Making an ID Determination: What You Need to Know

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Outline

• DSM-5 diagnostic criteria of ID/ASD
• Intersection of ID/ASD with criminal justice
  – Prevalence of ID/ASD in prisons
• SCOTUS decisions around ID and death penalty
• Best practices in making a determination of ID
  – Intellectual functioning
  – Adaptive behavior
  – Age of onset
• Common misbeliefs/misconceptions of ID
Pervasive Developmental Disorders (PDD)
- Autistic Disorder
- Asperger Syndrome
- Rett Syndrome
- Childhood Disintegrative Disorder
- PDD Not Otherwise Specified (NOS)

Autism Spectrum Disorder

1. Social Communication deficits: responding inappropriately in conversation, misreading nonverbal interactions, difficulty building friends appropriate to their own age.
Autism Spectrum Disorder

1. Social Communication deficits: responding inappropriately in conversation, misreading nonverbal interactions, difficulty building friends appropriate to their own age.
2. Restrictive Repetitive Behaviors (RRB): overly dependent on routines, highly sensitive to change in environment, intensely focused on inappropriate items.

3. MUST appear during early developmental period.
4. BOTH deficits 1 & 2 must be present for diagnosis.

ASD – Severity Level

1. Supports
2. Substantial Supports
3. Very Substantial Supports

1. Supports
2. Substantial Supports
3. Very Substantial Supports
ASD – Associated Conditions

Specifiers:

• With or without intellectual disability
• With or without language impairment
• Associated with a medical/genetic conditions (e.g., fragile x, etc.) or environmental factors
• Associated neurological or mental/behavioral disorders (ADHD, anxiety disorder, etc.)

Comorbidity: ASD + ID

• 1999: 25-30% of people with ASD => No ID (Szymanski & King, 1999).
• 2018: ~ 70% of people with ASD => No ID (Baio et al., 2018).

Prevalence of ASD

[Graph showing the prevalence of ASD over time]
Prevalence of ASD

![Graph showing prevalence of ASD from 2007 to 2018.](image)

### ASD and Criminal Justice

**Rates of offending?**
Published studies => rates vary tremendously across studies (2 – 26%) but most studies that compared rates of offending of adults with ASD with a comparison group (no Dx of ASD) => rates for ASD were same or slightly higher (King & Murphy, 2014).

**Rates of Incarceration?**
How many individuals in prisons have ASD? => Not many published studies overall.

Fazio et al. (2012) reported a prevalence of 4.4% of the incarcerated population in a US maximum security prison in Missouri had ASD.

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**ASD and Criminal Justice**

Berney (2004) because of the social communication deficits and repetitive/restrictive interests of ASD => people with ASD may often get into trouble for these offences:

- Stalking
- Computer crime
- Unprovoked violence
- Sexual offences
- Offences arising out of misjudged social relationships

Langstrom et al. (2009) found a greater likelihood of offending in people with ASD + psychotic disorder; ASD + substance use disorder; ASD + personality disorder.

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**References**

ASD and Criminal Justice

- 5% of youth with ASD had been charged with at least one offense (Cheely et al., 2012). In comparing charged youth with ASD, authors found that charged youth were significantly less likely to have comorbid ID.


<table>
<thead>
<tr>
<th>Charge</th>
<th>Youth with ASD</th>
<th>Comparison</th>
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<tbody>
<tr>
<td>Crimes against persons</td>
<td>40</td>
<td>112</td>
</tr>
<tr>
<td>Crimes against property</td>
<td>21</td>
<td>162</td>
</tr>
<tr>
<td>Drug law violations</td>
<td>4</td>
<td>38</td>
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<tr>
<td>Offenses against public order</td>
<td>31</td>
<td>387</td>
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<td>Disturbing schools</td>
<td>16</td>
<td>40</td>
</tr>
<tr>
<td>Probation violations</td>
<td>2</td>
<td>41</td>
</tr>
<tr>
<td>Status offenses</td>
<td>6</td>
<td>40</td>
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Core features of ASD that might be contributing factors to criminal justice (Howlin, 2004):

- Gullibility and their increased social naiveté may leave some people with ASD open to being manipulated/exploited by others.
- Disruption in routines/rituals, rigidity with adherence to rules might lead to some with ASD becoming overly anxious, upset, ... aggressive.
- Lack of understanding of, or poor ability to anticipate, social situations (poor social problem solving) – deficits in perspective-taking might lead some with ASD to become frustrated ... angry ... aggressive.
- Restricted interest/ intense pecuniary or OCD might lead some with ASD to commit an offence in the pursuit of that interest ... perhaps exacerbated by a failure/inability to anticipate the social implications of their actions.
Law Enforcement & ID/ASD

Training programs for law enforcement and mental illness => Crisis Intervention Team (CIT) training for law enforcement.

