



General Measurement Tools for Assessing Mental Health Problems Among Children and Adolescents with an Intellectual Disability: A Systematic Review

Marianne Berg Halvorsen¹ · Sissel Berge Helverschou² · Brynhildur Axelsdottir³ · Per Håkan Brøndbo⁴ · Monica Martinussen⁵

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Abstract

There is a need for more knowledge of valid and standardized measures of mental health problems among children and adolescents with intellectual disability (ID). In this study, we systematically reviewed and evaluated the psychometric properties of instruments used to assess general mental health problems in this population. Following PRISMA guidelines, we reviewed empirical research published from 1980 through February 2020 with an updated search in March 2021 in Medline, Embase, PsycINFO, Health and Psychological Instruments, CINAHL, ERIC, and Web of Science databases. Forty-nine empirical articles were included in this review. Overall, the review indicated consistently better documentation of the reliability and validity of instruments designed for the ID population compared to instruments developed for the general child population.

Keywords Assessment · Intellectual disability · Mental disorders · Mental health · Psychometrics

Cooccurring mental health disorders are more frequent in the intellectual disability (ID) population than in the general population (Einfeld et al., 2011; Munir, 2016). Mental health disorders result in reduced functioning and an increased need for help in everyday life at home, at school, or at work, in addition to difficulties due to ID (Einfeld et al., 2011; Halvorsen et al., 2019). These difficulties are associated with reduced quality of life for the person and the family (Hastings et al., 2001; Lin et al., 2009). Accordingly, careful assessment of mental health should be an essential

component of care for all people with ID and should be integrated into clinical practice. The identification of mental health (MH) disorders is, however, considered difficult due to the considerable symptom overlap between ID and MH disorders and the problems of distinguishing between the conditions (Einfeld et al., 2011). Additionally, accompanying communication difficulties and atypical symptom presentations associated with more severe ID make assessment challenging (Stratis & Lecavalier, 2015). The use of relatively broadband standardized instruments is generally recommended in the initial assessment of MH disorders. There are few currently available instruments that have been specifically developed for children and adolescents with ID (e.g., Aberrant Behavior Checklist [ABC]: (Aman & Singh, 1986); Developmental Behavior Checklist [DBC]: (Einfeld & Tonge, 1992), and accordingly, instruments not originally developed for this population are commonly used (e.g., Achenbach System of Empirically Based Assessment [ASEBA]; Strengths and Difficulties Questionnaire [SDQ; Goodman, 1997]). However, there is a need for more knowledge of valid and standardized measures of MH problems among children and adolescents with ID. A previous systematic review evaluated the suitability of MH measures, in terms of psychometric properties (i.e., reliability and validity), that are commonly used for people of all age groups

✉ Marianne Berg Halvorsen
marianne.berg.halvorsen@unn.no

¹ Department of Pediatric Rehabilitation, University Hospital of North Norway, P.O. Box 2, 9038 Tromsø, Norway

² NevSom Norwegian Centre of Expertise for Neurodevelopmental Disorders and Hypersomnias, Oslo University Hospital, Oslo, Norway

³ Regional Centre for Child and Adolescent Mental Health, Eastern and Southern Norway, Oslo, Norway

⁴ Department of Psychology, UiT The Arctic University of Norway, Tromsø, Norway

⁵ RKBU North, UiT The Arctic University of Norway, Tromsø, Norway

(i.e., children, adolescents, and adults) with severe and profound ID (Flynn et al., 2017). Flynn et al. (2017) found that very few measures were available and recommended (i.e., sound psychometric properties) for adults. Furthermore, they found no eligible studies reporting psychometric properties of instruments for children and adolescents with severe and profound ID. Accordingly, there is an urgent need for more knowledge about the reliability and validity of MH instruments used among children and adolescents across the whole ID spectrum. Such knowledge of measurement properties will provide the clinical and research field with important new knowledge regarding the strengths and weaknesses of these instruments and provide input to further developmental needs in this field.

Objective

This systematic review aimed to provide an overview of relevant general measures for assessing MH problems among children and youths with ID. More specifically, the research question was the following: What are the psychometric properties of measurement tools used to assess general MH problems in children and adolescents with ID at ages of 4–20 years? We set this age range (i) Because very few MH measurement tools have been developed for children under age four years and particularly for the ID population, and (ii) we wanted mainly children/youth samples because this was the focus of this review and including adults could provide findings that are not necessarily transferable to children.

Methods

The protocol for this systematic review was registered in PROSPERO, an international register for systematic reviews with health-related outcomes (CRD42020172186). PRISMA guidelines were used for the reporting process (Moher et al., 2009). The PRISMA checklist is available in Appendix I.

Inclusion and Exclusion Criteria

We included papers if they met the following criteria: (a) at least 70% of the sample in the study were reported as having an intellectual functioning equivalent to a full-scale intelligent quotient (FSIQ) ≤ 80 either by means of a standardized intelligence test or a diagnosis of ID or indirectly by parent report or being a pupil at a special school for children and youths with ID. (b) All studies were based on samples that included children and youths between the mean ages of 4–20 years. Samples reporting participant age above 25 years of age were excluded as the focus on this review were on children and adolescents. (c) Reported original data

on quantitative or psychometric outcomes for general MH measures published in a peer-reviewed journal or as a PhD dissertation. (d) Focused on the development, adaptation, or evaluation of a measure of MH. The inclusion criteria for MH problems were derived from the International Statistical Classification of Disease and Related Health Problems, 10th Revision (World Health Organization, 2010). Eligible MH problems and their key diagnostic symptoms, with onset usually occurring during childhood and adolescence, were classified as follows: (a) F20-29: schizophrenia, schizotypal, and delusional disorders; (b) F30-39: mood (affective) disorders; (c) F40-48; neurotic, stress-related and somatoform disorders; and (d) F91-94 behavioral and emotional disorders. Accordingly, we did not include disorders of adult personality and behavior (F60-69), organic mental disorders, disorders due to psychoactive substance abuse, behavioral syndromes associated with physiological disturbances and physical factors, neurodevelopmental disorders (ID, attention-deficit/hyperactivity disorder, autism spectrum disorders, or specific developmental disorders), motor disorders (Tourette syndrome), or other behavioral and emotional disorders with onset usually occurring in childhood and adolescence that are not within F91-94 (e.g., pica or stereotyped movement disorder).

We excluded the following types of papers: (a) Published before 1980 in accordance with Flynn et al. (2017) (b) used specific MH measures with fewer than two symptom domains as the focus in this review was on broadband/general measurement tools, (c) focused on evaluating psychotropic drug interventions, or (d) reported only descriptive mean scores for ID samples (e.g., genetic syndromes) with no other psychometric information.

Search Methods for Identification of Studies

We searched Medline (Ovid), Embase (Ovid), PsycINFO (Ovid), Health and Psychosocial Instruments (Ovid), CINAHL (EBSCO), ERIC (EBSCO), and Web of Science from 1980 through February 21st, 2020. The trial registers ClinicalTrials.gov and WHO International Clinical Trials Registry Platform (ICTRP) were also searched for ongoing and unpublished trials on May 16th, 2021. An updated search for each included measurement tool was performed on March 13th, 2021.

The search strategy was developed by an information librarian (BA) using a wide range of search terms for intellectual and developmental disabilities, MH issues, children and adolescents, and psychometric properties. No limits were applied to the study design, language, or publication type. The search strategy was adapted to each database (see complete search strategies in Appendix II).

The bibliographies of all included studies and previous systematic reviews were also searched for relevant studies.

We contacted experts in the field to identify additional unknown studies; four additional papers were identified in this manner, but none met the inclusion criteria (Brinkley et al., 2007; Kaat et al., 2014; Ono et al., 1996; Siegrifrid, 2000).

Study Selection

All titles and abstracts were independently screened by at least two reviewers (MBH, (screened all references), BA, SBH and MM) in Covidence. All full-text papers were independently screened (always MBH, in addition to SBH, BA, MM, or PHB). Disagreements were resolved by discussion, and if needed, a third author (MM) was consulted to reach a final decision.

Data Extraction (and Synthesis)

Data were extracted into a table format by one reviewer (MBH or BA) and were checked for accuracy by a second reviewer (SBH or PHB). The extracted data included study design, country, participant demographics (age and sex) and clinical characteristics (i.e., ID severity, adaptive level, comorbid diagnosis), rater characteristics (i.e., parent/caregiver, teacher or other), and information about the data analyses/psychometric properties.

The data were summarized for all the studies reporting on *each measurement tool*, with a narrative synthesis.

Methodological Quality of MH Measures

As the objective was to assess the psychometric properties of the MH measures as they appeared in the studies we identified, we did not assess the quality of the methods in the included studies themselves. Originally, we planned to use the COSMIN Risk of Bias Checklist (Mokkink et al., 2018) to evaluate the psychometric properties of identified MH measures. However, we found that this tool was more suitable for assessing outcome studies. Accordingly, we chose to use the EFPA review model for the description and evaluation of psychological and educational tests (European Federation of Psychologists' Association (EFPA), 2013) to guide the assessment of the psychometric properties (Table 1). More specifically, reliability (i.e., internal consistency, test–retest reliability, and interrater reliability) and validity (i.e., criterion validity, content validity, and construct validity) were evaluated by means of the interpretation guidelines from the EFPA review model (European Federation of Psychologists' Association (EFPA), 2013) using a four-point scale (0 = not reported/not applicable; 1 = inadequate; 2 = adequate; 3 = excellent/good). We did not evaluate the measure's reported norms. See Table 1 for more information. This quality assessment was independently conducted by MBH and SBH for 20 randomly chosen studies reporting psychometric statistics. The interrater reliability of these assessments showed an excellent degree of correspondence ($r = 0.92$) for the sum scores. Due to a high degree of correspondence in scoring, the remaining articles/studies ($n = 29$) were then randomly distributed between MBH and SBH. If uncertainty in scoring arose, this was discussed between

Table 1 Interpretation guidance from the EFPA Review Model (2013) to evaluate the psychometric quality of included measures

	Range	Rating
Sample size	Not reported/applicable $N < 100$ $N = 100–200$ $N > 200$	0 = not reported/applicable 1 = one inadequate study 2 = one adequate study 3 = large/more than one adequate study
Internal consistency: Cronbach's alpha	Not reported/applicable < .70 = .70–.79 ≥ .80	0 = not reported/applicable 1 = inadequate 2 = adequate 3 = good/excellent
Test–retest/interrater: coefficient	Not reported/applicable < .60 .60–.69 ≥ .70	0 = not reported/applicable 1 = inadequate 2 = adequate 3 = good/excellent
Convergent validity: correlation coefficient	Not reported/applicable < .55 .55–.64 ≥ .65	0 = not reported/applicable 1 = inadequate 2 = adequate 3 = good/excellent
Criterion-related Validity	Not reported/applicable < .20 .20–.34 ≥ .35	0 = not reported/applicable 1 = inadequate 2 = adequate 3 = good/excellent

MBH and SBH; if needed, a third author (MM) was consulted before an agreement was reached.

All studies pertaining to each individual measurement tool were then included *in the overall assessment of each measure*, allowing the authors to establish the weight of evidence for each measure in turn.

Results

Literature Selection

The literature searches resulted in 22,692 unique references. We excluded 20,069 after screening titles and abstracts, and we assessed 774 full-text articles, of which 725 were excluded (see Appendix III for excluded studies with exclusion reasons). A total of 49 trials/papers were ultimately included. Details of the study selection process and reasons for exclusion are provided in Fig. 1. There were very few cases where a third reviewer (MM) was required to resolve disagreements. We focused on assessment instruments of MH for children and adolescents with chronological ages of 4–20 years. Some assessment tools had additional supporting data for older age groups, but this information was not included in the current review.

MH Instruments

A total of 49 papers reporting on 10 instruments for assessing MH problems among children and adolescents with ID were identified and included (Aman et al., 1996; Baraldi et al., 2013; Borthwick-Duffy et al., 1997; Bostrom et al., 2016; Braga et al., 2018; Brereton et al., 2006; Brown et al., 2002; Chadwick et al., 2000; Clarke et al., 2003; Coe et al., 1999; Dekker et al., 2002a, 2002b, 2002c; Dieleman et al., 2018; Douma et al., 2006; Einfeld & Tonge, 1995; El-Keshky & Emam, 2015; Embregts et al., 2010; Emerson, 2005; Esbensen et al., 2018; Freund & Reiss, 1991; Hassiotis & Turk, 2012; Hastings et al., 2001; Haynes et al., 2013; Jacola et al., 2014; Kaptein et al., 2008; Koskentausta & Almqvist, 2004; Koskentausta et al., 2004; Marshburn & Aman, 1992; Masi et al., 2002; Matson et al., 1984; Mircea et al., 2010; Murray et al., 2020; Norris & Lecavalier, 2011; Oliver et al., 2003; Oubrahim & Combalbert, 2019; Reiss & Valenti-Hein, 1994; Rice et al., 2018; Rojahn & Helsel, 1991; Rojahn et al., 2010; Sansone et al., 2012; Taffe et al., 2007; Tasse & Lecavalier, 2000; Tasse et al., 1996; Tonge et al., 1996; van Lieshout et al., 1998; Wallander et al., 2006; Wolf, 1981; Wright, 2010) (see Tables 2 and 3). Of these instruments, seven were aimed for the intellectual and developmental disability (IDD) population (i.e., ID instruments), while three instruments were not originally designed

or aimed for use in this population (i.e., non-ID instruments) (Table 3).

The included assessment instruments were intended to screen for a relatively broad spectrum of problems, so-called broadband assessment instruments. The frequency, severity and duration of target behaviors were most often used to measure MH problems. Four papers gave a first report of the development or adaptation of a new instrument (Challenging Behavior Interview [CBI] (Oliver et al., 2003); Developmental Behavior Checklist [DBC] (Einfeld & Tonge, 1995); Nisonger Child Behavior Rating Form [NCBRF] (Aman et al., 1996); Reiss Scales for Children's Dual Diagnosis [Reiss] (Reiss & Valenti-Hein, 1994); Well-Being in Special Education Questionnaire [WellSEQ] (Bostrom et al., 2016)).

