

Developing behavioural indicators for intellectual functioning and adaptive behaviour for ICD-11 disorders of intellectual development

M. J. Tassé,¹ G. Balboni,² P. Navas,³ R. Luckasson,⁴ M. A. Nygren,⁵ C. Belacchi,⁶ S. Bonichini,⁷ G. M. Reed^{8,9} & C. S. Kogan¹⁰

¹ Nisonger Center & Department of Psychology, The Ohio State University, Columbus, OH, USA

² Department of Philosophy, Social and Human Sciences and Education, University of Perugia, Perugia, Italy

³ INICO & Department of Personality, Assessment and Psychological Treatment, University of Salamanca, Salamanca, Spain

⁴ Department of Special Education, University of New Mexico, Albuquerque, NM, USA

⁵ American Association on Intellectual and Developmental Disabilities, Washington, DC, USA

⁶ Department of Communication, Sciences Humanities and International Sciences, University of Urbino Carlo Bo, Urbino, Italy

⁷ Department of Developmental Psychology and Socialization, University of Padua, Padua, Italy

⁸ Department of Mental Health and Substance Abuse, World Health Organization, Geneva, Switzerland

⁹ Department of Psychiatry, Columbia University Vagelos College of Physicians and Surgeons, New York, NY, USA

¹⁰ School of Psychology, University of Ottawa, Ottawa, Canada

Abstract

Background We present the work conducted to arrive at deriving behavioural indicators that could be used to guide clinical judgement in determining the presence and severity of deficits in intellectual functioning and adaptive behaviour for the purpose of making a diagnosis of disorders of intellectual development.

Methods An interdisciplinary expert panel provided guidance in developing behavioural indicators for intellectual functioning. A national dataset of adaptive behaviour on a sample of individuals with a diagnosis of intellectual disability was used to develop the behavioural indicators for the adaptive behaviour. The adaptive behaviour data were analysed using a cluster analysis procedure to define the different severity groupings by chronological age groups.

Results We present a series of tables containing behavioural indicators across the lifespan for intellectual functioning and adaptive behaviour, including conceptual, social and practical skills. These tables of behavioural indicators have been proposed for use in the clinical version of the 11th revision of the International Classification of Diseases and Related Health Problems (ICD-11) to be published by the World Health Organization.

Conclusions The proposed behavioural indicators for disorders of ID described in the present article and to be included in the ICD-11 Clinical Descriptions and Diagnostic Guidelines are put forth to assist professionals in making an informed clinical decision regarding an individual's level of intellectual functioning and adaptive behaviour for the purpose of making a determination about the presence and severity of disorders of ID.

Correspondence: Dr Marc J. Tassé, Nisonger Center-UCEDD, The Ohio State University, 1581 Dodd Drive, Columbus, OH 43210, USA (e-mail: tasse.1@osu.edu).

Keywords adaptive behaviour, classification, disorders of intellectual development, ICD-11, intellectual functioning, WHO

The World Health Organization (WHO) is finalising the 11th revision of the International Classification of Diseases and Related Health Problems (ICD-11) due to be approved by the World Health Assembly in May, 2019. The ICD is used worldwide to provide a common nomenclature and standard diagnostic tool for global health statistics and reporting, clinical applications, epidemiology and health management. The revision process is unprecedented in its global reach and the level of participation by practitioners around the world and is supported by a rigorous programme of field testing of the proposed guidelines via an Internet-based platform (Keeley *et al.* 2016) with more than 15 000 clinician members of the WHO Global Clinical Practice Network (Reed *et al.* 2015) as well as with patients in participating clinical settings at international field study centres.

The ICD-11 encompasses all health conditions including the chapter titled Mental, Behavioural and Neurodevelopmental Disorders. The WHO Department of Mental Health and Substance Abuse was responsible for coordinating the revision of this portion of the ICD, including the development of the clinical descriptions and diagnostic guidelines informed by the work of Working Groups of internationally representative experts (First *et al.* 2015). The focus of the revision of the ICD Mental, Behavioural and Neurodevelopmental Disorders chapter was to incorporate current scientific evidence into a set of diagnostic guidelines intended to maximise clinical utility and global applicability (International Advisory Group for the Revision of ICD-10 Mental and Behavioural Disorders 2011). With respect to the development of guidelines for the neurodevelopmental disorders, one particular concern for the revision was to ensure that the guidelines provided an improved basis for the identification of individuals with disorders of intellectual development (disorders of ID), formerly referred to as mental retardation in ICD-10 (Salvador-Carulla *et al.* 2011). Individuals with disorders of ID are a highly vulnerable group that often also experienced poor physical and mental health (Emerson *et al.* 2016). Individuals with disorders of ID are three to four times more likely to suffer from mental health problems (Reiss 1994; Rojahn & Tassé 1996; Stremme & Diseth 2000; Smiley 2005; Cooper *et al.* 2007; Fletcher *et al.* 2016), are often excluded from full participation in societies and experience significant discrimination (Bruininks *et al.* 1988; Llewellyn *et al.*

2015). Within low-income and middle-income countries, affected individuals are often not identified correctly because standardised and validated clinical tests by appropriately trained mental health professionals are not readily available (Maulik *et al.* 2011).

While appropriately normed, comprehensive standardised tests with robust psychometric properties are the 'gold standard' for identifying and describing levels of severity of disorders of ID and intellectual impairment in autism spectrum disorder (ASD); access to such assessments is lacking in many countries. Lack of access to appropriate standardised assessment instruments likely contributes to the substantial fluctuations in the reported prevalence rates of disorders of ID across countries (Maulik *et al.* 2011). Proper identification is critical to ensure accurate epidemiological data and eligibility determination for needed care and specialised services, including early intervention, educational supports, personal care, vocational supports and other services/supports, to improve overall functioning and quality of life. In an effort to address the gaps in the availability of standardised assessment instruments to assist professionals' clinical judgement in making a determination about the presence of disorders of ID, the WHO has taken the innovative step of developing behavioural indicators. In the field of developmental disabilities, clinical judgement is considered appropriate when it is based on respect for the person and emerges from the clinician's specialised training and experience, specific knowledge of the person and environments, extensive data and use of critical thinking skills (Schalock & Luckasson 2014). In this paper, we suggest that the behavioural indicators can be a useful part of the 'extensive data' used by a clinician when appropriate standardised tests or professionals trained to administer such instruments are unavailable. In these situations, a diagnosis of disorders of ID might be possible through the assessment of behavioural indicators to inform the professional's clinical judgement regarding the presence and severity of impairments in both intellectual functioning and adaptive behaviour across conceptual, social and practical skills. The proposed guidelines for the ICD-11 disorders of ID state:

Where appropriately normed and standardised tests are not available, diagnosis of Disorders of

intellectual development requires greater reliance on clinical judgment based on appropriate evidence and assessment of behavioural indicators. (WHO 2018)

The behavioural indicators are provided as a standardised alternative guide to establishing severity levels for disorders of ID and intellectual disability in the context of ASD based on observed and informant reported behaviours (Ayuso-Mateos & Kogan, in press). The ICD-11 behavioural indicators are intended to assist clinicians in interpreting all available data and to guide their clinical judgement in determining the individual's level of functioning across all three domains in order to support a diagnosis of disorders of ID and to assign the appropriate severity level. Accordingly, the behavioural indicators tables will be included in the version of the ICD-11 classification of Mental, Behavioural and Neurodevelopmental Disorders intended for implementation by health professionals in clinical settings, referred to as the Clinical Descriptions and Diagnostic Guidelines (First *et al.* 2015).

The behavioural indicators also allow for the characterisation of varied presentations of disorders of ID across the lifespan including specific symptomatology as well as degree of intellectual and adaptive behaviour impairment. Moreover, the proposed ICD-11 diagnostic guidelines for ASD require the clinician to assess for the presence of a co-occurring disorder of ID. Therefore, the behavioural indicators can be used to guide the determination of the severity level of the disorders of ID in ASD, with guidance to the clinician to place more weight on the conceptual and practical adaptive behaviour domains rather than the social adaptive behaviour domain because deficits in social functioning are a core feature of ASD (Ayuso-Mateos and Kogan, in press).

This article describes the development of behavioural indicators of intellectual functioning and adaptive behaviour across age groups and severity levels of disorders of ID, including in the context of ASD. We present the procedure and analyses used to develop the behavioural indicators across the four discrete severity levels (i.e. mild, moderate, severe and profound) based on the person's adaptive behaviour (i.e. conceptual, social and practical skills) across different age groups (0–5, 6–18 and 18+ years old). The behavioural indicators tables are currently

undergoing field testing in clinical settings in Brazil, India, Italy, Sri Lanka and the UK in order to determine their reliability and convergent validity with standardised measures. Results of the field studies will inform further revision of the guidelines and provide information on their psychometric properties.

Method

Participants

Adaptive behaviour

Adaptive behaviour data from a sample of 658 individuals (60.5% male) with a confirmed diagnosis of intellectual disability were analysed to develop behavioural indicators. This sample was drawn from the larger standardisation sample used to norm the translation of the Vineland Adaptive Behaviour Scale – Second Edition (Vineland-II) in Italy. This larger norming sample consisted of a representative sample of the Italian general population of 2 666 individuals, aged 0 to 90 years (for more details on this sample, see Balboni *et al.* 2016a).