National Autistic Society (NAS) shows that > 90% of police/law enforcement professionals have no training to help them understand ASD (NAS, 2008).

- Arc of US National Center on Criminal Justice & Disability
  Pathways to Justice [https://www.thearc.org/NCCJD/training]
- Dennis Debbault – ASD and Law Enforcement Training
  [https://researchautism.org/autism-spectrum-and-law-enforcement-training/]
  - Core features / characteristics of ASD
  - De-escalation strategies
  - Interviewing a person with ASD
  - More practical tips...
- OSU/Nisonger Center – ODHP First Responder Disability Trainings & Resources
  [https://nisonger.osu.edu/education-training/ohio-disability-health-program/first-responder-disability-trainings-resources/]

ID and Criminal Justice

Rates of Incarceration

Not many good studies in USA – better (more recent) studies/estimates in Canada, UK, Australia.

USA (2-10%):
  - MacEachron (1979): ID in prisons = 1.8% - 9.8%
  - Veneziano & Veneziano (1996): ID in prisons = 4.2%
  - Petersilla (1997): ID in prisons = 1.8% – 4.2% (California)

Supreme Court of the United States

People with ID & capital punishment

- Hall v. Florida (2014)
- Moore v. Texas (2017)
The Supreme Court of the United States (Atkins v. Virginia, 2002) recognized that people with ID are less culpable due to their impaired ability to engage in logical reasoning, understand and process information, learn from their mistakes and experiences, communicate, control their impulses, and understand the reactions of others (Blume, Johnson, Marcus, & Paavola, 2014).

Barred the execution of people with ID

Death Penalty & ID

“One need only read the definitions of mental retardation ... to realize that the symptoms of the condition can readily be feigned...”
- Justice Scalia
(Dissenting opinion in Atkins v. Virginia, 2002)

Not everyone on death row has filed a claim for relief under Atkins v. Virginia (2002).
< 10% of all death row inmates have filed a claim for ID (Blume et al., 2014).

Death Penalty & ID
Blume and colleagues (2014):

<table>
<thead>
<tr>
<th>Prong 1 (IQ)</th>
<th>Prong 2 (AB)</th>
<th>Prong 3 (Age of onset)</th>
</tr>
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<tbody>
<tr>
<td>26%</td>
<td>57%</td>
<td>12%</td>
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<td></td>
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<td>2%</td>
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3% = unknown

Intellectual Disability

AAIDD

- Limitations in present functioning must be considered within the context of community environments typical of the individual’s age peers and culture.
- Valid assessment considers cultural and linguistic diversity as well as differences in communication, sensory, motor, and behavioral factors.
- Within an individual, limitations often coexist with strengths.
- An important purpose of describing limitations is to develop a profile of needed supports.
- With appropriate personalized supports over a sustained period, the life functioning of the person with intellectual disability generally will improve.

- Schalock et al. (2010), p. 3
Ohio Revised Code

5123.01 Department of developmental disabilities definitions.

Intellectual Disability:

Intellectual disability means a disability characterized by having significantly subaverage general intellectual functioning existing concurrently with deficiencies in adaptive behavior, manifested during the developmental period."

Amended by 132nd General Assembly File No. TBD, HB 49, §101.01, ef 12/31/2017.

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Intellectual Disability

Although the “term” for the condition has changed over time, the “definition” of intellectual disability over the past 45+ years has been quite consistent.

- Tassé, Luckasson, & Schalock (2016)

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AAIDD/DSM Last 45+ Years

[Intellectual disability] refers to subaverage general intellectual functioning which originates during the developmental period and is associated with impairment in one or more of the following: learning, social adjustment, and maturation.

