

August/September/October

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Articles

A program based on common technology to support communication exchanges and leisure in people with intellectual and other disabilities

Author(s): Lancioni, Giulio E.; Singh, Nirbhay N.; O'Reilly, Mark F.; Alberti, Gloria; Chiariello, Valeria; Campanella, Caterina; Grillo, Giovanna; Tagliente, Vincenzo

Source: Behavior Modification; Nov 2019; vol. 43 (no. 6); p. 879-897

Abstract: The aim of this study was to assess a new smartphone-based program version to allow seven participants with intellectual plus visual and/or motor disabilities and hesitant speech to send out and receive WhatsApp messages, make telephone calls, and access leisure activities. This program version relied on a Samsung A3 smartphone, which was automated through the MacroDroid application and responded to the input of specific cards and miniature objects. During the baseline (i.e., without the program), the participants' performance was zero or close to zero on communication and leisure. During the use of the program, the participants increased their frequency of WhatsApp messages sent out and received/listened to, and of leisure activities accessed. Their frequency of telephone calls averaged between virtually zero and slightly above one. The implications of the findings are discussed in relation to the technology used for the program and the applicability of the program in daily contexts.

Differential effects of Down's syndrome and Alzheimer's neuropathology on default mode connectivity

Author(s): Wilson, Liam R.; Vatansever, Deniz; Annus, Tiina; Williams, Guy B.; Hong, Young T.; Fryer, Tim D.; Nestor, Peter J.; Holland, Anthony J.; Zaman, Shahid H.

Source: Human Brain Mapping; Oct 2019; vol. 40 (no. 15); p. 4551-4563

Available at [Human Brain Mapping](#)

Abstract: Down's syndrome is a chromosomal disorder that invariably results in both intellectual disability and Alzheimer's disease neuropathology. However, only a limited number of studies to date have investigated intrinsic brain network organisation in people with Down's syndrome, none of which addressed the links between functional connectivity and Alzheimer's disease. In this cross-sectional study, we employed ¹¹C-Pittsburgh Compound-B (PiB) positron emission tomography in order to group participants with Down's syndrome based on the presence of fibrillar beta-amyloid neuropathology. We also acquired resting state functional magnetic resonance imaging data to interrogate the connectivity of the default mode network; a large-scale system with demonstrated links to Alzheimer's disease. The results revealed widespread positive connectivity of the default mode network in people with Down's syndrome (n = 34, ages 30–55, median age = 43.5) and a stark lack of anti-correlation. However, in contrast to typically developing controls (n = 20, ages 30–55, median age = 43.5), the Down's syndrome group also showed significantly weaker connections in localised frontal and posterior brain regions. Notably, while a comparison of the PiB-negative Down's syndrome group (n = 19, ages 30–48, median age = 41.0) to controls suggested that alterations in default mode connectivity to frontal brain regions are related to atypical development, a comparison of the PiB-positive (n = 15, ages 39–55, median age = 48.0) and PiB-negative Down's syndrome groups indicated that aberrant connectivity in posterior cortices is associated with the presence of Alzheimer's disease neuropathology. Such distinct profiles of altered connectivity not only further our understanding of the brain physiology that underlies these two inherently linked conditions but may also

potentially provide a biomarker for future studies of neurodegeneration in people with Down's syndrome.

The relationship of age, early motor skills and observable child behaviors in young children with developmental delays

Author(s): MacDonald, Megan; McIntyre, Laura Lee

Source: Research in Developmental Disabilities; Oct 2019; vol. 93

Abstract: Background: Children with disabilities often experience delays in one or more domains of development including motor skill delays. Delays in motor skill development may put children further behind their peers without disabilities in respect to aspects of early learning. Aims: The purpose of this study was to examine how gross motor skills mediated the relationship of age and the observable child behaviors of compliance and adaptive behavior in a group of young children (2–4 years) with developmental disabilities around one time point. Methods: Children with developmental disabilities (N = 113) were assessed on direct measures of motor skills and the child behaviors of compliance and adaptive behavior. Two independent simple mediation analyses were conducted using PROCESS, an ordinary least squares path analysis appropriate for small sample sizes. Results. Age had a positive relationship with gross motor skills ($a = .66, p < .001$) when the outcome variable was adaptive behavior and age had a positive relationship with gross motor skills ($a = .66, p < .001$) when the outcome variable was compliance. Conclusions: Motor skill development may promote or hinder development in other childhood behaviors such as compliance and adaptive behavior.

Cerebral palsy prevalence, subtypes, and associated impairments: A population-based comparison study of adults and children

Author(s): Jonsson, Ulrica; Eek, Meta N.; Sunnerhagen, Katharina S.; Himmelmann, Kate

Source: Developmental Medicine & Child Neurology; Oct 2019; vol. 61 (no. 10); p. 1162-1167

Abstract: Aim: To describe the prevalence of cerebral palsy (CP), subtype distribution, motor and intellectual impairment, and epilepsy in adults with CP compared with children with CP. Method: CP subtype and impairment data from the population-based CP register of western Sweden and population data from Statistics Sweden were used to compare surviving adults (n = 581; 244 females, 337 males) born between 1959 and 1978, with the same cohort as children (n = 723; 307 females, 416 males), and with the most recent cohort, born from 2007 to 2010 (n = 205; 84 females, 121 males). Results: Prevalence of CP in adults born between 1959 and 1978 was 1.14 per 1000. The occurrence of impairments differed between CP subtypes. Motor and intellectual impairment were closely related, regardless of subtype. Subtype distribution among survivors differed significantly from the original cohorts ($p=0.002$), and the most recent cohort ($p < 0.01$), tetraplegia and dyskinetic CP being less common in survivors. Severe motor impairment, intellectual disability, and epilepsy were less common among survivors than in the original cohorts ($p = 0.004, p = 0.002, p = 0.037$) and the most recent cohort ($p = 0.004, p = 0.008, p < 0.01$). Interpretation: Data on prevalence, subtype distribution, and impairments in children with CP are not applicable to adults with CP. Population-based studies of adults with CP are needed. What this paper adds Cerebral palsy (CP) subtypes are differently distributed in adults compared to children. The prevalence of impairments in adults with CP is related to CP subtype. Spastic tetraplegia and dyskinetic CP are less common in adults than children. Severe motor impairment, intellectual disability, and epilepsy are less common in adults. (PsycINFO Database Record (c) 2019 APA, all rights reserved) (Source: journal abstract)