The adaptive behaviour of these participants was assessed using the Italian version of the Vineland-II (Balboni *et al.* 2016a), a commonly used standardised measure of adaptive behaviour. Although all participants had a formal diagnosis of intellectual disability, information regarding the severity of intellectual disability was missing for 29.2% of the cases ($N = 192$). Of the 192 participants for whom a severity level of intellectual disability was missing, $n = 19$ were in the 0–5 age range, $n = 16$ were in the 6–18 age range and the remaining $n = 160$ were in the 18+ age range. The missing data in the 18 and older group included many older adults for whom the availability of standardised testing may not have been readily available at the time of diagnosis. For the remaining 466 cases, 20.1% were diagnosed with mild intellectual disability whereas 21.0% and 24.5% received a diagnosis of moderate and severe intellectual disability, respectively. Only 5.3% of the cases were considered as presenting profound intellectual disability. The diagnosis of intellectual disability was established using the ICD-10 (WHO 1992) criteria. Most individuals assessed were born in Italy (98.5%), and only seven cases had emigrated from other countries before the age of 3 years, having at least one parent who was Italian. Therefore, differences in adaptive behaviour due to

culture-specific characteristics are not expected to affect the results presented here.

The age of individuals with intellectual disability ranged from 2 to 66.0 years [$M = 29.1$; standard deviation (SD) = 17.2]. As expected, because of the lower life expectancy of individuals with intellectual disability, age distribution was slightly skewed and platykurtic, with a skewness of 0.199 (standard error = 0.095) and kurtosis of -1.076 (standard error = 0.190).

Two hundred thirteen individuals (32.4%) were younger than 16 years and, therefore, enrolled in compulsory (6 to 16 years old) or early childhood education (up to 6 years old). Most of them were attending to ordinary schools (93.7%). Over 88% of the adult population did not complete a secondary education.

Because the distribution of adaptive behaviour skills is generally known to be influenced by chronological age, participants were divided into three age groups (0–5, 6–18 and 18+ years old) whose main demographic characteristics are presented in Table 1.

Expert panel

In addition to the authors of this manuscript, an interdisciplinary panel of 15 intellectual and developmental disabilities experts was consulted for review and edits to our listings of behavioural indicators. This group of experts included professionals from psychology (7), paediatrics (1), psychiatry (2), special education (2), social work (1), speech and hearing (1) and dentistry (1). All professionals who participated on the expert panel had on average more than 10 years of clinical or research experience in the field of intellectual

disability and consisted of 14 experts from the USA and one from Spain. Eight members (53%) of the expert panel were women.

Instrument

Vineland Adaptive Behaviour Scale, Second Edition

The Vineland-II (Sparrow *et al.* 2005) is a well-established and widely used standardised scale of adaptive behaviour. The Vineland-II is a standardised norm-referenced assessment instrument that provides information on an individual's adaptive behaviour (from birth to 90 years old) across motor (0–6 years old), communication, daily living and socialisation skills. The Vineland-II provides standard scores ($M = 100$; $SD = 15$) for each of these domain scores as well as an adaptive behaviour composite score.

An Italian adaptation of the Vineland-II, approved by Pearson Editor (Minneapolis, USA), was used (Balboni *et al.* 2016a) for this study. This translation and adaptation of the original Vineland-II was conducted by a group of professionals with expertise in adaptive behaviour, development, neurodevelopmental disorders and psychometrics and followed the procedures recommended by Tassé & Craig (1999) as well as the International Test Commission Guidelines for Translating and Adapting Tests (International Test Commission 2005). Several studies have been conducted to assess the psychometric properties of the Italian adaptation of the Vineland-II. Reliability, internal consistency, test-retest, inter-rater (mother vs. father) and interviewer reliability were investigated and found to be good (Balboni *et al.* 2016a; Balboni *et al.* 2016b; Balboni *et al.* 2017).

Table 1 Demographic characteristics by age group

Age group	N	Gender		Age		Severity level				
		Male	Female	M	SD	Mild	Moderate	Severe	Profound	Unknown
0–5 years old	60	45 (75.0%)	15 (25.0%)	4.3	1.1	30 (50.0%)	10 (16.7%)	2 (3.3%)	1 (1.7%)	17 (28.3%)
6–18 years old	171	105 (61.4%)	66 (38.5%)	12.2	3.4	59 (34.5%)	46 (26.9%)	37 (21.6%)	14 (8.2%)	15 (8.8%)
18+ years old	427	248 (58.1%)	179 (41.9%)	39.3	12.0	43 (10.1%)	82 (19.2%)	122 (28.6%)	20 (4.7%)	160 (37.4%)

SD, standard deviation.

Procedure

Adaptive behaviour behavioural indicators

The data from the Vineland-II Italian standardisation sample were analysed, using cluster analysis procedures, to determine whether four discrete subgroups of adaptive behaviour deficits (i.e. mild, moderate, severe and profound) could be identified for each adaptive behaviour skill (i.e. conceptual, social and practical) in three different age groups (0–5, 6–18 and 18+ years old). Item stems were examined for skill content and organised by the three first authors into three broad categories of conceptual, social and practical skills. Largely, items from the Vineland-II communication skills fell into the conceptual domain, socialisation skills fell into the social domain and daily living skills fell into the practical domain. This grouping of behavioural indicators for adaptive behaviour was then validated and revised with input from the expert panel described previously.

Intellectual functioning behavioural indicators

An initial grouping of behavioural indicators for intellectual functioning was developed by aggregating cognitive skills identified from previously published references that included tables of behavioural indicators, including Grossman (1983) and Jacobson & Mulick (1996). Jacobson and Mulick compiled their listing of behavioural indicators from previously published data-based work using the Minnesota Developmental Programming System Behavioural Scales – Alternate Forms (Bock & Weatherman 1977). We, like Jacobson and Mulick, used a similar table of behavioural indicators found in Grossman (1983) for additional indicators and complement the indicators from Jacobson and Mulick. We compiled a complete listing of cognitively focused behavioural indicators and organised them by severity level and across chronological age (3 years and older). The behavioural indicators were sent electronically to the expert panel, described previously, for their review and endorsement of the intellectual functioning behavioural indicators.

Data analysis

K-means cluster analysis (Hartigan & Wong 1979) was performed on scores on Vineland-II domains

(communication, socialisation and daily living) for each three separate age groups: 0–5 years old ($N = 60$), 6–18 years old ($N = 171$) and 18 years old and above ($N = 427$). Although motor skills seem to be significantly related to adaptive behaviour in young children with neurodevelopmental disorders such as autism (MacDonald *et al.* 2013), motor skills domain scores were excluded from the analysis because they are more discriminating of physical limitations than intellectual disability (Tassé *et al.* 2012).

The goal of *k*-means is to minimise the sum of the squared error by consecutive iterations over a pre-specified number of clusters using the Euclidean metric for computing the distance between points (i.e. cases) and cluster centres (Jain 2010). The procedure keeps assigning cases and computing the cluster centres until changes are minimal. Consistent with intellectual disability theoretical framework, our aim was to empirically identify individuals as belonging to one of four clusters (i.e. 1: mild; 2: moderate; 3: severe; and 4: profound limitations in adaptive behaviour) that were found to be maximally independent of each other in terms of deficits in conceptual, social or practical skills, and contained individuals who are maximally homogeneous in terms of their limitations and abilities, enabling new cases to be assigned to one of these four groups within each adaptive behaviour domain for classification and diagnostic purposes.

Cluster analysis was performed blind to previous intellectual disability diagnostic grouping and Vineland-II composite scores: standardised residuals on each Vineland-II domain raw score obtained with a regression with chronological age as predictor were used as variables for clustering. Because *k*-means clustering is very sensitive to outliers (they could be selected as initial cluster centres), data were screened for normalcy and out of range values. No outliers were found (z scores lay between -0.19 and 2.28). Examination of the scatter plots and the histograms of residuals revealed approximately normally distributed variables, with some skewness across measures (especially for the 0 to 5 years old age group), indicating a tendency towards lower adaptive behaviour scores, a finding that is expected in a clinical sample (Papazoglou *et al.* 2013).

To verify the validity of our clusters, one-way analyses of variance were performed on each Vineland-II domain. Planned comparisons were carried out to test the *a priori* hypothesis that

individuals would score significantly lower as adaptive behaviour deficits increase as indicated by their category belonging (i.e. 1: mild; 2: moderate; 3: severe; and 4: profound).

To assess the stability of the cluster solution within each age group and adaptive behaviour domain, and due to the lack of any external criteria to establish criterion-referenced validity, the Punj & Stewart (1983) method of cross-validation was performed.

Data were analysed using SPSS for Windows (version 21.0, IBM, Armonk, NY, USA).

Results

Intellectual functioning

Table 2 presents the final set of behavioural indicators for intellectual functioning across the four severity levels and three chronological age groups.

Adaptive behaviour

Means and SDs of standardised residuals on each Vineland-II domain score for each cluster and age group are presented in Table 3. Four clusters were identified among age groups and domains. Adaptive behaviour skills increase with age, and this improvement is especially seen in individuals between the ages of 6 and 18 years old. From individuals who were 18 years old and older, overall adaptive behaviour skills plateaued, with some exceptions (i.e. social and daily living skills) within the groups with mild and moderate limitations.

