edwards, Georgina;Waite, Jane and Pearson, Effie

Abstract: Autistic individuals with intellectual disability are at greater risk of experiencing anxiety than their non-autistic peers without intellectual disability. Anxiety in this group may present as behaviour that challenges, often leading families to reach out to healthcare or support services. However, many families experience difficulties accessing services and, due

to the lack of research into evidence-based anxiety interventions for people with intellectual disability, may not receive individualised support once in a service. This study explored caregivers' experiences of accessing services for autistic individuals with intellectual disability, and their considerations when developing new interventions for this population. Interviews and focus groups were completed with 16 caregivers of autistic people with intellectual disability. Reflexive thematic analysis was used to develop five themes about service access experiences, and three themes about caregiver considerations for anxiety interventions. Caregivers reported that their experiences of accessing services did not meet their expectations, and considerations for future anxiety interventions were often reflective of this. Interventions being flexible to family circumstances to aid accessibility, the embedding of peer support in services, and skills that can be generalised across the lifespan could be applied when aiming to improve outcomes and develop interventions for this under-served population. Many autistic individuals with intellectual disability experience anxiety, and for those who use few or no words, anxiety may present as behaviour that challenges, such as self-injury and avoiding anxiety-provoking situations. Families report difficulty accessing support from services for autistic individuals experiencing anxiety. Moreover, once receiving support, effective interventions for autistic people with intellectual disability are limited. We completed individual and group discussions with 16 caregivers of autistic people with intellectual disability, to (a) explore their experiences of accessing services for anxiety and/or behaviour that challenges for their child; and (b) understand what matters to caregivers when developing interventions that have been designed for them and the autistic individual with intellectual disability that they support. Caregivers reported that services, in their experience, did not deliver the support that they expected, and that they often needed to 'fight' for support. Caregivers considered services and families working together, the inclusion of peer support, and families being offered interventions that are flexible to individual circumstances to be important. These considerations are valuable for clinicians and researchers developing interventions and aiming to improve outcomes for autistic people with intellectual disability and their families.

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

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

Publication Date: /07// ,2024

Journal: Dementia (14713012) 23(5), pp. 817-849

Abstract: Background: The life expectancy of people with a learning disability is increasing and with this comes a greater risk of developing dementia. Dementia poses new challenges for both family and formal learning disability carers as they try to support dementia's progressive nature and quality of life for their care recipient. This qualitative systematic review explores the evidence base of family and formal carers' experiences and needs of caring for someone with both a learning disability and dementia. Methods: Six electronic databases (PubMed, PsycINFO, Cochrane Library, Prospero, Scopus, CINAHL), were searched in May 2022, utilising a predefined search strategy. Thirteen papers fulfilled inclusion criteria and were included in in the review. Results: Thematic synthesis was used to explore and synthesise the

qualitative findings of the studies. Four conceptual themes were identified following analysis: Knowledge and skills, Accessing support, Repercussions of dementia for carers, Influences of continuity of caring role. Conclusion: There are significant training and educational needs for all carers who support the dual diagnosis of dementia and learning disability. Differences between family and formal carers relate to the organisational support and process available to formal carers. Parity across services combined with sufficiently trained carers may support dementia diagnosis and improve quality of care provided. Further research is needed to address environmental, and economic barriers carers face to facilitate ageing in place for their care recipients.

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14. Natural language acquisition and gestalt language processing: A critical analysis of their application to autism and speech language therapy

Authors: Hutchins, Tiffany L.;Knox, Sophie E. and Fletcher, E. C.

