



Determination of Intellectual Disability: Best Practice Guidelines

**April 1, 2016
revised March 1, 2018**

This document is also available at:

<https://hhs.texas.gov/doing-business-hhs/provider-portals/long-term-care-providers/local-intellectual-developmental-disability-authority-lidda/did-best-practice-guidelines>

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Purpose and Scope

As required by 40 Texas Administrative Code (TAC), Chapter 5, Subchapter D, Diagnostic Assessment, an authorized provider employed by or contracting with a local intellectual and developmental disability authority (LIDDA) or state supported living center (SSLC) must use the Determination of Intellectual Disability (DID) Best Practice Guidelines (BPG).

The DID BPG were developed by the Department of Aging and Disability Services (DADS) with input from authorized providers¹ across the State. The DID BPG are designed to assist authorized providers associated with a LIDDA or SSLC to conduct a DID or endorsement based on current best practice. The DID BPG provide guidance on Texas-specific eligibility for intellectual and developmental disability (IDD) programs and services. The DID BPG are not intended to replace or supplant published clinical references except where noted.

Adherence with the DID BPG will increase the quality and reliability of DID reports and endorsements. However, the Texas Health and Human Services Commission (HHSC) has the authority to require a new DID or endorsement to affirm eligibility for IDD services.

1. Diagnosis of Intellectual Disability

a) General guidelines

An accurate diagnosis of an *intellectual disability* (ID) requires clinical judgment and determination based on three basic criteria:

- impaired general intellectual functioning, defined as measured intelligence falling two or more standard deviations below the mean for an individual's age group;
- impaired adaptive functioning, defined as the degree to which an individual displays deficiencies to meet the standards of personal independence and social responsibility expected of the individual's age and cultural group; and
- age of onset occurring during the developmental period, meaning before the 18th birthday.

The purpose of a DID is to determine eligibility for services; however, the assessment should always be approached as a clinical process which determines whether the person has an ID or otherwise meets the criteria for IDD service eligibility. To that end, the assessment must be driven by sound clinical practices for differential diagnosis and consider mitigating factors (e.g., mental health issues, situational factors) that can affect the person's cognitive and adaptive functioning. Once an accurate diagnosis is achieved, then all eligibility criteria can be applied and eligibility can be determined along with recommendations.

¹ Associated with Tri-County Behavioral Healthcare, Texana Center, MHMR of Tarrant County, and the Alamo Area Council of Governments.

Given the unique challenges that may be encountered in the assessment of ID, authorized providers are reminded:

- that assessment instruments and tests do not take into account the actual life circumstances of the individual being assessed (e.g., stressors in the individual's daily life);
- that standardized intelligence tests must be administered in a controlled setting;
- to observe any circumstances that deviate from a controlled and standardized administration of a test (e.g., lack of privacy and other distractions) and describe such variations in the DID report with an opinion on the effect that these variables may have had on the results of testing; and
- to take into consideration cultural differences and lack of opportunities to exhibit the assessed behavior when assessing adaptive functioning.

b) Guidelines for children

The DSM-5 (page 41) recommends a diagnosis of “global developmental delay” (GDD) for children under the age of five years when the clinical severity level cannot be reliably assessed during early childhood. Children to whom this diagnosis would apply are those who are “...unable to undergo systematic assessments of intellectual functioning, including children who are too young to participate in standardized testing.” The DSM-5 specifies that this category requires reassessment after a period of time. Assignment of a diagnosis of ID for a child, especially a very young child, is often undesirable so this diagnostic option may make sense. However, from a practical standpoint, this new diagnosis presents a challenge to determining eligibility for HHSC services. For example, HHSC priority population served by LIDDAs includes children who are eligible for Early Childhood Intervention (ECI) services. When a child ages out of ECI services on the third birthday, the child is eligible to receive services funded by general revenue only if the child meets one of the other priority population criteria. A formal diagnosis of ID at that time would ensure continuity of critical services. Conversely, service disruption would result from even a temporary delay of the ID diagnosis (e.g., until the child turns five years old).

Based upon clinical judgment, an authorized provider has the discretion to “override” the diagnosis of GDD in favor of a formal diagnosis of ID for children under the age of five, if current measures of intellectual and adaptive functioning fall more than two standard deviations below the mean for the child's age and, given consideration of pertinent background variables, it is the conclusion of the authorized provider that current deficiencies represent a life-long condition.

To avoid an unnecessary disruption, an authorized provider has a duty to the child to consider relevant factors that can have a lasting impact on intellectual development. Some of the conditions and events strongly associated with a life-long pattern of intellectual sub-normality include:

- presence of a genetic disorder known to be associated with a life-long pattern of intellectual sub-normality (e.g., Down syndrome, Fragile X syndrome, Williams syndrome, Prader-Willi syndrome, Angelman syndrome);
- prenatal exposure to alcohol or illegal substances;
- physical illness experienced by the mother during pregnancy;

- lack of oxygen to the brain during labor or delivery;
- extremely premature delivery;
- childhood illness (e.g., meningitis) and some types of infections;
- onset of seizure activity at or shortly following delivery;
- inexplicable regression of attained milestones during the first 18 months of life; and
- other conditions associated with diminished intellectual capacity across the life span.