To verify the validity of identified clusters, one-way analyses of variance were performed on each Vineland-II domain standard score ($M = 100$; $SD = 15$) within each age group. Welch F statistic is reported when the assumption of equal variances between groups was not met (i.e. communication and daily living skills domain). Planned comparisons revealed that within the 0–5 and 6–18 years old age groups, individuals with mild deficits in adaptive behaviour scored higher on all Vineland-II domain scores (i.e. communication, socialisation and daily living skills) than those with moderate, severe and profound deficits, as did the individuals with moderate deficits compared with those with severe and profound limitations, and individuals with severe deficits scored higher in all adaptive behaviour domains than the group of individuals within the

profound deficits group (Tables 4 and 5). These results provide support for the validity of four distinct severity/ability groupings that can be identified using adaptive behaviour as measured by the Vineland-II.

A detailed examination of differences between clusters for 0–5 and 6–18 years old age groups is presented in Tables 6 and 7.

Regarding the 18 years and older age group, once differences between means and SDs of each Vineland-II domain standard scores were analysed for each cluster, a clear floor effect was observed in those whose adaptive behaviour skills were most impaired. The variance of this group reached a value of zero in all Vineland-II domains such that all individuals in the ‘profound limitations’ group received a standard score of 20 in communication, socialisation and daily living domains. These results have significant implications from a clinical point of view, because it corroborates the existence of a group whose adaptive behaviour limitations are of a severity level that they are not able to perform most adaptive skills. Planned comparisons were limited to mild, moderate and severe clusters, in order to test if they differed significantly from each other (Table 8). Furthermore, although statistically significant differences were found within clusters for communications and social skills domains, the distinction between severe and profound deficits was difficult to establish when assessing daily living skills, because individuals within these clusters are not able to perform all the activities that their peers without disorders of ID are capable of performing (Table 9).

To assess the stability of the four-cluster solution as a means of assigning diagnoses of severity levels, Punj & Stewart (1983) method of cross-validation was carried out. Data from individuals with disorders of ID were randomly split into two halves or subsamples of data. A k -means cluster analysis was performed on the first half, fixing the number of clusters ($N = 4$), and then those centres were used to classify the other half of the sample. This cluster assignment was then compared with the result obtained from a new k -means clustering analysis on the second half of the sample, without constraints for the specified number of groups. These two alternatives were then compared by calculating a Kappa agreement coefficient. Landis & Koch (1977) proposed the following benchmarks to assist the interpretation of the strength of agreement as measured by the Kappa statistic: 0.21–0.40 = fair;

Table 2 Behavioural indicators of intellectual functioning

Severity level	Early childhood (Determination of severity should be reassessed after appropriate educational services and supports are provided)	Childhood and adolescence (Determination of severity should be reassessed after appropriate educational services and supports are provided)	Adulthood (Determination of severity should be reassessed after appropriate educational services and supports are provided)
Mild	<p>By the end of this developmental period:</p> <ul style="list-style-type: none"> • Most will develop language skills and be able to communicate needs. Delays in the acquisition of language skills are typical and, once acquired, are frequently less developed than typically developing peers (e.g. more limited vocabulary). • Most can tell or identify their gender and age. • Most can attend to a simple cause-effect relationship. • Most can attend to and follow up to two-step instructions. • Most can make one-to-one correspondence or match to sample (e.g. organise or match items according to shape, size and colour). • Most can communicate immediate future goals (e.g. desired activities for the day). • Most can demonstrate preferences in relationships, activities, food and dress. <p><i>Literacy/Numeracy</i></p> <ul style="list-style-type: none"> • Most will develop emergent reading and writing skills. • Most will be able to recognise letters from their name, and some can recognise their own name in print. 	<p>During this developmental period, there is evidence of the emergence of or presence of the abilities listed below.</p> <ul style="list-style-type: none"> • Most can communicate effectively. • Most can tell or identify their age. • Most can initiate/invite others to participate in an activity. • Most can communicate about past, present and future events. • Most can attend to and follow up to three-step instructions. • Most can identify different denominations of money (e.g. coins) and count small amounts of money. • Most can cross street intersections safely (look in both directions, wait for traffic to clear before crossing and obey traffic signals). In contexts without busy intersections, most can follow socially acceptable rules necessary to ensure personal safety. • Most can communicate their future goals and participate in their health care. • Most can identify many of their relatives and their relationships. • Most can build skills for future employment. • Most are naive in anticipating full consequences of actions or recognising when someone is trying to exploit him or her. • Some can orient themselves in the community and travel to new places using familiar modes of transportation. <p><i>Literacy/Numeracy</i></p> <ul style="list-style-type: none"> • Most can read sentences with five common words. • Most can count and make simple additions and subtractions. 	<ul style="list-style-type: none"> • Most can communicate fluently. • Many can tell or identify their birth date. • Most can initiate/invite others to participate in an activity. • Most can communicate about past, present and future events. • Most can attend to and follow up to three-step instructions. • Most can identify different denominations of money (e.g. coins) and count money more or less accurately. • Most can orient self in the community and learn to travel to new places using different modes of transportation with instruction/training. • Some can learn the road laws and meet requirements to obtain a driver's licence. Travel is mainly restricted to familiar environments. • Most can cross residential street intersections safely (look in both directions, wait for traffic to clear before crossing and obey traffic signals). In contexts without busy intersections, most can follow socially acceptable rules necessary to ensure personal safety. • Most can communicate their decisions about their future goals, health care and relationships. • Most can match skills needed for employment that they desire. • Most remain naive in anticipating full consequences of actions or recognising when someone is trying to exploit him or her. • Most have difficulty in handling complex situations such as managing bank accounts and long-term money management. <p><i>Literacy/Numeracy</i></p> <ul style="list-style-type: none"> • Most can read and write up to approximately a level expected for someone who has attended 7 to 8 years of schooling (i.e. start of middle school) and read simple material for information and entertainment.

Table 2. (Continued)

Severity level	Early childhood (Determination of severity should be reassessed after appropriate educational services and supports are provided)	Childhood and adolescence (Determination of severity should be reassessed after appropriate educational services and supports are provided)	Adulthood (Determination of severity should be reassessed after appropriate educational services and supports are provided)
Moderate	<ul style="list-style-type: none"> • Most will develop language skills and be able to communicate needs. Delays in the acquisition of language skills are typical and once acquired are often less developed than typically developing peers (e.g. more limited vocabulary). • Most can follow one-step directions. • Most can self-initiate activities and participate in parallel play. Some develop simple interactive play. • Some can attend to a simple cause-effect relationship. • Most can distinguish between 'more' and 'less'. • Some can make one-to-one correspondence or match to sample (e.g. organise or match items according to shape, size and colour). • Most can demonstrate preferences in relationships, activities, food and dress. <p><i>Literacy/Numeracy</i></p> <ul style="list-style-type: none"> • Most can recognise symbols. 	<ul style="list-style-type: none"> • Most can communicate their needs effectively. • Most can tell or identify their age and gender. • Most can initiate/invite others to participate in an activity. • Most can communicate immediate experiences. • Most can attend to and follow up to two-step instructions. • Some can cross residential street intersections safely (look in both directions, wait for traffic to clear before crossing and obey lights and signal signals). In contexts without busy intersections, some can follow socially acceptable rules necessary to ensure personal safety. • Some can go independently to nearby familiar places. • Most can communicate preferences about their future goals when provided with options. • Most can communicate their preferences in their relationships, activities, food and dress. • Most can build basic skills for future employment. • Most are naive in anticipating full consequences of actions or recognising when someone is trying to exploit him or her. <p><i>Literacy/Numeracy</i></p> <ul style="list-style-type: none"> • Most will develop emergent reading and writing skills. • Most can recognise their own name in print. • Most can choose correct number of objects. • Some can learn to count up to 10. 	<ul style="list-style-type: none"> • Most can count, understand mathematical concepts and make simple mathematical calculations. • Most can communicate with reasonable fluency in short sentences. • Most can tell or identify their age. • Most can initiate/invite others to participate in an activity. • Most can communicate immediate experiences. • Most can attend to and follow up to two-step instructions. • Most can cross residential street intersections safely (look in both directions, wait for traffic to clear before crossing and obey lights and signal signals). In contexts without busy intersections, some can follow socially acceptable rules necessary to ensure personal safety. • Some can travel independently to familiar places. • Most can communicate and act on their preferences about their future goals, health care and relationships. • Some can match skills needed for semi-skilled employment under some supervision. • Most remain naive in anticipating full consequences of actions or recognising when someone is trying to exploit him or her. <p><i>Literacy/Numeracy</i></p> <ul style="list-style-type: none"> • Most can read sentences with three common words and can achieve a reading and writing level up to that expected of someone who has attended 4 to 5 years of schooling (i.e. several years of primary/elementary school). • Most can choose correct number of objects. • Most can count to 10 and in some cases higher.
Severe	<ul style="list-style-type: none"> • Most will develop various simple non-verbal strategies to communicate basic needs. 	<ul style="list-style-type: none"> • Most can use communication strategies to indicate preferences. 	<ul style="list-style-type: none"> • Most can use communication strategies to indicate preferences. • Most can self-initiate activities.