Publication Date: /05/22/ ,2024

Journal: Autism & Developmental Language Impairments , pp. 1-20

Abstract: Background and Aim: Recently, there has been a lot of interest surrounding the term gestalt language processor (GLP) which is associated with Natural Language Acquisition (NLA): a protocol intended to support the language development of autistic people. In NLA, delayed echolalia is presumed raw source material that GLPs use to acquire language in a stage-like progression from delayed echolalia to spontaneous speech. The aim of this article is to evaluate NLA in light of relevant literatures to allow scrutiny of NLA claims. Main contributions: First, we review the notion of gestalt language and situate it in the broader literature on language styles to update understanding of its significance. We then review the links from gestalt language processing to autism and identify definitional and conceptual problems and clarify the construct 'episodic memory'. We discuss the 'raw material view of delayed echolalia' and identify theoretical and empirical shortcomings. Finally, we review Blanc's language stages and their accompanying assessment and language support recommendations and challenge their validity. Conclusions & Implications: The term 'gestalt language processor' is definitionally and conceptually troubled, the assertion that autistic people are GLPs is misleading and unhelpful, and evidence is lacking that GLP represents a legitimate clinical entity. The theoretical basis of NLA lacks empirical support. NLA stages are implausible and their accompanying assessment and support recommendations lack justification. We recommend the use of alternate, individualized, theoretically-sound, evidence-based, neurodiversity-affirming supports that are sensitive and responsive to the heterogeneity that defines autism.

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15. Decision support tool for physical health (DST-PH): stratifying risks to reduce avoidable deaths in people with intellectual disability

Authors: Jaydeokar, Sujeet;Odiyoor, Mahesh;Bohen, Faye;Motterhead, Trixie and Acton, Daniel James

Publication Date: /03// ,2024

Abstract: Purpose: People with intellectual disability die prematurely and from avoidable causes. Innovative solutions and proactive strategies have been limited in addressing this disparity. This paper aims to detail the process of developing a risk stratification tool to identify those individuals who are higher risk of premature mortality. Design/methodology/approach: This study used population health management principles to conceptualise a risk stratification tool for avoidable deaths in people with intellectual disability. A review of the literature examined the existing evidence of causes of death in people with intellectual disability. A qualitative methodology using focused groups of specialist clinicians was used to understand the factors that contributed towards avoidable deaths in people with intellectual disability. Delphi groups were used for consensus on the variables for inclusion in the risk stratification tool (Decision Support Tool for Physical Health). Findings: A pilot of the Decision Support Tool for Physical Health within specialist intellectual disability service demonstrated effective utility and acceptability in clinical practice. The tool has also demonstrated good face and construct validity. A further study is currently being completed to examine concurrent and predictive validity of the tool. Originality/value: To the best of the authors' knowledge, this is the only study that has used a systematic approach to designing a risk stratification tool for identifying premature mortality in people with intellectual disability. The Decision Support Tool for Physical Health in clinical practice aims to guide clinical responses and prioritise those identified as at higher risk of avoidable deaths.

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16. Occupational Therapy Practice Guidelines for Autistic People Across the Lifespan

Authors: Patten, Kristie K.;Murthi, Kavitha;Onwumere, Dora D.;Skaletski, Emily C.;Little, Lauren M. and Tomchek, Scott D.

Abstract: Importance: Occupational therapy practitioners need evidence to support interventions that promote subjective well-being among autistic people and their families through optimal engagement and participation in occupations. Objective: These Practice Guidelines are informed by systematic reviews to expand knowledge of interventions that promote access, inclusion, engagement, and optimal participation in occupations that are meaningful to autistic people. Our intent was to foster occupational therapy practitioners' clinical decision-making and reasoning when working with autistic people and their care partners. Method: These Practice Guidelines were developed on the basis of four systematic reviews, supporting evidence and literature, along with continued revisions and integration through an iterative and collaborative process. Results: A total of 98 articles were included in the systematic reviews, which are the foundation for practice recommendations in these guidelines. Forty-eight of the systematic review articles were used to inform the clinical recommendations included in these Practice Guidelines. Conclusions and Recommendations: Strong to moderate evidence indicates the need for multidisciplinary, goal-oriented interventions to support autistic people in different contexts. Although there is only emerging evidence in the inclusion of autistic people's strengths, interests, and perspectives to guide occupational therapy interventions, such practices can enhance the delivery of neurodiversity-

