

Best Practice Guidelines for Diagnosing Intellectual Disability in People with Cultural and Linguistic Differences (CLD)

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INTRODUCTION

Assessment and diagnosis of Intellectual Disability in individuals with cultural and linguistic differences (CLD) poses a serious challenge to the competent evaluator. The measurement of intellectual ability and adaptive behavior is necessary in order to make a diagnosis of Intellectual Disability. Many of the standardized measures used for this purpose in the U.S. are culturally and linguistically biased, and may not be valid measures for the diagnosis of Intellectual Disability in CLD populations. In order to make accurate diagnosis, evaluators must be prepared to expand their evaluative technique and practice, with a greater reliance on informed clinical judgment.

This best practice protocol is designed as a guide for evaluators who are assessing intellectual ability and adaptive behavior skills in people with CLD to determine whether a diagnosis of Intellectual Disability is warranted. The common issues in evaluating individuals with CLD are discussed, and best practice procedures are recommended, but it is inevitable that each individual with CLD will offer a unique set of challenges. The competent evaluator will need to be flexible within the framework that this guide offers.

The underlying cause and subsequent treatment of Intellectual Disability is understood very differently depending on the cultural context. It is critical that the evaluator understand the specific cultural values regarding Intellectual Disability in order to provide relevant and sensitive assessment, diagnosis, and treatment recommendation. It is important to ascertain what the individual or family calls or names the individual's disability, what they think has caused the disability, when they think the disability started, how the disability affects the individual's functioning, and the role the individual plays in the family structure.

Evaluator Qualifications: The assessment and diagnosis of Intellectual Disability must be made by a licensed psychologist with competence in diagnosis of Intellectual Disability who has personally performed, supervised, or reviewed assessments that document all three components of the diagnosis, specifically: 1) Significantly subaverage cognitive functioning; 2) significantly subaverage abilities in adaptive behavior; and 3) onset before age 18.

The evaluator should demonstrate knowledge and experience with the assessment of individuals with cultural and linguistic differences, with specific attention to best-practice methodology. When making a diagnosis of Intellectual Disability in a person with CLD, the evaluator may

often have to rely on clinical judgment drawn from relevant experience and specific knowledge and attention to the critical factors involved in reliable and valid assessment of persons with CLD. To this end, the evaluator should demonstrate sensitivity to the specific cultural values of the individual assessed, with attention to the cultural perspectives regarding cause and treatment of Intellectual Disability.

Multiple Sources of Information: Whenever possible, it is important to gather information from multiple sources when diagnosing a person with CLD. Attention to the following information is recommended in order to support and/or confirm diagnosis:

- Interviews with primary care providers, family members, community members, social support service providers, teachers, and/or work supervisors in order to gather information regarding current functioning.
- Careful review of previous testing or evaluation
- Site visits for clinical observation at home, school, and/or work settings—attention should be paid to:
 - The way the person communicates
 - The way the person socializes
 - The activities in which the person engages
 - The friendships the person has
 - The roles the person plays
- When using an interpreter, attention should be paid to the individual's communication style with the interpreter, including the level of ease of communication and ability to engage in reciprocal communication.

Relevant History: A comprehensive background history is critical when evaluating a person with CLD. The information gathered should include birth history, family history, developmental history, language history, health history, behavioral history, educational history, trauma history, and acculturation status. Relevant information regarding the person's functioning in their country of origin should be included. It is important that the evaluator demonstrate cross-cultural awareness and sensitivity, understanding variations in family structure and roles, socialization patterns, expectations related to disability, and core values and beliefs influenced by cultural factors.

TESTING MEASURES

Recommended Measures for Testing Intellectual Ability: Traditional measures used in the United States to measure cognitive abilities of persons with cultural and linguistic differences are limited in the following ways: 1) Norming and standardization samples typically exclude people from CLD backgrounds. The measures are thus considered invalid for this population; 2)

English cognitive measures are considered biased because they do not approximate the cultural backgrounds of CLD people and favor people from majority cultural backgrounds; and 3) Traditional English cognitive measures used with CLD children yield scores that reflect English language knowledge instead of cognitive ability.