Table 2. (Continued)

Severity level	Early childhood (Determination of severity should be reassessed after appropriate educational services and supports are provided)	Childhood and adolescence (Determination of severity should be reassessed after appropriate educational services and supports are provided)	Adulthood (Determination of severity should be reassessed after appropriate educational services and supports are provided)
	<ul style="list-style-type: none"> • Some can self-initiate activities. • Most can attend to and respond to others. • Most can separate one object from a group upon request. • Most can stop an activity upon request. <p><i>Literacy/Numeracy</i></p> <ul style="list-style-type: none"> • Most can make rudimentary marks that are pre-cursors to letters on page. 	<ul style="list-style-type: none"> • Most can self-initiate activities. • Most can attend to and recognise familiar pictures. • Most can follow one-step instructions and stop an activity upon request. • Most can distinguish between 'more' and 'less'. • Most can separate one object from a group upon request. • Most can differentiate locations and associate meanings (car, kitchen, bathroom, school, doctor's office, etc.) • Most can communicate preferences about their relationships. • Some can build skills for future employment. <p><i>Literacy/Numeracy</i></p> <ul style="list-style-type: none"> • Most can recognise symbols. • Many can recognise own name in print. 	<ul style="list-style-type: none"> • Most can attend to and recognise familiar pictures. • Most can follow one-step instructions and stop an activity upon request. • Most can distinguish between 'more' and 'less'. • Most can separate one object from a group upon request. • Most can differentiate locations and associate meanings (car, kitchen, bathroom, school, doctor's office, etc.) • Most can communicate and act on their preferences about their relationships. • Some can do small parts of jobs or activities with appropriate social and visual/verbal supports. <p><i>Literacy/Numeracy</i></p> <ul style="list-style-type: none"> • Most can recognise common pictures (e.g. house, ball and flower). • Many can recognise letters from an alphabet.
Profound	<ul style="list-style-type: none"> • Many will develop non-verbal strategies to communicate basic needs. • Most can attend to and respond to others. • Most can start or stop activities with prompts and aids. <p><i>Literacy/Numeracy</i></p> <ul style="list-style-type: none"> • They will not learn to read or write. 	<ul style="list-style-type: none"> • Most will develop non-verbal strategies to communicate basic needs and communicate preferences. • Most can recognise familiar people in person and in photographs. • Most can perform very simple tasks with prompts and aids. • Some can separate one object from a group upon request. • Some can differentiate locations and associated meanings (car, kitchen, bathroom, school, doctor's office, etc.) • Most can communicate their preferences about their relationships. 	<ul style="list-style-type: none"> • Most will develop non-verbal strategies and some utterances/ occasional words to communicate basic needs and communicate preferences. • Most can attend to and recognise familiar pictures. • Most can perform very simple tasks with prompts and aids. • Some can separate one object from a group upon request. • Some can differentiate locations and associated meanings (car, kitchen, bathroom, school, doctor's office, etc.) • Most can communicate their preferences about their relationships.

Table 3 Adaptive behaviour clusters within adaptive behaviour domain and age group

Age group	Domain	Adaptive behaviour cluster							
		Mild		Moderate		Severe		Profound	
		M	SD	M	SD	M	SD	M	SD
0–5 years old (N = 60)	Communication	(N = 6) 0.32	0.20	(N = 14) –0.29	0.16	(N = 20) –0.78	0.15	(N = 20) –1.23	0.14
	Social skills	(N = 6) 0.28	0.15	(N = 12) –0.20	0.16	(N = 25) –0.68	0.12	(N = 17) –1.09	0.12
	Daily living	(N = 13) 0.05	0.14	(N = 11) –0.39	0.14	(N = 18) –0.86	0.11	(N = 18) –1.21	0.12
6–18 years old (N = 171)	Communication	(N = 46) 1.21	0.23	(N = 59) 0.49	0.21	(N = 32) –0.48	0.24	(N = 34) –1.31	0.16
	Social skills	(N = 41) 1.36	0.30	(N = 50) 0.39	0.22	(N = 35) –0.35	0.19	(N = 45) –1.05	0.21
	Daily living	(N = 28) 1.45	0.23	(N = 48) 0.64	0.23	(N = 61) –0.16	0.26	(N = 34) –1.17	0.26
18+ years old (N = 427)	Communication	(N = 123) 1.23	0.19	(N = 108) 0.46	0.24	(N = 85) –0.39	0.27	(N = 111) –1.35	0.25
	Social skills	(N = 90) 1.56	0.21	(N = 100) 0.64	0.27	(N = 93) –0.27	0.24	(N = 144) –1.11	0.21
	Daily living	(N = 69) 1.68	0.26	(N = 100) 0.80	0.29	(N = 111) –0.26	0.28	(N = 147) –1.23	0.28

SD, standard deviation.

Table 4 Difference scores and planned contrasts within each domain score: 0–5 years old

0–5 years old (N = 60)							
		M	SD	F _{3,59}	Planned comparisons	t	P
Communication skills	Mild (N = 6)	72.5	12.5	33.7**	Mild > moderate, severe and profound	6.25	0.001
	Moderate (N = 14)	58.7	6.14		Moderate > severe and profound	5.89	0.001
	Severe (N = 20)	48.8	10.2		Severe > profound	4.80	0.001
	Profound (N = 20)	34.7	9.1				
Social skills	Mild (N = 6)	83.6	5.1	60.15**	Mild > moderate, severe and profound	7.96	0.001
	Moderate (N = 12)	73.1	9.3		Moderate > severe and profound	9.08	0.001
	Severe (N = 25)	58.1	8.01		Severe > profound	5.95	0.001
	Profound (N = 17)	44.4	4.6				
Daily living skills	Mild (N = 13)	86.1	7.8	33.9**	Mild > moderate, severe and profound	8.79	0.001
	Moderate (N = 11)	65.8	11.1		Moderate > severe and profound	3.40	0.001
	Severe (N = 18)	57.7	8.7		Severe > profound	2.29	0.026
	Profound (N = 18)	50.0	12.1				

**P < 0.001.

SD, standard deviation.

Table 5 Difference scores and planned contrasts within each domain standard score: 6–18 years old

		6–18 years old (N = 171)					
		M	SD	F _{3,170}	Planned comparisons	t	P
Communication skills [†]	Mild (N = 46)	69.2	18.9	123.4**	Mild > moderate, severe and profound	6.25	0.001
	Moderate (N = 59)	40.4	16.2		Moderate > severe and profound	5.89	0.001
	Severe (N = 32)	24.8	9.8		Severe > profound	4.80	0.026
	Profound (N = 34)	20.6	2.2				
Social skills	Mild (N = 41)	80.9	17.2	112.1**	Mild > moderate, severe and profound	17.08	0.001
	Moderate (N = 50)	46.4	16.3		Moderate > severe and profound	6.32	0.001
	Severe (N = 35)	33.7	15.9		Severe > profound	2.60	0.010
	Profound (N = 45)	24.9	9.1				
Daily living skills [†]	Mild (N = 28)	91.6	12.9	199.2**	Mild > moderate, severe and profound	18.93	0.001
	Moderate (N = 48)	59.7	20.4		Moderate > severe and profound	9.62	0.001
	Severe (N = 61)	33.1	15.9		Severe > profound	3.37	0.001
	Profound (N = 34)	24.6	8.4				

**P < 0.001.

[†]Not equal variances assumed.

SD, standard deviation.

0.41–0.60 = moderate; 0.61–0.80 = very good; and 0.81–1.00 = almost perfect. Results indicated the stability of our cluster solution (Table 10), with no significant differences in cluster assignment within the 6–18 and 18+ years old age groups. However, results indicated some variation in cluster assignment within the 0–5 years old age group. This is not surprising because adaptive behaviour skills in early childhood are only just emerging. A detailed examination of differences in cluster assignment showed that this variability occurred in most cases (77.0%) in the assignment of severe and profound categories.

Discussion

The use of standardised instruments to inform clinical judgement remains, when available, the gold standard. However, in many countries around the world, there is a limited availability of standardised assessment instruments or professionals qualified to administer standardised tests (Evers *et al.* 2017). Maulik *et al.* (2011) highlighted how the disparities in availability of comprehensive standardised assessment instruments in many parts of the world have had a deleterious impact on the accurate identification of people with disorders of ID. The availability of the proposed behavioural indicators may be a useful standardised guide, in the absence of the availability

of comprehensive standardised tests, to interpret observed and informant reported behaviours to inform clinical judgement when making a diagnostic and severity determination of disorders of ID in lieu of idiosyncratic methodologies. These behavioural indicators also provide a helpful guide to informing clinical judgement in interpreting the available data in making a determination of co-occurring ASD and disorders of ID.

We compiled a list of behavioural indicators for intellectual functioning based on existing literature and input and validation from an interdisciplinary panel of intellectual disability experts. This list of behavioural indicators is made available to help guide clinical judgement in situations when a comprehensive standardised test of intelligence, or a qualified professional to administer such an instrument, is not available. Caution should be used when using these behavioural indicators and the decision to rule-in or rule-out, the presence of significant deficits for the purpose of making a diagnostic determination should rest on information from multiple sources.