Developing a diagnostic algorithm for the Music-Based Scale for Autism Diagnostics (MUSAD) assessing adults with intellectual disability

Author(s): Bergmann, Thomas; Heinrich, Manuel; Ziegler, Matthias; Dziobek, Isabel; Diefenbacher, Albert; Sappok, Tanja

Source: Journal of Autism and Developmental Disorders; Sep 2019; vol. 49 (no. 9); p. 3732-3752

Abstract: Initial studies have presented the Music-based Scale for Autism Diagnostics (MUSAD) as a promising DSM-5-based observational tool to identify autism spectrum disorder (ASD) in adults with intellectual disability (ID). The current study is the first to address its clinical utility in a new sample of 124 adults with ID (60.5% diagnosed with ASD). The derived diagnostic algorithm differentiated well between individuals with and without ASD (sensitivity 79%, specificity 74%, area under the curve = 0.81). Inter-rater reliability, assessed by the scorings of four independent experts in 22 consensus cases, was excellent (ICC = 0.92). Substantial correlations with scores from other ASD-specific measures indicated convergent validity. The MUSAD yields accurate and reliable scores, supporting comprehensive ASD diagnostics in adults with ID.

Diagnosis of autism spectrum disorder according to maternal-race ethnicity and country of birth: A register-based study

Author(s): Abdullahi, Ifrah; Wong, Kingsley; Bebbington, Keely; Mutch, Raewyn; Klerk, Nicholas; Cherian, Sarah; Downs, Jenny; Leonard, Helen; Glasson, Emma J.

Source: Journal of Autism and Developmental Disorders; Sep 2019; vol. 49 (no. 9); p. 3611-3624

Abstract: An increased prevalence of autism spectrum disorder (ASD) among children of immigrant backgrounds has been observed but clinical profiles are rarely compared. Diagnostic data from children with ASD notified to the Western Australian Register for Autism Spectrum Disorders were analysed according to maternal-race ethnicity and country of birth. A total of 4776 children aged between 0 and 18 years diagnosed with ASD from 1999 to 2017 were included. Those born to immigrant mothers from lower income countries were younger at the time of diagnosis, had an increased risk of intellectual disability and poorer presentations in the social and communication domains. Further work is required to understand environmental influences that may affect children born to immigrant mothers and to improve monitoring and assessments.

Characteristics associated with autism spectrum disorder risk in individuals with Down syndrome

Author(s): Channell, Marie Moore; Hahn, Laura J.; Rosser, Tracie C.; Hamilton, Debra; Frank-Crawford, Michelle A.; Capone, George T.; Sherman, Stephanie L.

Source: Journal of Autism and Developmental Disorders; Sep 2019; vol. 49 (no. 9); p. 3543-3556

Abstract: We examined autism spectrum disorder (ASD) risk in a large national sample of 203 individuals with Down syndrome, 6–25 years old, to determine the association of ASD risk with age, sex, IQ, adaptive behaviors, and maladaptive behaviors. We used a two-pronged approach by (1) considering ASD symptomatology continuously across the sample of individuals with DS and examining associations with each characteristic, and (2) dichotomizing our sample into high and low ASD risk groups and comparing groups on each characteristic. The pattern of results was largely similar across both types of analyses. ASD symptomatology/risk was negatively associated with IQ and adaptive behaviors and positively associated with certain types of maladaptive behaviors. Clinical implications for screening and therapeutic purposes are discussed.

Assessing autism in females: The importance of a sex-specific comparison

Author(s): Lundström, Sebastian; Mårland, Caroline; Kuja-Halkola, Ralf; Anckarsäter, Henrik; Lichtenstein, Paul; Gillberg, Christopher; Nilsson, Thomas

Source: Psychiatry Research; Sep 2019

Abstract: Autism spectrum disorder (ASD) is diagnosed more often in boys than girls. Here, we compared the degree of autism - and related disorders - symptomatology in boys and girls with a registered diagnosis of ASD. We used parent telephone interview A-TAC (Autism-Tics, ADHD and other Comorbidities) ratings of 30,392 twins aged 9 or 12 (including 308 boys and 122 girls with National Patient Register diagnoses of ASD) participating in the Child and Adolescent Twin Study in Sweden. We used z-scores for ASD-symptoms, standardized separately for boys and girls. Boys with a diagnosis of ASD had a higher raw mean score than girls with a diagnosis on the A-TAC ASD domain. However, utilizing the z-scores, girls with a diagnosis of ASD deviated further away from the female population mean than did the boys with ASD from the male population mean. Girls also had higher standardized mean values for symptoms of Attention-Deficit/Hyperactivity Disorder, Learning Disabilities and Oppositional Defiant Disorder. The findings suggest that girls diagnosed with autism may represent an even more extreme end of the female population autistic features distribution, than diagnosed boys from the male population autistic features distribution. Future studies may benefit from examining the use of sex-specific cut-off scores.

Scoping review of sexual health education interventions for adolescents and young adults with intellectual or developmental disabilities

Author(s): Schmidt, Elizabeth K.; Brown, Christopher; Darragh, Amy

Source: Sexuality and Disability; Sep 2019

Abstract: Abstract Individuals with intellectual and developmental disabilities (I/DD) may experience greater risk of sexually transmitted infections, higher rates of sexual abuse, and decreased sexual health knowledge, emphasizing the need for accessible, comprehensive sexual health education. The purpose of this scoping review was to identify the extent and nature of sexual health education interventions among individuals with I/DD ages 15–24 years. Six studies were included in the review. They investigated sexual health interventions for individuals with autism spectrum disorder and mild I/DD, covered a wide range of topics (e.g. puberty, healthy relationships), included multiple learning activities (e.g. illustrations, activity-based learning), and measured behavior and sexual health knowledge outcomes. Future research is needed in this area to assess intervention effectiveness.

