A Comprehensive Evaluation of the International Classification of Diseases, Eleventh Revision Behavioural Indicators for Disorders of Intellectual Development

Kyle Lemay

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School of Psychology
Faculty of Social Sciences
University of Ottawa

Table of Contents

List of Tables and Figures

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Content of Thesis and Contributions of Authors

This dissertation was written in a multiple article format and includes two articles. The first study, "An international field study of the ICD-11 behavioural indicators for disorders of intellectual development", and the second study, "Implementation of the International Classification of Diseases 11th revision behavioural indicators for disorders of intellectual development with co-occurring autism spectrum disorder", have both been published in the Journal of Intellectual Disability Research. Both are included in this thesis with permission from the journal editor.

This thesis was conducted in the context of the World Health Organization (WHO)'s International Classification of Diseases, Eleventh Revision (ICD-11) inclusion of a comprehensive set of Behavioural Indicators (BIs) within the Neurodevelopmental Disorders grouping. Study 1 of this thesis presents primary findings from the ICD-11 international field study, whereas study 2 focuses on secondary analyses of data collected during the field study.

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As the primary author for both manuscripts, I was responsible for the literature review, design, and conceptualisation of the research questions and methods, implementation of both studies, the programming and field testing of the study EFFS platform using QualtricsTM survey software (Provo, Utah), data cleaning and management, planning and execution of statistical analyses, interpretation of the results, and preparation of manuscripts and the thesis document

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General Abstract

This dissertation presents a comprehensive exploration of the International Classification of Diseases 11th revision (ICD-11) Clinical Descriptions and Diagnostic Requirements (CDDR) and embedded Behavioral Indicators (BIs) for disorders of intellectual development with or without co-occurring autism and their implementation in clinical settings. Reliable and valid diagnostic assessment measures are needed to improve access to care for individuals with disorders of intellectual development because they often have specific needs. Current intellectual and adaptive behaviour assessment measures require specialised services and training to administer that are costly, often rendering them unavailable or inaccessible in various contexts, such as in some low- and middle-income countries (LAMICs) and underserved populations. In the two studies presented in this dissertation, I aimed to investigate the reliability, validity, clinical utility, and implementation of the BIs used as a clinical support tool for disorders of intellectual development, particularly in settings when standardised assessment measures are not available or feasible.

In Study 1, we assessed the reliability, validity, and clinical utility of these BIs, shedding light on their effectiveness as a support tool for evaluating severity levels for individuals with disorders of intellectual development. We recruited a total of 206 children and adolescents (5–18 years old) with a suspected or established diagnosis of disorders of intellectual development from four sites across three countries [Sri-Lanka (n = 57), Italy (n = 60) and two sites in India (n = 89)]. We assessed inter-rater reliability, concurrent validity using the Leiter-3 for intellectual functioning and the Vineland Adaptive Behaviour Scales-II for adaptive behaviours as standardised measures, and clinical utility of the CDDR and BIs. The BIs demonstrated excellent inter-rater reliability (intra-class correlations ranging from 0.91 to 0.97) and good to excellent

concurrent validity (intra-class correlations ranging from 0.66 to 0.82) across sites. Compared to standardised measures, the BIs had more diagnostic overlap between intellectual and adaptive functioning. The BIs were rated as quick and easy to use and applicable across severities; clear and understandable with adequate to too much level of detail and specificity to describe disorders of intellectual development; and useful for intervention selection, prognosis assessments, communication with other health care professionals, and education efforts. The results of Study 1 support use of the BIs within the ICD-11 CDDR to assist with the accurate identification of severity ratings for individuals with disorders of intellectual development.

In Study 2, we examined the implementation of the BIs in real-world clinical settings and their application in cases of disorders of intellectual development with or without co-occurring autism, emphasising the importance of tailored clinical support tools for complex neurodevelopmental conditions. We included 116 children and adolescents (5–18 years old) with a suspected or established diagnosis of disorders of intellectual development were included across four sites [Italy (n = 18), Sri Lanka (n = 19) and two sites in India (n = 79)]. A principal component analysis was conducted to evaluate the application of the ICD-11 guidance for combining severity levels. Findings demonstrated that individuals with disorders of intellectual development and co-occurring autism tended to have more severe support needs compared to individuals without autism, and that the BIs classified more individuals with mild severity compared to standard measures, across all diagnostic presentations. Despite the need for additional time and consideration for individuals with co-occurring conditions, the BIs were deemed clinically useful. The findings suggest that the ICD-11 BIs can be effectively applied and implemented internationally in clinical settings for a broad range of presentations of individuals with neurodevelopmental disorders.

Overall, these studies explore the significance of utilising the ICD-11 CDDR and BIs as a clinical support tool in clinical practice for assessing individuals with disorders of intellectual development and co-occurring conditions such as autism. The findings highlight the utility of the BIs in providing reliable and valid severity assessments across diverse cultural and clinical settings, emphasising the need for tailored diagnostic tools for complex neurodevelopmental disorders. By demonstrating the feasibility and clinical applicability of the BIs, this research contributes to enhancing diagnostic accuracy, intervention planning, and overall care for individuals with intellectual development disorders, ultimately aiming to improve outcomes and quality of life for this population.

Chapter 1: General Introduction

The International Classification of Diseases (ICD) and Related Health Problems was developed by the World Health Organization (WHO) as a global diagnostic classification system for recording, reporting, and grouping health-related factors and conditions (World Health Organization, 1992, 2014). WHO finalised the ICD 11th revision (ICD-11) after approval by the World Health Assembly in May 2019. Publication of the ICD is part of WHO's core constitutional responsibilities and countries around the world continue to use the ICD as a framework for health information and reporting (Reed, 2010). The ICD is used for the following reasons: to monitor epidemics/threats to public health/disease burden, to define obligations of WHO member states to provide free and subsidised health care to their populations; to assess progress toward meeting public health objectives; to facilitate access to appropriate health care services; as a basis for guidelines for care and standards of practice; and to facilitate research into more effective treatments and prevention strategies (Reed, 2010). A revision of the ICD history and development as well as the general structure and guiding principles used by the ICD to promote and enhance global mental health (First, Reed, Hyman, & Saxena, 2015; Kogan, 2017) may further inform the revision process for the ICD-10. The development and use of a new WHO clinical support tool and the intended methodology that will be used to assess the psychometric properties of this tool will be described in this dissertation.

ICD-10 Revisions

A major focus of the ICD-10 revision was on the *Mental and Behavioural Disorder*s chapter with the goals: (1) to provide WHO member states with a better tool to help reduce disease burden; (2) to provide health professionals with better tools for identifying people in need of mental health services; and (3) to determine which treatments are most likely to be

effective at the point at which they are most likely to encounter opportunities for care (Reed, 2010). The ICD-11 for Mortality and Morbidity Statistics, a version used for health information coding, is currently available online for public use. The comprehensive specialist version of the ICD-11 for mental, behavioural and neurodevelopmental disorders, known as the Clinical Descriptions and Diagnostic Requirements (CDDR; WHO, 2024), is intended for use by global mental health professionals in clinical settings (Reed, 2010; Reed et al., 2019). This version provides guidance on clinical descriptions, essential (required) features (i.e., characteristic signs/symptoms of a disorder expected to be present in all cases), developmental presentations, differential diagnoses, boundary differentiation between normality and other disorders, culture-related features, additional features, and codes for each disorder (First, et al., 2015; Reed, 2010). In contrast to the essential features included in the ICD-11, the current version of the *Diagnostic and Statistical Manual of Mental Disorders (DSM-5)* requires some criteria to be present in all cases, and often requires a specified minimum number of symptoms to be present for a precise duration to confirm a diagnosis. The decision to include essential features in the guidelines was to improve validity and clinical utility by defining clear thresholds between normality and pathology, while also allowing for greater flexibility considering criticism that the DSM-5's thresholds are often unsupported by empirical evidence. (First et al., 2015; Westen, 2012).

The focus of the revisions for the CDDR ICD-10 *Mental and Behavioural* chapter was to maximise scientific validity, clinical utility, and global applicability (International Advisory Group for the Revision of the ICD Mental and Behavioural Disorders, 2011; First, et al., 2015). Rather than relying on diagnostic criteria, those involved with the revision process developed diagnostic guidelines to allow more flexibility and avoid pseudo-precision (e.g., a duration requirement of ‘several months’ instead of 6 months; First et al., 2015). Working groups were

also employed to include content experts from multiple disciplines and every world region to review available literature and datasets to inform decisions (First et al., 2015).

A newly introduced *Neurodevelopmental Disorders* diagnostic category combines behavioural and cognitive disorders whose core features arise during the developmental period. Unlike ICD-10, which lacked a dedicated group for these disorders and used varying terminology, ICD-11 describes a core feature of the *Neurodevelopmental Disorders* as having significant difficulties in the acquisition and execution of specific intellectual, motor, or social functions early in life (WHO, 2018). The ICD-11 includes groupings such as: disorders of intellectual development, developmental speech or language disorders, autism spectrum disorder (ASD), developmental learning disorder, developmental motor coordination disorder, attention deficit hyperactivity disorder (ADHD), stereotyped movement disorder, primary tics or tic disorders, secondary neurodevelopmental syndrome, other specified neurodevelopmental disorders, and neurodevelopmental disorders, unspecified (WHO, 2024). In the ICD-10, specific groupings for neurodevelopmental disorders were lacking, with terms such as "mental retardation," "disorders of psychological development," and "pervasive developmental disorder" used instead (Stein et al., 2020). Notable alterations include the reclassification of hyperkinetic disorder ADHD and the removal of the distinct pervasive developmental disorder subtypes, such as childhood autism and Asperger syndrome, which are now consolidated under ASD (Stein et al., 2020). The ICD-11 allows for the coexistence of autism and ADHD in the same individual, with an emphasis on early developmental onset rather than a specific age cutoff (Stein et al., 2020). The ICD-11’s lifespan perspective removes the groupings of childhood disorders (as structured in the ICD-10) and describes disorders across developmental lifespans. Finally, the ICD-11 marked a significant shift towards a dimensional approach in diagnostic classification

(Gaebel, Striker, Kerst, 2020). This change reflected a greater emphasis on capturing the current presentation of disorders, moving away from rigid categorical distinctions often focused on in the ICD-10 and DSM-5 (APA, 2013; WHO 1992; WHO 2024). By adopting a dimensional perspective, the ICD-11 aimed to provide a more nuanced understanding of the variability and complexity of mental health conditions while also aligning with a recovery-oriented model that recognises individuals' unique experiences and trajectories (Gaebel, Striker, Kerst, 2020). These changes reflect a move towards a more comprehensive and nuanced classification system for neurodevelopmental disorders compared to the previous iteration of the ICD-10.

Assessing severity levels of intellectual and adaptive functioning for the assessment of disorders of intellectual development may assist clinicians in accurately identifying strengths and areas that may require additional support, allowing for a more precise diagnostic profile (Tassé et al., 2019). Intellectual functioning refers to cognitive abilities such as reasoning and problem-solving, while adaptive functioning involves practical, social, and conceptual skills necessary for daily life. Although existing intellectual and adaptive behaviour assessment measures are comprehensive and have robust psychometric properties, the global applicability (e.g., availability, required training) of these measures are lacking (Robertson, Hatton, Emerson, & Yasamy, 2012). For instance, most measures require specialised services and training to administer that are costly, thus rendering them unavailable or inaccessible in various contexts, such as in some low- and middle-income countries (LAMICs; Kishore, Udipi, Seshadri, 2019; Robertson et al., 2012). Access to diagnostic services is not only a challenge in LAMICs, but also globally due to multiple barriers (e.g., availability, utilisation, relevance and effectiveness, and equity) preventing individuals from accessing appropriate services (Whittle, Fisher, Reppermund, & Trollor, 2019; Whittle, Fisher, Reppermund, Lenroot, & Trollor, 2018).

Minority groups, such as linguistic minorities, may face barriers in accessing appropriate diagnostic measures and services due to limited availability or cultural and linguistic barriers which may lead to disparities in diagnosis and potentially contribute to prejudice against these groups (Beauchamp et al., 2022; Magaña & Vanegas, 2021; Papoudi, Jørgensen, Guldberg, & Meadan, 2021). To ensure equitable access to diagnostic services for all individuals, regardless of their background or geographical location, it is essential to develop culturally sensitive and linguistically appropriate diagnostic measures and services. WHO developed a novel clinical support tool specific for disorders of intellectual development with or without co-occurring disorders, such as autism, to address the needs of diverse populations and reduce the potential for bias and discrimination throughout the diagnostic process. This tool is embedded within the CDDR for the ICD-11 *Mental, Behavioural and Neurodevelopmental Disorders* chapter.

Disorders of Intellectual Development and Autism Spectrum Disorder

For this thesis, we adhere to the terminology established by the ICD-11 CDDR (e.g., disorders of intellectual development, ASD, severity levels) for precise diagnostic practices. Nonetheless**,** it is important to recognize the significant impact of language on the communities we study, particularly concerning intellectual disability and autism. The medical model often frames disability as an inherent issue within an individual's body, attributing any disadvantages they face to their impairments, which can lead to an overemphasis on the need for fixing or rehabilitating these individuals (Goering, 2015; McKenzie, 2013). In contrast, the social model of disability defines disability as the restrictions imposed by societal structures that fail to accommodate individuals with physical impairments, thereby excluding them from full participation in social activities (Oliver, 2018). While we utilize terms such as "deficits," "disorder," and "symptoms" for clarity and consistency, it is crucial to acknowledge that these

terms often reflect a medical framework that can perpetuate beliefs that marginalize individuals with disabilities (Bottema-Beutel et al., 2021). Such language may not accurately capture the lived experiences of those with intellectual and developmental disabilities, potentially coming across as alienating and derogatory by emphasizing pathology over the social and contextual factors that shape their realities (Bottema-Beutel et al., 2021). A person-centered approach helps towards respecting the dignity and individuality of those affected. The complexities of language in this field highlights the importance of fostering a dialogue that honours the experiences of autistic individuals and those with intellectual disabilities.

Disorders of Intellectual Development

Disorders of intellectual development encompass a range of conditions characterised by limitations in intellectual functioning and adaptive behaviours. The transition from the ICD-10 classification of *Mental Retardation* to the ICD-11 designation of disorders of intellectual development signifies a significant shift in the conceptualisation and definition of such disorders (Harris, 2016). Intellectual disability, which is a term proposed by the American Association on Intellectual and Developmental Disabilities (AAIDD), is not used because in WHO family of classifications, disability is coded using the international classification of functioning (ICF) whereas the ICD is reserved for classifying disorders rather than their impact on functioning (Cuthbert, 2014; WHO, 2001). This change reflects a more contemporary understanding of the condition and aligns with the evolving perspectives on disability classification (Burack et al., 2021). The ICD-11 essential features (i.e., features that must be observed in every case of the disorder) for disorders of intellectual development include significant limitations (approximately two or more standard deviations below the mean) in intellectual functioning, adaptive behaviours, and onset during the developmental period, which are largely unchanged from ICD-

10 (Cooper & Kogan, 2023; Reed et al., 2019).

The inclusion of adaptive behaviours to the ICD-11 classification for intellectual development disorders is a step forward in understanding the multifaceted nature of these complex conditions (Schalock et al., 2002). Adaptive behaviours, encompassing conceptual, social, and practical skills, is recognised as integral to understanding the functional abilities and challenges faced by individuals with disorders of intellectual development (WHO, 2018). The ICD-11 maintains the severity levels (mild, moderate, profound, severe) but unlike the DSM-5 which only considers adaptive functioning, the ICD-11 considers both intelligence quotient (IQ) scores and behavioural indicators for intellectual functioning and adaptive behaviours in determining the severity level of the disorder (APA, 2013; WHO, 2018). When performing diagnostic evaluations for disorders of intellectual development, the broader context influencing the individual's development and testing capabilities must be considered. This includes factors such as co-occurring disorders, cultural background, primary language, environmental influences, available opportunities, and level of educational training (Cooper & Kogan, 2023). In cases where standardised measures are unavailable or inappropriate for use, a thorough clinical assessment becomes essential (Cooper & Kogan, 2023). This holistic approach acknowledges the interplay between intellectual functioning and adaptive behaviour in assessing the impact of intellectual disability across different developmental stages.

Despite the standardised criteria outlined in the ICD-11, it is essential to acknowledge the inherent heterogeneity within the population of individuals with disorders of intellectual development. The heterogeneity within this population arises from a range of factors, including many different etiologies (e.g., genetic disorders, environmental causes, traumatic brain injury, neurologic/brain disorders, nutritional deficiencies, inborn errors of metabolism, and no

identifiable causes), the age of onset, distinct cognitive profiles, adaptive functioning variations, behavioural characteristics, socio-emotional traits, severity levels of areas of functioning, the presence of co-occurring disorders, and responses to interventions (Bernard Paulais et al., 2019; Burack et al., 2021; Danielsson, Henry, Messer, & Rönnberg, 2012; Purugganan, 2018; Sajewicz-Radtke et al., 2022). For example, individuals with different genetic syndromes associated with disorders of intellectual development, such as fragile X syndrome, Angelman syndrome, or Down syndrome, may exhibit distinct cognitive and behavioural characteristics (Burack et al., 2021). Individuals with disorders of intellectual development often exhibit strengths in specific cognitive domains or adaptive skills, alongside areas where they may encounter challenges. For instance, individuals with Williams syndrome tend to have relative strengths in language and non-verbal reasoning, sociability, musical talents (e.g., remarkable musical sense and fluency), and significant weaknesses in visuospatial construction (Gilson, Monkaba, Mello, & Pegg, 2023; Weiss, Sharda, Lense, Hyde, & Trehub, 2021). By considering the heterogeneity within the population and recognising the individualised nature of cognitive and adaptive profiles, clinicians and researchers can tailor diagnostic practices and interventions to better meet the specific needs of individuals with disorders of intellectual development.

Prevalence

It has been estimated globally that approximately 0.62-3.00% of individuals have disorders of intellectual development (Harris, 2006; Lin et al., 2014; McKenzie, Milton, Smith, & Ouellette-Kuntz, 2016), with mild disorders of intellectual development being the most prevalent (85%) diagnosis (King, Toth, Hodapp, & Dykens, 2009). The highest prevalence estimates of disorders of intellectual development were in LAMICS, and in child and adolescent populations (Maulik, Mascarenhas, Mathers, Dua, & Saxena, 2011). Individuals with disorders

of intellectual development are highly vulnerable and marginalised groups that experience high incidence rates of physical and mental health difficulties (Cooper, Smiley, Morrison, Williamson, & Allan, 2007; Emerson, Hatton, Baines, & Robertson, 2016; Smiley, 2005; Strømme & Diseth, 2000). In addition to psychological distress, individuals with disorders of intellectual development experience significant stigmatisation and discrimination (Llewellyn, Vaughan, & Emerson, 2015), barriers to the utilisation of large public health resources (Maulik et al., 2011) and are often excluded from participation in societies in both social and clinical settings (Cobigo & Stuart, 2010; Corbett, 2011; Tassé et al., 2019).

Nosology

The notable differences in functioning observed among individuals with disorders of intellectual functioning contradict the belief in a uniform and homogeneous population, suggesting that this perception is misleading (Burack et al., 2021). Both scientific research and clinical practice advocate for dismantling the traditional concept of intellectual disability as a singular entity and population, in favour of recognising and addressing the diverse etiological groups within this population. This shift represents a crucial advancement in the ICD-11 compared to the DSM-5 (APA, 2013; WHO, 2018). While the DSM-5 continues to promote the misconception of disorders of intellectual development as a monolithic diagnostic entity through the term “Intellectual Developmental Disorder,” categorised within neurodevelopmental conditions, the ICD-11 acknowledges that below-average intellectual ability and impaired adaptive behaviours are common symptoms shared by a range of etiologically diverse conditions, characteristics, and levels of functioning (APA, 2013; Burack et al., 2021; WHO, 2018). This recognition marks a significant improvement in precision and nuance from the previous ICD-10 definition of disorders of intellectual development as a condition of "arrested or

incomplete development of the mind" (Cooper & Kogan, 2023; WHO 1992).

The ICD-11 also denotes severity levels using the specifiers “mild”, “moderate”, “severe”, “profound”, and “provisional” whereas severity is embedded within the diagnosis when using the DSM-5 and ICD-10. The ICD-11 CDDR offers a thoroughly developed behavioural indicators (BIs) table that provides a standardised method for determining severity levels when assessing intellectual functioning (not established previously) and adaptive behaviours, as opposed to the DSM-5 which lacks this level of detail (Cooper & Kogan, 2023). While the DSM-5 typically relies on IQ testing as a central component in assessing intellectual functioning and diagnosing disorders of intellectual development, the ICD-11 takes a more comprehensive approach by considering BIs for intellectual functioning and adaptive behaviours in addition to IQ scores (Cooper & Kogan, 2023). This difference in approach reflects varying perspectives on how to evaluate and classify disorders of intellectual development, with the ICD-11 emphasising a broader assessment of functioning beyond IQ scores.

The ICD-11 CDDR has adopted a hybrid approach for the classification of disorders of intellectual development, incorporating both categorical and dimensional elements (Widiger & Frances, 2002). Severity levels are primarily determined categorically using standardised measures, and dimensionally by evaluating a range of observable behaviours related to intellectual functioning and adaptive behaviours (Cilibrasi & Tsimpli, 2020). This dimensional assessment allows for behaviours to be placed on a continuum, reflecting the varying degrees of impairment and strengths within each category. By utilising a dimensional approach, a more nuanced understanding of an individual's abilities and challenges can be achieved, considering the complexity and variability within each area of functioning and severity level (Widiger & Frances, 2002). The assessment process involves converting the information gathered

dimensionally into a categorical framework, assigning individuals to distinct severity levels (e.g., mild, moderate, severe, profound) based on their observed level of impairment. While this categorical classification simplifies the presentation of information, it enables the grouping of individuals with disorders of intellectual development for diagnostic and intervention purposes (Widiger & Frances, 2002). By incorporating BIs for intellectual functioning, the ICD-11 CDDR enhances the dimensional framework, offering supplementary insights to delineate specific strengths and weaknesses beyond the categorical data derived from standardised assessment measures of intellectual functioning. The integration of both dimensional and categorical aspects in the assessment process allows for a comprehensive evaluation of individuals with disorders of intellectual development, balancing the detailed understanding provided by observable behaviours with the need for clear classifications for clinical decision-making.

Understanding the severity of intellectual disabilities provides a framework for tailoring effective compensatory strategies, guiding intervention planning, facilitating targeted remediation efforts, and accessing appropriate services (Ayuso-Mateos & Kogan, 2020). Such considerations may assist clinicians, researchers, and healthcare providers to create personalised plans that address individual challenges and strengths, prioritising interventions for overall well-being. Moreover, recognising the common co-occurrence of autism with disorders of intellectual development underscores the importance of comprehensively addressing the interplay between these conditions for optimal care and intervention strategies.

Autism Spectrum Disorder

Autism Spectrum Disorder (ASD) is a complex neurodevelopmental disorder characterised by persistent deficits with initiating and sustaining reciprocal social interaction and communication, and by a range of restricted, repetitive, and inflexible patterns of behaviour,

interests, or activities that are clearly atypical or excessive (WHO, 2024). Individuals with autism may exhibit a wide range of abilities, symptoms, and diverse etiologies, leading to the term "spectrum". While symptoms typically arise in early childhood, autism can clinically manifest at any age, with overt symptoms sometimes becoming more pronounced during adolescence or adulthood when individuals are faced with social demands that surpass their capacities (Greaves-Lord, Skuse, & Mandy, 2022). Early diagnosis and intervention tailored to the individual's needs can significantly improve outcomes and quality of life for individuals with autism.

Individuals diagnosed with autism form a highly diverse population, as seen in the wide range of expression and severity of core and associated symptoms, developmental trajectories, sex/gender differences, language abilities, cognitive functioning, adaptive behaviours, environmental influences, and co-occurring conditions (Hirota & King, 2023; Kamp-Becker, 2024). This diversity is reflected in the varied manifestations of autism, including individuals with disorders of intellectual development and limited language skills, as well as those with above-average intellectual and language abilities who face challenges in social communication (Hirota & King, 2023). A significant degree of heterogeneity is observed among individuals with autism, including differences in cognitive abilities (i.e., from disorders of intellectual development to exceptional cognitive skills in specific areas such as pattern recognition or memory), communication skills (i.e., from severe language impairments to advanced verbal skills buy struggle with pragmatic language or social communication), social interaction (i.e., from profound challenges in understanding social cues and forming relationships to a keen interest in socialising but with atypical social behaviours), focused interests and skills (e.g., music, art, mathematics, technology), and various sensory sensitivities. This diversity in autism

also extends to intervention responses and outcomes, impacting the accuracy of clinical diagnoses and shaping decision-making processes.

Prevalence

The number of individuals with autism continues to rise, with prevalence rates of approximately 0.6-2.3% in child and adult populations (Baird et al., 2006; Coo et al., 2008; Fombonne, 2003; Hirota & King, 2023; Ouellette-Kuntz et al., 2014). Individuals with autism have high morbidity and service utilisation rates due to their early onset, lifelong persistence, level of impairment, and lack of effective intervention and support for essential features (Järbrink, Fombonne, & Knapp, 2003; Simonoff et al., 2008). Individuals with autism face disparities in identification rates between middle- and high-income children compared to low-income children, highlighting the importance of addressing resource allocation and access to appropriate services, especially in low-income countries (Boat & Wu, 2015). The increasing heterogeneity and higher prevalence rates in autism identification may be influenced by our conceptualisation and classification of the disorder. By capturing a broader spectrum of symptoms and behaviors, the updated conceptualisation and classification of autism enable healthcare professionals to identify individuals who may have been previously undiagnosed or misclassified (Bertelli et al., 2022). This enhanced understanding of autism not only reflects the true heterogeneity of the disorder but also underscores the importance of ongoing research and refinement in conceptualising and classifying neurodevelopmental disorders.

