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Library Services

Current Awareness Bulletin
Learning Disability and Autism

This bulletin includes recent resources around Learning Disability and Autism. Other bulletins are available and can be found online on our Library Services webpage

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COVID related resources

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https://library.nhs.uk/coronavirus-resources/accessible-formats-2/

Our concerns about mental health, learning disability and autism services

Published: 7 May 2020

Our primary purpose is to keep people safe, and this remains the same throughout the coronavirus (COVID-19) outbreak. We continue to be concerned about mental health, learning disability and autism services, as highlighted in our restrictive practices review, and through inspection activity.

Articles

Clinicians' retrospective perceptions of failure to detect sexual abuse in a young man with autism and mild intellectual disability*

Author(s): Kildahl, Arvid Nikolai; Helverschou, Sissel Berge; Oddli, Hanne Weie

Source: Journal of Intellectual and Developmental Disability; Jun 2020; vol. 45 (no. 2); p. 194-202

Publication Type(s): Journal Peer Reviewed Journal Journal Article

Abstract: Background: Individuals with intellectual disability (ID) and autism spectrum disorder (ASD) are at increased risk of sexual abuse. However, little is known about facilitating detection and disclosure. One year after discharge from a specialised psychiatric ward, a young man with mild ID and ASD disclosed previously unknown sexual abuse. The aim of the present study was to explore clinicians' perceptions of their failure to detect abuse. Method: Interpretative phenomenological analysis was used to explore five staff members' perceptions, with data being collected through an individual, semi-structured interview. Results: Staff reported behaviours that, in retrospect, they understood as possible indicators of abuse and/or attempts by the patient to disclose. Factors contributing to non-detection included insufficient trauma sensitivity, lack of exploration, and diagnostic overshadowing. Conclusions: Symptoms of trauma should be routinely explored in individuals with ASD and ID referred for psychiatric assessment—even in the absence of known trauma or abuse. (PsycInfo Database Record (c) 2020 APA, all rights reserved) (Source: journal abstract)

"getting by": People with learning disability and the financial responsibility of independent living

Author(s): Conder, Jennifer Ann; Mirfin-Veitch, Brigit Frances

Source: British Journal of Learning Disabilities; May 2020

Publication Type(s): Journal Peer Reviewed Journal

Available at British Journal of Learning Disabilities - from Wiley Online Library Login with Athens Account details username: Athens Account password:

Abstract: Accessible summary People with learning disability who are living independently can find it hard to live well on their limited income. We interviewed 20 adults with learning disability who were living independently. They told us that living independently meant that they had choices. They also told us that it was difficult to afford things like going to dentists and doctors or going on holiday. Some liked to manage their own money while others liked having other people help them manage their money. Governments need to make sure people with learning disability are getting the support they need. Abstract Background Within Aotearoa New Zealand (ANZ), disability policy is directed at increasing choices for disabled people. However, funding to individuals remains insufficient to address wider social inequities that exist. While people with learning disability enjoy the freedom of living independently, they can be at risk of poor health outcomes and limited opportunities to fully engage within their community. Method This qualitative research explored the experience of living independently with 20 adults with learning disability within ANZ. Taking a constructivist perspective, interview transcripts were analysed to develop an understanding of their experience. Multiple readings resulted in comparison and contrast of data. The researchers discussed developing themes before settling on final themes. Results With regard to money management, two themes were identified. The first illustrates the challenges of managing a budget, while the second highlights what people's limited budgets meant in terms of how they were able to live. Conclusion This research reinforced previous studies whereby people with learning disability place a high value on having choices. However, it also demonstrated that social inequities within ANZ are not being addressed, as without other financial support, people on a benefit struggled to afford medical and dental care, or holidays and other leisure activities. (PsycInfo Database Record (c) 2020 APA, all rights reserved) (Source: journal abstract)

What works in community health education for adults with learning disabilities: A scoping review of the literature

Author(s): Owens, Rebecca; Earle, Sarah; McNulty, Cliodna; Tilley, Elizabeth

Source: Journal of Applied Research in Intellectual Disabilities; Apr 2020

Publication Type(s): Journal Peer Reviewed Journal

Available at Journal of applied research in intellectual disabilities : JARID - from Wiley Online Library Login with Athens Account details

Abstract: Background Research suggests there is insufficient good quality information regarding the effectiveness of health education aimed at adults with intellectual disabilities. By analysing the literature, this review aimed to identify what constituted effectiveness in this context. Method Relevant evaluations were extracted from bibliographic databases according to pre-specified criteria. Papers were analysed using QSR NVivo 11 by developing a narrative synthesis and analytic framework that identified and explored text addressing the research question. Results Twenty-two studies were included. The review identified two broad components of effective health education: mechanisms and context. Mechanisms included embedded programme flexibility, appropriate and accessible resources, and motivational delivery. An effective context included an accessible and supportive environment and longer term opportunities for reinforcement of learning. Conclusions Important gaps in the literature highlighted a

need for further research addressing community learning experiences of adults with intellectual disabilities as well as the effectiveness of infection prevention programmes. (PsycInfo Database Record (c) 2020 APA, all rights reserved) (Source: journal abstract)

Can we publish inclusive research inclusively? Researchers with intellectual disabilities interview authors of inclusive studies

Author(s): Riches, Tanya N.; O'Brien, Patricia M.

Source: British Journal of Learning Disabilities; Apr 2020

Publication Type(s): Journal Peer Reviewed Journal

Available at British Journal of Learning Disabilities - from Wiley Online Library Login with Athens Account details username: Athens Account password:

Abstract: Accessible summary We are a group of 17 inclusive researchers. Some have a disability, some work in the university, and some are support workers. In this paper, we interviewed 11 people who wrote inclusive research to find out what they thought. We asked how do you write inclusive research? Then, we asked two more questions: how were people with intellectual disabilities included in writing inclusive research? And, what got in the way of people with intellectual disabilities being included in writing inclusive research? We found that inclusive research is a process of learning together: listening and including people's experience of disability. The main finding was that writing and publishing inclusively in peer-reviewed literature was hard. Few researchers knew how to write or publish with people with intellectual disabilities. It will need more research to figure out how best to include people with intellectual disabilities in writing up studies. Abstract Background This study aimed to explore how researchers with intellectual disabilities were involved in writing up and publishing inclusive research, particularly in peer-reviewed journals. It was conducted over a year by members of the Centre for Disability Studies Inclusive Research Network representing 17 co-researchers (with intellectual disabilities, university and support agency staff) doing research together. Materials and Methods The research focused on facilitators/barriers to inclusive research. The main research question was as follows: "how do you write inclusive research?" As in, what did authors who had written inclusive research articles find helped people with intellectual disabilities get involved in the publication process? Also, what, if anything, got in the way of people with intellectual disabilities being involved? The group interviewed 11 university scholars with varied experience publishing collaboratively with people with intellectual disabilities (one self-identifying as disabled). Content analysis identified common themes. Results For the participants, inclusive research meant listening to and supporting people with the lived experience of disability. Researchers encountered numerous challenges in publishing, linked to what they perceived as "complex" and "unfair" universities, systems which governed funding. Instead of peer-reviewed articles, inclusive teams created many other outputs and focused on outcomes. Conclusions The main finding was that writing and publishing inclusive peer-reviewed literature was prohibitive. It would appear that those working in inclusive research are only at the start of devising ways to include their co-researchers with intellectual disabilities; it will need more research to articulate common strategies to include teams of people with intellectual disabilities in joint publications. (PsycInfo Database Record (c) 2020 APA, all rights reserved) (Source: journal abstract)

Clinical and cost effectiveness of staff training in the delivery of positive behaviour support (PBS) for adults with intellectual disabilities, autism spectrum disorder and challenging behaviour - randomised trial

Author(s): Strydom, Andre; Bosco, Alessandro; Vickerstaff, Victoria; Hunter, Rachael; Hassiotis, Angela

Source: BMC Psychiatry; Apr 2020; vol. 20

Publication Type(s): Journal Peer Reviewed Journal Journal Article

PubMedID: 32293383

Available at BMC psychiatry - from BioMed Central

Available at BMC psychiatry - from EBSCO (MEDLINE Complete)

