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Scaling methods to measure psychopathology in persons with intellectual disabilities

Johnny L. Matson [a,*], Brian C. Belva [a], Megan A. Hattier [a], Michael L. Matson [b]

[a] Louisiana State University, USA
[b] Center for Research, Disability Consultants, LLC, USA

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ABSTRACT

Psychopathology prior to the last four decades was generally viewed as a set of problems and disorders that did not occur in persons with intellectual disabilities (ID). That notion now seems very antiquated. In no small part, a revolutionary development of scales worldwide has occurred for the assessment of emotional problems in persons with ID. The first standardized test to emerge was the *Psychopathology Instrument for Mentally Retarded Adults* (*PIMRA*) in 1984. Since that time, an impressive number of measures of general psychopathology have emerged for adults and children as well as for persons across the full range of levels of ID. The purpose of this review was to provide a description of available measures, to review papers published on these measures, and to discuss emerging trends in test development. The trends in this body of information for enhancing differential diagnosis of psychopathology in persons with ID are discussed.

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ID is a condition that affects roughly 3% of the population worldwide. While many genetic conditions are known to cause ID, there are many social and cultural factors that also may exacerbate this problem (Asada, Tomiwa, Okada, & Itakura, 2010; Chen, Tseng, Hu, & Koh, 2010; Cheng & Chen, 2010; Matson, Kiely, & Bamburg, 1997; Matson, Smiroldo, & Bamburg, 1998). Common problems seen in persons with ID include deficits in social and adaptive/self-help skills (Lancioni et al., 2010; Lante, Reece, & Walkley, 2010; Leung, Mak, Lau, Cheung, & Lam, 2010; Liu et al., 2010; Shin, Shin, & Wang, 2010; Sun, Zhu, Shih, Lin, & Wu, 2010; Wise, Sevcik, Romski, & Morris, 2010; Wu, Qiu, Wong, Hernandez, & Zhao, 2010). Additionally, co-occurring problems such as epilepsy and challenging behaviors (CBs) occur at high rates (Embregts, du Bois, & Graef, 2010; Lambrechts, Van Den Noortgate, Eeman, & Maes, 2010; McCarthy et al., 2010; Rose, 2010; Williams, 2010).

One of the most heavily studied topics regarding problems that co-occur are mental health disorders. This situation is largely due to the fact that psychopathology is generally acknowledged to occur at much higher rates among persons with ID compared to the general population (Cherry, Paclawskyj, & Matson, 1997; Cherry, Penn, Matson, & Bamburg, 2000; Dekker & Koot, 2003; Dekker, Koot, van der Ende, & Verhulst, 2002; Emerson, 2003; Matson and Smiroldo 1997; Matson, Simroldo, Hamilton, & Baglio, 1997; Paclawskyj, Matson, Bamburg, & Baglio, 1997). Some specific disorders are more common than others. For example, children with ID are more likely to evince Attention-Deficit/Hyperactivity Disorder (ADHD) or pervasive developmental disorders (Koskentausta, Iivanainen, & Almqvist, 2002). ID and psychopathology are risk factors for a variety of other problems also including various CBs (Duncan, Matson, Bamburg, Cherry, & Buckley, 1999; Matson & Bamburg, 1999; Matson & Nebel-Schwalm, 2007; Mayville, Matson, Laud, Cooper, & Kuhn, 2005). However, these CBs are distinct disorders versus symptoms of psychopathology (Matson & Mayville, 2001; Sturmey, Laud, Cooper, Matson, & Fodstad, 2010a, Sturmey,

* Corresponding author at: Department of Psychology, Louisiana State University, Baton Rouge, LA 70803, USA.
E-mail address: johnmatson@aol.com (J.L. Matson).

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Laud, Cooper, Matson, & Fodstad, 2010b). Other serious deficits in self-help and social skills are evident (Coe et al., 1999; Kuhn, Matson, Mayville, & Matson, 2001; Matson, Bamburg, Cherry, & Paclawskyj, 1999; Matson, Rush, et al. 1999; Matson, Carlisle, & Bamburg, 1998; Matson & Kuhn, 2001; Matson, Smiroldo, et al., 1998; Smith & Matson, 2010a, 2010b). Physical disabilities are also more common with epilepsy being particularly common (Smith & Matson, 2010c).