affirming and trauma-informed practices. In addition, evidence is needed to support participation in activities of daily living (ADLs) for autistic youths. We recommend the use of strengths-based language to describe autistic people and the use of environmental adaptations, care partner education, and coaching to enhance occupational therapy service delivery. Plain-Language Summary: The literature is sparse regarding neurodiversity-affirming and trauma-informed practices for autistic youths, as well as for participation in activities of daily living (ADLs). These Practice Guidelines provide new information on positive mental health development; self-determination; ADLs, instrumental ADLs, play, and leisure occupations for children, adolescents, and adults; person-centered planning for adolescents and adults; and rest and sleep. Information on health management is also provided. Positionality Statement: This article uses the identity-first language autistic people. This nonableist language describes their strengths and abilities and is a conscious decision. This language is favored by autistic communities and self-advocates and has been adopted by health care professionals and researchers (Bottema-Beutel et al., 2021; Kenny et al., 2016). However, we respect the use of person-first language and have made a conscious decision to include research articles that have used this language. These Practice Guidelines support interventions that promote access, inclusion, engagement, and optimal participation in occupations that are meaningful to autistic people across the lifespan.

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17. **Menstrual education programs for girls and young women with intellectual and developmental disabilities: A systematic review**

Item Type: Journal Article

Authors: Randall, Kristina N.;Hopkins, Casey S. and Drew, Hannah

Publication Date: /07// ,2024

Journal: Journal of Applied Research in Intellectual Disabilities 37(4), pp. 1-13

Abstract: Background: Providing menstrual education and guidance for menstrual management for girls and young women with intellectual disabilities is recommended to ensure smooth pubertal transitions and to support menstrual self-agency. Method: The purpose of this systematic review is to explore menstrual education interventions for girls and young women with intellectual disabilities. Results: Nine studies were included. Interventions were provided in small groups (n = 4) and individually (n = 5). Most studies used dolls (n = 7) and task analysis (n = 7) to teach pad-replacement skills. All reported significant improvements in participant skills and/or knowledge following the intervention. Only one study addressed self-agency and self-esteem as an outcome of the intervention. Menstrual education for girls and young women with intellectual disabilities is largely focused on pad-replacement skills. Conclusion: Further research is needed to understand the impact of menstrual health and hygiene education on variables apart from skill improvement such as self-agency and long-term health outcomes related to menstrual health.

18. Mental age and intellectual disability: Psychologists' perspectives on the use of the term 'mental age' as it relates to adults with an intellectual disability

Authors: Rogers, Elaine M. and McGuire, Brian E.

Publication Date: /06// ,2024

Journal: Journal of Policy & Practice in Intellectual Disabilities 21(2), pp. 1-13

Abstract: Despite the growing international move away from the term 'mental age', the term continues to be used in some settings with adults with an intellectual disability. Arguably, the construct of 'mental age' conflicts with current rights-based approaches yet its continued use suggests that it may have certain utilities. This study aimed to explore the use of the construct of mental age in the context of supporting adults with an intellectual disability in Ireland, and its perceived value and limitations in clinical practice. Forty-three psychologists in Ireland responded to a 10-item online survey using a mix of closed and open-ended questions. Descriptive statistics were used and analysis was informed by reflexive thematic analysis. Twenty of the 43 respondents reported that mental age continues to be used in clinical practice. Analysis was informed by reflexive thematic analysis and identified five main themes: (1) negative connotations, (2) inconsistent with best practice, (3) supporting the person with an intellectual disability, (4) communicating about the person with intellectual disability and (5) moving on from mental age. The findings suggest that this construct is considered problematic and limited in its meaning and while there is a desire for change, there are challenges in finding an alternative method of communicating information about ability in a brief and easily understood way.