The impact of nhs change processes on art therapists working in ld services

Author(s): Ashby, Elizabeth

Source: International Journal of Art Therapy; Sep 2019

Abstract: The impact of working as art therapists in the NHS during protracted change processes, with people with learning disabilities (LD), was investigated in a qualitative heuristic doctoral study (Ashby, 2018), which considered concerns about emotional exhaustion and reduced efficacy, symptoms of burnout (Maslach, 1982), as a result of occupational stress. The researcher's own data was examined, and 15 art therapists employed by NHS Trusts across England were interviewed. This article explores how the research was conducted, its findings related to LD services in the NHS and wider employment issues, and addresses how the findings are relevant to all art therapists. Most burnout studies are quantitative and consider workplace sources of occupational stress, but this qualitative research importantly revealed how crucial personal sources of support and stress were in terms of aiding or reducing clinicians' capacities

to cope. There was evidence of job satisfaction, resilience, and personal growth developed over years of practice, and high levels of stress resulted in symptoms of burnout in some participants, but recovery was shown to be possible. Plain language summary Research into the impact of working as an art therapist in learning disability (LD) services in the NHS in England during long periods of change processes found sources of stress and of job satisfaction (Ashby, 2018). The doctoral research was qualitative, using heuristic methodology as the researcher had experience of the issues investigated, and 15 art therapists were interviewed. This article discusses the relevant literature, the way the research was done, and findings of the research; it applies the knowledge gained to the situations many art therapists experience in their practice with different organisations and work environments. The impact on art therapists was investigated as both positive and negative aspects of their working lives were evident, and sources of job satisfaction and of occupational stress were experienced, including burnout symptoms of emotional exhaustion and reduced capacity to work, though not depersonalisation (Maslach, 1982). Organisational sources of satisfaction and stress within NHS LD services were identified, and employment issues for art therapists became apparent in relation to job insecurity, within the depressed employment market. This qualitative research found that personal sources of support or stress could result in art therapists being able or unable to manage coping with occupational stress if multiple sources of stress were present. Burnout symptoms of emotional exhaustion and a reduced capacity to manage their workload resulted from these situations for some participants, however, those affected were able to recover when they addressed the occupational stress that had become too much for them; no participants avoided contact with service users.

Social worker perception of grandparent involvement where a parent has an intellectual disability

Author(s): Gur, Ayelet; Stein, Michael Ashley

Source: Research in Developmental Disabilities; Sep 2019; vol. 92

Abstract: Background: Family members of parents with intellectual disabilities (ID) are viewed as their main source of support. However, the existence of family involvement itself does not guarantee that such support will be beneficial. Aims: This study draws on the perspectives of social workers to describe and evaluate involvement by Israeli family members (grandparents) in the lives of their adult children with ID (parents with ID) who themselves have become parents. Method: A thematic analysis was conducted in 21 semi-structured interviews with social workers serving parents with ID through social service departments. Results: From the social workers' perspectives, grandparent attitudes regarding their adult children with ID procreating and parenting ranged from strong resistance to active encouragement. Two sub-themes of grandparent involvement were identified from the social workers' perspectives: the critical role of grandparent support, and the complex relationships between grandparents and the parents with ID. Two further and interrelated subthemes emerged on the role of social worker engagement with grandparents. Conclusions: Professionals should be aware that grandparent involvement can either support or undermine the parenting function of parents with ID. Social service professionals need to promote family involvement that empowers parents with ID by supporting their needs and roles, but without supplanting their primary parenting activities.

Dynamic sustained attention markers differentiate atypical development: The case of Williams syndrome and Down's syndrome

Author(s): Shalev, Nir; Steele, Ann; Nobre, Anna C.; Karmiloff-Smith, Annette; Cornish, Kim; Scerif, Gaia

Source: Neuropsychologia; Sep 2019; vol. 132

Available at [Neuropsychologia](#)

Abstract :Impaired sustained attention is considered an important factor in determining poor functional outcomes across multiple cognitive and behavioural disorders. Sustained attention is compromised for both children with Williams syndrome (WS) and Down's syndrome (DS), but specific difficulties remain poorly understood because of limitations in how sustained attention has been assessed thus far. In the current study, we compared the performance of typically developing children (N = 99), children with WS (N = 25), and children with DS (N = 18), on a Continuous Performance Task – a standard tool for measuring sustained attention. In contrast to previous studies, primarily focused on overall differences in mean performance, we estimated the extent to which performance changed over time on task, thus focusing directly on the sustained element of performance. Children with WS and children with DS performed more poorly overall compared to typically developing children. Importantly, measures specific to changes over time differentiated between children with the two syndromes. Children with WS showed a decrement in performance, whereas children with Down's syndrome demonstrated non-specific poor performance. In addition, our measure of change in performance predicted teacher-rated attention deficits symptoms across the full sample. An approach that captures dynamic changes in performance over assessments may be fruitful for investigating similarities and differences in sustained attention for other atypically developing populations.

An international survey of obesity and underweight in youth and adults with intellectual disabilities

Author(s): McConkey, Roy; Sadowsky, Molly; Shellard, Amy

Source: Journal of Intellectual and Developmental Disability; Sep 2019; vol. 44 (no. 3); p. 374-382

Abstract: Background: Increased levels of obesity have been reported for people with intellectual disability based on data mostly gathered in high income countries. Likewise few studies internationally have focussed on underweight in this population. Method: Data on obesity and underweight were analysed from nearly 86,500 youth and adults with intellectual disabilities drawn from 178 countries attending Special Olympic events. Results: Binary logistic regressions identified higher levels of obesity for athletes in high income countries—especially in North America—and for females and for adults aged 40 years and over; and for youth aged 8 to 10 years. Rates of underweight were higher for younger adults in low income countries of Asia-Pacific, and highest for males aged 11-13 from lower-middle income countries of Africa. Conclusions: Contrasting intervention strategies are needed globally to enable people with intellectual disabilities to achieve healthy weight.