- AAIDD (Heber, 1992)
- DSM-II (APA, 1968)

[Intellectual disability] is characterized by significant limitations both in intellectual functioning and in adaptive behavior as expressed in conceptual, social, and practical adaptive skills. The disability originates before age 18.

- AAIDD (Schalock et al., 2016)
- DSM-5 (APA, 2013)

Prevalence of ID in US has remained unchanged 1 – 2 %
Intellectual Functioning

DSM-5

Intellectual Disability (Intellectual Developmental Disorder)

A. Deficits in intellectual functions, such as reasoning, problem-solving, planning, abstract thinking, judgment, academic learning and learning from experience, and practical understanding confirmed by both clinical assessment and individualized, standardized intelligence testing.

- DSM-5, p. 33

DSM-5

Diagnostic Features (p. 37)

Criterion A refers to intellectual functions ... intellectual functioning is typically measured with individually administered and psychometrically valid, comprehensive, culturally appropriate, psychometrically sound tests of intelligence.
"IQ test scores are approximations of conceptual functioning but may be insufficient to assess reasoning in real-life situations and mastery of practical tasks. For example, a person with an IQ score above 70 may have such severe adaptive behavior problems in social judgment, social understanding, and other areas of adaptive functioning that the person's actual functioning is comparable to that of individuals with a lower IQ score. Thus, clinical judgment is needed in interpreting the results of IQ tests."

- DSM-5, p. 37

PRONG 1: Intellectual Functioning

Individualized assessment of general intellectual functioning:

- USE Comprehensive Standardized Measures:
  - WAIS/WISC/WPPSI
  - Stanford-Binet
  - Woodcock-Johnson Cognitive

- CAUTION/AVOID brief IQ tests or narrow-band IQ tests:
  - Test of Non-verbal Intelligence (TONI)
  - Comprehensive Test of Nonverbal Intelligence (C-TONI)
  - Leiter-R
  - Wechsler Abbreviated Scale of Intelligence
  - Wide Range Intelligence Test
  - Group administered tests

Diagnostic Features

Criterion A refers to intellectual functions … intellectual functioning is typically measured with individually administered and psychometrically valid, comprehensive, culturally appropriate, psychometrically sound tests of intelligence.

"… two standard deviations or more below the population mean, including a margin of measurement error (generally ± 5 points) … this involves a score of 65 – 75 (70 ± 5)."

[Standard Error of Measurement] (DSM-5, p. 37)

"Factors that may affect test scores include practice effects and the 'Flynn effect' (i.e., overly high scores due to out-of-date test norms)." (DSM-5, p. 37)
FACTORS THAT IMPACT TEST SCORES

- Reliability of a Test $\Rightarrow$ Standard Error of Measurement
- Practice Effects
- Aging of Test Norms “Flynn effect”

Standard Error of Measurement

The obtained score (e.g., full-scale IQ score or composite adaptive behavior score) from any standardized test is the test's approximate measure of the person's true ability on the construct assessed. All standardized tests have measurement error embedded in the obtained scores that they yield.

Standard error of measurement is directly related to the test's reliability. Lower reliability $\Rightarrow$ higher SEM.

All standardized tests report the SEM and the SEM is used to create a confidence interval around the scores obtained.

Standard Error of Measurement

Recommended best practice is generally to use $\pm 2$ SEM to create a confidence interval of 95% certainty when interpreting an obtained score for the purpose of making an ID determination (see: Schalock et al., 2012).

Hence, when AAIDD and DSM-5 say $\pm 5$ points they are using a rule-of-thumb that imposes a 95% confidence interval around the proposed cut-off score.

FACTORS THAT IMPACT TEST SCORES

- Reliability of a Test \( \Rightarrow \) Standard Error of Measurement
- Practice Effects
- Aging of Test Norms “Flynn effect”

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Practice Effects

Practice effects refer to gains in scores on cognitive tests that occur when a person is retested on the same instrument, or tested more than once on very similar ones.

These gains are due to the experience of having taken the test previously; they occur without the examinee being given specific or general feedback on test items, and they do not reflect growth or other improvement on the skills being assessed.