Abstract: Background: Although Positive Behaviour Support (PBS) is a widely used intervention for ameliorating challenging behaviour (CB), evidence for its use in adults with intellectual disability (ID) and comorbid autism (ASD) is lacking. We report a planned subsidiary analysis of adults with both ASD and ID who participated in a randomised trial of PBS delivered by health professionals. Methods: The study was a multicentre, cluster randomised trial conducted in 23 community ID services in England, participants were randomly allocated to either the delivery of PBS (n = 11 clusters) or to treatment as usual (TAU; n =12). One-hundred and thirteen participants (46% of all participants in the trial) had a diagnosis of ID, autism spectrum disorder and CB (ASD+); (47 allocated to the intervention arm, and 66 to the control). CB (primary outcome) was measured with the Aberrant Behaviour Checklist total score (ABC-CT). Secondary outcomes included mental health status, psychotropic medication use, health and social care costs and quality adjusted life years (QALYs) over 12 months. Results: There were no statistically significant differences in ABC-CT between ASD+ groups randomised to the two arms over 12 months (adjusted mean difference = − 2.10, 95% CI: − 11.3 7.13, p = 0.655) or other measures. The mean incremental cost of the intervention per participant was £628 (95% CI -£1004 to £2013). There was a difference of 0.039 (95% CI − 0.028 to 0.103) for QALYs and a cost per QALY gained of £16,080. Conclusions: Results suggest lack of clinical effectiveness for PBS delivered by specialist ID clinical teams. Further evidence is needed from larger trials, and development of improved interventions. (PsycInfo Database Record (c) 2020 APA, all rights reserved) (Source: journal abstract)

Adapting a measure of quality of life to children with Down syndrome for the development of evidence-based interventions

Author(s): Gómez, Laura E.; Verdugo, Miguel A.; Rodríguez, Mar; Morán, Lucía; Arias, Víctor B.; Monsalve, Asunción

Source: Psychosocial Intervention; Apr 2020; vol. 29 (no. 1); p. 39-48

Publication Type(s): Journal Peer Reviewed Journal Journal Article

Available at Psychosocial Intervention - from Unpaywall

Abstract: Research has highlighted that no instrument with adequate evidence of validity and reliability currently exists to assess quality of life (QoL) in children with Down syndrome (DS). Important limitations have been pointed out when existing QoL instruments for children with intellectual disability are applied to this population. The

main goal of this research is to adapt the KidsLife scale by selecting the most reliable and discriminant items for children and youth with DS. The sample was composed of 405 children with DS, aged between 4 and 21 years old, attending organizations that provide educational, social, and health services. The field-test version of the KidsLife scale was administered as an informant-report, completed by someone who knew the child well, and who had opportunities to observe him/her over long periods of time in different situations. Evidence of reliability and validity based on the internal structure of the scale is provided. According to the QoL model used to develop the scale, the solution showing the best fit to the data was the one with eight intercorrelated domains. Finally, the implications of the study, its limitations and suggestions for future research are discussed. (PsycInfo Database Record (c) 2020 APA, all rights reserved) (Source: journal abstract) La investigación ha puesto de manifiesto que actualmente no existen instrumentos que presenten una adecuada evidencia de validez y fiabilidad para evaluar la calidad de vida (CV) de los niños con síndrome de Down (SD). De hecho, se encuentran importantes limitaciones cuando se aplican a esta población instrumentos de CV diseñados para personas con discapacidad intelectual. El principal objetivo de este trabajo es adaptar la escala KidsLife seleccionando los ítems más fiables y con mayor poder discriminativo para los jóvenes con SD. La muestra estaba formada por 405 jóvenes con SD, con edades comprendidas entre los 4 y los 21 años que asistían a organizaciones proveedoras de servicios educativos, sociales y de salud. La versión piloto de la escala KidsLife la contestó un informante que conocía al joven o a la joven bien, teniendo la oportunidad de observarle durante periodos prolongados de tiempo en diferentes situaciones. Se proporcionan pruebas de la fiabilidad y validez basadas en la estructura interna de la escala. De acuerdo con el modelo de CV utilizado para el desarrollo de la escala, la solución que mostró mejor ajuste a los datos fue la de ocho dimensiones correlacionadas. Finalmente, se discuten las implicaciones del estudio, sus limitaciones y se hacen sugerencias para la investigación futura. (PsycInfo Database Record (c) 2020 APA, all rights reserved) (Source: journal abstract)

Practice parameter for the assessment and treatment of psychiatric disorders in children and adolescents with intellectual disability (intellectual developmental disorder)

Author(s): Siegel, Matthew; McGuire, Kelly; Veenstra-VanderWeele, Jeremy; Stratigos, Katharine; King, Bryan

Source: Journal of the American Academy of Child & Adolescent Psychiatry; Apr 2020; vol. 59 (no. 4); p. 468-496

Publication Type(s): Journal Peer Reviewed Journal Journal Article

Available at Journal of the American Academy of Child & Adolescent Psychiatry - from Unpaywall

Abstract: Intellectual disability (intellectual developmental disorder) (ID/IDD) is both a psychiatric disorder and a risk factor for co-occurring psychiatric disorders in children and adolescents. DSM-5 introduced important changes in the conceptualization and diagnosis of ID/IDD, and current research studies clarify assessment and treatment of co-occurring psychiatric disorders in this population. Optimal assessment and treatment of psychiatric illness in children and adolescents with ID/IDD includes modifications in diagnostic and treatment techniques, appreciation of variations in the clinical presentation of psychiatric disorders, an understanding of the spectrum of etiologies of behavioral

disturbance, and knowledge of psychosocial and medical interventions. (PsycInfo Database Record (c) 2020 APA, all rights reserved) (Source: journal abstract)

Prevalence of dementia in people with intellectual disabilities: Cross-sectional study

Author(s): Takenoshita, Shintaro; Terada, Seishi; Kuwano, Ryozo; Inoue, Tomokazu; Cyoju, Atsushi; Suemitsu, Shigeru; Yamada, Norihito

Source: International Journal of Geriatric Psychiatry; Apr 2020; vol. 35 (no. 4); p. 414-422

Publication Type(s): Journal Peer Reviewed Journal Journal Article

Available at International journal of geriatric psychiatry - from Wiley Online Library Medicine and Nursing Collection 2019 - NHS

Abstract: Background: There are only a few studies of the prevalence of dementia in people with intellectual disability (ID) without Down syndrome (DS), and there is a large difference in the prevalences between reported studies. Moreover, the prevalence of mild cognitive impairment (MCI) in ID has not been reported. We aimed to evaluate the prevalence of dementia in adults of all ages and the prevalence of MCI in people with ID. Furthermore, we tried to clarify the differences depending on the various diagnostic criteria. Methods: The survey included 493 adults with ID at 28 facilities in Japan. The caregivers answered a questionnaire, and physicians directly examined the participants who were suspected of cognitive decline. Dementia and MCI were diagnosed according to ICD-10, DC-LD, and DSM-5 criteria. Results: The prevalence of dementia was 0.8% for the 45 to 54 years old group, 3.5% for the 55 to 64 years old group, and 13.9% for the 65 to 74 years old group in people with ID without DS. The prevalence of MCI was 3.1% for patients 45 to 54, 3.5% for patients 55 to 64, and 2.8% for patients 65 to 74 with ID without DS. DSM-5 was the most inclusive in diagnosing dementia and MCI in people with ID. Conclusions: People with ID without DS may develop dementia and MCI at an earlier age and higher rate than the general population. Among the diagnostic criteria, DSM- 5 was the most useful for diagnosing their cognitive impairment. (PsycInfo Database Record (c) 2020 APA, all rights reserved) (Source: journal abstract)

Making sense of complexity: A qualitative investigation into forensic learning disability nurses' interpretation of the contribution of personal history to offending behaviour

Author(s): Lovell, Andrew; Skellern, Joanne

Source: British Journal of Learning Disabilities; Apr 2020

Publication Type(s): Journal Peer Reviewed Journal

Available at British Journal of Learning Disabilities - from Wiley Online Library Login with Athens Account details username: Athens Account password:

Abstract: Accessible Summary The role of an individual's personal history is important in influencing their development, especially whether they are likely to offend or engage in violent behaviour Learning disability nurses relationships with those with a history of violence or offending will improve with a more informed knowledge of how someone's offending behaviour is related to their background People with a learning disability can be supported best when the complexity of their lives is fully understood and properly

informs the therapeutic relationship. Abstract Background There is growing recognition that an individual's personal history can be extremely influential in shaping their future experience, though there has been a limited exploration in the context of learning disability and offending behaviour. Method Research questions related to participant interpretation of offending behaviour and individual and service responses. A series of focus groups comprising learning disability forensic nurses were conducted across all secure settings, high, medium and low. Results Three themes were produced: interpreting offending behaviour; the impact of personal history; responding therapeutically. The difficulties relating to understanding the relationship between offending behaviour and personal history significantly informed the construction of the most effective therapeutic relationships. Conclusions An increased focus on the impact of someone's background might inform nursing as it seeks to deliver care to individuals with increasingly complex needs in a time of service transition. (PsycInfo Database Record (c) 2020 APA, all rights reserved) (Source: journal abstract)

Relation between processing facial identity and emotional expression in typically developing school-age children and those with Down syndrome

Author(s): Barisnikov, Koviljka; Thomasson, Marine; Stutzmann, Jennyfer; Lejeune, Fleur

Source: Applied Neuropsychology: Child; 2020; vol. 9 (no. 2); p. 179-192

Publication Type(s): Journal Peer Reviewed Journal Journal Article

Abstract: The main purposes of this research were to examine the relation between the processing of face identity and emotion expressions and then discern the significance of emotional expressions using Bruce et al. tasks. Two studies were conducted. Study 1 examined 225 typically developing (TD) children age 4 to 12. Results suggested that early recognition of complete faces and interpretation of emotional expression might depend on local processing abilities, while the recognition of masked faces and emotion expression matching seemed to share configural processing. Study 2 compared 22 children with Down syndrome (DS) to two TD groups matched on mental age (MA group) and chronological age (CA group). Results showed that children with DS processed the identity of complete faces (local processing) similarly to the MA and CA groups. In contrast, their performances for masked faces (configural processing) indicated a developmental delay as they were only comparable to the MA group. Children with DS were also able to identify the emotion expressions according to labels as well as the two control groups, while they had more difficulties on the matching condition. Furthermore, specific difficulties in processing the surprise expression were observed, rather than general difficulties in encoding emotion expressions. Finally, their performances on emotion matching tasks seemed to be supported by local information processing, which might explain their lower scores compared to CA controls that mainly used configural information. These results could aid in the development of targeted interventions for DS to improve their social skills. (PsycInfo Database Record (c) 2020 APA, all rights reserved) (Source: journal abstract)

Path learning in individuals with Down syndrome: The floor matrix task and the role of individual visuo-spatial measures

Author(s): Meneghetti, Chiara; Toffalini, Enrico; Lanfranchi, Silvia; Carretti, Barbara

Source: Frontiers in Human Neuroscience; Mar 2020; vol. 14

Publication Type(s): Journal Peer Reviewed Journal Journal Article

Available at Frontiers in human neuroscience - from Europe PubMed Central - Open Access

Available at Frontiers in human neuroscience - from Unpaywall

Abstract: Environment learning is essential in everyday life. In individuals with Down syndrome (DS), this skill has begun to be examined using virtual exploration. Previous studies showed that individuals with DS can learn and remember paths in terms of sequences of turns and straight stretches, albeit with some difficulty, and this learning is supported by their cognitive abilities. This study further investigates environment learning in the DS population, newly examining their ability to learn a path from actual movements, and to learn increasingly long paths, and how their performance relates to their visuo-spatial abilities and everyday spatial activities. A group of 30 individuals with DS and 30 typically-developing (TD) children matched for receptive vocabulary performed a 4 × 4 Floor Matrix task in a grid comprising 16 squares (total area 2.3 × 2.3 meters). The task involved repeating increasingly long sequences of steps by actually moving in the grid. The sequences were presented in two learning conditions, called Observation (when participants watched the experimenter's moves), or Map (when they were shown a map reproducing the path). Several visuo-spatial measures were also administered. The results showed a clear difference between the two groups' performance in the individual visuo-spatial measures. In the Floor Matrix task, after controlling for visuo-spatial reasoning ability, both groups benefited to the same degree from the Observation condition vis-à-vis the Map condition, and no group differences emerged. In the group with DS, visuo-spatial abilities were more predictive of performance in the Floor Matrix task in the Observation condition than in the Map condition. The same was true of the TD group, but this difference was much less clear-cut. The visuo-spatial working memory and visualization tasks were the strongest predictors of Floor Matrix task performance. Finally, the group with DS showed a significant relation between Floor Matrix task performance in the Observation condition and everyday spatial activity. These results enlarge on what we know about path learning in individuals with DS and its relation to their visuo-spatial abilities. These findings are discussed within the frame of spatial cognition and the atypical development domain. (PsycInfo Database Record (c) 2020 APA, all rights reserved) (Source: journal abstract)

Using a daily report card to reduce off-task behaviors for a student with autism spectrum disorder

Author(s): Riden, Benjamin S.; Taylor, Jonté C.; Ruiz, Sal; Lee, David L.; Scheeler, Mary Catherine

Source: Journal of Behavioral Education; Mar 2020

Publication Type(s): Journal Peer Reviewed Journal

Abstract: AbstractDaily behavior report cards (DBRCs) have shown promise in reducing problematic classroom behaviors. The effectiveness of DBRCs has been used widely examined with respect to students with attention deficit hyperactivity disorder, specific learning disabilities, and other high incidence disabilities. Past research has primarily focused on students in primary grades, with a limited number of studies examining students in secondary grades, in particular students in high school. Even fewer studies

have examined the effectiveness of DBRCs implemented by novice special educators. The purpose of the current study was twofold: (1) to examine the effectiveness of a DBRC in reducing off-task classroom behavior for a high school student with autism spectrum disorder (ASD) and (2) to evaluate the delivery of an intensive intervention by a novice special education teacher. A preservice special education teacher implemented the intervention. A changing criterion design was used to examine the effectiveness of the intervention. We analyzed the data using visual analysis and calculated effect sizes using Tau-U. The results suggested that DBRCs are an acceptable and effective treatment for reducing off-task behavior with a student with ASD when implemented by a novice special education teacher. Data were collected to measure the novice teacher's implementation fidelity. Additionally, the results showed that a novice special education teacher can be trained to implement a behavior management program for a student presenting inappropriate classroom behaviors with high fidelity. (PsycInfo Database Record (c) 2020 APA, all rights reserved) (Source: journal abstract)

Meta-analysis of cognitive performance in neurodevelopmental disorders during adulthood: Comparisons between autism spectrum disorder and schizophrenia on the Wechsler Adult Intelligence Scales

Author(s): Kuo, Susan S.; Eack, Shaun M.

Source: Frontiers in Psychiatry; Mar 2020; vol. 11

Publication Type(s): Journal Peer Reviewed Journal Journal Article

Available at Frontiers in psychiatry - from Europe PubMed Central - Open Access

Available at Frontiers in psychiatry - from Unpaywall

Abstract: Autism Spectrum Disorder (ASD) and schizophrenia are neurodevelopmental disorders which show substantial cognitive heterogeneity in adulthood, yet it remains unclear whether cognitive profiles may overlap across these diagnoses. Thus, the aim of this review was to summarize comparisons between ASD and schizophrenia on nonsocial cognition in adulthood. To minimize between-study heterogeneity in a relatively small literature, subtest scaled scores from the Wechsler Adult Intelligence Scale were compared between ASD (N = 190) and schizophrenia (N = 260) in six studies comprising a total of 450 participants. Meta-analyses of 11 subtests indicated that participants with ASD demonstrated significantly better performance than schizophrenia for visuospatial perception and reasoning and problem solving (Hedge's g = 0.636), as well as visual attention and organization (g = 0.433-0.475). Participants with ASD also demonstrated better performance than those with schizophrenia for working memory (g = 0.334) and language (g = 0.275), and generally comparable performance on processing speed and verbal comprehension. These findings were largely stable across age, sex, intelligence quotient (IQ), intellectual disability, scale version, and age- and sex-matching. Overall, ASD and schizophrenia showed striking differences in visuospatial perception and reasoning and problem solving, small differences in working memory and language, and substantial overlap in processing speed and verbal comprehension. These cognitive profiles were generally stable from adolescence to middle adulthood. To our knowledge, this is the first review to summarize comparisons of nonsocial cognition in verbal adults with ASD or schizophrenia. These findings are consistent with and substantially extend prior meta-analyses of case-control studies for ASD and schizophrenia (8, 9), which also suggest that, in comparison to neurotypical controls, ASD demonstrates smaller cognitive impairments than schizophrenia across most

cognitive domains, particularly working memory, visuospatial learning/memory, and language. Our findings therefore highlight the importance of comparing cognition transdiagnostically to inform the etiologies of these neurodevelopmental disorders and to refine shared and unique targets for remediating cognition. (PsycInfo Database Record (c) 2020 APA, all rights reserved) (Source: journal abstract)