Association between waist circumference and hypertension in children and adolescents with intellectual disabilities

Author(s): Wyszynska, Justyna; Podgórska-Bednarz, Justyna; Dereń, Katarzyna; Mazur, Artur

Source: Journal of Intellectual and Developmental Disability; Sep 2019; vol. 44 (no. 3); p. 367-373

Abstract: Background: The prevalence of abdominal obesity (AO) is high in individuals with intellectual disability (ID). The aim of this study was to assess the prevalence of hypertension (HPT) in students with ID with different distributions of adipose tissue. Method: Study involved 568 participants with ID. AO was assessed on the basis of waist circumference (WC) measurements. Results: The risk of HPT was more than threefold higher in individuals with AO (OR = 3.38) than in the subjects with normal WC. Correlation between the prevalence of AO and HPT was observed in girls and individuals with mild levels of ID (OR = 6.07 and 7.67 respectively). The prevalence of HPT increases sharply in girls whose WC is greater than or equal to the 90

percentile, and in boys when it exceeds the 75th percentile. Conclusion: An association between WC and HPT was observed in abdominally obese students with ID

The intersection of intellectual and developmental disabilities and HIV: A scoping review

Author(s): Jung, James K. H.; Heifetz, Marina; Durbin, Anna; Lunsky, Yona

Source: Journal of Intellectual and Developmental Disability; Sep 2019; vol. 44 (no. 3); p. 346-356

Abstract: Background: HIV among individuals with intellectual and developmental disabilities (IDD) is rarely studied. This scoping review examined the HIV prevalence, health service use, prevention and risk behaviours among individuals with IDD. Method: Journal articles, book chapters and theses written in English and published from 1991 to 2017 in four academic databases (PubMed, PsycINFO, CINAHL and Web of Science) were eligible for inclusion. Results: From 1636 unique records, 32 documents were included in this review. They contained limited information on HIV prevalence and health service use by individuals with IDD and HIV. Most studies identified a poor understanding of HIV and high-risk behaviours, such as inconsistent condom use, among individuals with IDD. While HIV education programs were effective for this population, no studies identified educational interventions for their service providers. Conclusion: There is a need for educational programs and policies on HIV for both service providers and individuals with IDD

Exploring spontaneous interactions between people with profound intellectual and multiple disabilities and their peers

Author(s): Kamstra, A.; van der Putten, A. A. J.; Maes, B.; Vlaskamp, C.

Source: Journal of Intellectual and Developmental Disability; Sep 2019; vol. 44 (no. 3); p. 282-291

Available at [Journal of Intellectual and Developmental Disability](#) -

Abstract: Background: Peers living in the same group form important interaction partners for people with profound intellectual and multiple disabilities (PIMD). Given the severity of their disabilities, direct support persons (DSPs) play a significant role in facilitating interactions between these peers. This study explores the spontaneous interactions between persons with PIMD and the possibilities provided by DSPs related to physical positioning. Method: Observational data were obtained from 14 people with PIMD for three consecutive hours in a non-controlled situation. Results: Of all 213 observed interactions, 5.1% were with peers, 73.4% with DSPs, 14.9% with the observer, and 6.5% with others. In 61.3% of the observed timeframes, the participants with PIMD were positioned in a way that made it impossible to touch or/and to look at a peer. Conclusion: Generally, the observed positioning of the participants made contacts between peers nearly impossible. DSPs should create optimal conditions for interaction between peers.

Quality of life of persons with profound intellectual and multiple disabilities: A narrative literature review of concepts, assessment methods and assessors

Author(s): Nieuwenhuijse, Appolonia M.; Willems, Dick L.; van Goudoever, Johannes B.; Echteld, Michael A.; Olsman, Erik

Source: Journal of Intellectual and Developmental Disability; Sep 2019; vol. 44 (no. 3); p. 261-271

Available at [Journal of Intellectual and Developmental Disability](#)

Abstract: Background: The objective of this study was to provide an overview of concepts, methods of assessment and assessors in empirical studies on quality of life (QoL) of persons with

Profound Intellectual and Multiple Disabilities (PIMD). Method: A narrative literature review was conducted by searching electronic databases until December 2016, and the included studies were then analysed thematically. Results: Twenty-one articles were included in the analysis. Multidimensional concepts of QoL consisting of both subjective and objective components were found, although the articles used different distinctions for each. QoL was assessed by behavioural observations or interviews/questionnaires. Family members, primary caregivers and more distant observers (or a combination of these three) determined QoL. Triangulation of assessors and methodological pluralism were used. Conclusions: This review highlighted several components of QoL in persons with PIMD, as well as challenges in researching the QoL of persons who are not able to express themselves verbally. The distinction between objective and subjective QoL was difficult to clarify, with interpretation being both inevitable and necessary. Although triangulation is seen to be good practice in QoL assessment, the role of proxies in assessing the QoL of persons with PIMD needs further investigation.

Promoting the safety of children and young people with intellectual disability: Perspectives and actions of families and professionals

Author(s): Robinson, Sally; Graham, Anne

Source: Children and Youth Services Review; Sep 2019; vol. 104

Abstract: Background: Children and young people with intellectual disability experience high rates of abuse and neglect. In this Australian study, both children and young people with disability and their supporters shared their perspectives on safety and harm. This paper discusses how family members and professionals perceived and responded to priorities that had been separately identified by children and young people. Method: Semi-structured interviews were conducted with six family members and ten disability support professionals working in a range of contexts. Data was coded and thematically analysed. Results: Participants identified strategies that children and young people used when they felt unsafe, and tensions they regularly faced that made it difficult for them to be safe. Both family members and support professional perceived a need to build confidence and capability, embed support, and act on behalf of children and young people. Relationships were a priority for families, while professionals focused more on skill development. Systems were seen to play a causative role in impairing the capacity of children and young people to stay safe, through overly bureaucratic risk orientation, using too many staff young people didn't know, and poor understanding of disability-related needs in mainstream settings. Conclusions: The key role of supporters in building capability and advocating for children and young people is affirmed, along with the need for accessible, evidence-informed education around safety and positive relationship building, and ways to promote the agency of children and young people

