Learning Disabilities
Current Awareness Bulletin
March 2021

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Attention deficit hyperactivity disorder (ADHD) in adults with intellectual disability (CR230).

Royal College of Psychiatrists (RCPsych); 2021.

This report brings together the current evidence as applied in people with intellectual disabilities and it benefits from the expertise and knowledge of clinicians, built over years of experience working with people with intellectual disabilities. The evidence base will grow from more original research on ADHD in intellectual disability to understand how the disorder manifests in people with intellectual disability.

COVID-19 guide for social workers and occupational therapists supporting adults with learning disabilities or autistic adults.

Social Care Institute for Excellence (SCIE); 2021.

Updated: 20 January 2021. The vaccination programme is now underway and people are being offered their first vaccine in priority order. However, even when a person has had their vaccine, it remains vital that they continue to follow the measures outlined in this guide and the guidance on social distancing and wearing face coverings.

Title: Exploring how to deliver videoconference-mediated psychological therapy to adults with an intellectual disability during the coronavirus pandemic.

Citation: Advances in Mental Health & Intellectual Disabilities; Jan 2021; vol. 15 (no. 1); p. 20-32
Author(s): Rawlings ; Gaskell, Christopher; Rolling, Keeley; Beail, Nigel

Purpose: The novel coronavirus and associated restrictions have resulted in mental health services across the UK having to adapt how they deliver psychological assessments and interventions. The purpose of this paper is to explore the accessibility and prospective acceptability of providing telephone and videoconference-mediated psychological interventions in individuals with intellectual disabilities.

Design/methodology/approach: As part of a service evaluation, a mixed-methods questionnaire was developed and completed by clients who had been referred for psychological therapy at an adult intellectual disabilities' community health service in the north of England. All clients were assessed using the Red/Amber/Green (RAG) system by a consultant clinical psychologist for risk and potential suitability for indirect service delivery given their ability and needs.

Findings: Overall, 22 clients were invited to take part, of which, only seven (32%) were accepting of telephone or videoconference-mediated psychological therapy. Most of the clients were unable to engage in video-conference therapy and therefore, only suitable for phone therapy. This paper presents the remaining findings and discusses the clinical implications and unique considerations for intellectual disability services drawing on the existing literature.

Originality/value: This is the first paper that the authors are aware of, examining videoconference-mediated psychological therapy in this population. It is hoped the data will be used to help inform practice or policy when using such therapeutic approaches in adults with an intellectual disability.

Title: Cognitive Behaviour Therapy for People with Intellectual Disabilities—How Far Have We Come?

Citation: International Journal of Cognitive Therapy; Mar 2021; vol. 14 (no. 1); p. 114-132
Author(s): Hronis
Abstract: This review paper reflects on the existing literature on cognitive behaviour therapy for adults, adolescents and children with intellectual disabilities. People with intellectual disabilities have high rates of comorbid mental health disorders, but low rates of accessing treatments with limited treatment options available to them. Historically, they have been excluded from cognitive-based therapies such as cognitive behaviour therapy. However, recent research has shown that people with mild to moderate intellectual disabilities do have the capacity to engage in cognitive-based interventions. The review highlights the progress that has been made in the field of adapting CBT for people with intellectual disabilities, as well as the current gaps in the literature and suggestions for future research.

Title: A systematic review of emotion regulation measurement in children and adolescents diagnosed with intellectual disabilities.

Citation: Journal of Intellectual & Developmental Disability; Mar 2021; vol. 46 (no. 1); p. 90-99
Author(s): Girgis; Paparo, Josephine; Kneebone, Ian

Background: Emotion regulation is a challenge for many, in particular children with intellectual disabilities. To support understanding and the development of interventions in this area it is essential to identify valid and reliable measures.

Method: This systematic review aimed to identify measures that assess all five emotion regulation domains as described by the process model of emotion regulation; situation selection, situation modification, attention deployment, cognitive control, and response modulation. The validity and reliability of these measures was determined by the COSMIN Risk of Bias checklist.

