

# Mental Health Conditions and Challenging Behaviors in Individuals with Intellectual and Developmental Disabilities: Gap between Research and Care

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It is estimated that 13 percent of the population has an intellectual or developmental disability (IDD; Boyle et al., 2011) which is characterized by severe and chronic limitations in cognitive and/or physical functioning that appears prior to age 22 years and is likely to be lifelong (American Association on Intellectual and Developmental Disabilities, 2010). Individuals with IDD are at high risk for mental health conditions and challenging behaviors. Indeed, studies indicate that between one-third and one-half of children and adults with IDD met criteria for a mental health condition (e.g., Cooper, Smiley, Morrison, Williamson & Allan, 2007; Einfield & Tonge, 1996; Morgan, Leonard, Bouke, Jablensky, 2008). The prevalence of challenging behaviors such as aggression, disruptive behaviors, inattention, and self-injury vary across studies and by etiology (e.g., Eisenhower, Baker, & Blacher, 2005; Hartley, MacLean, Butler, Thompson, & Zarcone, 2005; Hartley, Sikora, & McCoy, 2008), but aggression alone is estimated to occur in 10-45% of individuals with IDD (Emerson et al., 2001; Grey, Pollard, McClean, MacAuley, & Hastings, 2010). To complicate matters more, comorbidity of mental health conditions and challenging behaviors is frequent. Estimates suggest that half of children and adults with IDD who met criteria for one mental health condition or exhibit one type of challenging behavior, also met criteria for additional mental health conditions or exhibit additional types of challenging behaviors (e.g., Cooper et al., 2007; Emerson et al., 2001; Hartley et al., 2008). Mental health conditions and challenging behaviors are a significant contributor to the high cost of IDD (e.g., Kanpp, Comas-Herrera, Astin, Beecham, & Pendaries, 2005; Allen, Lowe, Moore, & Brophy, 2007), which was estimated to be nearly \$400 billion in 2006 for adults in the U.S. (Anderson, Armour, Finkelstein, & Wiener, 2010).

Over the past few decades, a substantial body of research has been aimed at identifying effective tools for the detection, diagnosis, and treat-

ment of mental health conditions and challenging behaviors in individuals with IDD. Empirically-supported practices for detecting, diagnosing, and treating many mental health conditions and challenging behaviors in individuals with IDD have now been identified, although a great deal of research remains to be done. Unfortunately, there remains a gap between this research and actual clinical practice, suggesting a critical need for mechanisms to better disseminate education and training on best care standards for mental health and challenging behaviors in individuals with IDD.

## State of Clinical Care

Mental health conditions and challenging behaviors often go undetected and undiagnosed in individuals with IDD (e.g., Beange, McElduff, & Baker, 1995; Walsh & Heller, 2000). One factor reported to contribute to this under-detection is a lack of practitioner education and training. Without specialized training, mental health conditions and challenging behaviors are complicated to detect and diagnose in individuals with IDD. This difficulty derives from the high rate of comorbidity of conditions, complexity of understanding symptoms and behaviors in the developmental and social context of IDD, and the need to differentiate mental health conditions and challenging behaviors from symptoms and behaviors stemming from physical health problems, which are highly prevalent in the IDD population (e.g., Emerson & Baines, 2011). Moreover, detection and diagnosis of mental health conditions and challenging behaviors involves assessment of the internalized feelings and emotions of individuals with IDD, which requires unique strategies and screening/assessment methods.

Similarly, treatment options for mental health and behavioral challenges in individuals with IDD often are limited and not guided by empirical evidence. Despite their demonstrated efficacy, psychosocial treatments are not widely offered to individuals with IDD, and this has been

voiced as a concern by adults with IDD and their caregivers (McGillivray & McCabe, 2012; Weiss, Lunsky, Gracey, Canrisus, & Morris, 2009). When psychosocial treatments are offered, research suggests that these treatments are often not guided by empirically supported findings and best practice standards. For example, in a study of 625 individuals with ID living in community and institutional residences in Ontario, Canada, Feldman, Atkinson, Foti-Gervais, & Condillac (2004) found that when psychosocial treatments were used, the majority of these treatments lacked input from a qualified professional, did not have a written treatment plan, and there was no formal monitoring or evaluation of treatment effects to guide the plan. Thus, even among practitioners currently implementing psychosocial treatment practices with individuals with IDD, there is a critical need for enhanced practitioner skills to ensure that these practices are driven by empirical evidence.