Nosology

The ICD-11 ASD category marks a significant shift from previous iterations by consolidating Asperger's Syndrome, Pervasive Developmental Disorder (PDD), and Autism into a unified spectrum (WHO, 2024). The ICD-11 CDDR and DSM-5 criteria for ASD share a

similar view that individuals with autism represent a diverse spectrum with various presentations, emphasising persistent challenges in social communication/interaction and restricted, repetitive behaviours (Reed, 2021). Although the core features are maintained in ICD-11 (i.e., deficits in social interaction and social communication alongside restricted, repetitive, and inflexible patterns of behaviour and interests), a multi-categorical system of specifiers offering eight sub-categories of ASD diagnoses is used to capture characteristics of where along the spectrum a patient's symptoms can be described (WHO, 2018). To infer this process, qualifiers are used to describe: (1) co-occurring disorders of intellectual development; (2) level of functional language (i.e., non-verbal receptive and expressive language deficits used for instrumental purposes such as expressing personal needs and desires); and (3) loss of previously acquired skills (WHO, 2018).

The ICD-11 CDDR for ASD allows for a high variety of symptom combinations, capturing the diverse picture of autism, whereas the DSM-5 has more specific criteria for symptom presentation (Reed, 2021). In terms of social communication deficits, the DSM-5 requires three specific criteria to be met (i.e., deficits in (1) social-emotional reciprocity; (2) nonverbal communication; and (3) developing, maintaining, and understanding relationships), whereas the ICD-11 offers a more flexible approach with a list of seven manifestations that may be observed and closely align with the DSM-5 criteria (Reed, 2021). In terms of restricted behaviours, the DSM-5 focuses on symptoms typically seen in individuals with autism and co-occurring disorders of intellectual development, reflecting past associations between the two disorders (Reed 2021). On the other hand, the ICD-11 examples are more reflective of individuals without disorders of intellectual development, previously diagnosed with Asperger's Syndrome, which is now considered part of the autism spectrum (Reed, 2021). The DSM-5 is

more precise, requiring two out of four specified items, while the ICD-11 provides more flexibility and clinical judgement by offering a list of seven illustrative examples. The ICD-11 features a more comprehensive and varied definition of autism, requiring clinicians to have strong clinical skills and judgement to accurately discriminate between prominent features of autism from other disorders and boundaries with normality, particularly when there is the possibility of co-occurring mental health conditions (Kamp-Becker, 2024; Reed, 2021).

Co-occurring Disorders of Intellectual Development and Autism

Disorders of intellectual development and autism are neurodevelopmental disorders that present challenges due to their overlapping characteristics such as deficits in social abilities, communication, and restricted behaviours (Matson & Shoemaker, 2009). While disorders of intellectual development are primarily defined by deficits in intellectual functioning and adaptive behaviours, autism can manifest with or without accompanying disorders of intellectual development, making their differential diagnosis complex (Fodstad, Elias, & Sarawgi, 2020; Pedersen et al., 2017). For this reason, in addition to using the ‘with disorders of intellectual development’ qualifier for ASD, a co-occurring diagnosis of disorders of intellectual development is used including the level of severity as indicated by the new BIs within the ICD-11 CDDR. Early identification of individuals with an increased likelihood for co-occurring autism and disorders of intellectual development may allow for timely referral to appropriate early intervention services (Shaw et al., 2022).

The co-occurrence rates of autism and disorders of intellectual development have shifted over time, from over 70% to around 30%, possibly due to improved diagnostic criteria and assessment methods (Christensen et al., 2018; Fodstad, Elias, & Sarawgi, 2020; Fombonne, 2009; LaMalfa, Lassi, Bertelli, Salvini, & Placidi, 2004). Concerns about diagnostic

overshadowing and substitution have been raised, particularly in cases where obtaining a complete medical and developmental history is challenging (Leonard et al., 2010). As described, a new WHO clinical support tool using BIs developed for disorders of intellectual development with or without co-occurring autism that is accessible in LAMICs and underserved populations may improve global applicability, health-care services, and accurate identification of these disorders (Carulla et al., 2011). Additional details on the development of the BIs and their use for supporting the diagnosis disorders of intellectual development are provided below.

Development of the BIs and Use for Assessments

Development of the BI Tables

The World Health Organization ICD-11 developed the BI tables in partnership with the American Association on Intellectual and Developmental Disabilities (AAIDD) to assist in determining intellectual and adaptive behaviour functioning when there is a lack of locally appropriate standardised, normed tests available to characterise patient needs, which is often the case in LAMICs and underserved populations (Tassé et al., 2019). The BIs provide users with a summary of objective descriptions of observable behaviours typically used for assessment purposes to indicate the presence or absence of particular skills, competencies, or abilities. The use of BIs in clinical practice aims to provide further clarity, reliability, and validity by summarising behavioural observations and retrospective reports that are typically observed in the population of interest.

The assessment measure uses BIs of intellectual and adaptive behaviour functioning to characterise patient needs. These BIs are proposed to help determine the presence and severity of disorders of intellectual development across the lifespan. The BIs of intellectual functioning were established based on a review of literature and available tables from Jacobson and Mulick

(1996) of characteristic features by ability level across chronological age which were then validated and revised by an expert panel. The BIs of adaptive behaviour were established using a national dataset on a sample diagnosed with disorders of intellectual development (*n* = 658) using the Vineland Adaptive Behaviour Scale – Second Edition (Vineland-II; Sparrow, Cicchetti, & Balla, 2005), a standardised scale of adaptive behaviour, in Italy. The BI tables provide descriptors of behaviours expected at each severity level (mild, moderate, severe, and profound) and for each of three age groups (early childhood [0-5 years old], childhood and adolescence [6-18 years old], and adulthood [18+ years old]; Tassé et al., 2019). Separate tables are divided by the three age groups to determine the severity level of intellectual functioning and adaptive behaviour functioning (See Appendix A-D for BI tables). The BIs developed for disorders of intellectual development provide additional guidance for adjusting levels of severity for disorders of intellectual development with the presence of co-occurring disorders.

Clinical Interview Guidelines for the BIs

A crucial aspect of diagnosing disorders of intellectual development is to ensure that sufficient information is gathered from a clinical interview. Although different sites and countries may use different interview forms and resources to gather information, eight essential areas should be covered prior to using the BI's to diagnose disorders of intellectual development (Kishore et al., 2019; Tassé et al., 2019). These areas include: (1) basic socio-demographic data of the participant and family members; (2) pre- and peri-natal circumstances of participant; (3) developmental history; (4) current level of development (assessed in at least two settings such as home and school); (5) medical and psychiatric history; (6) current psychiatric symptoms and all medications; (7) treatment history; and (8) behavioural observations (Kishore, et al., 2019; Tassé et al., 2019).

Since disorders of intellectual development are classified as neurodevelopmental disorders, it is essential to gather information regarding the individual's history (King et al., 2009). It has been established that prevalence rates for disorders of intellectual development differ depending on socio-demographic factors. For instance, approximately 200 million children do not reach their developmental potential in LAMICS (Grantham-McGregor et al., 2007). Poverty, malnutrition, infectious diseases, substance use, and inadequate cognitive stimulation are factors that should be assessed due to their life-long consequences on development (Lake, 2011; Mwaniki, Atieno, Lawn, & Newton, 2012; Scherzer, Chhagan, Kauchali, & Susser, 2012). Children who come from low-income families are also more likely to have behavioural problems/disorder (e.g., withdrawn, aggressive), poor receptive language abilities, and parents who are more likely to be stressed, depressed, harsh, and unresponsive compared to more affluent children (Berger, Paxson, & Waldfogel, 2009). In addition, there are various pre- and peri-natal complications that could inform a diagnosis of disorders of intellectual development. Based on a systematic review and meta-analysis by Huang and colleagues (2016), it is recommended that clinicians assess ten prenatal factors (i.e., advanced maternal age, low maternal education, third or more parity, maternal alcohol use, maternal tobacco use, maternal diabetes, maternal hypertension, maternal epilepsy, maternal asthma, and systemic inequities disproportionately affecting Black mothers), one perinatal factor (i.e., preterm birth), and two neonatal factors (i.e., male sex and low birth weight). These factors have been significantly associated with increased risk for disorders of intellectual development. The inclusion of systemic inequities affecting Black mothers highlights how structural racism, unequal access to healthcare, and related social determinants of health may contribute to increased risks (Crear-Perry et al., 2021). This underscores the need for culturally sensitive, non-

stigmatizing approaches when incorporating such factors into diagnostic considerations.

Developmental milestones such as gross motor development (e.g., crawling, walking, fine motor, feeding/eating, drawing), language development (e.g., first words, sentences), adaptive skills and required skills for everyday living (e.g., toileting, self-care skills), social development (e.g., playing and working with others), and emotional development (e.g., temperament, anxious, fussy) should be assessed, especially in early childhood as indicators for disorders of intellectual development (Bellman, Byrne, & Sege, 2013). Gathering information on the individual's current level of development and functioning is crucial in understanding the presenting problem and reason for referral. The current level of development, supplemented with behavioural observations, is the main factor considered when using the BIs to indicate severity levels in intellectual and adaptive functioning.

Diagnoses of comorbid medical, behavioural, and psychiatric disorders along with medications and treatment history can help inform how the BIs will be used. It is important to note that many individuals with a disorders of intellectual development diagnosis also experience co-occurring autism (Matson & Shoemaker, 2009). When there is a co-occurring ASD diagnosis, the level of severity for disorders of intellectual development is determined by placing less emphasis on the social skills domain in the assessment of adaptive behaviour functioning given that this is a core feature of autism (Ayuso-Mateos & Kogan, 2020). It has been established that epilepsy is a common medical comorbidity with mild and increasing severity of disorders of intellectual development with prevalence rates of 15%-30% up to 50%, respectively (Kishore et al., 2019). This medical comorbidity is important since children with epilepsy may also present with impaired adaptive skills (Villarreal, Riccio, Cohen, & Park, 2014). Individuals with disorders of intellectual development are also at a 3-5 times higher risk of any psychiatric

disorder than the general population at any age (Kishore et al., 2019). Individuals with disorders of intellectual development often experience social discrimination and deprivation which may result in psychiatric comorbidities that affect adaptive functioning (Cooper et al., 2007; Emerson, et al., 2016; Smiley, 2005; Strømme & Diseth, 2000). Many psychiatric disorders are underreported, misdiagnosed, or undertreated due to diagnostic overshadowing and masking of a disorders of intellectual development diagnosis (Kishore et al., 2019). Careful identification of the causes and contributing factors of deficits in intellectual and adaptive functioning when using the BIs should improve accurate diagnoses. Since medications and interventions of comorbid conditions can improve adaptive functioning, careful examination and potential reassessment after treatable conditions have been assessed should also be considered (Kishore et al., 2019). To properly identify severity levels of disorders of intellectual development, one should carefully assess the causes and potential interventions and supports of intellectual and adaptive functioning impairments.

General Assessment Guidelines for using the BIs

The collection of intellectual and adaptive behaviour functioning from collateral sources and behavioural observation is essential when standardised measures are inappropriate given the individual's cultural and linguistic background. When using the BIs to assess intellectual functioning (i.e., IQ), information should be gathered by interviewing collateral sources and through behavioural observation to determine: Communication skills (i.e., verbal or non-verbal, breadth of vocabulary, ability to express needs and desires, ability to describe past events accurately; Awareness of self-characteristics); Ability to follow instructions (single step, multi-step); Ability to understand cause and effect and categorisation; Ability to express preferences including people, places, and activities; Reading and writing skills (i.e., ability to recognise

letters and numbers, use these for functional ends (e.g., for counting money); Ability to initiate appropriate social interactions and understand manipulation; Ability to navigate and travel safely; and Ability to use skills in a work or school setting (Tassé et al., 2019). Information for adaptive behaviour functioning should be gathered to determine: Conceptual functioning (i.e., reasoning, planning, organising, reading, writing, memory, symbolic/internal representation, communication skills); Social functioning (i.e., interpersonal competency (e.g., relationships), social judgment, emotion regulation); and Practical functioning (i.e., self-care, recreation, employment (including domestic chores), health and safety, transportation). The overall severity level for disorders of intellectual development is determined by considering the levels of intellectual functioning and domains of adaptive behaviours (conceptual, social, and practical) holistically. In ICD-11 a 'Provisional' specifier can be applied instead of severity for children younger than 4 years of age, as well as when testing or assessments are not possible. The CDDR also provides guidance on how to use the information collected.

Upon collecting information from the clinical interview with parents/caregivers and behavioural observations, the clinician indicates a severity level after it is determined that the individual qualifies for a diagnosis of disorders of intellectual development. The BI tables can be used as guidance to confirm levels of severity for intellectual functioning and the three domains of adaptive behaviour functioning, which are then used to confirm the overall severity of disorders of intellectual development. According to Tassé and colleagues (2018), there are eight steps that should be followed when using the BIs: (1) the BI table in Appendix A is used for Intellectual functioning and the table that corresponds to the correct age group for adaptive behaviours (Appendix B - D); (2) information should be gathered from the interview with parents/caregivers and behavioural observations to select a level of severity for each of

intellectual functioning and the three domains of adaptive behaviours; (3) examine all aspects of the BIs and consider whether the majority of the descriptors fit for the patient; (4) examine the level above and below (e.g., if "Moderate" was selected, examine the BIs for "Mild" and "Severe", respectively) and consider if these BIs are a better match; (5) if "Mild" or "Profound" was selected, only look at the next adjacent level to see if the BIs for that level fit better; (6) choose a final level for intellectual functioning; (7) repeat for each domain of adaptive behaviours (four separate final ratings will be selected at this point); and (8) the final level of severity should be assigned on the basis of the level at which the majority of the individual's intellectual ability and adaptive behaviours across all three domains fall. For example, if intellectual functioning and two of three adaptive behaviour domains are determined to be 3 to 4 SD below the mean, "Moderate DID" would be the most appropriate diagnosis. However, this formulation may vary according to the nature and purpose of assigning the diagnosis as well as the degree to which affected behaviour(s) impact overall functioning (Tassé et al., 2019; WHO, 2024).

General Standards of Clinical Judgement when Diagnosing Disorders of Intellectual Development

The clinician's clinical judgement is an essential feature when using the BIs to assess severity levels to confirm a diagnosis of disorders of intellectual development. As described by Luckasson and Schalock (2015), there are 10 clinical judgement standards that have been developed to follow in the field of disorders of intellectual development. These 10 standards include: (1) explicit and implicit respect for individuals with disorders of intellectual development and specific and extensive knowledge of individual and environmental factors; (2) the use of research-based best practices in diagnosis, classification, and planning supports; (3)

relevant training, experience, and expertise in the field of disorders of intellectual development; (4) extensive collection and systematic use of data to make decisions and formulate recommendations; (5) the employment of critical thinking skills (e.g., analysis, alignment, synthesis, systems thinking, and transformational thinking); (6) consistent use of professional standards and ethics while striving for improvement; (7) consideration and integration of influencing factors (e.g., social-ecological model) at the microsystem, mesosystem, and macrosystem for diagnosis, classification, and planning supports; (8) alignment of diagnosis, classification, and support planning to referral questions; (9) incorporation of multidimensionality of human functioning in diagnosis, classification, and supports planning; and (10) focus on personal outcomes related to human functioning and personal well-being. These clinical judgement guidelines should improve service delivery and help guide clinical decision-making when using the BIs to diagnose disorders of intellectual development.

Cultural Competence

A key aspect when using the BIs is to compare individuals with others within their own culture. To effectively assess how an individual compares in terms of intellectual and adaptive functioning with peers of similar age, gender, linguistic, and cultural backgrounds, the clinician should consider multicultural factors within their assessment (e.g., American Psychological Association [APA]; Clauss-Ehlers, Chiriboga, Hunter, Roysircar, & Tummala-Narra, 2019), and employ cultural competence when working with ethnically diverse populations (Huey, Tilley, Jones, & Smith, 2014; Sue, Zane, Nagayama, & Berger, 2009). These considerations become particularly significant when individuals are living as minorities in a country, as their experiences and societal influences may differ from the dominant culture (Norbury & Sparks, 2013). In a diverse country such as Canada, known for its multiculturalism and dedication to

diversity, understanding these nuances is essential for precise and equitable diagnostic assessments (Canada, 1971; Statistics Canada, 2022a,b). To ensure fairness and accuracy using the BIs, clinicians should: compare the individual's intellectual and adaptive functioning levels with age peers in typical (i.e., natural) community environments; consider the use of culturally and linguistically relevant individual assessments using psychometrically sound instruments, when available and applicable; and have adequate expertise and training regarding disorders of intellectual development constructs, assessment strategies, and familiarity assessing individuals with disorders of intellectual development (Luckasson & Schalock, 2015; Luckasson & Schalock, 2013; Shogren, Luckasson, & Schalock, 2014). For instance, even if one culture has children that outperform other children in some areas (e.g., Austrian/German tend to achieve higher scores on daily living and socialisation skills compared to Italian children) partially due to ethnic differences in child rearing (emphasis on autonomy), clinicians should compare performance of individuals with other children within their culture (Taverna, Bornstein, Putnick, & Axia, 2011). Therefore, clinicians need to be aware of their cultural competence and compare norms of skills being assessed (i.e., intellectual and adaptive behaviours) within the context of one's culture.

Another consideration is that the Vineland-II was used to create the BIs for adaptive functioning, yet there is no indication that this test had been normed for use with any specific cultures or ethnicities (Allen-Meares, 2008). This makes it clear that international field trials are necessary to establish whether clinicians and other relevant stakeholders (e.g., client, client's caregivers) agree that the adaptive functioning at various developmental stages/ages are appropriate for individuals of various demographic backgrounds. Although the guidelines for intellectual functioning were developed through consensus by an expert panel (Tassé et al.,

2019), it would be important to validate and revise the adaptive behaviours by including the expertise of collaborators from other cultures, especially those working in LAMICs.

Although the BIs would be useful in LAMICs, the clinical sample used to establish the BIs were from Italy, a high-income country. A benefit with a sample consisting of individuals from the same geographic location is an increase in internal validity by reducing culture-specific characteristics explaining the differences in adaptive behaviour (Tassé et al., 2019). A potential downside to this approach is that clinicians may implement different diagnostic strategies and/or that individuals with disorders of intellectual development have different symptom presentations within LAMICs which will not be captured in the development of these guidelines. It is important to assess whether the BIs demonstrate psychometric robustness across various cultures to enhance the global applicability of the guidelines. This aim may be assessed by conducting an international study using the BIs and including individuals from multiple sites in low-, middle-, and high-income countries to account for these potential differences and to assess the psychometric properties of the BIs.

Field Testing

Although the BIs for disorders of intellectual development were developed based on expert input and factor analysis (Tassé et al., 2019), formal validation in different clinical settings used by diverse clinicians is necessary to assess whether the BIs function as intended (First et al., 2015). Field testing of revised classification systems ensures that the proposed definitional changes to diagnoses and diagnostic guidelines function as intended and are considered an improvement over previous conceptualisations (First et al., 2015). A major goal of field testing for the ICD-11 revision process is to improve the clinical utility of classification. WHO defined clinical utility as the ability of diagnostic constructs to facilitate conceptualisation,

understanding, and communication among users regarding diagnoses, to facilitate implementation (e.g., interpretability, ease of use, time required for use) for system users in clinical practice, and to provide system users with prognostic information and considerations for intervention planning (Reed, 2010). WHO asserted that their classification system should provide clinically useful information without being too cumbersome for the user given the system's function in providing and obtaining valid data for health policy and decision-making (First et al., 2015; Reed et al., 2013; Roberts et al., 2012).

There are two main types of field-testing trials implemented to inform clinical utility of guidelines: developmental field trials (e.g., formative studies) and evaluative field trials (e.g., case-controlled vignette studies, ecological implementation studies). Developmental field trials are designed to gather information to further inform revision of the classification prior to publication (First, 2016). Formative studies are developmental field trials that use large international surveys of professional organisations' membership regarding perspectives on classification, patterns of use, and perceived necessary changes (Keeley et al., 2016). These studies are used to inform the structure of the classification for mental disorders.

Following formative field studies (Keeley et al., 2016; Tassé et al., 2019), which have been conducted for the BIs, evaluative field trials are designed to establish psychometric properties of the classification through implementation in various clinical settings after a nosology is published (First, 2016). Case-controlled vignette studies were implemented worldwide in multiple languages over the Internet through a multidisciplinary network of over 15,000 mental health professional members of the Global Clinical Practice Network (gcp.network) to assess clinical utility, including decision-making processes of proposed changes to ICD-11 (Evans et al., 2015). The ecological implementation field studies for the ICD-11

described in the thesis assess the reliability, validity, and clinical utility of the proposed guidelines in settings where the classification will be used (Reed 2010; Keeley et al., 2016).

Psychometric Properties of Assessment Measures

There are three principal psychometric properties of measurement instruments: reliability (consistency), validity (accuracy), and clinical utility which are described in detail below (for reviews see: McKechnie & Fisher, 2022; Swan et al., 2023). It is important to note that reliability, validity, and clinical utility are not fixed qualities that measurement instruments inherently possess. These properties can vary depending on the construct being measured, the context in which the instrument is used (e.g., target population and raters), as well as how the instrument is utilised and the purpose of the scores generated (Swan et al., 2023).

Reliability

Reliability refers to the consistency or stability of the measurement process across time or between raters and/or within raters. Reliability is assessed through internal consistency (i.e., extent to which items are unidimensional and interrelated in measuring the same construct), stability (i.e., test-retest reliability; the ability to produce the same results when used at two different time points), and equivalence (i.e., inter-rater reliability; examining whether the same results are obtained when two or more observers use the same instrument), with the importance of these properties varying based on how, by whom, and in what context the instrument is used (McKechnie & Fisher, 2022). In accordance with classical test theory, reliability is associated with measurement error, and an instrument is considered reliable when it produces the same results upon repeated measurements, indicating freedom from random error (Mokkink et al., 2020). For example, a reliability coefficient of 0.90 suggests that 10% of the observed variance is attributed to random measurement error (McDowell, 2006). While an assessment measure may

be deemed reliable without being valid, measures cannot be truly deemed valid unless it is reliable. The first study of this thesis focuses on establishing the equivalence (inter-rater reliability) of the BIs embedded in the ICD-11 CDDR.

Inter-rater reliability

Inter-rater reliability aims to examine the strength of agreement or level of consensus between multiple independent raters providing ratings for the same event without any discussion or collaboration (Kimberlin & Winterstein, 2008; Salkind, 2011). The reliability is assessed by examining the correlation of scores from different raters for continuous variables or by calculating the coefficient of agreement for categorical variables, commonly using Intraclass Correlation Coefficients (ICCs) and weighted Kappas (Gwet, 2008). This method considers the agreement beyond chance that could be expected when two raters classify events into categories based on specific criteria. Statistical analyses provide reliability coefficients ranging from 0 (no similarity) to 1.0 (perfect agreement). Currently, an ICC or weighted Kappa value of 0.70 is deemed sufficient, values greater than 0.75 are considered strong (Portney & Watkins, 2009; Prinsen et al., 2018).

Establishing inter-rater reliability is important to assess when clinical judgments are made by multiple raters or reviewers using the same assessment measure across different individuals. This is particularly important in situations like abstracting data from medical charts, conducting clinical interviews, and/or ensuring consistent diagnostic practices within the healthcare setting (Kimberlin & Winterstein, 2008). By carefully monitoring and ensuring our diagnostic assessment measures have adequate inter-rater reliability, we can increase confidence that independent experts would reach the same conclusions, thus increasing the credibility and accuracy of diagnostic assessment practices. To optimise inter-rater reliability, precise

operational definitions of variables and thorough training for observers are necessary. Training should focus on applying scoring criteria consistently and making decisions based on predefined guidelines (Kimberlin & Winterstein, 2008). Regular checks for inter-rater reliability throughout the study, clarification of disagreements, and maintaining a criterion level of agreement are recommended (Kimberlin & Winterstein, 2008). Such considerations were considered for establishing the inter-rater reliability of the ICD-11 CDDR BIs for disorders of intellectual development in study 1 of this thesis (Lemay et al., 2022).

Validity

Validity refers to the precision of an instrument and focuses on systematic measurement error by assessing the extent to which an instrument accurately measures a specific construct, such as intellectual functioning, within its intended context (e.g., diagnostic assessment for disorders of intellectual development; Kimberlin & Winterstein, 2008; Portney, 2020). Although validity is not an inherent property of the instrument itself, it reflects the meaningful and relevant interpretations of the test scores within a specific context. Evaluating an instrument's validity, therefore, requires consideration of the intended context, circumstances, and target population (Swan et al., 2023). Validity encompasses various properties including face validity (i.e., extent to which informed stakeholders believe that items on a measure appear representative of the target construct of interest at a surface level), content validity (i.e., relevance and comprehensiveness of the instrument are embedded in its development methodology, ensuring that it accurately measures the target construct), construct validity (i.e., relationship between the instrument and other instruments or outcomes of interest), and criterion validity (i.e., relationship between the instrument under analysis and the “gold-standard” or best available measure; Swan et al., 2023). During instrument development, items should align with theoretical foundations

(content validity), followed by assessing the instrument's construct (construct validity), and comparing it to an external standard (criterion validity; McKechnie & Fisher, 2022). Provided the previous establishment of content validity and construct validity through developmental field trials, the first study of this thesis focuses on evaluating the criterion validity of the BIs embedded in the ICD-11 CDDR.

