**Title**: Systematic literature review of the psychometric methods and characteristics of instruments measuring anxiety symptoms in people with intellectual disability

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**Introduction**: Anxiety disorders are up to six times more common in people with intellectual disability (ID) than in the general population (Cooper et al., 2007; Emerson, 2003; Salazar et al., 2015; Simonoff et al., 2008). However, clinically significant levels of anxiety are often not identified in people with ID. Commonly used screening instruments rely on a person's ability to verbalize their worries, which cognitive or communication difficulties can obstruct (Carruthers et al., 2020; Hallett et al., 2013). In response, researchers have developed new instruments or tested the applicability of existing instruments for people with ID. This study builds on prior systematic literature reviews (SLRs) of psychometric studies of anxiety instruments for adults with ID (Hermans et al., 2011) and for children and young people (CYP) with ID (Reardon et al., 2015). It assesses the reported psychometric methodological choices, psychometric characteristics, risk of bias, and the applicability of the findings to people with ID, as well as the instruments' accuracy, item content, and suitability for routine use.

**Method**: PROSPERO-registered, this study adheres to PRISMA guidelines. It uses QUADAS-2 (Whiting, 2011), the Contemporary Psychometrics Checklist (Vitoratou et al., 2023), and Characteristics of Assessment Instruments for Psychiatric Disorders in Persons with Intellectual Developmental Disorders (Zeilinger et al., 2012) to assess the studies’ risk of bias and applicability to anxiety in ID, authors’ psychometric methods, and the instruments' suitability for implementation, respectively. Where homogeneity allows, data will be meta-analyzed using inverse variance methods using *metafor* for R. Other data will be summarized narratively.

**Results**: Of the 5,475 peer-reviewed articles published between January 2010 and July 2023 identified by Ovid MEDLINE, PsycINFO, Embase, and Web of Science, 28 qualified for inclusion. Eleven evaluate questionnaires in CYP, ten in adults, and seven in all age groups. Collectively, the studies seek to measure anxiety symptoms in people with ID, including those with Down, Fragile X, Prader-Willi, and Rett syndromes and autism. Initial findings indicate that while ten CYP studies apply good or satisfactory psychometric methods that yield good or satisfactory internal consistency results, only one does for exploratory factor analysis and three for confirmatory factor analysis. None of the CYP studies indicate good sensitivity or specificity of the instruments. Three CYP studies provide limited information on the suitability of the instruments for routine use.

**Discussion:** Measuring anxiety in people with ID has recently become a focus of publications. However, gaps in the literature on anxiety screening measures for people with ID remain, such as diagnostic test accuracy analyses in CYP and assessments of the suitability of the instruments for routine use in low-resource settings.

**References:**

Carruthers, S., Kent, R., Hollocks, M. J., & Simonoff, E. (2020). Brief Report: Testing the Psychometric Properties of the Spence Children’s Anxiety Scale (SCAS) and the Screen for Child Anxiety Related Emotional Disorders (SCARED) in Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders*, *50*(7), 2625–2632. https://doi.org/10.1007/s10803-018-3774-8

Cooper, S.A., Smiley, E., Morrison, J., Williamson, A., & Allan, L. (2007). Mental ill-health in adults with intellectual disabilities: Prevalence and associated factors. *British Journal of Psychiatry*, *190*(1), 27–35. https://doi.org/10.1192/bjp.bp.106.022483

Emerson, E. (2003). Prevalence of psychiatric disorders in children and adolescents with and without intellectual disability. *Journal of Intellectual Disability Research*, *47*(1), 51–58. https://doi.org/10.1046/j.1365-2788.2003.00464.x

Hallett, V., Lecavalier, L., Sukhodolsky, D. G., Cipriano, N., Aman, M. G., McCracken, J. T., McDougle, C. J., Tierney, E., King, B. H., Hollander, E., Sikich, L., Bregman, J., Anagnostou, E., Donnelly, C., Katsovich, L., Dukes, K., Vitiello, B., Gadow, K., & Scahill, L. (2013). Exploring the Manifestations of Anxiety in Children with Autism Spectrum Disorders. *Journal of Autism and Developmental Disorders*, *43*(10), 2341–2352. https://doi.org/10.1007/s10803-013-1775-1

Hermans, H., van der Pas, F. H., & Evenhuis, H. M. (2011). Instruments assessing anxiety in adults with intellectual disabilities: A systematic review. *Research in Developmental Disabilities*, *32*(3), 861–870. https://doi.org/10.1016/j.ridd.2011.01.034

Reardon, T. C., Gray, K. M., & Melvin, G. A. (2015). Anxiety disorders in children and adolescents with intellectual disability: Prevalence and assessment. *Research in Developmental Disabilities*, *pp. 36*, 175–190. https://doi.org/10.1016/j.ridd.2014.10.007

Salazar, F., Baird, G., Chandler, S., Tseng, E., O'Sullivan, T., Howlin, P., Pickles, A., & Simonoff, E. (2015). Co-occurring Psychiatric Disorders in Preschool and Elementary School-aged Children with Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders*, *45*(8), 2283–2294. https://doi.org/10.1007/s10803-015-2361-5

Simonoff, E., Pickles, A., Charman, T., Chandler, S., Loucas, T., & Baird, G. (2008). Psychiatric Disorders in Children With Autism Spectrum Disorders: Prevalence, Comorbidity, and Associated Factors in a Population-Derived Sample. *Journal of the American Academy of Child & Adolescent Psychiatry*, *47*(8), 921–929. https://doi.org/10.1097/CHI.0b013e318179964f

Vitoratou, S., Uglik-Marucha, N., Hayes, C., & Pickles, A. (2023). *An introductory comprehensive guide for assessing measurement tool quality: The Contemporary Psychometrics (ConPsy) Checklist*. OSF. https://doi.org/10.31234/osf.io/t2pbj

Whiting, P. F. (2011). QUADAS-2: A Revised Tool for the Quality Assessment of Diagnostic Accuracy Studies. *Annals of Internal Medicine*, *155*(8), 529. https://doi.org/10.7326/0003-4819-155-8-201110180-00009

Zeilinger, E. L., Nader, I. W., Brehmer-Rinderer, B., Koller, I., & Weber, G. (2012). CAPs‐IDD: Characteristics of Assessment Instruments for Psychiatric Disorders in Persons with Intellectual Developmental Disorders. *Journal of Intellectual Disability Research*, *57*, 10.

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