

**Determining Eligibility  
for Services to Persons  
With Developmental  
Disabilities in Montana:  
A Staff Reference Manual**

**(6<sup>th</sup> Edition – 2013)**

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# PREFACE

This book is the sixth edition of a Manual that was first written and used in 1989 at workshops for persons involved in the administration and delivery of state sponsored developmental disabilities services. The current revision involves an integration of the new concepts and terms in DSM-5, which was published in May of 2013. In addition, it seeks to bring greater clarity to the developmental disability eligibility determination process based on the experience of the past 2 years. Over the years this Manual has evolved from a technical reference to assist State officials in understanding psychological evaluations and testing issues to a collaboration with the staff of the Developmental Disabilities Program (DDP) to bring as much clarity and consistency as possible to the eligibility process. Finally, previous additions of the Manual were designed to be used by a large number of professionals and program staff in Montana who were involved in making eligibility decisions (e.g., Quality Improvement Specialists and regional managers for adults, Family Support Specialists and program coordinators for children's services). Now the initial decision in all cases is made by one person, an Eligibility Specialist in the DDP office in Helena. Nevertheless, everyone involved in DDP services still needs to understand the process and this Manual should make this as transparent as possible. It is also hoped that the current Manual will continue to help the reader accomplish the following goals:

1. Increase understanding of current tests and other assessment procedures used in psychological evaluations for persons with developmental disabilities.
2. Interpret historical data from social history, educational, medical and psychological records in order to determine if a developmental delay was present before age 18.
3. Develop a working understanding of basic statistical terms and other technical information used in psychological reports, including DSM-5 nomenclature for diagnoses.
4. Understand state and federal laws regarding eligibility issues for services to persons who have developmental disabilities.
5. Make a referral for psychological evaluations in order to have specific diagnostic questions addressed.
6. Increase understanding of the relationship between neurological disorders and developmental disabilities.
7. Generate a working understanding of autism spectrum disorder.
8. Improve our knowledge of dual diagnosis issues.

9. Be familiar with the Eligibility Determination Forms (Appendices L and M) used to determine whether or not an applicant meets Montana guidelines regarding eligibility for services to persons with developmental disabilities.
10. Provide a clear understanding of the term “untestable” and ways to resolve this issue (see Appendix K).
11. Be acquainted with Montana’s new operational eligibility criteria for Developmental Disabilities Services (see Appendix I).
12. Identify the new requirements for psychological evaluation reports that will be used to make eligibility decisions (see Appendix J).
13. Be aware of Montana's DDP eligibility determination procedures (See Appendix N).

As I first noted in 1996, these kinds of goals are ambitious. To achieve them, the interested reader will need to read and study the Manual in detail. After directed effort, a reader with experience in the field of developmental disabilities should be able to accomplish the above goals.

For a Manual like this to be successful and truly workable, I believe that 3 factors are necessary as noted below:

1. It needs to rest on a secure legal foundation
2. It needs to be based on sound psychological practice and state of the art approaches used in the field of developmental disabilities.
3. It needs to be practical and able to be consistently implemented on a day to day basis in a state governing agency.

Regarding point number 1 above, I have been blessed to work with Cary Lund, the attorney for the Montana DDP, who was literally invaluable in his close attention to detail to ensure that the Manual is legally sound. The second point rests on my 43 years of experience in the field of developmental disabilities in many diverse settings (state institution, group home, day programs, psychological evaluations, and consultation at all levels of service delivery in the State of Montana). To achieve the third point, I invited the staff of the DDP to review the 2 final drafts of the Manual, and review it they did! I received 1-3 pages of detailed feedback and suggestions each from Jannis Conselyea, Tim Plaska, Carla Rime and Connie Orr. Their ideas were fantastic, and went a long way towards helping me formulate the final version contained herein. Thank you one and all. I must also mention one other name that cannot be left out of this acknowledgment section, i.e., my dear, sweet wife, Dr. Ann Cook, who was always willing to help me compensate for my digital limitations and challenges. Finally, I am also very indebted to Denise Watkins for her talent and expertise in formatting the final draft.

Please remember that it was never intended for you to memorize this Manual. I hope you will

keep it readily available and refer to it often as a reference for technical information and procedural guidelines that can assist you in your day-to-day work. I wish you the best of luck in this regard. If you have comments or suggestions for future revisions of the Manual, please send them to me at the address listed below.

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November 1, 2013

# **INTRODUCTION**

## **Departmental Statement As To The Purpose Of This Manual**

Developmental disabilities services provided by the State of Montana are almost entirely delivered through Medicaid funded home and community services programs. Medicaid funded home and community services programs are governed by written approval documents entered into with the federal government. In accordance with federal and state law, the requirements and limitations expressed in those approval documents are binding upon the Department Of Public Health And Human Services in the administration of those types of developmental disabilities services. This Manual and certain state adopted rules are denoted by the approval document for each home and community developmental disabilities program as being the authorities by which the Department is to determine eligibility for the developmental disabilities Medicaid funded home and community based services program.

While there is an established definition of developmental disability appearing at 53-20-102 and 53-20-202, Montana Code Annotated (MCA) and there is the federal definition of intellectual disability, the application of those legal definitions and other criteria as may be necessary for the establishment and administration of the Medicaid home and community developmental disabilities services programs, necessitates the adoption of technical criteria and professional processes by which to assure the consistency and integrity of the eligibility determinations that are to be made as to individual persons. This Manual, drawn from professional knowledge and experience in the field of psychology and more particularly the realm of intellectual and related disabilities, serves those purposes.

# CHAPTER 1

## LABELING, CLASSIFICATION, AND HISTORICAL ISSUES REGARDING MENTAL MEASUREMENTS AND PSYCHOLOGICAL TESTING

The notion that there are individual variations in intelligence is a topic that has been discussed and noted from the earliest times of recorded history. Plato wrote about this issue more than two thousand years ago. Because persons who are delayed in their development have always been with us, it is not surprising that a large number of terms have been used to describe these persons. The term "idiot" originated in 1300, while "dullard" appeared in 1440. "Dolt" was introduced in 1543 and "dunce" in 1577. A "natural fool" was legally defined during the Renaissance as one congenitally deficient in reasoning powers. However, the real definition of a person with cognitive delays has always been a social judgment. A fool was a fool if he acted like one, and how he was treated depended upon how he fit into the world view of those doing the defining. In 2013, we are still struggling to find appropriate ways to deal with definitions and nomenclature for persons who have disabilities. DSM-5 now uses the term "Intellectual Disability" instead of "Mental Retardation," which is consistent with the American Association on Intellectual and Developmental Disabilities (See Appendix E). The Montana legislature also recently adopted this change, which was finalized into law by October of 2013. Therefore, progress is being made since, for the most part, we are all now using the same term. In fact, on October 5, 2010, President Obama signed "Rosa's law" (see Public Law 111-256), which changes the phrase "mental retardation" to "intellectual disability" in all federal statutes where specific agencies have the discretion to make this change (e.g., this change does not yet apply to the social security program). However, the term "Intellectual Disability" is still defined somewhat differently by these various entities (i.e., DSM-5, AAIDD, state and federal governments).

Some people have raised legitimate concerns about potential problems with labeling other people, calling it a stigmatizing process. However, both my master's and doctoral research projects (Cook and Wollersheim, 1976; Cook, 1976) suggested that a person's behavior and appearance could be even more powerful than a label in terms of negatively impacting the social judgment of middle school peers. In addition, there may be an informal or automatic labeling process that takes place when a person is exposed to someone whose behaviors and/or appearance differ significantly from the expected norm. Finally, we need to remember that classification is a basic activity of scientists. There are many functions of classification and these are briefly described below (Bauras, 1999):

1. Record keeping, data collection, compilation of statistical information.
2. Communicating with third parties (e.g., insurers and governmental agencies).
3. Eligibility for services (i.e., being a gate keeper to decide who gets services).
4. Communication between professionals and between professionals and lay persons.
5. Research.
6. Legal purposes (e.g., informed consent, ability to participate in legal proceedings, ability to participate in contracts).

## 7. Service planning, monitoring and evaluation.

When we use this Manual to determine eligibility for persons with a developmental disability in the state of Montana, we are engaging in most, if not all, of the various functions of classification described above. However, one purpose stands out above all others, i.e., being a gate keeper. If we compare government services to insurance companies, there is a fairly clear analogy in this regard. Because of limited resources, governments must put some limits on who gets special services and who does not. At that point, Montana's Eligibility Specialist and other DDP professionals are functioning as gate keepers to decide who gets through the gate and who must look elsewhere for assistance. Some people call this resource allocation, while others call it rationing. However, no matter what it is called, it is a huge responsibility, and it is one that I do not take lightly. That is why we will try to look at this issue in a fair and comprehensive manner in order to consider the many detailed and complex aspects of this difficult, but nevertheless important decision-making process. We should also remember that gate keeping is not just a yes/no decision. It also includes making referrals or recommendations for other appropriate services that might be helpful for a particular person.