Criterion Validity

Criterion validity provides evidence regarding how well scores on a newly developed measure correlate with other normed, validated, and established "gold standard" measures of the same construct or very similarly related constructs (Kimberlin & Winterstein, 2008). Criterion validity can be further broken down into predictive validity (i.e., criterion measurement is obtained after the administration of the instrument, and the ability of the test to accurately predict the outcome criteria is evaluated) and concurrent validity (i.e., examining the correlation of scores between a newly developed and a validated instrument measured at the same time within the same individuals; Kimberlin & Winterstein, 2008). Since the BIs are utilised in real-time during clinical interviews for diagnostic purposes rather than for predicting outcome criteria such as in prevention studies, the emphasis of the first study of this thesis was to evaluate the concurrent validity of these indicators. Establishing concurrent validity of a novel assessment measure may offer advantages over solely using the established gold standard measure such as ease of use, decreased time and cost requirements, or the ability to provide supplemental information alongside traditional measures if feasible and available.

Clinical Utility

Clinical utility, as defined by WHO, refers to the capability of diagnostic concepts to facilitate effective communication (e.g., between practitioners, patients, families, administrators),

their practical applicability and implementation characteristics (e.g., ease of use, goodness of fit, clarity, time required for diagnosis) in clinical practice, and their contribution to clinical decision-making for appropriate selection of interventions or support strategy development (Reed, 2010). Although reliability and validity are essential requirements for assessment measures utilised for diagnostic classification systems, it is not sufficient (Hopewell et al., 2018). While a measure may excel in terms of accuracy and precision, it may not be used as intended if practicality and implementation in the real world is missing. Factors such as cost, feasibility, timeliness, and the relevance of the information provided must be considered to ensure that the measure is utilised by professionals and stakeholders to improve diagnostic assessment outcomes and/or guide intervention (Reed, 2010). To be considered clinically valuable, assessment measures should possess qualities of validity, reliability, user-friendliness, and precision, enabling practitioners to utilise these measures effectively and seamlessly in practice (Reed et al., 2015). Moreover, their widespread application and acceptance across various countries helps demonstrate generalisability and global outreach of such measures (Reed et al., 2018).

Critiques have been raised against existing diagnostic systems for their limited clinical utility due to blurred boundaries between diagnostic categories, leading to a substantial number of mental disorder diagnoses categorised as "Unspecified" in the ICD or as "Not Otherwise Specified" in the DSM (Andreasen, 2007; First, 2010; Kamp-Becker, 2024; Kendell & Jablensky, 2003; Luciano et al., 2020; Maj, 2018). The heterogeneity observed within clinical populations and diagnostic categories may result in individuals meeting criteria for multiple disorders simultaneously, suggesting that different disorders may capture various aspects of an underlying condition or that diagnostic criteria for some disorders are overly broad, encompassing normal variations in mood and behaviour (Krueger, Chentsova-Dutton, Markon,

Goldberg, & Ormel, 2003; Krueger at al., 2018; Luciano et al., 2020; Maj, 2015; Van Loo, Romeijn, de Jonge, & Schoevers, 2013; Zimmerman, Morgan, & Stanton, 2018). These considerations were explored when establishing the clinical utility for the ICD-11 CDDR BIs in the first study of this thesis, and when assessing the implementation of the BIs for disorders of intellectual development with or without co-occurring autism in the second study of this thesis.

Thesis Goals and Relevance

Valid, reliable, and clinically useful diagnostic assessment tools are needed to improve access to care for individuals with disorders of intellectual development with or without co-occurring autism. Delays in diagnosis and intervention contribute to increased morbidity and high service utilisation (Järbrink, Fombonne, & Knapp, 2003). The BIs embedded in the ICD-11 CDDR for intellectual functioning and adaptive behaviours are aimed to help characterise patient needs (First, Reed, Hyman, & Saxena, 2015; International Advisory Group for the Revision of the ICD Mental and Behavioural Disorders, 2011). Currently, there is a lack of accessible and practical measures in low and middle-income countries that have been validated/translated (Robertson, Hatton, Emerson, & Yasamy, 2012). Diagnosis in high income countries, such as Canada, also requires specialised services (Robertson, Hatton, Emerson, & Yasamy, 2012). (Kogan & Paterniti, 2017).

The thesis is composed of two separate studies that draw on a single data base collected as part of the International ICD-11 Field Study for Neurodevelopmental Disorders. In the first study, an international field test was conducted to evaluate the inter-rater reliability, concurrent validity (by comparing BIs with standardised measures of intellectual functioning and adaptive behaviours), and clinical utility of the BIs within the ICD-11 CDDR for individuals with disorders of intellectual development. It is hypothesised that interrater reliability between

clinicians will be found to be good to excellent, convergent validity between standardised instruments and the BIs will be found to be good to excellent, and clinical utility will be reported as good to excellent. The second study explores the diversity of co-occurring disorders of intellectual development and autism by investigating the global implementation of the BIs in the context of these commonly co-occurring disorders. It is hypothesised that the clinical support tool will be implemented as intended and that the tool will be rated similarly regarding clinical utility when used for disorders of intellectual development with or without co-occurring autism.

The studies in this thesis establish the validity, reliability, clinical utility, and implementation characteristics for disorders of intellectual development with or without autism of a low-cost comprehensive clinical support tool developed by the WHO. The BIs may substantially improve the accurate identification and clinical description of individuals with disorders of intellectual development with or without co-occurring autism in low-, middle-, and underserved regions of high-income countries (e.g., in First Nations communities). The development of a valid and accessible clinical support tool may reduce health disparities among various population groups that are currently underrepresented in research and clinical communities. This novel WHO clinical support tool is anticipated to improve access to care for individuals with disorders of intellectual development. This thesis aims to improve health delivery for Canadians affected by disorders of intellectual development with or without autism, as well as improve health care efficiency and service costs. These data will also be used by WHO Secretariat for ongoing ICD-11 development.

Author's Note on Modifications

This thesis contains slight modifications to previously published work (i.e., Lemay et al., 2022; Lemay et al., 2024) to ensure consistency with the structure and requirements of this

manuscript. These changes include minor edits for clarity, formatting adjustments, and the integration of additional explanations pertinent to the scope of this thesis. These modifications do not alter the primary findings or interpretations of the original work.

An International Field Study of the ICD-11 Behavioural Indicators for Disorders of Intellectual Development (Study 1; Lemay et al., 2022)

Abstract

Background: The World Health Organization (WHO) has approved the 11th Revision of the International Classification of Diseases (ICD-11). A version of the ICD-11 for Mental, Behavioural and Neurodevelopmental Disorders for use in clinical settings, called the Clinical Descriptions and Diagnostic Requirements (CDDR), has also been developed. The CDDR includes behavioural indicators (BIs) for assessing the severity of disorders of intellectual development (DID) as part of the section on neurodevelopmental disorders. Reliable and valid diagnostic assessment measures are needed to improve identification and treatment of individuals with DID. Although appropriately normed, standardised intellectual and adaptive behaviour assessments are considered the optimal assessment approach in this area, they are unavailable in many parts of the world. This field study tested the BIs internationally to assess the inter-rater reliability, concurrent validity, and clinical utility of the BIs for the assessment of DID. Methods: This international study recruited a total of 206 children and adolescents (5–18 years old) with a suspected or established diagnosis of DID from four sites across three countries [Sri-Lanka (n = 57), Italy (n = 60) and two sites in India (n = 89)]. Two clinicians assessed each participant using the BIs with one conducting the clinical interview and the other observing. Diagnostic formulations using the BIs and clinical utility ratings were collected and entered independently after each assessment. At a follow-up appointment, standardised measures (Leiter-3, Vineland Adaptive Behaviour Scales-II) were used to assess intellectual and adaptive abilities. Results: The BIs had excellent inter-rater reliability (intra-class correlations ranging from 0.91 to 0.97) and good to excellent concurrent validity (intra-class correlations ranging from 0.66 to

0.82) across sites. Compared to standardised measures, the BIs had more diagnostic overlap between intellectual and adaptive functioning. The BIs were rated as quick and easy to use and applicable across severities; clear and understandable with adequate to too much level of detail and specificity to describe DID; and useful for treatment selection, prognosis assessments, communication with other health care professionals, and education efforts. Conclusions: The inclusion of newly developed BIs within the CDDR for ICD-11 Neurodevelopmental Disorders must be supported by information on their reliability, validity, and clinical utility prior to their widespread adoption for international use. BIs were found to have excellent inter-rater reliability, good to excellent concurrent validity, and good clinical utility. This supports use of the BIs within the ICD-11 CDDR to assist with the accurate identification of individuals with DID, particularly in settings where specialised services are unavailable.

Keywords Behavioural indicators, Classification, Clinical utility, Disorders of intellectual development, ICD-11, Intellectual disability, Learning disability (UK), Reliability, Validity

Introduction

The International Classification of Diseases (ICD) and Related Health Problems was developed by the World Health Organization (WHO) as a global diagnostic classification system for recording, reporting, and grouping health-related factors and conditions (World Health Organization 1992, 2014). The WHO finalised the 11th revision of the ICD (ICD-11) after approval by the World Health Assembly in May 2019. The WHO Mental Health and Substance Use Department also developed a version of the ICD-11 for Mental, Behavioural and Neurodevelopmental Disorders that includes more comprehensive information necessary for implementation in clinical settings, called the Clinical Descriptions and Diagnostic Requirements (CDDR) (Reed 2010; Reed et al. 2019). [The ICD-11 CDDR was previously referred to as the Clinical Descriptions and Diagnostic Guidelines (CDDG), but the name was changed due to the recent development of WHO policies related to documents referred to as 'guidelines', which were not considered to be applicable.] The CDDR provides information on essential (required) features, developmental presentations, differential diagnoses, boundary differentiation between normality and other disorders, culture-related features, and other features for each disorder (First et al. 2015). A core focus in the development of the ICD-11 chapter on Mental, Behavioural and Neurodevelopmental Disorders and the CDDR was to maximise reliability, validity, clinical utility and global applicability (International Advisory Group for the Revision of the ICD Mental and Behavioural Disorders 2011; First et al. 2015).

Although existing intellectual and adaptive behaviour assessment measures are comprehensive and have robust psychometric properties, the global applicability of these measures is lacking (Robertson et al. 2012). For instance, underserved regions and some low-income and middle-income countries (LAMICs) may lack linguistically appropriate measures

that are normed, standardised, and psychometrically validated to assess intellectual functioning and/or adaptive behaviours (Robertson et al. 2012; Kishore et al. 2019). Most measures also require specialised services and training to administer that are costly, thus rendering them unavailable or inaccessible in various contexts (Robertson et al. 2012; Kishore et al. 2019). The ICD-11 aims to address this disparity by embedding a comprehensive set of behavioural indicator (BI) tables that are affordable, accessible, and clinically useful within the CDDR for those lacking access to appropriate resources (refer to Tassé et al. 2019). The use of BIs in clinical practice aims to provide further clarity, reliability, and validity by summarising behavioural observations and retrospective reports that are typically observed in the population of interest. Specific BIs characterising severity levels for disorders of intellectual development (DID) are lacking (Carulla et al. 2011).

It has been estimated that globally 0.62–3.00% of individuals have DID (Harris 2006; McKenzie et al. 2016), with mild DID being the most prevalent (85%) diagnosis (King et al. 2009). The ICD-11 conceptualisation of intellectual and adaptive functioning are improved by replacing the concept of arrested or incomplete development of the mind as a required feature (WHO 1992; Girimaji and Pradeep 2018). The ICD-11 also highlights the significance of impairment in adaptive behaviours together with impairment of intellectual functioning when determining severity level and diagnosing DID at various developmental stages (Schalock et al. 2002). Adaptive behaviour is defined according to functioning within conceptual, social, and practical skills (WHO 2018). The essential features in the CDDR for DID include significant limitations (operationalised as two or more standard deviations below the mean on standardised measures) of both intellectual functioning and adaptive behaviours with onset during the developmental period. When normed and standardised tests are available, limitations are

determined separately for intellectual functioning, whereas conceptual, social, and practical domains are assessed independently and then combined to determine the overall level of adaptive behaviour. In ICD-11, there are four levels of severity (mild, moderate, severe, and profound) assigned according to intellectual functioning and adaptive behaviour functioning (WHO 2018). The BIs provide additional guidance for interpreting levels of severity for DID with the presence of co-occurring disorders. For example, when an individual with DID has co-occurring autism spectrum disorder (ASD), clinicians are advised to interpret results by placing less emphasis on the social skills domain in the assessment of adaptive behaviour functioning as this is a core feature of autism (Ayuso-Mateos and Kogan 2020). Although the BIs for DID were developed based on expert input and factor analysis (Tassé et al. 2019), formal validation in different clinical settings used by diverse clinicians is necessary to assess whether the BIs function as intended (First et al. 2015).

Field testing of revised classification systems ensures that the proposed changes to diagnoses and diagnostic requirements function as intended and are considered an improvement over previous conceptualisations (Keeley et al. 2016). The present study is a multi-site international field study that evaluates reliability, validity, and clinical utility in settings where the classification will be used. The aim of this study was to assess the psychometric properties of the newly developed BIs to inform their global implementation with individuals with DID. The objectives of this study were to (1) field test the newly developed BIs embedded in the ICD-11 CDDR for classification of DID severity in three countries with different languages, cultures, and income levels; and (2) assess and evaluate the clinical utility, inter-rater reliability, and concurrent validity of the BIs within the ICD-11 CDDR.

Methods

This quantitative, observational (correlational) design is an international, collaborative, and cross-cultural psychometric study that was coordinated at the University of Ottawa in Canada. This study received ethics approval from the University of Ottawa Office of Research Ethics and Integrity (protocol no. H-03-18-371). Ethics approval was also received at each participating site [India: National Institute of Mental Health & Neuro Sciences (NIMHANS); All India Institute of Medical Sciences, New Delhi (AIIMS), Sri Lanka: Teaching Hospital Peradeniya, Italy: Oasi Research Institute-IRCCS (Oasi IRCCS)].

Participants

A total of 206 children and adolescents (aged 5 to 18 years) with a suspected or established diagnosis of DID were recruited in three countries at four study sites [India: NIMHANS (n = 35); AIIMS (n = 54), Sri Lanka: Teaching Hospital Peradeniya (n = 57), Italy: Oasi IRCCS (n = 60)]. Participating study clinicians, site coordinators, and site supervisors were required to attend an online clinician training on the ICD-11 CDDR for Neurodevelopmental Disorders and a procedural training for the BIs prior to data collection. All clinician raters had a degree in psychology or psychiatry and were adequately trained to administer psychological tests.

The following inclusion/exclusion criteria were applied when assessing eligibility of participants: (1) aged 5 to 18 years at the time of recruitment; (2) known or suspected of having DID with or without co-occurring autism; (3) not under the care of clinician raters; (4) not currently incapacitated due to severe physical illness or pain; (5) not currently at imminent risk of self-harm, danger to others or experiencing serious medication side effects requiring immediate medical attention. Participants under the age of five were excluded as these

individuals might have received a provisional diagnosis. Adults were excluded due to feasibility given that some study sites only serve children and adolescents. Participants with severe behavioural disorders and/or severe motor impairments and/or those who appeared to not be able to sustain attention long enough for valid scores on the test of intellectual functioning were excluded at the outset of recruitment. Although data on standardised measures of intellectual functioning were unobtainable for some individuals due to their inability to complete cognitive testing, the exact number was not recorded at each site, as this information was neither solicited nor provided by the site coordinators; however, we sought to collect a sample of individuals encompassing the full range of severity.

Materials

Data Collection Process

All study activities were tracked by site coordinators using REDCap, a secure web platform designed to support data collection, management, and monitoring (Harris et al. 2009). Data collected and monitored included consent and registration, clinical interview scheduling, clinical rater assignment (clinician ID, name and role) and date of each assessment, reporting of adverse events, and confirmation of study termination. Clinicians entered their diagnostic conceptualisation and an assessment of the clinical utility of the CDDR and the BIs on an Electronic Field Study System (EFSS), a web-based data collection platform developed using Qualtrics (Provo, USA). Approximately 30–40 min were required to complete data entry. Each site, clinician, and participant were provided unique identification codes. All data were monitored, stored, and managed centrally at the University of Ottawa. Although the clinical interview could be conducted in the local languages, English was used for the standardised measures and data collection by all sites except one (Italy) where a local translation of the

requirements was needed by participating clinicians.

Demographics

Both clinician and participant information were collected. Clinicians filled out an online registration form to verify their country and site, name and ID, date of birth, country of origin, language preferences, profession, and years of formal professional experience (Table 1). Participants' demographic information included date of birth, developmental stage, and gender (Table 2). Participant characteristics (i.e., previous medical diagnoses, previous psychiatric diagnoses, additional psychiatric symptoms, current medications, and previous treatment) were also collected (Table 3).

11th Revision of the International Classification of Diseases behavioural indicators and Neurodevelopmental Disorders requirements

The ICD-11 BIs are embedded in the CDDR for ICD-11 for DID as an alternative way to assess intellectual and adaptive behaviour functioning when appropriately normed and standardised tests are not available. BI are provided to distinguish severity levels (i.e., mild, moderate, severe and profound) for three age groups (0–5; 6–18; +18 years old) in order to help characterise the needs of people with DID (refer to Tassé et al. 2019). The BIs for adaptive behaviour functioning are identified for each adaptive skill (i.e., conceptual, social, and practical). Clinicians were provided the ICD-11 Neurodevelopmental Disorders requirements with the embedded BIs for DID.

Table 1

Clinician demographics by site

Variable	Total (*N*=51; %)	Italy (Oasi IRCCS; *N*=5; %)	Sri Lanka (Teaching Hospital Peradeniya; *N*=5; %)	India (AIIMS; *N*=18; %)	India (NIMHANS; *N*=23; %)
Age, years (Mean±SD)	35.2 ± 8.7	47.8 ± 10.5	44.4 ± 13.1	28.9 ± 2.6	35.4 ± 5.4
Gender, *N* (%)					
Men	26 (51.0)	0	0	13 (72.2)	13 (56.5)
Women	25 (49.0)	5 (100)	5 (100)	5 (27.8)	10 (43.5)
Level of proficiency in English, *N* (%)					
Low	1 (2.0)	0	0	0	1 (4.3)
Intermediate	8 (15.7)	5 (100)	0	0	3 (13.0)
Advanced	16 (31.4)	0	4 (80.0)	8 (44.4)	4 (17.4)
Completely Fluent	26 (51.0)	0	1 (20.0)	10 (55.6)	15 (65.2)
Clinical Profession, *N* (%)					
Psychiatry	39 (76.5)	0	3 (60.0)	16 (88.9)	20 (87.0)
Psychology	9 (17.6)	5 (100)	0	2 (11.1)	2 (8.7)
Other	3 (6.0)	0	2 (40.0)	0	1 (4.3)
Years of experience, (Mean±SD)	6.6 ± 7.7	22.2 ± 11.1	9.0 ± 8.4	1.9 ± 1.3	6.4 ± 4.8

Table 2

Participant demographics by site

Variable	Total (*N*=206; %)	Italy (Oasi IRCCS; *N*=60; %)	Sri Lanka (Teaching Hospital Peradeniya; *N*=57; %)	India (AIIMS; *N*=54; %)	India (NIMHANS; *N*=35; %)
Age, years (Mean±SD)		9.55 ± 3.68	10.3 ± 3.59	12.6 ± 3.66	12.21 ± 3.834
Gender, *N* (%)					
Male	142 (69)	44 (73)	39 (68)	37 (69)	22 (63)
Female	64 (31)	16 (27)	18 (32)	17 (31)	13 (37)

Table 3

Participant characteristics by site

Variable	Total (*N*=206)	Italy (Oasi IRCCS; *N*=60)	Sri Lanka (Teaching Hospital Peradeniya; *N*=57)	India (AIIMS; *N*=54)	India (NIMHANS; *N*=35)
Previous medical diagnoses, *N* (%)					
Epilepsy/Seizure Disorder	27 (13)	9 (15)	5 (9)	9 (17)	4 (11)
Down's Syndrome	5 (2)	0	3 (5)	0	2 (6)
Dysmorphism	3 (1)	3 (5)	0	0	0
Previous psychiatric diagnoses, *N* (%)					
Disorders of Intellectual Development	20 (10)	13 (22)	0	4 (7)	3 (9)
Attention-Deficit Hyperactivity Disorder	17 (8)	5 (8)	7 (12)	0	5 (14)
Autism Spectrum Disorders	10 (5)	10 (17)	0	0	0
Disorders of speech and language	9 (4)	6 (10)	0	0	3 (9)
Mixed specific developmental disorders	5 (2)	5 (8)	0	0	0
Global Developmental Delay	5 (2)	5 (8)	0	0	0
Behavioural Disorders	3 (1)	3 (5)	0	0	0

Emotional Disorders	3 (1)	3 (5)	0	0	0
Learning Disorder	3 (1)	3 (5)	0	0	0
Obsessive Compulsive Disorder	3 (1)	3 (5)	0	0	0
Additional psychiatric symptoms, *N* (%)					
Attention related difficulties	18 (9)	5 (8)	8 (14)	2 (4)	3 (9)
Aggressiveness	6 (3)	3 (5)	0	3 (6)	0
Irritability	5 (2)	0	0	3 (6)	2 (6)
Emotional disturbances	3 (1)	3 (5)	0	0	0
Oppositional Defiant Features	3 (1)	0	3 (5)	0	0
Anxiety in social situations	3 (1)	0	0	0	3 (9)
Difficulty with academics	2 (1)	0	0	0	2 (6)
Current Medications in Use, *N* (%)					
Atypical antipsychotic	30 (28)	7 (12)	0	21 (39)	2 (6)
Anticonvulsant	28 (26)	8 (13)	9 (16)	7 (13)	4 (11)
Stimulant	10 (9)	0	8 (14)	0	2 (6)
Hormone	4 (4)	2 (3)	2 (4)	0	0
Benzodiazepines	5 (2)	0	0	5 (9)	0
Antihypertensive	2 (1)	0	0	0	2 (6)
Selective serotonin reuptake inhibitor	2 (1)	0	0	0	2 (6)
Previous Treatment, *N* (%)					
Psychomotor Therapy	38 (36)	38 (63)	0	0	0
Speech Therapy	15 (15)	15 (25)	0	0	0
Psychoeducational intervention	6 (3)	6 (10)	0	0	0

Only variables that affected >5% of the sample at any site are reported

Vineland Adaptive Behaviour Scale – Second Edition (VABS-II)

The Vineland Adaptive Behaviour Scale – Second Edition (VABS-II) is a widely used, individually administered interview designed to measure adaptive behaviour (Sparrow et al. 2005). The structured interview version was selected as a measure to assess the three domains of adaptive behaviour that reflect areas assessed by the BIs. The domains and subdomains used in this study were communication (receptive, expressive, and written), daily living skills (personal, domestic, and community) and socialisation (interpersonal relationships, play and leisure time, and coping skills). These domains were chosen because they correspond to the conceptual, practical, and social skills assessed by the BIs, enabling direct comparisons between the two instruments. While the VABS-II also includes other domains, such as Motor Skills (gross and fine motor subdomains) and an optional Maladaptive Behaviour section, these were not included in the analysis. Motor Skills was excluded because it is less directly relevant to the core areas of adaptive functioning assessed by the BIs in this study, and Maladaptive Behaviour was excluded as it falls outside the primary focus on adaptive skills.

Scores for each subdomain are summed to yield the domain composite scores, which are then summed to form the adaptive behaviour composite (ABC). Raw scores were converted to standard scores, V-scale scores, and percentile ranks. Both the domain composite scores and the Adaptive Behaviour Composite (ABC) score were utilized in this study. The ABC was specifically used as a criterion to determine whether adaptive behaviours were sufficiently impaired to meet the threshold for a diagnosis, ensuring a comprehensive overview of overall adaptive functioning. However, the detailed comparisons between the VABS-II and the BIs were conducted at the domain level to maintain alignment with the constructs of conceptual, practical, and social skills as defined in the study. The VABS communication domain was compared with

BIs conceptual skills, the VABS socialisation domain was compared with the BIs social skills, and the VABS daily living skills was compared with the BIs practical skills.

The inter-rater reliability reported in the literature across the three domains was between 0.71–0.83 (Sparrow et al. 2005). The validity for the VABS-II was deemed robust based on test content, response process, test structure, clinical groups, and relationships to other measures (Sparrow et al. 2005). The internal consistency reported in the literature for the three domains and ABC were between 0.84–0.93 and 0.93–0.97, respectively (Sparrow et al. 2005). The internal consistency in our study across all sites were found to be acceptable for communication ($n = 215$; $\alpha = 0.74$), good for daily living skills ($n = 213$; $\alpha = 0.83$), excellent for socialisation ($n = 215$; $\alpha = 0.90$), and excellent for the ABC ($n = 213$; $\alpha = 0.93$).

Leiter International Performance Scale - Third Edition (Leiter-3)

The Leiter-3 (Roid et al. 2013) is a norm-referenced individually administered non-verbal measure of intelligence. The four subtests required to derive the nonverbal intellectual functioning include figure ground, form completion, classification and analogies, and sequential order. Raw scores on each test were converted into normalised/scaled scores (mean = 10, standard deviation = 3), percentiles, and age equivalence in accordance with the manual (Roid et al. 2013). The sum of scaled scores is used to establish nonverbal intellectual functioning scores for each individual (Roid et al. 2013). The nonverbal intellectual functioning domain was compared with the BIs intellectual functioning domain.

Evidence of adequate to good content, criterion, and construct validity has been reported in the literature (Roid et al. 2013). The internal consistency reported in the literature for the four subtests and nonverbal intellectual functioning across all age levels were between 0.78–0.95 and

0.94–0.98, respectively (Roid et al. 2013). The internal consistency in our study across all sites was found to be excellent for non-verbal intellectual functioning ($n = 211$; $\alpha = 0.93$).