If a child is three to four years of age and has experienced one of the events or conditions listed above, it would be prudent to commit to an ID diagnosis for the sake of service continuity. However, in recognition that IQ scores can be flexible and unreliable at such an early age, a child who is diagnosed before age five should be reassessed with a full comprehensive assessment at age five, or earlier if the child demonstrates acquisition or loss of skills that affect general intellectual ability. The DID report should include a recommendation to reassess the child and offer guidance as to when reassessment should occur.

Assessing young children requires experience and specialized training. If an examiner does not have the required expertise and training, referral to a professional who is trained is recommended. If referral to a more experienced provider is not possible, the authorized provider should:

- consult with a colleague, teacher or other professional with relevant background and training to ensure that the unique issues of children with developmental delays are considered;
- reserve additional time for observation or review of reports of the child's behaviors and performance in a variety of settings (e.g., community, home, and school) if necessary;
- establish rapport and adjust the testing schedule to the child's attention span as needed;
- recognize that a score based on subtests alone, remains a partial assessment of cognitive ability that only approximates an IQ score;
- interpret all test results with caution, especially if the child is age three or younger; and
- explain any test modifications in the DID report since any deviation from standardized procedures can affect the validity of the scores obtained.

2. Selection of Assessment Instruments and Tests

a) General guidelines

The selection of the proper test to assess a person's abilities is an initial critical step in conducting a valid assessment. The most current versions of the Standards for Educational and Psychological Testing (American Psychological Association), the Diagnostic and Statistical Manual of Mental Disorders (American Psychiatric Association), and Intellectual Disability: Definition, Classification and Systems of Supports (American Association on Intellectual and Developmental Disabilities) should be used as a reference for practice. These references discuss the importance of selecting valid, reliable tests; administering tests; and addressing other critical considerations, such as test setting and instructions to the examinee. Measures of intelligence and adaptive functioning that are generally accepted for the diagnosis of ID must be established instruments with a body of published research that supports the reliability and validity of the test and its use with persons who have ID.

These instruments include, but are not limited to, current versions of the following:

- Intelligence Tests:
 - *Wechsler Intelligence Scale for Children*;
 - *Wechsler Adult Intelligence Scale*;
 - *Stanford-Binet Intelligence Scale*; and
 - *Woodcock-Johnson Tests of Cognitive Ability*.
- Adaptive Functioning Tests:
 - *Vineland Adaptive Behavior Scales (VABS)*;
 - *Adaptive Behavior Assessment System (ABAS)*;
 - *Inventory for Client and Agency Planning (ICAP)*; and
 - *Scales of Independent Behavior (SIB)*.

These measures satisfy the professional standards for validity and reliability required for their use in the analysis of general intellectual functioning in persons being evaluated for ID. The same is true for standardized versions of these measures available for use with individuals whose primary language is not English. An authorized provider should avoid the use of the same intelligence test less than two years apart.

b) For individuals with blindness or other visual impairment

When selecting an appropriate testing instrument for an individual with blindness or other visual impairment, best practice dictates the use of a test normed on that population and on which the examiner has been trained. If an examiner does not have the required expertise and training, referral to a professional who is trained is recommended.

If referral is not feasible, an authorized provider may opt to administer select subtests (e.g., *Wechsler Verbal Scales*) from an array of assessment instruments in combination with an adaptive behavior instrument. If the individual's skills preclude the use of a verbal subtest, an authorized provider may use a rating scale (e.g., *Developmental Profile*). The *Haptic Intelligence Scale* may be an option for an adult who reads Braille (even if the authorized provider does not). Finally, although not recommended as the first choice for any initial evaluation, the current version of the *Slosson Intelligence Test* contains materials and instructions with adaptations for use with persons who are visually impaired.

Regardless of the assessment instrument used, an authorized provider who has limited training and expertise should:

- consult with a colleague, teacher or other professional with relevant background and training to ensure that the unique developmental issues of an individual with a visual impairment are considered;
- reserve additional time for observation or review of reports of the individual's behaviors and performance in a variety of settings (e.g., community, home, school, work) as necessary;
- recognize that a score based on subtests alone remains a partial assessment of cognitive ability that only approximates an IQ score;

- interpret all test results with caution if using a test that was not normed on individuals with vision impairments; and
- explain any test modifications in the DID report since any deviation from standardized procedures can affect the validity of the scores obtained.

c) For individuals with a motor impairment

When selecting an assessment instrument to use with an individual with a motor impairment, the examiner should follow the guidance provided above for visual impairment. Global intelligence measures have subtests that require the use of fine motor skills. For individuals with impairment of fine motor or hand-eye coordination, use of verbal subtests only may suffice. The severity of motor impairments may not be evident until tests are administered. Rationale for not administering, or for not scoring motor subtests, should be delineated in the DID report.

d) For individuals with a communication impairment

When selecting assessment instruments to use with an individual who has a communication impairment an examiner should first carefully determine the person's communication skills, hearing ability and preferred style of communication. For example, a person may not exhibit verbal language skills, but may be able to point reliably, respond using a communication board or gesture yes/no through head movements or eye gaze. In addition, the examiner should identify if the person understands language (receptive skills) but has difficulty producing language (expressive skills).