The modern testing movement began in 1905 with the introduction of the *Binet-Simon Scale*. It was revised in 1908 and many times thereafter as the contemporary testing movement began to take shape in America. The term mental age was first used in 1908 and the concept of the intelligence quotient was identified in 1912 by Stern and Kuhlmann. The intelligence quotient is actually a ratio as noted below:

$$IQ = \frac{MA}{CA} \times 100$$

where MA = mental age in years or months as determined by a mental test, and CA = chronological age in years or months since birth. The Wechsler scales were originally devised by David Wechsler in 1939. These have also been revised many times and are probably the most commonly used tests of intelligence in the United States today.

The goal of intelligence testing has generally been to identify persons who have special needs in order to help them by providing various kinds of special services. By using a test, psychologists have attempted to apply scientific methodology to achieve this goal. Rather than using subjective criteria, psychologists utilize standardized tests which evaluate performance on the same activities administered in the exact same manner to all individuals in order to compare a given person's performance with a norm group.

Over the years, a great many diverse ideas about the basic nature of intelligence have been proposed, but a few themes are common to most definitions. These include:

1. The capacity to learn.
2. The totality of the knowledge which has been acquired.
3. The ability to adjust or adapt to the environment, particularly to new situations.

Thorndike originally discriminated between three kinds of intelligence as follows:

1. Social intelligence – the ability to understand and deal with persons.
2. Concrete intelligence – the ability to understand and deal with things (as in skilled trades or tasks involving mechanical aptitude).
3. Abstract intelligence – the ability to understand and deal with verbal and mathematical symbols.

Some theories have attempted to portray intelligence as primarily a unitary phenomenon (a general factor of intelligence), while others have emphasized very specific factor analyses in order to identify specific intellectual skills such as verbal fluency, quantitative reasoning, speed of reactions, and rote memory. A factor analysis is a way to use statistical methodology in order to identify specific factors that are independent of each other, but which nevertheless contribute to the overall global intelligence that is being measured.

Current genetic research clearly indicates that heredity and genetic factors both influence individual differences in IQ scores. Genetically related individuals raised apart have highly correlated IQ's and identical twins show higher correlations than do fraternal twins. The most recent studies in this regard indicate that about 50 percent of the variation in IQ scores is due to hereditary factors. Of some interest, these studies are showing somewhat lower estimates of the effects of heredity than studies in the 1970's, which suggested that about 70% of the variability in IQ scores was due to genetic factors. Of even more interest is the current thinking that environmental conditions can affect IQ scores by about 20-25 points. Thus, a young child functioning in the mildly cognitively delayed range could potentially be helped with special programs to function within the normal range, and some studies have found this kind of dramatic result with highly structured and intensive early intervention programs.

Another major area of controversy regarding intelligence tests relates to the concept of culture-fair or "culture free" tests. Language, speed, literacy, and verbal test content are among the factors known to be affected by culture. Researchers have attempted to develop tests which would be culture free, but many people now agree that no test will be equally "fair" to all cultures. Some traditional IQ tests in the United States have been criticized as placing too much stress on language and showing a middle or upper class bias in their content. In general, performance tests which are nonverbal tend to minimize, but not eliminate this bias. In Montana, this issue is probably most important in regards to Native American minorities. If you are referring a person who is Native American for a psychological evaluation, it would be helpful to ask the psychologist to provide an in-depth assessment of adaptive behavior and to analyze the various subtests to see if cultural factors might be depressing overall IQ scores. Tests that are less related to cultural bias could be incorporated into such an evaluation (e.g., Raven's Progressive Matrices). However, you need to remember that even these types of tests do not eliminate cultural bias. In fact, one could make the point that if all cultural influences were eliminated from a test, then it would cease to predict anything of value within that culture.

Psychologists have constructed their tests using a large number of mathematical, scientific, and statistical procedures in order to ensure that the items are reliable and valid. A summary of these statistical terms is included in Appendix A. Tabular information to help one understand the meaning of IQ and percentile rank scores is contained in Appendices B, C and D.

## Summary Points to Remember

- ✓ Labels for people with developmental disabilities have been used for at least 2000 years.
- ✓ Labeling is a social judgment that is affected by cultural norms and values.
- ✓ Classification has many purposes in science, including record keeping, communication, research, and a variety of legal purposes.
- ✓ Determining eligibility is a gate keeping process that ultimately determines how government resources will be rationed to those with special needs.
- ✓ Psychological tests related to intelligence have been used for over 100 years.
- ✓ Intelligence testing is a classification process used to identify persons with special needs in order to help them access specialized services.
- ✓ Intelligence involves a capacity for learning and development.
- ✓ Intelligence can be significantly affected by environmental variables related to stimulation
- ✓ Intelligence tests should be as culturally fair as possible, though this can be an elusive goal in some circumstances.

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# CHAPTER 2

## WHAT IS A DEVELOPMENTAL DELAY?

As we saw in Chapter 1, humans have always struggled with the challenge of knowing when a developmental difference represents a significant difference. We all want to help children who are delayed in their development, but how do we know when they are delayed? If a child is not walking by 14 months of age, are they "slow" in learning this milestone? If a two-year-old child is not talking, what does this mean?

The following are screening guidelines that indicate what cut-off points can be useful for determining when a particular milestone is significantly slow or delayed:

- A. Gross Motor Skills:**
  - 1. Child is not able to sit independently by nine months.
  - 2. Child is not walking independently by 19 months of age.
  - 3. Motor assessment standard scores of 75 or lower.
  
- B. Speech and Language Skills:**
  - 1. The child is not talking at all by age two.
  - 2. There are no sentences by age three.
  - 3. Communication assessment standard scores of 75 or lower.
  
- C. Cognitive Development:**
  - 1. Child has IQ scores on a standardized test of intelligence that are 75 or lower.
  
- D. Self Help Skills:**
  - 1. Not able to feed self with spoon and fork by age three.
  - 2. Not toilet trained by age four.
  - 3. Not able to dress self by age five.
  - 4. Adaptive behavior assessment standard scores of 75 or lower.
  
- E. Social Skills:**
  - 1. Lack of interest in social relationships by age two.
  - 2. Inability to make friends within peer group by age six.
  - 3. Social skills assessment standard scores of 75 or lower.
  
- F. Educational Skills:**
  - 1. Child's grade level performance is delayed by at least three years in reading, arithmetic, and written language after age 10 (fourth grade).
  - 2. Educational assessment standard scores of 75 or lower.

The checklist noted above can be used as a guideline for reviewing educational, developmental, and social history records. An adult who is determined to be developmentally disabled would have exhibited delays in all or nearly all of the developmental milestones in the checklist. If

only one or two checks are present, this likely means that the person had a more specific type of problem (e.g., specific learning disability) rather than a more generalized type of problem (e.g., developmental disability).

The meaning or interpretation of IQ scores can be fairly confusing. Appendix D shows the cut-off points for both IQ scores and percentile ranks for the various categories of cognitive development. Thus, an IQ score of 90-109 is average, while an IQ score of 80-89 is low average, and so forth. Similarly, a percentile rank of 33 is average, while a percentile rank of 7 is in the borderline category. If you do not know how to interpret an IQ score in a psychological evaluation report, you can look it up in Appendix D in order to determine its meaning.

## Summary Points to Remember

- ✓ The childhood developmental history for persons who are eligible for Developmental Disabilities Services (DDS) will normally show significant delays in most skill areas (with the possible exception of motor skills).
- ✓ An adult person with a diagnosis of developmental disability should as a child have exhibited a generalized delay in most, if not all, areas of childhood development.
- ✓ Based on the classification table from Appendix D, an IQ score of 92 is average, while an IQ score of 81 is in the low average range.



# CHAPTER 3

## DESCRIPTION OF PSYCHOLOGICAL TEST INSTRUMENTS

**INTRODUCTION:** The world of psychological test instruments can seem like a confusing maze that is riddled with jargon, or an alphabet soup of acronyms that would confuse virtually anyone who is not a diehard psychologist who specializes in evaluations. The purpose of this chapter is to shed some light on the various tools used to evaluate persons with potential developmental disabilities so that these procedures are better understood and somewhat more transparent in terms of their use and purpose. This is not a list of approved tests. Each clinician who performs an evaluation needs to use his/her own judgment as to what is the most appropriate test for each particular person.