Such practice effects denote an aspect of the test itself, a kind of systematic, built-in error that is associated with the specific skills the test measures.

- Kaufman (1994)


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Practice Effects

Practice Effects: The shorter the interval between test-retesting on the same instrument, the larger the practice effects.

Although the artificial increase on the obtained FSIQ due to the re-administration of the same IQ test to the same individual on average is approximately 5 points, the practice effects on the FSIQ can be as high as 15 points (Kaufman, 1994).
FACTORS THAT AFFECT TEST SCORES

- Reliability of a Test => Standard Error of Measurement
- Practice Effects
- Aging of Test Norms "Flynn effect"

**Flynn Effect:**

Using data from 14 nations, Flynn discovered that there have been IQ gains ranging from 5 to 25 points in a single generation (Flynn, 1984, 1987, 1998).

Scores obtained on IQ tests have been steadily rising for the past 60 years on average 0.3 points per year after a test has been normed.

Over the years – people are performing better (getting higher scores) on IQ tests.

“Flynn effect” is not a theory – this is an empirical fact that has been clearly established.


**Flynn Effect**

Flynn reported a greater increase in the Wechsler Performance IQ, which is more heavily loaded on fluid abilities, than on the Wechsler Verbal IQs. On average, the Full Scale IQ increases by approximately 0.3 points for every year elapsed since the test was normed (Flynn, 1999).

Flynn Effect

“The now well-known Flynn effect must be considered to avoid the undue effects of out-of-date norms…. The newest revision and most recent norms for a test should be used…”


“The point is that a person tested on an outdated test will earn spuriously high scores as each year goes by, and that amount of spuriousness amounts to about 3 [IQ] points per decade for Americans (p. 503).


Flynn Effect & Typical Clinical Practice

Do we correct for Flynn effect in everyday ID determinations?

We don’t correct for the Flynn effect in everyday practice – why do it in Atkins hearings?

- Hagan, Drogin, & Guilmette (2008)

Flynn Effect & Typical Clinical Practice

Do we correct for Flynn effect in everyday ID determinations?

“…the necessity of precision and reliability in the determination [of intellectual disability] increases with the stakes. Quite simply, death is different.”

- Cunningham & Tassé (2000; p. 454)
Flynn Effect & Typical Clinical Practice

Do we correct for Flynn effect in everyday ID determinations?

“…the necessity of precision and reliability in the determination of intellectual disability increases with the stakes. Quite simply, death is different.”
- Cunningham & Tassé (2010; p. 414)

Do we measure for malingering in everyday ID determinations?

“Ultimately, I disagree with Flynn’s explanation of the Flynn effect, but I agree with his position that IQs should be adjusted for the effect in death penalty cases.”

“IQ test scores should be corrected for any high-stakes decision that employs these assessments, including capital offense cases, if scores are not corrected, then diagnostic standards must change with each generation. Arguments against correction ignore expert consensus about the assessment of intellectual disabilities and do not take into account the wide acceptance of the FE [Flynn effect].”
- Fetcher et al., 2010; p. 472.


Flynn Effect & Typical Clinical Practice

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Flynn Effect & Typical Clinical Practice

Do we correct for Flynn effect in everyday ID determinations?

“… Quite simply, death is different.”
- Cunningham & Tassé, 2010; p. 414.

“For now, best practice is the application of the Flynn correction as a constant by year across the distribution.”
- Reynolds et al., 2010; p. 480.


DSM-5

Diagnostic criteria for ID and the “directly related to...” phrase
“Directly related…” phrase in the DSM-5

DSM-5 (APA, 2013; p. 38):

“To meet diagnostic criteria for intellectual disability, the deficits in adaptive functioning must be directly related to the intellectual impairments described in Criterion A.”

Separate Constructs

- Intellectual functioning
- Adaptive behavior

Related (or in correlated) but separate... studies have reported a low to moderate correlation between the measures (Intelligence & Adaptive Behavior) of r = .20 – .50 (Harrison & Oakland, 2003; Sparrow, Balla, & Cicchetti, 2005).