Overall, the identified instruments reported their development/framework through a widely defined bottom-up approach (i.e., descriptive-empirical approach) based on specific descriptors of children's functioning. These individual symptoms (i.e., items) were either based on other existing questionnaires (e.g., the NCBRF was adapted from the Child Behavior Rating Form, and the SDQ was adapted from the Rutter Questionnaire) and/or based on a literature review of the field, expert consultation, or case files from IDD services (i.e., the ID instruments). The ASEBA and the latest version (e.g., Child Behavior Checklist [CBCL]) specifically reported six additional subscales based on the Diagnostic and Statistical Manual of Mental Disorders (DSM) (Achenbach & Rescorla, 2001). The ASEBA (i.e., CBCL, Teacher Rating Form [TRF], and Youth Self Report [YSR]) was the most comprehensive measure identified in terms of the number of items (i.e., 120 items) compared to the other measures (mean number of 53 items). The SDQ, on the other hand, lacked DSM-oriented subscales.

It is noteworthy that the majority of the instruments were proxy or informant-based measures with the exception of the WellSEQ (Bostrom et al., 2016), an ID instrument, and the ASEBA and SDQ, both non-ID instruments, which also offered a youth self-report form. Five papers reported using the youth self-report form (ASEBA: (Douma et al., 2006); SDQ: (Embregts et al., 2010; Emerson, 2005; Haynes et al., 2013); WellSEQ: (Bostrom et al., 2016)). The other papers reported using parent/primary caregiver, teacher, and (health) care staff as informants (Table 2). All identified studies/papers reporting on instruments were in the English language. Moreover, all instruments were originally developed in English, with the exception of the WellSEQ (Bostrom et al., 2016), which was developed in the Swedish language. However, the majority of the identified measures had one or more studies that reported psychometric properties for non-English versions, with the exception of the ABC (Aman & Singh, 1986) and Behavior Problem Checklist (BPC) (Quay & Peterson, 1975, 1983) (see Table 2).

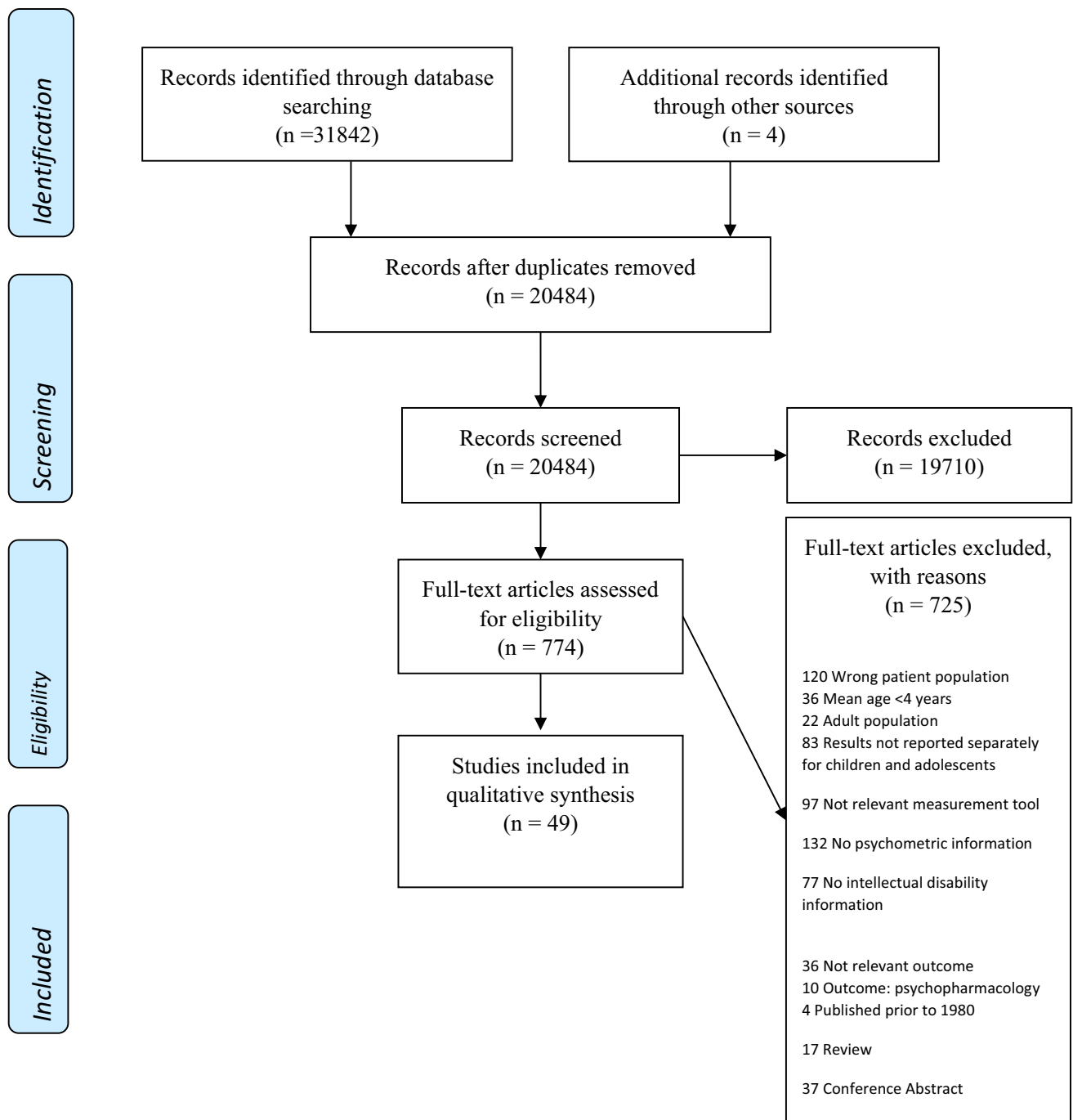


Fig. 1 PRISMA Flow Diagram

We found that most papers used the ASEBA (11 papers) followed by the DBC (10 papers) and further followed by, in descending order, the SDQ (7 papers), ABC/NCBRF (6 papers each), Behavior Problems Inventory-01 (BPI-01) (4 papers), BPC (3 papers), and CBI/Reiss/WellSEQ (1 paper each). For seven of the measures, the researcher by whom it was developed was involved in its evaluation (ABC: Brown et al., 2002; Marshburn & Aman, 1992; BPI-01: Baraldi

et al., 2013; Mircea et al., 2010; Rojahn et al., 2010; CBI: Oliver et al., 2003; DBC: Brereton et al., 2006; Clark et al., 2003; Dekker et al., 2002a, b, c; Einfeld & Tonge, 1995; Taffe et al., 2007; Tong et al., 1996; NCBRF: Aman et al., 1996; Tasse et al., 1996; Rojahn et al., 2010; Tasse & Lecavalier, 2000; Reiss: Reiss & Valentin-Hein, 1994; WellSEQ: Bostrom et al., 2016).

Table 2 Overview of studies: study characteristics and psychometric data

Measure	Author, year	Country	Sample description	IQ/adaptive level	N	Study design	Rater	Psychometric properties
ABC	Brown et al. (2002) ^a	US	Special education 56% boys. Age range 6–22 years	FSIQ ≤ 80 indexed by school placement	601	Cross-sectional	Parent	Factor structure (EFA/CFA) Internal consistency Interrater agreement Convergent validity (VABS)
	Chadwick et al. (2000)	UK	Special education. 62% boys. Age range 4–11 years	Severe ID defined by means of adaptive level	102	Cross-sectional	Parent (n = 102) Teacher (n = 65)	Factor structure (EFA) Internal consistency Test–retest Interrater reliability
	Freund & Reiss, 1991	US	Outpatients. 69% boys. Age range 3–25 years	Borderline to severe FSIQ: <i>M</i> = 53.0 (<i>SD</i> = 14.9) Adaptive level: NR	110/94	Cross-sectional	Parent (n = 110) Teacher (n = 94)	Factor structure (EFA) Internal consistency Test–retest Interrater reliability
	Marshburn and Aman (1992) ^a	US	Special education. Gender frequency: NR. Age range 6–21 years	FSIQ ≤ 80. Indexed by school placement FSIQ/adaptive level: NR	666	Cross-sectional	Teacher	Factor structure (EFA). Internal consistency Norms
	Rojahn and Helsel (1991)	US	Inpatient psychiatric unit. 75% boys. Age range 3–23 years	Borderline to profound ID FSIQ/adaptive level: NR	199	Follow-up	Direct care staff	Factor structure (EFA) Internal consistency. Interrater reliability Criterion validity
ASEBA CBCL	Sansone et al. (2012)	US	Fragile X. 73% boys. Age range 3–25 years	FSIQ: <i>M</i> = 58.0 (<i>SD</i> = 18.3)	630	Cross-sectional	Parent/guardian	Factor structure (EFA/CFA)
	Borthwick-Duffy et al. (1997)	US	Children with ID. 52% boys. Age range 8–20 years	Mild to profound ID FSIQ: NR	67	Cross-sectional	Parent	Factor structure (EFA)
	Braga et al. (2018)	Brazil	Williams syndrome 38% boys. Age range 4–6 years	NR	8	Cross-sectional	Parent/caregiver	Convergent validity (BPI-01)
CBCL and TRF	Dekker et al. (2002a) ^a	Netherlands	Special education. 60% boys. Age range 6–18 years Control group from general population	Borderline to moderate ID FSIQ/adaptive level: NR	1041/1855	Follow-up	Parent (CBCL) and teacher (TRF)	Internal consistency (CBCL and TRF) Test–retest (CBCL) Interrater (CBCL and TRF) Convergent validity (DBC)
CBCL	Dieleman et al. (2018)	Belgium/Netherlands	Down syndrome. 55% boys. Age range 4–19 years	NR	67	Cross-sectional	Parent	Internal consistency

Table 2 (continued)

Measure	Author, year	Country	Sample description	IQ/adaptive level	N	Study design	Rater	Psychometric properties
YSR	Douma et al. (2006) ^a	Netherlands	Special education. Gender frequency: NR. Age range 11–18 years. Control group from general population (N = 1047)	Borderline to moderate ID FSIQ: $M = 66.8$ ($SD = 12.1$) Adaptive level: NR	281/1047	Longitudinal	YSR and parent CBCL	Internal consistency Interrater. Construct validity (Multitrait-multimethod). Criterion validity
CBCL	Esbensen et al. (2018)	US	Down syndrome. Gender frequency: NR. Age range 6–18 years	IQ: $M < 48$ ($SD < 11$) Adaptive level: NR	88	Cross-sectional	Parent (teacher interrater)	Internal consistency. Interrater. Convergent validity (ABC and NCBRF)
CBCL	Koskentausta et al. (2004) ^a	Finland	Community sample. 61% boys. Age range 6–13 years	Mild to profound ID based on IQ scores/adaptive scores. FSIQ: NR	90	Cross-sectional	Parent/caregiver	Convergent validity (DBC). Criterion validity
CBCL	Jacola et al. (2014)	US	Down syndrome rec. 46% boys. Age range 12–18 years	IQ: $M = 43.38$ ($SD = 18.29$). Adaptive: NR	52	Cross-sectional	Parent/caregiver	Convergent validity (BASC-2 clinical and adaptive scales)
CBCL	Masi et al. (2002)	Italy	ID and concurrent depressive disorder and/or anxiety disorder sample. 58% boys. Age range 11–18 years	Mild to moderate ID. FSIQ: $M = 56.7$ ($SD = 4.4$). Adaptive scores: NR	50	Cross-sectional	Parent	Convergent validity (PIMRA, Zung Depression Scale, and Zung Anxiety Scale)
CBCL	van Lieshout et al. (1998)	Belgium/Netherlands	Prader-Willi Syndrome. 50% boys. Age range 3–20 years	Mild to moderate ID. FSIQ/adaptive: NR	39	Cross-sectional	Parent	Internal consistency
CBCL	Wallander et al. (2006)	Netherlands	Population-based. 60% boys. Age range 6–18 years	Borderline to moderate/severe ID indexed by school placement	968	Prospective	Parent/guardian	Internal consistency Test-retest
TRF	Wright (2010)	US	Special education. 58% boys. Age range 12–18 years	IQ: $M = 63.70$ ($SD = 9.65$) (mild ID)	48	Cross-sectional	Teacher	Internal consistency Convergent/divergent validity (ABI)

Table 2 (continued)

Measure	Author, year	Country	Sample description	IQ/adaptive level	N	Study design	Rater	Psychometric properties
<i>BPC</i>	Coe et al. (1999)	US	Down syndrome (n = 44). Age range 6–15 years. Control group with non-ID (n = 44)	ID level not reported. VABS total: <i>M</i> = 51.4	88	Cross-sectional	Parent, teacher	Interrater
	Matson et al. (1984)	US	Students with ID and control group non-ID. 58% boys. Mean age: 15 years	ID group: mild to moderate ID FSIQ/adaptive: NR	259 (ID)/306 (control)	Cross-sectional	Teacher	Factor structure (EFA)
	Wolf (1981)	US	Special education. 87% boys. Age range 11–16 years	NR	39	Follow-up	Teacher/aid	Interrater Test–retest
<i>BPI-01</i>	Baraldi et al. (2013)	Brazil	ID group (n = 30) and non-ID (n = 30). 63% boys. Age range 6–18 years	Normal to moderate ID FSIQ reported. Adaptive: NR	30/30	Cross-sectional	Parent/guardian	Internal consistency. Convergent validity (CBCL)
	Mircea et al. (2010) ^a	Romania	Children with ID. 44% boys. Age range 3–23 years	Mild to profound ID. FSIQ/adaptive: NR	115	Cross-sectional	Caregiver	Internal consistency. Convergent validity (NCBRF)
	Rojahn et al. (2010) ^a	US	Special education. 68% boys. Age range 5–22 years	Mild to profound ID FSIQ/adaptive: NR	237	Follow-up	Parent/guardian (n = 63) Teacher (n = 27)	Factor structure (CFA) Internal consistency. Test–retest Interrater
	Oubrahim and Combalbert (2019)	France	Specialized institutions. 49% boys. Age range 7–24 years	Mild to profound ID. IQ level based clinical records. FSIQ/adaptive: NR	305	Cross-sectional	Care staff	Factor structure (CFA). Internal consistency. Interrater
<i>CBI</i>	Oliver et al. (2003))	UK	Child sample from schools with severe ID. 68% boys. Age range 4–12 years	Severe ID FSIQ/adaptive score: NR	47	Cross-sectional	Teacher	Content validity Convergent validity (ABC)

Table 2 (continued)