If a person cannot express verbal language but is able to understand verbal directions, the performance or nonverbal sections of a comprehensive test of intelligence may provide a valid estimate of intellectual ability. If a person is unable to understand verbal instructions, a test for hearing impaired individuals, such as *the Leiter International Performance Scale* may be appropriate to use. In all cases, the authorized provider should consult the test manual to determine if using a portion of a test is endorsed by the test developer or if the manual contains specific recommendations regarding the use of the test with people suspected of ID or ASD. Any variations from usual testing processes, such as extending the test over several sessions or using yes/no choices to answer questions, should be explained in the DID report.

Similar considerations may be necessary when no test is available in the individual's dominant language. In these situations, an interpreter may be used if allowed by the test developers. If an interpreter is not available or is not advised in the test manual, it may be justified to use the most current version of a nonverbal assessment instrument, such as the *Wechsler Nonverbal Scale*, the *Leiter International Performance Scale*, the *Universal Nonverbal Intelligence Test (UNIT)* or the *Comprehensive Test of Nonverbal Intelligence*. The rationale for selecting a nonverbal measure should be explained in the assessment report.

e) Use of brief assessment instruments and tests

Authorized providers are discouraged from using brief tests of intelligence to establish an individual's initial eligibility for IDD programs. However, in limited situations an exception may be warranted. For example:

- the individual presents with a well-established, documented testing history based on broad-based batteries and brief test results are consistent with testing history;
- the individual participated in multiple cognitive tests while in school that yielded consistent scores, yet a more current IQ score is required;
- a particular broad-based battery of tests does not have sufficient "floor" or basal level (i.e., insufficient number of items) to adequately evaluate an individual's true mental abilities; or
- an individual does not have adequate attention and concentration to tolerate a full scale measure and their adaptive functioning and history are consistent with intellectual disability.

If an authorized provider uses a brief IQ test (e.g., *Kaufman Brief Intelligence Test* or *Slosson Intelligence Test*) or an abbreviated battery (e.g., *Wechsler Abbreviated Scale of Intelligence* or *Stanford-Binet Abbreviated Battery*), the authorized provider must explain the rationale for this choice and justify its use in the DID report. However, any significant change (including a decline or improvement) in functioning since the last evaluation would rule against the use of a brief test.

f) When a standardized intellectual assessment cannot be successfully administered

If an individual's intellectual functioning is severely or profoundly impaired, it may be necessary to use a developmental rating scale (e.g., *Developmental Profile*) in an effort to provide a profile of abilities. Even in cases in which age-appropriate norms are not available, the use of *age equivalents* may have merit in depicting an individual's range of competencies and deficiencies. Age equivalents are norm-referenced scores, but they differ from standard scores and percentiles in that their purpose is not to indicate where the individual's raw score falls in relation to the distribution of scores for other individuals of the same age. Rather, age equivalents indicate the age level at which the average person in the population performs the same skill as the individual who is being assessed. Age equivalents should be interpreted with caution to avoid suggesting that an individual "is like" someone at a younger chronological age and inadvertently promote situations in which the individual is treated as if he or she was a child. Age equivalents should be explained in the context of specific skills, rather than as a conclusion about general functioning.

In some situations, an individual's limitations may be so extensive that a full scale IQ score cannot be obtained from a standardized intelligence test. In these situations, an estimate of the individual's IQ score, or, IQ score equivalent should be stated with clinical justification. For example, if an individual's ability to comprehend oral instruction or visual demonstration is not adequate for a formal appraisal of general intellectual functioning, the use of an Adaptive Behavior Composite (e.g., provided by the *VABS*) may serve as an estimate of the individual's intellectual functioning when accompanied by a clinical justification explained in the DID report. However, not all measures of adaptive behavior (e.g., *ABAS*, *ICAP*, and *SIB*) are appropriate for establishing an IQ score equivalent.

g) Optional supplementary tests

Absent a broad-based intellectual battery, the use of supplementary tests allow for the construction of a more detailed profile to reflect an individual's unique set of relative strengths and weaknesses. When assessing individuals who are moderately or severely intellectually impaired, it can be advantageous to employ supplementary tests to probe other related areas of functioning, such as:

- expressive language development (e.g., the current versions of the *Expressive Vocabulary Test* or *Expressive One-Word Picture Vocabulary Test*);
- receptive language development (e.g., the current versions of the *Peabody Picture Vocabulary Test* or *Receptive One-Word Picture Vocabulary Test*);
- and
- visual-motor integration (e.g., the current versions of the *Beery-Buktenica Developmental Test of Visual-Motor Integration* or *Bender-Gestalt Test*).