### I. Cognitive Measures - General

- A. Bayley Scales of Infant and Toddler Development - Third Edition (BSID-III) - The 2005 edition of the Bayley Scales is generally considered to be the assessment instrument of choice for young children in the age range from 1 to 42 months. The Bayley III evaluates a child in the areas of cognition, motor development, language development, social-emotional development, and adaptive behavior.
- B. Kaufman Assessment Battery for Children - Second Edition (KABC-II). The KABC-II is appropriate for persons in the age range from 3 to 18. The subtests of the KABC-II measure simultaneous processing, sequential processing, planning, learning, and knowledge. The KABC-II subtests are designed to minimize verbal instructions and responses. Because they have few demands for language, some psychologists believe that the KABC-II is one of the better options for meeting standards of cultural fairness when assessing people from different cultural backgrounds. This could be particularly true for Native Americans in the State of Montana.
- C. Stanford-Binet Intelligence Scales (SB-5)- 5th Edition. The fifth edition of the Stanford-Binet provides norms from two up to 85+ years. Besides providing a general measure of intelligence, the Stanford-Binet also provides a profile across five different ability areas that include Fluid Reasoning, Knowledge, Quantitative Reasoning, Visual-Spatial Processing, and Working Memory. These five factors are assessed with both non-verbal and verbal tasks and activities. The SB-5 is now consistent with the Wechsler Scales in providing standard scores with a mean of 100 and a standard deviation of 15. Summary measures include a Non-Verbal IQ, a Verbal IQ, and a Full Scale IQ score.

D. Wechsler Adult Intelligence Scale-Fourth Edition (WAIS-IV) 2008. The WAIS-IV is probably the most commonly used instrument for evaluating cognitive abilities in adults. The test has been normed for adults who range in age from 16 to 90. However, if adults have a mental age of five or less, they would probably be functioning too low for the WAIS-IV to be an appropriate assessment measure. The WAIS-IV no longer provides a Verbal IQ score or a Performance IQ score. Rather, it uses four Index scores and a Full Scale IQ score as the basic composite scores. A brief description of these summary standard scores is provided below:

1. Verbal Comprehension Index – Tests in this area measure a person’s understanding of conceptual and categorical relationships in words, general vocabulary, and basic knowledge that has been acquired. Verbal Comprehension is now an optional subtest in this area.
2. Perceptual Reasoning Index – This index score summarizes non-verbal reasoning abilities related to matching block design patterns, identifying missing elements in a visual matrix, and combining visual shapes to solve a puzzle.
3. Working Memory Index – Memory subtests include a number of short-term auditory sequential memory skills with numbers, and the ability to remember arithmetic thought problems.
4. Processing Speed Index – This portion of the WAIS-IV evaluates the adult’s ability to copy and scan geometric symbols in a paper-pencil format that emphasizes motor speed.
5. Full Scale IQ Score – As a global summary, the Full Scale IQ Score provides a measure of the person’s overall intellectual ability across the ten core verbal and non-verbal subtests of the WAIS-IV.

In their report, some psychologists will provide a complete listing of all obtained scores, while others will provide only an interpretation of the basic findings. All psychologists should identify strengths and weaknesses so that the interested reader can determine which ability areas are deficient and which are within normal limits.

The standard error of measurement (SEm) of the WAIS-IV (like all tests) varies by age and for each component of the test. For example, for the Full Scale IQ score, the SEm ranges from 2.12 at age 65-69 to 2.60 at age 16-17. By multiplying the SEm by 2, we can compute the 95% confidence interval for a given measure. Thus, for a 16-year-old who achieved a Full Scale IQ score of 71, we could be 95% confident that the true score would fall in the range between 65.8 and 76.2. The SEm for the Index scores are all higher than the Full Scale IQ

score. In order to make this issue as clear as possible, the best approach is to ask a psychologist to give the 95% confidence interval for all summary/ composite measures.

- E. Wechsler Intelligence Scale for Children -Fourth Edition (WISC-IV). The WISC-IV has the same general format as the WAIS-IV noted above, except that the item content is geared towards children in the 6-16 year range. Like the WAIS-IV, the WISC-IV also provides Index Scores, which are standard scores based on a logical/statistical analysis of the subtest content being evaluated. The Perceptual Reasoning Index Score from the WISC-IV is similar to the Perceptual Organization Index Score from the WAIS-IV. The other index scores are also very similar (Verbal Comprehension, Working Memory, Processing Speed) to the index scores described above for the WAIS-IV. Finally, the WISC-IV is also available in an integrated version which provides some additional, specialized diagnostic subtests which can be used to support clinical judgment and guide intervention planning.
- F. Wechsler Preschool and Primary Scale of Intelligence - Fourth Edition (WPPSI-IV). The new WPPSI-IV provides a measure of intelligence for children in the age range from two years, six months up to seven years, seven months. The WPPSI-IV provides similar information to that noted with the other Wechsler scales described above, but its summary scores include a Verbal Comprehension Index (VCI), a Visual Spatial Index (VSI), a Working Memory Index (WMI), a Fluid Reasoning Index (FRI), a Processing Speed Index (PSI), and a Full Scale IQ score. A number of ancillary index scores can also be computed by using some of the expanded optional subtests.
- G. Woodcock-Johnson III (WJ III) - Tests of Cognitive Abilities. The WJ III Tests of Cognitive Abilities provide a standard battery of ten tests and an extended battery of ten additional tests. These tests are appropriate for persons 2-90+ years of age. While the WJ III Tests of Cognitive Abilities provide comprehensive information about a person's overall intelligence and more specific cognitive clusters, the test tends to be used fairly infrequently in the State of Montana.
- H. Differential Abilities Scales - Second Edition (DAS-II) 2007. The DAS-II consists of 20 cognitive subtests which can be used as an Early Years core battery for children 2 years-6 months to 6 years-11 months, or as a School-Age core battery to assess children ages 7 years to 17 years-11 months. Both batteries provide a General Conceptual Ability score (GCA), which is a composite score related to general reasoning and conceptual abilities that is similar to a Full Scale IQ score. The DAS-II purports to measure cognitive abilities that are important for learning. The subtests measure a variety of cognitive abilities that include verbal and visual working memory, immediate and delayed recall, visual recognition and matching, processing and naming speed, phonological

processing, and understanding of basic number concepts.

## II. Cognitive Measures - Nonverbal

- A. Comprehensive Test of Nonverbal Intelligence - Second Edition (CTONI-2). The CTONI-2 provides a comprehensive measure of non-verbal reasoning in persons from 6 through 90 years. It takes one hour to administer and provides subtests related to picture and geometric analogies, picture and geometric categories, and picture and geometric sequences. The CTONI-2 attempts to eliminate as many sources of cultural, gender, racial, and linguistic bias as possible. A shorter version of this test is the Test of Nonverbal Intelligence, 4<sup>th</sup> Edition (TONI-4), which can be used for screening nonverbal cognitive abilities.
- B. Leiter International Performance Scale-Revised (Leiter-R). The Leiter-R is completely non-verbal. It does not require spoken or written words from the examiner or child. The Leiter-R is appropriate for persons in the age range from 2 to 21 years. It is much more comprehensive than the original Leiter. It now provides a profile of domains that include Visualization, Reasoning, Memory, and Attention. This test can be used for persons with cognitive delay, English as a second language, persons from diverse cultures, and people who are hearing impaired, motor impaired, or suffering from traumatic brain injury or communication disorders.
- C. Raven's Progressive Matrices - Raven's Progressive Matrices are a series of three nonverbal tests that assess mental ability by requiring the person to solve visual problems presented in abstract figures and designs. The tests can be used from the five year up to the adult level. They are most helpful for people who have a significant language impairment or come from a minority cultural background where there may be a need to use a test that is less culturally biased.
- D. Universal Non-Verbal Intelligence Test (UNIT). The UNIT is appropriate for children between the ages of 5 and 18. Of the six subtests in the UNIT, three assess short-term memory and three assess reasoning. The test activities are designed to be relatively universal and appropriate for cross-cultural groups. It also provides multiple tasks, rather than a single activity such as matrices. The UNIT is completely non-verbal and is administered in pantomime. Thus, it requires no language on either the examiner's or the student's behalf.