Results: Of the 10 measures identified, only the Anxiety, Depression, and Mood Scale possessed moderate levels of evidence. However, this measure does not assess all five domains of emotion regulation.

Conclusions: Future research would benefit from the development of both informant and self-report measures for children and adolescents with intellectual disabilities, that assess all the five domains of emotion regulation.

Title: Supporting Adults with Intellectual Disabilities with Relationships and Sex: A Systematic Review and Thematic Synthesis of Qualitative Research with Staff.

Citation: Sexuality & Disability; Mar 2021; vol. 39 (no. 1); p. 113-146
Author(s): Charitou; Quayle, Ethel; Sutherland, Alan

Abstract: Staff working with individuals with Intellectual Disabilities (ID) play an important role in enabling them to fulfill their sexual and romantic needs. Given the lack of recent reviews providing a synthesis of qualitative research in this population, the present review explored how staff working with individuals with ID in a variety of capacities (e.g. support workers, service managers, nurses, educators, psychologists, social workers) perceived their role in relation to supporting sexuality and relationships. A systematic search of EMBASE, PsychINFO, MEDLINE, CINAHL, ASSIA and SCOPUS was carried out and identified articles were rated against inclusion and exclusion criteria, as well as quality criteria. Findings were analyzed using thematic synthesis. The application of criteria resulted in the inclusion of 15 articles. Four themes were identified: (a) "Attitudes towards sexuality and relationships: A right and a challenge", (b) "Responding to sexuality and relationships: A conflicted discourse", (c) "Uncertainty and lack of systemic support", and (d) "Influences on decision-making". Findings suggest that staff hold ambivalent attitudes and often respond inconsistently to issues relating to service users’ sexuality. Role uncertainty, fear of accountability, lack of training and policy, as well as factors related to employing organizations and family caregivers were identified as barriers. The findings highlight the importance of providing training and supervision for staff in order to address ambivalent attitudes and anxieties, further developing national and local policy in relation to sexuality and relationships, and supporting family caregivers to meaningfully work alongside staff on issues relating to service users’ sexuality.
Title: Securing sexual justice for people with intellectual disability: A systematic review and critical appraisal of research recommendations

Citation: Journal of Applied Research in Intellectual Disabilities; Mar 2021
Author(s): Ginn, Hannah G.

Background: People with intellectual disability contend with significant restrictions to their sexual expression and partnered relationships. This review examines the types of recommendations scholars offer in their qualitative research involving participants with intellectual disability discussing sexuality and intimate relationships.

Method: A systematic review of peer-reviewed studies published between 1972 and July 2018 yielded a sample of 26 studies. Thematic analysis was used to taxonomize scholars’ recommendations.

Results: Six distinct forms of recommendations were identified. The most frequently offered and most strongly emphasized recommendation across studies aimed to change individuals with intellectual disability. In contrast, a minority of studies prioritized engaging individuals as informants, eliciting individuals’ wishes, enabling relationships and fostering ideological change. No studies placed the greatest weight on promoting systems change.

Conclusions: Recommendations in the literature have predominantly emphasized individual as opposed to environmental changes. I consider the ramifications of this and argue for a reorientation towards systems change. (PsycInfo Database Record (c) 2021 APA, all rights reserved)  (Source: journal abstract)

Title: COVID-19 and intellectual disability/autism spectrum disorder with high and very high support needs: issues of physical and mental vulnerability.

Citation: Advances in Mental Health & Intellectual Disabilities; Jan 2021; vol. 15 (no. 1); p. 8-19
Author(s): Buonaguro ; Bertelli, Marco O.

Purpose: The COVID-19 outbreak has profoundly plagued the world, and current health efforts are focused on providing prevention and ensuring access to intensive services for people with the most severe symptomatology. Nevertheless, disasters tend to affect vulnerable subjects disproportionately, and individuals with intellectual disabilities/autism spectrum disorder with high and very high support needs (PwID/ASD-HSN) seem to be counted among the hardest hit populations. The present paper aims to provide a comprehensive discussion and evaluation of COVID-19 related issues specific to PwID/ASD-HSN.