Clinical Utility Questions

Clinical utility of the CDDR including the BIs were analysed quantitatively [i.e., eight questions scored on a 4-point Likert scale from 0 (not useful/clear at all) to 4 (extremely useful/clear)] on clarity, level of detail and specificity, interpretability, ease of application, usefulness for treatment selection, prognosis assessments, patient communication, and education efforts

Procedure

After obtaining the ethical approval from their respective institutional ethics body, each site recruited participants to the study by referral, and child assent and parent/caregiver consent were obtained. At each site, participants were assessed by a clinician rater registered in their country to assess and manage neurodevelopmental disorders using the ICD-11 CDDR for DID, including the BIs, to ascertain their intellectual and adaptive behaviour functioning. A second clinician observed the assessment conducted by the primary interviewer (i.e., the first clinician), and was instructed to only ask follow-up questions at the end of the assessment. Clinicians were prevented from accessing prior diagnoses (when applicable) and were instructed to collect sufficient clinical information to make a diagnosis regarding the index condition as well as additional mental disorders. Clinicians then independently entered their diagnostic conceptualisation and completed an assessment of the clinical utility of the CDDR including the BIs on the EFSS data collection platform within 48 h of assessment to reduce recall bias. These data were used to establish inter-rater reliability of the BIs. The child or adolescent was also

assessed by a separate clinician rater with competency using standardised, normed instruments to determine their nonverbal intellectual (Leiter-3) and adaptive behaviour (VABS-II) functioning to establish the concurrent validity of the BIs with standardised tests.

Data analysis

Data were scanned for extreme outliers (z score > ± 3.29), which were adjusted in the dataset through winsorisation (Kwak and Kim 2017). Data normality for the Leiter-3 and VABS-II were assessed using tests of skewness and kurtosis, the Shapiro–Wilk test of normality, and visually using histograms. Subsequently, all data were analysed using SPSS for Windows (version 24; IBM Corp 2016). The data were analysed based on the final diagnostic formulations for DID. Inter-rater reliability and concurrent validity were assessed using a variant of the intra-class correlation (ICC; Hallgren 2012). Data were combined across sites to increase the power to detect differences across severity levels. In the present study, clinicians were not able to select 'not applicable' on the EFSS when designating severity levels for domains in adaptive functioning for the BIs. Although this was not an issue for intellectual functioning, as this is an essential feature for DID, this may have been an issue for selecting severity levels for adaptive behaviour as an individual could have normal functioning in one domain and be found to be in the clinical range (e.g., 'mild') in the other two domains, likely resulting in an overall rating of adaptive behaviour in the clinical range. To account for this issue, the concurrent validity was analysed two ways: first using the raw data provided (concurrent validity – raw); second by collapsing functioning that was considered higher than meeting criteria for 'mild' on the Vineland-2 (i.e., 'not applicable' and 'mild' were all considered 'mild' cases; concurrent validity – adjusted). Therefore, the concurrent validity for the BIs in this study are likely found between the raw and adjusted values; both are presented. The ICC is a one-way, random effects, single-

measures model. Internal consistency of the BIs (both primary and observer clinician raters) and standardised measures were evaluated using nonparametric Kendall's tau-b correlation coefficients to examine the correlations between the final diagnostic formulation variables (i.e., intellectual functioning, adaptive behaviours, and overall severity) for DID. The validity, reliability and internal consistency of the BIs were compared to previously established criteria (Hunsley and Mash 2008). Descriptive statistics were performed to assess the clinical utility of the BIs for DID embedded within the ICD-11 Neurodevelopmental Disorders requirements.

Results

Clinician demographics are reported in Table 1. On average, clinicians were English-proficient psychiatrists and clinical psychologists between their late twenties to late forties with approximately 7 years of experience. Participant demographics are reported in Table 2. On average, participants were 11 years old and most were male. Participant characteristics (combined and individual countries/sites) are reported in Table 3. Most participants had not been previously diagnosed with medical or psychiatric conditions, did not present with other psychiatric symptoms, had not received treatment, and were not taking medication.

Psychometric analyses

Inter-rater reliability was assessed by evaluating the consistency of severity ratings across the domains of intellectual, conceptual, social, and practical functioning, as well as overall severity levels, assigned independently by clinicians provided with identical clinical information. Concurrent validity was examined by comparing the severity ratings assigned by clinicians using the BIs to those obtained from standardised measures, specifically the Leiter-3 for intellectual functioning and the VABS-II for adaptive behaviors, including overall severity levels. The ICCs

for inter-rater reliability and concurrent validity for the BIs collapsed across sites are shown in Table 4. The inter-rater reliability across domains and overall functioning were excellent (ICCs > 0.90). The concurrent validity (raw and adjusted) was good for intellectual functioning (0.71–0.73), excellent for conceptual skills (0.75–0.77), good for social skills (0.66–0.68), good for practical skills (0.68–0.73), and excellent for overall functioning (0.76–0.82). All ICCs were statistically significant (P < 0.05).

Table 4

Intra-Class Correlations (ICCs) for ICD-11 BIs for individuals receiving a DID diagnosis collapsed across sites

Variables	Inter-rater Reliability (*n*)	Concurrent Validity - Raw (*n*)	Concurrent Validity - Adjusted (*n*)
Intellectual	0.97 (175)	0.71 (167)	0.73 (167)
Conceptual	0.91 (175)	0.75 (172)	0.77 (172)
Social	0.93 (175)	0.66 (172)	0.68 (172)
Practical	0.94 (175)	0.68 (172)	0.73 (172)
Overall	0.97 (176)	0.76 (166)	0.82 (166)

*All variables were p<0.05 (2-tailed)

Internal consistency of the BIs are presented in Tables 5 and 6 for diagnostic formulations conducted by the primary clinician and observer clinician, respectively. Correlation coefficients were comparable between clinicians for the BIs, ranging from 0.84 to 0.97. All correlations were statistically significant (P < 0.001, two-tailed). Internal consistencies of the standardised measures (Leiter-3 and VABS-II) are presented in Table 7. Correlation coefficients for the standardised measures ranged from 0.53–0.83.

Table 5

Internal Consistency (Kendall's tau-b) and 95% Confidence Intervals [CIs] of the Primary Clinician Ratings using the BIs

	1	2	3	4	5
1. Intellectual (n=177)	-				
2. Conceptual (n=177)	0.89 [0.86-0.91]	-			
3. Social (n=177)	0.88 [0.86-0.90]	0.88 [0.86-0.90]	-		
4. Practical (n=177)	0.89 [0.87-0.91]	0.84 [0.80-0.86]	0.88 [0.85-0.90]	-	
5. Overall (n=177)	0.97 [0.96-0.97]	0.91 [0.89-0.93]	0.92 [0.90-0.93]	0.91 [0.89-0.92]	-

*All variables were p<0.001 (2-tailed)

Table 6

Internal Consistency (Kendall's tau-b) of the Observer Clinician Ratings using the BIs

	1	2	3	4	5
1. Intellectual (n=179)	-				
2. Conceptual (n=179)	0.90 [0.88-0.92]	-			
3. Social (n=179)	0.83 [0.80-0.86]	0.84 [0.81-0.87]	-		
4. Practical (n=179)	0.88 [0.85-0.90]	0.86 [0.83-0.89]	0.85 [0.82-0.88]	-	
5. Overall (n=179)	0.96 [0.95-0.96]	0.93 [0.92-0.94]	0.88 [0.85-0.90]	0.92 [0.90-0.93]	-

*All variables were p<0.001 (2-tailed)

Table 7

Internal Consistency (Kendall's tau-b) of the Standardised Measures Clinician Ratings using the Leiter-3 (nonverbal intellectual functioning) and the VABS-II (communication, socialisation, and daily living skills)

	1	2	3	4	5
1. Nonverbal Intellectual Functioning (n=113)	-				
2. Communication (n=112)	0.60 [0.53-0.66]	-			
3. Socialisation (n=112)	0.53 [0.46-0.60]	0.76 [0.71-0.80]	-		
4. Daily Living Skills (n=112)	0.59 [0.52-0.65]	0.75 [0.70-0.79]	0.75 [0.71-0.79]	-	
5. Overall (n=112)	0.72 [0.67-0.77]	0.83 [0.80-0.86]	0.81 [0.77-0.84]	0.83 [0.80-0.86]	-

*All variables were p<0.001 (2-tailed)

Clinical utility of the ICD-11 CDDR and BIs are presented for single diagnoses of DID in Table 8, and for co-occurring diagnoses such as DID with autism and DID with other neurodevelopmental (e.g., attention deficit hyperactivity disorder), mental (e.g., major depressive disorder) and/or behavioural disorders (e.g., oppositional defiant disorder) in Table 9. An

independent samples t test grouping single diagnosis with co-occurring diagnoses for intellectual, adaptive functioning and overall functioning across sites had P values above 0.05, indicating that there were no significant differences between single and co-occurring presentations. In general, most clinicians indicated that the BIs within the ICD-11 CDDR were quite to extremely clear and understandable, that the BIs had about the right to too much amount of detail and specificity; were quite easy to apply across severities; were shorter or took about the same amount of time to apply as their usual clinical practice; and were quite useful for treatment selection, prognosis assessments, communication with other health care professionals, and education efforts.

Table 8

Clinical Utility of the ICD-11 CDDR and BIs across DID Severity from all Clinician Raters

Clinical Utility Variables	Response Options	DID Severity (n = 267)			
		Mild (n=135; %)	Moderate (n=61; %)	Severe (n=37; %)	Profound (n=32; %)
Extent to which the Diagnostic Requirements were Clear and Understandable Overall as Applied to this Patient	Not at all clear and understandable	0	0	0	0
	Somewhat clear and understandable	5 (4)	8 (13)	3 (8)	0
	Quite clear and understandable	114 (84)	45 (74)	33 (89)	29 (91)
	Extremely clear and understandable	16 (12)	8 (13)	1 (3)	3 (9)
Level of Detail and Specificity of the Disagnostic Requirements/BIs for the Diagnosis/Diagnoses Applied to this Patient	Insufficient detail and specificity	4 (3)	2 (3)	1 (3)	0
	About the right amount of detail and specificity	77 (57)	47 (77)	31 (84)	32 (100)
	Too much detail and specificity	54 (40)	12 (20)	5 (13)	0
Extent to which the ICD-11 CDDR	Very difficult to apply	0	0	0	0

Imposed Requirements that were difficult to assess/apply to this patient	Somewhat difficult to apply	15 (11)	5 (8)	3 (8)	2 (6)
	Quite easy to apply	112 (83)	51 (84)	31 (84)	29 (91)
	Extremely easy to apply	8 (6)	5 (8)	3 (8)	1 (3)
Amount of Time Needed to Apply all of the Diagnostic Requirements/BIs to this Patient Compared to Usual Clinical Practice	Much longer than my usual clinical practice	0 (0)	1 (2)	0 (0)	0 (0)
	Somewhat longer than my usual clinical practice	41 (30)	14 (23)	10 (27)	4 (13)
	About the same as my usual clinical practice	86 (64)	41 (67)	23 (62)	27 (84)
	Shorter than my usual clinical practice	8 (6)	5 (8)	4 (11)	1 (3)
How Useful Would the Diagnostic Requirements be in Helping to Select a Treatment for this Patient?	Not at all useful	0 (0)	0 (0)	0 (0)	1 (3)
	Somewhat useful	20 (15)	9 (15)	4 (11)	3 (9)
	Quite useful	112 (83)	48 (79)	33 (89)	28 (88)
	Extremely useful	3 (2)	4 (7)	0 (0)	0 (0)
How Useful Would the Diagnostic Requirements be in Helping you to Assess this Patient's Prognosis	Not at all useful	3 (2)	0 (0)	0 (0)	1 (3)
	Somewhat useful	26 (19)	9 (15)	4 (11)	4 (13)
	Quite useful	99 (73)	50 (82)	32 (86)	27 (84)
	Extremely useful	7 (5)	2 (3)	1 (3)	0 (0)
Communication with Other Health Care Professionals	Not at all useful	0 (0)	0 (0)	0 (0)	0 (0)
	Somewhat useful	10 (7)	5 (8)	2 (5)	5 (16)
	Quite useful	112 (83)	51 (84)	33 (89)	27 (84)
	Extremely useful	13 (10)	5 (8)	2 (5)	0 (0)
Educating Patients/Family About Condition	Not at all useful	0 (0)	0 (0)	0 (0)	0 (0)
	Somewhat useful	26 (19)	9 (15)	4 (11)	3 (9)

	Quite useful	97 (72)	45 (74)	32 (86)	29 (91)
	Extremely useful	12 (9.0)	7 (11)	1 (3)	0 (0)

Table 9

Clinical Utility of the ICD-11 CDDR and BIs for Co-occurring Diagnoses

Clinical Utility Variables	Response Options	DID and Autism (*n*=29; %)				DID and other Neurodevelopmental / Mental / Behavioural Disorders (*n*=91; %)			
		Mild (*n*=11)	Moderate (*n*=10)	Severe (*n*=8)	Profound (*n*=0)	Mild (*n*=57)	Moderate (*n*=23)	Severe (*n*=8)	Profound (*n*=3)
Extent to which the Diagnostic Requirements were Clear and Understandable Overall as Applied to this Patient	Not at all clear and understandable	0	0	0	0	0	0	0	0
	Somewhat clear and understandable	0	1 (10)	0	0	1 (2)	1 (4)	2 (25)	0 (0)
	Quite clear and understandable	6 (55)	7 (70)	4 (50)	0 (0)	50 (88)	14 (61)	6 (75)	3 (100)
	Extremely clear and understandable	5 (45)	2 (20)	4 (50)	0 (0)	6 (10)	8 (35)	0 (0)	0 (0)
Level of Detail and Specificity of the Disagnostic Requirements/BIs for the Diagnosis/Diagnoses Applied to this Patient	Insufficient detail and specificity	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)
	About the right amount of detail and specificity	7 (64)	4 (40)	6 (75)	0 (0)	29 (51)	12 (52)	5 (63)	2 (67)
	Too much detail and specificity	4 (36)	6 (60)	2 (25)	0 (0)	28 (49)	11 (48)	3 (37)	1 (33)
Extent to which the ICD-11 CDDR Imposed	Very difficult to apply	0 (0)	1 (10)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)
	Somewhat	2 (18)	0 (0)	0 (0)	0 (0)	2 (3)	1 (4)	0 (0)	0 (0)

Requirements that were Difficult to Assess/Apply to this Patient	difficult to apply								
	Quite easy to apply	6 (55)	6 (60)	5 (63)	0 (0)	50 (88)	18 (78)	7 (88)	3 (100)
	Extremely easy to apply	3 (27)	3 (30)	3 (37)	0 (0)	5 (9)	4 (17)	1 (12)	0 (0)
Amount of Time Needed to Apply all of the Diagnostic Requirements/BIs to this Patient Compared to Usual Clinical Practice	Much longer than my usual clinical practice	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	1 (4)	0 (0)	0 (0)
	Somewhat longer than my usual clinical practice	1 (9)	0 (0)	0 (0)	0 (0)	14 (25)	2 (9)	2 (25)	1 (33)
	About the same as my usual clinical practice	5 (46)	9 (90)	6 (75)	0 (0)	36 (63)	14 (61)	6 (75)	2 (67)
	Shorter than my usual clinical practice	5 (45)	1 (10)	2 (25)	0 (0)	7 (12)	6 (26)	0 (0)	0 (0)
How Useful would the Diagnostic Requirements be in Helping to Select a Treatment for this Patient?	Not at all useful	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)
	Somewhat useful	0 (0)	1 (10)	2 (25)	0 (0)	9 (16)	4 (17)	3 (38)	1 (33)
	Quite useful	10 (91)	9 (90)	6 (75)	0 (0)	47 (82)	17 (74)	5 (62)	2 (67)
	Extremely useful	1 (9)	0 (0)	0 (0)	0 (0)	1 (2)	2 (9)	0 (0)	0 (0)
How Useful would the Diagnostic Requirements be in	Not at all useful	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)
	Somewhat	0 (0)	1 (10)	3 (37)	0 (0)	9 (16)	3 (13.0)	2 (25)	0 (0)

Helping you to Assess this Patient's Prognosis	useful								
	Quite useful	8 (73)	9 (90)	5 (63)	0 (0)	48 (84)	19 (83)	6 (75)	3 (100)
	Extremely useful	3 (27)	0 (0)	0 (0)	0 (0)	0 (0)	1 (4)	0 (0)	0 (0)
Communication with Other Health Care Professionals	Not at all useful	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)
	Somewhat useful	0 (0)	0 (0)	1 (12)	0 (0)	1 (2)	1 (4.3)	2 (25)	1 (33)
	Quite useful	9 (82)	10 (100)	7 (88)	0 (0)	51 (89)	21 (91)	6 (75)	2 (67)
	Extremely useful	2 (18)	0 (0)	0 (0)	0 (0)	5 (9)	1 (4)	0 (0)	0 (0)
Educating Patients/Family about Condition	Not at all useful	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)
	Somewhat useful	0 (0)	2 (20)	3 (38)	0 (0)	7 (12)	2 (9)	3 (38)	1 (33)
	Quite useful	9 (82)	8 (80)	5 (62)	0 (0)	45 (79)	20 (87)	5 (62)	2 (67)
	Extremely useful	2 (18)	0 (0)	0 (0)	0 (0)	5 (9)	1 (4)	0 (0)	0 (0)

Discussion

The ICD-11 includes BIs for DID within the CDDR for Neurodevelopmental Disorders to improve assessment and diagnostic practices for individuals, particularly in settings where appropriately normed and standardised testing is not available or not feasible (Tassé et al. 2019). This international field study examined the inter-rater reliability, concurrent validity, and clinical utility of the BIs in three countries to inform the global implementation of the ICD-11 and the CDDR. The ability to recognise, detect, and assign severity levels for intellectual, adaptive, and overall levels of functioning for DID in a valid and reliable way through direct behavioural observations and informant reported behaviours would be a major innovation with the potential to impact the identification and treatment of people with DID around the world, particularly in low- and middle-income countries (LAMICs) where most of the world's population lives (The World Bank Group 2022).

Inter-rater reliability of the BIs was established by comparing the severity levels of each of the domains (i.e., intellectual, conceptual, social, and practical) and the overall severity level assigned using the BIs by independent clinicians presented with the same clinical information. The results of the ICCs for inter-rater reliability across sites was found to be excellent (Table 4; Hunsley and Mash 2008), indicating that clinicians derive similar diagnoses with the BIs when presented with the same information. Overall, compared to other standardised, normed, and validated measures, the ICD-11 BIs were generally consistent with other studies of measures of intellectual functioning [e.g., Wechsler Intelligence Scale for Children – Fourth and Fifth Edition (WISC-IV/V; Wechsler 2014)], and adaptive behaviour functioning [e.g., Adaptive Behaviour Assessment System – Third Edition (ABAS-3; Harrison and Oakland 2015)] reported in the literature on inter-rater reliability.

Concurrent validity of the BIs was established by comparing the severity levels of each of the domains (i.e., intellectual, conceptual, social, and practical) and the overall severity level that clinicians' assigned using the BIs with those determined by the standardised measures (i.e., VABS-II and Leiter-3). The results of the ICCs using both methods of analysis ranged from good to excellent levels of reliability (Table 4; Hunsley and Mash 2008). Lower concurrent validity data may be due, in part, to the nature of combining two separate standardised measures with different administration methods and domains and comparing them to a single measure (i.e., the BIs). Specifically, the Leiter-3 is a test of nonverbal intellectual functioning, and the VABS-II is a structured interview that assesses communication, socialisation, and daily living skills whereas the ICD-11 CDDR uses BIs to assess intellectual and adaptive behaviour functioning. The concurrent validity of the BIs were also generally consistent with the reported concurrent validity among other measures of intellectual and adaptive functioning (refer to Sparrow et al. 2005; Banks and Franzen 2010; Roid et al. 2013; Wechsler 2014).

As a naturalistic study, clinicians were provided with minimal training on the ICD-11 CDDR and associated BIs, prevented from accessing prior diagnoses, provided with minimal guidance on how to conduct their clinical interviews or how to make a diagnosis, and instructed to enter their diagnostic formulation independently without consultations. Nonetheless, the ICCs for the BIs were comparable, and in some cases greater than standardised diagnostic instruments. An explanation for these findings may be that the BIs are aligned with the routine history taking and mental state examination and the clinicians were trained and experienced to gather details outlined in the BIs and CDDR. These findings were also consistent across sites and countries, supporting the use of BIs internationally given their good reliability and validity.

In general, results from the internal consistency analyses suggest a high degree of

interrelatedness between intellectual functioning, adaptive behaviours and the overall severity of DID using the BIs (Tables 5 and 6), whereas the standardised measures (Leiter-3 and VABS-II) appear to tap more distinct constructs (Table 7). As discussed, this may be due to the nature of combining two separate standardised measures that use different administration methods and domains. Based on the correlation coefficient confidence intervals, the internal consistencies of the standardised measures (ranging from 0.53 to 0.83) were significantly lower than the BIs (ranging from 0.83 to 0.97). These findings suggest that there is more diagnostic overlap between intellectual and adaptive functioning using the BIs, likely due to the inherently less rigid diagnostic requirements and more weight being placed on the decision-making abilities of the clinician (First et al. 2015).

The clinical utility of the BIs were assessed across levels of severity (i.e., mild to profound) separately for DID without co-occurring disorders (Table 8), and DID with co-occurring disorders (Table 9) to account for the complexities and large degree of clinical heterogeneity in DID with co-occurring disorders (especially autism; Casanova et al. 2020). The BIs may be clinically useful for individuals with DID regardless of whether co-occurring disorders are present, given that there was no significant difference in ratings of clinical utility or in severity levels for intellectual functioning, adaptive behaviours, and overall functioning between single and co-occurring presentations. Despite smaller sample sizes in the present study for people diagnosed with DID and co-occurring disorders, it appears that the ICD-11 CDDR and BIs are generally clear and understandable, quick and easy to apply across severities and useful in facilitating treatment selection, prognosis assessments, communication with other health care professionals, and education efforts, although according to clinicians they include perhaps too much detail and specificity. On the other hand, providing less detail and specificity

could affect consistency across classification users and whether the CDDR are used as intended. The results of this study suggest that the ICD-11 BIs may be used as an alternative resource to establish the severity of DID under conditions when psychometrically sound, appropriately normed and standardised measures for intellectual functioning and adaptive behaviour are not available or not feasible.

Limitations and Future Directions

There are several potential limitations to our study. First, findings from our study would benefit from replication with larger samples with greater diversity across sites and countries to improve generalisability and global applicability of the ICD-11 CDDR and BIs for DID. Although clinicians varied widely by age (range: 29 to 48 years old) and years of experience (range: 2–22 years), most were psychiatrists. A sample of clinicians that vary in profession (e.g., psychologists, primary care physicians, and paediatricians) and setting may improve generalisability among healthcare and system users, especially in LAMICs where resources and access to healthcare professionals may be limited. A larger sample size is recommended to further assess for clinically meaningful differences between single diagnoses of DID from those with co-occurring diagnoses in which clinicians are instructed to adjust their use of the CDDR and BIs (e.g., placing less weight on the social domain for adaptive behaviours in individuals with co-occurring autism).

Second, our findings would benefit from replication studies that include clinics in various countries that service more diverse clinical presentations to ensure clinicians are applying the CDDR and BIs across the full spectrum of severity levels for DID. Within our study, most participants were diagnosed with mild to moderate DID at the Oasi IRCCS site in Italy and the NIMHANS site in India, mild DID at the Peradeniya site in Sri Lanka, and severity levels

spanning from mild to profound at the AIIMS site in India. These variations in clinical presentation help explain the large discrepancy in concurrent validity among sites with individuals presenting with subthreshold to mild DID. Furthermore, if clinicians typically see certain levels of severity for DID at their site, they may be primed to designate similar diagnostic formulations within a smaller range of options without needing to use all the information provided by the BIs. A narrowed range of participant clinical presentations may increase inter-rater reliability due to fewer severity levels considered when diagnosing.

Finally, the current study's eligibility criteria required participants to be aged 5 to 18 years. Although some clinicians used the BIs for early childhood (i.e., participants aged 5 years), most used the BIs for childhood and adolescence (i.e., participants aged 6–18 years). These age restrictions were put in place due to the limited sample size per site, to accommodate participants typically seen across sites, and to prioritise the facilitation of early DID diagnoses. Given these restrictions, the results from this study may not generalise to populations in early childhood (18 years). Future studies should conduct similar investigations focusing on these populations to assess the reliability, validity, and clinical utility of the ICD-11 CDDR and BIs for individuals with DID across the lifespan.

Conclusions

This international field study was conducted in clinical settings in three countries of varying language, culture, and income level to assess the performance of the BIs embedded in the ICD-11 CDDR for DID. The BIs were assessed in several ways including whether clinicians interpret and apply the BIs as intended by the developers of the requirements, derive similar diagnostic formulations using the BIs when presented with the same case presentation information (inter-rater reliability), and compared to the use of validated, normed, and

standardised assessment measures of intellectual and adaptive functioning (concurrent validity). The BIs were also assessed for their clinical utility. Findings suggest that the BIs have excellent inter-rater reliability, good to excellent concurrent validity, and good clinical utility across sites, suggesting good to excellent global applicability of the BIs in various clinical settings, irrespective of language, culture, economic status, and assessment/diagnostic practices. These findings will be used to inform the global implementation of the ICD-11 and the CDDR. Implemented in the context of the CDDR, BIs provide a much needed tool to identify and evaluate the severity of limitations in intellectual and adaptive functioning for DID in a valid and reliable way through direct behavioural observations and informant-reported behaviours. Their use in settings where appropriately normed, standardised measures and specialised services are unavailable has the potential to impact the identification and treatment of people with DID around the world, particularly in lower-resource settings. By facilitating early diagnosis and intervention in these settings, the BIs can contribute to improved individual and community outcomes and reduce health disparities for people living with DID.

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Conflict of Interests

The authors certify that they have no affiliations with or involvement in any organisation or entity with any financial or non-financial interest in the subject matter or materials discussed in this manuscript. Unless specifically stated, the views expressed in this paper are those of the authors and do not represent the official policies or positions of the WHO. There was no source of funding for the conduct of this study.

No conflicts of interest have been declared.

Data Availability Statement

Author elects to not share data.