Biopsychosocial factors associated with depression and anxiety in older adults with intellectual disability: Results of the wave 3 intellectual disability supplement to the irish longitudinal study on ageing

Author(s): Bond, L.; Carroll, R.; Mulryan, N.; O'Dwyer, M.; O'Connell, J.; Monaghan, R.; Sheerin, F.; McCallion, P.; McCarron, M.

Source: Journal of Intellectual Disability Research; Mar 2020

Publication Type(s): Journal Peer Reviewed Journal

Available at Journal of intellectual disability research : JIDR - from Wiley Online Library Medicine and Nursing Collection 2019 - NHS

Abstract: Background Depression and anxiety are amongst the most prevalent mental health disorders in the older population with intellectual disability (ID). There is a paucity of research that pertains to associative biopsychosocial factors for depression and anxiety in this population. The aim of this study is to determine the biopsychosocial factors associated with depression and anxiety in a population of older adults with ID in Ireland. Methods The study was part of 'The Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing'. Depressive symptoms were assessed using the Glasgow Depression Scale for people with a Learning Disability. Anxiety symptoms were measured using the Glasgow Anxiety Scale for people with a Learning Disability. The cross-sectional associations of depression and anxiety with biopsychosocial parameters were measured using a variety of self-report and proxy-completed questionnaires. Results For the study population, 9.97% met the criteria for depression, and 15.12% met the criteria for an anxiety disorder. Participants meeting criteria for depression were more likely to be taking regular mood stabiliser medications and to exhibit aggressive challenging behaviour. Participants meeting criteria for anxiety were more likely to have sleep difficulties and report loneliness. Participants meeting criteria for either/both depression and anxiety were more likely to report loneliness. Conclusions This study identified both treatable and modifiable, as well as unmodifiable, biopsychosocial factors associated with depression and/or anxiety in older adults with ID. A longitudinal study follow-up will further develop our knowledge on the causality and direction of associated biopsychosocial factors with depression and anxiety in older adults with ID and better inform management strategies, prevention policies and funding of services. (PsycInfo Database Record (c) 2020 APA, all rights reserved) (Source: journal abstract)

Teaching a physical activity to students with mild to moderate intellectual disability using a peer-delivered simultaneous prompting procedure: A single-case experimental design study

Author(s): Park, Gwitaek; Collins, Belva C.; Lo, Ya-yu

Source: Journal of Behavioral Education; Mar 2020

Publication Type(s): Journal Peer Reviewed Journal

Abstract: AbstractAppropriate physical education program for students with an intellectual disability can increase their engagement in inclusive physical activity; however, fewer than a quarter of students with an intellectual disability meet the current physical activity guidelines. In this study, we used a single-case multiple probe across participants design to examine the effects of a peer-delivered simultaneous prompting procedure on a chained task of shooting a basketball and nontargeted (The term "collateral skill" is sometimes used) content learning (related to fine motor, gross motor, and movement knowledge). Four middle school students with mild to moderate intellectual disability participated in this study. Three students without a disability served as the peer tutors to deliver the simultaneous prompting procedure and to collect probe data. The study took place in an inclusive physical education setting. Results of the study demonstrated a functional relation between the participants' improved motor performance of basketball shooting and the intervention. All three participants with available maintenance data retained their chained motor performance up to 2 or 3 weeks after the intervention ended; however, only one participant slightly improved the nontargeted content learning. Limitations and implications for practice and future research are discussed. (PsycInfo Database Record (c) 2020 APA, all rights reserved) (Source: journal abstract)

Expressive language sampling as a source of outcome measures for treatment studies in fragile X syndrome: Feasibility, practice effects, test-retest reliability, and construct validity

Author(s): Abbeduto, Leonard; Berry-Kravis, Elizabeth; Sterling, Audra; Sherman, Stephanie; Edgin, Jamie O.; McDuffie, Andrea; Hoffmann, Anne; Hamilton, Debra; Nelson, Michael; Aschkenasy, Jeannie; Thurman, Angela John

Source: Journal of Neurodevelopmental Disorders; Mar 2020; vol. 12

Publication Type(s): Journal Peer Reviewed Journal Journal Article

Available at Journal of neurodevelopmental disorders - from BioMed Central

Available at Journal of neurodevelopmental disorders - from ProQuest (Health Research Premium) - NHS Version

Abstract: [Correction Notice: An Erratum for this article was reported in Vol 12[11] of Journal of Neurodevelopmental Disorders (see record 2020-24703-001). In the original article, the author name Leonard Abbeduto was misspelled as Leonardkk Abbeduto. The original article has been corrected.] Background: The evaluation of treatment efficacy for individuals with fragile X syndrome (FXS) or intellectual disability (ID) more generally has been hampered by the lack of adequate outcome measures. We evaluated expressive language sampling (ELS) as a procedure for generating outcome measures for treatment research in FXS. We addressed: (a) feasibility, (b) practice effects over two administrations, (c) test-retest reliability over the repeated administrations, and (d) construct validity. We addressed these issues for the full sample as well as for subgroups defined by age, IQ, and ASD status. Methods: Participants were 106 individuals with FXS between ages 6 and 23 years who had IQs within the range of intellectual disability ($IQ \leq 70$). ELS procedures for collecting samples in conversation and narration were followed and analyzed separately. Five measures were derived from transcripts segmented into C-units (i.e., an independent clause and its modifiers): number of C-units per minute (talkativeness), number of different word roots (vocabulary), C-unit length in morphemes (syntax), percentage of C-units containing dysfluency (utterance planning),

and percentage of C-units that were fully or partly unintelligible (articulatory quality). ELS procedures were administered twice at 4-week intervals for each participant. Standardized tests and informant reports were administered and provided measures for evaluating construct validity of ELS measures. Results: We found low rates of noncompliance, suggesting the task can be completed meaningfully by most individuals with FXS, although noncompliance was higher for younger, lower IQ, and more autistic participants. Minimal practice effects and strong test-retest reliability over the 4-week interval were observed for the full sample and across the range of ages, IQs, and autism symptom severity. Evidence of convergent construct validity was observed for the measures of vocabulary, syntax, and unintelligibility for the full sample and across the range of IQ and autism symptom severity, but not for participants under age 12. Conversation and narration yielded largely similar results in all analyses. Conclusions: The findings suggest that the ELS procedures are feasible and yield measures with adequate psychometric properties for a majority of 6 to 23 years with FXS who have ID. The procedures work equally well regardless of level of ID or degree of ASD severity. The procedures, however, are more challenging and have somewhat less adequate psychometric properties for individuals with FXS under age 12. (PsycInfo Database Record (c) 2020 APA, all rights reserved) (Source: journal abstract)

Declarative memory and structural language impairment in autistic children and adolescents

Author(s): Anns, Sophie; Gaigg, Sebastian B.; Hampton, James A.; Bowler, Dermot M.; Boucher, Jill

Source: Autism Research; Mar 2020

Publication Type(s): Journal Peer Reviewed Journal

Available at Autism research : official journal of the International Society for Autism Research - from Wiley Online Library Medicine and Nursing Collection 2019 - NHS