## III. Cognitive and Developmental Screening Tools

- A. Developmental Screening Measures. There are a large number of developmental screening measures that are used extensively across Montana and the country as a whole. These include the Developmental Profile 3 (DP-3), the Brigance Inventory of Early Development-III, the Developmental Indicators for the

Assessment of Learning-Third Edition (DIAL-3), the Developmental Observation Checklist System (DOCS), the Battelle Developmental Inventory - Second Edition, and the Shiopley-2. These scales are very appropriate to use for initial screenings and program planning purposes. In some cases, they may provide a fairly accurate profile of the child's current functioning and skills. However, it is important to remember that screening tools do not provide a diagnosis. Thus, these types of measures should not generally be used to determine a person's eligibility for services in the area of developmental disabilities unless that person is "untestable" with comprehensive standardized tests and a clinician is forced to use a developmental checklist to document functioning levels and help estimate the severity of an obvious developmental disability. Please see Appendix K for additional details regarding this issue.

- B. Kaufman Brief Intelligence Test - Second Edition (KBIT-2). The KBIT-2 provides a screening measure of intelligence that takes approximately 20 minutes (compared to 60-120 minutes for most other diagnostic tests). The KBIT-2 provides a quick assessment of both verbal and non-verbal reasoning abilities. If a person scored in the normal range on this test, it would be reasonable to use these results to rule out a developmental disability. However, if the person demonstrates low average or borderline deficits, then further diagnostic testing would certainly be indicated to provide a more comprehensive assessment. Finally, if a person has a long history of significant developmental delays (e.g., IQ scores of 50-55), then it might be appropriate to use a KBIT-2 just to confirm that this individual is still functioning at the same basic level.
- C. Wechsler Abbreviated Scale of Intelligence-Second Edition (WASI-II). The purpose of the WASI-II is similar to the KBIT-II described above. It provides a reliable, but brief measure of intellectual ability for persons in the age range from 6 to 90. It allows you to use either a two or four-subtest format. The two-subtest form can be administered in about 15 minutes. The four-subtest form can be administered in 30 minutes. The same cautionary statements noted above for the KBIT-II are applicable to the WASI-II. Thus, the WASI-II could be useful for persons who are thought to have intellectual abilities that are average (or above), or cognitively delayed at a moderate level or lower. The WASI-II cannot provide diagnostic information useful for eligibility purposes in persons who are in the mildly cognitively delayed or borderline range.

**IV. Neuropsychological** – Neuropsychologists have special training that allows them to evaluate brain functions. These evaluations may take from four to eight hours or even longer. Neuropsychologists attempt to describe or rule out neuro-cognitive deficits that can be important in establishing a diagnosis, functional impairment, prognosis, or treatment recommendations in a person who may have some type of neurological disorder. This Manual will not attempt to summarize the large number of neuropsychological tests that are currently available. These tests can be used to evaluate

specialized mental processes, visual motor skills, memory, learning new information, specific language skills, educational skills, problem-solving, and various attentional processes. A few examples of test batteries that may be used by psychologists or neuropsychologists are listed below:

- A. *Detroit Tests of Learning Aptitude - Fourth Edition (DTLA-4)*. The *DTLA-4* provides a comprehensive evaluation of cognitive functioning. It measures basic abilities as well as showing the effects of language, attention, and motor abilities on test performance.
  - B. *Developmental Test of Visual-Motor Integration (VMI) - Fifth Edition*. This test is appropriate for persons aged 2 to 18. The *VMI* can be administered in just 10-15 minutes and it involves copying geometric figures in a pencil-paper format.
  - C. *Halstead-Reitan Neuropsychological Test Battery*. This battery consists of nine specialized tests designed to discriminate between brain damaged and normal persons. The total administration time for this battery can require six to seven hours. Sometimes shorter forms of the battery are administered. Experienced neuropsychologists use this battery to detect the presence of brain damage, to specify the type of neuropsychological deficits present, and to make treatment/remediation suggestions.
  - D. *Wechsler Memory Scale - Third Edition (WMS-III)*. This test provides a comprehensive assessment of memory. It takes about one hour to administer and has 11 different subtests to evaluate memory for both auditory and visual stimuli. The test also assesses both immediate and delayed recall. This test is appropriate for persons in the age range from 16 to 89.
  - E. *Wide Range Assessment of Memory and Learning - Second Edition (WRAML2)*. The *WRAML2* assesses verbal and non-verbal learning, as well as memory (immediate and delayed). The *WRAML2* is appropriate for persons in the age range from 5 to 90. The *WRAML2* can assess a person's ability to acquire new skills in an actual teaching-learning format.
- V. **Adaptive Behavior** – Measures of adaptive behavior evaluate a person's ability to cope with the demands of their environment. The authors of the *Vineland Adaptive Behavior Scales (Vineland-II)* define adaptive behavior as “the performance of daily activities required for personal and social sufficiency.” They then identify four important principles which are used to clarify their definition. These are listed below:
- 1. Adaptive behavior is age-related and becomes more complex as a person grows older.
  - 2. Adaptive behavior is defined by the expectations, standards, and judgments of

other people. This is best done by persons who live, work, and interact with the person.

3. Adaptive behavior is modifiable. It can become better or worse depending on interventions and environmental changes.
4. Adaptive behavior is “defined by typical performance, not ability.” Thus, a person might have the ability to brush their teeth, but if they do not do so, their adaptive behavior score would be lower.

The above definition helps us to see that a good measure of adaptive behavior assesses a person’s ability to be appropriately self-sufficient (based on age level expectations) in all areas of life responsibilities (e.g., self-help, social, community, motor, and other skills). Adaptive behavior measures try to determine what the person is capable of doing on a typical day rather than trying to measure their “ability” to learn, which is generally considered to be the domain of the cognitive test procedures described in Section I above. The main cautionary note regarding adaptive behavior instruments is that they are generally reliant upon the report of parents, teachers, or other caregivers. Previous experience indicates that these ratings can range from being highly valid in many cases, to being invalid or fairly misleading in other cases. The person responsible for administering the adaptive behavior assessment should try to determine the validity of the information that is gathered in any type of paper-pencil, self-report format. In cases where parents or caregivers cannot read well or understand the written questions, the items can either be read to the caregiver (e.g., see ABAS-II in letter A below), or an interview format conducted by a trained professional can be utilized to try to obtain a more valid assessment (see Vineland-II in letter G below). Following are some of the most widely used adaptive behavior instruments:

- A. Adaptive Behavior Assessment System - Second Edition (ABAS-II). The ABAS-II comes in several different forms that make it appropriate for ages 0-89 years. The ABAS-II provides standard score measures for conceptual, social, and practical skills, as well as an overall adaptive behavior score called the General Adaptive Composite (GAC). The reliability and validity of the ABAS-II tend to be quite good, but this instrument does rely exclusively on parent, teacher, or caregiver reports, rather than on observation or interviews. If the caregiver cannot read well, the items can be read aloud by a professional. If the parent/caretaker is not thought to be a reliable historian, then the use of this instrument might not be helpful.
- B. Adaptive Behavior Evaluation Scale - Revised Second Edition (ABES-R2). The ABES-R2 has a form available for children in the age range from 4 to 12 and also from 13 to 18 years. It is available in both home and school versions. Like the ABAS-II, the ABES-R2 assesses the three adaptive behavior domains defined in the 2002 AAMR definition of mental retardation: the Conceptual domain

(communication and functional academics), the Social domain (social, leisure, and self-direction), and the Practical domain (self-care, home living, community use, health and safety, and work). Also, like the ABAS-II, the ABES-R2 relies exclusively on parent or teacher reports.