With these limitations in mind, the following non-verbal tests of intellectual ability are those most widely used to measure intellectual ability for non-English language populations:

- Comprehensive Test of Nonverbal Intelligence–Second Edition (CTONI-2) (ages 6 - 89:11)
- Wechsler Nonverbal Scale of Ability (WNV) (ages 4:0 through 21:11)
- Universal Nonverbal Intelligence Test (UNIT) (ages 5:0 through 17:11)
- Leiter-R (ages 2 – 21)

Whichever of these measures is used, the evaluator must be sensitive to the linguistic demands and cultural loading of the measure. Levels of acculturation and language proficiency operate as attenuating variables; the greater the difference between an individual’s background and the background of the norm group, the more likely the test will measure lower performance as a function of the lack of comparability in the person’s experience. Cultural and linguistic differences thus serve to depress the scores of diverse populations. The testing measure should be understood as one piece of the evaluation process, with attention to the qualitative interpretation of the results.

A helpful way to illustrate the effects of cultural loading and linguistic demand is illustrated in the following matrix (Rhodes et al, 2005, p.190):

		Degree of Linguistic Demand		
		Low	Moderate	High
Degree of Cultural Loading	Low	Performance Least Affected		Increasing Effect of Language Difference
	Moderate			
	High	Increasing Effect of Cultural Difference		Performance Most Affected (combined effect of culture and language differences)

Any measure can be assessed against this matrix, thus making transparent the degree of cultural loading and linguistic demand of the particular measure. Using this matrix can assist the

evaluator in determining whether test results were influenced primarily by the individual's cultural or linguistic difference rather than by actual or real ability.

Measures for the Assessment of Adaptive Behavior: Adaptive behavior, as it is measured to determine diagnosis for developmental disability, generally comprises three skill types:

- Conceptual skills—the individual's receptive and expressive language, reading and writing, money concepts, self-control, and responsibility
- Social skills—includes interpersonal skills, social responsibility, self-esteem, gullibility, naïveté, social problem solving, and the ability to follow rules/obey laws and to avoid being victimized
- Practical skills—the skills needed for basic maintenance of daily living (eating, mobility, toileting, dressing) and instrumental activities of daily living (meal preparation, housekeeping, transportation, taking medications, money management, maintenance of safe environment)

Adaptive behavior is highly culturally defined, with measures normed and standardized for the U.S. population. Many in the CLD population will not have had exposure to experiences or expectations that allow for accurate measurement of adaptive behavior using current standardized measures. With this in mind, it is recommended that standardized measures of adaptive behavior be used guardedly, with the understanding that cultural differences may have significant impact on a person's assessed level of adaptive functioning.

It is recommended that adaptive behavior measures always be used in an interview format and with careful attention paid to comparison between the individual's functioning and the cultural expectations of the individual's functioning in any specific area assessed. In some cases, it will be important to assess adaptive behavior through direct observation in the context in which the behavior occurs.

The use of an interpreter with cultural knowledge is ideal during assessment of adaptive behavior. The interpreter not only translates the interaction but can assist with provision of relevant cultural information and explanation. Adaptive behavior assessed by teachers or service providers unfamiliar with the specific culturally-based expectations of the individual's adaptive behavior may not be as accurate as assessments made by family or community members.

The most widely used instruments to assess adaptive behavior include:

- Vineland Adaptive Behavior Scales—Third Edition (Vineland-3) (ages birth-90)
- Adaptive Behavior Assessment System-Third Edition (ABAS-3) (ages 0-89)
- Scales of Independent Behavior-Revised (SIB-R) (ages infancy-90+)

The SIB-R includes a Short Form option that assesses primary adaptive behavior skills and can be very useful as a tool in evaluation of adaptive behavior for individuals with low acculturation and lack of exposure to tasks and skills assessed.