Design/methodology/approach: Commentary on available literature and analysis of new preliminary data on PwID/ASD-HSN's physical and psychic vulnerability factors. This knowledge is fundamental to provide families and caregivers special advice to counteract the risks associated with the current pandemic.

Findings: PwID/ASD-HSN represent one of the most vulnerable population to the COVID-19 outbreak and the associated factors of mental distress for several reasons, including multimorbidity, low levels of health literacy, difficulties to understand and communicate, reliance on other people for care, low compliance with complex hygiene rules, the strong need of routine/sameness and low adaptive skills.

Originality/value: In the present work, the authors analyze the specific factors of physical and mental vulnerability in PwID/ASD-HSN, corroborating the dissertation with a discussion on the first data published worldwide and with preliminary data collected on the Italian territory for what concerns prevalence rates of COVID-19 and complications in persons with PwID/ASD-HSN and signs and symptoms of psychic distress during the mass quarantine period.
Title: Social networks and people with intellectual disabilities: A systematic review

Author(s): Harrison, Rachel Abigail; Bradshaw, Jill; Forrester-Jones, Rachel; McCarthy, Michelle; Smith, Sharon

Background: Despite the importance of social networks for health and well-being, relatively little is known about the ways in which adults with intellectual disabilities in the U.K. experience their social networks.

Method: A systematic review was completed to identify research focused on the social networks of adults with intellectual disabilities. Studies published from 1990 to 2019 were identified. Studies were thematically analysed.

Results: Quantitative, qualitative and mixed methods studies were analysed to identify key factors influencing social networks. Experiences of people with intellectual disabilities identified themes of identity, powerlessness, inclusion, family and support. These themes are discussed with reference to theories of stigma and normalisation.

Conclusions: Stigma and normalisation can be used to better understand the needs, desires and dreams of people with intellectual disabilities for ordinary relationships, from which they are regularly excluded. Implications for policy and practice are discussed in relation to building and repairing often spoiled identities. (PsycInfo Database Record (c) 2021 APA, all rights reserved) (Source: journal abstract)

Title: Is speech and language therapy effective at improving the communication of adults with intellectual disabilities?: A systematic review

Author(s): Wood, Siân; Standen, Penny

Background: A significant proportion of adults with intellectual disabilities (ID) experience speech, language and communication difficulties which are associated with poor physical and mental health outcomes. Speech and language therapy (SLT) interventions are an important way to address these communication difficulties, yet there is limited available evidence to provide information about the effectiveness of the different approaches used for this heterogeneous group.

Methods & procedures: A systematic search across relevant databases was performed. Information on methodological details of each relevant study, along with descriptions of the SLT interventions employed, were extracted and the Crowe Critical Appraisal Tool (CCAT) was used to assess quality. Findings were discussed in a narrative synthesis grouped by target communication skill.

Outcomes & results: A total of 10 relevant studies met the inclusion criteria. These were predominantly interventions aimed directly at adults with ID to improve speech, increase augmentative and alternative communication (AAC) use and develop interaction skills, with one study addressing work with carers. The included studies were all rated as low quality. There is weak preliminary evidence that SLT input can improve the communication skills of adults with ID.

Conclusions & implications: There is insufficient evidence to draw strong conclusions about the effectiveness of SLT in this population. Further high-level evidence across speech, language and communication domains is urgently needed. What this paper adds What is already known on the subject There is limited evidence for community health interventions used with adults with ID. Previous reviews of SLT interventions found a lack of evidence base for this population. Some areas of SLT practice such as AAC have demonstrated potential benefits and other areas including speech work, social communication skills and training for communication partners have some evidence base for children with ID but there is currently insufficient evidence for adults with ID. What this paper adds to existing knowledge The study systematically reviews the current evidence base available when considering the effectiveness of SLT intervention for adults with ID. It provides weak evidence to
suggest SLT intervention can improve communication in this population and highlights the need for clinically relevant, robustly designed studies to be undertaken in this field. What are the potential or actual clinical implications of this work? The lack of high-quality studies with sufficient power to draw conclusions about effectiveness means SLTs are not able to base their intervention choices on firm evidence. There is an urgent need to conduct robust research into the effectiveness of SLT interventions for adults with ID. (PsycInfo Database Record (c) 2021 APA, all rights reserved) (Source: journal abstract)