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19. Improving support and planning ahead for older people with learning disabilities and family carers: a mixed-methods study

Authors: Ryan, Sara;Wallace, Louise;Tilley, Elizabeth;Tuffrey-Wijne, Irene;Mikulak, Magdalena;Anderson, Rebecca;Vaid, Angeli;Bebbington, Pam;Keagan-Bull, Richard;Morrissey, Emmie and Martin, Angela

Publication Date: /06// ,2024

Journal: Health and Social Care Delivery Research 12(16), pp. 1-161

Abstract: Background: People with learning disabilities are living longer. Despite government policy to encourage people to lead supported lives in their community, family carers often maintain support due to dissatisfaction with services. This can lead to people moving from the family home in a crisis.; Objectives: (1) Find out what is known about health needs and resources for older people with learning disabilities (aged ≥ 40 years); (2) identify exemplars of good services for older people with learning disabilities; (3) explore service exemplars through ethnographic case studies; (4) evaluate support for older people with learning disabilities and their families through co-producing and testing future planning tools and (5) co-produce recommendations and resources.; Design and Methods: Work package 1 rapid scoping reviews - three reviews focused on the health and social care needs of older people with learning disabilities and 'behaviours that challenge others', and family carers, and the co-

ordination of support for this group. Work package 2 scoping and mapping exemplars of good practice - analysis of published service standards to assess excellence criteria, by mapping services, interviews (n = 30), survey (n = 9) and informal discussion with commissioners. Work package 3 ethnography of case studies of exemplar provision; independent supported living (n = 4); residential/nursing home (n = 2); day activities (n = 1), Shared Lives (n = 2). Fieldwork (20 days per model), interviews (n = 77) with older people with learning disabilities, family carers, support staff and commissioners. Work package 4 - co-producing and testing resources for older people with learning disabilities and their families involved interviews and focus groups with 36 people with learning disabilities, parents, and siblings, and experience-based co-design with 11 participants. Eight families evaluated the resources. Work package 5 - three stakeholder workshops co-produced service recommendations.; Findings: The reviews confirmed an inadequate evidence base concerning the experiences and support of family carers and older people with learning disabilities and 'behaviours that challenge others'. Criteria of excellence were produced, and a shortlist of 15 services was identified for consideration in work package 3. The ethnographic work found that environmental, organisational and social factors were important, including supporting independence and choice about who people live with, matching staff to people, consistent relationships and adapting to ageing. Practices of institutionalisation were observed. In work package 4, we found that families were worried about the future and unsupported to explore options. 'Planning Ahead' cards and a booklet to record discussions were produced, and the evaluation was positively rated. Finally, formative discussion informed recommendations. Outputs include training packages, a carers' forum, a film, a podcast and academic papers.; Conclusions: There is little focus on older people with learning disabilities and family carers. Services vary in their approach to planning for older-age support. Families are unsupported to plan, leaving people without choice. 'Behaviours that challenge others' was found to be unhelpful terminology. Recommendations: A new strategy is recommended for older people with learning disabilities and family carers that encompasses commissioning practices, professional input and peer learning, proactive support in ageing well and excellent service design.; Limitations: The COVID-19 pandemic created recruitment challenges. Reliance on providers for recruitment resulted in a lack of diversity in work package 3. Families' plans, and therefore change, may be frustrated by insufficient service resources.; Future Work: Given the lack of focus in this area, there is a range of future work to consider: experiences of older people with learning disabilities from diverse ethnic backgrounds; supporting people to age and die 'in place'; best practice regarding designing/commissioning services, including housing; the role of social workers; access to nature; accessing mainstream support; and evaluation of the 'Planning Ahead' cards.; Trial Registration: This trial is registered as ISRCTN74264887.; Funding: This award was funded by the National Institute for Health and Care Research (NIHR) Health and Social Care Delivery Research programme (NIHR award ref: NIHR129491) and is published in full in Health and Social Care Delivery Research ; Vol. 12, No. 16. See the NIHR Funding and Awards website for further award information.