IQ & AB correlation coefficients

Decision point (approx. 2 SD < mean): r = .20 - .30

References:
Separate Constructs

Intellectual functioning ↔ Adaptive behavior

Decision point (approx. 2 SD < mean): \( r = 0.20 - 0.30 \)

<table>
<thead>
<tr>
<th></th>
<th>55</th>
<th>70</th>
<th>85</th>
<th>100</th>
<th>115</th>
<th>130</th>
<th>145</th>
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</table>
Cause of AB deficits

One does not need to establish the precise cause or identify the culprit risk factors that explain the adaptive behavior deficits, nor find the exact etiology of the intellectual functioning and/or adaptive behavior deficits, so long as both have their onset during the developmental period, a determination of intellectual disability should be made.

- Tassé, Luckasson, & Schalock (2016)
“Even if [Moore] had met his burden to prove significantly subaverage intellectual functioning and significant limitations in adaptive functioning, he was still required to show further that the adaptive deficits are ‘related’ to limited intellectual functioning.”

- State of Texas
  (Brief for the respondent in Moore v. Texas, 2016; p. 48)

“The [Court of Criminal Appeals of Texas] furthermore concluded that Moore’s record of academic failure, along with the childhood abuse and suffering he endured, detracted from a determination that his intellectual and adaptive deficits were related. … Those traumatic experiences, however, count in the medical community as ‘risk factors’ for intellectual disability. Clinicians rely on such factors as cause to explore the prospect of intellectual disability further, not to counter the case for a disability determination.”

- SCOTUS
  (Moore v. Texas, 2017; slip opinion, pp. 13-14)
Define Adaptive Behavior

*Adaptive behavior* is the collection of conceptual, social, and practical skills that are learned and performed by people in their everyday lives – indexed on chronological age and related to one’s culture.

- Schalock et al. (2010)


Intellectual Disability

"... is characterized by significant limitations both in intellectual functioning and in adaptive behavior as expressed in conceptual, social, and practical adaptive skills. The disability originates before age 18."

- Schalock et al., 2010; p. 1
- APA, 2013; p. 33


Adaptive Behavior

Conceptual skills:

*language, functional academics, self-direction, money management, time concepts.*
Adaptive Behavior

Conceptual skills:
language, functional academics, self-direction, money management, time concepts.

Social skills:
interpersonal skills, responsibility, self-esteem, wariness/naïveté, follow rules, etiquette, social problem solving.

Practical skills:
activities of daily living, occupational skills, safety, health-care, travel.
Adaptive Behavior

"Adaptive behavior is assessed using both clinical evaluation and individualized, culturally appropriate, psychometrically sound measures. Standardized measures are used with knowledgeable informants (e.g., parent or other family member, teacher, counselor, care provider) and the individual to the extent possible."

- DSM-5 (APA, 2013; p. 37)

Adaptive Behavior

"The concept of adaptive skills implies an array of competencies and provides a foundation for three key points: (a) the assessment of adaptive behavior is based on the person's typical (not maximum) performance, (b) adaptive skill limitations often coexist with strengths, and (c) the person's strengths and limitations in adaptive skills should be documented within the context of community and cultural environment typical if the person's age peers and tied to the person's need for individualized supports."


Adaptive Behavior

"Adaptive functioning may be difficult to assess in a controlled setting (e.g., prisons, detention centers); if possible corroborative information reflecting functioning OUTSIDE those settings should be obtained."

- DSM-5 (APA, 2013; p. 38)
Standardized AB Scales

200+ adaptive behavior scales have been developed (Schalock, 1999).


Conceptual
Social
Practical

1. Vineland Adaptive Behavior Scales – 3
2. Adaptive Behavior Assessment System – 3
3. Scales of Independent Behavior-R
4. Adaptive Behavior Scales – School
Who can administer/interpret an AB test?

“...professional (e.g., psychologist, social worker, case manager), one who has training in assessment and direct work experience with people with ID, and one who has had previous assessment experience.”
- p. 51 (Schalock et al., 2010)

“The interviewer should be a professional (such as a psychologist, case manager, social worker, or teacher) who has completed at least a Bachelor's degree, has had direct work experience with people with ID or closely related developmental disabilities, and who has had previous assessment experience.”
- DABS (Tassé et al., 2017; p. 14)

Adaptive Behavior Assessment

Interview

vs.

Rating Scales

Dx/Outcome Data

vs.