The examiner should also consider that while a person may be reported to be “nonverbal,” this may be true for oral expression and not written expression. In those situations, an authorized provider should allow an individual the option to respond by using an electronic tablet, a communication board, or pen and paper. Deviations from standardized administration or the use of a nontraditional approach, such as alternate response modalities or an adaptive measure in lieu of an intelligence test, must be explained in the DID report.

If an individual has a mild intellectual impairment, it is also often advantageous to employ supplementary tests to probe related abilities, such as academic achievement, in an effort to compare and contrast general intellectual functioning with functional scholastic skills. Tests such as the *Wide Range Achievement Test* and the *Woodcock-Johnson Achievement Battery* are well- normed examples.

Supplementary test information may be available through academic records. The authorized provider may request reports from an individual's school records to obtain a fuller picture of the person's skills and abilities. While these tests may not contribute to a diagnosis of ID, they can provide valuable information for determining age of onset and for developing recommendations that may inform subsequent treatment planning and service delivery decisions.

3. Validation of Previous Assessment and Test Results

Validation refers to accepting the results of one or more specific assessment measures that were administered by another professional. In trying to decide whether or not to validate previous test results, an authorized provider must consider:

- how old the testing is;
- developmental changes that have occurred since the testing; and
- if the instrument used was appropriate to the individual.

The current DID report must include a statement by an authorized provider attesting to the validity of a previous test. **A previous assessment or test is not eligible for validation if completed when the individual was under age 22 and the testing was done more than five years ago.**

4. Interpretation of Assessment and Test Results

a) Intelligence tests

General intellectual functioning is a multi-faceted concept. As described in the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (pages 33 & 37) and the User's Guide: Intellectual Disability: Definition, Classification and Systems of Support (pages 1-5), intellectual functioning consists of the ability to reason, make plans, solve problems, think abstractly, comprehend complex ideas, make judgments, and learn from instruction and experience.

While formal diagnosis of ID requires the use of a properly constructed and administered cognitive or intellectual measure, an authorized provider also must exercise clinical judgment to interpret the obtained scores in reference to the assessment instrument's strengths and limitations, age of norms used for validity, and other factors (e.g., practice effect, fatigue, difficulty sustaining focused attention, competing idiosyncratic thoughts). Additionally, the full scale IQ score is a composite of multiple subtests. For example, if there is statistically significant variability in an individual's scores on particular subtests due to known clinical conditions (e.g., traumatic brain injury), the full scale IQ score may not be a valid summary measure of overall intellectual functioning. It is important that the authorized provider describe relative cognitive strengths and weaknesses when interpreting these derived scores in order to provide an accurate depiction of functioning. This interpretation is useful for making recommendations and planning.

Another variable in the interpretation of test results is the "standard error of measurement" or SEM. Developers of standardized tests provide information about the SEM to reflect the reliability (i.e., precision) of the scores derived from a test. The SEM is the variation around a "true score" (i.e., the score that would be obtained if the test had perfect reliability). Although clinical practice allows and encourages the use of SEM and sound clinical judgment, **the DID assessment process is first and foremost an eligibility assessment for HHSC services.** The State has established a fixed IQ cut-off score to determine eligibility for IDD programs. Infrequently, an authorized provider may find an individual does not meet eligibility to receive those services even though the individual has a diagnosis of ID based on DSM-5 criteria, including an IQ score higher than service eligibility criteria. Nevertheless, an authorized provider who conducts eligibility determinations must apply HHSC eligibility criteria to conclude that an individual has a *qualifying* diagnosis of ID under the agency's rules. The authorized provider should also be prepared to explain the criteria for diagnosis versus eligibility.

b) Adaptive behavior assessments

Compared to previous versions, the DSM-5 places a greater emphasis on adaptive functioning in the diagnosis of ID (and a corresponding decreased emphasis on standardized IQ tests) in two ways. First, the manual states that a diagnosis should be "based on *both* clinical assessment and standardized testing of intellectual and adaptive functions" indicating that exclusive reliance on standardized tests is inadequate. Second, the DSM-5 (pages 33-36) is the first edition to classify level of severity based on adaptive functioning rather than IQ score. The DSM-5 explains that "the various levels of severity are defined on the basis of adaptive functioning, and not IQ scores, because it is adaptive functioning that determines the level of supports required." In other words, the DSM-5 recognizes that adaptive

functioning has greater practical significance because it is a better indicator of the individual's ability to function in society. Title 40 TAC Chapter 5, Subchapter D (Diagnostic Assessment), §5.153, defines the term "adaptive behavior" as "the effectiveness with or degree to which an individual meets the standards of personal independence and social responsibility expected of the individual's age and cultural group as assessed by a standardized measure."