- C. Adaptive Behavior Scales - Revised (ABS-R). The 1993 version of the Adaptive Behavior Scales comes in both a school edition (ABS-S:2) and a residential and community edition (ABS-RC:2). This scale takes 15 to 30 minutes to administer. The ABS-S:2 has been useful for children who have mental retardation, autism, or behavior disorders. The school edition is appropriate for children ages three to 21. This test was normed on 1,000 people with developmental disabilities who attend public school and 1,000 persons without developmental disabilities. The ABS-RC:2 is normed on persons aged 18 to 80 with developmental disabilities in residential and community settings.
- D. Inventory for Client and Agency Planning (ICAP). The ICAP is an adaptive behavior measure that addresses nine different areas, including current descriptive information, diagnostic status, functional limitations and needed assistance, adaptive behavior, problem behavior, residential placement, daytime program, support services, and social and leisure activities. The adaptive behavior section leads to a "training implications profile" which portrays a visual representation of the person's motor skills, social and communication, personal living, and community living skills.
- E. Pediatric Evaluation of Disability Inventory (PEDI). The PEDI is an adaptive behavior assessment instrument that attempts to link functional capabilities and defined goals. The PEDI incorporates parent observation and can be used to document changes after interventions have taken place. The program can be useful with children in the age range from 6 months to 7 years. It provides information in the domains of self-care, mobility, and social functioning.
- F. Scales of Independent Behavior - Revised (SIB-R). This 1996 scale provides a comprehensive assessment of 14 areas of adaptive behavior and eight areas of problem behavior. The age norms run from infancy to 80+ years. The full scale takes 45 - 60 minutes, while the short form or early development form can be administered in 15 - 20 minutes. The full scale form samples motor skills, social interaction and communication skills, personal living skills, and community living skills. A variety of standard scores are provided. The adaptive behavior scale items of the ICAP are actually a subset of the SIB. Thus, these two instruments show a high correlation.
- G. Vineland Adaptive Behavior Scales - Second Edition (Vineland-II). The Vineland-II now has an expanded age range that goes from birth to age 90. It

samples communication, daily living skills, socialization, motor skills, and maladaptive behaviors. It yields standard scores based on a mean of 100 and a standard deviation of 15 (e.g., the Adaptive Behavior Composite and Domain standard scores) which can easily be compared to the IQ scores from the cognitive testing to see if consistent delays are noted in both areas. It also has subtest scores for the Subdomain areas that are called v-scale scores, which have a mean of 15 and a standard deviation of 3. The *Vineland-II* utilizes three different formats. One involves a semistructured interview format (Survey Interview Form) that allows a professional to interview a parent/caregiver using open-ended questions. The interviewer makes the final decision on scoring. I have found the Survey Interview Form works best if the interviewer is familiar with the applicant before doing the assessment. Please note that this instrument was **NOT** designed to be administered over the phone with a parent/caretaker for a person who has never been seen or observed by the interviewer. Often the interviewer can administer some of the items directly to the person being evaluated (e.g., asking age, address, counting to 10, reading some words, performing a math problem, reading the newspaper, etc). However, the applicant should not be present during the actual interview process. The Survey Interview Form can be especially helpful in cases that might involve factors such as reading or cognitive challenges in the parent, or caretaker/caregiver bias. If these issues are not present, then the *Vineland-II* also provides a Parent/Caregiver Rating Form in which the parent or caregiver simply fills out a paper-pencil rating scale. Finally, the *Vineland-II* has a Teacher Rating form (TRF) which allows teachers to report on a child's adaptive behavior at school using a paper-pencil format. In 2007, the *Vineland-II* also provided an Expanded Interview Form, which yields an even more comprehensive and valid assessment of adaptive behavior. The standard of measurement (SEm) of the Composite Score for the *Vineland-II* ranges from 2.25 to 4.02 points. Thus, the 95% confidence interval for most persons would be +/- 5 to 8 points. It is imperative to know the 95% confidence interval in order to correctly interpret the adaptive behavior scores for eligibility purposes, which is available via the computer generated report.

## VI. Achievement Measures

- A. *Kaufman Test of Educational Achievement, Second Edition (KTEA-II)*. The *KTEA-II* is available in both brief and comprehensive forms. The comprehensive form is appropriate for ages 4 years, 6 months through 25 years. The brief form is appropriate for ages 4 years, 6 months through 90+ years. The *KTEA-II* provides an assessment of reading, math, written language, and oral language.
  
- B. *Peabody Individual Achievement Test - Revised/Normative Update (PIAT-R/NU)*. The *PIAT-R/NU* is appropriate for persons in the range from 5 to 23 years. It takes 60 minutes to administer. The subtests are related to general knowledge,

ability to read sight words, reading comprehension, written expression, and both math and spelling skills.

- C. Wechsler Individual Achievement Test - Third Edition (WIAT-III). The WIAT-III is appropriate for persons in the age range from 4 to 51. The WIAT-III was designed to provide direct comparisons with all of the various Wechsler intelligence scales. The WIAT-III samples both oral and written expression, as well as basic academic skills related to reading, arithmetic, and written language.
- D. Wide Range Achievement Test 4 (WRAT4). The WRAT4 provides a quick screening for identifying achievement skills related to sentence comprehension, reading sight words, spelling from dictation, and doing arithmetic computation. The test administration takes 15-45 minutes and is appropriate for persons in the age range from 5 to 94.
- E. Woodcock-Johnson III (WJ III) Tests of Achievement. The Woodcock-Johnson III Tests of Achievement are normed for persons from age 2 to 90+. The tests provide both a standard and an extended battery, with the latter providing more in-depth diagnostic information. The WJ III samples a wide variety of skills related to reading, arithmetic, written language, and general knowledge.

## **VII. Measures of Personality and Emotional Functioning**

- A. Beck Depression Inventory-II (BDI-II). The BDI-II consists of 21 items that utilize a self-report format in which the client responds to choices about a variety of symptoms related to depression. It permits a rating of depression that goes from mild to severe. Although it is one of the most widely used instruments for detecting depression, it takes just five minutes to complete.
- B. Children's Depression Inventory (CDI). The CDI is a self report scale which requires at least a first grade reading level and was designed for school children ages seven to 17. The long form consists of 27 items. The short form contains only 10 items and can be used as a quick screening measure. The CDI looks at several aspects of depression (negative mood, interpersonal problems, low self esteem), but does not address other personality issues.
- C. Children's Depression Rating Scale - Revised (CDRS-R). The CDRS-R is used to diagnose depression and determine its severity in children in the age range from 6 to 12. This tool is based on a semi-structured interview with the child (or an adult informant who knows the child well). It can be administered in 15-20 minutes. The interview rates 17 symptom areas related to DSM-IV criteria for a diagnosis of depression.
- D. Incomplete Sentences Blank. This type of technique is more of a clinical

procedure rather than a standardized test. It is projective in nature and allows a client to complete sentences related to a large number of different themes and issues. Examples of incomplete sentences might include "My greatest fear\_\_\_\_", "What annoys me\_\_\_\_", "I am best when\_\_\_\_", "I wish\_\_\_\_", or "My greatest worry is\_\_\_\_". I use the technique to obtain a sample of written language. I also find it helpful to have clients complete this form while they are waiting for their initial appointment. I can then utilize some of their responses as a way to begin our interview and at the same time identify possible problem areas that need to be checked out more closely. The "test" is generally non-threatening and can yield useful information for both children and adults who can work successfully with a paper/pencil format.

- E. Millon Clinical Multiaxial Inventory-III (MCMI-III). The MCMI-III is normed for adults 18 years and older with an eighth grade reading level. The test takes 25 minutes in a paper-pencil format that involves 175 true/false questions. The MCMI-III provides information about a wide variety of personality patterns and clinical syndromes. The validity of the tests can also be assessed by the clinician. Information related to anxiety, depression, anti-social patterns, or psychotic processes can be obtained.
- F. Minnesota Multiphasic Personality Inventory - Revised (MMPI-2). The MMPI is now available in both a revised version (MMPI-2) and an adolescent version (MMPI-A). All questions are true/false, with the client having the option of not responding to a given question, which is scored as "cannot say". The scale does not attempt to provide a general description of personality, but rather to determine the presence or absence of abnormal behaviors or emotional problems that fall into major categories of dysfunction. The ten clinical scales are related to physical and health complaints, depression, psychological dependency, attitudes toward social responsibility, relationships with the opposite sex, interpersonal sensitivity and distrust of others, anxiety and compulsiveness, possible psychotic thought processes, emotional lability and impulsivity, and introversion-extroversion. Four validity scales are also provided and these help the clinician to determine if a valid profile has been obtained. The MMPI-2 is most responsibly used as one part of a psychological evaluation. It should not be looked at in isolation, but should be combined with a clinical interview and other assessment data in order to check consistency and determine the meaning of particular scores or personality patterns. The MMPI-2 requires a 6th grade reading level and takes 60-90 minutes to complete.
- G. The Sixteen Personality Factor Questionnaire (16PF) Fifth Edition. The 16PF is a personality inventory that has clients respond to questions utilizing a multiple choice format. Rather than just trying to identify psychopathology, the 16PF attempts to describe the person's general personality functioning. The fifth edition's 185 items measure levels of warmth, reasoning, emotional stability,

dominance, and twelve additional personality traits.