In order to develop the data-based behavioural indicators of adaptive behaviour functioning, we used a large Italian population dataset that was part of the norming sample of the Italian translation of the Vineland-II, a well-validated standardised adaptive behaviour scale originally developed in the USA. The

Table 6 Behavioural indicators of adaptive behaviour for the 0–5 years old

	Conceptual	Social	Practical
Severity level	Reasoning, planning, organising, reading, writing, memory, symbolic/internal representation and communication skills	Interpersonal competency (e.g. relationships), social judgement and emotion regulation	Self-care, recreation, employment (including domestic chores), health and safety and transportation
Mild	<ul style="list-style-type: none"> • Most can perform basic listening skills with a 15-min attention span. Most need help to sustain their attention for 30 min. • Most are able to follow simple two-step instructions. They need help following a three-step or 'if-then' type of instruction. • Most can state their age and name and identify close family members when asked. • Many have a 100-word vocabulary. Most ask 'wh' question (who, what, where and why), but most will need help using pronouns and tense verbs. • Most are not able to relate in detail their experiences or give a detailed account of their experiences. • Most will understand the simple concepts of time, space, distance and spatial relationships. <p><i>Literacy</i></p> <ul style="list-style-type: none"> • Many will not learn reading/writing skills. If present, reading skills will be limited to identifying some letters of the alphabet. Only some will be able to recognise their own name in print. 	<ul style="list-style-type: none"> • Most can perform independently basic skills related to social interaction such as imitation, showing affection to familiar persons as well as friend-seeking behaviour, expressing emotions and answering basic questions. • Most will need frequent encouragement and assistance in offering help to others, sharing interests or perspective taking. They are able to engage in play with others, even with minimal supervision although they will need assistance taking turns, following rules or sharing. • Most are able to demonstrate polite behaviour (saying 'please' and 'thank you') although they may need help apologising, demonstrating appropriate behaviour with strangers or waiting for the appropriate moment to speak in a social context. • Most will need help to modify their behaviour in accordance to changing social situations or when there is a change in their routines. 	<ul style="list-style-type: none"> • Most will learn the majority of basic eating, washing face and hands, toileting and self-care skills. • Most will acquire independence in dressing (may need help to button/fasten clothes) and night-time continence. • Most can use simple household devices. • Most will need supports with bathing, using utensils, toileting such as cleaning after passing stools and brushing teeth. • Most can learn the concept of danger and avoid hot objects. • Most will be able to independently help with simple household chores but will often need assistance with more complex tasks such as putting away clothes or cleaning up their rooms. • With some assistance, most can learn the concept of money (although will be unable to learn the value of the different denominations, e.g. coins), can count to 10 and follow basic rules around the home. • Will be unable to learn days of the week, learn and remember phone numbers.
Moderate	<ul style="list-style-type: none"> • Most will independently point to common objects when asked and follow one-step instructions. Some will need supports to perform basic skills such as following simple two-step instructions. • Most can state their own name. • Most will have basic communication skills such as formulating one-word requests, using simple phrases, using other people's customary ways of addressing (mommy, papa and sister) but will need help with full names. • Most speak at least 50 words and name/point at least 10 objects when asked. 	<ul style="list-style-type: none"> • Most are able to perform independently some of the basic skills related to social interaction, although they might need some help making new friends, answering basic social questions or expressing their emotions. • Most are able to play with peers and show interest in play/interact with others but may need more supervision/supports to play cooperatively with others, play symbolically, take turns, follow rules of a game and share objects. • Most would not be able to perform more complex social skills involving inter-personal interactions such as 	<ul style="list-style-type: none"> • Most can learn the majority of basic eating skills but may need more assistance than their same-age peers with toilet training and dressing themselves (some help needed to button/fasten). • Most will learn to ask to use the toilet, drink from a cup and feed themselves with a spoon, and some may become toilet trained during daytime. Will often need supports with brushing teeth, bathing and using utensils. • With some supports, most can learn to use simple household devices and carry out simple chores such as putting away their footwear.

Table 6. (Continued)

	Conceptual	Social	Practical
Severity level	Reasoning, planning, organising, reading, writing, memory, symbolic/internal representation and communication skills	Interpersonal competency (e.g. relationships), social judgement and emotion regulation	Self-care, recreation, employment (including domestic chores), health and safety and transportation
	<ul style="list-style-type: none"> • Most are not able (or will need a lot of support) to use past tense verbs, pronouns or 'wh' questions. <p><i>Literacy</i></p> <ul style="list-style-type: none"> • Most will not learn reading or writing skills but know how to use pens and pencils and make marks on a page. 	<ul style="list-style-type: none"> • offering help to others, empathy, sharing their interests with others or perspective taking. 	<ul style="list-style-type: none"> • Most can learn the concept of danger although some assistance will be needed when using sharp objects (e.g. scissors). • Many will be able to help with very simple household chores such as cleaning fruits and vegetables. • Most will not acquire the understanding of the concept of money and time.
Severe	<ul style="list-style-type: none"> • Most can perform independently the most basic skills such as wave goodbye, identify parent/caregiver, point to a desired object and point or gesture to indicate their preference, and understand the meaning of no and yes. • Most will need supports to point to/ identify common objects, follow one-step instructions and sustain their attention to listen to a story for at least 5 min. • Most would not be able to state their age correctly and will speak less than 50 recognisable words. They may need help formulating one-word requests and using first names or nicknames of familiar people, naming objects, answering when called upon and using simple phrases. <p><i>Literacy</i></p> <ul style="list-style-type: none"> • Most will not learn reading and writing skills. 	<ul style="list-style-type: none"> • Most will need help to perform basic social skills such as imitation or showing interest and preferences in social interactions with their peers. • Most are able to show interest when someone else is playful and to play simple games. • Most will need significant supports to play in a cooperative way, play symbolically or seek others for play/ leisure activities. Most will also need significant help with transitions – changing from one activity to another or using polite social responses such as 'please' and 'thank you'. • Most would not be able to engage in turn taking, following rules or sharing objects. 	<ul style="list-style-type: none"> • Most can learn many of the basic eating skills but will need substantially more assistance than their same-age peers with toilet training, learning to use a cup and spoon and putting on clothes. • Most can learn to use simple household devices with consistent supports. • Most will have difficulty learning to master many self-care skills, including using the toilet independently. • Most will not be able to learn the concept of danger and will require close supervision in areas such as the kitchen. • Some may learn basic cleaning skills such as washing hands but will consistently need assistance. • Most will not learn the concept of money, time or numbers.
Profound	<ul style="list-style-type: none"> • Most will master only the most basic communication skills such as turning their eye gaze and head towards a sound. • They will need prompting to orient towards people in their environment, respond when their name is called and understand the meaning of yes and no. • They are able to cry when hungry or wet, smile and make sounds of 	<ul style="list-style-type: none"> • Most may be able to perform only the most basic social skills such as smiling, orienting their gaze, looking at others/ objects or showing basic emotions. • Some might be able to perform other basic social skills with a lot of support/ prompting, such as showing preference for people or objects, imitating simple movements and expressions or engaging in reciprocal social interactions. 	<ul style="list-style-type: none"> • Most will need help performing even the most basic eating, dressing, drinking and bathing skills. • Most will be unable to learn to be independent using the toilet, being dry during the day, bathing or washing self at the sink and using a fork and knife. • Most will need constant supervision around potentially dangerous situations in the home and community.

Table 6. (Continued)

	Conceptual	Social	Practical
Severity level	<p>Reasoning, planning, organising, reading, writing, memory, symbolic/internal representation and communication skills</p> <p>pleasure, but it may be difficult to get their attention. <i>Literacy</i></p> <ul style="list-style-type: none"> • They will not learn to read or write. 	<p>Interpersonal competency (e.g. relationships), social judgement and emotion regulation</p> <ul style="list-style-type: none"> • Some can show interest when someone else is playful but will need a lot of supports to play simple games. Will have difficulty adapting to changes and transitions in activity/location. • Most will be unable to follow rules of a social game. 	<p>Self-care, recreation, employment (including domestic chores), health and safety and transportation</p> <ul style="list-style-type: none"> • Most will be unable to clean up after themselves and will need help with even basic chores, such as picking up belongings to put away. • Most will be not able to learn to independently use the telephone or other simple devices around the home.

results obtained from the statistical analyses on these data were then validated with a group of interdisciplinary clinicians with expertise in the field of intellectual disability. The development of the behavioural indicators for the intellectual functioning component was based on a review of literature, available tables of characteristic features by ability level and input from a second interdisciplinary panel of intellectual disability experts.

Interpretation of our study results and the proposed behaviour indicators must be placed in the context of some methodological limitations. A limitation of our study includes the small sample size for the youngest group of participants (0–5 years old). It is possible that our data would have yielded slightly different results with a larger sample, but we are confident that these results were verified and adjusted using the panel of clinical experts. Another limitation of this study is reliance on adaptive behaviour assessment results from an Italian sample, and the classification of these individuals may not fully generalise to individuals in low-income or middle-income countries. The challenge here remains the availability of a large data set of adaptive functioning assessments of individuals from low-income or middle-income countries. The field trials of the ICD-11 that are currently under way by the WHO will provide insight into the performance and clinical utility of the behavioural indicators in a wider range of countries. The behavioural indicators may need to

be revised depending on the results from these field studies.

We used the proposed four-level system of classification of disorders of ID, proposed in the ICD-11 (WHO 2018) consisting of mild, moderate, severe and profound. Although there is a strong tendency to classify conditions such as disorders of ID, exactly how and on what basis this is done continues to be debated (Schalock & Luckasson 2015; Shogren *et al.* 2017; Painter *et al.* 2018). The American Association on Intellectual and Developmental Disabilities abandoned entirely the classification of the condition of intellectual disability more than 25 years ago (Luckasson *et al.* 1992). A classification model based on the person's support needs was proposed and is gaining some support (Luckasson *et al.* 1992; Luckasson *et al.*, 2002; Schalock *et al.* 2010; Shogren *et al.* 2017). In its most recent edition of the Diagnostic and Statistical Manual for Mental Disorders, the American Psychiatric Association has abandoned the use of IQ scores in favour of the person's level of adaptive functioning, when determining the severity level of intellectual disability (APA 2013).