Abstract: Two experiments tested the hypothesis that a plausible contributory factor of structural language impairment in Autism Spectrum Disorder (ASD) is impaired declarative memory. We hypothesized that familiarity and recollection (subserving semantic and episodic memory, respectively) are both impaired in autistic individuals with clinically significant language impairment and learning disability (ASDLI/LD); whereas recollection is selectively impaired in autistic individuals with typical language (ASDTL). Teenagers with ASDLI/LD (n = 19) and primary school age children with ASDTL (n = 26) were compared with teenagers with learning disability (LD) (n = 26) without autism, and primary school aged typically developing (TD) children (n = 32). Both experiments provided strong support for the hypothesized links between declarative memory processes and lexical-semantic facets of language in the two autistic groups, but not in the TD group. Additional findings of interest were that declarative memory processes and lexical-semantic knowledge were also linked in the LD group and that the ASD groups—and to a lesser extent the LD group—may have compensated for declarative memory impairments using spared visual-perceptual abilities, a finding with potential educational implications. Relative difficulties with familiarity and recollection in ASDLI/LD and LD may help explain structural language impairment, as investigated here, but also the broader learning disabilities found in these populations. Autism Res 2020. © 2020 International Society for Autism Research, Wiley Periodicals, Inc. Lay Summary Language impairment and learning disability affect 45% of the autistic population yet the factors that may be contributing to them is remarkably under-

researched. To date there are no explanations of the lexical semantic (word meaning) abnormalities observed in ASD. We found that declarative memory is associated with lexical semantic knowledge in autism and learning disability but not in typical development. Difficulties with declarative memory may also be compensated for using visual-perceptual abilities by autistic and learning-disabled adolescents, which has positive implications for educationalists. (PsycInfo Database Record (c) 2020 APA, all rights reserved) (Source: journal abstract)

Feelings of hopelessness in mothers of children with neurodevelopmental disorders

Author(s): Hemati Alamdarloo, Ghorban; Majidi, Farzad

Source: International Journal of Developmental Disabilities; Mar 2020

Publication Type(s): Journal Peer Reviewed Journal

Available at International Journal of Developmental Disabilities - from Maney Online Sign in under Institutional Access and choose OpenAthens Federation from the geographic list then click on Coventry & Warwickshire P/Trust and enter Athens details

Available at International Journal of Developmental Disabilities - from Coventry & Warwickshire Partnership Trust Libraries Print holdings Local Print Collection
, [location] : Brian Oliver Centre Library - Coventry & Warwickshire Partnership NHS Trust. [title_notes] : formerly British Journal of Developmental Disabilities.

Abstract: The aim of the present study was to compare feelings of hopelessness in mothers of children with neurodevelopmental disorders. The statistical population of the study included all mothers of children with neurodevelopmental disorders in Shiraz, Iran. The sample consisted of 150 mothers of children with neurodevelopmental disorders, including 50 mothers of children with autism spectrum disorder (ASD), 50 mothers of children with intellectual disability (ID), and 50 mothers of children with specific learning disorder (SLD) and they were selected by convenience sampling method. The data were collected during the years 2015–2016. The Beck Hopelessness Scale (BHS; Beck et al.) was used for measuring the feelings of hopelessness. The one-way ANOVA and MANOVA tests were used for the data analysis. The results showed that the feelings of hopelessness and the two subscales of feelings of hopelessness, i.e. negative expectations of the future and the loss of motivation in association with the future, in mothers of children with ASD were significantly higher than those of the other two groups of mothers. It was also observed that mothers of children with ID, compared to mothers of children with SLD, had higher levels of feelings of hopelessness, negative expectations of the future, and negative feelings in association with the future. Additionally, the findings revealed that mothers of children with ASD, compared to mothers of children with SLD, had higher levels of negative feelings in association with the future. Therefore, adopting preventive and intervention programs which can help mothers of children with neurodevelopmental disorders, especially mothers of children with ASD, to overcome their feelings of hopelessness are of great importance. (PsycINFO Database Record (c) 2020 APA, all rights reserved) (Source: journal abstract)

The effect of probabilistic context on implicit temporal expectations in Down Syndrome

Author(s): Mento, Giovanni; Scerif, Gaia; Granziol, Umberto; Franzoi, Malida; Lanfranchi, Silvia

Source: Frontiers in Psychology; Mar 2020; vol. 11

Publication Type(s): Journal Peer Reviewed Journal Journal Article

Available at Frontiers in psychology - from Europe PubMed Central - Open Access

Abstract: One of the most important sources of predictability that human beings can exploit to create an internal representation of the external environment is the ability to implicitly build up subjective statistics of events' temporal structure and, consequently, use this knowledge to prepare for future actions. Stimulus expectancy can be subjectively shaped by hierarchically nested sources of prediction, capitalizing on either local or global probabilistic rules. In order to better understand the nature of local-global proactive motor control in Down Syndrome, in the present study a group of participants with Down Syndrome (DS group; n = 28; mean age 29.5 ± 13 years; range 10–54) and a group of typically developing participants matched by either gender or mental age (TD-MA group; n = 28; 5.6 ± 1 years; range 4–8) were administered a novel motor preparation task, defined as the Dynamic Temporal Prediction (DTP) task. In the DTP, the temporal preparation to imperative stimuli is implicitly shaped by the local increase of expectancy. This is manipulated trial-by-trial as a function of the preparatory fore-period interval (Stimulus-Onset Asynchrony or SOA). In addition, temporal preparation can be also implicitly adjusted as a function of global predictive context, so that a block-wise SOA-distribution bias toward a given preparatory interval might determine a high-order source of expectancy, with functional consequences on proactive motor control adjustment. Results showed that in both groups motor preparation was biased by temporal expectancy when this was locally manipulated within-trials. By contrast, only the TD-MA group was sensitive to global rule changes: only in this cohort was behavioral performance overall impacted by the SOA probabilistic distribution manipulated between-blocks. The evidence of a local-global dissociation in DS suggests that the use of flexible cognitive mechanisms to implicitly extract high-order probabilistic rules in order to build-up an internal model of the temporal properties of events is disrupted in this developmental disorder. Moreover, since the content of the information to be processed in the DTP task was neither verbal nor spatial, we suggest that atypical global processing in Down Syndrome is a domain-general rather than specific aspect characterizing the cognitive profile of this population. (PsycInfo Database Record (c) 2020 APA, all rights reserved) (Source: journal abstract)

The Girona declaration on borderline intellectual functioning

Author(s): Martínez-Leal, Rafael; Folch, Annabel; Munir, Kerim; Novell, Ramon; Salvador-Carulla, Luis

Source: The Lancet Psychiatry; Mar 2020; vol. 7 (no. 3); p. e8

Publication Type(s): Journal Peer Reviewed Journal Journal Article

Available at The lancet. Psychiatry - from Unpaywall

Abstract: With the development of the latest DSM and ICD classifications, borderline intellectual functioning has ceased to be conceptualised as a diagnostic code and is increasingly less a focus of clinical attention. Even though DSM 5 does not provide a specific recommendation for identification of borderline intellectual functioning, unlike the ICD, it advocates an innovative non-Gaussian neurodevelopmental approach to

differential diagnosis between mild intellectual disability/intellectual developmental disorder (ID/IDD) and borderline intellectual functioning. The absence of a definition of borderline intellectual functioning therefore begs the question as to how such a differential diagnosis can be made between mild ID/IDD and borderline intellectual functioning in the absence of any specified criteria—an obvious contradiction in terms. (PsycINFO Database Record (c) 2020 APA, all rights reserved)

Lexical decision performance using the divided visual field technique following training in adults with intellectual disabilities with and without Down syndrome

Author(s): Mashal, Nira; Yankovitz, Bat-el; Lifshitz, Hefziba

Source: Laterality: Asymmetries of Body, Brain and Cognition; Mar 2020; vol. 25 (no. 2); p. 177-197