Measure	Author, year	Country	Sample description	IQ/adaptive level	N	Study design	Rater	Psychometric properties
<i>DBC-P</i>	Brereton et al. (2006)	Australia	ASD sample, 85% boys. Age range 3–24 years ID sample: 58% boys. Age range 4–18 years	ASD sample: normal to severe ID ID sample: borderline to profound ID Formal IQ test. FSIQ/adaptive: NR	381 (ASD)/550 (ID)	Cross-sectional	Parent/caregiver	Criterion-related validity
	Clark et al. (2003)	Australia	Unselected patients with ID attending psychiatric clinic on at least two occasions. Gender/age: NR	NR	37	Follow-up	Parent	Criterion-related validity
	Dekker et al. (2002a) ^a	Australia/Netherlands	Combined sample: epidemiological prevalence study/nonresidential school, daycare center. 59% boys. Age range 3–22 years	Mild to profound ID indexed from school/daycare placement	1536	Cross-sectional	Parent and teacher	Factor structure (EFA) Internal consistency
	Dekker et al. (2002a) ^a	Netherlands	Nonresidential school settings/special education/day centers. 60% boys. Age range 6–18 years	IQ from < = 80. Borderline to profound ID, indexed from placement	1057/930	Cross-sectional/follow-up	Parents (n = 1057) Teachers (n = 930) Both (n = 851)	Internal consistency Test–retest. Interrater Convergent validity (CBCL) Divergent validity (Vineland) Criterion validity
	Einfeld and Tonge (1995)	Australia	Population-based study. 60% boys. Age range 4–18 years	Mild to profound ID. FSIQ/adaptive score: NR	1093	Cross-sectional/follow-up	Parent/caregiver	Content validity. Factor structure (EFA). Internal consistency. Test–retest- Interrater. Convergent validity. Criterion validity
	Hassiotis and Turk (2012)	UK	Clinical service sample: 64% boys. Age range 12–19 years	Mild to profound ID FSIQ: NR VABS total: $M = 35$ ($SD = 16$)	75	Cross-sectional	Parent and teacher	Criterion validity (agreement ICD-10 diagnoses)

Table 2 (continued)

Measure	Author, year	Country	Sample description	IQ/adaptive level	N	Study design	Rater	Psychometric properties
	Hastings et al. (2001)	UK	Special education. 68% boys. Age range 4–18 years	High proportion likely severe to profound ID. FSIQ/adaptive score: NR	531	Cross-sectional	Parent and teacher	Factor structure (EFA). Internal consistency
	Koskentausta and Almqvist (2004) ^a	Finland	Community sample. 63% boys. Age range 6–13 years	Mild to profound ID based on IQ scores/adaptive scores. FSIQ: NR	85	Cross-sectional	Parent	Interrater. Convergent validity (ABS total Maladaptive Behavior). Criterion validity
<i>DBC-P24/short form</i>	Taffe et al. (2007)	Australia/other countries for cross-validation	Epidemiological ID sample. Cross-validation samples from England, Finland, and the Netherlands in addition to genetic syndrome subgroups	Mild to profound ID. FSIQ/adaptive score: NR	51–1057	Longitudinal/cross-sectional data from first three waves	Parent/caregiver	Criterion validity
	Tonge et al. (1996)	Australia	Community epidemiological prevalence study. > 50% boys. Age range 4–20 years. Community sample (n = 450). Validation sample (n = 448)	Mild to profound ID. FSIQ/adaptive score: NR	1093/450/448	Cross-sectional	Parent/caregiver	Factor structure (EFA). Internal consistency
<i>NCBRF: Problem Behavior section</i> Parent/teacher versions	Aman et al. (1996) ^a	US	Outpatients. 65% boys. Age range 3–16 years	Majority IQ range 55–70. Adaptive: NR	326/260	Cross-sectional	Parent (n = 326) and teacher (n = 260)	Content validity. Factor structure (EFA). Internal consistency. Interrater. Convergent validity (ABC)
	Mircea et al. (2010) ^a	Romania	Children with ID noninstitutional housing. 44% boys. Age range 3–23 years	Mild to profound ID FSIQ/adaptive: NR	115	Cross-sectional	Teacher	Internal consistency Convergent validity (BPI-01)

Table 2 (continued)

Measure	Author, year	Country	Sample description	IQ/adaptive level	N	Study design	Rater	Psychometric properties
	Norris and Lecavallier (2011)	US	Special education/outpatients. 64% boys. Age range 5–18 years	Borderline to profound ID FSIQ/adaptive: NR	399	Cross-sectional	Parent/caregiver	Factor structure (CFA) Internal consistency Convergent validity (DBC) Criterion validity
	Rojahn et al. (2010) ^a	US	Special education. 68% boys. Age range 4–22 years	Mild to profound ID FSIQ/adaptive: NR	237	Cross-sectional/ test–retest	Parent/guardians (n = 63) Teacher (n = 27 for interrater; n = 24 test/retest)	Factor structure (CFA) Internal consistency Test–retest Interrater reliability (teacher-teacher/teacher-parent) Convergent validity (BPI-01) Norms
	Tasse et al. (1996) ^a	US	See Aman et al. (1996) above. Identical sample					
	Tasse and Lecavallier (2000)	Canada/French version	Students. 62% boys. Age range 4–18 years	Mild to profound ID FSIQ: NR	109	Cross-sectional	Parent/teacher	Interrater
<i>Reiss Scales</i>	Reiss and Valentini-Hein (1994)	US	Two independent community samples with children and adolescents with ID. Sample 1: 61% boys. 78% under 11 years. Sample 2: 60% boys. Age range 4–21 years	Mild to profound ID FSIQ/adaptive: NR	313/270	Cross-sectional	Parent/caretaker or teacher	Content validity Factor structure (EFA) Internal consistency Criterion validity (diagnosis)
<i>SDQ</i>	El-Keshky and Emam (2015)	Saudi Arabia/Oman	Students with learning disability. Mean age: 8 years	IQ below 80 indexed by school placement. FSIQ/adaptive: NR	323 (SA)/229 (Omani)	Cross-sectional	Teacher	Factor structure (CFA). Internal consistency
	Embregts et al. (2010)	Netherlands	60% boys. Age range 12–16 years	Mild ID FSIQ/adaptive: NR	45		Self-report Parent Teacher	Internal consistency

Table 2 (continued)

Measure	Author, year	Country	Sample description	IQ/adaptive level	N	Study design	Rater	Psychometric properties
	Emerson, (2005)	UK	Population-based sample children with/without ID. 77% boys, ID sample. Age range 11–15 years	NR	98 (ID)/4074 (control)	Cross-sectional	Self-report. Parent. Teacher	Internal consistency. Interrater. Criterion validity
	Haynes et al. (2013)	Australia	Children with ID from schools. 63% boys. Age range 9–14 years	Mild ID. Formal IQ/adaptive tests. FSIQ/adaptive: NR	128	Cross-sectional	Self-report	Content validity Factor structure (EFA/CFA) Internal consistency Internal consistency Criterion validity
	Kaptein et al. (2008)	Netherlands	Special education. 59% boys. Age range 6–12 years Non-ID control group (n = 707)	Mild to moderate ID FSIQ/adaptive: NR	260/707	Cross-sectional	Parent	Internal consistency Criterion validity
	Murray et al. (2020)	UK	Cohort children with ID. 68% boys. Age range 4–15 years	FSIQ: NR. VABS-II total scores: M = 58	626	Cross-sectional	Parent	Convergent validity (DBC)
	Rice et al. (2018)	Australia/UK	Children with ID from mental health clinics/Down syndrome. 66% boys. Age range 4–17 years	NR	83	Cross-sectional	Parent	Convergent validity (DBC)
<i>WellSEQ</i>	Boström et al. (2016)	Sweden	Special education. 71% boys. Age range 12–16 years	NR	113/67 (parents)/97 (teacher ratings)	Cross-sectional/parent	Self-report. Parent. Teacher	Content validity. Internal consistency. Test-retest. Interrater. Convergent validity (SDQ)

ABC Aberrant Behavior Checklist, *ABI* Adaptive Behavior Inventory, *ASEBA* Achenbach System of Empirically Based Assessment; *BPC* Behavior Problem Checklist, *BPI-01* Behavior Problem Inventory, *CBCL* Child Behavior Checklist, *CBI* Challenging Behavior Interview, *DBC* Developmental Behavior Checklist, *FSIQ* full-scale IQ, *NCBRF* Nisonger Child Behavior Rating Form, *NR* not reported, *Reiss Scales* Reiss Scales for Children's Dual Diagnosis, *SDQ* Strengths and Difficulties Questionnaire, *TFR* Teacher Rating Form, *VABS* Vineland Adaptive Behavior Scales, *YSR* Youth Self Report, *WellSEQ* Well-being in Special Education Questionnaire

^aReport data from the same study

Table 3 Description of included instruments from all studies

Instrument	Purpose/ composition	Administration and scoring	Framework
<i>ID instruments</i>			
<i>Aberrant Behavior Checklist-Community version (ABC-C; Aman & Singh, 1986, 2017)</i>	58 items, 5 subscales: Irritability, Social Withdrawal, Stereotypic Behavior, Hyperactivity, Non-Compliance, Inappropriate Speech	Proxy 4-point scale (0–3)	Empirically developed
<i>Behavior Problems Inventory (BPI-01; Rojahn et al. (2001)</i>	49 items, 3 subscales: Self-Injurious Behavior, Stereotyped Behavior, Aggressive/Destructive Behavior	Proxy 5-point frequency scale (0–4) 3-point severity scale (0–3)	Empirically developed
<i>Challenging Behavior Interview (CBI; Oliver et al., 2003)</i>	Two parts. Part I identifies the occurrence of 5 forms of behaviors: Self-Injury, Physical Aggression, Verbal Aggression, Disruption of the Environment, Inappropriate Vocalizations. Part II: 14 subscales measuring the frequency, duration and implication of the episodes	Proxy Part II: 4- or 5-point scale (e.g., 1–5)	Definitions of challenging behavior (e.g., Emerson, 1998) underscoring the need to include a broad assessment of its impact. Review of the literature on challenging behavior assessment instruments
<i>Developmental Behavior Checklist (DBC; Einfield & Tonge, 1992)</i>	96 items, 6 subscales: Disruptive, Self-Absorbed, Communication Disturbance, Anxiety, Social Relating, Antisocial Total Behavior Problem Score	Proxy: Primary carer and teacher versions 3-point scale (0–2)	Empirically developed
<i>Nisonger CBRF Problem Behavior Section (Nisonger; Aman et al., 1996)</i>	60 items; 6 subscales: Conduct Problems, Insecure/anxious, Hyperactivity; Self-Injury/Stereotypic, Self-Isolated/Ritualistic, Overly Sensitive	Proxy: Parent and teacher versions 4-point scale (0–3)	Adapted/modified the Child Behavior Rating Form ^a . Empirically developed
<i>Reiss Scales for Children's Dual Diagnosis (Reiss; Reiss & Velestin-Hein, 1994)</i>	60 items, 10 subscales: Anger/Self-Control, Anxiety Disorder, Attention Deficit, Autism, Conduct Disorder, Depression, Poor Self-Esteem, psychosis, Somatoform Behavior, Withdrawn/Isolated	Proxy 3-point scale (0–2)	Empirically developed. Adapted from the adult version
<i>Well-Being in Special Education Questionnaire (WellSEQ; Bostrom et al., 2016)</i>	42 items ^b . 5 scales: Mental Health, Mental Ill-Health, Family Relations, School Environment, Peer Relations and Conflict	Youth Self-Report and proxy: Parent and teacher versions 3-point scale (0–2)	Literature review, expert consultations and workshops with special education students
<i>Non-ID instruments</i>			
<i>Behavior Problem Checklist (BPC; Quay & Peterson, 1975, 1983)</i>	77 items, 6 subscales: Conduct Disorder, Socialized Aggression, Attention Problem-Immaturity; Anxiety-Withdrawal, Psychotic Behavior, Motor Excess An additional set of 12 items do not load on any factor but largely assess Social Withdrawal	Proxy 3-point scale (0–2)	Empirically developed

Table 3 (continued)

Instrument	Purpose/ composition	Administration and scoring	Framework
<p><i>ASEBA: Child Behavior Checklist (CBCL)</i>; Achenbach, 1991; Achenbach & Rescorla, 2001)</p> <p>120 items, 8 syndrome subscales: Withdrawn, Somatic Complaints, Anxious/Depressed, Social Problems, Thought Problems, Attention Problems, Delinquent behavior, Aggressive Behavior</p> <p>2 broadband scales: Internalizing and Externalizing. A total problems score</p> <p>The 2001 version includes in addition 6 DSM-oriented subscales: Affective Problems, Anxiety Problems, Somatic Problems, Attention Deficit/Hyperactivity Problems, Oppositional Defiant Problems, Conduct problems</p>	<p>Youth self-report</p> <p>Proxy: Parent report and teacher report forms</p> <p>3-point scale (0–2)</p>	<p>Empirically developed</p> <p>DSM-oriented scales (latest version)</p>	
<p><i>Strengths and Difficulties Questionnaire (SDQ)</i>; Goodman, 1997, 1999)</p> <p>25 items, 5 subscales: Conduct Problems, Emotional problems, Hyperactivity/Inattention, Peer Relationships, Prosocial Behavior</p> <p>2 broadband scales: Internalizing and Externalizing</p> <p>A total difficulties score</p> <p>Extended version includes Impact Supplement: 6 items</p>	<p>Youth self-report version</p> <p>Proxy: Parent and teacher versions</p> <p>3-point scale (0–2)</p> <p>4-point scale (0–3)</p>	<p>Modified the Rutter Questionnaire. Empirically developed</p>	

Parent/primary caregiver versions of the instruments, where they exist, are described as other versions of the instruments overlap to a very large extent

^aEdelbrock (1985)

^bSelf-report version

In relation to participant samples, the vast majority included mixed samples of people with ID with the exception of pure syndrome-specific samples in alphabetical order: i) Down syndrome (Coe et al., 1999; Dieleman et al., 2018; Esbensen et al., 2018; Jacola et al., 2014); ii) Fragile X (Sansone et al., 2012), iii) Prader-Willi syndrome (van Lieshout et al., 1998) and iii) Williams syndrome (Braga et al., 2018). The majority of the studies included samples, in which the major proportion were reported with up to a moderate ID level, with the exception of a few studies reporting a high proportion of likely more severe ID (Chadwick et al., 2000; Hastings et al., 2001; Oliver et al., 2003). It should be noted, as shown in Table 2, that in general, very few studies reported formal IQ data and/or data concerning participants' adaptive function level. FSIQ was reported only with the ABC (two papers), ASEBA (five papers), and BPI-01/NCBRF (one paper each). In relation to sex, overall, the papers reported on samples consisting of a higher proportion of boys, with the exception of five studies (ASEBA: Braga et al., 2018; Jacola et al., 2014); BPI-01 (Mircea et al., 2010; Oubrahim & Combalbert, 2019); NCBRF: (Mircea et al., 2010)). Moreover, population-based samples were reported by six papers (ASEBA: (Wallander et al., 2006); DBC: (Dekker et al., 2002a, b, c; Einfeld & Tonge, 1995; Taffe et al., 2007; Tonge et al., 1996); SDQ: (Emerson, 2005)), and special education/school samples were reported by 19 papers (ABC: Brown et al., 2002; Chadwick et al., 2000; Marshburn & Aman, 1992); ASEBA: (Dekker et al., 2002a, b, c; Douma et al., 2006; Wright, 2010); BPC: (Matson et al., 1984; Wolf, 1981); BPI-01: (Rojahn et al., 2010); CBI: (Dekker et al., 2002a, b, c; Oliver et al., 2003); DBC: (Hastings et al., 2001); NCBRF: (Norris & Lecavalier, 2011; Rojahn et al., 2010; Tasse & Lecavalier, 2000); SDQ: (El-Keshky & Emam, 2015; Haynes et al., 2013; Kaptein et al., 2008); WellSEQ: (Bostrom et al., 2016)). The remaining papers reported on some form of community samples, specific syndrome samples (as noted above) or patient samples (Table 2). Regarding sample sizes, 30 papers reported a sample size of 100 participants or more, as shown in Table 2.