The lack of practitioners in most parts of the world who have specialized training in the detection, diagnosis, and treatment of mental health conditions and challenging behaviors in individuals with IDD is costly as it results in mismanagement of these conditions. Indeed, Lunsky and Elserafi (2012) found that adults with IDD and mental health conditions were more than *twice* as likely as adults with IDD without mental health conditions to have 10 or more visits to the emergency room in a two-year period. Mental health conditions have also been shown to be the primary reason for hospital admission in adults with IDD (Balogh, Hunter, & Ouellette-Kuntz, 2005; Cowley, Newton, Sturme, Bouras, & Holt, 2005). Emergency room visits and hospitalizations are not only costly (Cadwell, Srebotnjak, Wang, & Hsia, 2013) and ill-equipped for the ongoing treatment of mental health conditions and challenging behaviors, but professionals in these settings report not feeling prepared to treat individuals with IDD. In a study of emergency room physicians in Toronto, Canada, IDD was identified as one of the three disorders that physicians felt least comfortable diagnosing in regard to mental health conditions (Lunsky, Gracey, & Gelfand, 2008). It is therefore not surprising that caregivers of adults with IDD report high levels of dissatisfaction and frustration with care in these settings (Reichard & Turnbull, 2004; Weiss et al., 2009).

### Growing Research

In response to the need for valid approaches to detect and diagnosis mental health conditions and

behavioral challenges in individuals with IDD, a variety of training strategies (e.g., Hartley & MacLean, 2006) and screening/assessment tools (e.g., Psychiatric Assessment Schedule for Adults with Developmental Disabilities [Moss, 2002], Self-Report Depression Questionnaire [Reynolds & Baker, 1988], and Reiss screen for Maladaptive Behaviors [Reiss, 1988]) have been developed over the past several decades specifically for individuals with IDD. In addition, there are now specialized diagnostic manuals and guidelines for evaluating mental health conditions and challenging behaviors in individuals with IDD (e.g., *Diagnostic Manual-Intellectual Disability*; Fletcher, Loschen, Stavrakaki, & First, 2007). These diagnostic resources clarify symptom presentations within an IDD context, offer strategies for deciphering comorbidity and differential diagnosis, and provide guidelines for considering underlying physical health conditions.

Psychotropic medication is often the standard treatment for mental health conditions and challenging behaviors in individuals with IDD (e.g., Bradford, 1996; Brylewski & Duggan, 2001). Indeed, studies suggest that one-third to one-half of adults with IDD are taking psychotropic medications (Lott et al., 2004; Lunsky & Elserafi, 2012; Spreat, Conroy, Fullerton, 2004), with many adults with IDD reported to be taking multiple psychotropic medications (e.g., Lunsky & Elserafi, 2012). There are examples of well-developed pharmacotherapy guidelines for treating certain mental health conditions and behavioral challenges in individuals with IDD (e.g., Deb, Clarke, & Unwin, 2006); however, there is a critical need for more research in this area. There is also a need to ensure that professionals stay up-to-date on the current state of pharmacotherapy research in an IDD population as there is evidence that medications are regularly dispensed to treat mental health conditions and challenging behaviors for which there is no evidence of their effectiveness. For example, psychotropic medications are commonly used to treat aggression in individuals with IDD despite a lack of evidence that these medications lead to reductions in aggression (Matson & Neal, 2009).

Psychosocial treatments have been shown to be feasible and effective strategies for managing mental health conditions and behavioral challenges in children with adults with IDD. Studies have shown that individuals with IDD are able to engage in and benefit from psychosocial treatments (e.g., Harvey, Boer, Meyer, & Evans, 2009; Neidert, Dozier, Iwata, & Hafen, 2010; Veree-

nooghe & Langdon, 2013). For example, there is vast literature on the effectiveness of applied behavior analysis for the treatment of a variety of challenging behaviors in both children (e.g., Borrero & Vollmer, 2006; McGee & Ellis, 2000) and adults with IDD (Hassiotis et al., 2009; Roscoe, Iwata, & Goh, 1998). There is also growing evidence that cognitive behavioral therapy (CBT) is an efficacious psychosocial treatment for a variety of mental health conditions and challenging behaviors in children and adults with IDD. For example, several studies using randomized control trial designs have compared CBT to wait-list control conditions and shown significant improvements in anger for the CBT condition that were maintained at 3 to 12 month follow-ups (see Vereennooghe & Langdon, 2013 for review). Moreover, several studies suggest that adults with mild to moderate levels of ID reported decreases in depressive symptoms following CBT (e.g., Hartley et al., 2015; Hassiotis et al., 2013; McCabe, McGillivray, & Newton, 2006). Children and adolescents with autism spectrum disorder without ID have also been shown to experience declines in symptoms of anxiety with CBT treatments (e.g., Chalfant, Rapee, & Carroll, 2007). As another example, dialectical behavior therapy has been shown to result in large reductions in the challenging behavior of adults with IDD (Brown, Brown, & Dibiasio, 2013).