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Implementation of the International Classification of Diseases 11th revision behavioural indicators for disorders of intellectual development with co-occurring autism spectrum disorder (Study 2; Lemay et al., 2024)

Abstract

Background: The classification of mental, behavioural and neurodevelopmental disorders in the World Health Organization's International Classification of Diseases 11th revision (ICD-11) includes a comprehensive set of behavioural indicators (BIs) within the neurodevelopmental disorders grouping. BIs can be used to assess the severity of disorders of intellectual development in situations in which standardised measures of intellectual functioning and adaptive behaviours are not available or feasible. This international study examines the implementation characteristics of the BIs and compares them to standardised measures for assessing the severity of intellectual impairment and adaptive behaviours in disorders of intellectual development and autism. The clinical utility of the ICD-11 and the fidelity of its application in international clinical settings were also assessed. Methods: A total of 116 children and adolescents (5–18 years old) with a suspected or established diagnosis of disorders of intellectual development were included across four sites [Italy (n = 18), Sri Lanka (n = 19) and two sites in India (n = 79)]. A principal component analysis was conducted to evaluate the application of the ICD-11 guidance for combining severity levels. Results: Assessment using the BIs showed a higher proportion of individuals classified with mild severity, whereas the standardised measures indicated a higher proportion of severe ratings. Additionally, individuals with co-occurring autism tended to have more severe impairments compared with those without autism, as indicated by both BIs and standardised measures. Overall, the BIs were considered clinically useful, although more time and consideration were required when applying the

guidelines for individuals with a co-occurring disorder of intellectual development and autism. The principal component analysis revealed one principal component representing overall disorders of intellectual development severity levels. Conclusions: The ICD-11 BIs can be implemented as intended in international clinical settings for a broad range of presentations of individuals with neurodevelopmental disorders. Use of the BIs results in similar severity diagnoses to those made using standardised measures. The BIs are expected to improve the reliability of severity assessments in settings where appropriate standardised measures for intellectual and adaptive behaviours are not available or feasible.

Keywords autism spectrum disorder, behavioural indicators, classification, disorders of intellectual development, ICD-11, WHO

Introduction

The World Health Organization (WHO 2021) included a comprehensive set of behavioural indicators (BIs) for disorders of intellectual development in the Clinical Descriptions and Diagnostic Requirements (CDDR) for the International Classification of Diseases 11th revision (ICD-11): Mental, Behavioural and Neurodevelopmental Disorders. BIs are intended to assist clinicians in assigning the level of severity of disorders of intellectual development, particularly when standardised measures of intellectual functioning and adaptive behaviours that are locally normed, linguistically appropriate and culturally relevant are not available or feasible (Robertson et al. 2012; Kishore et al. 2019). BIs can be used as part of assessments to indicate the presence or absence of particular skills, competencies or abilities. The ICD-11 BIs for disorders of intellectual development describe a set of common expected observable behaviours for groups of individuals with disorders of intellectual development with similar levels of severity of impairment at different stages of development (Tassé et al. 2019). The BIs delineate typical behavioural manifestations observed across levels of severity based on intellectual and adaptive behaviours. In previous studies, the BIs were found to have excellent inter-rater reliability, good to excellent concurrent validity and good clinical utility (Lemay et al. 2022). Additional research is needed to investigate clinician decision-making and adherence to the guidance for BIs provided in the ICD-11 CDDR when they are implemented in real-world clinical settings.

The ICD-11 CDDR includes clinically useful information regarding how to identify and correctly diagnose co-occurring disorders, which is intended to improve the global applicability of the ICD-11 and encompass the full heterogeneity observed among individuals (Reed 2010; First et al. 2015). Within the neurodevelopmental disorders, one such common co-occurrence is

between disorders of intellectual development and autism. Social functioning deficits are a core feature of autism and overlap with the social domain of adaptive behaviours used to diagnose the level of severity of disorders of intellectual development (Thurm et al. 2019). In the context of co-occurring autism and disorders of intellectual development, the ICD-11 CDDR instructs clinicians to place less emphasis on the social skills domain in the assessment of adaptive behaviours of the disorder of intellectual development (Ayuso-Mateos & Kogan 2020). This is consistent with the finding that standardised assessment tools for diagnosing disorders of intellectual development may overestimate the severity of the disorder, particularly in the social domain of adaptive behaviours, due to overlapping deficits in social functioning for individuals with co-occurring autism (Thurm et al. 2019).

Although standardised and normed assessment instruments are commonly regarded as the 'gold standard' for evaluating intellectual functioning and adaptive behaviours as independent constructs (Sparrow et al. 2005; Roid et al. 2013), their availability is often limited, especially, in non-English speaking countries (Pontrelli Mecca et al. 2022). The BI tables are used to confirm the overall severity of the disorders of intellectual development by determining individual levels of severity in intellectual functioning and three domains of adaptive behaviours (Tassé et al. 2019). The ICD-11 CDDR indicates that the overall level of severity should be assigned based on clinical judgement, considering the average severity level across all domains of the individual's intellectual ability and adaptive behaviours. However, this may vary according to the nature and purpose of the assessment as well as the degree to which affected behaviours impact overall functioning. It is possible that variations in clinical judgement may lead to divergent severity-level ratings for the same individual. Thus, the degree to which clinical

judgement may affect the inter-rater reliability of diagnoses based on the BIs is an important area for study.

The objectives of the present study were to (1) compare severity-level ratings for intellectual functioning, adaptive behaviours and overall functioning for individuals assigned a co-occurring diagnosis of a disorder of intellectual development and autism with those who were assigned a diagnosis of a disorder of intellectual development only; (2) evaluate the perceived clinical utility of the ICD-11 CDDR when used for individuals with a co-occurring diagnosis of a disorder of intellectual development and autism; and (3) confirm whether the ICD-11 CDDR guidance on how to combine the four domains of BIs (i.e. intellectual functioning, conceptual, social and practical skills) into an overall severity rating is being applied as intended by clinicians working in international settings. Overall, the goal of the present study is to assess whether severity profiles obtained in an international field study reflect an accurate application of the BIs as intended by its developers.

Methods

This study was part of the international field study of the ICD-11 BIs for disorders of intellectual development; a comprehensive description of the methods can be found in Lemay et al. (2022). The study was an international, collaborative and cross-cultural study coordinated at the University of Ottawa in Canada. Ethics approval was obtained from the University of Ottawa Office of Research Ethics and Integrity (protocol no. H-03-18-371). Ethics approval was also obtained at each participating site [India: All India Institute of Medical Sciences (AIIMS) and National Institute of Mental Health & NeuroSciences (NIMHANS); Italy: Oasi Research Institute-IRCCS (Oasi IRCCS); and Sri Lanka: Teaching Hospital Peradeniya].

Participants

A total of 206 children and adolescents (aged 5–18 years) were recruited in three countries at four study sites. After applying our inclusion/exclusion criteria (see below), a total of 116 participants were included in this study [India: NIMHANS (n = 22) and AIIMS (n = 57); Sri Lanka: Teaching Hospital Peradeniya (n = 19); and Italy: Oasi IRCCS (n = 18)]. Participating study clinicians, site coordinators and site supervisors attended a 2-h online training on the ICD-11 neurodevelopmental disorders guidelines and a 1-h online procedural training for the BIs prior to data collection. Most clinician raters were psychologists or psychiatrists who were authorised to administer and interpret psychological tests. Three clinicians identified with 'other' related professions (i.e. counselling therapist, occupational therapist and medical doctor) and were trained to utilise the BIs.

The following inclusion criteria were applied when assessing the eligibility of participants: (1) aged 5–18 years at the time of recruitment; (2) known or suspected of having a disorder of intellectual development with or without co-occurring autism, based on supplemental clinical information provided to clinicians; (3) not under the care of any of the clinician raters; (4) not currently incapacitated due to severe physical illness or pain; and (5) not currently at imminent risk of self-harm, danger to others or experiencing serious medication side effects requiring immediate medical attention. To limit the number of preliminary/provisional diagnoses given to young participants, those under the age of 5 were excluded. Adults were excluded due to feasibility, given that some study sites only provide services to children and adolescents. Participants with severe behavioural disorders and/or severe motor impairments and/or those who were determined not to be able to sustain attention long enough for valid scores on the test of intellectual functioning were excluded at the outset of recruitment because this would

preclude the ability to obtain data from the standardised assessment measures of intellectual functioning necessary for comparing the performance of the BIs. Although data on standardised measures of intellectual functioning may have been unobtainable for some individuals due to their inability to complete cognitive testing, we sought to collect data from a sample of individuals encompassing the full range of severity levels. Finally, only participants who qualified for a diagnosis of disorders of intellectual development using both the BIs and standardised measures were included in this study.

Materials

Data collection process

All study activities were tracked by site coordinators using REDCap, a secure web platform designed to support data collection, management and monitoring (Harris et al. 2009). Clinicians entered their diagnostic conceptualisation and an assessment of the clinical utility of the guidelines and the BIs on an Electronic Field Study System, a web-based data collection platform developed using Qualtrics™ (Provo, UT, USA). All data were monitored, stored and managed centrally at the University of Ottawa. Materials for clinician training were provided in English at all sites except Italy, where Italian translations were provided to improve comprehension. However, the assessment process was conducted in each participant's primary language across all sites.

Demographics

Both clinician and participant information was collected. Clinician demographics are shown in Table S1, and participants' demographics are shown in Table 10. Data regarding a range of clinical characteristics (e.g. previous medical diagnoses, previous mental disorder

diagnoses, additional symptoms, current medications and previous treatment) were collected and are also shown in Table 10.

Table 10

Participant demographics and characteristics by site

Variable	Total (*N*=116; %)	Italy (Oasi IRCCS; *N*=18; %)	Sri Lanka (Teaching Hospital Peradeniya; *N*=19; %)	India (AIIMS; *N*=57; %)	India (NIMHANS; *N*=22; %)
Age, years (Mean±SD)	11.7 ± 3.81	9.61 ± 3.88	11.47 ± 3.79	12.35 ± 3.76	11.91 ± 3.48
Gender, *N* (%)					
Male	77 (66.4)	10 (55.6)	13 (68.4)	39 (68.4)	15 (68.2)
Female	39 (33.6)	8 (44.4)	6 (31.6)	18 (31.6)	7 (31.8)
Previous medical diagnoses, *N* (%)					
Epilepsy/Seizure Disorder	17 (14.7)	3 (16.7)	2 (10.5)	9 (15.8)	3 (13.6)
Dysmorphic Features	3 (2.6)	3 (16.7)	0	0	0
Previous mental disorder diagnoses, *N* (%)					
Disorders of Intellectual Development	11 (9.5)	5 (27.8)	0	3 (5.3)	3 (13.6)
Attention-Deficit Hyperactivity Disorder	5 (4.3)	1 (5.6)	2 (10.5)	1 (1.8)	1 (4.5)
Disorders of speech and language	4 (3.4)	4 (22.2)	0	0	0
Global Developmental Delay	2 (1.7)	2 (11.1)	0	0	0
Behavioural Disorders	2 (1.7)	2 (11.1)	0	0	0
Additional symptoms, *N* (%)					
Attention related difficulties	11 (9.5)	2 (11.1)	3 (15.8)	4 (7.0)	2 (9.1)
Aggressiveness	7 (6.0)	3 (16.7)	1 (5.3)	3 (5.3)	0
Anxiety in social situations	3 (2.6)	0	0	0	3 (13.6)
Self-injurious behaviours	3 (2.6)	2 (11.1)	1 (5.3)	0	0
Current Medications, *N* (%)					
Atypical antipsychotic	33 (28.4)	4 (22.2)	1 (5.3)	27 (47.4)	1 (4.5)
Anticonvulsant	15 (12.9)	4 (22.2)	2 (10.5)	7 (12.3)	2 (9.1)
Previous Treatment, *N* (%)					
Psychomotor Therapy	17 (14.7)	17 (94.4)	0	0	0
Speech Therapy	17 (14.7)	17 (94.4)	0	0	0
Psychoeducational intervention	6 (5.2)	6 (33.3)	0	0	0

Only variables that affected >10% of the sample at any site are reported. Oasi IRCCS, Oasi Research Institute-IRCCS; AIIMS, All India Institute of Medical Sciences; NIMHANS, National Institute of Mental Health & NeuroSciences; SD, standard deviation.

International Classification of Diseases 11th revision behavioural indicators and neurodevelopmental disorders guidelines

The BIs are provided in a series of tables in the CDDR for disorders of intellectual development, part of the grouping for neurodevelopmental disorders. The BI tables describe intellectual and adaptive behaviour (conceptual, social and practical) functioning characteristic of different severity levels (i.e. mild, moderate, severe and profound) for three age groups (0–5, 6–18 and 18+ years old) (Tassé et al. 2019). The BIs for adaptive behaviours are identified for each adaptive skill (i.e. conceptual, social and practical). In this study, severity was coded as follows: mild = 1, moderate = 2, severe = 3 and profound = 4. All clinicians were provided the CDDR for ICD-11 neurodevelopmental disorders with the embedded BIs.

Clinical utility questions

Clinical utility of the CDDR, including the BIs, was analysed quantitatively [i.e. eight questions scored on a 3- to 4-point Likert scale from 0 (not useful/clear at all) to 3–4 (extremely useful/clear)] on interpretability; ease of application; and usefulness for treatment selection, prognosis assessments, client communication and education efforts (Reed 2010; Robles et al. 2022). Specific wording of clinical utility questions and response options were adapted from Reed et al. (2018) and are presented in Table S2.

Vineland Adaptive Behaviour Scale – Second Edition

The Vineland Adaptive Behaviour Scale – Second Edition (VABS-II; Sparrow et al. 2005) was used to assess adaptive behaviours. For this study, the VABS communication domain was compared with the BI's conceptual skills, the VABS socialisation domain was compared

with the BI's social skills and the VABS daily living skills were compared with the BI's practical skills.

Leiter International Performance Scale – Third Edition

The Leiter International Performance Scale – Third Edition (Leiter-3; Roid et al. 2013) was used to measure non-verbal intelligence. For this study, the non-verbal intellectual functioning domain was compared with the BI's intellectual functioning domain.

Childhood Autism Rating Scale

The presence and severity of symptoms of autism were assessed with the Childhood Autism Rating Scale (CARS; Schopler et al. 1980). For this study, participants who obtained a score of 30 or greater on the CARS were considered to meet the diagnostic requirements for autism.

Procedure

After obtaining ethical approval from their respective institutional ethics bodies, each site recruited participants for the study by referral. Clinicians licensed in each country assessed participants using revised guidelines for disorders of intellectual development, including the BIs. Clinicians were blinded by prior diagnoses and collected sufficient clinical information for a diagnosis and to identify additional mental and behavioural conditions. Clinicians entered their diagnostic conceptualisation and completed an assessment of the guidelines and BIs on a web-based platform within 48 h. The child or adolescent was also assessed separately for non-verbal intellectual and adaptive behaviours using standardised instruments (Leiter-3 and VABS-II).

Data analysis

Data were scanned for extreme outliers (z score > ±3.29) to assess for data entry errors. Subsequently, all data were analysed using SPSS for Windows (version 24; IBM Corp 2016).

Sample descriptive analyses

Severity levels for intellectual functioning, adaptive behaviours and overall functioning were collected using BIs and standardised measures (Leiter-3 and VABS-II) for individuals with disorders of intellectual development with and without co-occurring autism (Table 11). Descriptive analyses were performed to summarise the number of individuals at each severity level using BIs and standardised measures. A two-sample t-test was performed to compare standardised scores of the standardised measures between the two groups, while a Mann–Whitney U test compared severity levels of the ICD-11 BIs between the two groups. Descriptive analyses were also conducted to assess the clinical utility of ICD-11 CDDR and BIs for individuals with disorders of intellectual development and co-occurring autism.

Table 11

Severity level distributions between groups using the BIs and standardised measures

Behavioural Indicators										
	Disorders of intellectual development (*n* = 76; %)					Disorders of intellectual development & Autism (*n* = 40; %)				
	Intellectual	Conceptual	Social	Practical	Overall	Intellectual	Conceptual	Social	Practical	Overall
Mild	33 (43.4)	33 (43.4)	35 (46.1)	40 (52.6)	36 (47.4)	7 (17.5)	8 (20.0)	7 (17.5)	6 (15.0)	7 (17.5)
Moderate	25 (32.9)	21 (27.6)	26 (34.2)	19 (25.0)	23 (30.3)	11 (27.5)	6 (15.0)	9 (22.5)	11 (27.5)	10 (25.0)
Severe	13 (17.1)	18 (23.7)	10 (13.2)	11 (14.5)	12 (15.8)	11 (27.5)	13 (32.5)	12 (30.0)	11 (27.5)	12 (30.0)
Profound	5 (6.6)	4 (5.3)	5 (6.6)	6 (7.9)	5 (6.6)	11 (27.5)	13 (32.5)	12 (30.0)	12 (30.0)	11 (27.5)
Standardised Measures (Leiter-3 & VABS-II)										
	Disorders of intellectual development (*n* = 76; %)					Disorders of intellectual development & Autism (*n* = 40; %)				
	Intellectual	Conceptual	Social	Practical	Overall	Intellectual	Conceptual	Social	Practical	Overall
Mild	21 (28)	45 (59.2)	47 (61.8)	41 (53.9)	12 (15.8)	0	8 (20.0)	11 (27.5)	8 (20.0)	3 (7.5)
Moderate	24 (32)	21 (27.6)	18 (23.7)	22 (28.9)	52 (68.4)	6 (15.0)	15 (37.5)	9 (22.5)	12 (30.0)	16 (40.0)
Severe	31 (41)	10 (13.2)	9 (11.8)	13 (17.1)	12 (15.8)	34 (85.0)	17 (42.5)	17 (42.5)	20 (50.0)	21 (52.5)
Profound	N/A	0	2 (2.6)	0	0	N/A	0	3 (7.5)	0	0

Principal component analysis

A principal component analysis (PCA) was conducted to assess the application of ICD-11 guidance on combining severity levels of intellectual functioning and adaptive behaviours for individuals diagnosed with a disorder of intellectual development (N = 116 participants). The PCA included four variables: intellectual, conceptual, social, and practical functioning. The purpose of the PCA was to determine the number of factors contributing to the overall severity levels of disorders of intellectual development. Prior to conducting the PCA, the data's suitability was assessed to ensure no significant outliers, missing values or lack of a linear relationship between variables. Sampling adequacy was also confirmed before proceeding with the analysis.

Results

The dataset contained no outliers. Severity-level distributions for intellectual functioning and adaptive behaviours (i.e. conceptual, social and practical) using the BIs and standardised measures (i.e. Leiter-3 and VABS-II) for individuals with disorders of intellectual development with and without co-occurring autism are reported in Table 11. When the BIs were used, a positive skew was observed across all variables for disorders of intellectual development, with a higher proportion of individuals classified with mild severity and decreasing proportions in the moderate, severe and profound severity levels. In contrast, the standardised measures indicated a higher proportion of ratings indicating severe intellectual functioning, a positive skew from mild to severe for adaptive behaviours and moderate overall severity levels. Individuals with disorders of intellectual development with co-occurring autism tend to have more severe impairments compared with those with only disorders of intellectual development when using either the BIs or standardised measures. When combining groups (i.e. disorder of intellectual development with

or without co-occurring autism), over 10% of the sample were assessed with profound severity across all domains with the BIs, whereas only 4.3% of the sample were identified with profound levels of severity within the social domain of adaptive behaviours alone with the standardised measures.

Severity-level comparisons

Comparisons of severity-level ratings for intellectual functioning, adaptive behaviours, and overall functioning (the latter determined by aligning with the level at which the majority of an individual's intellectual functioning and adaptive behaviours across all three domains—conceptual, social, and practical—fell, following established ICD-11 CDDR and BI guidelines) for individuals diagnosed with a disorder of intellectual development (DID) without co-occurring autism and those with DID and co-occurring autism are presented in Table 12. As expected, there was a statistically significant difference in standardised scores for the social domain of adaptive behaviours such that individuals diagnosed with disorders of intellectual development alone were rated as less severe than individuals with disorders of intellectual development and co-occurring autism. Similarly, IQ scores for intellectual functioning and standardised scores for the conceptual and practical domains of adaptive behaviours, as well as overall scores, were all rated as less severe for individuals with disorders of intellectual development alone compared with individuals with disorders of intellectual development with co-occurring autism.

Table 12

Severity comparisons between individuals with disorders of intellectual development without co-occurring autism and disorders of intellectual development, with co-occurring autism for intellectual functioning, adaptive behaviours, and overall functioning using standardised measures (Leiter-3 & Vineland-II)

		N	Mean / Mrank	Standard Deviation	df	*t* / Mann-Whitney U	*Z*	*p*-value (two-sided)	Effect sise (Cohen's d / eta^2)
Intellectual	Disorders of intellectual development	76	45.25	12.04	114	2.626	-	.010	.513
	Disorders of intellectual development & Autism	40	39.18	11.44					
Conceptual	Disorders of intellectual development	76	53.61	12.06	114	4.705	-	<.001	.919
	Disorders of intellectual development & Autism	40	42.35	12.59					
Social	Disorders of intellectual development	76	52.93	13.34	114	3.959	-	<.001	.773
	Disorders of intellectual development & Autism	40	42.28	14.60					
Practical	Disorders of intellectual development	76	56.03	17.34	114	4.755	-	<.001	.929
	Disorders of intellectual development & Autism	40	40.83	14.30					
Overall*	Disorders of intellectual development	76	50.44	-	116	944.00	-3.804	<.001	.126
	Disorders of intellectual development & Autism	40	76.90	-					

*Performed using a Mann-Whitney U Test due to Ordinal data.

VABS-II, Vineland Adaptive Behaviour Scale – Second Edition.

Comparisons of BIs for individuals with disorders of intellectual development with and without co-occurring autism are reported in Table 13. Analyses resulted in similar findings as the standardised measures, with significantly higher severity ratings for the disorders of intellectual development with co-occurring autism compared with disorders of intellectual development without co-occurring autism when using the BIs.

Table 13

Severity comparisons between individuals with disorders of intellectual development without co-occurring autism and disorders of intellectual development with co-occurring autism for intellectual functioning, adaptive behaviours, and overall functioning using the BIs

		N	Mean rank	Mann-Whitney U	*Z*	*p*-value (two-sided)	Effect sise (eta^2)
Intellectual	Disorders of intellectual development	76	50.42	906.0	-3.723	<.001	0.121
	Disorders of intellectual development & Autism	40	73.85				
Conceptual	Disorders of intellectual development	76	49.89	866.0	-3.958	<.001	0.136
	Disorders of intellectual development & Autism	40	74.85				
Social	Disorders of intellectual development	76	49.18	811.5	-4.302	<.001	0.161
	Disorders of intellectual development & Autism	40	76.21				
Practical	Disorders of intellectual development	76	48.89	790.0	-4.445	<.001	0.172
	Disorders of intellectual development & Autism	40	76.75				

Overall	Disorders of intellectual development	76	49.69	850.5	-4.066	<.001	0.144
	Disorders of intellectual development & Autism	40	75.24				

BIs, behavioural indicators.

Clinical utility of the International Classification of Diseases 11th revision Clinical Descriptions and Diagnostic Requirements and behavioural indicators for disorders of intellectual development with co-occurring autism spectrum disorder

Comparisons of clinical utility questions when using the ICD-11 CDDR and BIs for individuals with disorders of intellectual development with and without co-occurring autism are reported in Table 14. The clinical utility of the BIs was rated highly. No significant differences were observed between those clinicians using the CDDR to make diagnoses for participants with disorders of intellectual development with or without co-occurring autism on all variables except for requiring significantly more time (small to moderate effect) when implementing the CDDR and BIs for individuals diagnosed with co-occurring autism.

Table 14

Clinical utility comparisons of the ICD-11 CDDR and BIs between groups

		N	Mean rank	Mann-Whitney U	*Z*	*p*-value (two-sided)	Effect sise (eta^2)
Clear and understandable	Disorders of intellectual development	76	56.47	1365.5	-1.217	.224	.013
	Disorders of intellectual development & Autism	40	62.36				
Level of detail and specificity	Disorders of intellectual development	76	57.34	1431.5	-.700	.484	.004
	Disorders of intellectual development & Autism	40	60.71				
Imposing requirements	Disorders of intellectual development	76	55.83	1317.0	-1.643	.100	.023

that are difficult to assess/apply	Disorders of intellectual development & Autism	40	63.58				
Amount of time to apply compared to usual practice	Disorders of intellectual development	76	53.75	1159.0	-2.499	.012*	.054
	Disorders of intellectual development & Autism	40	67.53				
Usefulness for treatment selection	Disorders of intellectual development	76	59.90	1413.5	-.942	.346	.008
	Disorders of intellectual development & Autism	40	55.84				
Usefulness for assessing patient prognosis	Disorders of intellectual development	76	58.66	1508.0	-.108	.914	<.001
	Disorders of intellectual development & Autism	40	58.20				
Communication with other health care professionals	Disorders of intellectual development	76	61.03	1327.5	-1.668	.095	.024
	Disorders of intellectual development & Autism	40	53.69				
Educating patients/family about condition	Disorders of intellectual development	76	60.26	1386.0	-1.102	.270	.011
	Disorders of intellectual development & Autism	40	55.51				

*$P < 0.05$.
ICD-11, International Classification of Diseases 11th revision; CDDR, Clinical Descriptions and Diagnostic Requirements; BIs, behavioural indicators.