Methodological Quality of MH Measures

The quality assessment of the psychometric properties in terms of reliability and validity of the MH measures as they appeared in the papers/studies indicated overall summary scores ranging from 0% (i.e., the relevant properties not reported; (Tasse & Lecavalier, 2000)) to 89% (i.e., the majority of the properties documented in large sample and found to be good/excellent properties; (Einfeld & Tonge, 1995)) (Table 4).

All measures except the BPC and CBI were supported by evidence regarding internal consistency, and in general, the internal consistency of the scales across instruments was

adequate (i.e., 0.70–0.79) to good/excellent (≥ 0.80) (see Table 1 and Method for more details). Evidence of interrater reliability was found for all measures with the exception of the CBI and Reiss; however, with few exceptions (i.e., BPI-01 and DBC), the evidence indicated inadequate agreement (i.e., < 0.60) in most instances. In terms of consistency over time, although there was no evidence found (i.e., it was not examined/reported) for the CBI, Reiss, and SDQ, all other measures were supported by adequate (i.e., 0.60–0.69) or good/excellent test–retest reliability (i.e., ≥ 0.70) with the exception of the BPC (i.e., inadequate reliability: ≤ 0.60). However, studies examining test–retest reliability were inadequate in terms of small sample sizes ($N < 100$), although there were some exceptions (ASEBA: Dekker et al., 2002a, b, c; Wallander et al., 2006); DBC: (Einfeld & Tonge, 1995)).

Regarding the validity of the measures, little evidence of criterion-related validity and content validity was found. Most of the studies used clinician-rated diagnosis/caseness as a criterion or examined meaningful/hypothesized group differences in subscale scores across diagnostic groups (ABC: (Rojahn & Hessel, 1991); ASEBA: (Douma et al., 2006; Koskentausta et al., 2004); DBC: (Brereton et al., 2006; Clarke et al., 2003; Dekker et al., 2002a, b, c; Einfeld & Tonge, 1995; Hassiotis & Turk, 2012; Koskentausta & Almqvist, 2004); NCBRF: (Norris & Lecavalier, 2011; Reiss & Valenti-Hein, 1994)). Regarding the SDQ, Emerson (2005) reported correspondence between subscale scores and diagnoses from a diagnostic interview (Development and Well-Being Assessment; (Goodman et al., 2000) that had not been validated for persons with ID. We identified more reports of criterion-related validity (i.e., clinician-rated diagnosis/caseness/hypothesized group differences in subscale scores across diagnostic groups) that were reported as good/excellent (i.e., ≥ 0.35) for the DBC compared to the other measures, and no evidence on this aspect for the BPC, BPI-01, CBI, and WellSEQ (Table 4). Evidence of content validity was reported for most of the ID measures (CBI, DBC, NCBRF, Reiss, and WellSEQ) and for one non-ID measure (SDQ).

The majority of measures were supported by evidence of construct validity in terms of correlations between instruments assessing similar constructs, with the exception of the BPC and Reiss, where no evidence was found. Regarding the non-ID instruments, evidence of construct validity was reported for the ASEBA and SDQ, where ID instruments were the most commonly used benchmarks (in alphabetical order: ABC, BPI-01, DBC, NCBRF, and Psychopathology Instrument for Mentally Retarded Adults) (see Table 2). Likewise, evidence of construct validity was reported for the ID instruments, where the other ID measures were most often used as benchmarks (in alphabetical order: ABC, BPI-01, DBC, and NCBRF) (Tables 2 and 4). In relation to

Table 4 Quality assessment of instruments

Instrument/study	Internal consistency Max score: 6	Test-retest reliability Max score: 6		Interrater reliability Max score: 6		Criterion validity Max score: 6	Content validity Max score: 3	Construct validity Max score: 9		Sum score/%	
		N size	Size of coeffic	N size	Size of coeffic			N size	Factor analysis		Correlation similar con-structs
ABC-C											
Brown et al. (2002)	3	0	0	0	0	0	0	3	2	0	11/31%
Chadwick et al. (2000)	0	0	0	1	2	0	0	1	0	2	6/17%
Freund & Reiss, 1991. Parent	2	3	1	3	1	1	0	2	3	0	16/44%
Teacher	2	3	1	2	1	1	0	2	3	0	15/42%
Marshburn & Aman, 1992)	3	3	0	0	0	0	0	3	2	0	11/31%
Rojahn & Helsel, 1991)	2	3	0	0	2	1	0	2	2	0	17/47%
Sansone et al. (2012)	0	0	0	0	0	0	0	3	1	0	4/11%
ABC Total Score											
ASEBA											
Borthwick-Duffy et al. (1997)	0	0	0	0	0	0	0	1	2	0	3/8%
Braga et al. (2018)	0	0	0	0	0	0	0	1	0	3	4/11%
Dekker et al. (2002a, b, c)											
Parent	3	2	3	3	3	1	0	3	0	3	21/58%
Teacher	3	2	0	0	3	1	0	3	0	3	15/42%
Dieleman et al. (2018)	1	2	0	0	0	0	0	0	0	0	3/8%
Douma et al. (2006)	3	2	0	0	3	1	0	3	0	1	18/50%
Esbensen et al. (2018)	1	2	0	0	1	1	0	1	0	1	7/19%
Koskentausta et al. (2004)	0	0	0	0	0	0	0	1	0	3	6/17%
Jacola et al. (2014)	0	0	0	0	0	0	0	1	0	2	3/8%
Masi et al. (2002)	0	0	0	0	0	0	0	1	0	2	3/8%
Van Lieshout et al. (1998)	1	2	0	0	0	0	0	0	0	0	3/8%
Wallander et al. (2006)	3	3	3	3	0	0	0	0	0	0	12/33%
Wright, 2010)	1	3	0	0	0	0	0	1	0	3	8/22%

Table 4 (continued)

Instrument/study	Internal consistency		Test-retest reliability		Interrater reliability		Criterion validity		Content validity		Construct validity		Sum score/%	
	Max score: 6	Size of coeffic	Max score: 6	Size of coeffic	Max score: 6	Size of coeffic	Max score: 6	Size of coeffic	Max score: 3	Content validity	Max score: 9	N size		
	Sample (N) size	Size of coeffic	N size	Size of coeffic	N size	Size of coeffic	N size	Size of coeffic	Content validity	N size	Factor analysis	Correlation similar con-structs		
ASEBA Total														
<i>BPC</i>														
Coe et al. (1999)	0	0	0	0	1	1	0	0	0	0	0	0	0	106
Matson et al. (1984)	0	0	0	0	0	0	0	0	0	3	1	0	0	2/6%
Wolf, 1981)	0	1	1	1	1	1	0	0	0	0	0	0	0	4/11%
BPC Total														
<i>BPI-01</i>														
Baraldi et al. (2013)	1	2	0	0	0	0	0	0	0	1	0	2	0	6/17%
Mircea et al. (2010)	2	3	0	0	0	0	0	0	0	2	0	3	0	10/28%
Rojahn et al. (2010)	3	2	1	3	1	2	0	0	0	3	1	3	0	19/53%
Oubrahim & Combalbe, 2019)	3	2	0	0	1	3	0	0	0	3	3	0	0	15/42%
BPI-01 Total														
<i>CBI</i>														
Oliver et al. (2003)	0	0	0	0	0	0	0	0	3	1	0	2	0	50
<i>CBI Total</i>														
<i>DBC</i>														
Brereton et al. (2006)	0	0	0	0	0	0	3	3	0	0	0	0	0	6/17%
Clark et al. (2003)	0	0	0	0	0	0	1	2	0	0	0	0	0	3/8%
<i>Dekker et al. (2002b)</i>														
<i>Parent</i>	3	2	0	0	0	0	0	0	0	3	3	0	0	11/31%
<i>Teacher</i>	3	2	0	0	0	0	0	0	0	3	3	0	0	11/31%
<i>Dekker et al. (2002c)</i>														
<i>Parent</i>	3	2	1	2	1	3	3	3	0	3	0	3	0	24/67%
<i>Teacher</i>	3	2	1	3	1	3	3	3	0	3	0	3	0	25/69%
Einfield & Tonge, 1995)	3	2	3	3	3	3	1	3	3	3	2	3	0	32/89%
Hassiotis & Turk, 2012)	0	0	0	0	0	0	1	2	0	0	0	0	0	3/8%

Table 4 (continued)

Instrument/study	Internal consistency		Test-retest reliability		Interrater reliability		Criterion validity		Content validity		Construct validity		Sum score/%
	Max score: 6	Size of coeffic	Max score: 6	Size of coeffic	Max score: 6	Size of coeffic	Max score: 6	Size of coeffic	Max score: 3	Max score: 9	Max score: 9	Max score: 9	
	Sample (N) size	Size of coeffic	N size	Size of coeffic	N size	Size of coeffic	N size	Size of coeffic	Content validity	N size	Factor analysis	Correlation similar con-structs	
Hastings et al. (2001)	3	2	0	0	0	0	0	0	0	3	2	0	10/28%
Koskentausta & Almqvist, 2004)	0	0	0	0	1	2	1	0	0	2	0	3	11/31%
Tonge et al. (1996)	3	2	0	0	0	0	0	0	0	3	2	0	10/28%
Taffe et al. (2007)	0	0	0	0	0	0	3	3	0	0	0	0	6/17%
DBC Total													152
<i>NCBRF</i>													
Aman et al. (1996)													
<i>Parent</i>	3	3	0	0	2	1	0	0	3	3	3	3	21/58%
<i>Teacher</i>	3	3	0	0	2	1	0	0	3	3	3	0	18/58%
Mircea et al. (2010)	2	3	0	0	0	0	0	0	0	2	0	3	10/28%
Norris & Lecavallier, 2011)	3	3	0	0	0	0	1	2	0	3	2	2	16/44%
Rojahn et al. (2010)	3	2	1	3	1	2	0	0	0	3	1	3	19/53%
Tasse et al. (1996)	0	0	0	0	2	1	0	0	0	0	0	0	3/8%
<i>Parent</i>													
<i>Teacher</i>	0	0	0	0	2	1	0	0	0	0	0	0	3/8%
Tasse & Lecavallier, 2000)	0	0	0	0	0	0	0	0	0	0	0	0	0/0%
NCBRF Total													90
<i>Reiss Scales</i>													
Reiss & Valentini-Hein, 1994)	3	2	0	0	0	0	1	1	3	3	3	0	16/44%
Reiss Total													16
<i>SDQ</i>													
El-Keshky & Emam, 2015)	3	2	0	0	0	0	0	0	0	3	2	0	10/28%
Embregts et al. (2010)	1	2	0	0	0	0	0	0	0	0	0	0	3/8%
<i>Parent</i>													
<i>Teacher</i>	1	2	0	0	0	0	0	0	0	0	0	0	3/8%
<i>Self-report</i>	1	1	0	0	0	0	0	0	0	0	0	0	2/6%

Table 4 (continued)

Instrument/study	Internal consistency		Test-retest reliability		Interrater reliability		Criterion validity		Content validity		Construct validity		Sum score/%
	Max score: 6	Size of coeffic	Max score: 6	Size of coeffic	Max score: 6	Size of coeffic	Max score: 6	Size of coeffic	Max score: 3	Content validity	Max score: 9	Factor analysis	
	Sample (N) size	Size of coeffic	N size	Size of coeffic	N size	Size of coeffic	N size	Size of coeffic	Content validity	N size	Factor analysis	Correlation similar con-structs	
Emerson, (2005)	1	1	0	0	1	1	1	1	0	0	0	0	6/17%
Haynes et al. (2013)	2	1	0	0	0	0	0	0	1	2	1	0	7/19%
Kaptein et al. (2008)	3	2	0	0	0	0	3	3	0	0	0	0	11/31%
Murray et al. (2020)	0	0	0	0	0	0	0	0	0	3	0	2	5/14%
Rice et al. (2018)	0	0	0	0	0	0	0	0	0	1	0	2	3/8%
SDQ Total													50
<i>WellSEQ</i>													
Bostrom et al. (2016)	2	2	1	2	1	1	0	0	3	1	0	2	15/42%
WellSEQ Total													15

Quality sum score (possible range 0–36)

ABC Aberrant Behavior Checklist, ASEBA Achenbach System of Empirically Based Assessment, BPC Behavior Problem Checklist, BPI-01 Behavior Problem Inventory, CBI Challenging Behavior Interview, DBC Developmental Behavior Checklist, NCBRF Nisonger Child Behavior Rating Form, Reiss Reiss Scales for Children's Dual Diagnosis, SDQ Strength and Difficulties Questionnaire, WellSEQ Well-being in Special Education Questionnaire

^aDekker et al. (2002b)

^bDekker et al. (2002c)

sample sizes and reported evidence of construct validity, the NCBRF was examined in the most studies that were large enough ($N > 200$ in four studies), followed by the BPI-01 and DBC (both had $N > 200$ in two studies and $N = 100$ – 200 in one study), ASEBA ($N > 200$ in two studies), and SDQ ($N > 200$ in one study). Moreover, papers/studies examining the CBI and WellSEQ both reported evidence of construct validity using inadequate sample sizes ($N < 100$).