Title: Psychological ehealth interventions for people with intellectual disabilities: A scoping review

Citation: Journal of Applied Research in Intellectual Disabilities; Mar 2021
Author(s): Oudshoorn, Cathelijn E. M.; Frielink, Noud; Nijs, Sara L. P.; Embregts, Petri J. C. M.

Background: The use of eHealth, which has accelerated in the wake of the COVID-19 pandemic, could contribute to the access to tailor-made psychological interventions for people with intellectual disabilities.

Method: A scoping review was conducted on peer-reviewed studies between 1996–2019.

Results: Thirty-three studies reported on the use of psychological eHealth interventions focused on mental health problems and/or challenging behaviour. The vast majority of these studies reported on interventions that were delivered at the individual level. The context in which these interventions were delivered varied, primarily ranging from the home setting to residential settings, as well as day or activity centres and schools. The studies described various types of interventions: telehealth interventions, computerized cognitive behavioural therapy, and interventions focused on (social) learning principles targeting challenging behaviour.

Conclusions: eHealth provides new opportunities for both therapists and lay-therapists to deliver psychological interventions. Future studies should focus on the effectiveness of psychological eHealth interventions. (PsycInfo Database Record (c) 2021 APA, all rights reserved) (Source: journal abstract)

Title: Pharmacotherapy of attention deficit/hyperactivity disorder in individuals with autism spectrum disorder: A systematic review of the literature

Citation: Journal of Psychopharmacology; Mar 2021; vol. 35 (no. 3); p. 203-210
Author(s): Joshi, Gagan; Wilens, Timothy; Firmin, Elizabeth S.; Hoskova, Barbora; Biederman, Joseph

Aim: To assess the empirical evidence for the treatment of attention deficit/hyperactivity disorder (ADHD) in populations with autism spectrum disorder (ASD).

Methods: A systemic PubMed, PsychINFO, Embase, and Medline database search of peer-reviewed literature was conducted. Included in the review were controlled trials published in English with sample sizes ≥10 participants examining the safety and efficacy of anti-ADHD medication in ASD populations. Data was extracted on relevant variables of study design, demographics, associated psychopathology, medication dose, efficacy, and tolerability.

Results: Nine controlled trials met the inclusion and exclusion criteria: five with methylphenidate, three with atomoxetine, and one with guanfacine. Sample sizes ranged from 10 to 128 with 430 children participating across all the trials. In all the trials, treatment response was significantly superior to placebo. However, almost all trials assessed only hyperactivity, and most included only participants with intellectual disability with high levels of irritability. None of the trials distinguished agitation from hyperactivity. The response on hyperactivity for methylphenidate and atomoxetine was less than that observed in the neurotypical population; however, the response for guanfacine surpassed results observed in neurotypical populations. Treatment-emergent mood lability (i.e. mood dysregulation and mood-related adverse events) was frequently associated with methylphenidate and guanfacine.
treatments. Worse treatment outcomes were associated with individuals with lower intellectual capability compared with those with higher IQs.

**Conclusions:** There is a scarcity of controlled trials examining ADHD treatments in ASD populations, particularly in intellectually capable individuals with ASD and in adults. Response to ADHD medications in ASD were adversely moderated by the presence of intellectual disability and mood lability. (PsycInfo Database Record (c) 2021 APA, all rights reserved) (Source: journal abstract)

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**Title:** Making effective reasonable adjustments for women with learning disabilities during pregnancy.