Supports/Intervention Planning

Respondent vs. Self-Report

- Why should we be cautious with self-reported AB for the purpose of diagnosing an intellectual disability?
Respondent vs. Self-Report

- Caution with self-report – purpose of diagnosing an intellectual disability.
  - “Cloak of competence” / mask deficits
  - Exaggerate skills

Interview vs. Rating Scale

What are the advantages of interviewing respondents versus using rating scales?

- Reduces likelihood of reading error on the part of the respondent;
- Provides immediate opportunity to address questions about an item stem or provide clarifying information if the respondent appears confused or uncertain regarding the content of the item;
- Provides examiner with the opportunity to observe the latency between the reading of the item and the response; indication of time respondent takes to think about item stem before responding.
- Allows the examiner to monitor the respondent’s attention and tailor the pace of administration to the respondent’s needs.
- Allows the examiner the opportunity to probe some responses and assess the reliability of the respondent.

Interview vs. Rating Scale

What are the advantages of interviewing respondents versus using rating scales?

A comprehensive review of assessment of AB concluded:

“Both structured and semi-structured interviews, when performed by well trained and experienced clinicians, appear to be the best available safeguard against threats to the reliability and the validity of adaptive behavior assessment.”
- National Research Council (2002; p. 186)

“A major advantage that the professional interviewer provides [versus simply giving the rating form to respondents] is as a corrective against various sources of inaccuracy that can affect a parent questionnaire Approach.”
- Sparrow et al. (2006; p. 8)


Selecting Respondents/Informants

“. . .the respondent should be someone living in the same home as the examinee; or, if the examinee is in a residential care setting, someone who provides care in that setting…. If the examinee is a child, the primary caregiver is usually the best respondent, because he or she has the most detailed knowledge concerning the child’s everyday functioning across the broad ranges of domains covered by the Vineland-3…. If the examinee is an adult no longer living in the childhood home, a spouse, roommate, institutional care provider, or other adult living with the examinee usually makes the best respondent.”
- Sparrow et al., 2016; p. 16

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- Sparrow et al., 2016; p. 16


- Anyone who had the opportunity to observe the individual function on a regular basis, over an extended period of time, in one or more natural contexts (e.g., home, community, school, job, etc.);
- Knowledgeable – preferably lived with person (e.g., parent, grandparent, older sibling, spouse, direct support worker, etc.);
- Often requires more than one informant / measure -> Check measure re: multiple informants, convergence/contradictions;
- Informant bias must be taken into account if ratings have consequences for rater;
- Make sure the informant is reporting on observations of actual skill performance and not outcome (e.g., looked neatly dressed).

parents, grandparents, aunts/uncles, OLDER siblings, teachers, employers, spouse, room-mate/housemate, etc.

Adaptive Behavior Assessment (Tassé, 2009)

In addition to the use of standardized measures of adaptive behavior it is crucial to obtain corroborating information from other sources:
- social and family history
- medical records
- school records
- social security administration records
- employment history
- etc.

Additional sources of information include educational, developmental, medical, and mental health evaluations. Scores from standardized measures and interview sources must be interpreted using clinical judgment.

- APA (2013; DSM-5; p. 37)

Adaptive Behavior Assessment

This is very subjective

Objective

• when using standardized assessment tools - select appropriate measures of adaptive behavior (normed on typical population).
• use multiple informants/contexts.
• typical respondents are: parents/guardians, grandparents, teachers, direct support staff, ... know well the person.
• CAUTION!!! relying on self-report.
• assess in environments typical of individuals age and culture.
• assess typical/actual functioning and NOT capacity or maximum ability.
• many social adaptive skills not assessed on current measure of adaptive behavior (e.g., gullibility, naiveté).
• adaptive behavior and problem behavior are separate constructs – that are unrelated.

SOURCE: AAIDD User’s Guide (Schalock et al., 2012; p. 50)
1. Adjusted FSIQ – for depression & anxiety Dx.

2. Adjusted AB scores – for growing up in low SES, poor school performance (correction formula).

- Denkowski & Denkowski (2008)

https://www.youtube.com/watch?v=xibZH4V0yRs
Common Misconceptions & Misbeliefs

Common Misconception

I'll know it when I see it.