Publication Type(s): Journal Peer Reviewed Journal Journal Article

Abstract: Studies of brain lateralization in individuals with non-specific intellectual disability and Down syndrome suggest atypical brain lateralization to speech perception. According to the biological dissociation model, the right hemisphere (RH) mediates speech perception and the left hemisphere (LH) mediates motor control in Down syndrome. The current study aimed to test, for the first time, brain lateralization in both non-specific intellectual disability and Down syndrome, compared to individuals with typical development. Furthermore, bilateral word presentation was utilized to assess interhemispheric communication. Twenty adults with non-specific intellectual disability, 14 adults with Down syndrome, and 30 adults with typical development participated in the study. Participants in the non-specific intellectual disability and Down syndrome groups were trained to perform the task prior to the experiment. The results showed that whereas hemispheric lateralization did not differ between individuals with non-specific intellectual disability and typical development, individuals with DS showed reduced brain lateralization in comparison to adults with typical development. All three groups showed no significant difference between words presented to the LH and bilaterally. Our results also show that individuals with intellectual disabilities can benefit from training programmes and that they may perform equally as fast as their typically developing peers. (PsycINFO Database Record (c) 2020 APA, all rights reserved) (Source: journal abstract)

The association of paternal IQ with autism spectrum disorders and its comorbidities: A population-based cohort study

Author(s): Gardner, Renee M.; Dalman, Christina; Rai, Dheeraj; Lee, Brian K.; Karlsson, Håkan

Source: Journal of the American Academy of Child & Adolescent Psychiatry; Mar 2020; vol. 59 (no. 3); p. 410-421

Publication Type(s): Journal Peer Reviewed Journal Journal Article

Abstract: Objective: Original case descriptions of autism noted that parents of the affected children tended to be highly educated and intelligent, a characterization that has

endured publicly. Recent genetic studies indicate that risk for autism spectrum disorders (ASD) is associated with high intelligence. We examined the association between paternal intelligence and ASD, considering co-occurring intellectual disability (ID) and attention-deficit/hyperactivity disorder (ADHD). Method: We used a register-based cohort study design including 360,151 individuals with fathers conscripted to the Swedish military, resident in Stockholm, Sweden, born from 1984 to 2008, and followed until December 31, 2011, for diagnosis of ASD, ADHD, and/or ID. Risk of neurodevelopmental disorders relative to paternal IQ (rated on a 9-point scale) was assessed using a score of 5 (average intelligence) as the referent in models accounting for potentially nonlinear relationships and clustering of siblings. Results: We observed an association between high paternal IQ and offspring risk of ASD without ID/ADHD in models adjusted for individual and family characteristics (OR IQ = 9 1.32, 95% CI 1.15−1.52), an association that appeared to be driven largely by the fathers' score on the technical comprehension portion of the test (OR Technical IQ = 9 1.53, 95% CI 1.31−1.78). Conversely, low paternal IQ was associated with ASD + ID (OR IQ = ı1.78, 95% CI 1.27−2.49) and ASD + ADHD (OR IQ = 11.40, 95% CI 1.16−1.70); low paternal IQ was strongly associated with ID (OR IQ = 1 4.46, 95% CI 3.62−5.49) and present also for ADHD (OR IQ = 11.56, 95% CI 1.42−1.72)] without co-occurring ASD or ID. Conclusion: The relationship between paternal IQ and offspring risk of ASD was nonmonotonic and varied by the presence of co-occurring disorders, probably reflecting phenotypic diversity among affected individuals. (PsycInfo Database Record (c) 2020 APA, all rights reserved) (Source: journal abstract)

Relations between everyday executive functioning and language in youth with down syndrome and youth with autism spectrum disorder

Author(s): Udhnani, Manisha; Perez, Megan; Clasen, Liv S.; Adeyemi, Elizabeth; Lee, Nancy Raitano

Source: Developmental Neuropsychology; 2020; vol. 45 (no. 2); p. 79-93

Publication Type(s): Journal Peer Reviewed Journal Journal Article

Abstract: Language and executive functioning are major impairments in many neurodevelopmental disorders, but little is known about the relations between these constructs, particularly using parent-report. Thus, the current research sought to examine relations between executive function and language in two groups-Down syndrome (DS; n = 41; M age = 11.2) and autism spectrum disorder (ASD; n = 91; M age = 7.7). Results were as follows: in DS, executive function predicted pragmatic, but not structural language after covarying for age, sex, and social functioning; in ASD, executive function predicted both. Findings highlight the interrelatedness of language and executive functioning and may have implications for intervention development. (PsycINFO Database Record (c) 2020 APA, all rights reserved) (Source: journal abstract)

24. Parents' perspectives on participation of young children with attention deficit hyperactivity disorder, developmental coordination disorder, and/ or autism spectrum disorder: A systematic scoping review

Author(s): Coussens, Marieke; Van Driessen, Evy; De Baets, Stijn; Van Regenmortel, Jasmine; Desoete, Annemie; Oostra, Ann; Vanderstraeten, Guy; Waelvelde, Hilde Van; Van de Velde, Dominique

Source: Child: Care, Health and Development; Mar 2020; vol. 46 (no. 2); p. 232-243

Publication Type(s): Journal Peer Reviewed Journal Journal Article

Available at Child: care, health and development - from Wiley Online Library Medicine and Nursing Collection 2019 - NHS

Abstract: Background: During the early years of a child's life, participation is essential for learning and development. Children with disabilities are at risk for decreased participation. The interplay between environment and participation is identified as one of the most important factors influencing successful participation. The objective of this scoping review was to synthesize peer-reviewed literature about barriers and facilitators of participation according to the perspective of parents of children younger than 6 years with Attention Deficit Hyperactivity Disorder (ADHD), Autism Spectrum Disorder (ASD), and/ or Developmental Coordination Disorder (DCD). Methods: The scoping review followed Arksey and O'Malley's framework. Relevant studies were identified by a comprehensive search of scientific databases (PubMed and Web of Science). Studies describing perspectives of parents regarding their child's participation, written in English, and published between 2001 and September 2017 were included. Results: A total of 854 articles were retrieved, with 13 meeting the criteria. Elements contributing to perceived barriers and facilitators were identified and organized according to the International Classification of Functioning, Child–Youth framework. Concepts contained in these studies were linked to "activities and participation" (general tasks and demands, such as bedtime and dinner routines, and social, civic life, such as play and leisure). Environment-focused factors identified were situated on "support and relationships, " "attitudes, " and "services, systems, and policies." Conclusion: The review revealed guidelines focusing on family-centred care, communication with, and providing information to parents with young children with developmental disabilities (ADHD, DCD, and/ or ASD). (PsycINFO Database Record (c) 2020 APA, all rights reserved) (Source: journal abstract)

Osteoporosis pathology in people with severe motor and intellectual disability

Author(s): Sakai, Tomoko; Honzawa, Shiho; Kaga, Makiko; Iwasaki, Yuji; Masuyama, Tatsuo

Source: Brain & Development; Mar 2020; vol. 42 (no. 3); p. 256-263

Publication Type(s): Journal Peer Reviewed Journal Journal Article

Abstract: Objectives: We assessed the severity and pathology of osteoporosis in children and adults with severe motor and intellectual disabilities (SMID) by evaluating bone enzymes, by which we aimed to determine adequate treatment approaches for preventing fractures. Methods: Ninety patients (44 men, 46 women; mean age, 34.5 years) underwent bone quality assessment. Quantitative ultrasonography (QUS) was used to measure the T-score and Z-score of the calcaneus, and blood tests were used to measure bone-specific alkaline phosphatase and tartrate-resistant acid phosphatase 5b levels as bone formation and resorption markers, as well as calcium, phosphorous, and parathyroid hormone levels as routine examination. Results: Bone formation and resorption marker levels were within normal ranges in adults, although they were high during the growth period in children and adolescents and in elderly women. Patients receiving tube feeding showed a significantly lower Z-score than those without tube feeding. Tube feeding was a significant factor for the Z-score, whereas age, vitamin supplements, and anti-epileptic

drugs were not. Conclusions: The severity of osteoporosis in SMID started during the growth period and seems to be caused by a lack of an effective increase in bone mineral density. Any treatment should be started during the growth period. More study about tube feeding is needed. (PsycInfo Database Record (c) 2020 APA, all rights reserved) (Source: journal abstract)

A review on functional analyses of tics

Author(s): Goldman, Kissel J.; DeLeon, Iser G.