A well-established area of research on psychopathology in persons with ID has been the development of tests to evaluate these mental health conditions. This paper is a review of the available general measures of psychopathology used for persons with ID. Studies that have been published on these scales' psychometric properties are discussed. As recently as 1996, Einfeld and Tonge (1996) lamented the lack of psychometrically sound instruments to measure psychopathology in persons with ID. A very positive development since that time has been the extensive development of scaling methods. There have been excellent reviews published recently on measures specific to adults with ID and depression (Hermans & Evenhuis, 2010) and in measures of anxiety for persons with ID (Hermans, van der Pas, & Evenhuis, 2011). Thus, we will focus on general measures of psychopathology in the present review.

1. History

The first scale for assessing psychopathology for persons with ID appeared in 1983 (Kazdin, Matson, & Senatore, 1983). The authors describe the *Psychopathology Instrument for Adults with Mental Retardation* (*PIMRA*). This scale, which is still in widespread use today and has been translated into many languages, was designed by the second author and modeled after structured interviews such as the *Schedule for Affective Disorders and Schizophrenia* which were very popular at the time (Endicott & Spitzer, 1978). The *PIMRA* was designed to be a much briefer interview. Also, given the fact that many persons with ID might have difficulty self-reporting, a corresponding caregiver form was also developed. Presently, 31 studies had been published using the *PIMRA* as a primary measure. Other studies have relied on the *PIMRA* as an anchor scale to establish the validity of other general measures of psychopathology for individuals with ID (e.g. *Child Behavior Checklist* [*CBCL*]; Masi, Brovedani, Mucci, & Favilla, 2002).

The reader should consider the context in which this instrument first appeared. At that point in time, there was considerable debate among mental health professionals about whether psychopathology existed or could occur in persons with ID, or with children in general for that matter. Thus, the *PIMRA* was a statement about the existence of these conditions as much as it was a method of measuring psychopathology in persons with ID. Since 1982, scale development in this area has accelerated. Fig. 1 provides information on the total number of studies published since 1983.

2. The scales

Fourteen general measures of psychopathology were located with published studies employing persons with ID. A number of these scales have been studied infrequently. For the purposes of this paper, we are defining infrequently studied scales as those where six or fewer papers have been published. Refer to Table 1 for a list of infrequently studied measures discussed in this paper. The second category is labeled frequently studied scales and is defined as measures with seven or more papers published, where they were included. Refer to Table 2 for a list of these frequently studied measures. We have not included measures that are primarily geared to assess autism or therapy success.

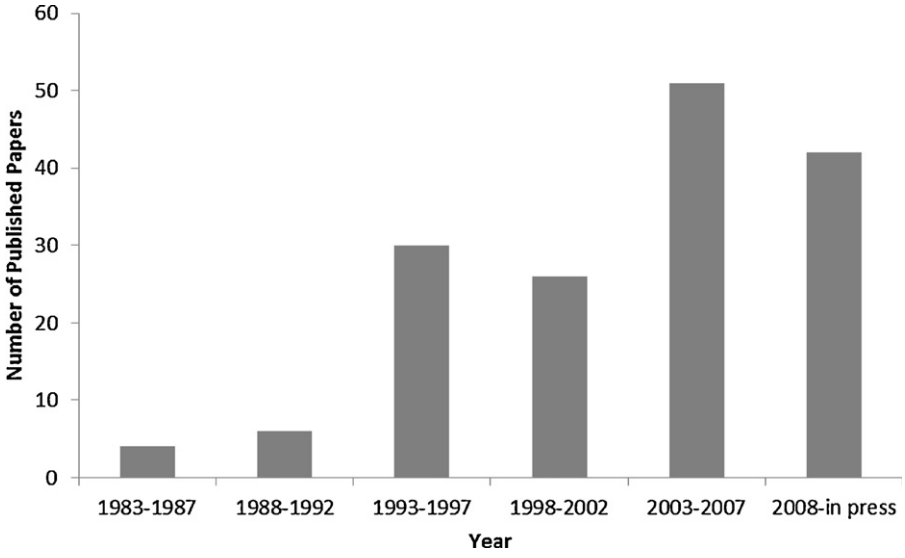

Fig. 1. Number of published papers on general measures of psychopathology for persons with intellectual disabilities ($N = 169$).

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