Modification of Measures: As is always the case, it is recommended to administer normed measures following manual instructions. However, because of the particular challenges faced in testing people with CLD, the competent and skilled evaluator may use his or her clinical expertise and judgment and determine that modifications to the testing administration are necessary. If modifications are necessary, it is recommended to first administer the normed measure following manual instructions and then test with modifications. The evaluator should clarify if and how modifications are made during the testing session. Data interpreted through modified means should be interpreted qualitatively rather than quantitatively, and all necessary testing modifications should be explained in the report.

Modifications can include providing the instructions in simpler terms in native language, providing a demonstration of the task, extending or removing time limits, changing the presentation and response modes, breaking down the test over several testing sessions, and providing prompts and feedback that aid in problem solving.

INTERPRETERS

(Much of the information for this section was drawn directly from chapter six in Rhodes et. al., 2005)

Use of Interpreters: It is recommended to use an interpreter in cases where the examinee is not fluent in English language and the evaluator does not speak the native language of the examinee.

Role of Interpreter: The role of the interpreter is to convey information from one language to the other in oral modality. This role requires an ability to stay emotionally uninvolved with the content of discussions and to maintain neutrality and confidentiality.

Selection of Interpreter: Ideally, the interpreter should be fluent in English and the native/primary language of the examinee. It is important to ask whether the interpreter has written as-well as spoken fluency, particularly if the interpreter is asked to translate written material. Interpreters with cultural knowledge are ideal because they not only translate but also bridge the cultural gap. There are many terms and phrases that must be viewed within a cultural framework to be able to gain a full understanding of meaning during the interpretation process. It is best practice not to use friend and family members as interpreters if the option exists. A family or friend may be more likely to manipulate information, confidentiality may be breached, and the family balance may be upset. The interpreter should be free from any real or perceived bias based on caste, tribe, religion or other prejudice.

The evaluator should determine whether the individual/family has an established relationship with an interpreter who could be used for purposes of the assessment. Much of the information that is conveyed through the interpreter may be sensitive and it is best to minimize the number of individuals with access to confidential information.

Training of Interpreter: Ideally, the interpreter should receive training in the terms, procedures, and rationale for the assessment process and evaluation instruments. The concept of standardization and strict assessment procedures must be clearly communicated and understood by the interpreter.

Individuals serving as an interpreter during the assessment process should:

- Develop an understanding of the purpose of the session and the materials and procedures that will be used.
- Clarify any areas of concern or uncertainty prior to the start of the session.
- Provide a self-introduction to the examinee and explain the interpreter's role in the assessment process.
- Interpret everything that is said to the examinee; do not make assumptions regarding the importance or relevance of the information requiring interpretation.
- Reflect the pace, tone, and inflection of the speaker.
- Maintain neutrality throughout the process and monitor any emotional reaction to the events that are discussed and the decisions that are reached.
- Inquire about any words, terms, or statements that are unclear or unknown while the process is taking place; accurate interpretation is more important than seamless interpretation.
- Maintain the confidentiality of all aspects of the assessment process.

What the evaluator can do to make the interpretation process better:

- Allow time before the testing session for the interpreter to review and become familiarized with the purpose of the assessment and the assessments tools being used
- Look at and speak to the examinee, not the interpreter.
- Encourage interpreters to ask questions as necessary during the testing session.
- Throughout the testing session, speak in short, simple sentences; avoid idioms, metaphors, or colloquialisms (unless drawn from the examinee's native language); use specific terms and avoid jargon; and allow the interpreter time to translate all messages.
- Allow extra time for interpretation and clarification; interpreted procedures will take longer.
- Do not hold side conversations while the interpreter is talking.
- Meet with the interpreter after the session to debrief and discuss any issues that arose during the process. These may include: general impressions including ease of communicating, difficulty understanding, language development, age-appropriateness of

communications, vocabulary, etc.; impressions of how culturally typical client appeared for age/gender; impressions of communication style including ease of communicating, whether content of communication was typical for culture.

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