Exploratory factor analysis (EFA) was used with all measures except the CBI and WellSEQ, and these studies most often used principal component analysis (Table 2). The measure that had the factor structure (FS) examined in the most papers/studies was the ABC (five studies), followed by the DBC (four studies), NCBRF (three studies), BPI-01 (two studies), and ASEBA/BPC/Reiss (all one study each). In regard to the ABC, all studies except one reported adequate to good/excellent FS (Tables 2 and 4). In addition, Sansone et al. (2012) reported an inadequate FS in a syndrome-specific sample (Fragile X) and suggested an alternative FS, with one factor unchanged (inappropriate speech), four modified (irritability, hyperactivity, lethality/withdrawal, and stereotypy), and a new social avoidance factor. Borthwick-Duffy et al. (1997) reported an adequate FS for ASEBA–CBCL only for the broadband internalizing and externalizing factors, although the analysis was based on an inadequate sample size ($N < 100$). An inadequate FS was also reported for the BPC in a large study (Matson et al., 1984). The FS of the BPI-01 using confirmatory FA (CFA) was found to be good/excellent in one large study in a specialized ID institution in France and inadequate in a large special education sample in the US (Table 4). In regard to the DBC, all studies were large; most studies reported an adequate FS, and one reported a good/excellent FS, all by means of EFA (Table 4). Regarding the NCBRF, good/excellent FS was reported in one large study among outpatients using EFA, adequate FS in a large CFA study among special education students/outpatients, and inadequate FS in another large CFA study among special education students (Table 4). The only study that examined the Reiss was large and reported a good/excellent FS (Reiss & Valenti-Hein, 1994). The FS of the SDQ in terms of the broader internalizing and externalizing subscales (alongside the fifth prosocial subscale) was found to be adequate in one large study among students from Saudi Arabia and Oman using CFA (El-Keshky & Emam, 2015) and inadequate in a smaller sample ($N = 128$) of students from Australia examining the original five-factor structure (Table 4).

In relation to self-report, the ASEBA–YSR and WellSEQ were the only measures with evidence of reported adequate aspects of reliability and an adequate aspect of validity (see Table 4). However, the evidence was not confirmed by supporting studies.

Based on the EFPA review model (see Method), all studies examining each individual measurement tool were then included in the overall assessment of each measure (Table 5), allowing us to establish the weight of evidence for each measure.

As seen in Table 5, the DBC was the only measure with at least two aspects of reliability (i.e., test–retest and inter-rater) assessed as good/excellent by two studies, in addition to all validity aspects assessed with evidence of good/excellent with more than one supporting study in relation to criterion and construct validity (convergent validity). The ABC, NCBRF and BPI-01 had two or more aspects of reliability and validity assessed as good/excellent, but at least two aspects of reliability and validity, each in the good/excellent range, were not confirmed by a supporting study. The non-ID measure ASEBA had two aspects of reliability assessed as good/excellent, as reported by two studies, but only convergent validity was reported as good/excellent by supporting studies, and no other validity aspect was assessed in the good/excellent range. The remaining four measures (Reiss, CBI, SDQ, WellSEQ) had no aspects of reliability assessed as good/excellent with supporting studies, although the Reiss had two aspects of validity assessed as good/excellent with no supporting study, and comparably, the CBI/SDQ/WellSEQ had one aspect of validity assessed as good/excellent. The BPC had no aspect of reliability or validity assessed as good/excellent or adequate.

Furthermore, the average psychometric quality, based on the sum score (maximum possible quality score = 35; Table 4) for each measurement tool as they were scored during the quality assessment of the studies, indicated relatively large differences. In general, quality for the ID measures ($M = 12.03$, $SD = 7.30$) was better than for the non-ID measures ($M = 6.64$, $SD = 5.16$) (Table 5). Moreover, the average psychometric quality (Table 5) based on the quality assessment sum score was quite similar among the different ID measures, although the number of studies reporting psychometric properties for each measure greatly varied (e.g., DBC in 10 papers versus WellSEQ in 1 paper). Therefore, when examining, for instance, the ID measures Reiss and WellSEQ with a relatively high average psychometric quality score, it is important to be aware that the documentation was very limited, as shown in the associated standard deviation values in Table 5.

Discussion

Careful assessment of MH is recommended among all people with ID due to the high vulnerability of this population for developing MH disorders. Our systematic review on the measurement properties of general MH instruments used with children and adolescents with ID identified

Table 5 Summary of overall quality of the psychometric properties of each assessment

Assessment	Reliability			Validity				Overall quality assessment score <i>M (SD)</i>
	Internal consistency	Test–Retest	Inter-Rater	Criterion	Content	Construct		
						Factor structure	Convergent	
ABC	GE (4)	GE (1)	A (1) IA (2)	GE (1)	NR	GE (1) A (3) IA (1)	A (1)	11.43 (4.99)
ASEBA	GE (2) A (5)	GE (2)	IA (3)	A (1) IA (1)	NR	A (1)	GE (4) A (2) IA (2)	8.15 (6.32)
BPC	NR	IA (1)	IA (2)	NR	NR	IA (1)	NR	3.33 (1.15)
BPI-01	GE (1) A (3)	GE (1)	GE (1) A (1)	NR	NR	GE (1) IA (1)	GE (2) A (1)	12.50 (5.69)
CBI	NR	NR	NR	NR	GE (1)	NR	A (1)	6 (–)
DBC	A (5)	GE (2)	GE (2) A (1)	GE (4) A (2) IA (1)	GE (1)	GE (1) A (3)	GE (3)	12.67 (9.31)
NCBRF	GE (3) A (1)	GE (1)	A (1) IA (2)	A (1)	GE (1)	GE (1) A (1) IA (1)	GE (3) A(1)	11.25 (8.35)
Reiss	A (1)	NR	NR	IA (1)	GE (1)	GE (1)	NR	16 (–)
SDQ	A (3) IA (3)	NR	IA (1)	GE (1) IA (1)	IA (1)	A (1) IA (1)	A (2)	5.56 (3.24)
WellSEQ	A (1)	A (1)	IA (1)	NR	GE (1)	NR	A (1)	15 (–)

Numbers in parentheses indicate the number of studies that reported on a given psychometric property.

A adequate, *GE* good–excellent, *IA* inadequate, *NR* not reported, *ABC* Aberrant Behavior Checklist, *ASEBA* Achenbach System of Empirically Based Assessment, *BPC* Behavior Problem Checklist, *BPI-01* Behavior Problem Inventory, *CBI* Challenging Behavior Interview, *DBC* Developmental Behavior Checklist, *NCBRF* Nisonger Child Behavior Rating Form, *Reiss* Reiss Scales for Children's Dual Diagnosis, *SDQ* Strength and Difficulties Questionnaire, *WellSEQ* Well-being in Special Education Questionnaire

documentation for ten instruments. The instruments can be divided into two main groups: instruments specifically developed or adapted for the ID population (ID instruments: Aberrant Behavior Checklist [ABC], Behavior Problems Inventory [BPI-01], Challenging Behavior Inventory [CBI], Developmental Behavior Checklist [DBC], Nisonger Child Behavior Rating Form [NCBRF], Reiss Scales for Children's Dual Diagnosis [Reiss], and Well-Being in Special Education Questionnaire [WellSEQ]) and instruments developed for the general child population (non-ID instruments: Achenbach System of Empirically Based Assessment [ASEBA], Behavior Problem Checklist [BPC educational setting], and Strengths and Difficulties Questionnaire [SDQ]). All identified instruments were screening measures to be used in an initial assessment of MH problems. Of the identified instruments, only the ASEBA had DSM-oriented subscales. The other instruments, including the additional ASEBA subscales, were based on specific descriptors of children's functioning (e.g., from a literature review, case files, expert consultations, or other existing measures), which were then

refined through empirical results and most often from principal component analysis.

The main finding from the present systematic review was consistently better documentation of reliability and validity in terms of higher overall average quality assessment (sum) scores for the ID instruments than for the non-ID instruments. Overall, there were comparable average quality assessment sum scores among the different ID instruments in situations where we identified measures with the most papers reporting psychometric properties (i.e., ABC, BPI-01, DBC, and NCBRF). For the ID instruments CBI, Reiss, and WellSEQ, the findings were more limited due to very little documentation (i.e., one paper each reporting psychometric properties). Regarding the non-ID instruments, the ASEBA gained a higher overall quality score than the other non-ID instruments (i.e., BPC and SDQ). Nevertheless, the average overall quality score for the ASEBA was lower than that for the ID instruments ABC, BPI-01, DBC, and NCBRF.

When examining the overall assessment of each measure in more detail, the DBC was the only measure with most

aspects of reliability (test–retest and interrater) and all aspects of validity (criterion, content, factor structure, and convergent validity) assessed as good/excellent, with more than one supporting study for at least two aspects of reliability and validity. The other ID instruments, the ABC, BPI-01, and NCBRF, had several aspects of reliability and validity assessed as good/excellent but fewer supporting studies than the DBC. Regarding the non-ID instruments, the ASEBA had two aspects of reliability (internal consistency and test–retest) assessed as good/excellent by two studies, however, with the exception of convergent validity, other validity aspects were not assessed as good/excellent. There was less evidence for SDQ suitability in terms of reliability and validity compared to ASEBA suitability. Based on the documentation identified for the BPC (i.e., no aspects assessed as good/excellent or adequate), we would not recommend the continued use of this instrument in its current form for this population, and this is probably reflected by the most recent identified study using the BPC being 22 years old (Coe et al., 1999). Regarding documentation of construct validity, in terms of correlations between instruments measuring similar constructs (convergent validity), most of the studies using non-ID measures (e.g., the ASEBA) used ID instruments as benchmarks. Moreover, documentation of construct validity in terms of factor structure was limited for both the non-ID measures ASEBA and SDQ, and these analyses favored the use of the broadband scales (i.e., internalizing and externalizing scales) over the more specific subscales.

It is important to emphasize that the vast majority of studies reporting psychometric properties in the present systematic review involved samples primarily consisting of children and adolescents with a borderline to moderate ID level. This finding is consistent with the findings from a relatively recent systematic review among people of all age groups with severe or profound ID, which found no eligible studies (i.e., at least 70% of the sample within a severe/profound ID level) reporting psychometric properties of measures for children and adolescents (Flynn et al., 2017). Whether the various instruments are suitable for children and adolescents with severe and profound ID is therefore largely unknown and should be investigated in future studies. Furthermore, regarding the ID status of the participants, the majority of the studies in the present systematic review used an administrative operationalization of ID status (e.g., school placement). Accordingly, with few exceptions, a formal IQ assessment or adaptive assessment was not conducted or reported. An implication of this is that the ID concept/condition was loosely defined; therefore, we cannot rule out that the studies included children and adolescents who would not qualify for a formal ID diagnosis.

The perspective of the child or adolescent in terms of self-report measures was very limited, as identified in the present review. The vast majority of studies used informant-based

measures completed by parents/caregivers, teachers and (health) care staff. We identified three self-report measures (i.e., the ASEBA, SDQ, and WellSEQ), in which the non-ID measure ASEBA–YSR and the ID measure WellSEQ reported very limited data indicating adequate reliability and validity mainly in samples with mild ID (Bostrom et al., 2016; Douma et al., 2006). However, the evidence was not confirmed by supporting studies. Further development and refinement of the usage of self-reporting, if possible, will be an important development area for the field. The use of multiple informants, including the youths themselves, is recommended, as individuals who have difficulties conveying information on symptoms verbally may display these in varying ways, and no single informant is likely to have a complete overview of another person's life (Stratis & Lecavalier, 2015). The heterogeneity of ID suggests that a single measure able to identify MH problems across the ID population is unlikely to be constructed in the near future, thereby underscoring the importance of individualized, multimodal and multi-informant approaches to assessment (Halvorsen et al., 2022). MH assessment is recommended by the use of standardized measures where the clinician also considers the strengths and weaknesses of the instrument, which has been the focus of the current systematic review.

Our findings should be interpreted in the context of the strengths and limitations of the study. To our knowledge, this review is the first recent systematic review to examine the psychometric properties of measurement tools used to assess general MH problems in children and adolescents across the whole ID spectrum. We did not limit the review to ID instruments only, as the field (clinic and research community) is characterized by the use of ID and non-ID instruments. We limited the review to studies using mainly children/adolescent samples and did not include findings from studies that used mixed-age samples that also included adults above 25 years of age. We chose to do so because a mixed age range than includes adults can provide findings that are not necessarily transferable to children. Additionally, studies that reported only prevalence rates (or instrument mean scores of MH problems/disorders) in children and adolescents with ID were not eligible because they did not report psychometric properties. We did not evaluate the measure's norms as norming data for the measures was only reported by two of the studies (ABC: Marshburn & Aman, 1992; NCBRF; Tasse et al., 1996), and norms for measures published in manuals through publishers were not included. Another limitation of the study was that we did not calculate inter-rater reliability for the full-text review and data extraction. We did however calculate inter-rater reliability for the quality assessment for 20 randomly chosen studies reporting psychometric properties, and these assessments showed an excellent degree of correspondence ($r = 0.92$) for the sum scores. Finally, the vast majority of the identified measures

had one or more studies that reported psychometric properties for the non-English versions. It is important for future studies to establish linguistic equivalence and to determine consistency of the measure's psychometric properties.

Conclusion

This systematic review contributes to the field of MH assessment among children and adolescents with ID by examining the psychometric properties of measurement tools used to assess general MH problems in children and adolescents

with a borderline to moderate level of ID. Our findings support the use of standardized ID instruments as the first choice in an initial assessment. Very few self-report measures have been developed for children and adolescents with ID, and very few studies have examined their suitability. How to integrate the youths' perspectives in assessing MH problems is an important focus area in the future.