I'll see it when I know it.

Common Misbeliefs

“...incorrect stereotypes that these individuals [with ID] cannot have friends, jobs, spouses, or be good citizens.”

- Snell et al. (2009)
What are the distinguishing facial/physical features of ID?

There are NONE!

“Spotting ID”

Who are they?

• They won’t necessarily stand out
• Some are passive … others aggressive
• Some are quiet … others loud
• Some are funny … others boring
• Some are polite … others rude

… more often

• a follower … than a leader
• easily duped ⇒ gullible
• does better with structured/concrete tasks
• difficulty dealing with abstract concepts
• functions better when a benefactor is helping
• copes poorly in unknown / less predictable situations
ID Determination

Who do you want to talk to…
• Parents/grandparents/guardians
• Older siblings
• Younger siblings (with caution)
• Aunts/uncles
• Teachers, coaches
• Friends, girl friends
• Spouse
• Employers, supervisors, co-workers
• Neighbors

“Compared to others kids/peers of/at same age…”:
• What was this his development like?
• When were milestones achieved? (walk, talk, toilet, wash, etc.)
• Making and keeping friends?
• Playing in the neighborhood?
• School behavior/performance?
• Was he given responsibilities (e.g., mow lawn, keep room clean, run errands, baby sit other kids, etc.) and how did he do?
• Responsible with money?

Records/Info You Want/Need
• Family history / genealogy (relatives with disabilities)
• Medical records / pregnancy / birth information
• Good understanding about home environment – where did he grow up
• School records (class placement, testing, school behavior & performance)
• Previous psychological testing (reasons for referral)
• Previous diagnoses
• Employment history / records
• Social Security Administration
• Department of Motor Vehicles
• Dept. of Corrections
• Other state or government agency (e.g., state DD dept.)
Caution

- Most laypeople have non-fact based ideas of what a person with "intellectual disability" looks like, is able to do or not do, etc.…
  - This includes parents, teachers, lawyers, judges, and mental health experts. Avoid questions like "do you think he has intellectual disability?"
- Most people with an intellectual disability will NOT admit to having it.
  - "I'd rather be executed than be called 'retarded'."
- Most people with intellectual disability can tell the difference between right and wrong – they just often make poor choices.
- Keep your own myths, misconceptions, and non-fact based notions about intellectual disability at the forefront of your mind.

AAIDD

ASSUMPTIONS:

- Limitations in present functioning must be considered within the context of community environments typical of the individual's age peers and culture.
- Valid assessment considers cultural and linguistic diversity as well as differences in communication, sensory, motor, and behavioral factors.
- Within an individual, limitations often coexist with strengths.
- An important purpose of describing limitations is to develop a profile of needed supports.
- With appropriate personalized supports over a sustained period, the life functioning of the person with intellectual disability generally will improve.
  - Schalock et al. (2010), p. 3

Common Misbeliefs

"Most individuals with [intellectual disability] will have strengths and areas of ability (see Luckasson et al., 2002). These strengths may confound a layperson or a professional with limited clinical experience with individuals who have mild [intellectual disability]. These laypersons may erroneously interpret these pockets of strengths and skills as inconsistent with [intellectual disability] because of their misconceptions regarding what someone with mental retardation can or cannot do."
  - Tassé (2009)
He doesn’t look “retarded”

A “retarded” person can’t do that... Come on!

My cousin Jack has Down syndrome and he would never hurt a fly.

No typical woman would be attracted to a guy with intellectual disability.

A “retarded” person can’t drive a car... Come on!

No typical woman would be attracted to a guy if he had intellectual disability.

He doesn’t look... or talk...

My cousin Jack has Down syndrome and he would never hurt a fly.

No typical woman would be attracted to a guy with intellectual disability.

A “retarded” person can’t drive a car... Come on!

Intellectual Disability … “look”

“ID”... like Lennie

“... Most Texas citizens might agree that Steinbeck’s Lennie should, by virtue of his lack of reasoning ability and adaptive skills, be exempt [of the death penalty]. But, does a consensus of Texas citizens agree that all persons who might legitimately qualify for assistance under the social services definition of [intellectual disability] be exempt from an otherwise constitutional penalty?”