The proposed behavioural indicators for disorders of ID described in the present article and to be included in the ICD-11 Clinical Descriptions and Diagnostic Guidelines are put forth to assist professionals, especially in the absence of the availability of robust comprehensive standardised assessment tools, in making an informed clinical

Table 7 Behavioural indicators of adaptive behaviour for the 6–18 years old

	Conceptual	Social	Practical
Severity level	Reasoning, planning, organising, reading, writing, memory, symbolic/internal representation and communication skills	Interpersonal competency (e.g. relationships), social judgement and emotion regulation	Self-care, recreation, employment (including domestic chores), health and safety and transportation
Mild	<ul style="list-style-type: none"> • Most will need some help to sustain their attention for 30-min period. • Most can follow three-step instructions. • Most will acquire sufficient communication skills to use pronouns, possessives and regular tenses, as well as be able to ask 'wh' question (e.g. who, what, where, when or why). • Many will need support to tell a narrative story or to give someone simple directions. They also need assistance to explain their ideas using multiple examples, detail short-term goals and steps to achieve them, stay on the topic in group conversations and move from one topic to another. <p><i>Literacy</i></p> <ul style="list-style-type: none"> • Most will have reading and writing skills that are limited to approximately up to that expected of someone who has attended 4 to 5 years of schooling (i.e. several years of primary/elementary school). 	<ul style="list-style-type: none"> • Some may have more concrete understanding of social situations and may need supports understanding some types of humour (i.e. teasing others), making plans and knowing to let others know about these plans as needed, control their emotions when faced with disappointment, knowing to avoid dangerous activities or situations that may not be in their best interest (e.g. taken advantage of or exploited). • Some may need some supports initiating conversation, organising social activities with others or talking about shared interests with peers/friends. • Some may need substantial support to talk about personal things, emotions or understanding social cues. • Most are able to play outdoor sports or other social games in groups although they need help to play games with more complex rules (e.g. board games). 	<ul style="list-style-type: none"> • Most will learn to perform independently most dressing, toileting and eating skills. • Most will learn to independently manage activities of daily living such as brushing teeth, bathing and showering. • Most will need some support getting around the community and being safe (e.g. although they will know to stay to the side of routes with car traffic) and may continue to need support to check for traffic before crossing a street. • Many may be vulnerable to being taken advantage of in social situations. May continue to need some supports for telling time, identifying correct day/dates on calendar, making and checking the correct change at the store and being independent with basic health-maintaining behaviours. • If available, many can learn to use computers and cell phones for school and play. • Will learn basic work skills at nearly the same pace as their same-age peers but will require greater repetition and structure for mastery.
Moderate	<ul style="list-style-type: none"> • Most need help to perform skills such as following instructions containing 'if-then' as well as sustaining their attention to listen to a story for at least a 15-min period. • Most can say at least 100 words, use negatives, use simple sentences and state their first and last name or name and their locality/place of residence. • Some may need help using pronouns, possessives or past tense verbs. • Some may need supports telling basic parts of a story or asking 'wh' questions (e.g. when, where, why and who). • Most will not learn complex conversation skills (i.e. express their ideas in abstract manner or in more than one way). <p><i>Literacy</i></p>	<ul style="list-style-type: none"> • Some may need support expressing their emotions or concerns, knowing when others might need their help, showing emotions appropriate to the situation/context or knowing what others like or want. • Most need a lot of help initiating a conversation, waiting for the appropriate moment to speak, meeting friends and going on social outings or talking about shared interests with others. • Most will need help following rules when playing simple games or going out with friends. • Some will need supports changing routines and transitioning between activities/places or behaving appropriately in accordance to social 	<ul style="list-style-type: none"> • Most can learn to feed themselves, use the toilet and dress (including putting shoes/footwear on correct feet). • Most will often continue to need supports to attain independence for bathing and showering, brushing teeth, selecting appropriate clothing, being independent and safe in the home and community. • Most will continue to have difficulty using a knife to cut food, use the cooking appliances safely, use household products safely and do household chores. • Most will not acquire the understanding of taking care of their health.

Table 7. (Continued)

	Conceptual	Social	Practical
Severity level	Reasoning, planning, organising, reading, writing, memory, symbolic/internal representation and communication skills	Interpersonal competency (e.g. relationships), social judgement and emotion regulation	Self-care, recreation, employment (including domestic chores), health and safety and transportation
Severe	<ul style="list-style-type: none"> • Most will have reading and writing skills that will be limited to approximately up to that expected of someone who has attended 3 to 4 years of schooling (i.e. 2 years of primary/elementary school). • May need support with reading simple stories, writing simple sentences and writing more than 20 words from memory. • Most will be able to say the names of few animals, fruits and foods prepared in the home. 	<ul style="list-style-type: none"> • Most individuals would not be able to share with others about their past day's events/activities and will need supports managing conflicts or challenging social interactions and recognising/avoiding dangerous social situations. 	<ul style="list-style-type: none"> • Most will learn basic work skills but later than same-age peers.
Profound	<ul style="list-style-type: none"> • Most will be able to independently make simple one-word requests, use first names of familiar individuals and name at least 10 familiar objects. • Some may need help following instructions and would not be able to use pronouns, possessives, regular past tenses or state their age. • With help, some may be able to ask 'wh' questions (e.g. when, why, what and where), use at least 100 recognisable words, use negatives and relate their experiences in simple sentences. <p><i>Literacy</i></p> <ul style="list-style-type: none"> • Most will have reading and writing skills that will be limited to identifying some letters of the alphabet. • Most will be able to count up to 5. 	<ul style="list-style-type: none"> • Some may need support demonstrating friend-seeking behaviour or engaging in reciprocal social interactions. • Most need help expressing their emotions or showing empathy. • Most would not know to offer help to others without cues or prompting, show appropriate emotions in social situations, engage in conversations or query others about their interests. • Most need support to play cooperatively. With a lot of help, some might be able to start/end a conversation appropriately, say 'please' and 'thank you' when appropriate or respond to a change in their routine. • Most will have difficulty following social rules as well as rules associated with games such as turn-taking or sharing toys. Most will be unable to participate in social or other games with complex rules. 	<ul style="list-style-type: none"> • Most can learn to independently put on and take off clothing, feed themselves with hand or a spoon and use the toilet. • They will often continue to need supports to attain independence for putting shoes or other footwear on the correct feet, buttoning and fastening clothing, bathing and showering. • Most individuals will not learn the rules and safe behaviours in the home and community, doing household chores or checking for correct change when purchasing items. • Some will learn basic work skills but later than same-age peers.

Table 7. (Continued)

Severity level	Conceptual	Social	Practical
	Reasoning, planning, organising, reading, writing, memory, symbolic/internal representation and communication skills	Interpersonal competency (e.g. relationships), social judgement and emotion regulation	Self-care, recreation, employment (including domestic chores), health and safety and transportation
	parent/caregiver's name and point to objects to express their preferences. • Most indicate when they are hungry or wet by making a vocalisation or crying, smile and make sounds to indicate they are happy/sad. • Some may not be able to effectively use communication to get the attention of others in their environment. <i>Literacy</i> • Most will not learn to read or write.	negative reactions if not done with supports. • Most would not be able to engage in cooperative social play and will need a lot of help modulating their behaviour to different social cues.	• Most individuals will not learn rules and safe behaviours in the home and community. • Most will require a lot of supervision to remain on task and be engaged in basic vocational or pre-vocational skills.

Table 8 Difference scores and planned contrasts within each domain standard score: 18+ years old

		18+ years old (N = 427)						
		M	SD	F _{2,315}	Planned comparisons	t	P	
Communication skills [†]	Mild (N = 123)	60.1	25.1	117.0**	Mild > moderate, severe	11.41	0.001	
	Moderate (N = 108)	27.3	9.1		Moderate > severe			7.95
	Severe (N = 85)	20.2	1.1					
	Profound (N = 111)	20.0	0.00					
Social skills [†]	Mild (N = 90)	60.2	24.5	140.2**	Mild > moderate, severe	14.40	0.001	
	Moderate (N = 100)	25.1	8.1		Moderate > severe			6.28
	Severe (N = 93)	20.1	0.20					
	Profound (N = 144)	20.0	0.00					
Daily living skills [†]	Mild (N = 69)	67.0	16.8	308.1**	Mild > moderate, severe	20.32	0.001	
	Moderate (N = 100)	29.2	10.2		Moderate > severe			8.94
	Severe (N = 111)	20.0	0.01					
	Profound (N = 147)	20.0	0.0					

**P < 0.001.

[†]Not equal variances assumed.

decision regarding an individual's level of intellectual functioning and adaptive behaviour for the purpose of making a determination about the presence and severity of disorders of ID. It is also anticipated that the behavioural indicators will improve the quality of the data accessible to governments and

the WHO about the prevalence of different severity levels of disorders of ID, which in turn inform policy development and resource allocation across multiple sectors (e.g. early intervention, education, health, work and social services). Additional empirical work is needed to further validate the proposed behavioural