Combining four domains to assign an overall severity rating

A PCA was conducted to evaluate whether the ICD-11 guidance for how to combine four levels of severity [i.e. intellectual functioning and adaptive behaviours (conceptual, social and practical)] into an overall severity rating is being applied as intended by the authors of the ICD-11. Inspection of the correlation matrix showed that all variables had at least one correlation coefficient greater than 0.3. The overall Kaiser–Meyer–Olkin measure was 0.89, with individual Kaiser–Meyer–Olkin measures all greater than 0.8, classifications of ‘meritorious’ according to Kaiser (1974). Bartlett’s test of sphericity was statistically significant ($P < 0.001$), indicating that the data were likely factorisable. PCA revealed one component that had an eigenvalue greater than 1, which explained 93.8% of the total variance. Visual inspection of the scree plot indicated

that one component should be retained (Cattell 1966). In addition, a one-component solution met the interpretability criterion. As such, one component (overall disorders of intellectual development severity) was retained. Because a one-factor model was derived, rotation modelling was not necessary.

Discussion

This study examined the implementation characteristics of the ICD-11 BIs (Tassé et al. 2019; Lemay et al. 2022) for assessing the severity of disorders of intellectual development, including when they are used with individuals with and without co-occurring autism. The ICD-11 BIs may serve as an alternative resource for assessing the severity of disorders of intellectual development in situations when psychometrically sound, linguistically appropriate, culturally relevant, normed and/or standardised measures for intellectual functioning and adaptive behaviour are not available or feasible (Robertson et al. 2012; Kishore et al. 2019). The current study compared severity-level ratings, assessed the clinical utility of the neurodevelopmental disorders clinical requirements and evaluated the fidelity of the application of the BIs in international clinical settings.

Severity-level comparisons revealed that participants with disorders of intellectual development without co-occurring autism were rated as having less severe ratings for intellectual functioning and across all domains of adaptive behaviours than individuals with co-occurring autism (Table 12). These findings were consistent whether clinicians used standardised measures (Table 13) or the BIs (Table 14). The age covariate for the standardised measures also suggests that older participants tend to have more severe impairments. These findings align with previous research that finds greater severity in intellectual functioning and adaptive behaviours in individuals with disorders of intellectual development and co-occurring autism, suggesting

greater difficulties in cognitive abilities and adaptive behaviours (Matson & Shoemaker 2009; Cervantes & Matson 2015; Glennon et al. 2017; Bradbury et al. 2022), which may become more severe with age (Pugliese et al. 2015; Alvares et al. 2020). The relationship between age and severity of disorders of intellectual development and autism may not necessarily be solely caused by the natural progression of the condition but also by the fact that families may seek help for milder disabilities earlier on, while those with more severe disabilities may be brought to clinics at older ages due to the need for specialised care (Sapiets et al. 2021). This may also reflect the 'telescoping effect', in which parents report a later age of onset of symptom recognition and reporting for older children compared with parents of younger children (Ozonoff et al. 2018). This is particularly evident in low- and middle-income countries (LAMICs), where limited services are offered in clinics, leading families to rely on their own resources for education and rehabilitation (WHO 2011).

The severity and presentation of disorders of intellectual development and autism between Western countries and LAMICs can be influenced by cultural, socio-economic and healthcare system variations (Samadi 2022). In Western countries, individuals with autism, particularly those who have milder symptoms, are identified and diagnosed at a higher rate due to better access to healthcare services, increased awareness and understanding of autism and specialised diagnostic and intervention resources (Ruparelia et al. 2016; de Leeuw et al. 2020). In LAMICs, individuals with disorders of intellectual development are more likely to seek clinical attention compared with individuals with autism alone, possibly due to limited access to healthcare services, a lack of awareness and understanding of autism, cultural stigmas and the prioritisation of individuals with more severe disabilities (Doherty et al. 2020; Babatunde et al. 2021; Divan et al. 2021). Consequently, a higher proportion of individuals with disorders of

intellectual development may be identified and seek services in LAMICs compared with those with higher functioning autism. It is important to recognise that these generalisations do not apply to every individual in high-income countries or LAMICs, as there is a wide range of variability within and between countries.

The findings suggest that the ICD-11 CDDR and BIs are considered clinically useful by clinicians using them to diagnose individuals with disorders of intellectual development, with or without co-occurring autism (Table 14). However, clinicians found that individuals with disorders of intellectual development and co-occurring autism require additional time and consideration when implementing the guidelines, likely reflecting complexities arising from symptom overlap, diagnostic overshadowing and ambiguous symptom presentation described in previous research (Rosen et al. 2018). Despite the extra time required to apply the guidelines for individuals with disorders of intellectual development and co-occurring autism compared with those without, the clinical usefulness of the CDDR and BIs remained similar for both groups compared with usual practice. Overall, the ICD-11 CDDR and BIs were found to be clinically useful, with excellent inter-rater reliability and good to excellent concurrent validity (Lemay et al. 2022).

The PCA results suggested that clinicians are applying the ICD-11 requirements as intended by combining the four levels of severity for intellectual and adaptive behaviours into a single rating (i.e. one-factor model; Tassé et al. 2019). This model, therefore, supports the feasibility and validity of the ICD-11 requirements and the BIs for integrating four severity levels to establish a comprehensive overall rating for disorders of intellectual development.

Limitations and future directions

This study has some limitations. First, the sample of participants was relatively small and may not be representative. Second, recruitment of individuals with disorders of intellectual development with co-occurring autism was not included as a purpose for data collection procedures in the original study (Lemay et al. 2022). Findings from our study would benefit from replication with larger samples and greater diversity, including comparisons with other co-occurring mental, behavioural and neurodevelopmental disorders, across sites and countries to improve generalisability and global applicability of the ICD-11 CDDR and BIs for disorders of intellectual development.

Third, most participants presented with mild to moderate severity levels for disorders of intellectual development. These findings emphasise the need to include a more even distribution of individuals presenting with the full spectrum of severity levels in intellectual functioning and adaptive behaviours in future studies. Current standardised measures for intellectual functioning, such as the Leiter-3, categorise individuals into different levels of intellectual disability (ID), including mild, moderate and severe, but exclude those with profound ID (Roid et al. 2013). In contrast, the BIs incorporate a broader range of severity levels by including profound severity. This exclusion criterion may result in grouping individuals with distinct challenges and severity levels. Further research is needed to investigate the impact of including severe and profound severity levels in diagnostic practices using BIs. Such research can provide insight into how different severity levels in intellectual functioning and adaptive behaviours relate to overall functioning, quality of life and intervention needs.

Fourth, relying solely on the CARS as the primary measure for diagnosing autism has inherent limitations. Despite its widespread use in clinical and research settings, the CARS has

faced criticism for lacking cross-cultural validation compared with more contemporary diagnostic measures, such as the Autism Diagnostic Observation Schedule (ADOS; Lord et al. 2001; Stevanovic et al. 2021). Utilising the CARS as the sole diagnostic measure may fail to capture the breadth and complexity of autism symptoms, potentially leading to inaccurate or missed diagnoses. However, practical challenges, such as cost, limited access to specialised centres, language barriers and cultural considerations, may hinder the widespread use of rigorous diagnostic tools like the ADOS in international settings (Pontrelli Mecca et al. 2022). LAMICs may face additional challenges, including limited resources and a shortage of trained professionals, making the consistent adoption and use of stringent diagnostic measures such as the ADOS not feasible. These challenges highlight the importance of considering limitations when interpreting results, prompting future research to explore ways to address these issues and develop more accessible and culturally appropriate diagnostic tools for autism in diverse international settings, particularly those with limited resources.

The ICD-11 CDDR provides a standardised framework for the diagnosis and classification of disorders of intellectual development that helps ensure reliability in clinical practice and research. Proper training is crucial to ensure clinicians understand and apply the requirements of the ICD-11 CDDR faithfully. Without appropriate training, clinicians may misinterpret or incorrectly apply these criteria, leading to inaccurate diagnoses and potentially inappropriate treatment plans (Merten et al. 2017). It also facilitates research efforts, as consistent application of the guidelines allows for accurate comparison of data across different settings and facilitates the identification of patterns and trends in prevalence globally.

Conclusions

Overall, the goal of the present study was to assess whether severity profiles inferred by field trial data reflected accurate application of the BIs as intended by its developers. By examining clinician diagnostic patterns and severity-level assignments, we aimed to gain a deeper understanding of the implementation characteristics of the ICD-11 CDDR for individuals with co-occurring diagnoses. Findings demonstrate that individuals with co-occurring autism have higher severity ratings compared with those without autism. The study also finds that the ICD-11 CDDR and BIs are considered clinically useful in diagnosing these disorders, although diagnosing individuals with co-occurring autism may take more time. The results support the ICD-11 guidance for combining severity levels into an overall rating and provide empirical evidence for the model's utility in assessing intellectual functioning and adaptive behaviours. The findings support the use of clinical judgement when determining the level of severity. Overall, the results of this study indicate that the ICD-11 CDDR and associated BIs are a reliable and valid measure for assessing severity levels in disorders of intellectual development with or without co-occurring disorders, such as autism. This study contributes to our understanding of the assessment, diagnosis and intervention strategies for individuals with IDs, particularly in the presence of co-occurring autism.

Author Contributions

K.R.L. designed and implemented the study, conducted the analyses and interpretation of the data and drafted the manuscript. C.S.K. received funding, supervised the project, contributed to the conception and design of the study and interpretation of the data, and contributed to all steps of the manuscript writing. G.M.R contributed to the conception and design of the study, interpretation of the data, and revised the manuscript critically for important intellectual content.

T.R. and J.W.K. contributed to the implementation of the study, interpretation of the data, and revised the manuscript critically for important intellectual content. R.B., S.B., S.C., P.G., M.T.K., J.V.S.K., M.R., A.R. and P.S. contributed to the acquisition and interpretation of the data and revised the manuscript critically for important intellectual content. All authors provided final approval of the manuscript and agreed to be accountable for all aspects of the work.

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Conflict of Interest

The authors certify that they have no affiliations with or involvement in any organisation or entity with any financial or non-financial interest in the subject matter or materials discussed in this manuscript. Unless specifically stated, the views expressed in this paper are those of the authors and do not represent the official policies or positions of the WHO.

Data Availability Statement

Research data are not shared.

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Table S1

Clinician demographics by site

Variable	Total (*N*=51; %)	Italy (Oasi IRCCS; *N*=5; %)	Sri Lanka (Teaching Hospital Peradeniya; *N*=5; %)	India (AIIMS; *N*=18; %)	India (NIMHANS; *N*=23; %)
Age, years (Mean±SD)	35.2 ± 8.7	47.8 ± 10.5	44.4 ± 13.1	28.9 ± 2.6	35.4 ± 5.4
Gender, *N* (%)					
Men	26 (51.0)	0	0	13 (72.2)	13 (56.5)
Women	25 (49.0)	5 (100)	5 (100)	5 (27.8)	10 (38.5)
English proficiency, *N* (%)					
Low	1 (2.0)	0	0	0	1 (4.3)
Intermediate	8 (15.7)	5 (100)	0	0	3 (13.0)
Advanced	16 (31.4)	0	4 (80.0)	8 (44.4)	4 (17.4)
Completely Fluent	26 (51.0)	0	1 (20.0)	10 (55.6)	15 (65.2)
Clinical Profession, *N* (%)					
Psychiatry	39 (76.5)	0	3 (60.0)	16 (88.9)	20 (87.0)
Psychology	9 (17.6)	5 (100)	0	2 (11.1)	2 (8.7)
Other	3 (5.9)	0	2 (40.0)	0	1 (4.3)
Years of experience, (Mean±SD)	6.6 ± 7.7	22.2 ± 11.1	9.0 ± 8.4	1.9 ± 1.3	6.4 ± 4.8

Table S2

Clinical utility questions and response options

Clinical utility variables	Response options
Extent to which the diagnostic requirements were clear and understandable overall as applied to this patient	Not at all clear and understandable Somewhat clear and understandable Quite clear and understandable Extremely clear and understandable
Level of detail and specificity of the diagnostic requirements/BIs for the diagnosis/diagnoses applied to this patient	Insufficient detail and specificity About the right amount of detail and specificity Too much detail and specificity

Extent to which the ICD-11 CDDR imposed requirements that were difficult to assess/apply to this patient	Very difficult to apply Somewhat difficult to apply Quite easy to apply Extremely easy to apply
Amount of time needed to apply all of the diagnostic requirements/BIs to this patient compared to usual clinical practice	Much longer than my usual clinical practice Somewhat longer than my usual clinical practice About the same as my usual clinical practice Shorter than my usual clinical practice
How useful would the diagnostic requirements be in helping to select a treatment for this patient?	Not at all useful Somewhat useful Quite useful Extremely useful
How useful would the diagnostic requirements be in helping you to assess this patient's prognosis	Not at all useful Somewhat useful Quite useful Extremely useful
Communication with other health care professionals	Not at all useful Somewhat useful Quite useful Extremely useful
Educating patients/family about condition	Not at all useful Somewhat useful Quite useful Extremely useful

Chapter 4. General Discussion

The World Health Organization (WHO) included behavioral indicators (BIs) for disorders of intellectual development in the Clinical Descriptions and Diagnostic Requirements (CDDR) section of the International Classification of Diseases 11th revision (ICD-11) for Mental, Behavioral, and Neurodevelopmental Disorders (WHO, 2024). This revision process aimed to enhance global applicability, scientific validity, and clinical utility of the classification system (First et al., 2018; Gaebel, Stricker, & Kerst, 2020; Gaebel, Zielasek, & Reed, 2017; Keeley et al., 2016; Reed et al., 2019). The introduction of the BIs represents a concerted effort to enhance the clinical utility and practical application for this section of the ICD-11 by providing support for determining severity levels for disorders of intellectual development (Tassé et al., 2019). The BIs are designed to be used in conjunction with standardised measures; however, there is a lack of linguistically appropriate assessment measures that are normed, standardised, psychometrically validated, and accessible or feasible for use in low and middle-income countries (LAMICs; Kishore, Udipi, Seshadri, 2019; Robertson et al., 2012). Additionally, there is a need for specialised services particularly in high-income countries, such as Canada (Robertson, et al., 2012; Whittle et al., 2018; Whittle, et al., 2019). The main objective of the research presented in this thesis, therefore, was to conduct an international field study in diverse cultural and linguistic settings to assess the BIs. More specifically, the aims of these studies are to: (1) investigate the reliability (i.e., inter-rater), validity (i.e., concurrent), and clinical utility ratings of the BIs for disorders of intellectual development, and (2) explore the implementation characteristics and clinical utility ratings of the BIs for disorders of intellectual development when considering co-occurring autism to ensure the BIs and ICD-11 CDDR are functioning and being used as intended. These objectives reflect a comprehensive approach to

understanding and improving diagnostic assessment outcomes and help inform interventions and support services in the context of disorders of intellectual development and related conditions.

In this thesis, we acknowledge the influence of language on the communities we examine, particularly in relation to intellectual disability and autism. The medical model typically views disability as an intrinsic problem within an individual, attributing their challenges to their impairments and often leading to an excessive focus on the need for rehabilitation (Goering, 2015; McKenzie, 2013). Conversely, the social model of disability frames disability as the result of societal barriers that prevent individuals with physical impairments from fully participating in social life (Oliver, 2018). While we use terms like "deficits," "disorder," and "symptoms" for clarity and consistency, it is important to recognize that these terms can reflect a medical perspective that reinforces ableist ideologies—beliefs that marginalize those with disabilities (Bottema-Beutel et al., 2021). Such terminology may fail to accurately represent the lived experiences of individuals with intellectual and developmental disabilities, potentially appearing alienating and derogatory by focusing on pathology rather than the social and contextual factors that influence their lives. Therefore, while we follow the terminology set forth by the ICD-11 CDDR for accurate diagnostic purposes, we recognize the importance of a more person-centered approach that honors the dignity and individuality of those affected.

Both studies in this thesis assess clinical utility and provide insights into how the CDDR including BIs are utilised in clinical practice. The first study suggests that the BIs have excellent inter-rater reliability, good to excellent concurrent validity, and good clinical utility (i.e., quick, easy to use, and applicable) for assessing severity levels for disorders of intellectual development. It was also demonstrated that there is greater diagnostic overlap (i.e., higher correlation of scores) between intellectual functioning and adaptive behaviours using the BIs,

which utilise the same method for assessing severity levels with both constructs, compared to standardised measures that evaluate these constructs separately. The second study focused on implementation characteristics and demonstrated that assessments using the BIs classified a higher proportion of individuals with mild severity levels compared to standardised measures and indicated that individuals with co-occurring autism tended to have more severe severity levels across areas of functioning compared to those with disorders of intellectual development alone. Clinical utility of the BIs for co-occurring disorders of intellectual development and autism were found to be comparable when used to diagnose disorders of intellectual development alone, although there is a need for additional time and consideration assessing individuals with co-occurring conditions. In contrast to the previous classification system (i.e., ICD-10), which lacked methodology for determining severity, the ICD-11 provides a structured approach to assess severity levels for disorders of intellectual development, particularly in situations where standardised measures cannot be utilised as recommended in the CDDR. The findings demonstrate the importance of reliable, valid, and clinically useful assessment measures in clinical practice and highlight the potential of the ICD-11 BIs to improve diagnostic accuracy and help inform intervention and support needs for this population when implemented on a global scale.

Importance of Findings

The development and dissemination of a clinical support tool (i.e., BIs) that is valid, reliable, clinically useful, and widely available for characterizing severity levels for intellectual functioning and adaptive behaviours when diagnosing disorders of intellectual development can be useful for teaching, training, research, and clinical practice. Assessing the psychometric properties and global applicability of the BIs provides preliminary evidence for the success of the

WHO in meeting their aims of: (1) providing WHO Member States with improved measures to help reduce the disease burden of mental, behavioural and neurodevelopmental disorders, and (2) to provide health professionals with improved measures for identifying people in need of mental health services and help establish which treatments are most likely to be effective, at the point at which they are most likely to encounter opportunities for care (Reed, 2010; Stein et al., 2020).

The purpose of developing and implementing the BIs was to provide ICD-11 users with a tool to accurately identify severity levels and prioritize individuals with disorders of intellectual development who may require diagnostic assessment (Tassé, 2021). Individuals with disorders of intellectual development often encounter significant barriers to accessing timely and accurate diagnostic services, such as a lack of specialized care providers, communication and language barriers, and inadequate support systems (Breuer, Pelle, Leusink, Linehan, & Naaldenberg, 2024). These barriers frequently result in delayed or inaccurate diagnoses, which may make the identification of appropriate needs more difficult leading to suboptimal outcomes (Breuer et al., 2024). Misdiagnosis and under-recognition of disorders of intellectual development can complicate care, since service providers may lack the necessary training or awareness to accurately identify these conditions (Carulla et al., 2011). This lack of knowledge or familiarity with objective behavioural indicators of disorders of intellectual development can lead to incorrect determination of level of severity, further hindering access to appropriate care, understanding needs, and guiding further steps (Carulla et al., 2011).

Costs associated with specialized diagnostic assessments should not be viewed as a burden on families or society, but rather as an essential investment in identifying needs early and aligning individuals with appropriate services. Inadequate or delayed diagnosis means that individuals are less likely to receive appropriate support early on, leading to more complex and

costly services in the future. The long-term financial and societal costs associated with the absence of early and accurate assessments are far greater, as individuals may experience worsening outcomes, leading to increased dependency and higher future costs (Bottema-Beutel et al., 2021; Carulla et al., 2011; Kumar & Lal, 2024). Therefore, the priority should be on improving access to timely and accurate diagnostic assessments, since these are key to ensuring that individuals' needs are correctly identified and addressed at an early stage. The individuals most affected by these systemic failures are those with disorders of intellectual development and autism themselves, rather than society or taxpayers at large (Bottema-Beutel et al., 2021). Additionally, the limited availability of diagnostic services, particularly in LAMICs and underserved populations, exacerbates challenges in accurately identifying individuals' needs and aligning them with the resources they require (Kishore, Udipi, Seshadri, 2019; Robertson et al., 2012). The CDDR and BIs aim to address the critical need for accurate assessment by providing a cost-effective, clinically useful, and globally applicable tool for evaluating the severity of disorders. By ensuring accurate identification of severity levels, the BIs help ensure that individuals are aligned with the appropriate diagnostic pathways, leading to more tailored and appropriate resources. The availability of the BIs as a free clinical support tool, which considers heterogeneity, language, and cultural factors, has the potential to improve accessibility for accurate assessment and better characterization of individuals' needs.

Assessment of Severity Levels for Disorders of Intellectual Development

Numerous studies strongly support the implementation of a multidimensional classification system for disorders of intellectual development, emphasising the need to move beyond solely relying on IQ-based assessments to characterise the disorder (e.g., Harris & Greenspace, 2016). The American Association on Intellectual and Developmental Disabilities

(AAIDD) highlights the inadequacy of IQ ranges as the sole determinant of cognitive functioning or clinical severity level (Schalock, Luckasson, & Tassé, 2021). The Working Group proposes that clinical severity levels for disorders of intellectual development should consider various clinical descriptors, with IQ scores being just one of several crucial factors. The inclusion of multiple clinical descriptors, such as BIs for intellectual functioning and adaptive behaviours, aid in predicting outcomes, allocating resources, and facilitating communication among professionals, families, and individuals seeking services. The ICD-11 CDDR and BIs are intended to support service providers in identifying and prioritizing the appropriate services and benefits for individuals with disorders of intellectual development. Although the BIs were developed as part of this effort, they are not yet widely implemented or used on a large scale, as countries are still in the midst of implementing ICD-11 worldwide (Carulla et al., 2011; Lemay et al., 2022).

Accurately determining severity levels for disorders of intellectual development supports service providers in informing assessment and treatment planning. This severity assessment provides basic information that can guide further evaluations and inform effective resource allocation, especially in settings with limited resources. Establishing severity levels also fosters effective communication among healthcare professionals, educators, caregivers, and individuals with disorders of intellectual development, facilitating collaboration in multidisciplinary care teams (Adams et al., 2021). Furthermore, assessing severity assists in predicting prognosis, monitoring progress, and adjusting interventions as needed, while also influencing legal and policy decisions regarding service eligibility and access to benefits (Fletcher, Lyon, Fuchs, & Barnes, 2018). Understanding the severity of disorders of intellectual development contributes to enhancing the quality of life for individuals with disorders of intellectual development by

guiding personalised care planning and ensuring tailored support that addresses their unique needs (Schalock, Bonham, & Verdugo, 2008).

The observation that individuals with co-occurring autism tend to exhibit greater severity in intellectual functioning and adaptive behaviours compared to those with disorders of intellectual development alone (at least in the current sample) sheds light on the complex nature of these co-occurring disorders. Clinicians and researchers should consider the unique challenges and complexities that arise when addressing the needs of individuals with both disorders of intellectual development and autism. The combination of social communication challenges and repetitive/restricted behaviors seen in individuals with both disorders of intellectual development and autism leads to even greater limitations in daily functioning compared to those with disorders of intellectual development alone (Thurm, Farmer, Salzman, Lord, & Bishop, 2019). Previous research has demonstrated that poor emotion regulation is linked to self-injury, while difficulties in social communication are associated with stereotyped behaviours (Martinez-González, Cervin, & Piqueras, 2022). Findings have also demonstrated the tendency for increased severity levels to be associated with challenges in emotion recognition, as well as in the social-perceptual domain and in everyday social functioning, for individuals with disorders of intellectual development and co-occurring autism (Tamas, Brkic Jovanovic, Stojkov, Cvijanović, & Meinhardt–Injac, 2024). Thus, while restricted and repetitive behaviors may act as coping mechanisms and aid in emotion regulation, their effects on daily activities should be considered within the context of the emotional and social challenges faced by these individuals. Additionally, previous studies indicate that adaptive behaviours are notably lower than expected based on intellectual functioning in individuals with autism (Alvares et al., 2020; Chandler et al., 2022; Tamm, Day, & Duncan, 2022). On the other hand, individuals with autism are often

classified as “low-” or “high-functioning” based on cognitive test scores, but recent research suggests this approach overlooks important differences in their abilities and support needs (Furnier et al., 2024). In this regard, adaptive behaviour scores reveal significant variation in functioning among children with autism that is not captured by cognitive ability or autism symptom severity alone, highlighting the value of using adaptive behavior assessments to better understand and address their needs (Furnier et al., 2024). Understanding the increased complexity of intellectual and adaptive functioning for individuals with co-occurring autism and disorders of intellectual development highlights the multifaceted nature of these co-occurring conditions. Recognizing this complexity can support more accurate diagnostic assessments and help identify areas where further evaluation may be beneficial.

The CDDR explicitly directs clinicians to reduce the emphasis placed on the social skills domain when evaluating the severity of disorders of intellectual development in individuals with co-occurring autism, recognising that social functioning deficits are a fundamental aspect of autism (Ayuso-Mateos & Kogan, 2020). However, findings from Study 2 call into question the degree to which clinicians followed this recommendation (Lemay et al., 2024). Individuals with co-occurring autism were rated with significantly higher severity across all domains of functioning, including social functioning, compared to those with disorders of intellectual development alone. The uniformity in severity ratings across different domains when applying the CDDR and BIs further complicates the evaluation of adherence to these guidelines. For example, many individuals classified with severe disorders of intellectual development were also rated as having severe impairments in intellectual functioning and adaptive behaviors (i.e., conceptual, social, and practical). As a result, the decision to place less weight on social functioning may not have significantly influenced the overall severity classification due to the

uniformity of severity ratings across domains. Furthermore, the study's reliance on quantitative data restricts our understanding of the clinicians' thought processes, as we lack qualitative insights into how they incorporated the CDDR guidance into their assessments. Therefore, while it seems that clinicians may have implemented the guidelines in practice, further exploration of their clinical judgment and reasoning is necessary to ensure that the CDDR recommendations are effectively applied in future evaluations.

Clinical Utility of the Behavioural Indicators

Evaluating the clinical utility of the BIs for disorders of intellectual development is essential to determine their likelihood of regular use by clinicians. Clinical utility ensures that the BIs are practical, efficient, and beneficial for everyday clinical practice, which is critical to adoption by service providers. Additionally, widespread use of such tools in clinical encounters contributes to aggregated data that can inform health policy decisions at various levels (Reed, 2010). Health classifications act as the bridge between health encounters and health information. If a classification system is overly complex and fails to offer clinically relevant information, it may not be effectively utilised, impacting the quality of data for health policy and decision-making (Reed, 2010). Enhancing clinical utility was a key objective in developing the ICD-11 CDDR to enhance mental health data and ultimately decrease the burden of mental health disorders. This thesis has provided evidence supporting the achievement of these objectives for disorders of intellectual development through the implementation of the new BIs in international settings. The BIs were deemed to have adequate interpretability, ease of application, usefulness for intervention selection, prognosis assessments, client communication, and client education efforts.