Content validation of the Quality of Life Inventory—Disability

Author(s): Epstein, Amy; Williams, Katrina; Reddihough, Dinah; Murphy, Nada; Leonard, Helen; Whitehouse, Andrew; Jacoby, Peter; Downs, Jenny

Source: Child: Care, Health and Development; Sep 2019; vol. 45 (no. 5); p. 654-659

Abstract :Background: Focus is shifting to better understand the lived experiences of children with intellectual disability in relation to their quality of life (QOL). Yet no available QOL measures are grounded in the domains important for this population. We previously conducted qualitative parent caregiver interviews identifying QOL domains in children with intellectual disability to constitute a new measure of QOL. This study describes the content validity of the Quality of Life Inventory—Disability (QI-Disability), a parent-report measure developed for children with intellectual disability. Methods and Results: Questionnaire items were extracted from a qualitative dataset of 77 parent caregiver interviews. To establish content validation, a draft of

QI-Disability was administered to 16 parent caregivers of children with intellectual disability (Down syndrome, Rett syndrome, cerebral palsy, or autism spectrum disorder). Parents participated in a cognitive interviewing procedure known as the "think-aloud" method. The process of item generation, cognitive debriefing, and refinement of QI-Disability prior to its pilot testing are described. A conceptual framework is presented. Conclusions: Satisfactory content validity is reported, where ongoing consumer feedback shaped the dataset from which the final items were selected. Use of QI-Disability for children with intellectual disability will allow for greater insight into service utility and targeted intervention.

Formal modeling of the Resistance to Peer Influence Questionnaire: A comparison of adolescent boys and girls with and without mild-to-borderline intellectual disability

Author(s): Dekkers, Laura M. S.; Bexkens, Anika; Hofman, Abe D.; De Boeck, Paul; Collot d'Escury, Annematt L.; Huizenga, Hilde M.

Source: Assessment; Sep 2019; vol. 26 (no. 6); p. 1070-1083

Available at [Assessment](#)

Abstract: Items of the Resistance to Peer Influence Questionnaire (RPIQ) have a tree-based structure. On each item, individuals first choose whether a less versus more peer-resistant group best describes them; they then indicate whether it is "Really true" versus "Sort of true" that they belong to the chosen group. Using tree-based item response theory, we show that RPIQ items tap three dimensions: A Resistance to Peer Influence (RPI) dimension and two Response Polarization dimensions. We then reveal subgroup differences on these dimensions. That is, adolescents with mild-to-borderline intellectual disability, compared with typically developing adolescents, are less RPI and more polarized in their responses. Also, girls, compared with boys, are more RPI, and, when high RPI, more polarized in their responses. Together, these results indicate that a tree-based modeling approach yields a more sensitive measure of individuals' RPI as well as their tendency to respond more or less extremely.

Assessing general cognitive and adaptive abilities in adults with Down syndrome: A systematic review

Author(s): Hamburg, Sarah; Lowe, Bryony; Startin, Carla Marie; Padilla, Concepcion; Coppus, Antonia; Silverman, Wayne; Fortea, Juan; Zaman, Shahid; Head, Elizabeth; Handen, Benjamin L.; Lott, Ira; Song, Weihong; Strydom, André

Source: Journal of Neurodevelopmental Disorders; Aug 2019; vol. 11

Available at [Journal of Neurodevelopmental Disorders](#) - from BioMed Central

Abstract: Background: Measures of general cognitive and adaptive ability in adults with Down syndrome (DS) used by previous studies vary substantially. This review summarises the different ability measures used previously, focusing on tests of intelligence quotient (IQ) and adaptive behaviour (AB), and where possible examines floor effects and differences between DS subpopulations. We aimed to use information regarding existing measures to provide recommendations for individual researchers and the DS research community. Results: Nineteen studies reporting IQ test data met inclusion for this review, with 17 different IQ tests used. Twelve of these IQ tests were used in only one study while five were used in two different studies. Eleven studies reporting AB test data met inclusion for this review, with seven different AB tests used. The only AB scales to be used by more than one study were the Vineland Adaptive Behaviour Scale (VABS; used by three studies) and the Vineland Adaptive Behavior Scale 2nd Edition (VABS-II; used by two studies). A variety of additional factors were identified which make comparison of test scores between studies problematic, including different score types provided between studies (e.g. raw scores compared to age-equivalent scores) and different participant inclusion criteria (e.g. whether individuals with cognitive decline were

excluded). Floor effects were common for IQ tests (particularly for standardised test scores). Data exists to suggest that floor effects may be minimised by the use of raw test scores rather than standardised test scores. Raw scores may, therefore, be particularly useful in longitudinal studies to track change in cognitive ability over time. Conclusions: Studies assessing general ability in adults with DS are likely to benefit from the use of both IQ and AB scales. The DS research community may benefit from the development of reporting standards for IQ and AB data, and from the sharing of raw study data enabling further in-depth investigation of issues highlighted by this review.

Memory and standing balance after multisensory stimulation in a snoezelen room in people with moderate learning disabilities

Author(s): Toro, Brigitte

Source: British Journal of Learning Disabilities; Aug 2019

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Abstract: Accessible Summary Multisensory stimulation improves attention, which can also improve memory and standing balance of people with learning disabilities, even at a high age. Improved standing balance and body awareness may help reduce falls in people with moderate learning disabilities. Therapeutic treatments could be more effective if preceded by multisensory stimulation. Abstract Background The Snoezelen room provides a multisensory environment for people with learning disabilities. Method Thirty-five residents were recruited from a convenience sample of people living in a residential centre. A repeated-measures, within-subject design was used to evaluate the participants during three conditions: a) Snoezelen room, b) control period and c) watching television. The outcome measures were digit span memory tests and Romberg balance tests. One-way repeated-measures ANOVAs and paired-samples t tests were performed on the data. Results ANOVA results show that there was a significant effect over time in the amount of digits remembered and in balancing ability between the three conditions ($p < .0005$). T tests confirmed that the Snoezelen condition was responsible for the significant improvements in memory and balancing ability. Conclusion Participants performed significantly better with memory tasks and balancing skills after having attended multisensory stimulation in a Snoezelen room. This may be due to improved mindfulness, which is correlated with improvements of concentration, learning ability and motor skills caused by neurophysiologic changes of the brain.