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20. **Measurement tools for behaviours that challenge and behavioural function in people with intellectual disability: A systematic review and meta-analysis of internal consistency, inter-rater reliability, and test-retest reliability**

Authors: Shelley, Lauren;Jones, Chris;Pearson, Effie;Richards, Caroline;Crawford, Hayley;Paricos, Arianna;Greenhill, Courtney;Woodhead, Alixandra;Tarver, Joanne and Waite, Jane

Abstract: Behaviours that challenge (BtC) are common in people with intellectual disability (ID) and associated with negative long-term outcomes. Reliable characterisation of BtC and behavioural function is integral to person-centred interventions. This systematic review and meta-analytic study quantitatively synthesised the evidence-base for the internal consistency, inter-rater reliability, and test-retest reliability of measures of BtC and behavioural function in people with ID (PROSPERO: CRD42021239042). Web of Science, Embase, PsycINFO and MEDLINE were searched from inception to March 2024. Retrieved records (n = 3691) were screened independently to identify studies assessing eligible measurement properties in people with ID. Data extracted from 83 studies, across 29 measures, were synthesised in a series of random-effects meta-analyses. Subgroup analyses assessed the influence of methodological quality and study-level characteristics on pooled estimates. COSMIN criteria were used to evaluate the measurement properties of each measure. Pooled estimates ranged across measures: internal consistency (0.41-0.97), inter-rater reliability (0.29-0.93) and test-retest reliability (0.52-0.98). The quantity and quality of evidence varied substantially across measures; evidence was frequently unavailable or limited to a single study. Based on current evidence, candidate measures with the most evidence for internal consistency and reliability are discussed; however, continued assessment of measurement properties in ID populations is a key priority.; Competing Interests: Declaration of competing interest All authors declare that they have no conflicts of interest. (Copyright © 2024 The Authors. Published by Elsevier Ltd.. All rights reserved.)

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21. Why do we continue to exclude the most vulnerable in our society in diabetes research and education? Addressing the challenges presented by people with intellectual disability

Authors: Taggart, Laurence

Abstract: People with an intellectual disability are more likely to develop diabetes compared to their non-disabled peers. There has been a history of exclusion of people with an intellectual disability from diabetes research and education: we must now challenge this from a human rights perspective. In challenging these perceptions, we must identify the ethical and methodological reasons for exclusion and offer practical solutions to these challenges. These barriers to inclusion focus on three core areas. Firstly, individual factors concerning the person with the disability (can the person give their own informed consent, can the person read/write, completion of self-report measures?). Secondly, factors concerning the methodology and design of the research study (can studies recruit the numbers needed, can people with intellectual disability understand/accept randomisation?). And, thirdly, system/organisational factors pertaining to the enablers/barriers to engaging in and completing research studies (buy-in from senior managers, staff acting as gatekeepers, maternalistic attitudes held by gatekeepers, fidelity of intervention delivery). This Janet Kinson paper will explore these

intentional and unintentional exclusion criteria that are so often applied to people with an intellectual disability in research trial studies. This paper will dispel the myths and offer solutions for including people with an intellectual disability in diabetes research and education. Using the UK national diabetes structured education programme, DESMOND, this paper will highlight the types of reasonable adjustments that can be made to adapt this programme suitable for adults with an intellectual disability: called DESMOND-ID. This paper will demonstrate how, with reasonable adjustments, this newly-adapted DESMOND-ID education programme then can be tested within a National Institute for Health and Care Research clinical randomised control trial across the UK investigating the programme's clinical and cost-effectiveness. Copyright © 2024 John Wiley & Sons.

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22. Responding to distressed behaviour at the intersection of learning disability and neurodivergence

Authors: Udonsi, Patience

Publication Date: /06// ,2024

Journal: Learning Disability Practice 27(3), pp. 35-44

Abstract: Why you should read this article: • To enhance your understanding of neurodivergence • To recognise the need to reframe behaviours that challenge as expressions of distress or unmet needs • To contribute towards revalidation as part of your 35 hours of CPD (UK readers) • To contribute towards your professional development and local registration renewal requirements (non-UK readers). People who are neurodivergent, including autistic people, may perceive the world differently from neurotypical people. At times, this can prompt them to demonstrate so-called 'behaviour that challenges', which may be better termed 'distressed behaviour'. Distressed behaviour can occur for several reasons, from processing information to feeling unwell, tired or hungry. Some people with learning disabilities are autistic and this may increase the likelihood that they will demonstrate distressed behaviour. It is crucial that healthcare professionals who work with people with learning disabilities understand neurodivergence and are equipped to respond effectively to distressed behaviour in neurodivergent service users. This article supports these healthcare professionals to improve the quality of life of service users and those around them by understanding neurodivergence better and developing appropriate strategies for responding to distressed behaviour.