Table 9 Behavioural indicators of adaptive behaviour for 18+ years old

	Conceptual	Social	Practical
Severity level	Reasoning, planning, organising, reading, writing, memory, symbolic/internal representation and communication skills	Interpersonal competency (e.g. relationships), social judgement and emotion regulation	Self-care, recreation, employment (including domestic chores), health and safety and transportation
Mild	<ul style="list-style-type: none"> • Most will master listening and communication skills, although some may need help to stay on topic in group conversations, move from one topic to another, express ideas in more than one way or state complete home address. • Most will probably not be able to give complex directions and describe long-term goals. <p><i>Literacy</i></p> <ul style="list-style-type: none"> • Most can read and understand material up to that expected of someone who has attended 4 to 5 years of schooling (i.e. several years of primary/elementary school) and will master some writing skills, although they may have difficulty writing reports and long essays. 	<ul style="list-style-type: none"> • Most can independently meet others for the purpose of making new friends, can participate in social outings on a regular basis and talk about personal feelings. • Most can independently initiate a conversation and talk about shared interests with others. • Most can understand social cues and are able to regulate their conversation based on their interpretation of other people's feelings. • Most are able to play complex social games and team sports, although may need supports with understanding the rules. • Most can learn to weigh the possible consequences of their actions before making a decision in familiar situations but not in new or complex situations and know right from wrong. • Most need help recognising when a situation or relationship might pose dangers or someone might be manipulating them for their own gain. • Most can initiate planning of a social activity with others. Some can be engaged in an intimate relationship, others might need more supports to do so. 	<ul style="list-style-type: none"> • Most will be independent in household chores, being safe around the home and using the telephone and TV; some will learn operating the gas or electric stove. • Most will often continue to need some supports to attain independence with more complex domestic skills (e.g. small household repairs), comparative shopping for consumer products, following a healthy diet and being engaged in health promoting behaviours, caring for themselves when sick or knowing what to do when they are sick/ill. • Many can learn to live and work independently, work at a part-time or full-time job with competitive wages – support at work will depend on the level of complexity of the work and may fluctuate with life transitions. • Some can learn to drive a motor vehicle or a bicycle, manage simple aspects of a bank account, prepare simple meals and if available, use a computer or other digital devices. Many will learn to use public transport with minimal help. • Most will continue to need supports with more complex banking needs, paying bills, driving in busy roads and parenting skills.
Moderate	<ul style="list-style-type: none"> • Most will need a lot of support to be able to attend to various tasks for more than a 15-min period as well as following instructions or directions from memory (i.e. with a 5-min delay). • Most will master the following communication skills: simple descriptions, using 'wh' questions (e.g. what, when, why and where) or relating their experiences using simple sentences. • With help, most are able to follow three-step instructions. • Most will continue frequently needing help with using language containing past 	<ul style="list-style-type: none"> • Some will need help learning how to share interests or engaging in perspective taking. • Some may need supports initiating conversations and introducing themselves to unfamiliar people. • Most need significant supports engaging in regular social activities, planning social activities with others, understanding social cues and knowing what are appropriate/inappropriate conversation topics. • Most will need significant supports engaging in social activities requiring transportation. 	<ul style="list-style-type: none"> • Some will learn to master dressing (may need some help selecting appropriate clothing to wear for weather), washing, eating and toileting needs. • Most are able to be safe around the home, use the telephone, use the basic features of a TV and use simple appliances/household articles (e.g. switches, stoves and microwave). • Some may continue to need supports with bathing and showering, using more complex household appliances (e.g. stove) safely, meal preparation or using cleaning products safely.

Table 9. (Continued)

	Conceptual	Social	Practical
Severity level	Reasoning, planning, organising, reading, writing, memory, symbolic/internal representation and communication skills	Interpersonal competency (e.g. relationships), social judgement and emotion regulation	Self-care, recreation, employment (including domestic chores), health and safety and transportation
	tenses and describing their experiences in detail. <ul style="list-style-type: none"> • Most will not learn more complex conversation skills (e.g. expressing ideas in more than one way). <i>Literacy</i> <ul style="list-style-type: none"> • Most will acquire some reading and writing skills such as letters of the alphabet, writing at least three simple words from an example and writing their own first and last name. They will need significant supports to write simple sentences or read simple stories at about that expected of someone who has attended 3 to 4 years of schooling (i.e. 2 years of primary/elementary school). 	<ul style="list-style-type: none"> • Most are unable to be engaged in more social or other games with complex rules (e.g. board games). • Most will need help providing socially polite responses such as 'please' and 'thank you'. • Most are unable to recognise when a social situation might pose some danger to them (e.g. potential for abuse or exploitation). 	<ul style="list-style-type: none"> • Many will understand the function of money but struggle with making change, budgeting and making unplanned purchases. • Most will need supports being safe in the community and living independently. They will need substantial supports for employment – finding and keeping a job. • Most will not likely be able to travel independently to new places, have a developed concept of time sufficient to tell time independently and know when they are late.
Severe	<ul style="list-style-type: none"> • Will often need life-long supports to recall and comply with instructions given 5 min prior and sustain their attention to a story for a 15-minute period. Most are able to listen and attend to a story for a period of at least 5 min. • Most can make sounds or gestures to get the attention of individuals in their environment and can make their needs known. • They may need help using simple phrases, describing objects and relating their experiences to others, speaking at least 100 recognisable words, using negatives, possessives and pronouns and asking 'wh' questions. <i>Literacy</i> <ul style="list-style-type: none"> • Reading and writing skills will be limited to identifying some letters of the alphabet, copying simple words from an example and attempting to write their name. 	<ul style="list-style-type: none"> • All will need help in social situations, showing and expressing their emotions in an appropriate manner and engaging in a reciprocal conversation with others. • Most can play simple social games such as catching and throwing a ball but may need help choosing friends to play with. They need a lot of help to play symbolically and follow the rules while playing games such as turn-taking or sharing toys. They will need help with transition – changing from one activity to the next or an unexpected change in routine. • Most will not spontaneously use polite forms such as 'please', 'excuse me' and 'thank you' or respectful/customary ways of addressing others. They will need significant support starting, maintaining and ending conversations with others. • Most do not recognise when a social situation might pose a danger to them (e.g. potential for abuse or exploitation) or discern dangers potentially associated with strangers. 	<ul style="list-style-type: none"> • Most will need some supports for even basic personal hygiene, domestic skills, home and community skills. • Most will be able to drink independently from a cup and learn to use basic utensils for eating. Some may continue to need supports getting dressed. • Many may learn independent toileting if provided an established routine. Most will be unable to care for their own belongings, perform household chores independently, cooking or care for their health. • Most will need substantial supports to travel independently, plan and do shopping and banking of any sort. • Most will require significant supports to be engaged in paid employment.
Profound	<ul style="list-style-type: none"> • Most are able to turn their head and eye gaze towards sounds in their 	<ul style="list-style-type: none"> • Most will not spontaneously show interest in peers or unfamiliar individuals. 	<ul style="list-style-type: none"> • Most will need supports performing even the most basic self-care, eating, washing and domestic skills.

Table 9. (Continued)

Severity level	Conceptual	Social	Practical
	Reasoning, planning, organising, reading, writing, memory, symbolic/internal representation and communication skills	Interpersonal competency (e.g. relationships), social judgement and emotion regulation	Self-care, recreation, employment (including domestic chores), health and safety and transportation
	<p>environment and respond to their name when called.</p> <ul style="list-style-type: none"> • Most will use sounds and gestures to get parent/caregiver's attention and express their wants, and some will have the understanding of the meaning of yes and no. Some are able with prompting to wave good-bye, use their parent's/caregiver's name/customary ways of addressing others and point to objects to express their preferences. • Most will cry or make vocalisations when hungry or wet, smile and make sounds of pleasure. • Most are not able to follow instructions or story being told. • Most will have only rudimentary knowledge of moving around within their house. <p><i>Literacy</i></p> <ul style="list-style-type: none"> • Most will not learn to read or write. 	<ul style="list-style-type: none"> • With significant supports, most are able to imitate simple actions/behaviours or show concern for others. • Most will not engage in reciprocal/back-and-forth conversation. • Most will not spontaneously use polite forms such as 'please', 'excuse me' and 'thank you'. • Most are unable to anticipate changes in routines. Social interactions with others will be very basic and limited to essential wants and needs. • Most are unable to recognise when a social situation might pose some danger to them (e.g. potential for abuse or exploitation). 	<ul style="list-style-type: none"> • Some may learn independent toileting during the day, but night-time continence will be more difficult. • Most will have difficulty picking out whether appropriate clothing and zipping and snapping clothes. • Most will need supervision and supports for bathing, including safely adjusting water temperature and washing/drying. • Most will be unable to independently clean or care for their living environment, including clothing and meal preparation. • All will need substantial supports with health matters, being safe in the home and community, learning the concept of days of the week and time of day. • Most will be extremely limited in their vocational skills, and engagement in employment activities will necessitate structure and supports.

Table 10 Stability of the cluster solution (Kappa statistic)

Age group	Domain		
	Communication	Social skills	Daily living
0–5 years old	0.63	0.58	0.57
6–18 years old	0.94	0.77	0.95
18+ years old	0.86	0.93	0.86

indicators in guiding professionals and researchers in determining the presence and severity of disorders of ID.

alone are responsible for the views expressed in this paper and they do not necessarily represent the decisions, policy, or views of the WHO.

Acknowledgments

Geoffrey M. Reed is a member of the Secretariat, Department of Mental Health and Substance Abuse, World Health Organization (WHO). The authors

Source of funding

This work was supported in part with funding from the U.S. Administration on Intellectual and

Developmental Disabilities (grant No. 99-DD-0621) to the first author.