The effects of inclusive soccer program on motor performance and sport skill in young adults with and without intellectual disabilities

Author(s): Chen, C. -C. (J. J.); Ryuh, Y. -J.; Fang, Q.; Lee, Y.; Kim, M. -L.

Source: Journal of Developmental and Physical Disabilities; Aug 2019; vol. 31 (no. 4); p. 487-499

Abstract: This study aimed at investigating the effect of inclusive soccer program on motor performance and sport skill in young adults with and without intellectual disabilities (ID). Twelve participants with ID and twelve typical partners practiced 50-min each session, twice a week for 15-week long. All participants were encouraged to perform the practice at moderate exercise intensity. Measures of manual dexterity, mobility and soccer skills were tested pre- and post-program. This study showed participants with ID were able to perceive and report a number of exertion level in response to the intensity of exercise. In addition, participants with and without ID improved their performance in the Purdue Pegboard Test and Special Olympics Soccer Skill test. Thus, the mutual benefits in physical and motor performance were also evident in the typical partners. Our findings can encourage school and community to implement the inclusive

sport programs. Lastly, the comparison groups and more measures are needed to generalize the findings to the large group.

A population-based study of the behavioral and emotional adjustment of older siblings of children with and without intellectual disability

Author(s): Hayden, Nikita K.; Hastings, Richard P.; Totsika, Vasiliki; Langley, Emma

Source: Journal of Abnormal Child Psychology; Aug 2019; vol. 47 (no. 8); p. 1409-1419

Available at [Journal of Abnormal Child Psychology](#)

Abstract: This is the first study on the behavioral and emotional adjustment of siblings of children with intellectual disabilities (ID) to use a population-based sample, from the third wave of the Millennium Cohort Study (MCS); a UK longitudinal birth cohort study. We examined differences between nearest-in-age older siblings (age 5–15) of MCS children (likely mainly with mild to moderate ID) identified with ID (n = 257 siblings) or not (n = 7246 siblings). The Strengths and Difficulties Questionnaire (SDQ) measured all children's adjustment. For SDQ total problems, 13.9% of siblings of children with ID and 8.9% of siblings of children without had elevated scores (OR 1.65; 95% CI 1.04, 2.62; p = 0.031). Similar group differences were found for SDQ peer and conduct problems. In logistic regression models, variables consistently associated with older sibling adjustment were: adjustment of the MCS cohort child, older sibling being male, family socio-economic position, primary carer psychological distress, and being from a single parent household. The ID grouping variable was no longer associated with adjustment for all SDQ domains, except siblings of children with ID were less likely to be identified as hyperactive (OR 0.30; 95% CI 0.10, 0.87; p = 0.027). Some older siblings of children with ID may be at additional risk for behavioral and emotional problems. Group differences were related mainly to social and family contextual factors. Future longitudinal research should address developmental pathways by which children with ID may affect sibling adjustment. (

Do astrocytes play a role in intellectual disabilities?

Author(s): Cresto, Noémie; Pillet, Laure-Elise; Billuart, Pierre; Rouach, Nathalie

Source: Trends in Neurosciences; Aug 2019; vol. 42 (no. 8); p. 518-527

Abstract : Neurodevelopmental disorders, including those involving intellectual disability, are characterized by abnormalities in formation and functions of synaptic circuits. Traditionally, research on synaptogenesis and synaptic transmission in health and disease focused on neurons, however, a growing number of studies have highlighted the role of astrocytes in this context. Tight structural and functional interactions of astrocytes and synapses indeed play important roles in brain functions, and the repertoire of astroglial regulations of synaptic circuits is large and complex. Recently, genetic studies of intellectual disabilities have underscored potential contributions of astrocytes in the pathophysiology of these disorders. Here we review how alterations of astrocyte functions in disease may interfere with neuronal excitability and the balance of excitatory and inhibitory transmission during development, and contribute to intellectual disabilities.

Referent selection in children with Autism Spectrum Condition and intellectual disabilities: Do social cues affect word-to-object or word-to-location mappings?

Author(s): Field, Charlotte; Lewis, Charlie; Allen, Melissa L.

Source: Research in Developmental Disabilities; Aug 2019; vol. 91

Abstract: Background: There is conflicting evidence regarding whether children with Autism Spectrum Condition (ASC) and intellectual disabilities (ID) follow social pragmatic cues such as a speaker's eye gaze or pointing towards a novel object to assist mapping a new word onto a new object (e.g. fast mapping). Aims: We test fast mapping from a speaker's gaze and pointing

towards objects in children with ASC and ID with varying chronological and receptive language ages compared with receptive language matched groups of typically developing (TD) children. Methods and Procedure: Across eight trials, a speaker gazed and/or pointed towards one out of two objects while saying a new word. Pointing was either 'referential' (with intention), or 'incidental' (without obvious intention). To investigate whether children formed more robust word-to-object links rather than associative word-to-location ones, we reversed the original location of the objects in half of the test trials. Outcomes and Results: Children with ASC were as successful as TD children using social cues to form word-to-object mappings. Surprisingly, children with ID did not fast map from referential pointing, or when objects changed location. Conclusions and Implications: Children with ID may use different processes to facilitate word learning compared to TD children and even children with ASC

Views of professionals about the educational needs of children with neurodevelopmental disorders