Source: Behavior Modification; Mar 2020; vol. 44 (no. 2); p. 296-315

Publication Type(s): Journal Peer Reviewed Journal Journal Article

Abstract: Tic disorders are characterized by a class of responses assumed to be neurobiological in origin. Still, several studies have shown that tic frequency can be influenced by antecedent environmental events and social consequences. Prior reviews have summarized the effects of environmental events but have not examined relations between tic diagnosis, behavioral deficits (e.g., intellectual disability), tic topography, and the consequences observed to maintain tics. These variables might be important when attempting to predict or identify relevant consequences. A more thorough understanding of the variables that maintain and give rise to tics might also be useful in predicting responsiveness to treatment and intervention refinement. We reviewed and summarized results from the 13 attempts to experimentally identify maintaining consequences for tics (i.e., functional analyses) that have been published to date. We examined patterns of functions across tic diagnoses (i.e., Tourette's syndrome or not), communication impairments (i.e., an intellectual disability or reported language difficulty), and tic topography. Results suggested that individuals with Tourette's syndrome and those without communication impairments are more likely to have functional analysis outcomes consistent with automatic reinforcement, but exceptions in both directions highlight the utility of functional analysis in treating tics. (PsycINFO Database Record (c) 2020 APA, all rights reserved) (Source: journal abstract)

Neurogenesis, myelination, and circuitry: The case for a distributed therapeutic regimen in Down syndrome

Author(s): Haydar, Tarik F.

Source: American Journal on Intellectual and Developmental Disabilities; Mar 2020; vol. 125 (no. 2); p. 100-102

Publication Type(s): Journal Peer Reviewed Journal Journal Article

Available at American journal on intellectual and developmental disabilities - from ProQuest (Health Research Premium) - NHS Version

Abstract: One of the overriding hopes of the Down syndrome (DS) research community is to arrive at a better understanding of how trisomy 21 affects brain development and function, and that doing so will improve quality of life and independence for people with DS. In searching for the underlying causes of intellectual disability in DS, researchers and clinicians have studied how changes to genes and cells may relate to motor and cognitive function. Thus far, alterations in many areas of the central nervous system have been found and it is now known that, beginning before birth, different changes occur in different areas over the course of life. Because of these spatial and temporal variations,

multiple approaches for addressing motor and cognitive function must be considered. (PsycInfo Database Record (c) 2020 APA, all rights reserved) (Source: journal abstract)

The search for biomarkers of Alzheimer's disease in Down syndrome

Author(s): Handen, Benjamin L.

Source: American Journal on Intellectual and Developmental Disabilities; Mar 2020; vol. 125 (no. 2); p. 97-99

Publication Type(s): Journal Peer Reviewed Journal Journal Article

Available at American journal on intellectual and developmental disabilities - from ProQuest (Health Research Premium) - NHS Version

Abstract: Adults with Down syndrome are at high risk for Alzheimer's disease (AD), with most individuals developing clinical dementia by their late 60s. This increased risk for AD has been attributed, at least in part, to triplication and overexpression of the gene for amyloid precursor protein (APP) on chromosome 21, leading to elevated levels of amyloid b peptides. This article offers a brief overview of our current knowledge of AD in the DS population. In addition, information on a NIA/NICHD-funded, multicenter longitudinal study of biomarkers of AD in adults with DS is provided. (PsycInfo Database Record (c) 2020 APA, all rights reserved) (Source: journal abstract)

Current research approaches to Down syndrome: Translational research perspectives

Author(s): Capone, George T.

Source: American Journal on Intellectual and Developmental Disabilities; Mar 2020; vol. 125 (no. 2); p. 93-96

Publication Type(s): Journal Peer Reviewed Journal Journal Article

Available at American journal on intellectual and developmental disabilities - from ProQuest (Health Research Premium) - NHS Version

Abstract: Translational research means different things to different people. In the biomedical research community, translational research is the process of applying knowledge from basic biology and clinical trials to techniques and tools that address critical medical needs such as new therapies. Translational research then is a ‘‘bench to bedside’’ bridge specifically designed to improve health outcomes (Wetmore & Garner, 2010). In this sense, animal models or cell culture systems may be used to learn about basic underlying genetic and physiologic systems that are exceedingly difficult to study in human subjects (Reeves et al., 2019). This has been a major theme in Down syndrome (DS) research since the mid-1980s when mouse models that approximate the condition of trisomy 21 (Ts21) first became available (Das & Reeves 2011). Translational research has recently taken on a more expansive meaning, as the process of turning observations from the laboratory, the clinic, and the community can all lead to new therapeutic approaches to improve population health outcomes (Rubio et al., 2010). This model has received increased attention in the last decade as it is clear that improving developmental outcomes for people with DS requires a community effort on the part of all stakeholders (Capone, 2010). (PsycInfo Database Record (c) 2020 APA, all rights reserved) (Source: journal abstract)

Advancing knowledge of Down syndrome brain development and function with human stem cells

Author(s): Bhattacharyya, Anita

Source: American Journal on Intellectual and Developmental Disabilities; Mar 2020; vol. 125 (no. 2); p. 90-92

Publication Type(s): Journal Peer Reviewed Journal Journal Article

Available at American journal on intellectual and developmental disabilities - from ProQuest (Health Research Premium) - NHS Version

Abstract: Our bodies are made up of over 250 specific cell types, and all initially arise from stem cells during embryonic development. Stem cells have two characteristics that make them unique: (1) they are pluripotent, meaning that they can differentiate into all cell types of the body, and (2) they are capable of self-renewal to generate more of themselves and are thus able to populate an organism. Human pluripotent stem cells were first isolated from human embryos twenty years ago (Thomson et al., 1998) and more recently, technology to reprogram somatic cells, such as skin and blood, to induced pluripotent stem cells has emerged (Park et al., 2008; Takahashi et al., 2007; Yu et al., 2007). Induced pluripotent stem cells, or iPSCs, are particularly valuable as disease specific iPSCs can be generated from individuals with specific genetic mutations diseases. Researchers have harnessed the power of stem cells to understand many aspects of developmental biology in model organisms (e.g. worms, mice) and more recently, in humans. Human stem cells in culture recapitulate development. For example, formation of the brain occurs prenatally and follows a specific pattern of timing and cell generation. Human stem cells in the culture dish follow a similar pattern when exposed to developmental cues and can thus be used to understand aspects of prenatal human brain development that are not accessible by other means. Disease-specific iPSCs are a valuable tool to model neural development in specific neurodevelopmental disorders like Down syndrome. Down syndrome is a classic developmental disorder; mistakes that are made during development of a particular organ system result in the characteristics of the disorder. In the brain, mistakes during prenatal brain development lead to intellectual disability. Trisomy 21 (Ts21) iPSCs generated from somatic cells of Down syndrome individuals may enable us to understand the mistakes made during Down syndrome brain development. (PsycInfo Database Record (c) 2020 APA, all rights reserved) (Source: journal abstract)

The potential role of nurses in leading positive behaviour support.

Author(s): Savarimuthu, Darren

Source: British journal of nursing (Mark Allen Publishing); Apr 2020; vol. 29 (no. 7); p. 414-418

Publication Type(s): Journal Article

Available at British journal of nursing (Mark Allen Publishing) - from MAG Online Library Click on Sign In at the top of the page and then when the OPENATHENS link appears click this and enter your Athens Account

Abstract: Positive behaviour support (PBS) has become the preferred intervention in the management of challenging behaviour in learning disability and mental health services. However, there is an absence of literature on nurses' views and experience of PBS.

Nurses are passive in PBS plan development while other professionals, such as clinical psychologists, often take the lead. While nurses see clinical psychologists as experts in PBS, they feel this could create a barrier that hinders its full potential and a more multidisciplinary approach would be beneficial. Nurses could take a pivotal role in delivering PBS plans if they were able to take a leading role, and this would benefit service users as nurses work far more closely with them than other professionals.

Database: Medline

Cognitive functioning in children with Prader-Willi syndrome during 8 years of growth hormone treatment.