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23. The use of proxy measurement of internal states in people with intellectual disability: A scoping review

Authors: Webb, Kristen;Cuskelly, Monica and Owen, Ceridwen

Publication Date: /07// ,2024

Journal: Journal of Applied Research in Intellectual Disabilities 37(4), pp. 1-15

Abstract: Background: The measurement of internal states of people with an intellectual disability is challenging. Given these difficulties, proxy respondents are sometimes used.

However, the literature provides some caution about the validity of the use of proxy respondents. Aims: This review aims to identify the available evidence regarding the use of proxy respondents in the measurement of internal states of people with intellectual disabilities. Method: The Arksey and O'Malley scoping review framework was used for this review, refined with the Joanna Briggs Institute Methodology. Results: Results indicate there are some differences in the findings reported with respect to the efficacy of the use of proxy respondents. These may be due to a number of inconsistencies and weaknesses in examinations of their utility. Conclusions: If proxy-reports are to be useful in understanding the internal states of people with intellectual disability, researchers need to address the shortcomings revealed by this review.

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24. Psychiatric care for people with Prader-Willi syndrome—characteristics, needs and barriers

Authors: Wieting, Jelte;Herrmann, Theresa;Deest-Gaubatz, Stephanie;Eberlein, Christian Karl;Bleich, Stefan;Frieling, Helge and Deest, Maximilian

Abstract: Background: Prader-Willi syndrome (PWS) is commonly associated with intellectual disability, but also with a specific behavioural phenotype and a high predisposition to psychiatric comorbidity. This study examines the psychiatric care situation of people with PWS. Method: A structured online questionnaire was administered to carers of people with PWS living in Germany, asking about demographic, diagnostic and treatment parameters as well as personal experiences. Results: Of 77 people with PWS, 44.2% had at least one psychiatric comorbid diagnosis. The main reasons for seeking psychiatric care were emotional outbursts and aggressive behaviour. 34.9% reported that they were currently seeking psychiatric care without success. However, 32.5% of PWS had been treated with psychotropic medication, mainly antipsychotics. Conclusions: Psychiatric comorbidity appears to be undertreated in PWS, especially in the ambulatory setting. Uncertainty among mental health care providers may also lead to frequent off-label use of psychotropic medications.

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25. Eye movement desensitisation and reprocessing as a treatment for PTSD, trauma, and trauma related symptoms in children with intellectual disabilities: a general review

Authors: Williamson, Chloe Louise and Rayner-Smith, Kelly

Abstract: Purpose: This paper aims to discuss the utility of eye movement desensitization and reprocessing (EMDR) therapy as a treatment for children with intellectual disabilities (ID) who have experienced trauma. Design/methodology/approach: Relevant National Institute for Health and Care Excellence (NICE) guidance and literature were reviewed to provide support

for the use of EMDR as a treatment for trauma in children with ID. Findings: There is a growing body of evidence which demonstrates that EMDR therapy is successful for the treatment of trauma in adults and children. However, for children with ID, the research is limited despite those with ID being more likely than non-disabled peers to experience trauma such as abuse or neglect. Practical implications: EMDR can only be facilitated by trained mental health nurses, psychiatrists, psychologists (clinical, forensic, counselling or educational) or occupational therapists or social workers with additional training. Finally, general practitioners who are experienced in psychotherapy or psychological trauma and have accreditation. Therefore, this highlights that there may be a lack of trained staff to facilitate this intervention and that those who are generally working with the client closely and long term such as learning disability nurses are not able to conduct this intervention. Originality/value: This paper presents an account of NICE guidance and evidence of the efficacy of EMDR as a treatment for adults, children and those with ID.

Sources Used:

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

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