**Citation:** Learning Disability Practice; Mar 2021

**Author(s):** Daniels; Douglass, Emma

**Abstract:** Why you should read this article: • To enhance your awareness of the barriers that pregnant women with learning disabilities may experience in accessing maternity care • To identify reasonable adjustments that can be made to improve the care of pregnant women with learning disabilities • To learn about a service improvement initiative designed to raise healthcare professionals' awareness of the needs of women with learning disabilities during pregnancy An increasing number of women with learning disabilities are forming relationships and having children. These women are likely to have additional needs during pregnancy and to experience barriers in their access to maternity services. This article details a literature review on maternity care for women with learning disabilities during pregnancy and explains how the findings were used to inform the planning of a service improvement initiative. The literature review identified that this patient population is inconsistently and ineffectively supported by maternity services. Based on these findings, a service improvement initiative was designed to raise awareness of the needs of women with learning disabilities during pregnancy among healthcare professionals working in maternity services in Devon, England. It was decided that a one-day conference be held for up to 120 delegates in the summer of 2021. Its outcomes will be used to advance the service improvement initiative, create learning disability champions and provide practical suggestions on how reasonable adjustments can be made for women with learning disabilities during pregnancy.

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**Title:** Personalized Goals for Positive Behavioral Support: Engaging Directly with Children who have Intellectual and Developmental Disabilities.

**Citation:** Journal of Child & Family Studies; Feb 2021; vol. 30 (no. 2); p. 375-387

**Author(s):** Gore; McGill, Peter; Hastings, Richard Patrick

**Abstract:** Stakeholder involvement is fundamental to Positive Behavioral Support yet research in this area rarely obtains views of children with Intellectual and Developmental Disabilities. This study aimed to develop and demonstrate a means of engaging directly with children to identify personalized goals and priorities for their future support. An augmented communication approach was used to facilitate interviews with children who had a range of disabilities and displayed behavior that challenges. The interviewer asked children about activities, their own behavior, a caregiver’s behavior, and quality of life to focus future potential assessment and intervention. We completed interviews in at least some areas with 9 out of 14 children. Children prioritized goals for future support and evidenced insight into behavior, needs, and preferences. These findings have promising implications for further direct engagement of children with disabilities throughout a support pathway to achieve outcomes rich in social validity. Highlights: This study interviewed children with Intellectual and Developmental Disability about their goals and priorities for support. An augmentative communication approach (Talking Mats) was used. Children who completed interviews identified goals and priorities for their behavior, caregivers and other life areas. It is possible to engage directly with some children who have intellectual and developmental disabilities in behavior support research and practice.
Title: The impact of covid-19 restrictions in the united kingdom on the positive behavioural support of people with an intellectual disability

Citation: British Journal of Learning Disabilities; Feb 2021
Author(s): Murray, George C.; McKenzie, Karen; Martin, Rachel; Murray, Aja

Accessible summary: The way that people with an intellectual disability are supported is very important. The COVID-19 virus has changed the way that staff help people with an intellectual disability. We wanted to know about those changes and whether learning about positive behavioural support (PBS) helped staff to cope with them. The main changes were that people with an intellectual disability could not go out or see family and friends as often. Staff came up with new things to do for the people they supported, and PBS learning seemed to help staff to cope.

Abstract background: It has been suggested that COVID-19 and the associated restrictions are likely to have a negative impact on the provision of positive behavioural support (PBS) to people with an intellectual disability.

Methods: Fifty-eight staff, who had recently completed an accredited positive behavioural support (PBS) programme, responded to an online questionnaire, which asked them to rate the impact of COVID-19 on factors related to PBS.

Results: Participants reported a neutral or somewhat positive impact on all the areas measured, with the exception of the activities and quality of life of those they supported, which were somewhat negatively affected. The participants rated the learning from their PBS programme as helping them cope with COVID-19 to some extent. Examples of positive and negative effects and ways in which PBS helped staff to cope are presented.

Conclusions: Many staff developed creative solutions that allowed them to provide PBS despite the COVID-19 restrictions. PBS learning appeared to help staff cope with the negative impact of the restrictions. (PsycInfo Database Record (c) 2021 APA, all rights reserved) (Source: journal abstract)

Sources Used:
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