Author(s): Donze, S H; Damen, L; Mahabier, E F; Hokken-Koelega, A C S

Source: European journal of endocrinology; Apr 2020; vol. 182 (no. 4); p. 405-411

Publication Type(s): Journal Article

Abstract: ObjectiveChildren with Prader-Willi syndrome (PWS) have mild to moderate cognitive impairment. Short-term studies showed positive effects of growth hormone (GH) on cognitive development. This study investigated the effects of 8 years of GH on cognitive development in children with PWS. We also investigated whether starting GH during infancy results in higher cognitive functioning after 8 years of GH.DesignLongitudinal study in 43 children with PWS during 8 years of GH (median age at GH start 8.1 years). Cognitive functioning after 8 years was compared to another group of 22 children with PWS (median age at GH start 1.4 years).MethodsCognitive functioning was measured by Wechsler Intelligence Scale for Children. Vocabulary, Similarities and Block Design subtests were expressed as standard deviation scores (SDS) and total IQ (TIQ) calculated.ResultsEstimated mean (95%CI) Block Design SDS changed from -2.2 (-2.6; -1.8) at GH start to -1.8 (-2.2; -1.4) after 8 years of GH (P = 0.18), similarly SDS from -1.5 (-2.1; -0.9) to -1.3 (-1.9; -0.7, P = 0.66) and TIQ from 66 (60; 72) to 69 (63; 75, P = 0.57). Vocabulary SDS remained similar, being -1.9 (-2.3; -1.4) at GH start and -1.9 (-2.4; -1.5) after 8 years (P = 0.85). After 8 years of GH Vocabulary, SDS and TIQ were higher in the children who started GH during infancy, compared to those who started GH later in childhood (P < 0.01, P = 0.04, respectively).ConclusionsCognitive functioning in children with PWS remains similar during long-term GH and develops at the same pace as healthy peers.

Database: Medline

Reducing inequalities and inequities for patients with intellectual disabilities.

Author(s): Flood, Bernadette

Source: BMJ (Clinical research ed.); Apr 2020; vol. 369 ; p. m1334

Publication Type(s): Letter

PubMedID: 32238347

Available at BMJ (Clinical research ed.) - from BMJ Journals

Database: Medline

Significant Improvements in Mortality After the Fontan Operation in Children With Down Syndrome.

Author(s): Sarno, Lauren A; Walters, Henry L; Bondarenko, Igor; Thomas, Ronald; Kobayashi, Daisuke

Source: The Annals of thoracic surgery; Mar 2020; vol. 109 (no. 3); p. 835-841

Publication Type(s): Research Support, Non-u.s. Gov't Multicenter Study Journal Article

Abstract:BACKGROUNDDown syndrome (DS) is considered a risk factor for mortality associated with the Fontan operation. The objective was to show the contemporary short-term outcome of the Fontan operation for a functionally univentricular heart in patients with DS and non-DS, along with an analysis of significant predictors for in-hospital mortality.METHODSThis was a retrospective study using The Society of Thoracic Surgeons Congenital Database to assess in-hospital mortality and its predictors in patients with DS and non-DS undergoing the Fontan operation over 16 years (2001-2016). The primary outcome was in-hospital mortality. Statistical analysis was performed using univariable and multivariable logistic regression models.RESULTSOur study cohort consisted of 12,074 patients (81 DS and 11,993 non-DS). The overall in-hospital mortality rate significantly improved in the recent era (2009-2016): 2.4% to 1.3%, P < .001. The DS group had a higher in-hospital mortality rate (12.3% vs 1.6%, P < .001) with an odds ratio of 8.6 (95% confidence interval, 4.4-17.0). The DS group had a higher 30-day mortality rate, a longer median postoperative length of stay, and a higher incidence of postoperative complications. The multivariable model showed that DS was the strongest predictor of in-hospital mortality, with an odds ratio of 11.6 (95% confidence interval, 5.1-26.4), adjusted for other significant variables including era effect, weight, and primary cardiac diagnosis.CONCLUSIONSThe in-hospital mortality for the Fontan operation significantly improved in the contemporary era. DS was a significant risk factor for in-hospital morbidity and mortality associated with the Fontan operation.

Database: Medline

Ocular alignment, media, and eyelid disorders in Down syndrome.

Author(s): Makateb, Ali; Hashemi, Hassan; Farahi, Azadeh; Mehravaran, Shiva; Khabazkhoob, Mehdi; Asgari, Soheila

Source: Strabismus; Mar 2020; vol. 28 (no. 1); p. 42-48

Publication Type(s): Journal Article

Abstract: Background: Determining the age and gender distribution of ocular disorders in Down syndrome patients aged 10 to 30 years.Methods: In this study, 226 of 250 invited patients through special needs schools, the National Down Syndrome Society, and relevant nonprofit organizations were included. In Noor Eye Hospital, the patients underwent a complete eye examination by a general ophthalmologist and suspect cases were reexamined by a sub-specialist. Examinations included ocular alignment, conjunctiva, eyelid, lacrimal system, cornea, iris, and lens assessment.Results: Mean age of participants was 16.05 ± 4.82 years and 53.0% were male. The most common ocular abnormalities were blepharitis (81.9%, 95% CI:78.0 to 85.3), lens opacity (37.8%, 95% CI:33.3 to 42.3), strabismus (23.4%, 95% CI:19.5 to 27.4; 21.2% esotropia, 0.9% exotropia, and 1.8% dissociated vertical deviation), floppy eyelid (19.9%, 95% CI:16.3 to 23.9), posterior embryotoxon (17.7%, 95% CI:14.2 to 21.2) and nystagmus (11.7%, 95% CI:8.9 to 15.0). Based on independent sample t test, the prevalence of nystagmus (P = .041) and congenital lens opacity (P<0.001) significantly increased with age. There

was no significant inter-gender difference in the prevalence of any of the studied disorders by chi-square test.Conclusion: In young patients with Down syndrome, the prevalence of ocular pathologies appears to be high and increase with aging. It can be resulted from the cumulative prevalence of undiagnosed or untreated cases. Findings of the study can be a reliable reference for health policy in terms of screening for eye disease and addressing eye care needs.

Database: Medline

Impact of oral conditions of children/adolescents with Down syndrome on their families' quality of life.

Author(s): Carrada, Camila Faria; Scalioni, Flávia Almeida Ribeiro; Abreu, Lucas Guimarães; Ribeiro, Rosangela Almeida; Paiva, Saul Martins

Source: Special care in dentistry : official publication of the American Association of Hospital Dentists, the Academy of Dentistry for the Handicapped, and the American Society for Geriatric Dentistry; Mar 2020; vol. 40 (no. 2); p. 175-183

Publication Type(s): Journal Article

Available at Special care in dentistry : official publication of the American Association of Hospital Dentists, the Academy of Dentistry for the Handicapped, and the American Society for Geriatric Dentistry - from Wiley Online Library Medicine and Nursing Collection 2019 - NHS

Abstract:AIMSTo assess the impact of oral conditions among children/adolescents with Down syndrome (DS) on the Oral Health-related Quality of Life (OHRQoL) of their families in comparison with a group without DS.METHODS AND RESULTSFamilies of 144 children/adolescents with DS aged 4-18 years were compared with families of individuals without DS. Dental caries experience (DMFT/dmft), clinical consequences of untreated dental caries (PUFA/pufa), gingival bleeding (GBI), visible plaque (VPI), and malocclusion were evaluated. Parents/caregivers answered the Family Impact Scale (FIS) and questionnaires on sociodemographic conditions and the health of children/adolescents. Data analysis included chi-square test and Poisson regression. There was no difference between groups regarding the impact of the children's/adolescents' oral condition on their families' OHRQoL for all domains and the total FIS score ($P > 0.05$). A negative impact on the OHRQoL of families of children/adolescents with DS was determined by dental caries (PR = 3.95, CI = 2.09-7.46), clinical consequences of untreated dental caries (PR = 1.83, CI = 1.18-2.84), defined malocclusion (PR = 2.75, CI = 1.23-6.13), and severe malocclusion (PR = 2.82, CI = 1.02-7.74).CONCLUSIONThere is no difference on the OHRQoL of families of children/adolescents with and without DS. Dental caries experience, clinical consequences of untreated dental caries, defined malocclusion, and severe malocclusion determined the negative impact on the OHRQoL of families of children/adolescents with DS. **Database:** Medline

Key Journals

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