Appendix I PRISMA 2020 Checklist

Section and Topic	Item #	Checklist item	Location where item is reported
TITLE			
Title	1	Identify the report as a systematic review.	Titlepage 1
ABSTRACT			
Abstract	2	See the PRISMA 2020 for Abstracts checklist.	Page 2
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of existing knowledge.	Page 3-4
Objectives	4	Provide an explicit statement of the objective(s) or question(s) the review addresses.	Page 4
METHODS			
Eligibility criteria	5	Specify the inclusion and exclusion criteria for the review and how studies were grouped for the syntheses.	Page 4-5
Information sources	6	Specify all databases, registers, websites, organisations, reference lists and other sources searched or consulted to identify studies. Specify the date when each source was last searched or consulted.	Page 6
Search strategy	7	Present the full search strategies for all databases, registers and websites, including any filters and limits used.	Appendix II
Selection process	8	Specify the methods used to decide whether a study met the inclusion criteria of the review, including how many reviewers screened each record and each report retrieved, whether they worked independently, and if applicable, details of automation tools used in the process.	Page 6-7
Data collection process	9	Specify the methods used to collect data from reports, including how many reviewers collected data from each report, whether they worked independently, any processes for obtaining or confirming data from study investigators, and if applicable, details of automation tools used in the process.	Page 7
Data items	10a	List and define all outcomes for which data were sought. Specify whether all results that were compatible with each outcome domain in each study were sought (e.g. for all measures, time points, analyses), and if not, the methods used to decide which results to collect.	Page 7
	10b	List and define all other variables for which data were sought (e.g. participant and intervention characteristics, funding sources). Describe any assumptions made about any missing or unclear information.	Page 7
Study risk of bias assessment	11	Specify the methods used to assess risk of bias in the included studies, including details of the tool(s) used, how many reviewers assessed each study and whether they worked independently, and if applicable, details of automation tools used in the process.	Page 7-8
Effect measures	12	Specify for each outcome the effect measure(s) (e.g. risk ratio, mean difference) used in the synthesis or presentation of results.	N/A
Synthesis methods	13a	Describe the processes used to decide which studies were eligible for each synthesis (e.g. tabulating the study intervention characteristics and comparing against the planned groups for each synthesis (item #5)).	N/A
	13b	Describe any methods required to prepare the data for presentation or synthesis, such as handling of missing summary statistics, or data conversions.	N/A
	13c	Describe any methods used to tabulate or visually display results of individual studies and syntheses.	N/A
	13d	Describe any methods used to synthesize results and provide a rationale for the choice(s). If meta-analysis was performed, describe the model(s), method(s) to identify the presence and extent of statistical heterogeneity, and software package(s) used.	N/A
	13e	Describe any methods used to explore possible causes of heterogeneity among study results (e.g. subgroup analysis, meta-regression).	N/A
	13f	Describe any sensitivity analyses conducted to assess robustness of the synthesized results.	N/A
Reporting bias assessment	14	Describe any methods used to assess risk of bias due to missing results in a synthesis (arising from reporting biases).	N/A
Certainty assessment	15	Describe any methods used to assess certainty (or confidence) in the body of evidence for an outcome.	N/A



PRISMA 2020 Checklist

Section and Topic	Item #	Checklist item	Location where item is reported
RESULTS			
Study selection	16a	Describe the results of the search and selection process, from the number of records identified in the search to the number of studies included in the review, ideally using a flow diagram.	Page 9
	16b	Cite studies that might appear to meet the inclusion criteria, but which were excluded, and explain why they were excluded.	Appendix III
Study characteristics	17	Cite each included study and present its characteristics.	Table 2
Risk of bias in studies	18	Present assessments of risk of bias for each included study.	Table 4
Results of individual studies	19	For all outcomes, present, for each study: (a) summary statistics for each group (where appropriate) and (b) an effect estimate and its precision (e.g. confidence/credible interval), ideally using structured tables or plots.	N/A
Results of syntheses	20a	For each synthesis, briefly summarise the characteristics and risk of bias among contributing studies.	N/A
	20b	Present results of all statistical syntheses conducted. If meta-analysis was done, present for each the summary estimate and its precision (e.g. confidence/credible interval) and measures of statistical heterogeneity. If comparing groups, describe the direction of the effect.	N/A
	20c	Present results of all investigations of possible causes of heterogeneity among study results.	N/A
	20d	Present results of all sensitivity analyses conducted to assess the robustness of the synthesized results.	N/A
Reporting biases	21	Present assessments of risk of bias due to missing results (arising from reporting biases) for each synthesis assessed.	N/A
Certainty of evidence	22	Present assessments of certainty (or confidence) in the body of evidence for each outcome assessed.	N/A
DISCUSSION			
Discussion	23a	Provide a general interpretation of the results in the context of other evidence.	Page 19-20
	23b	Discuss any limitations of the evidence included in the review.	Page 21
	23c	Discuss any limitations of the review processes used.	Page 21
	23d	Discuss implications of the results for practice, policy, and future research.	Page 21-22
OTHER INFORMATION			
Registration and protocol	24a	Provide registration information for the review, including register name and registration number, or state that the review was not registered.	Page 4
	24b	Indicate where the review protocol can be accessed, or state that a protocol was not prepared.	Page 4
	24c	Describe and explain any amendments to information provided at registration or in the protocol.	Page 7
Support	25	Describe sources of financial or non-financial support for the review, and the role of the funders or sponsors in the review.	Title page
Competing interests	26	Declare any competing interests of review authors.	Title page
Availability of data, code and other materials	27	Report which of the following are publicly available and where they can be found: template data collection forms; data extracted from included studies; data used for all analyses; analytic code; any other materials used in the review.	N/A

From: Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. *BMJ* 2021;372:n71. doi: 10.1136/bmj.n71
For more information, visit: <http://www.prisma-statement.org/>

Appendix II Search strategies

Date of search: 21st of February 2020

Date of updated search 13th of March 2021. The search was for the outcome measures included from the 2020 search, in Ovid databases limited to publication date since the first search.

Searches for ongoing and unpublished trials 16th of May 2021

Information specialist: Brynhildur Axelsdottir baxelsdottir@gmail.com

Total number of hits from all databases: 31.842

Additional records identified through other sources: 6

Total number of hits after removing duplicates: 20.850

PsycINFO <1967 to February Week 2 2020> (Ovid interface)

#	Searches
1	intellectual development disorder/or anencephaly/or crying cat syndrome/or down's syndrome/or adaptive behavior/or cognitive impairment/or fetal alcohol syndrome/or fragile x syndrome/or prader willi syndrome/or rett syndrome/or savants/ or williams syndrome/or developmental disabilities/or specific language impairment/or learning disorders/or exp learning disabilities/
2	((intellectual* or mental* or developmental* or learning* or cognit*) adj3 (disab* or impair* or handicap* or disorder* or subnormal* or deficient* or difficult*)),ti,ab
3	(retard* or rett* or prader willi or fragile X or Crying cat or cri du chat or savants or William* syndrome* or (down* adj2 syndrome*)),ti,ab
4	1 or 2 or 3
5	mental disorders/or child psychopathology/or adolescent psychopathology/or dual diagnosis/or comorbidity/or exp behavior problems/or behavior disorders/or conduct disorder/or exp disruptive behavior disorders/or emotional disturbances/
6	((mental* or emotional* or psych*) adj2 (disorder* or disturbance* or ill* or well-being or health* or disease* or abnormal* or patholog* or problem* or condition*)),ti,ab

#	Searches
7	((behavi* or conduct* or anger) adj3 (problem* or disorder*)).ti,ab
8	5 or 6 or 7
9	(childhood birth 12 yrs or adolescence 13 17 yrs).ag
10	(child* or kid or kids* or minors* or juvenil* or adoles* or youth* or youngster* or teen* or preteen* or boy or boys* or girl* or pediatri* or paediatr*).ti,ab,id
11	9 or 10
12	4 and 8 and 11
13	measurement/or exp psychometrics/or psychological assessment/ or behavioral assessment/or cognitive assessment/or "communication and language measures"/or "mental health and illness assessment"/or psychosocial assessment/or structured clinical interview/
14	(psychometric* or instrument* or inventor* or self-report* or validat* or validity or reliab* or norm or norms or (measurement* adj tool*)).ti,ab
15	13 or 14
16	4 and 8 and 12
17	15 and 16
18	limit 17 to yr="1980 -Current"

Ovid MEDLINE(R) and Epub Ahead of Print, In-Process & Other Non-Indexed Citations, Daily and Versions(R) < 1946 to February 19, 2020 > (Ovid interface)

#	Searches
1	intellectual disability/or cri-du-chat syndrome/or de lange syndrome/or down syndrome/ or mental retardation, x-linked/ or prader-willli syndrome/or rubinstein-taybi syndrome/or trisomy 13 syndrome/or wagr syndrome/or williams syndrome/ or Developmental Disabilities/ or exp Learning Disabilities/or Specific Language Disorder/
2	((intellectual* or mental* or developmental* or learning* or cognit*) adj3 (disab* or impair* or handicap* or disorder* or subnormal* or deficien* or difficult*)).ti,ab
3	(retard* or rett* or prader willi or fragile X or Crying cat or cri du chat or savants or William* syndrome* or (down* adj2 syndrome*)).ti,ab
4	1 or 2 or 3
5	Mental disorders/or "disruptive, impulse control, and conduct disorders"/or Child Behavior Disorders/or "Diagnosis, Dual (Psychiatry)"/or Problem Behavior/or "attention deficit and disruptive behavior disorders"/

#	Searches
6	((mental* or emotional* or psych*) adj2 (disorder* or disturbance* or ill* or well-being or health* or disease* or abnormal* or patholog* or problem* or condition*)).ti,ab
7	((behavi* or conduct* or anger) adj3 (problem* or disorder*)).ti,ab
8	5 or 6 or 7
9	exp Child/or exp Adolescent/or Minors/or exp Pediatrics/
10	(child* or kid or kids* or minors* or juvenil* or adoles* or youth* or youngster* or teen* or preteen* or boy or boys* or girl* or pediatri* or paediatr*).ti,ab,id
11	9 or 10
12	4 and 8 and 11
13	exp Psychiatric Status Rating Scales/or psychological tests/or behavior rating scale/or psychometrics/
14	(psychometric* or instrument* or inventor* or self-report* or validat* or validity or reliab* or norm or norms or (measurement* adj tool*)).ti,ab
15	13 or 14
16	12 and 15
17	limit 16 to yr="1980 -Current"

Embase < 1980 to 2020 Week 07 > (Ovid interface)

#	Searches
1	mental deficiency/or mental retardation malformation syndrome/ or down syndrome/or de lange syndrome/or fragile x syndrome/ or prader willi syndrome/or williams beuren syndrome/ or x linked mental retardation/ or wagr syndrome/or cat cry syndrome/or developmental disorder/or learning disorder/or language disability/
2	((intellectual* or mental* or developmental* or learning* or cognit*) adj3 (disab* or impair* or handicap* or disorder* or subnormal* or deficien* or difficult*)).ti,ab
3	(retard* or rett* or prader willi or fragile X or Crying cat or cri du chat or savants or William* syndrome* or (down* adj2 syndrome*)).ti,ab
4	1 or 2 or 3

#	Searches	#	Searches
5	mental disease/or comorbidity/or behavior disorder/or disruptive behavior/or problem behavior/ or conduct disorder/or emotional disorder/	4	((mental* or emotional* or psych*) adj2 (disorder* or disturbance* or ill* or well-being or health* or disease* or abnormal* or patholog* or problem* or condition*)).ti,ab
6	((mental* or emotional* or psych*) adj2 (disorder* or disturbance* or ill* or well-being or health* or disease* or abnormal* or patholog* or problem* or condition*)).ti,ab	5	((behavi* or conduct* or anger) adj3 (problem* or disorder*)).ti,ab
7	((behavi* or conduct* or anger) adj3 (problem* or disorder*)).ti,ab	6	4 or 5
8	5 or 6 or 7	7	(child* or kid or kids* or minors* or juvenil* or adoles* or youth* or youngster* or teen* or pre-teen* or boy or boys* or girl* or pediatr* or paediatr*).ti,ab
9	exp child/or exp adolescent/or exp adolescence/or exp childhood/or exp pediatrics/	8	3 and 6 and 7
10	(child* or kid or kids* or minors* or juvenil* or adoles* or youth* or youngster* or teen* or preteen* or boy or boys* or girl* or pediatr* or paediatr*).ti,ab,kw,hw,jx	CINAHL EBSCO	
11	9 or 10	S1	(MH "De Lange Syndrome") OR (MH "Cri-Du-Chat Syndrome") OR (MH "Down Syndrome") OR (MH "Intellectual Disability + ") OR (MH "Williams Syndrome") OR (MH "WAGR Syndrome") OR (MH "Prader-Willi Syndrome")
12	4 and 8 and 11	S2	(MH "Developmental Disabilities")
13	psychologic assessment/or psychologic test/or mental test/ or psychological interview/ or psychological rating scale/ or psychometry/or structured interview/	S3	(MH "Learning Disorders + ")
14	(psychometric* or instrument* or inventor* or self-report* or validat* or validity or reliab* or norm or norms or (measurement* adj tool*)).ti,ab	S4	TI ((intellectual* or mental* or developmental* or learning* or cognit*) N3 (disab* or impair* or handicap* or disorder* or subnormal* or deficient* or difficult*)) OR AB ((intellectual* or mental* or developmental* or learning* or cognit*) N3 (disab* or impair* or handicap* or disorder* or subnormal* or deficient* or difficult*))
15	13 or 14	S5	TI (retard* or rett* or prader willi or fragile X or Crying cat or cri du chat or savants or William* syndrome* or (down* N2 syndrome*)) OR AB (retard* or rett* or prader willi or fragile X or Crying cat or cri du chat or savants or William* syndrome* or (down* N2 syndrome*))
16	12 and 15	S6	S1 OR S2 OR S3 OR S4 OR S5
Health and Psychosocial Instruments < 1985 to January 2020 > (Ovid interface)		S7	(MH "Mental Disorders")
#	Searches	S8	(MH "Diagnosis, Dual (Psychiatry)")
1	((intellectual* or mental* or developmental* or learning* or cognit*) adj3 (disab* or impair* or handicap* or disorder* or subnormal* or deficient* or difficult*)).ti,ab	S9	(MH "Child Behavior Disorders")
2	(retard* or rett* or prader willi or fragile X or Crying cat or cri du chat or savants or William* syndrome* or (down* adj2 syndrome*)).ti,ab	S10	(MH "Disruptive Behavior")
3	1 or 2		