References

- APA (2013) *Diagnostic and Statistical Manual of Mental Disorders*, 5th edn. American Psychiatric Publishing, Arlington, VA.
- Ayuso-Mateos J. L. & Kogan C. S. (in press) Management and treatment of intellectual disability. In: *The New Oxford Textbook of Psychiatry (3rd Edition)* (eds J. R. Geddes, N. C. Andreasen & G. M. Goodwin). Oxford University Press, Oxford.
- Balboni, G., Belacchi, C., Bonichini, S. & Coscarelli, A. (2016a) Vineland-II. Vineland Adaptive Behaviour Scales Second Edition. Survey Interview Form. Standardizzazione Italiana [Vineland-II. Vineland Adaptive Behaviour Scales Second Edition. Survey Interview Form. Italian standardization]. Giunti OS, Firenze, Italy.
- Balboni G., Incognito O., Belacchi C., Bonichini S. & Cubelli R. (2017) Vineland-II Adaptive Behavior Profile of Children with Attention-deficit/Hyperactivity Disorder or with Specific Learning Disorders. *Research in Developmental Disabilities* **61**, 55–65.
- Balboni G., Tasso A., Muratori F. & Cubelli R. (2016b) The Vineland-II in Preschool Children with Autism Spectrum Disorders: An Item Content Category Analysis. *Journal of Autism and Developmental Disorders* **46**, 42–52.
- Bock W. H. & Weatherman R. F. (1977) *Minnesota Developmental Planning Systems Behavior Scale – Revised*. University of Minnesota, Minneapolis, MN.
- Bruininks R. H., Hill B. K. & Morreau L. E. (1988) Prevalence and implications of maladaptive behaviors and dual diagnosis in residential and other service programs. In: *Mental Retardation and Mental Health*, pp. 3–29. Springer, New York, NY.
- Cooper S.-A., Smiley E., Morrison J., Williamson A. & Allan L. (2007) Mental Ill-health in Adults with Intellectual Disabilities: Prevalence and Associated Factors. *British Journal of Psychiatry* **190**, 27–35.
- Emerson E., Hatton C., Baines S. & Robertson J. (2016) The Physical Health of British Adults with Intellectual Disability: Cross Sectional Study. *International Journal for Equity in Health* **15**, 1–9.
- Evers A., McCormick C. M., Hawley L. R., Muñoz J., Balboni G., Bartram D. *et al.* (2017) Testing Practices and Attitudes towards Tests and Testing: An International Survey. *International Journal of Testing* **17**, 158–90.
- First M. B., Reed G. M., Saxena S. & Hyman S. E. (2015) The Development of the ICD-11 Clinical Descriptions and Diagnostic Guidelines for Mental and Behavioral Disorders. *World Psychiatry* **14**, 82–90.
- Fletcher R. J., Barnhill J. & Cooper S. A. (2016) *Diagnostic Manual – Intellectual Disability (2nd Edition): A Textbook of Diagnosis of Mental Disorders in Persons with Intellectual Disability (DM-ID-2)*. NADD Press, Kingston, NY.
- Grossman H. J. (ed.) (1983) *Classification in Mental Retardation*. American Association on Mental Retardation, Washington, DC.
- Hartigan J. A. & Wong M. A. (1979) Algorithm AS 136: A *k*-means Clustering Algorithm. *Journal of the Royal Statistical Society: Series C: Applied Statistics* **28**, 100–8.
- International Advisory Group for the Revision of ICD-10 Mental and Behavioural Disorders (2011) A Conceptual Framework for the Revision of the ICD-10 Classification of Mental and Behavioural Disorders. *World Psychiatry* **10**, 86–92.
- International Test Commission (2005) International Guidelines on Test Adaptation. Available at: https://www.intestcom.org/files/guideline_test_adaptation.pdf (retrieved 2 February 2018).
- Jacobson J. J. & Mulick J. A. (1996) *Manual of Diagnosis and Professional Practice in Mental Retardation*. American Psychological Association, Washington, DC.
- Jain A. K. (2010) Data Clustering: 50 Years beyond *K*-means. *Pattern Recognition Letters* **31**, 651–66.
- Keeley J. W., Reed G. M., Roberts M. C., Evans S. C., Medina-Mora M. E., Robles R. *et al.* (2016) Developing a Science of Clinical Utility in Diagnostic Classification Systems: Field Study Strategies for ICD-11 Mental and Behavioral Disorders. *American Psychologist* **71**, 3–16.
- Landis J. R. & Koch G. G. (1977) The Measurement of Observer Agreement for Categorical Data. *Biometrics* **33**, 159–74.
- Llewellyn G., Vaughan C. & Emerson E. (2015) Discrimination and the health of people with intellectual disabilities. In: *International Review of Research in Developmental Disabilities*, vol. **48**, pp. 43–72. Academic Press, New York, NY.
- Luckasson R., Borthwick-Duffy S., Buntinx W. H. E., Coulter D. L., Craig E. M., Reeve A. *et al.* (2002) *Mental Retardation: Definition, Classification, and Systems of Supports*, 10th edn. American Association on Mental Retardation, Washington, DC.
- Luckasson R., Coulter D. L., Polloway E. A., Reiss S., Schalock R. L., Snell M. E. *et al.* (1992) *Mental Retardation: Definition, Classification, and Systems of Supports*, 9th edn. American Association on Mental Retardation, Washington, DC.
- MacDonald M., Lord C. & Ulrich D. A. (2013) The Relationship of Motor Skills and Social Communicative Skills in School-aged Children with Autism Spectrum Disorder. *Adapted Physical Activity Quarterly* **30**, 271–82.
- Maulik P. K., Mascarenhas M. N., Mathers C. D., Dua T. & Saxena S. (2011) Prevalence of Intellectual Disability: A Meta-analysis of Population-based Studies. *Research in Developmental Disabilities* **32**, 419–36.

- Painter J., Ingham B., Trevithick L., Hastings R. P. & Roy A. (2018) Identifying Needs-based Groupings among People Accessing Intellectual Disability Services. *American Journal on Intellectual and Developmental Disabilities* **123**, 426–42.
- Papazoglou A., Jacobson L. A. & Zabel T. A. (2013) More than Intelligence: Distinct Cognitive/Behavioural Clusters Linked to Adaptive Dysfunction in Children. *Journal of the International Neuropsychological Society* **19**, 189–97.
- Punj G. & Stewart D. W. (1983) Cluster Analysis in Marketing Research: Review and Suggestions for Application. *Journal of Marketing Research* **20**, 134–48.
- Reed G. M., Rebello T. J., Pike K. M., Medina-Mora M. E., Gureje O., Zhao M. *et al.* (2015) WHO's Global Clinical Practice Network for Mental Health. *The Lancet Psychiatry* **2**, 379–80.
- Reiss S. (1994) *Handbook of Challenging Behavior: Mental Health Aspects of Mental Retardation*. IDS Publishing Corporation, Worthington, OH.
- Rojahn J. & Tassé M. J. (1996) Psychopathology in mental retardation. In: *Manual of Diagnosis and Professional Practice in Mental Retardation* (eds J. W. Jacobson & J. A. Mulick), pp. 147–56. American Psychological Association, Washington, DC.
- Salvador-Carulla L., Reed G. M., Vaez-Azizi L. M., Cooper S. A., Leal R. M., Bertelli M. *et al.* (2011) Intellectual Developmental Disorders: Towards a New Name, Definition and Framework for “Mental Retardation/Intellectual Disability” in ICD-11. *World Psychiatry* **10**, 175–80.
- Schalock R. L., Borthwick-Duffy S. A., Bradley V. J., Buntinx W. H. E., Coulter D. L., Craig E. *et al.* (2010) *Intellectual Disability: Diagnosis, Classification, and Systems of Supports*, 11th edn. American Association on Intellectual and Developmental Disabilities, Washington, DC.
- Schalock R. L. & Luckasson R. (2014) *Clinical Judgment*, 2nd edn. American Association on Intellectual and Developmental Disabilities, Washington, DC.
- Schalock R. L. & Luckasson R. (2015) A Systematic Approach to Subgroup Classification in Intellectual Disability. *Intellectual and Developmental Disabilities* **53**, 358–66.
- Shogren K. A., Shaw L. A., Wehmeyer M. L., Thompson J. R., Lang K. M., Tassé M. J. *et al.* (2017) The Support Needs of Children with Intellectual Disability and Autism: Implications for Supports Planning and Subgroup Classification. *Journal of Autism and Developmental Disorders* **47**, 865–77.
- Smiley E. (2005) Epidemiology of Mental Health Problems in Adults with Learning Disability: An Update. *Advances in Psychiatric Treatment* **11**, 214–22.
- Sparrow S. S., Cicchetti D. V. & Balla D. A. (2005) *Vineland-II: Vineland Adaptive Behaviour Scales*, 2nd edn. Pearson Assessments, Minneapolis, MN.
- Stremme P. & Diseth R. H. (2000) Prevalence of Psychiatric Diagnoses in Children with Mental Retardation: Data from a Population-based Study. *Developmental Medicine and Child Neurology* **42**, 266–70.
- Tassé M. J. & Craig E. M. (1999) Critical issues in the cross-cultural assessment of adaptive behavior. In: *Adaptive Behavior and Its Measurement: Implications for the Field of Mental Retardation* (ed. R. L. Schalock), pp. 161–84. American Association on Mental Retardation, Washington, DC.
- Tassé M. J., Schalock R. L., Balboni G., Bersani H., Borthwick-Duffy S. A., Spreat S. *et al.* (2012) The Construct of Adaptive Behaviour: Its Conceptualization, Measurement, and Use in the Field of Intellectual Disability. *American Journal on Intellectual and Developmental Disabilities* **117**, 291–303.
- WHO (1992) Manual of the International Statistical Classification of Diseases, Injuries, and Causes of Death (10th revision). Author, Geneva, Switzerland.
- WHO (2018). ICD-11 for mortality and morbidity statistics. Available at: <https://icd.who.int/browse11> (retrieved 9 September 2018)

Accepted 1 December 2018