### VIII. Behavior Checklists

- A. *The Attention Deficit Disorders Evaluation Scale - Third Edition (ADDES-3)*. This is another scale with both parent and teacher ratings to assess ADHD symptoms in children. Subscales help the clinician to see if the child has problems with being either inattentive or hyperactive-impulsive. The home version rating form has 46 items, while the school version rating form has 60 items. These scales provide one portion of an overall assessment of the child. They are not a diagnostic instrument, but rather a screening that needs to be combined with other procedures (e.g., developmental history, direct observation of the child's behavior, parent and child interviews, more specific neuropsychological tests, etc.).
- B. *Autism Diagnostic Interview - Revised (ADI-R)*. The *ADI-R* has 93 items that focus on language-communication, reciprocal social interaction, and restricted, repetitive, and stereotyped behaviors and interests. The *ADI-R* can be useful in making a formal diagnosis, as well as for treatment and educational planning. It involves an interview format in which the interviewer records and codes the informant's responses. It can take from 1.5 to 2.5 hours to administer and score.
- C. *Autism Diagnostic Observation Schedule- Second Edition (ADOS-2)*. The *ADOS-2* was published in 2012. This revised ADOS now has a Toddler Module for children 12 - 30 months. The five modules of the *ADOS-2* allow clinicians to assess and diagnose autism spectrum disorders across ages (12 months to adults), developmental levels, and language skills (no speech to reciprocal conversational skills). Administration test time is usually 1 hour or less. The *ADOS-2* utilizes a group of standardized behavioral observations which are coded and scored after the standardized assessment with the client has been completed. Most experts consider the *ADOS-2* to be the state-of-the-art assessment instrument for autism spectrum disorder.
- D. *Autism Spectrum Rating Scales (ASRS)*. This recent autism assessment instrument allows parents and/or teachers to evaluate a child or adolescent (ages 2-18) for possible symptoms or behaviors related to autism spectrum disorder(ASD). This is the first nationally standardized, norm-referenced ASD rating scale, which puts it in a class by itself as of this writing. The full form takes about 20 minutes for the informant to complete. A shorter screening version that takes 5 minutes is also available. The *ASRS* provides results across a number of different areas (e.g., social/communication, unusual behaviors, and self-regulation). This instrument can contribute to a diagnosis of autism spectrum disorder, but is not a diagnostic instrument per se. As with all paper-pencil measures completed by caretakers, the *ASRS* is susceptible to being mis-read or misinterpreted, as well as various kinds

of informant bias. Nevertheless, it appears to be a useful tool in the clinician's assessment repertoire.

- E. *Behavior Assessment System for Children - Second Edition (BASC-2)*. The *BASC-2* provides a comprehensive system for measuring behavior and emotions for persons in the age range from 2 to 22. The *BASC-2* can provide parent and teacher ratings, as well as the client's own self-report. The *BASC-2* provides a relatively quick and easy assessment for a wide variety of psychological difficulties in children and young adults (e.g., aggression and anxiety, attention problems, conduct problems, depression, hyperactivity, social skills, withdrawal, etc.).
  
- F. The *Childhood Autism Rating Scale: Second Edition (CARS-2)*. The *CARS-2* uses a 4 point rating of a child's behavior (age 2 and over) in 15 areas that are related to autism. The scale allows the evaluator to assess verbal and non-verbal communication, stereotypic behaviors, self stimulation, and social relationships. The *CARS-2* has different versions available for younger and lower functioning children, as well as higher functioning children. It also has an unscored questionnaire for parents or caregivers. The *CARS-2* test publishers state that the *CARS-2* can be administered in 5-10 minutes, but I have always found that it takes at least an hour, along with time spent before the administration to play with or interview the child to become familiar with them. Again, this scale should be used in conjunction with other procedures in an overall comprehensive evaluation of the child.
  
- G. *Conners' Rating Scales - Revised (CRS-R)*. The *Conners' Scales* provide parent and teacher ratings for ADHD symptoms and other behavior problems. The scales are available in both long and short forms. The scales provide a screening that can be utilized for children in the age range from 3 to 17. The *CRS-R* are valuable tools for routine screening, but cannot stand alone to make a diagnosis.
  
- H. *Devereux Scales of Mental Disorders (1994)*. The *Devereux Scales* can be useful in determining whether a child is experiencing or is at risk for an emotional or behavioral disorder. There are 111 items for children (ages five to 12) and 110 items for adolescents (ages 13 to 18). The form can be completed by any adult who has known the child for at least four weeks. Thus, the same form is used for both parent and teacher ratings (though separate norms are provided for each). These scales sample a variety of problems including conduct disorder symptoms, ADHD, anxiety and depression, and autism. These scales take approximately 15 minutes to complete and are based on DSM-IV categories.
  
- I. *Gilliam Asperger's Disorders Scale (GADS)*. The *GADS* provides a quick screening measure for detecting Asperger's Disorder. It uses 32 items as well as giving parents an opportunity to complete eight items to describe their child's

early development. The GADS uses the most current definitions and diagnostic criteria for Asperger's Disorder. The GADS is appropriate for persons in the age range from 3 to 22 years. It takes only about five to ten minutes to complete the rating scale.

- J. Giliam Autism Rating Scale, Second Edition (GARS-2). The GARS-2 is another behavior rating scale that can be used to screen for autism. It is appropriate for persons in the age range from 3 to 22 years. It evaluates behavior patterns related to stereotyped behaviors, communication, and social interaction. It takes five to ten minutes to complete the questionnaire.
  
- K. Social Communication Questionnaire (SCQ). Previously known as the Autism Screening Questionnaire, the Social Communication Questionnaire involves 40 yes/no questions that can be completed by a primary caregiver in less than ten minutes. The purpose of the SCQ is to determine if a referral for a complete diagnostic evaluation for autism is necessary or not. The SCQ is appropriate for anyone over the age of four (as long their mental age exceeds 2.0 years). The SCQ involves a current form, which looks at the child's behavior over the most recent three month period. This is also a lifetime form, which addresses the child's entire developmental history. The SCQ is recommended as a way to do routine screening for children suspected of having autism spectrum disorder.

# Summary Points to

## Remember

- ✓ The tests described in this chapter, with the exception of the Vineland-II for adaptive behavior, are not a list of approved tests.
- ✓ Clinicians use clinical judgment to determine which test is appropriate for each particular person.
- ✓ Non-verbal tests are useful for a variety of persons with special needs, i.e., severe cognitive delay, English as a second language, minority groups, people who are hearing or motor impaired, and people suffering from traumatic brain injury or communication disorders.
- ✓ Adaptive behaviors are the day-to-day activities that are necessary for individuals to get along with others and take care of themselves.
- ✓ Adaptive behavior measures are designed to determine how a person performs on a day-to-day basis (rather than their “ability” to learn, which is typically assessed using cognitive test procedures).
- ✓ Variables affecting the measurement of adaptive behavior can include reading skills, ability to understand concepts, and various kinds of bias in the primary caregiver.
- ✓ The Vineland-II Survey Interview Form is **NOT** intended to be filled out by a parent or caretaker, completed over the telephone, or administered when there is no familiarity with the person being evaluated.
- ✓ Screening measures should normally not be used to make a diagnosis unless a person is “untestable” (See Appendix K).

# CHAPTER 4

## CLINICAL DEFINITIONS OF DISABILITIES

This chapter provides definitions for a wide variety of diagnoses frequently seen in the field of developmental disabilities. These conditions are outlined below:

- I. **INTELLECTUAL DISABILITY** –This term has recently been extensively adopted as a replacement for the term mental retardation. The Diagnostic and Statistical Manual of Mental Disorders - Fifth Edition (DSM-5) establishes three criteria for intellectual disability as follows:
  - A. Deficits in intellectual functions, such as reasoning, problem solving, planning, abstract thinking, judgment, academic learning, and learning from experience, confirmed by both clinical assessment and individualized, standardized intellectual testing.
  - B. Deficits in adaptive functioning that result in failure to meet developmental and socio-cultural standards for personal independence and social responsibility. Without ongoing support, the adaptive deficits limit functioning in one or more activities of daily life, such as communication, social participation, and independent living, across multiple environments, such as home, school, work, and community.
  - C. Onset of intellectual and adaptive deficits during the developmental period (i.e., during childhood or adolescence). Though no precise age cut-off is specified in DSM-5, the state of Montana requires age 18 (while the federal definition requires age 22) as the criterion for onset of deficits in relation to eligibility for services to persons with a developmental disability.