S11	TI ((mental* or emotional* or psych*) N2 (disorder* or disturbance* or ill* or well-being or health* or disease* or abnormal* or patholog* or problem* or condition*)) OR AB ((mental* or emotional* or psych*) N2 (disorder* or disturbance* or ill* or well-being or health* or disease* or abnormal* or patholog* or problem* or condition*))	S4	DE "Down Syndrome"
S12	TI ((behavi* or conduct* or anger) N3 (problem* or disorder*)) OR AB ((behavi* or conduct* or anger) N3 (problem* or disorder*))	S5	TI ((intellectual* or mental* or developmental* or learning* or cognit*) N3 (disab* or impair* or handicap* or disorder* or subnormal* or deficient* or difficult*)) OR AB ((intellectual* or mental* or developmental* or learning* or cognit*) N3 (disab* or impair* or handicap* or disorder* or subnormal* or deficient* or difficult*))
S13	S7 OR S8 OR S9 OR S10 OR S11 OR S12	S6	TI (retard* or rett* or prader willi or fragile X or Crying cat or cri du chat or savants or William* syndrome* or (down* N2 syndrome*)) OR AB (retard* or rett* or prader willi or fragile X or Crying cat or cri du chat or savants or William* syndrome* or (down* N2 syndrome*))
S14	(MH "Adolescence+ ") OR (MH "Child") OR (MH "Minors (Legal)")	S7	S1 OR S2 OR S3 OR S4 OR S5 OR S6
S15	(MH "Pediatrics")	S8	DE "Mental Disorders"
S16	TI (child* or kid or kids* or minors* or juvenil* or adoles* or youth* or youngster* or teen* or preteen* or boy or boys* or girl* or pediatri* or paediatr*) OR AB (child* or kid or kids* or minors* or juvenil* or adoles* or youth* or youngster* or teen* or preteen* or boy or boys* or girl* or pediatri* or paediatr*)	S9	DE "Comorbidity"
S17	S14 OR S15 OR S16	S10	DE "Multiple Disabilities"
S18	S6 AND S13 AND S17	S11	DE "Behavior Disorders"
S19	(MH "Psychometrics") OR (MH "Psychological Tests+")	S12	TI ((mental* or emotional* or psych*) N2 (disorder* or disturbance* or ill* or well-being or health* or disease* or abnormal* or patholog* or problem* or condition*)) OR AB ((mental* or emotional* or psych*) N2 (disorder* or disturbance* or ill* or well-being or health* or disease* or abnormal* or patholog* or problem* or condition*))
S20	(MH "Measurement Issues and Assessments")	S13	TI ((behavi* or conduct* or anger) N3 (problem* or disorder*)) OR AB ((behavi* or conduct* or anger) N3 (problem* or disorder*))
S21	(MH "Structured Interview")	S14	S8 OR S9 OR S10 OR S11 OR S12 OR S13
S22	TI (psychometric* or instrument* or inventor* or self-report* or validat* or validity or reliab* or norm or norms or (measurement* N tool*)) OR AB (psychometric* or instrument* or inventor* or self-report* or validat* or validity or reliab* or norm or norms or (measurement* N tool*))	S15	DE "Adolescents" OR DE "Early Adolescents" OR DE "Late Adolescents"
S23	S19 OR S20 OR S21 OR S22	S16	DE "Children" OR DE "Pre-adolescents" OR DE "Young Children"
S24	S18 AND S23	S17	DE "Youth" OR DE "Disadvantaged Youth"
S25	S18 AND S23	S18	DE "Pediatrics"
ERIC EBSCO			
S1	DE "Intellectual Disability"		
S2	DE "Developmental Disabilities"		
S3	DE "Learning Disabilities"		

		Updated search 13th of March 2021 APA PsycInfo <2002 to March Week 1 2021 >	
		#	Searches
S19	TI (child* or kid or kids* or minors* or juvenil* or adoles* or youth* or youngster* or teen* or preteen* or boy or boys* or girl* or pediatri* or paediatr*) OR AB (child* or kid or kids* or minors* or juvenil* or adoles* or youth* or youngster* or teen* or preteen* or boy or boys* or girl* or pediatri* or paediatr*)		
S20	S15 OR S16 OR S17 OR S18 OR S19		
S21	S7 AND S14 AND S20		
S22	DE "Psychological Testing"	2	(dbc* or cbcl* or sdq*).ti,ab
S23	DE "Psychometrics"	3	1 or 2
S24	DE "Structured Interviews"	4	intellectual development disorder/ or anencephaly/or crying cat syndrome/or down's syndrome/ or adaptive behavior/or cognitive impairment/or fetal alcohol syndrome/or fragile x syndrome/ or prader willi syndrome/or rett syndrome/or savants/or williams syndrome/or developmental disabilities/or specific language impairment/or learning disorders/or exp learning disabilities/
S25	DE "Measures (Individuals)"		
S26	DE "Behavior Rating Scales"		
S27	TI (psychometric* or instrument* or inventor* or self-report* or validat* or validity or reliab* or norm or norms or (measurement* N tool*)) OR AB (psychometric* or instrument* or inventor* or self-report* or validat* or validity or reliab* or norm or norms or (measurement* N tool*))	5	((intellectual* or mental* or developmental* or learning* or cognit*) adj3 (disab* or impair* or handicap* or disorder* or subnormal* or deficien* or difficult*).ti,ab
S28	S22 OR S23 OR S24 OR S25 OR S26 OR S27		
S29	S21 AND S28		
Web of Science Ebsco		6	(retard* or rett* or prader willi or fragile X or Crying cat or cri du chat or savants or William* syndrome* or (down* adj2 syndrome*).ti,ab
# 1 TS = ((intellectual* or mental* or developmental* or learning* or cognit*) NEAR/3 (disab* or impair* or handicap* or disorder* or subnormal* or deficien* or difficult*)) 147,112		7	4 or 5 or 6
# 2 TS = (retard* or rett* or prader willi or fragile X or Crying cat or cri du chat or savants or William* syndrome* or (down* NEAR/2 syndrome*)) 30,022		8	(childhood birth 12 yrs or adolescence 13 17 yrs).ag
# 3 #2 OR #1167,234		9	(child* or kid or kids* or minors* or juvenil* or adoles* or youth* or youngster* or teen* or preteen* or boy or boys* or girl* or pediatri* or paediatr*).ti,ab,id
# 4 TS = ((mental* or emotional* or psych*) NEAR/2 (disorder* or disturbance* or ill* or well-being or health* or disease* or abnormal* or patholog* or problem* or condition*))319,377		10	8 or 9
# 5 TS = ((behavi* or conduct* or anger) NEAR/3 (problem* or disorder*))58,355		11	7 and 10
# 6 #5 OR #4356,855		12	3 and 11
# 7 TS = (child* or kid or kids* or minors* or juvenil* or adoles* or youth* or youngster* or teen* or preteen* or boy or boys* or girl* or pediatri* or paediatr*)814,572		13	(202,002* or 202,003* or 202,004* or 202,005* or 202,006* or 202,007* or 202,008* or 202,009* or 202,010* or 202,011* or 202,012* or 202,101* or 202,102* or 202,103*).up
# 8 TS = (psychometric* or instrument* or inventor* or self-report* or validat* or validity or reliab* or norm or norms or (measurement* NEAR tool*))659,485		14	12 and 13
# 9 #8 AND #7 AND #6 AND #35,435			
Indexes = SSCI, A&HCI Timespan = 1980–2020			

Ovid MEDLINE(R) and Epub Ahead of Print, In-Process, In-Data-Review & Other Non-Indexed Citations and Daily < 2017 to March 09, 2021 >

#	Searches
1	(nisonger* or aberrant* or reiss or overt or deveurex or ((develop* or child*) adj behav* adj checklist*) or (strength* adj2 difficult* adj question*) or (well-being adj2 special*) or (disabilit* adj assessment*) or (challeng* adj behav* adj interview)).ti,ab
2	(dbc* or cbcl* or sdq*).ti,ab
3	1 or 2
4	intellectual disability/or cri-du-chat syndrome/or de lange syndrome/or down syndrome/or mental retardation, x-linked/or prader-willi syndrome/or rubinstein-taybi syndrome/or trisomy 13 syndrome/or wagr syndrome/or williams syndrome/or Developmental Disabilities/or exp Learning Disabilities/or Specific Language Disorder/
5	((intellectual* or mental* or developmental* or learning* or cognit*) adj3 (disab* or impair* or handicap* or disorder* or subnormal* or deficien* or difficult*).ti,ab
6	(retard* or rett* or prader willi or fragile X or Crying cat or cri du chat or savants or William* syndrome* or (down* adj2 syndrome*).ti,ab
7	4 or 5 or 6
8	exp Child/or exp Adolescent/or Minors/or exp Pediatrics/
9	(child* or kid or kids* or minors* or juvenil* or adoles* or youth* or youngster* or teen* or preteen* or boy or boys* or girl* or pediater* or paediatr*).ti,ab,id
10	8 or 9
11	7 and 10
12	3 and 11
13	(2020 feb or 2020 mar or 2020 apr or 2020 may or 2020 jun or 2020 jul or 2020 aug or 2020 sep or 2020 oct or 2020 nov or 2020 dec or 2021 jan or 2021 feb or 2021 mar).dp
14	(202,002* or 202,003* or 202,004* or 202,005* or 202,006* or 202,007* or 202,008* or 202,009* or 202,010* or 202,011* or 202,012* or 202,101* or 202,102* or 202,103*).dt
15	13 or 14
16	12 and 15

Embase < 1996 to 2021 Week 09 >

#	Searches
1	(nisonger* or aberrant* or reiss or overt or deveurex or ((develop* or child*) adj behav* adj checklist*) or (strength* adj2 difficult* adj question*) or (well-being adj2 special*) or (disabilit* adj assessment*) or (challeng* adj behav* adj interview)).ti,ab
2	(dbc* or cbcl* or sdq*).ti,ab
3	1 or 2

#	Searches
4	mental deficiency/or mental retardation malformation syndrome/or down syndrome/or de lange syndrome/or fragile x syndrome/or prader willi syndrome/or williams beuren syndrome/or x linked mental retardation/or wagr syndrome/or cat cry syndrome/ or developmental disorder/or learning disorder/or language disability/
5	((intellectual* or mental* or developmental* or learning* or cognit*) adj3 (disab* or impair* or handicap* or disorder* or subnormal* or deficien* or difficult*).ti,ab
6	(retard* or rett* or prader willi or fragile X or Crying cat or cri du chat or savants or William* syndrome* or (down* adj2 syndrome*).ti,ab
7	4 or 5 or 6
8	exp child/or exp adolescent/or exp adolescence/or exp childhood/or exp pediatrics/
9	(child* or kid or kids* or minors* or juvenil* or adoles* or youth* or youngster* or teen* or preteen* or boy or boys* or girl* or pediater* or paediatr*).ti,ab,kw,hw,jx
10	8 or 9
11	7 and 10
12	3 and 11
13	limit 12 to yr= "2020 -Current"

Searches for ongoing and unpublished trials

ClinicalTrials.gov

31 Studies found for: psychometric | Intellectual Disability OR mental health | Child (birth-17)

<https://clinicaltrials.gov/ct2/results?cond=Intellectual+Disability+OR+mental+health&term=psychometric+cntry=&state=&city=&dist=&Search=Search&age=0>

WHO International Clinical Trials Registry Platform (ICTRP)

<https://apps.who.int/trialsearch/>

intellect* OR mental*AND psychometric* propertie* limited clinical trials in children

Appendix III Supplementary material: Excluded studies with exclusion reasons

- Abdelghani, E. A., Apollonsky, N., Bernstein, B., & Tarazi, R. (2017). Steady-state cognitive function and pain severity in youth with sickle cell disease. *Blood. Conference: 59th Annual Meeting of the American Society of Hematology, ASH, 130*(Supplement 1). Exclusion reason: Wrong patient population
- Abozeid, M., Hamouda, M., Bahry, H., Elmadny, A., Alakbawy, A., & Ismail, A. (2011). Psychiatric morbidity among a sample of orphanage children in Cairo. *European Child and Adolescent Psychiatry, 1*(1), S166-S167. <https://doi.org/10.1007/s00787-011-0181-5>. Exclusion reason: Conference Abstract
- Accordino, R. E., Kidd, C., Polite, L. C., Henry, C. A., & McDougle, C. J. (2016). Psychopharmacological interventions in autism spectrum disorder. *Expert Opinion on Pharmacotherapy, 17*(7), 937-952. <https://doi.org/10.1517/14656566.2016.1154536>. Exclusion reason: Review
- Acharya, A. K. (2016). A study on adolescent mental disorders prevalent in our country. a study. *Indian Journal of Psychiatry, 58* (5 Supplement 1), S120. Exclusion reason: Wrong patient population
- Achenbach, T. M., & Dumenci, L. (2001). Advances in empirically based assessment: Revised cross-informant syndromes and new DSM-oriented scales for the CBCL, YSR, and TRF: Comment on Lengua, Sadowski, Friedrich, and Fisher (2001). *Journal of Consulting and Clinical Psychology, 69*(4), 699-702. <https://doi.org/10.1037/0022-006X.69.4.699>. Exclusion reason: Theoretical article/Comment
- Achenbach, T. M., Dumenci, L., & Rescorla, L. A. (2003). DSM-Oriented and Empirically Based Approaches to Constructing Scales From the Same Item Pools. *Journal of Clinical Child and Adolescent Psychology, 32*(3), 328-340. https://doi.org/10.1207/S15374424JCCP3203_02. Exclusion reason: Wrong patient population
- Achtergarde, S., Becke, J., Beyer, T., Postert, C., Romer, G., & Muller, J. M. (2014). Preschool-age male psychiatric patients with specific developmental disorders and those without: Do they differ in behavior problems and treatment outcome? *Infants & Young Children, 27*(4), 359-377. <https://doi.org/10.1097/IYC.000000000000020>. Exclusion reason: Wrong patient population
- Adamo, N., Michelini, G., Cheung, C. H. M., Buitelaar, J. K., Asherson, P., Rijdsdijk, F., & Kuntsi, J. (2019). Does Co-Occurring Anxiety Modulate ADHD-Related Cognitive and Neurophysiological Impairments? *Journal of Attention Disorders, 1087054719879499*. <https://doi.org/10.1177/1087054719879499>. Exclusion reason: Wrong patient population
- Adams, D., & Allen, D. (2001). Assessing the need for reactive behaviour management strategies in children with intellectual disability and severe challenging behaviour. *Journal of Intellectual Disability Research, 45*(4), 335-343. Exclusion reason: No psychometric information
- Adams, D., Handley, L., Simkiss, D., Walls, E., Jones, A., Knapp, M., . . . Oliver, C. (2018). Service Use and Access in Young Children with an Intellectual Disability or Global Developmental Delay: Associations with Challenging Behaviour. *Journal of Intellectual & Developmental Disability, 43*(2), 232-241. Exclusion reason: No psychometric information
- Adams, D., Paynter, J., Clark, M., Roberts, J., & Keen, D. (2019). The Developmental Behaviour Checklist (DBC) profile in young children on the autism spectrum: The impact of child and family factors. *Journal of Autism and Developmental Disorders, 49*(8), 3426-3439. <https://doi.org/10.1007/s10803-019-04067-0>. Exclusion reason: Wrong patient population
- Adams, H., de Blicke, E. A., Mink, J. W., Marshall, F. J., Kwon, J., Dure, L., . . . Pearce, D. A. (2006). Standardized assessment of behavior and adaptive living skills in juvenile neuronal ceroid lipofuscinosis. *Developmental Medicine & Child Neurology, 48*(4), 259-264. <https://doi.org/10.1017/S0012162206000570>. Exclusion reason: Not relevant measurement tool
- Adams, P. N. (1998). Utilizing behavioral diagnostics to reduce disruptive behavior in public school settings with children and adolescents with severe emotional and behavioral disorders. *Dissertation Abstracts International: Section B: The Sciences and Engineering, 58*(7-B), 3913. Exclusion reason: Not relevant outcome
- Adeosun, I. I., Ogun, O. C., Ijarogbe, T., Bello, A. O., Adegbohun, A., & Omigbodun, O. O. (2012). Self-injurious behaviour in Nigerian children with intellectual disability. *Neuropsychiatrie de l'Enfance et de l'Adolescence, 1*(1), S170. <https://doi.org/10.1016/j.neurenf.2012.04.253>. Exclusion reason: Conference Abstract
- Adrien, J.-L., Roux, S., Couturier, G., Malvy, J., Guerin, P., Debuly, S., . . . Barthelemy, C. (2001). Towards a new functional assessment of autistic dysfunction in children with developmental disorders: The Behaviour Function Inventory. *Autism, 5*(3), 249-264. <https://doi.org/10.1177/1362361301005003003>. Exclusion reason: Wrong patient population
- Advokat, C. D., Mayville, E. A., & Matson, J. L. (2000). Side effect profiles of atypical antipsychotics, typical antipsychotics, or no psychotropic medications in persons with mental retardation. *Research in Developmental Disabilities, 21*(1), 75-84. [https://doi.org/10.1016/s0891-4222\(99\)00031-1](https://doi.org/10.1016/s0891-4222(99)00031-1). Exclusion reason: Wrong patient population
- Agarwal, V., Sitholey, P., Kumar, S., & Prasad, M. (2001). Double-blind, placebo-controlled trial of clonidine in hyperactive children with mental retardation. *Mental Retardation, 39*(4), 259-267. <https://doi.org/10.1352/0047-6765%20010039040259>