A standardized measure in adaptive behavior is used to determine if an individual has limitations and based on their significance to assign an adaptive behavior level (ABL). In accordance with 40 TAC §5.155, an authorized provider must assign an ABL in the DID.

The State requires an ABL assignment based on the following levels and descriptors:

- ABL I = "mild" deficits or limitations in adaptive skills;
- ABL II = "moderate" deficits or limitations in adaptive skills;
- ABL III = "severe" deficits or limitations in adaptive skills;
- ABL IV = "profound"² deficits or limitations in adaptive skills; and
- ABL 0 = Less than "mild" deficits or limitations in adaptive skills.

When determining the specific ABL (i.e., 0, I, II, III, or IV), an authorized provider should refer to the administered ABL instrument's manual for score interpretation (e.g., composite score, adaptive level description, percentile rank, age equivalent) and assign the ABL based on clinical judgment using the severity descriptions in the DSM-5 and the score interpretations from the administered ABL instrument's manual. When an authorized provider determines it is appropriate to assign an ABL inconsistent with score interpretations, the authorized provider must explain the rationale and clinical justification in the DID report.

5. Establishing Origination of ID during the Developmental Period

As required in 40 TAC Chapter 5, Subchapter D concerning Diagnostic Assessment, §5.155(d)(3)(C), an authorized provider must provide evidence supporting origination of ID during the individual's developmental period, meaning before the 18th birthday. This includes review of the following (as available):

- reports concerning the cause of the suspected intellectual disability;
- results of all relevant assessments;
- types of services the individual has received or is receiving;
- reports by other people to include the individual's family and friends;
- educational records; and
- previous and current psychological and psychiatric treatments and diagnoses.

School records may be a reliable source of historical information to determine age of onset. For example, if an individual receives Special Education services, the school must retain records (including results of individualized testing) for seven years. Also, schools must permanently maintain a child's academic achievement record to include student demographics, school and student data, and the record of courses and credits earned.

²This term has the same meaning as "extreme," the term used in 40 TAC §9.238 and §9.239.

Finally, if school records have been destroyed or are otherwise unavailable, a parent or guardian may be able to provide a copy of each Admission, Review, and Dismissal (ARD) meeting provided by the school. A request of records from a school requires written consent of the individual or legally authorized representative. An authorized provider must make efforts to obtain as much supporting evidence as possible and include in the DID report a detailed description of the information and sources used to make this determination. Regardless of the source, records should be requested in a timely manner to allow review by an authorized provider before an assessment is conducted.

6. Endorsement of a Previous Assessment

a) General guidelines

Endorsement of a previous assessment (including a DID) refers to accepting the assessment and the findings of another provider without changes or additions. **When appropriate, an endorsement is completed in lieu of a DID.**

The previous assessments subject to endorsement may have been completed by a school district, a public or private agency, an authorized provider associated with a different LIDDA, or other source (e.g., a managed care organization or state agency), but in all cases, the most recent DID report should be an accurate reflection of the individual's current ability. **All required elements of a DID report in rule (40 TAC Chapter 5, Subchapter D Diagnostic Assessment, §5.155) must be present in the DID report being endorsed.**

Before determining whether or not to endorse a previous assessment, an authorized provider must interview the individual and consider:

- how old the testing is;
- developmental and physical health changes that have occurred since the testing;
- if the instruments used were appropriate for the individual;
- if all the necessary elements are present;
- if there are inconsistent intellectual or functional ability scores; and
- the purpose for which the assessment will be used.

Best practice suggests having the authorized provider conduct the interview in person (i.e., face-to-face). If a face-to-face interview with the individual is not feasible, an authorized provider may use an alternative (e.g., video calling using a Smart phone or other technology) as long as it offers an interface with the individual in real time. The written endorsement should describe how the interview was conducted. The endorsement must include a statement attesting to the DID report being accepted with the previous DID report attached.

b) Endorsement of a previous assessment of a child

When evaluating a child who was subject to previous testing, an authorized provider should consider the age of the child when previously tested. The younger the child, the less likely previous testing will be an accurate reflection of current functioning. In most cases, a new DID is warranted if the previous assessment is more than three years old. In all cases, a new DID is required if the previous assessment was completed when the individual was under age 22 *and* the testing is more than five years old, in which case the previous assessment would not be eligible for endorsement.

7. Explanation of Findings

A good integration and summary of findings helps in communicating the results of testing to the individual and to the family or other interested parties. The explanation should include the results of the testing, an explanation of the current diagnoses, description of the individual's strengths and limitations, and eligibility status. An individual and others should be given time to ask questions to gain a better understanding of the findings. The authorized provider should provide contact information for additional questions that may arise after the results are presented.