### **Pathway for Narrowing the Gap**

In summary, there is indeed a growing body of evidence for guiding best care practices for the detection, diagnosis, and treatment of many mental health conditions and challenging behaviors in individuals with IDD. Yet, this empirical evidence is not being used to inform actual practice. The result is an ineffective system that is unsatisfying to both professionals and individuals with IDD and their caregivers. Before large-scale system changes are likely to be adopted, however, care practices that have documented benefits in detecting, diagnosing, and treating mental health conditions and challenging behaviors in individuals with IDD will also need to demonstrate cost-savings. There is scant research on the cost-savings of care practices for mental health conditions or challenging behaviors in the field of IDD. The handful of studies that have examined cost savings are small in scale but show promising results (Felce et al., 2015; Hassiotis et al., 2009; Hudson, Jauernig, & Wilken, 1995). For example, in a study of 63 adults with ID with challenging behaviors, Hassiotis et al. (2009) found that

adults with ID who received behavioral therapy by providers with specialized training, in addition to standard treatment (i.e., pharmacotherapy), demonstrated greater reductions in their challenging behaviors and subsequently reduced reliance on community supports, as compared to adults with ID who were randomly assigned to receive only standard treatment. The additional cost of the behavior therapy made this option more expensive initially, but this additional cost was more than offset by the reduced need for community supports following treatment. Felce and colleagues (2015) similarly found early evidence that CBT for anger management not only led to improvements in behaviors and symptoms, but also reductions in the use of health and social care resources. These reductions in the use of care resources quickly compensated for the additional cost of the CBT treatment and had the potential to result in a fairly substantial long-term cost-savings (Felce et al., 2015). It will be important for researchers in the field of IDD to continue to evaluate cost-savings of specialized training and empirically-supported treatments if efforts to alter the broader system of care are to be successful.

Moving forward, there is also a need to identify mechanisms for increasing education and training on best care standards for mental health conditions and behavioral challenges in individuals with IDD. Accreditation and certification programs are widely used in the health care field (e.g., Greenfield & Braithwaite, 2008; Nasca, Philberg, Brigham, & Flynn, 2013) for ensuring that care practices are driven by empirical evidence. To date, accreditation and certification programs are largely unused in the field of IDD. Such systems provide a viable process for improving care practices for mental health conditions and challenging behaviors in individuals with IDD as they define the standards of acceptable practice within a field based on empirical evidence, offer education and training based on these standards, and provide a process for measuring compliance with these standards. The accreditation and certification bodies, thereby, play an important role in fostering quality improvement in care practices. Specifically, there is evidence that accreditation systems serve as an agent of change by making organizations/ providers aware of evidence-based practices and motivating them to adhere to these standards. In a systematic review of 66 studies evaluating the impact of several national health care accreditation programs, Greenfield and Braithwaite

(2008) concluded that there were consistent findings across studies that accreditation programs promoted change in health care practices and increases in professional development. Accreditation and certification programs may also provide a path for improving care practices related to the detection, diagnosis, and treatment of mental health conditions in individuals with IDD.

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## Culturally-Informed Care

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### Abstract

The term culturally-informed care, unlike trauma-informed care, may be relatively new to service providers (i.e. direct caregivers, therapists, etc.) and other professionals working with people with mental health issues or persons with disabilities. However, its necessity may be dated back to the beginning of the human service field when individuals may have resided in asylums or suffered other forms of social injustices at various cultural and global levels. Oakes (2011) argued that cultural competency has been lauded as an effective, direct intervention to address health care disparity issues; however the

clarification of the cultural competency process in the professional development of mental health care providers working with health care disparity populations has been repeatedly identified as a critical empirical need. Considering the aforementioned, this article attempts to initiate or encourage conversations around the significance of culturally-informed care in the delivery of service/treatment to people with mental health issues, developmental disabilities, or intellectual disabilities.

### Culturally-Informed Care

While service/treatment provision for people