Author(s): Van Herwegen, Jo; Ashworth, Maria; Palikara, Olympia

Source: Research in Developmental Disabilities; Aug 2019; vol. 91

Abstract: Background: Professionals play a key role in supporting children with special educational needs in schools. However, the views of those working with neurodevelopmental disorders are less known. Aims: This study examined the views of professionals (including teachers, teaching assistants, educational psychologists, speech and language therapists, physio and occupational therapists etc.) working with children with Williams Syndrome (WS), Down Syndrome (DS) or with Autism Spectrum Disorders (ASD) in terms of how informed professionals are about the disorder and their views about the type of support these children need to be receiving. Methods and procedures: Professionals working with 77 children with ASD, 26 with DS and 38 with WS completed an online questionnaire. Outcomes and results: Professionals in all three groups highlighted relevant areas of difficulty for these children, but they did not recognise some of the less phenotypical difficulties that children with a specific disorder may experience. In addition, there was a disconnect between the difficulties identified by the professionals and the type of specialist support that may be necessary. Conclusions and implications: Although professionals have a lot of knowledge about the specific neurodevelopmental disorders, further evidence-based training would allow more effective support for children with neurodevelopmental disorders in the classroom but also equip professionals better and raise their confidence in meeting these children's needs. (

Mindset and perseverance of adolescents with intellectual disabilities: Associations with empowerment, mental health problems, and self-esteem

Author(s): Verberg, Fenneke; Helmond, Petra; Otten, Roy; Overbeek, Geertjan

Source: Research in Developmental Disabilities; Aug 2019; vol. 91

Abstract: Background: Mindset refers to the implicit assumptions about the malleability of attributes such as intelligence, behavior, and personality. Previous research has shown that people endorsing a growth mindset show better academic and mental health outcomes than those with a fixed mindset. However, little is known about the mindset of youth with intellectual disabilities (ID) and its association with mental health. Methods: Adolescents with (n = 247) and without (n = 96) mild to borderline ID completed questionnaires about mindset and perseverance, empowerment, mental health problems, and self-esteem. Results: Adolescents with ID endorse a more fixed mindset of emotion and behavior than adolescents without ID. No significant differences were found for mindset of intelligence and perseverance. In addition, within the group of youth with ID some differences in mindset and perseverance were found based on level of intellectual disability, gender, and comorbidities, but not for age. Finally, a

growth mindset of emotion and behavior and perseverance, but not mindset of intelligence, were negatively related to mental health problems in youth with ID. Conclusion and implications: Overall, findings indicate that teaching youth with ID a growth mindset of emotion and behavior and perseverance may be a potentially successful endeavour to improve mental health in adolescents with ID.

Atypical eating behaviors in children and adolescents with autism, ADHD, other disorders, and typical development

Author(s): Mayes, Susan Dickerson; Zickgraf, Hana

Source: Research in Autism Spectrum Disorders; Aug 2019; vol. 64 ; p. 76-83

Abstract: Background: Previous research has not yet examined the prevalence of atypical eating behaviors in children and adolescents with autism compared to those with ADHD, other disorders, and typical development. Method: The sample comprised 2102 children: 1462 with autism, 327 with other disorders (e.g., ADHD, intellectual disability, language disorder, and learning disability), and 313 typical children, 1–18 years of age (mean 7.3). Atypical eating behaviors were assessed with the Checklist for Autism Spectrum Disorder based on a standardized parent interview conducted by licensed psychologists. Results: Atypical eating behaviors were significantly more common in autism (70.4%) than in children with other disorders (13.1%) and typical children (4.8%). For children with autism who had atypical eating behaviors, the most common behavior was limited food preferences (88%), followed by hypersensitivity to food textures (46%), other peculiar patterns most often eating only one brand of food (27%), pocketing food without swallowing (19%), and pica (12%). Grain products and/or chicken (usually nuggets) were the preferred foods for 92% of children with autism who had limited food preferences. For children with autism who had atypical eating behaviors, 25% had three or more atypical eating behaviors (vs. 0% for children with other disorders or typical development). Only children with autism had pica or pocketed food. Conclusions: The number and types of atypical eating behaviors found only in children with autism and not in children with other disorders or typical development should alert clinicians to the possibility of autism and the need to evaluate for autism in order to facilitate early identification and access to evidence-based treatment.

Selection and evaluation of Internet information by adults with intellectual disabilities

Author(s): Salmerón, Ladislao; Fajardo, Inmaculada; Gómez-Puerta, Marcos

Source: European Journal of Special Needs Education; Aug 2019; vol. 34 (no. 3); p. 272-284

Abstract: Internet offers people with intellectual disabilities (ID) unique opportunities to access information and to participate in society. But concerns have been raised about the potential risks they face when accessing the Internet (e.g. giving credit to false information, being exposed to manipulative content). As part of the current debate between positive risk-taking and overprotection, our study empirically tested the extent to which 43 adults with ID identified and selected topically relevant as well as trustworthy web pages while searching the Internet for several topics (e.g. Can social networks use your pictures for advertisement?). Participants also justified their search decisions. Results revealed that while searching familiar topics (i.e. social networks), participants selected more relevant and trustworthy pages than irrelevant and less trustworthy ones. Searches of less familiar topics (i.e. daily health), were carried out randomly, that is, without applying a specific criterion. Results point to the importance of topic familiarity on people's with ID performance on Internet searching tasks. This pattern of results suggests

that, first, we should avoid overprotection when people with ID search for familiar topics and, second, they need more support when searching for information about less familiar topics

Whorlton hall, winterbourne ... person-centred care is long dead for people with learning disabilities and autism

Author(s): Richards, Michael

Source: Disability & Society; Aug 2019

Available at [Disability & Society](#)

Abstract: Since the Winterbourne View abuse scandal in the United Kingdom, there have been responses and reports which have aimed at preventing this from happening again; however, more cases have emerged, including at Whorlton Hall, UK. There appears to be no hurry by the UK government to ensure a cultural shift occurs which places disabled people as the driving force in leading improvements in tackling systematic abuse in institutions that are meant to show compassion and care for people. In response, this article argues that person-centred care in its current form is out of date and needs to be scrapped in exchange for a new perspective that encapsulates People First values, which could go some way in ensuring that disabled people are no longer treated and classed as sub-humans.