Due to the differences in the eligibility criteria for services funded by general revenue (GR) and Medicaid-funded programs, it may be important to explain how these differences apply to the individual's situation. For example, eligibility for GR services as a person with ASD does not consider an individual's IQ score or ABL, compared to Medicaid programs which consider one or both, depending on the program and an individual's level of care (see Sections 8 – 11 of this document). The different eligibility requirements can be confusing therefore, providing a clear explanation should serve to minimize misunderstandings.

For an overview of eligibility criteria, see the Summary Chart of Eligibility Requirements for IDD Programs and Services on page 17 of this document.

8. Eligibility for Services Funded by General Revenue

The LIDDAs offer a variety of services and supports (based on local needs) funded by General Revenue (GR) to members of the IDD priority population.

a) Based on an intellectual disability

Effective April 1, 2016, eligibility for services funded by general revenue (GR) requires an IQ of 69 or below. Prior to April 1, 2016, the IQ cut-off score was 70. The change to 69 aligns GR and Medicaid program requirements (as described elsewhere in this document).

Note: if an individual was determined eligible for GR services based on an IQ score of 70 documented before April 1, 2016, the individual will remain eligible as long as the most recent DID or endorsement indicating an IQ score of 70 remains valid, as determined by an authorized provider associated with the LIDDA providing a GR service.

b) Based on autism spectrum disorder

A diagnosis of autism spectrum disorder (ASD) must be based on the DSM-5 which encompasses all previous subtypes (e.g., autistic disorder, Asperger’s Disorder) of the DSM-IV-TR category “pervasive developmental disorder” (PDD).

Note: if an individual was determined eligible for GR services based on a diagnosis of a PDD documented before November 15, 2015, the individual will remain eligible as long as the most recent DID or endorsement indicating a PDD diagnosis remains valid, as determined by an authorized provider associated with the LIDDA providing a GR service.

Symptoms of ASD must be present in the early developmental period but might not fully manifest until social demands exceed limited coping capacities, or may be mitigated by learned strategies later in life. Onset typically follows one of two patterns. In one, symptoms are evident early in the first year of life. In the second, symptoms emerge later in the second year, after a loss (regression) of previously acquired skills.

A DID should be completed even when it is suspected that the individual does not have ID and instead may have ASD. When diagnosing ASD, an authorized provider should use a combination of interview, observation and testing to gather diagnostic information in a structured manner. The diagnostic protocol should include:

- a clinical interview with a knowledgeable informant to gather pertinent background information;
- a period of structured behavioral observation;
- standardized assessment of cognitive abilities;
- standardized assessment of adaptive behavior; and
- use of a valid and reliable autism assessment instrument.

An authorized provider uses clinical judgment to select the autism assessment tool or rating scale he or she considers the most appropriate for a particular individual. Instruments such as the *Childhood Autism Rating Scale*, the *Autism Spectrum Rating Scales*, the *Autism Diagnostic Interview*, *Autism Diagnostic Observation Schedule*, and the *Gilliam Autism Rating Scale* are among those with proven utility in the differential diagnosis of ASD. The aforementioned instruments provide a reliable route toward assessing a predetermined set of social, communication, and behavioral qualities using a standard set of ratings that reflect key diagnostic features, and they also allow for a distinction between *lack* of particular skills and *deviance* associated with the presence of ASD. Supplemental instruments such as the *Social Communication Questionnaire (SCQ)* or the *Social Responsiveness Scale—Second Edition (SRS-2)* may also be employed at the clinical judgment of the authorized provider.

In contrast to Medicaid program eligibility (described elsewhere in this document) eligibility for GR services based on an individual having ASD, does not require the individual to have a particular IQ score or ABL.

c) Nursing facility residents

If a DID is requested to determine a nursing facility resident’s eligibility for IDD specialized services, an authorized provider must conduct a DID in accordance with the DID requirements described elsewhere in this document.

9. Eligibility for the Intermediate Care Facility for Individuals with an Intellectual Disability and Related Conditions Program

As required by §9.244 in 40 TAC, Chapter 9, Subchapter E concerning ICF/IID Programs – Contracting, a LIDDA may request enrollment of an applicant by HHSC in the Intermediate Care Facility for Individuals with an Intellectual Disability and Related Conditions (ICF/IID) Program.³

Eligibility for the ICF/IID program requires an individual to meet one of the following two levels of care (LOC):

- **LOC I criteria as described in §9.238:**
 - a) **full scale IQ score of 69 or below; or a full scale IQ score of 75 or below with a primary diagnosis by a licensed physician of a related condition; and**
 - b) **ABL of I, II, III, or IV (i.e., mild to extreme deficits).**

- **LOC VIII criteria as described in §9.239:**
 - a) **primary diagnosis by a licensed physician of a related condition; and**
 - b) **ABL of II, III, or IV (i.e., moderate to extreme deficits) obtained by administering a standardized assessment of adaptive behavior.**

In determining the individual’s LOC, an authorized provider must conduct a DID (or endorsement of a previous assessment) as described elsewhere in this document.