The DSM-5 allows a clinician to specify 4 levels of severity of intellectual disability that include mild, moderate, severe, and profound. However, these levels are no longer tied to specific IQ scores. Please see the DSM-5 text for their detailed guidelines recommended for rating severity based on limitations in conceptual, social, and practical domains. Also, we should note that DSM-5 no longer makes any mention of the old term “borderline intellectual functioning.” However, it does allow for diagnosing an Unspecified Intellectual Disability (Intellectual Developmental Disorder) in persons over the age of 5 when standardized assessment of cognitive development is rendered difficult or impossible due to “sensory or physical impairments, locomotor disability, severe behavior problems, or co-occurring mental disorder” (see page 41 in DSM-5). Please note that this is also related to the “untestable” issue which is discussed in detail in Appendix K of this Manual. Finally, as we shall see in Chapter 9 and Appendix I, it is very important to remember that DSM-5 guidelines are **not** the standard used for defining an intellectual disability according to DDP eligibility determination procedures. While the term “intellectual disability” now appears in Montana statute, the Montana

Legislature provided that for the purpose of the administration of human services, the adoption of the term would not result in changes in meaning that would differ from the prior usage of the term "mental retardation". Consequently, the definition of intellectual disability adopted in the DSM-5 is not currently applied by the State of Montana.

- II. AUTISM SPECTRUM DISORDER (ASD)** - Persons with a diagnosis of more severe levels of autism spectrum disorder as defined in the new DSM-5 may have limited intellectual functioning and be considered to have a developmental disability. In DSM-5, Autism Spectrum Disorder encompasses disorders previously referred to as high-functioning autism, atypical autism, pervasive developmental disorder not otherwise specified (PDD-NOS), childhood disintegrative disorder, and Asperger's disorder. To qualify for this disorder, a person must show persistent deficits in social communication and social interaction behaviors across multiple contexts, as well as restricted and repetitive patterns of behavior, interests and activities. These symptoms need to be present from early childhood and limit or impair everyday functioning. ASD is then rated according to 3 specific levels that essentially relate to the person's need for supports (i.e., Level 1= requiring support, Level 2=requiring substantial support, or Level 3=requiring very substantial support). The severity of social communication difficulties and the person's restrictive and repetitive behaviors are each rated separately. All of these guidelines are now very detailed and complex. Please read the DSM-5 text to better understand these issues.

Therefore, in order to determine if a person with autism spectrum disorder has a developmental disability, it is important to determine whether the person has significant impairment of intellectual functioning and adaptive behavior and needs the kinds of specialized services required by other developmentally disabled persons.

- III. ATTENTION DEFICIT HYPERACTIVITY DISORDER (ADHD)** – A person with a diagnosis of ADHD typically would not have an impairment of intellectual functioning commensurate with intellectual disability and therefore would not be considered to be developmentally disabled. ADHD can be diagnosed in children or adults. Persons with this disorder have significant symptoms of inattention and hyperactivity/impulsivity. The symptoms need to be noted before age 12 and must result in clinically-significant impairment in social, academic, or occupational functioning. These persons can be diagnosed according to whether or not they have the combined presentation, the predominantly inattentive presentation, or the predominantly hyperactive/impulsive presentation.
- IV. LEARNING DISABILITIES** - A person with a diagnosis of learning disabilities typically does not have an impairment of intellectual functioning commensurate with intellectual disability and therefore would not be considered to be developmentally disabled. In the typical case, a person with learning disabilities has an IQ within normal limits. Persons with specific learning disabilities have one or more areas of educational achievement that

are significantly below the level we would expect on the basis of their chronological age. DSM-5 defines learning disabilities as "specific learning disorders" and specifies them in areas related to reading, mathematics or written expression. In diagnosing a learning disability it is important to determine that these are not due to intellectual disabilities, visual or hearing impairments, other mental or neurological disorders, psychosocial adversity, lack of proficiency in the language of academic instruction, or inadequate educational instruction. DSM-5 guidelines rate the severity of the learning disability as being mild, moderate, or severe.

- V. **CEREBRAL PALSY** – Some persons with a diagnosis of cerebral palsy may have limited intellectual functioning and be considered to have a developmental disability. Cerebral palsy is a general category and not a specific diagnosis. Widely varying conditions are subsumed under this one label when symptoms involve a disorganization of motor control due to damage to the brain which is caused by genetic, prenatal, neonatal, or postnatal factors. These types of brain abnormalities may be due to malformations, rare hereditary degenerative central nervous system diseases, acquired post-natal abnormalities of a traumatic or infectious nature, or brain injury during the birth process. There are indications that oxygen deprivation before and during birth plays a more important role than does mechanical injury. Specific symptoms can include spasticity (limbs are rigidly immobilized by constant muscular contractions), dyskinesia (abnormal motor patterns and postures), chorea (rapid, jerky, involuntary movements), athetosis or athetoid movements (slow worm-like, purposeless movements), dystonia (muscle tone above normal), or tremors. Ataxia (impairment of postural activity in walking) occurs in about five percent of cerebral palsy cases. The presence of cerebral palsy does not necessarily mean that there is also an intellectual disability. IQ scores can be quite variable, depending on the degree of neurological impairment. Therefore, in order to determine if a person with cerebral palsy has a developmental disability, it is important to determine whether the person has significant impairment of intellectual functioning and adaptive behavior and needs the kinds of specialized services required by other developmentally disabled persons.
- VI. **EPILEPSY (SEIZURE DISORDER)** – Some persons with a diagnosis of epilepsy may have limited intellectual functioning and be considered to have a developmental disability. A seizure may be defined as a transitory disturbance in the function of the brain which develops suddenly, ceases spontaneously, and exhibits a conspicuous tendency to recur. Spontaneous neuronal excitation starts at a specific location in the brain. It may remain localized or spread to other areas. About one person in 20 has a seizure at some time in his/her life. About one in 160 develops chronic seizures, often referred to as epilepsy. Seizures beginning before age six months that are not caused by high fever usually reflect Central Nervous System (CNS) malformation, birth injury, metabolic error, or infection. Seizures beginning between ages two and 20 years may be related to genetic factors. Seizures occurring between ages 20 and 35 may be the result of trauma, drug abuse, or infection. Seizures occurring after age 35 may be related to a brain tumor or other medical problem. Many different kinds of seizures have been described in the literature,

but they will not be discussed here (See Chapter 5). The bulk of the evidence available supports the view that seizures per se are not a major contributor to intellectual disability. There is no evidence that persons with petit mal seizures have IQ's that are in any way different from the normal population. Therefore, in order to determine if a person with epilepsy has a developmental disability, it is important to determine whether the person has significant impairment of intellectual functioning and adaptive behavior and needs the kinds of specialized services required by other developmentally disabled persons.

**VII. OTHER CONDITIONS** – There are a large number of medical diagnoses, other than mental illness, which are closely related to intellectual disability because there may be significant impairment in general intellectual functioning and adaptive behavior. Examples might include spina bifida, hydrocephalus, muscular dystrophy, multiple sclerosis, lead or mercury poisoning, brain tumors, etc. In order to look at eligibility for services to developmentally disabled persons, it is important to evaluate the functional limitations involved. This cannot be determined by looking at a single diagnostic label or test score, but rather at the person's overall functioning level. Therefore, in order to determine if a person with another condition has a developmental disability, it is important to determine whether the person has significant impairment of intellectual functioning and adaptive behavior and needs the kinds of specialized services required by other developmentally disabled persons. More detailed information on this topic is contained in Chapter 5, Chapter 9, and Appendix I.

**IX. SPECIAL POPULATIONS** –

A. ***Children*** - Public Law 99-457 (and its subsequent amendments) allows states to avoid diagnostic terms such as autistic or mentally retarded with children under the age of six. The emphasis is on looking at developmental delays across all areas of development. Provision is made for allowing young children to be designated as "at risk" for a developmental disability on the basis of either medical or environmental factors. This is very helpful, because we now know that intellectual disability is not a diagnosis that can be reliably made in young children. Also, we know that intellectual disability as a diagnosis does not carry the inevitable prognosis that it will be permanent. Some young children may initially appear to be slow in development, but they later make significant progress to the point where they are no longer disabled as they grow older. DSM-5 now uses the term Global Developmental Delay for children under the age of 5 who are at risk for an intellectual disability, but are unable to undergo systematic assessment of intellectual functioning (see page 41 in DSM-5).