Screening for intellectual disability with the Child and Adolescent Intellectual Screening Questionnaire: A modified Delphi approach

Author(s): Mckenzie, Karen; Murray, George; Murray, Aja; Martin, Rachel; Tanfield, Yasmin; Delahunty, Lauren; Hutton, Linda; Murray, Kara R.; O'hare, Anne

Source: Developmental Medicine & Child Neurology; Aug 2019; vol. 61 (no. 8); p. 979-983

Publication Date: Aug 2019

Abstract: Aim: To develop a consensus framework to evaluate the impact of screening for intellectual disability, using the Child and Adolescent Intellectual Disability Screening Questionnaire (CAIDS-Q) in paediatric neurodevelopment clinics. Method: A modified Delphi survey with four phases (literature review; initial development of framework [participants=11 parents, 8 professionals]; qualitative interviews [participants=4 parents, 15 professionals]; questionnaire development [participants=31 parents, 14 professionals] was used to develop the consensus framework. The framework was used to evaluate the impact of screening on six paediatricians and 31 parents of children who had participated in a previous paediatric screening project. Results: Twelve of the original 20 items were retained based on levels of endorsement of 60 per cent or above. Direct benefits of using the CAIDS-Q were: indicating the child's level of functioning, increasing awareness of intellectual disability, helping to identify children with intellectual disability, and identifying potentially vulnerable children. Benefits related to subsequent diagnostic assessment were: promoting greater understanding of the child, identification of support needs, and receipt of support, particularly for the child at school. Interpretation: The use of the CAIDS-Q had a number of direct and indirect benefits for children, families, and services as reported by parents and paediatricians. What this paper adds A 12-item framework was developed to evaluate the impact of screening for intellectual disability. Direct benefits of the Child and Adolescent Intellectual Disability Screening Questionnaire include increasing awareness and identification of intellectual disability. Indirect benefits included increased identification of support needs and receipt of support.

New approaches to studying early brain development in Down syndrome

Author(s): Baburamani, Ana A.; Patkee, Prachi A.; Arichi, Tomoki; Rutherford, Mary A.

Source: Developmental Medicine & Child Neurology; Aug 2019; vol. 61 (no. 8); p. 867-879

Available at [Developmental Medicine & Child Neurology](#)

Abstract: Down syndrome is the most common genetic developmental disorder in humans and is caused by partial or complete triplication of human chromosome 21 (trisomy 21). It is a complex condition which results in multiple lifelong health problems, including varying degrees of intellectual disability and delays in speech, memory, and learning. As both length and quality of life are improving for individuals with Down syndrome, attention is now being directed to understanding and potentially treating the associated cognitive difficulties and their underlying biological substrates. These have included imaging and postmortem studies which have identified decreased regional brain volumes and histological anomalies that accompany early onset dementia. In addition, advances in genome-wide analysis and Down syndrome mouse models are providing valuable insight into potential targets for intervention that could improve neurogenesis and long-term cognition. As little is known about early brain development in human Down syndrome, we review recent advances in magnetic resonance imaging that allow non-invasive visualization of brain macro- and microstructure, even in utero. It is hoped that together these advances may enable Down syndrome to become one of the first genetic disorders to be targeted by antenatal treatments designed to 'normalize' brain development. What this paper adds Magnetic resonance imaging can provide non-invasive characterization of early brain development in Down syndrome. Down syndrome mouse models enable study of underlying pathology and potential intervention strategies. Potential therapies could modify brain structure and improve early cognitive levels. Down syndrome may be the first genetic disorder to have targeted therapies which alter antenatal brain development.

Pharmacotherapy for mood and anxiety disorders in older people with intellectual disability in comparison with the general population

Author(s): Axmon, Anna; El Mrayyan, Nadia; Eberhard, Jonas; Ahlström, Gerd

Source: BMC Psychiatry; Aug 2019; vol. 19

Available at [BMC Psychiatry](#) - from BioMed Central

Available at [BMC Psychiatry](#) - from EBSCO (MEDLINE Complete)

Abstract: Background: People with intellectual disability (ID) have high prevalence of psychiatric disorders, but even higher rates of prescription of psychotropic drugs. Methods: Using Swedish national registers, we identified a group of older people with ID and diagnosis of mood disorders (ICD-10 codes F32-F39) and/or anxiety (ICD-10 code F4) during 2006–2012 (n = 587) and a referent group of people from the general population with the same diagnoses during the same time period (n = 434). For both groups, we collected information on prescription of anxiolytics, hypnotics and sedatives, antidepressants, and GABA-agonists. Results: Among those with a diagnosis of anxiety, people with ID were more likely than those in the general population to be prescribed anxiolytics (Relative Risk 1.32 [95% Confidence Interval 1.19–1.46]) and GABA-agonists (1.10 [1.08–1.31]). Moreover, among those with anxiety but without mood disorders, ID was associated with increased prescription of antidepressants (1.20 [1.03–1.39]). Within the ID cohort, behaviour impairment and MSP (i.e. moderate, severe, or profound) ID was associated with increased prescription of anxiolytics, both among those with anxiety (1.15 [1.03–1.30] for behaviour impairment and 1.23 [1.10–1.38] for MSP ID) and among those with mood disorders (1.14 [0.97–1.35] for behaviour impairment and 1.26 [1.04–1.52] for MSP ID). Moreover, MSP ID was associated with increased prescription of GABA-agonists among those with anxiety (1.23 [1.10–1.38]). Conclusions: The excess prescription of anxiolytics but not antidepressants may suggest shortages in the psychiatric health care of older people with intellectual disability and mood and anxiety disorders. (

Feelings of siblings having a brother/sister with Down syndrome

Author(s): Takataya, Kumiko; Mizuno, Eriko; Kanzaki, Yuki; Sakai, Ikue; Yamazaki, Yoko

Source: Archives of Psychiatric Nursing; Aug 2019; vol. 33 (no. 4); p. 337-346

Abstract: This article examined the experiences of a disabled child's siblings and their thoughts toward their disabled brother/sister. Challenges face by the family, positive and negative effects of having a disabled sibling are highlighted.

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