The State maintains the *HHS Approved Diagnostic Codes for Persons with Related Conditions* which is posted at www.hhs.texas.gov. These codes are based on the federal definition of a “related condition”⁴ and the International Statistical Classification of Diseases and Related Health Problems, 10th Revision (ICD-10).

If eligibility for ICF/IID is based on an individual having a related condition, an authorized provider should ensure that the individual’s record includes a) written documentation of a physician’s diagnosis of a condition that appears on *HHS Approved Diagnostic Codes for Persons with Related Conditions*; and b) completion of *Form 8662 (Related Condition Eligibility Screening Instrument)*.

³ A program provider may request enrollment of an applicant by HHSC only if the applicant has received ICF/IID services from a non-state operated facility during the 180 days before the enrollment request; and is not moving from or seeking admission to an SSLC. In this situation, neither a DID or endorsement by the LIDDA is required.

⁴ Code of Federal Regulations, Title 42, §435.1009 states that a related condition is a severe and chronic disability that: (A) is attributable to (i) cerebral palsy or epilepsy; or (ii) any other condition, other than mental illness, found to be closely related to mental retardation because the condition results in impairment of general intellectual functioning or adaptive behavior similar to that of persons with mental retardation, and requires treatment or services similar to those required for those persons with mental retardation; (B) is manifested before the person reaches 22 years of age; (C) is likely to continue indefinitely; and (D) results in substantial functional limitations in three or more of the following areas of major life activity: (i) self-care; (ii) understanding and the use of language; (iii) learning; (iv) mobility; (v) self-direction; and (vi) capacity for independent living.

As described in Section 8 of this document, **a diagnosis of ASD determined by the authorized provider without regard to IQ score or ABL may render an individual eligible for GR services. However, a qualifying diagnosis for ICF/IID (and the other Medicaid programs described below) must fit the federal definition of a related condition and also be approved by HHSC as a related condition.** ASD does not appear on *HHS Approved Diagnostic Codes for Persons with Related Conditions*; therefore, a diagnosis corresponding to ASD must be used for ICF/IID eligibility. Examples of a possible corresponding diagnosis include autistic disorder or Asperger's Disorder, depending on the individual's presentation as determined by a licensed physician.

10. Eligibility for the Home and Community-based Services and Texas Home Living Waiver Programs

The Home and Community-based Services (HCS) and Texas Home Living (TxHmL) waiver program rules in 40 TAC Chapter 9, Subchapter D, §9.158 and Subchapter N, §9.556, require an authorized provider to conduct a DID (or endorsement of a previous assessment) on behalf of the requesting LIDDA for individuals enrolling in the HCS or TxHmL waiver programs. Eligibility criteria for HCS and TxHmL require individuals to meet the ICF/IID LOC I criteria with one exception. If an individual is moving from a nursing facility, eligibility for HCS or TxHmL may be determined based on the individual meeting the LOC VIII criteria (see Section 9 of this document).

11. Eligibility for Community First Choice Services (non-waiver) with ICF/IID LOC
Eligibility for Community First Choice (CFC) with an ICF/IID LOC requires a DID, or endorsement of a previous assessment, conducted by an authorized provider on behalf of a LIDDA. To be eligible for CFC provided through a Medicaid managed care organization (MCO), an individual must meet ICF/IID LOC I or VIII (see Section 9 of this document).

Note: Following a determination of eligibility for CFC non-waiver services provided through a Medicaid MCO, the State requires an authorized provider associated with a LIDDA to conduct a standardized measure of adaptive behavior level at least once every five (5) years.

12. Court Ordered Determination of Intellectual Disability for HHSC Guardianship

In accordance with the Estates Code, the judge for the court with jurisdiction for granting guardianship will accept a DID or endorsement, only if either is completed within 24 months before the guardianship hearing date.

In addition to conducting or endorsing a DID for submission to the court, the authorized provider should also conduct an assessment of the individual using Form 2190, *Capacity Assessment for Self-Care and Financial Management* and submit the assessment to the court.

13. Determination of Intellectual Disability Report Elements

In 40 TAC Chapter 5, Subchapter D concerning Diagnostic Assessment, §5.155 describes the minimum requirements for a DID report but does not prescribe a particular format or outline. The following outline of reporting elements is offered to help ensure the development of a comprehensive and quality DID report.

a) INFORMATION ABOUT THE INDIVIDUAL

Provide the individual's name, date of birth, gender, date of assessment, age at time of the assessment and related information.

b) RELEVANT BACKGROUND INFORMATION

Provide the following based on information from a review of formal, written records (e.g., LIDDA or school records, CARE) and interviews with informants:

- *Family medical/psychiatric history, culture, living situation, stability, etc.*
- *Individual's birth, developmental milestones, formal education, service history, employment history, and interactions with the law, legal/illegal drug use.*
- *Previous and current psychiatric diagnoses and treatments with the providers' names and credentials.*
- *Previous diagnosis of a pervasive developmental disorder (e.g., autism, Asperger's Syndrome), or ASD, including date of diagnosis with the providers' names and credentials.*
- *Significant medical history, health conditions, and medications.*
- *If applicable, based on documentation of a condition that appears on HHS Approved Diagnostic Codes for Persons with Related Conditions, the diagnosis, ICD- 10 code, provider's name and credentials, and date of diagnosis.*

c) PREVIOUS DIAGNOSTIC ASSESSMENT AND TEST RESULTS

- *For each event, provide the name of the instruments used, date of testing, individual's age on date of testing, diagnosis/results and provider's name and credentials.*
- *Cover all relevant information, including the results from a previously completed Form 8662, Related Conditions Eligibility Screening Instrument.*

d) CURRENT BEHAVIORAL OBSERVATIONS

Describe the individual's presentation, physical appearance/ characteristics, social skills, affect, and other observations used to inform your conclusions.

e) CURRENT ASSESSMENT RESULTS/FINDINGS

- *Intellectual and Cognitive Ability*
 - o *Provide the name(s) of instruments; date when instrument(s) administered, overall intellectual functioning score; composite or full scale scores; cluster, area and specific or subscale scores, if available; for each test, relative strengths and weaknesses; and*

- *Describe testing conditions, accommodations or technology used and impact of conditions on test performance (e.g., cultural background, primary language, communication style, lack of rapport, physical or sensory impairments, motivation, attentiveness, and emotional factors).*
- *Adaptive Behavior*
 - *Provide the name(s) of the instrument(s), date when instrument(s) administered, overall adaptive behavior score; composite or full scale scores; individual scale scores, if available; describe your informants to include their relationship to the individual, and report the adaptive behavior level based on your findings.*
 - *Describe testing conditions, accommodations/ technology used, and impact of conditions on test performance, as applicable: cultural background, primary language, communication style, lack of rapport, physical/sensory impairments, motivation, attentiveness, emotional factors etc.*
- *Social and Psychological Functioning: Provide your findings based on use of other tools, if applicable, including an ASD scale, projective measures, etc. Include a description of your informants and their relationship to the individual, if known.*

f) SUMMARY

- *Describe the individual's age and gender and briefly describe reason for this assessment.*
- *Diagnostic impressions (as applicable):*
 - *ID: provide the IQ score, ABL, and evidence of date of onset before age 18. Include the diagnosis and applicable DSM and ICD-10 codes.*
 - *Related condition: provide the diagnosis, date of the diagnosis and licensed physician who made the diagnosis, applicable ICD-10 code, adaptive behavior level, and evidence of date of onset before age 22.*
 - *ASD: provide the applicable DSM and ICD-10 codes and evidence of date of onset.*
 - *No ID, RC or ASD: provide the basis/rationale for your conclusions.*

g) RECOMMENDATIONS

Your recommendations should be responsive to the identified purpose of the assessment and presenting questions and clearly supported by information contained in the report.

h) SIGNATURE

Include your name, credentials, licensure number (if applicable), title, and certified authorized provider number (if applicable).

Summary Chart of Eligibility Requirements for IDD Programs and Services

Funding Source/ Program	IQ Score or Other Diagnosis	Adaptive Behavior Level (ABL)	Reference	Responsible for Determination
General Revenue	IQ score of 70 or below if determined before April 1, 2016	Level I, II, III, or IV	<u>DSM-IV-TR</u> or <u>DSM-5</u> HHSC/Local Intellectual and Developmental Disability Authority (LIDDA) Performance Contract, Attachment A-1, Article 2.1.8*	Authorized Provider (AP) on behalf of a LIDDA
	IQ score of 69 or below if determined April 1, 2016 or later	Level I, II, III, or IV	<u>DSM-5</u> HHSC/LIDDA Performance Contract, Attachment A-1, Article 2.1.8*	AP on behalf of a LIDDA
	Pervasive developmental disorder (including autism) diagnosed before November 15, 2015	N/A	<u>DSM-IV-TR</u>	AP on behalf of a LIDDA
	Autism spectrum disorder	N/A	<u>DSM-5</u>	AP on behalf of a LIDDA
Medicaid - ICF/IID - HCS - TxHmL - CFC (non-waiver)	LOC I: IQ = 69 or below <i>or</i> IQ = 75 or below with a related condition	Level I, II, III, or IV	<u>DSM-5</u> for IQ score and ABL <u>ICD-10</u> and <i>DADS Approved Diagnostic Codes for Persons with Related Conditions*</i>	IQ score and ABL by an AP on behalf of a LIDDA Related condition by a licensed physician
	LOC VIII:** Related condition	Level II, III, or IV	<u>ICD-10</u> and <i>HHS Approved Diagnostic Codes for Persons with Related Conditions *</i>	ABL by an AP on behalf of a LIDDA Related condition by a licensed physician

*www.hhs.texas.gov

**For HCS and TxHmL, an applicant who meets LOC VIII must be transitioning or diverting from a nursing facility.