The decision to provide specific guidelines that allow for increased flexibility and require clinical judgement is valuable because traditional diagnostic systems (e.g., ICD-10 and DSM-5) are commonly used but not always consistently or comprehensively applied (First et al., 2018). While many professionals consider diagnostic classification systems important for communication and treatment planning, some do not adhere to their recommended use, leading to the prevalence of unofficial diagnostic labels tailored to individual patients (First et al., 2018). Most clinicians determined the CDDR and BIs to be clear, appropriately detailed, easy to implement, and valuable for both intervention selection and prognosis assessments (Lemay et al., 2022). Although the ICD-11 CDDR and BIs were deemed valid, reliable, and clinically useful across settings, a small percentage of respondents noted challenges, including excessive detail and difficulty in applying the tools in certain contexts. These findings support the need for ongoing education and training to ensure that the BIs are consistently and accurately utilized, while also addressing potential barriers to their effective implementation. This balance of feedback highlights the overall utility of the CDDR and BIs, while recognizing areas for refinement to enhance their applicability in diverse settings.

Implementation strategies and considerations for clinical practice change

The successful integration of evidence-based innovations in supporting disorders of intellectual development and autism necessitates a comprehensive, strategic approach that aligns effective practices within healthcare systems and diagnostic practices (Grol, Wensing, Eccles, & Davis, 2013). Effective implementation requires systematic incorporation of meaningful changes that address the specific needs of patients and their caregivers (May et al., 2007). To effectively overcome the multifaceted challenges associated with implementing interventions in this

specialized field, it is imperative to deliver care that is efficient, safe, timely, and, most importantly, patient-centered (Grol & Wensing, 2020).

Service providers can enhance both service delivery and clinical outcomes by employing a diverse array of implementation strategies. These include management, motivation, social interaction, capability reinforcement, and control (Grol & Wensing, 2020). From a management perspective, establishing flexible and clear guidelines is essential (First et al., 2018; Grol & Wensing, 2020; Reed, 2010). This aligns with the clinical utility findings related to the CDDR and BIs as outlined in the studies of this thesis. The CDDR and BIs should not only support clinical judgment but also cultivate an environment conducive to change. This is particularly important when addressing complex conditions such as disorders of intellectual development and autism, which often require personalized approaches and needs (Schalock, Bonham, & Verdugo, 2008).

To address educational and training needs, motivational strategies could be employed through practical workshops aimed at improving engagement with the CDDR and BIs (Grol & Wensing, 2020). Moreover, interdisciplinary collaboration is integral to effective care, strengthened through role-playing exercises that foster social interaction and teamwork (Schmidt, Porter, Rivera-Amill, & Appleyard, 2023). By providing opportunities for clinicians to interact, we can build a community that promotes shared responsibility, which is crucial for navigating the complexities of care for individuals with disorders of intellectual development and autism (Schmidt et al., 2023).

Utilizing various theoretical frameworks—such as cognitive, educational, motivational, social learning, organizational change, and complexity theories—establishes a solid basis for addressing the challenges of implementing a new clinical support tool (i.e., BIs) for disorders of

intellectual development (Grol, Wensing, Bosch, Hulscher, & Eccles, 2013). The participation approach encourages clinicians to engage actively in refining and adapting guidelines. This collaborative effort facilitates gradual implementation, leading to stronger communication and understanding among all stakeholders, including patients and their families (Grol et al., 2013).

The process of effective change implementation in healthcare is inherently systematic and involves distinct stages: formulating comprehensive proposals, assessing current performance levels, analyzing the characteristics of the target population and care settings, and developing tailored strategies to facilitate the desired changes (Grol & Wensing, 2013). Continuous evaluation and the integration of improvements into routine practices by understanding the barriers and facilitators that influence this change process are crucial for sustainable implementation (Grol & Wensing, 2013). Relevant stakeholders' commitment and active involvement in developing and refining implementation strategies are fundamental to ownership, which in turn boosts the likelihood of successful adoption of new practices that enhance patient outcomes and align with evidence-based care (Grol & Wensing, 2013). Embedding an effective clinical support tool—such as BIs—within the CDDR for disorders of intellectual development in clinical practice calls for a thoughtfully coordinated implementation strategy that prioritizes education, collaboration, and adaptability to deliver high-quality supportive care. Equipping clinicians with tools and strategies to effectively communicate the purpose and outcomes of diagnostic assessments (e.g., using the BIs to explain severity levels and areas assessed) ensures that patients and families gain a clear understanding of the diagnostic process and its implications for identifying needs and next steps (Al-Worafi, Ming, & Alseragi, 2024).

Early and Accurate Assessments Informing Intervention and Support Implications

The challenges in accessing specialised diagnostic services, particularly in LAMICs and among racial and cultural minority groups, highlight the disparities in healthcare provision globally (Rothe & Gogineni, 2022; Saran, White, & Kuper, 2020). The requirement for costly specialised training and services to administer existing standardised assessment measures often renders them inaccessible in many contexts, exacerbating the barriers to accurate diagnosis and appropriate interventions (Kishore, Udipi, Seshadri, 2019; Robertson et al., 2012). These challenges are compounded by various factors such as limited availability, utilisation, relevance, effectiveness, and equity in diagnostic services worldwide (Whittle, Fisher, Reppermund, & Trollor, 2019; Whittle, Fisher, Reppermund, Lenroot, & Trollor, 2018). Linguistic minorities may face additional hurdles in accessing culturally and linguistically appropriate diagnostic measures, leading to potential disparities in diagnosis and contributing to prejudice within these communities (Beauchamp et al., 2022; Magaña & Vanegas, 2021; Papoudi, Jørgensen, Guldberg, & Meadan, 2021). The use of a clinical support tool that is valid, reliable, clinically useful, culturally sensitive, linguistically appropriate, and cost-effective (i.e., the BIs) may reduce these disparities and ensure equitable access to diagnostic services for individuals with disorders of intellectual development with or without co-occurring disorders, regardless of their background or location. Currently, clinicians often rely on *ad hoc* methods to determine severity levels for disorders of intellectual development which could be inconsistent across different settings, leading to variability in diagnostic practices (Siegel et al., 2020). The findings from Study 1 and Study 2 of this thesis suggest that the BIs can be implemented as a standardised alternative support tool, which will be translated into many languages, to promote consistency and reliability in assessments when standardised assessment measures are not available or feasible.

The research outcomes from this thesis have the potential to empower healthcare professionals in underserved regions to implement evidence-based assessment strategies, reduce disparities in access to care, and promote equitable intervention and support outcomes for vulnerable populations. This approach can also facilitate early identification of developmental challenges, leading to timely interventions and support services that can enhance outcomes and quality of life for individuals in underserved populations.

Although beyond the scope of this thesis, accurate identification of severity levels of support needs can help inform intervention targets. A recent scoping review examining mental health services and intervention for individuals with mild disorders of intellectual development emphasised the importance of tailored and well-coordinated services, coherent service models, and explicit integration of disorders of intellectual development in mental health policy (Walton, Medhurst, Madhavan, & Shankar, 2022). Difficulties regarding delays in service access were more prominent for those with co-occurring disorders and ambiguity regarding the symptoms and severity levels for disorders or intellectual development and the coordination of mental health services (Walton et al., 2022). The ICD-11 CDDR and associated BIs may deliver cost-effective and evidence-based guidelines that can be used to facilitate training, awareness, and inclusivity to ensure prompt access to services and offer more suitable intervention and support needs by fully capturing BIs for intellectual functioning and adaptive behaviours for individuals with disorders of intellectual development.

Early recognition and appropriate support systems are necessary in empowering individuals with disorders of intellectual development to lead healthy and productive lives. Identifying disorders of intellectual development during developmental years, from childhood through adolescence, enables timely interventions and support services that positively influence

the individual's development and overall well-being (WHO, 2021). Tailoring intervention based on severity levels of support needs, the identified underlying cause, if any, and the presence of co-occurring disorders, optimises functioning and fosters independent living (Patel, Apple, Kanungo, & Akkal, 2018). Individuals with disorders of intellectual development with severe support needs often require lifelong intensive supports, including access to medical care, educational interventions, community-based support, and suitable accommodations for enhanced well-being (Patel, Apple, Kanungo, & Akkal, 2018).

The CDDR and BIs can significantly enhance the diagnostic process for individuals with disorders of intellectual development by establishing a valid, reliable, and clinically useful support tool for assessments of intellectual functioning and adaptive behaviours across diverse clinical settings, ensuring that individuals are evaluated consistently regardless of their geographical, language, or cultural context (Cooper & Kogan, 2023; Kogan & Paterniti, 2017). The implementation of the BIs and CDDR among healthcare providers can minimize disparities in access to diagnosis, particularly in LAMICs and underserved regions where resources may be limited (Carulla, 2011; Kishore, Udipi, Seshadri, 2019; Robertson et al., 2012). By incorporating BIs into the assessment process, clinicians may gain a more comprehensive understanding of an individual's functional abilities, behavioural characteristics, and support needs, particularly when used in conjunction with current standardized measures of intellectual functioning and adaptive behaviours (Tassé et al., 2019). This comprehensive approach can significantly improve severity level assessments by evaluating the characteristics, features, and behaviors of individuals with disorders of intellectual development. By offering deeper insights to the heterogeneity observed among individuals with disorders of intellectual development, the BIs and CDDR can provide further context that could be used to tailor interventions and support services, ensuring they

effectively address the distinct needs of each individual (Doody, Hennessy, Moloney, Lyons, & Bright, 2023). Ultimately, the use of BIs can lead to more equitable access to diagnosis and appropriate resources, fostering better outcomes for individuals with disorders of intellectual development and their families. While the CDDR and BIs may not singularly transform lives, their combined role in promoting equitable access to diagnosis and subsequent interventions can foster a more inclusive environment for individuals with disorders of intellectual development across diverse healthcare settings globally.

Canadian Relevance and Global Applicability

Ensuring that the BIs consider multicultural, diverse, and multilingual implications within Canada is important due to the country's commitment to preserving and enhancing its multicultural heritage, as enshrined in Section 27 of the Canadian Charter of Rights and Freedoms. With 23.0% of Canadians being foreign-born and over 450 ethnic or cultural origins reported, Canada's inclusive and progressive immigration policies have fostered a rich tapestry of cultural diversity (Statistics Canada, 2022a,b). Moreover, the presence of over 200 home-spoken languages emphasises the need for culturally sensitive and multilingual approaches in healthcare settings (Statistics Canada, 2022c). As the first country to adopt an official multiculturalism policy in 1971 to promote equality and cultural diversity, Canada places a strong emphasis on respecting and celebrating different cultural backgrounds (Canada, 1971). Therefore, incorporating multicultural considerations into the BIs is essential to ensure that assessments are culturally relevant, inclusive, and respectful of the diverse population in Canada, ultimately promoting equitable healthcare access and outcomes for all individuals.

The importance of incorporating multicultural, diverse, and multilingual considerations in BIs extends beyond Canada to the global context due to the significant influence of cultural

factors on mental health disorders (Gopalkrishnan, 2018). Diverse cultural perspectives shape the experience and intervention of these disorders, highlighting the necessity for a standardised approach that integrates cultural information into diagnostic and intervention procedures (Anderson et al., 2003). The methodology established in this thesis involved training sessions for the implementation of the CDDR and BIs across three countries: India, Sri Lanka, and Italy. Training sessions did not include structured guidelines for incorporating cultural considerations into clinical interviews beyond what is included in the CDDR and BIs. Additionally, at the time of the study, the CDDR did not yet feature the Cultural Presentations section, which has since been integrated into the published ICD-11 CDDR. Results from both studies demonstrated no significant differences in patient characteristics or inherent characteristics of the CDDR and BIs (i.e., validity, reliability, and clinical utility) across sites, even where local translation of materials was necessary. These findings suggest that the CDDR and BIs possess global applicability, possibly transcending language and/or cultural barriers (Gureje, Lewis-Fernandez, Hall, & Reed, 2019, 2020). This comprehensive framework aspires to enhance global mental health care by promoting equitable access and improved outcomes for individuals from diverse cultural backgrounds.

The integration of Canadian and global standards in health data and statistics is essential for establishing a universal classification system that provides a standardised framework for global consistency and comparability (Patel et al., 2023). Methodological rigor that supports harmonising data through a common language and structure for classification allows healthcare systems to aggregate and compare data while minimising the loss of information at the clinical encounter level (Cheng et al., 2024; Patel et al., 2023). For instance, the clinicians involved in this thesis independently provided their diagnostic conceptualisations and assessments of clinical

utility via a web-based platform, obtaining similar results across sites. These findings reinforce the importance of establishing clear standards obtaining and sharing data to enhance diagnostic accuracy and consistency. The adoption of these global standards could lead to improved diagnostic accuracy by incorporating updated scientific evidence, knowledge, and international clinical consensus (Patel et al., 2023). Standardised practices also support global research efforts and advocacy initiatives in mental health, underscoring the necessity for a collaborative and comprehensive approach to healthcare data management and analysis (WHO, 2022). Connecting study results to the broader context of health data standards highlights the interplay between robust data practices and improved health outcomes on an international scale.

The research findings from this thesis may facilitate training and global implementation of the ICD-11 CDDR and associated BIs. The cross-cultural collaboration fostered by the research can facilitate knowledge exchange and the adoption of best practices, further enhancing the implementation of the BIs on a global scale. Additionally, the integration of the BIs into policy frameworks and continuing education programs will ensure sustained use and dissemination of updated practices. This concerted effort to enhance training and global implementation of the BIs may not only improve clinical outcomes but also advance research in the field by promoting standardised assessment practices, facilitating data sharing, and encouraging further studies to refine and validate these clinical support tools in diverse clinical populations.

The BIs also provide research implications by providing a structured and evidence-based approach to identifying and assessing cognitive, adaptive, and behavioral processes, particularly for individuals with disorders of intellectual development. The development and validation of the BIs involved collaboration with international experts, enhancing the credibility of the research

findings and ensuring more accurate classification of participants according to their severity levels (Tassé et al., 2019). By utilizing BIs, researchers can establish clear operational definitions for constructs like intellectual functioning and adaptive behaviours, allowing for more precise participant recruitment and assessment (e.g., see Ghaderi & Cobigo, 2024). The CDDR and BIs provide a framework for assessing intellectual and adaptive functioning across diverse populations and settings, enabling researchers to conduct comparative analyses and synthesize data effectively through meta-analyses (Katapodi & Northouse, 2011). The cultural sensitivity of the BIs also minimizes cultural loading, facilitating equitable research outcomes that account for environmental influences across different populations (Gureje, Lewis-Fernandez, Hall, & Reed, 2019, 2020). The structured approach of the BIs allows for the collection of qualitative data through interviews with reliable informants, complementing quantitative assessments for a holistic view of participants. Incorporating clinical judgment based on the BIs and CDDR into research may also enhance ecological validity by aligning research findings with real-world experiences. The CDDR and BIs may significantly augment the robustness and ecological validity of research designs by bridging developmentally informed and culturally sensitive theoretical constructs with practical applications, ensuring that findings are reflective of real-world complexities faced by participants.

Limitations and Future Directions

While the findings from this thesis make significant contributions to the field of clinical psychology through the evaluation of the ICD-11 BIs for disorders of intellectual development, it is important to acknowledge and address the limitations of the findings. Several next steps for further analyses will also be proposed to advance the understanding and application of the BIs in clinical practice.

First, replication studies with larger and more diverse samples across multiple sites and countries would enhance the generalisability and reliability of the findings. The inclusion of children and adolescents aged 5-18 years with suspected or established diagnoses of disorders of intellectual development from specific sites in Sri Lanka, Italy, and India may limit the generalisability of the results to broader populations of individuals with disorders of intellectual development. The homogeneity of the sample in terms of age range and geographic location may restrict the applicability of the findings to diverse cultural contexts and age groups. Moreover, the exclusion of individuals with disorders of intellectual development who do not fit the specified exclusion criteria may introduce selection bias and limit the representativeness of the study samples. Replication studies should consider including individuals with a wider range of age groups, cultural backgrounds, severity levels distributions, and clinical presentations to ensure the applicability of the behavioral indicators across diverse populations. Given resource constraints and goals for this thesis focusing on facilitating early and accurate diagnoses, future studies should aim to replicate findings by assessing the validity, reliability, clinical utility, and implementation characteristics of the BIs for intellectual functioning and adaptive behaviours for individuals with disorders of intellectual development in adult populations (i.e., 18+ years of age). Such studies can aim to validate the use of the ICD-11 BIs across the lifespan for individuals with disorders of intellectual development to improve diagnostic accuracy and help characterise individual needs when receiving a late/delayed diagnosis. Future studies could consider continuing to assess validity, reliability, clinical utility, and implementation of the BIs for disorders of intellectual development in diverse cultural contexts to ensure their cross-cultural applicability and relevance. Studies could also expand upon findings by further investigating potential cultural differences in the manifestation of specific characteristics, features, traits, and

behaviors associated with disorders of intellectual development and assess the impact of cultural factors on the assessment and diagnosis using the BIs for such disorders.

Second, future research should consider conducting a receiver operating characteristic (ROC) curve analysis and interpret area under the curve (AUC) values to assess the diagnostic accuracy of the BIs and compare results with performance on standardised measures. Assessing diagnostic accuracy is needed in situations where the BIs are used to communicate a diagnosis of disorders of intellectual development in situations where appropriate standardised measures are unavailable or unfeasible due to various constraints. Such a study could be designed by recruiting and assigning participants to two groups based on previous diagnostic status: those who have a confirmed previous diagnosis of disorders of intellectual development (cases) and those who do not meet criteria and do not have a previous diagnosis of disorders of intellectual development (controls). Similar diagnostic procedures outlined in this thesis can be used with both the BIs and standardised measures independently to determine participants' diagnostic status. Sensitivity, specificity, positive predictive value, and negative predictive value could be calculated based on the results using the BIs and standardised measures for cases and controls. The ROC curve would be generated to assess the diagnostic accuracy of the criteria by plotting sensitivity against 1-specificity for different threshold values of the diagnostic measures. The AUC would be calculated to determine the overall diagnostic accuracy of the diagnostic criteria. The AUC value would indicate how well the diagnostic criteria discriminate between cases and controls. The diagnostic performance of the BIs can then be directly compared to the standardised measures by analysing their ROC curves and calculating the AUC values. The higher the AUC values, the more accurate the diagnostic measure is in distinguishing between cases and controls. Such an analysis was not completed as part of this thesis since participants

recruited at each study site did not consistently have a previous diagnosis (e.g., some were new patients) that could be used as an appropriate criterion variable. Within the dataset of this thesis, only 20 out of 206 individuals had a previous diagnosis of disorders of intellectual development, which is not a large enough sample to conduct this analysis and make meaningful interpretations of the findings.

Third, there is a call to expand the scope of research to include comparisons with other co-occurring mental, behavioural, and neurodevelopmental disorders to assess the specificity and sensitivity of the BIs for disorders of intellectual development. Although this thesis focused the frequently co-occurring diagnosis of autism, individuals with disorders of intellectual development are also at a high risk for co-occurring mental health conditions such as major depressive disorder, bipolar disorder, anxiety disorders, psychotic illnesses, and impulse control disorders (Pinals, Hovermale, Mauch, & Anacker, 2022). Given the vast heterogeneity and diagnostic overlap with distinct features of disorders of intellectual development in relation to other co-occurring conditions, the BIs should continue to be assessed and ensure that they are able to accurately capture symptom presentations while providing useful information for differentiating between other co-occurring disorders to improve differential diagnosis and intervention planning.

Fourth, future research should consider conducting longitudinal studies to assess the predictive validity of the BIs for disorders of intellectual functioning in predicting long-term outcomes, intervention response, and functional abilities over time. Studies could explore the association between changes in BI severity ratings with improvements across intellectual functioning, adaptive behaviors, and overall functioning in individuals with disorders of intellectual development. Conducting longitudinal studies may help improve intervention

strategies and inform policy decisions when working with individuals diagnosed with disorders of intellectual development.

Finally, future studies should explore integration of the BIs with other standardised measures of intellectual functioning and adaptive behaviors to enhance the comprehensive assessment of individuals with disorders of intellectual development. These studies could aim to investigate the validity and clinical utility of combining different assessment measures used in various settings to improve diagnostic accuracy, intervention and support planning, and outcome evaluation for individuals with disorders of intellectual development. Continued evaluation of the BIs with other "gold-standard" assessment measures for intellectual functioning and adaptive behaviours will help ensure that the criteria assessed in the BIs are up-to-date and reflect current and accurate evaluations of severity for individuals with disorders of intellectual development.

General Conclusions

Evaluating the BIs within the ICD-11 CDDR provide significant contributions to clinical diagnostic practices for disorders of intellectual development. These international field studies demonstrate the reliability, validity, clinical utility, and implementation characteristics of the BIs in assessing disorders of intellectual development severity with or without co-occurring autism across diverse settings. The findings highlight the potential of the BIs to be used along standardised measures for assessing severity levels of individuals with disorders of intellectual development, especially in regions lacking specialised assessment measures. By establishing the global applicability of the BIs and their effectiveness in identifying deficits in intellectual functioning and adaptive behaviors, the research supports improved identification, intervention, and outcomes for individuals with disorders of intellectual development worldwide. The integration of these indicators within the ICD-11 CDDR addresses disparities in access to

reliable diagnostic measures, promoting equitable care and enhancing diagnostic practices. The emphasis on clinical utility underscores the potential of these indicators to facilitate early intervention and support planning, particularly in resource-limited settings. Overall, the thesis highlights the importance of widely available and feasible standardised assessment measures in advancing diagnostic practices, improving global access to care, reducing health disparities, and enhancing support for individuals with disorders of intellectual development. The research outcomes have significant implications for clinical practice, policy development, and future research efforts in enhancing the assessment and intervention of individuals with disorders of intellectual development on a global scale.

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APPENDIX A

Behavioural Indicators Table of Intellectual Functioning (Tassé et al., 2019)

SEVERITY LEVEL	Early Childhood *(Determination of severity should be reassessed after appropriate educational services and supports are provided)*	Childhood & Adolescence *(Determination of severity should be reassessed after appropriate educational services and supports are provided)*	Adulthood *(Determination of severity should be reassessed after appropriate educational services and supports are provided)*
MILD	By the end of this developmental period: • Most will develop language skills and be able to communicate needs. Delays in the acquisition of language skills are typical and once acquired are frequently less developed than typically-developing peers (e.g., more limited vocabulary). • Most can tell or identify their gender and age. • Most can attend to a simple cause-effect relationship. • Most can attend to and follow up to 2-step instructions. • Most can make one-to-one correspondence or match to sample (e.g., organise or match items according to shape, sise, colour).	During this developmental period, there is evidence of the emergence of or presence of the abilities listed below. • Most can communicate effectively. • Most can tell or identify their age. • Most can initiate/invite others to participate in an activity. • Most can communicate about past, present and future events. • Most can attend to and follow up to 3-step instructions. • Most can identify different denominations of money (e.g., coins) and count small amounts of money. • Most can cross street intersections safely (look in both directions, wait for traffic to clear before crossing, obey traffic signals). In contexts	• Most can communicate fluently. • Many can tell or identify their birth date. • Most can initiate/invite others to participate in an activity. • Most can communicate about past, present, and future events. • Most can attend to and follow up to 3-step instructions. • Most can identify different denominations of money (e.g., coins) and count money more or less accurately. • Most can orient self in the community and learn to travel to new places using different modes of transportation with instruction / training. • Some can learn the road laws and meet requirements to obtain a driver's license. Travel is mainly restricted to familiar environments.