282001%29039%3C0259:DBPCTO%3E2.0.CO;2. Exclusion reason: Outcome: psychopharmacology

Ahuja, A., Martin, J., Langley, K., & Thapar, A. (2013). Intellectual disability in children with attention deficit hyperactivity disorder. *Journal of Pediatrics*, *163*(3), 890-895. e891. <https://doi.org/10.1016/j.jpeds.2013.02.043>. Exclusion reason: No psychometric information

Aishworiya, R., Chan, P. F., Kiing, J. S. H., Chong, S. C., & Tay, S. K. H. (2016). Sleep Patterns and Dysfunctions in Children with Learning Problems. *Annals Academy of Medicine Singapore*, *45*(11), 507-512. Exclusion reason: Not relevant measurement tool

Aito, C., Mizoguchi, Y., Yamamoto, M., Seguchi, Y., Yatsuga, C., Nishimura, T., . . . Monji, A. (2019). Oxytocin levels and sex differences in autism spectrum disorder with severe intellectual disabilities. *Psychiatry Research*, *273*, 67-74. <https://doi.org/10.1016/j.psychres.2018.12.139>. Exclusion reason: Results not reported separately for children and adolescents

Akefeldt, A., Gillberg, C., & Larsson, C. (1991). Prader-Willi syndrome in a Swedish rural county: Epidemiological aspects. *Developmental Medicine & Child Neurology*, *33*(8), 715-721. <https://doi.org/10.1111/j.1469-8749.1991.tb14950.x>. Exclusion reason: No psychometric information

Aktepe, E., & Sonmez, Y. (2012). Psychiatric and organic comorbidities in children diagnosed with mental retardation in a university hospital. *Yeni Symposium: psikiyatri, noroloji ve davranis bilimleri dergisi*, *50*(2), 67-75. Exclusion reason: Conference Abstract

Alaimo, J. T., Barton, L. V., Mullegama, S. V., Wills, R. D., Foster, R. H., & Elsea, S. H. (2015). Individuals with Smith-Magenis syndrome display profound neurodevelopmental behavioral deficiencies and exhibit food-related behaviors equivalent to Prader-Willi syndrome. *Research in Developmental Disabilities*, *47*, 27-38. <https://doi.org/10.1016/j.ridd.2015.08.011>. Exclusion reason: Results not reported separately for children and adolescents

Alexander, R. T., Crouch, K., Halstead, S., & Piachaud, J. (2006). Long-term outcome from a medium secure service for people with intellectual disability. *Journal of Intellectual Disability Research*, *50*(4), 305-315. <https://doi.org/10.1111/j.1365-2788.2006.00806.x>. Exclusion reason: Results not reported separately for children and adolescents

Alfieri, P., Demaria, F., Licchelli, S., Santonastaso, O., Caciolo, C., Digilio, M. C., . . . Vicari, S. (2019). Obsessive Compulsive Symptoms and Psychopathological Profile in Children and Adolescents with KBG Syndrome. *Brain Sciences*, *9*(11). <https://doi.org/10.3390/brainsci9110313>. Exclusion reason: No psychometric information

Algozzine, B. (2012). *Disturbing Behavior Checklists" Technical Manual*. Retrieved from <http://search.ebscohost.com/login.aspx?direct=true&db=eric&AN=ED529898&site=ehost-live>

Algozzine, B., Ysseldyke, J., & Minnesota Univ, M. I. f. R. o. L. D. (1982). *Learning Disabilities as a Subset of School Failure: The Oversophistication of a Concept*. Retrieved from <http://search.ebscohost.com/login.aspx?direct=true&db=eric&AN=ED218852&site=ehost-live>

Algozzine, B., & Ysseldyke, J. E. (1983). Learning disabilities as a subset of school failure: The oversophistication of a concept. *Exceptional Children*, *50*(3), 242-246. Exclusion reason: No psychometric information

Allen, D., Lowe, K., Brophy, S., & Moore, K. (2009). Predictors of restrictive reactive strategy use in people with challenging behaviour. *Journal of Applied Research in Intellectual Disabilities*, *22*(2), 159-168. <https://doi.org/10.1111/j.1468-3148.2008.00484.x>. Exclusion reason: Results not reported separately for children and adolescents

Allen, D., Lowe, K., Moore, K., & Brophy, S. (2007). Predictors, costs and characteristics of out of area placement for people with intellectual disability and challenging behaviour. *Journal of Intellectual Disability Research*, *51*(6), 409-416. <https://doi.org/10.1111/j.1365-2788.2006.00877.x>. Exclusion reason: Results not reported separately for children and adolescents

Allgaier, A. K., Pietsch, K., Fruhe, B., Sigl-Glockner, J., & Schulte-Korne, G. (2012). SCREENING FOR DEPRESSION IN ADOLESCENTS: VALIDITY OF THE PATIENT HEALTH QUESTIONNAIRE IN PEDIATRIC CARE. *Depression and Anxiety*, *29*(10), 906-913. <https://doi.org/10.1002/da.21971>. Exclusion reason: Wrong patient population

Allgaier, A.-K., Fruhe, B., Pietsch, K., Saravo, B., Baethmann, M., & Schulte-Korne, G. (2012). Is the Children's Depression Inventory Short version a valid screening tool in pediatric care? A comparison to its full-length version. *Journal of Psychosomatic Research*, *73*(5), 369-374. <https://doi.org/10.1016/j.jpsychores.2012.08.016>. Exclusion reason: Wrong patient population

Alrojoloh, L., Beayno, A., Shamseddeen, W., Ghandour, L., Akoury Dirani, L., & Maalouf, F. (2019). 4.67 Chronic Physical Illness and Psychiatric Comorbidities in Lebanese Adolescents. *Journal of the American Academy of Child and Adolescent Psychiatry*, *58* (10 Supplement), S242. <https://doi.org/10.1016/j.jaac.2019.08.307>. Exclusion reason: Conference Abstract

Altepeter, T. S., & Breen, M. J. (1989). The Home Situations Questionnaire (HSQ) and the School Situations Questionnaire (SSQ): Normative data and an evaluation of psychometric properties. *Journal of Psychoeducational Assessment*, *7*(4), 312-322. <https://doi.org/10.1177/073428298900700404>. Exclusion reason: Wrong patient population

Althaus, M., Minderaa, R. B., & Dieneske, H. (1994). The assessment of individual differences between young children with a pervasive developmental disorder by means of behaviour scales which are derived from direct observation.

Journal of Child Psychology & Psychiatry & Allied Disciplines, 35(2), 333-349. Exclusion reason: Not relevant measurement tool

Alvarez, Z. C. (2016). Gender equivalence as perceived by students, parents, and teachers on the behavior assessment system for children, second edition. *Dissertation Abstracts International: Section B: The Sciences and Engineering*, 76(11-B(E)), No Pagination Specified. Exclusion reason: No intellectual disability information

Alves, D., Sousa, M., Henriques, M., & De Lemos, M. S. (2013). A triadic model for learning disabilities. *Atencion Primaria*, 2), 48-49. <https://doi.org/10.1016/S0212-6567%2813%2970032-5>. Exclusion reason: Conference Abstract

Al-Yagon, M. (2012). Subtypes of attachment security in school-age children with learning disabilities. *Learning Disability Quarterly*, 35(3), 170-183. Exclusion reason: Not relevant measurement tool

Al-Yagon, M. (2013). Adolescents with LD: Socioemotional and behavioral functioning and attachment relationships with fathers, mothers, and teachers. *European Child and Adolescent Psychiatry*, 1), S220. <https://doi.org/10.1007/s00787-013-0423-9>. Exclusion reason: Conference Abstract

Al-Yagon, M. (2016). Perceived Close Relationships with Parents, Teachers, and Peers: Predictors of Social, Emotional, and Behavioral Features in Adolescents With LD or Comorbid LD and ADHD. *Journal of Learning Disabilities*, 49(6), 597-615. Exclusion reason: Not relevant measurement tool

Amador, J. A., Forns, M., & Martorell, B. (2001). Sensitivity and specificity of parents' and teachers' ratings of Attention Deficit Hyperactivity Disorder. *Anuario de Psicologia*, 32(4), 65-78. Exclusion reason: Not relevant measurement tool

Aman, M., Buitelaar, J., De Smedt, G., Wapenaar, R., & Binder, C. (2005). Pharmacotherapy of Disruptive Behavior and Item Changes on a Standardized Rating Scale: Pooled Analysis of Risperidone Effects in Children with Subaverage IQ. *Journal of Child and Adolescent Psychopharmacology*, 15(2), 220-232. <https://doi.org/10.1089/cap.2005.15.220>. Exclusion reason: Outcome: psychopharmacology

Aman, M., Leone, S., Lecavalier, L., Park, L., Buican, B., & Coury, D. (2008). The Nisonger Child Behavior Rating Form: Typical IQ version. *International Clinical Psychopharmacology*, 23(4), 232-242. <https://doi.org/10.1097/YIC.0b013e3282f94ad0>. Exclusion reason: Wrong patient population

Aman, M. G. (1991). Review and evaluation of instruments for assessing emotional and behavioural disorders. *Australia and New Zealand Journal of Developmental Disabilities*, 17(2), 127-145. Exclusion reason: Review

Aman, M. G., Buican, B., & Arnold, L. (2003). Methylphenidate treatment in children with borderline IQ and

mental retardation: Analysis of three aggregated studies. *Journal of Child and Adolescent Psychopharmacology*, 13(1), 29-40. <https://doi.org/10.1089/104454603321666171>. Exclusion reason: No psychometric information

Aman, M. G., Burrow, W. H., & Wolford, P. L. (1995). The Aberrant Behavior Checklist-Community: factor validity and effect of subject variables for adults in group homes. *American Journal of Mental Retardation*, 100(3), 283-292. Exclusion reason: Adult population

Aman, M. G., De Smedt, G., Derivan, A., Lyons, B., & Findling, R. L. (2002). Double-blind, placebo-controlled study of risperidone for the treatment of disruptive behaviors in children with subaverage intelligence. *The American Journal of Psychiatry*, 159(8), 1337-1346. <https://doi.org/10.1176/appi.ajp.159.8.1337>. Exclusion reason: Outcome: psychopharmacology

Aman, M. G., & Gharabawi, G. M. (2004). Treatment of Behavior Disorders in Mental Retardation: Report on Transitioning to Atypical Antipsychotics, With an Emphasis on Risperidone. *The Journal of Clinical Psychiatry*, 65(9), 1197-1210. <https://doi.org/10.4088/JCP.v65n0907>. Exclusion reason: Review

Aman, M. G., Kern, R. A., McGhee, D. E., & Arnold, L. (1993). Fenfluramine and methylphenidate in children with mental retardation and ADHD: Clinical and side effects. *Journal of the American Academy of Child & Adolescent Psychiatry*, 32(4), 851-859. <https://doi.org/10.1097/00004583-199307000-00022>. Exclusion reason: Outcome: psychopharmacology

Aman, M. G., Kern, R. A., McGhee, D. E., & Arnold, L. (1993). Fenfluramine and methylphenidate in children with mental retardation and attention deficit hyperactivity disorder: Laboratory effects. *Journal of Autism and Developmental Disorders*, 23(3), 491-506. <https://doi.org/10.1007/BF01046052>. Exclusion reason: No psychometric information

Aman, M. G., Marks, R. E., Turbott, S. H., Wilsher, C. P., & Merry, S. N. (1991). Clinical effects of methylphenidate and thioridazine in intellectually subaverage children. *Journal of the American Academy of Child & Adolescent Psychiatry*, 30(2), 246-256. <https://doi.org/10.1097/00004583-199103000-00013>. Exclusion reason: Outcome: psychopharmacology

Aman, M. G., Norris, M., Kaat, A. J., Andrews, H., Choo, T. H., Chen, C., . . . Erickson, C. (2020). Factor structure of the aberrant behavior checklist in individuals with fragile x syndrome: Clarifications and future guidance. *Journal of Child and Adolescent Psychopharmacology*, 30(8), 512-521. <https://doi.org/10.1089/cap.2019.0177>. Exclusion reason: Results not reported separately for children and adolescents

Aman, M. G., & Rojahn, J. (1994). THE PSYCHOMETRIC CHARACTERISTICS OF THE PRESCHOOL BEHAVIOR QUESTIONNAIRE IN PRESCHOOLERS

- WITH DEVELOPMENTAL HANDICAPS. *Journal of Developmental and Physical Disabilities*, 6(4), 311-325. <https://doi.org/10.1007/bf02578418>. Exclusion reason: Not relevant measurement tool
- Aman, M. G., Singh, N. N., Stewart, A. W., & Field, C. J. (1985). The aberrant behavior checklist: a behavior rating scale for the assessment of treatment effects. *American Journal of Mental Deficiency*, 89(5), 485-491. Exclusion reason: Results not reported separately for children and adolescents
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Declarations

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