- Ex Parte Briseno (2004)
What percentage of students with ID graduated from high school with a REGULAR high school diploma?

REGULAR High School Diploma

"Graduated with a ‘regular high school diploma’ refers to students ages 14 through 21 served under IDEA, Part B, who exited an educational program through receipt of a high school diploma identical to that for which students without disabilities were eligible. These were students with disabilities who met the same standards for graduation as those for students without disabilities" [emphasis mine].


What percentage of students with ID graduated from high school with a REGULAR high school diploma?

National Longitudinal Transition Study
A Study of Post-High School Outcomes of Youth with Disabilities up to 8 Years After High School

Newman et al. (2011)
Funded by the U.S. Dept. of Education

Persons with ID: Marriage and Parenting

Persons with ID: Marriage and Parenting

Parenting and marital status of young adults with ID/MR

<table>
<thead>
<tr>
<th>Status</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ever had or fathered a child</td>
<td>25.3%</td>
</tr>
<tr>
<td>Married</td>
<td>10.3%</td>
</tr>
</tbody>
</table>

- Newman et al., 2011, p. 118
Persons with ID and Banking

Persons with ID and Banking

<table>
<thead>
<tr>
<th>Financial Independence at the Time of the Interview</th>
</tr>
</thead>
<tbody>
<tr>
<td>Percentage of Young Adults with ID Who Had A:</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>Savings Account 42.0%</td>
</tr>
<tr>
<td>Checking Account 29.0%</td>
</tr>
<tr>
<td>Credit Card 19.4%</td>
</tr>
</tbody>
</table>

- Newman et al., 2011; p. 123

Community Activities
- Driver's License
- Voter registration
Community Activities

<table>
<thead>
<tr>
<th>Community Participation 8 Years Post-HS - Adults with ID/MR</th>
<th>10/24/2018</th>
<th>Newman et al., 2011; p. 106</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lessons or classes outside of school</td>
<td>13.2%</td>
<td></td>
</tr>
<tr>
<td>A volunteer or community service activity</td>
<td>18.9%</td>
<td></td>
</tr>
<tr>
<td>A community group (e.g., sports team, bible club, church)</td>
<td>36.0%</td>
<td></td>
</tr>
<tr>
<td>Percentage who had a driver’s license or learner’s permit</td>
<td>39.2%</td>
<td></td>
</tr>
<tr>
<td>Percentage of eligible youth registered to vote</td>
<td>62.1%</td>
<td></td>
</tr>
</tbody>
</table>

Adults with Intellectual Disability
8 Years After Leaving High School
- Post-secondary education
- Attending college/university

Adults with Intellectual Disability
8 Years After Leaving High School
- Newman et al., 2011; p. 19

Percentage enrolled in postsecondary school

| Any Postsecondary School | 28.7% |
| 2-year or Community College | 13.9% |
| Vocational, Business, or Technical School | 16.4% |
| 4-year College | 6.7% |

- Newman et al., 2011; p. 19
How can you determine if a person has an Intellectual Disability?

You cannot tell by looking at them!
You cannot tell by talking to them!
You cannot tell by watching them!

Low IQ
Low AB
Onset < 18

Only through a rigorous individualized assessment of the person’s functioning
1. Intellectual Functioning
2. Adaptive Behavior
3. Age of Onset

Resources


Concluding Remarks

- People with ID/ASD are much more likely to be a victim of crime than a perpetrator of crime.
- DSM-5, AAIDD, ICD-11: Same Diagnostic Criteria
  - Significant deficits in Intellectual Functioning.
  - Significant deficits in Adaptive Behavior:
    - Conceptual Skills
    - Social Skills
    - Practical Skill
  - Onset of these deficits is manifested during the developmental period => Dx can be made > 18.
- Assessment includes standardized measures and other corroborating/clinical information.

Concluding Remarks

- Psychometric limitations of our assessment protocols must be taken into consideration.
- ID/ASD determination is informed by clinical judgment.
- Severity level of ID is now determined by the individual's severity of adaptive behavior deficits.
- Severity level of ASD is determined similarly by the person's support needs.
- Many – including experienced clinicians – have misconceptions and “implicit biases” towards people with ID.