	• Most can communicate their immediate future goals (e.g., desired activities for the day) • Most can express their likes and dislikes in relationships (e.g., who they prefer to spend time with), activities, food, and dress. *Literacy / Numeracy* • Most will develop emergent reading and writing skills. • Most will be able to recognise letters from their name and some can recognise their own name in print.	without busy intersections, most can follow socially acceptable rules necessary to ensure personal safety. • Most can communicate their future goals and participate in their health care. • Most can identify many of their relatives and their relationships. • Most can apply existing abilities in order to build skills for future semi-skilled employment (i.e., involving the performance of routine operations) and in some cases skilled employment (e.g., requiring some independent judgment and responsibility). • Most are naive in anticipating full consequences of actions or recognizing when someone is trying to exploit him/her. • Some can orient themselves in the community and travel to new places using familiar modes of transportation. *Literacy / Numeracy* • Most can read sentences with five common words. • Most can count and make simple additions and subtractions.	• Most can cross residential street intersections safely (look in both directions, wait for traffic to clear before crossing, obey traffic signals). In contexts without busy intersections, most can follow socially acceptable rules necessary to ensure personal safety. • Most can communicate their decisions about their future goals, health care, and relationships (e.g., who they prefer to spend time with). • Most can apply existing abilities in the context of semi-skilled employment (i.e., involving the performance of routine operations) and in some cases skilled employment (e.g., requiring some independent judgment and responsibility). • Most remain naive in anticipating full consequences of actions or recognizing when someone is trying to exploit him/her. • Most have difficulty in handling complex situations such as managing bank accounts and long-term money management. *Literacy / Numeracy*

			• Most can read and write up to approximately a level expected for someone who has attended 7 to 8 years of schooling (i.e., start of middle school), and read simple material for information and entertainment. • Most can count, understand mathematical concepts, and make simple mathematical calculations
MODERATE	• Most will develop language skills and be able to communicate needs. Delays in the acquisition of language skills are typical and once acquired are often less developed than typically-developing peers (e.g., more limited vocabulary). • Most can follow one-step directions. • Most can self-initiate activities and participate in parallel play. Some develop simple interactive play. • Some can attend to a simple cause-effect relationship. • Most can distinguish between "more" and "less." • Some can make one-to-one correspondence or match to sample (e.g., organise or	• Most can communicate their needs effectively. • Most can tell or identify their age and gender. • Most can initiate/invite others to participate in an activity. • Most can communicate immediate experiences. • Most can attend to and follow up to 2-step instructions. • Some can cross residential street intersections safely (look in both directions, waiting for traffic to clear before crossing, obey lights and signal signals). In contexts without busy intersections, some can follow socially acceptable rules necessary to ensure personal safety. • Some can go independently to nearby familiar places.	• Most can communicate with reasonable fluency in short sentences. • Most can tell or identify their age. • Most can initiate/invite others to participate in an activity. • Most can communicate immediate experiences. • Most can attend to and follow up to 2-step instructions. • Most can cross residential street intersections safely (look in both directions, wait for traffic to clear before crossing, obey lights and signal signals). In contexts without busy intersections, some can follow socially acceptable rules necessary to ensure personal safety. • Some can travel independently to familiar places. • Most can communicate their preferences about their future goals, health care, and relationships (e.g.,

	match items according to shape, sise, colour). • Many can express their likes and dislikes in relationships (e.g., who they prefer to spend time with), activities, food, and dress. *Literacy / Numeracy* • Most can recognise symbols.	• Most can communicate preferences about their future goals when provided with options. • Most can express their likes and dislikes in relationships (e.g., who they prefer to spend time with), activities, food, and dress. • With support, most can apply existing abilities in order to build skills for future semi-skilled employment (i.e., involving the performance of routine operations) • Most are naive in anticipating full consequences of actions or recognizing when someone is trying to exploit him/her. *Literacy / Numeracy* • Most will develop emergent reading and writing skills. • Most can recognise their own name in print. • Most can choose correct number of objects • Some can learn to count up to 10.	who they prefer to spend time with) and will often act in accordance with these preferences. • Some can apply existing abilities in the context of semi-skilled employment (i.e., involving the performance of routine operations). • Most remain naive in anticipating full consequences of actions or recognizing when someone is trying to exploit him/her. *Literacy / Numeracy* • Most can read sentences with three common words and can achieve a reading and writing level up to that expected of someone who has attended 4 to 5 years of schooling (i.e., several years of primary/elementary school). • Most can choose correct number of objects • Most can count to 10 and in some cases higher.

SEVERE	• Most will develop various simple non-verbal strategies to communicate basic needs. • Some can self-initiate activities. • Most can attend to and respond to others. • Most can separate one object from a group upon request. • Most can stop an activity upon request. • Most can express their likes and dislikes in relationships (e.g., who they prefer to spend time with), activities, food, and dress when given concrete choices (e.g., with visual aids). *Literacy / Numeracy* • Most can make rudimentary marks that are pre-cursors to letters on page	• Most can use communication strategies to indicate preferences. • Most can self-initiate activities. • Most can attend to and recognise familiar pictures. • Most can follow 1-step instructions and stop an activity upon request. • Most can distinguish between "more" and "less." • Most can separate one object from a group upon request. • Most can differentiate locations and associate meanings (car, kitchen, bathroom, school, doctor's office, etc.) • Most can express their likes and dislikes in relationships (e.g., who they prefer to spend time with), activities, food, and dress when given concrete choices (e.g., with visual aids). • With support, some may be able to apply existing abilities in order to build skills for future unskilled employment (i.e., involving performing simple duties) or semi-skilled employment (i.e., involving performing routine operations). *Literacy / Numeracy*	• Most can use communication strategies to indicate preferences. • Most can self-initiate activities. • Most can attend to and recognise familiar pictures. • Most can follow 1-step instructions and stop an activity upon request. • Most can distinguish between "more" and "less." • Most can separate one object from a group upon request. • Most can differentiate locations and associate meanings (car, kitchen, bathroom, school, doctor's office, etc.) • Most can communicate their preferences about their future goals, health care, and relationships (e.g., who they prefer to spend time with) when given concrete choices (e.g., with visual aids). • Some can apply existing skills to obtain unskilled employment (i.e., involving performing simple duties) or semi-skilled employment (i.e., involving performing routine operations) with appropriate social and visual/verbal supports. • *Literacy / Numeracy*

		• Most can recognise symbols • Many can recognise own name in print.	• Most can recognise common pictures (e.g., house, ball, flower). • Many can recognise letters from an alphabet.
PROFOUND	• Many will develop non-verbal strategies to communicate basic needs. • Most can attend to and respond to others. • Most can start or stop activities with prompts and aids • Many can express their likes and dislikes in relationships (e.g., who they prefer to spend time with), activities, food, and dress when given concrete choices (e.g., with visual aids). *Literacy / Numeracy* • They will not learn to read or write.	• Most will develop strategies to communicate basic needs and preferences. • Most can recognise familiar people in person and in photographs. • Most can perform very simple tasks with prompts and aids. • Some can separate one object from a group upon request. • Some can differentiate locations and associated meanings (car, kitchen, bathroom, school, doctor's office, etc.) • Many can express their likes and dislikes in relationships (e.g., who they prefer to spend time with), activities, food, and dress when given concrete choices (e.g., with visual aids).	• Most will develop non-verbal strategies and some utterances /occasional words to communicate basic needs and preferences. • Most can attend to and recognise familiar pictures. • Most can perform very simple tasks with prompts and aids. • Some can separate one object from a group upon request. • Some can differentiate locations and associated meanings (car, kitchen, bathroom, school, doctor's office, etc.) • Many can communicate their preferences about their future goals, health care, and relationships (e.g., who they prefer to spend time with) when given concrete choices (e.g., with visual aids).

APPENDIX B

Behavioural Indicators Table of Adaptive Behaviour for Early Childhood (Up to 6 Years Of Age; Tassé et al., 2019)

SEVERITY LEVEL	*Conceptual*	*Social*	*Practical*
	Reasoning, planning, organizing, reading, writing, memory, symbolic/internal representation, communication skills.	*Interpersonal competency (e.g., relationships), social judgment, emotion regulation*	*Self-care, recreation, employment (including domestic chores), health and safety, transportation*
MILD	• Most can perform basic listening skills with a 15- minute attention span. Most need help to sustain their attention for 30 minutes. • Most are able to follow simple 2-step instructions. They need help following a three-step or "if-then" type of instruction. • Most can state their age, first and last name when asked. • Many have a 100-word vocabulary. Most ask "wh" question (who, what, where, why) but most will need help using pronouns and tense verbs. *Literacy*	• Most can perform independently basic skills related to social interaction such as imitation, showing affection to familiar persons as well as friend-seeking behavior, expressing emotions, and answering basic questions. • Most will need frequent encouragement and assistance in offering help to others, sharing interests, orperspective taking. They are able to engage in play with others, even with minimal supervision although they will need assistance taking turns, following rules, or sharing. • Most are able to demonstrate polite behavior (saying "please", "thank you") although they may need help	• Most will learn the majority of basic eating, washing face and hands, toileting, and self-care skills. • Most will acquire independence in dressing (may need help to button/fasten clothes) and nighttime continence. • Most can use simple household devices. • Most will need supports with bathing, using utensils, and brushing teeth. • Most can learn the concept of danger and avoid hot objects.

	• Many will not learn reading/writing skills. If present, reading skills will be limited to identifying some letters of the alphabet. Will be able to recognise theirown name in print.	apologizing, demonstrating appropriate behavior with strangers, or waiting for the appropriate moment to speak in a social context. • Most will need help to modify their behavior in accordance to changing social situations or when there is a change in their routines.	• Most will be able to independently help with simple household chores, but will often need assistance with more complex tasks such as putting away clothes or cleaning up their rooms. • With some assistance, most can learn the concept of money (although will be unable to learn the value of the different denominations, e.g., coins), can count to 10, and follow basic rules around the home. • Will be unable to learn days of the week, learn and remember phone numbers.
MODERATE	• Most will independently point to common objects when asked and follow 1-step instructions. Some will need supports to perform basic skills such as following simple 2-step instructions. • Most can state their own first name.	• Most are able to perform independently some of the basic skills related to social interaction, although they might need some help making new friends, answering basic social questions, or expressing their emotions. • Most are able to play with peers and show interest in play/interact with	• Most can learn the majority of basic eating skills, may need more assistance than their same-age peers with toilet training and dressing themselves (some help needed to button/fasten). • Most will learn to ask to use the toilet, drink from a cup, feed themselves with a spoon, and

	• Most will have basic communication skills such as: formulating one-word requests, using simple phrases, using other people's first names or nicknames but will need help with last name. • Most speak at least 50 words and name/point at least 10 objects when asked. • Most are not able (or will need a lot of support) to use past tense verbs, pronouns or "wh" questions. *Literacy* • Most will not learn reading or writing skills.	others, but may need more supervision/supports to play cooperatively with others, play symbolically, take turns, follow rules of a game and share objects. • Most won't be able to perform more complex social skills involving inter-personal interactions such as offering help to others, empathy, sharing their interests with others or perspective taking.	become toilet trained during daytime. Will often need supports with brushing teeth, bathing, and using utensils. • With some supports, most can learn to use simple household devices. • Most can learn the concept of danger although some assistance will be needed when using sharp objects (e.g., scissors). • Many will be able to help with simple household chores (i.e., putting their things away in their room, and cleaning up after themselves). • Most will not acquire the understanding of the concept of money and time.
SEVERE	• Most can perform independently the most basic skills such as wave good-bye, say the name of a parent/caregiver, point to a desired object and point or gesture to indicate their preference, and understanding the meaning of no and yes.	• Most will need help to perform basic social skills such as imitation or showing interest and preferences in social interactions with their peers.	• Most can learn many of the basic eating skills but will need more assistance than their same-age peers with toilet training, learning to use a cup and spoon, and putting on clothes.

	• Most will need supports to point to/identify common objects, follow 1-step instructions, and sustain their attention to listen to a story for at least 5 minutes. • Most won't be able to state their age correctly and will speak less than 50 recognizable words. They may need help formulating 1-word requests and using first names or nicknames of familiar people, naming objects, answering when called upon, and using simple phrases. *Literacy* • Most will not learn reading and writing skills.	• Most are able to show interest when someone else is playful and to play simple games. • Most will need significant supports to play in a cooperative way, play symbolically or seek others for play/leisure activities. Most will also need significant help with transitions - changing from one activity to another or using polite social responses such as "please" and "thank you". • Most won't be able to engage in turn-taking, following rules or sharing objects.	• Most can learn to use with some supports simple household devices. • Most will have difficulty learning to master many self-care skills, including using the toilet independently. • Most will not be able to learn the concept of danger and will require close supervision in areas such as the kitchen. • Some may learn basic cleaning skills but will need assistance. • Most will not learn the concept of money, time, or numbers.
PROFOUND	• Most will master only the most basic communication skills such as turning their eye gaze and head towards a sound. • They will need prompting to orient towards people in their environment, respond when their name is called,	• Most may be able to perform only the most basic social skills such as smiling, orienting their gaze, looking at others/objects, or showing basic emotions. • Some might be able to perform other basic social skills with a lot of	• Most will need help performing even the most basic eating, dressing, drinking, and bathing skills. • Most will be unable to learn to be independent using the toilet, being dry during the day, bathing

	and understand the meaning of yes and no. • They are able to cry when hungry or wet, smile and make sounds of pleasure, but it may be difficult to get their attention. *Literacy* • They will not learn to read or write.	support/prompting, such as showing preference for people or objects, imitating simple movements and expressions, or engaging in reciprocal social interactions. • Some can show interest when someone else is playful, but will need a lot of supports to play simple games. Will have difficulty adapting to changes and transitions in activity/location. • Most will be unable to follow rules of a social game.	or washing self at the sink, using a fork and knife. • Most will need constant supervision around potentially dangerous situations in the home and community. • Most will be unable to clean up after themselves; will need help with even basic chores, such as picking up belongings to put away. • Most will be not able to learn to independently use the telephone or other simple devices around the home.

APPENDIX C

Behavioural Indicators Table of Adaptive Behaviour for Childhood and Adolescence (6 to 18 Years of Age; Tassé et al., 2019)

SEVERITY LEVEL	*Conceptual*	*Social*	*Practical*
	Reasoning, planning, organizing, reading, writing, memory, symbolic/internal representation, communication skills	*Interpersonal competency (e.g., relationships), social judgment, emotion regulation*	*Self-care, recreation, employment (including domestic chores), health and safety, transportation*
MILD	• Most will need some help to sustain their attention for 30–minute period. • Most can follow 3-step instructions. • Most will acquire sufficient communication skills to use pronouns, possessives and regular tenses, as well as be able to ask "wh" question (e.g., who, what, where, when or why). • Many will need support to tell a narrative story or to give someone simple directions. They also need assistance to explain their ideas using multiple examples, detail short-term goals and steps to achieve them, stay on the topic in group conversations and move from one topic to another.	• Some may have more concrete understanding of social situations and may need supports understanding some types of humor (i.e., teasing others), making plans and knowing to let others know about these plans as needed, control their emotions when faced with disappointment, knowing to avoid dangerous activities or situations that may not be in their best interest (e.g., taken advantage of or exploited). • Some may need some supports initiating conversation, organizing social activities with others or talking about shared interests with peers/friends. • Some may need substantial support to talk about personal things, emotions, or understanding social cues.	• Most will learn to perform independently most dressing, toileting, and eating skills. • Most will continue to frequently need supports to attain independencefor brushing teeth, bathing and showering, getting around the community and being safe (e.g., although they will know to stay to the side of routes with car traffic) may continue to need support to check for traffic before crossing a street. • Many may be vulnerable to being taken advantage of in social situations. May continue to need some supports for telling time, identifying correct day/dates on calendar, making and checking

	Literacy • Most will have reading and writing skills that arelimited to approximatelyup to that expected of someone who has attended 4 to 5 years of schooling (i.e., several years of primary/elementary school).	• Most are able to play outdoor sports or other social games in groups although they need help to play games with more complex rules (e.g., board games).	the correct change at the store, being independent with basic health-maintaining behaviors. • If available, many can learn to use computers for school and play. • Will learn basic work skills at about the same pace as their same-age peers but will need more repetition and structure.
MODERATE	• Most need help to perform skills such as following instructions containing ”if-then” as well as sustaining their attention to listen to a story for at least a 15-minute period. • Most can say at least 100 words, use negatives, use simple sentences and state their first and last name. • Some may need help using pronouns, possessives, or past tense verbs. • Some may need supports telling basic parts of a story or asking “wh” questions (e.g., when, where, why, who, etc.).	• Some may need support expressing their emotions or concerns, knowing when others might need their help, showing emotions appropriate to the situation / context, or knowing what others like or want. • Most need a lot of help initiating a conversation, waiting for the appropriate moment to speak, meeting friends and going on social outings or talking about shared interests with others. • Most will need help following rules when playing simple games or going out with friends.	• Most can learn to feed themselves, use the toilet, and dress (including putting shoes on correct feet). • Most will often continue to need supports to attain independence for bathing and showering, brushing teeth, selecting appropriate clothing, being independent and safe in the home and community. • Most will continue to have difficulty using a knife to cut food, use the cooking appliances safely, use household products safely, and do household chores.

	• Most will not learn complex conversation skills (i.e., express their ideas in abstract manner or in more than one way). *Literacy* • Most will have reading and writing skills that will be limited to approximately up to that expected of someone who has attended 3 to 4 years of schooling (i.e., two years of primary/elementary school). • May need support with reading simple stories, writing simple sentences, and writing more than 20 words from memory.	• Some will need supports changing routines and transitioning between activities/places, or behaving appropriately in accordance to social situations and knowing what to do in social situations involving strangers. • Most individuals won't be able to share with others about their past day's events/activities, will need supports managing conflicts or challenging social interactions and recognizing/avoiding dangerous social situations.	• Most will not acquire the understanding of taking care of their health. • Most will learn basic work skills later than same-age peers.
SEVERE	• Most will be able to independently make simple one-word requests, use first names of familiar individuals and name at least 10 familiar objects. • Some may need help following instructions and won't be able to use pronouns, possessives, regular past tenses, or state their age.	• Some may need support demonstrating friend-seeking behavior, or engaging in reciprocal social interactions. • Most need help expressing their emotions or showing empathy. • Most won't know to offer help to others without cues or prompting, show appropriate emotions in social situations, engage in conversations or query others about their interests.	• Most can learn to independently put on and take off clothing, feed themselves with a spoon, use the toilet. • They will often continue to need supports to attain independence for putting shoes on the correct feet, buttoning and fastening clothing, bathing and showering.

	• With help, some may be able to ask "wh" questions (e.g., when, why, what, where, etc.) use at least 100 recognizable words, use negatives, and relate their experiences in simple sentences. *Literacy* • Most will have reading and writing skills that will be limited to identifying some letters of the alphabet, and recognizing their own printed name.	• Most need support to play cooperatively. With a lot of help, some might be able to start/end a conversation appropriately, say "please" and "thank you" when appropriate, or respond to a change in their routine. • Most will have difficulty following social rules as well as rules associated with games such as turn-taking or sharing toys. Most will be unable to participate in social or other games with complex rules.	• Most individuals will not learn the rules and safe behaviors in the home and community, doing household chores or checking for correct change when purchasing items. • Some will learn basic work skills later than same-age peers.
PROFOUND	• Most will have basic communication skills such as orienting their eye gaze and turning their head to locate a sound, responding to their name, getting a parent/caregiver's attention, expressing their needs, and demonstrating an understanding of the meaning of yes and no. • With significant supports, some will be able to wave "good-bye", use their parent/caregiver's name, and point to objects to express their preferences.	• Most will need some help to perform basic social skills such as showing interest and affection for persons familiar to them, engage in social interactions, or discriminate between acquaintances. • Some can perform certain social skills such as imitation, showing interest in peers, or empathy. • For some, transitioning between social contexts and activities willelicit negative reactions if not done with supports.	• Most will need exceptional supports with basic hygiene and washing, picking up after themselves, clearing their place at the kitchen table, being safe in the kitchen, and using hot water. • Most will be unable to learn to prepare foods or assist in the kitchen, use simple household devices (e.g., microwave). • Most individuals will not learn rules and safe behaviors in the home and community.

	• Most indicate when there are hungry or wet by making a vocalization or crying, smile, and make sounds to indicate they are happy/sad. • Some may not be able to effectively use communication to get the attention of others in their environment. *Literacy* • Most will not learn to read or write.	• Most won't be able to engage in cooperative social play and will need a lot of help modulating their behavior to different social cues.	• Most will require a lot of supervision to remain on task and be engaged in basic vocational or pre-vocational skills.

APPENDIX D

Behavioural Indicators Table of Adaptive Behaviour Adulthood (18+ Year of Age)

SEVERITY LEVEL	*Conceptual*	*Social*	*Practical*
	Reasoning, planning, organizing, reading, writing, memory, symbolic/internal representation, communication skills	*Interpersonal competency (e.g., relationships), social judgment, emotion regulation*	*Self-care, recreation, employment (including domestic chores), health and safety, transportation*
MILD	• Most will master listening and communication skills, although some may need help to stay on topic in group conversations, move from one topic to another, express ideas in more than one way or states complete home address. • Most will probably not be able to give complex directions and describe long-term goals. *Literacy* • Most can read and understand material up to that expected of someone who has attended 4 to 5 years of schooling (i.e., several years of primary/elementary school) and	• Most can independently meet others for the purpose of making new friends, can participate in social outings on a regular basis, and talk about personal feelings. • Most can independently initiate a conversation and talk about shared interests with others. • Most can understand social cues and are able to regulate their conversation based on their interpretation of other people's feelings. • Most are able to play complex social games and team sports, although may need supports with understanding the rules.	• Most will be independent in household chores, being safe around the home, and using the telephone. • Most will often continue to need some supports to attain independence with more complex domestic skills (e.g., small household repairs), comparative shopping for consumer products, following a healthy diet and being engaged in health promoting behaviors, caring for themselves when sick or knowing what to do when they are sick/ill. • Many can learn to live and work independently, work at a part-time or full-time job with competitive wages – support at

	will master some writing skills, although they may have difficulty writing reports and long essays.	• Most can learn to weigh the possible consequences of their actions before making a decision and know right from wrong. • Most need help recognizing when a situation or relationship might pose dangers or someone might be manipulating them for their own gain. • Most can initiate planning of a social activity with others. Some can be engaged in an intimate relationship, others might need more supports to do so.	work will depend on the level of complexity of the work and may fluctuate with life transitions. • Some can learn to drive a car, manage simple aspects of a bank account, prepare simple meals, and if available, use a computer or other digital devices. • Most will continue to need supports with more complex banking needs, paying bills, and parenting skills.
MODERATE	• Most will need a lot of support to be able to listen to a story for more than a 15-minute period as well as following instructions or directions from memory (i.e., with a 5–minute delay). • Most will master the following communication skills: simple descriptions, using "wh" questions (e.g., what, when, why, where, etc.) or relating their experiences using simple sentences.	• Some will need help learning how to share interests or engaging in perspective taking. • Some may need supports initiating conversations and introducing themselves to unfamiliar people. • Most need significant supports engaging in regular social activities, planning social activities with others, understanding social cues, and knowing what are	• Some will learn to master dressing (may need some help selecting appropriate clothing to wear for weather), washing, eating and toileting needs. • Most are able to be safe around the home, use the telephone and use simple appliances (e.g., microwave). • Some may continue to need supports with bathing and showering, using more complex

	• With help, most are able to follow 3-step instructions. • Most will continue frequently needing help with using language containing past tenses and describing their experiences in detail. • Most will not learn more complex conversation skills (e.g., expressing ideas in more than one way). *Literacy* • Most will acquire some reading and writing skills such as: letters of the alphabet, writing at least three simple words from an example, and writing their own first and last name. They will need significant supports to write simple sentences or read simple stories at about that expected of someone who has attended 3 to 4 years of schooling (i.e., two years of primary/elementary school).	appropriate/inappropriate conversation topics. • Most will need significant supports engaging in social activities requiring transportation. • Most are unable to be engaged in more social or other games with complex rules (e.g., board games). • Most will need help providing socially polite responses such as “please”, “thank you”. • Most are unable to recognise when a social situation might pose some danger to them (e.g., potential for abuse or exploitation).	household appliances (e.g., stove) safely, meal preparation, or using cleaning products safely. • Many will understand the function of money but struggle with making change, budgeting and making unplanned purchases. • Most will need supports being safe in the community and living independently. They will need substantial supports for employment – finding and keeping a job. • Most will not likely be able to travel independently to new places, have a developed concept of time sufficient to tell time independently and know when they are late.
SEVERE	• Will often need life-long supports to recall and comply with instructions given 5 minutes prior, sustain their	• All will need help in social situations, showing and expressing their emotions in an appropriate manner,	• Most will need some supports for even basic personal hygiene,

	attention to a story for a 15 minute period. Most are able to listen and attend to a story for a period of at least 5 minutes. • Most can make sounds or gestures to get the attention of individuals in their environment and can make their needs known. • They may need help using simple phrases, describing objects and relating their experiences to others, speaks at least 100 recognizable words, using negatives, possessives and pronouns, and asking "wh" questions. *Literacy* • Reading and writing skills will be limited to: identifying some letters of the alphabet, copying simple words from an example and writing their first and last name.	and engaging in a reciprocal conversation with others. • Most can play simple social games but may need help choosing friends to play with. They need a lot of help to play symbolically, follow the rules while playing games such as turn-taking or sharing toys. They will need help with transition - changing from one activity to the next or an unexpected change in routine. • Most will not spontaneously use polite forms such as "please", "excuse me", "thank you", etc. They will need significant support starting, maintaining and ending conversations with others. • Most do not recognise when a social situation might pose a danger to them (e.g., potential for abuse or exploitation) or discern dangers potentially associated with strangers.	domestic skills, home and community skills. • Most will be able to drink independently from a cup and learn to use basic utensils for eating. Some may continue to need supports getting dressed. • Many may learn independent toileting if provided an established routine. Most will be unable to care for their own belongings, perform household chores independently, cooking, or care for their health. • Most will need substantial supports to travel independently, plan and do shopping and banking of any sort. • Most will require significant supports to be engaged in paid employment.
PROFOUND	• Most are able to turn their head and eye gaze toward sounds in their environment and respond to their name when called.	• Most will not spontaneously show interest in peers or unfamiliar individuals.	• Most will need supports performing even the most basic self-care, eating, washing, and domestic skills.

	• Most will use sounds and gestures to get parent/caregiver's attention, express their wants, and some will have the understanding of the meaning of yes and no. Some are able with prompting to wave good-bye, use their parent/caregiver's name, and point to objects to express their preferences. • Most will cry or make vocalizations when hungry or wet, smile, and make sounds of pleasure. • Most are not able to follow instructions or story being told. *Literacy* • Most will not learn to read or write.	• With significant supports, most are able to imitate simple actions/behaviors or show concern for others. • Most will not engage in reciprocal/back-and-forth conversation. • Most will not spontaneously use polite forms such as "please", "excuse me", "thank you", etc. • Most are unable to anticipate changes in routines. Social interactions with others will be very basic and limited to essential wants and needs. • Most are unable to recognise when a social situation might pose some danger to them (e.g., potential for abuse or exploitation).	• Some may learn independent toileting during the day but nighttime continence will be more difficult. • Most will have difficulty picking out whether appropriate clothing and zipping and snapping clothes. • Most will need supervision and supports for bathing, including safely adjusting water temperature and washing/drying. • Most will be unable to independently clean or care for their living environment, including clothing and meal preparation. • All will need substantial supports with health matters, being safe in the home and community, learning the concept of days of the week and time of day. • Most will be extremely limited in their vocational skills and

			engagement in employment activities will necessitate structure and supports.