B. ***Older Persons*** - In general, the same standards for diagnosing a developmental disability in an older person would apply as would be the case for a younger adult. However, numerous special problems occur. Records that are 50 or more years old may not be available to document the person's history, or these records may be woefully inadequate. If old records use diagnostic terms such as mentally retarded or autistic, I would suggest a fair amount of skepticism and a careful look at current

functioning. If current adaptive behavior levels are found to be significantly low, then including the person in programs for consumers who have developmental disabilities may well be indicated. Two special cases suggest themselves. If former records suggest a developmental disability, but current adaptive behavior levels seem relatively good, I would request an evaluation from a licensed clinical psychologist. Conversely, if there is no history of a developmental disability, but current adaptive behavior/general functioning seems low, then I would request an evaluation that would probably include a complete medical examination as well as a psychological evaluation to rule out conditions such as organic brain syndrome, Alzheimer's disease, or other medical/ neurological disorders. In summary, elderly persons will still need to meet the DDP eligibility policies described in Appendix I.

- C. ***Sensory Impairments*** - Persons who have only hearing or visual impairments are not typically considered to be developmentally disabled. For example, a person with a severe to profound hearing impairment might present with normal nonverbal reasoning along with a possible delay in verbal reasoning. This would not meet the developmental disability eligibility criteria in Appendix I. A person with significant visual impairment may require special testing procedures (e.g., Braille formats), along with verbal testing to fully assess their intellectual abilities. However, to be eligible for developmental disabilities services, persons with sensory acuity impairments must exhibit significant impairment of intellectual functioning that is similar to an intellectual disability and requires similar treatment.

- X. **PSYCHIATRIC DISORDERS** - A person with only a diagnosis of a psychiatric disorder typically would not have an impairment of intellectual functioning commensurate with intellectual disability and therefore would not be considered to be developmentally disabled. However, as covered in detail in Chapter 7 on dual diagnosis, there are many persons with a diagnosis of developmental disability who also have a diagnosis for one or more significant forms of mental illness.

I should also note that DSM-5 no longer uses a multi-axial system with five distinct axes for specifying personality disorders, general medical conditions, psychosocial and environmental problems, and a global assessment of functioning. However, clinicians can still report relevant medical conditions (similar to Axis III), and they can also use a V code to identify other conditions or stresses that may be a focus of clinical attention. Examples could include specifying relationship difficulties, lack of housing, financial stresses, etc. Thus, the V code can be used in a manner similar to the old Axis IV. Finally, the DSM-5 has moved to a new paradigm which recognizes that most disorders occur along a continuum. Thus, labels like Intellectual Disability, Autism, and Schizophrenia are all being conceptualized as occurring across a spectrum of severity, with somewhat diverse manifestation of symptoms.

Certain state and federal definitions are provided in Appendices F and H. Interested parties should check with the Developmental Disabilities Program (DDP) for the State of

Montana (phone: 406-444-2995) in order to learn what criteria and procedures may apply in any given situation [e.g., nursing home placement, Children’s Waiver Services (CWS), Children’s Autism Waiver (CAW), services for children under age 3, etc.].

## Summary Points to Remember

- ✓ The term “intellectual disability” is now used by DSM-5, the State of Montana, the federal government, and the American Association on Intellectual and Developmental Disabilities (AAIDD).
- ✓ The DSM-5 definition of an intellectual disability is somewhat more vague than in previous editions of the DSM.
- ✓ In the absence of other qualifying data, mental health diagnoses such as ADHD would not be considered to be a developmental disability.
- ✓ Persons with a medical disorder (cerebral palsy, epilepsy, Alzheimer’s disease, etc.) still require a comprehensive psychological evaluation to specify functional limitations and impairments.
- ✓ Two other new DSM-5 diagnoses include Global Developmental Delay (for “at risk” children under age 5), and Unspecified Intellectual Disability for persons over age 5 who are essentially untestable, which is an issue covered in great detail in Appendix K of this Manual.
- ✓ A person with cerebral palsy or epilepsy who does not have a “substantial disability” would not be eligible for services for persons with a developmental disability (see Chapter 9 and Appendix D).



# CHAPTER 5

## NEUROLOGICAL DISORDERS

Because a neurological disorder can be the basis of eligibility for services to persons with a developmental disability, it is important to have a good understanding of this area. Therefore, I have decided to devote an entire chapter to this topic. Please keep in mind that the summary information contained in this chapter is admittedly brief. By comparison, a basic textbook in this area would be at least 1,000 pages. My intention is to provide an overview of the kinds of disorders that can affect the nervous system and cause disabilities that are similar to intellectual disability and may require similar treatment. For a given disease, the actual symptoms experienced by a particular person may vary rather dramatically. For example, 50% of the patients affected by some diseases (e.g., homocystinuria) may be intellectually disabled, while the other 50% may have normal or near-normal intelligence. However, it is hoped that the information in this chapter will provide a basic framework for better understanding neurological disorders when reviewing medical reports prior to making eligibility decisions.

The following outline was originally adapted from Menkes (1995), and then supplemented by more current references in this area (Menkes, Sarnat, and Maria, 2000; David, 2005):

- I. **METABOLIC DISEASES** - These disorders occur because of single gene defects which cause the body to be unable to metabolize a particular substance. A few basic examples will be listed below:
  - A. ***Phenylketonuria (PKU)*** - These children cannot metabolize phenylalanine into tyrosine. Untreated children generally have severe cognitive delays. If these children are identified and given early treatment (restricting the dietary intake of phenylalanine), they generally have normal IQs, though some risk factors for learning disabilities may still be present.
  - B. ***Homocystinuria*** - This represents a defect in the metabolism of sulfur amino acids. Effects of this disorder can include cognitive delays and physical disabilities. As noted above, IQ scores can be quite variable with these patients.
  - C. ***Lowe Syndrome*** - This disorder results in severe intellectual disability and a number of physical problems because of a defect in amino acid transport.
  - D. ***Galactosemia*** - Children with this disorder cannot process the lactose in either human or cow's milk. If these children are given lactose-free products, they may do well, but some cognitive deficits or learning disabilities may still be present, possibly because of in utero effects. If galactosemia is untreated, growth failure, liver problems, and significant cognitive delays can occur.

- E. ***Other Metabolic Diseases*** – Other metabolic diseases which can result in significant developmental delays include Hurler's Syndrome, Hunter's Syndrome, San Filippo Syndrome, Tay-Sachs Disease, Niemann-Pick Diseases, Smith-Lemli-Opitz Syndrome and Lesch-Nyhan Syndrome.

**II. INHERITED DEGENERATIVE DISEASES** - These disorders also are thought to occur primarily because of the mutations of a single gene, but the exact biochemical explanation is still unknown. Examples include:

- A. ***Huntington's Disease*** - Although symptoms usually begin between ages 35 and 40, about five percent of patients are younger than 14. Chronic and progressive degeneration of the brain are present in these cases.
- B. ***Other Degenerative Brain Diseases*** – Examples of other degenerative brain diseases include Rett Syndrome, Alexander Disease and Retinitis Pigmentosa (a common cause of heredity visual impairment).

**III. CHROMOSOMAL ANOMALIES** - These involve gains or losses of portions or entire chromosomes. Examples include:

- A. ***Down Syndrome*** - These patients have either an extra chromosome 21 or an effective trisomy for chromosome 21 by its translocation to another chromosome (14, 21, or 22).
- B. ***Other Trisomies*** – Other trisomies can occur on chromosome 13 and 18, though 90% of the latter group will die by one year of age.
- C. Some chromosome abnormalities do not result in developmental disabilities. An example is Klinefelter Syndrome, where reported IQ scores are either normal (mean IQ of 96 in one study) or near normal (IQs were 10 points lower than controls in another study).
- D. ***Fragile X Syndrome*** – Another common disorder is Fragile X Syndrome (approximately one per 1,000). These children have dysmorphic features and either cognitive delays or significant learning disabilities. Fragile X Syndrome can result in symptoms of autism, but not in all cases. Females tend to be affected to a lesser degree and may have IQ scores that are either normal or in the borderline range.
- E. Other examples of chromosomal anomalies that can cause developmental disabilities include Prader-Willi Syndrome, Angelman Syndrome ("happy puppet" syndrome) and Cornelia de Lange Syndrome.

- IV. **MALFORMATIONS OF THE CENTRAL NERVOUS SYSTEM** - These occur because the central nervous system does not develop properly in utero or in the early developmental period.
- A. ***Spina Bifida*** - This involves a failure of bone fusion in the spinal column. The defect may occur at various points along the spine. The site of lesion will then determine the type of symptoms that will be experienced. Whereas these children typically have normal intelligence, their medical management may be so complicated that they may actually be hospitalized for a large percentage of their life. Physical disabilities may be mild or severe depending on the site of the lesion.
  - B. ***Other Malformations*** – Other examples of malformations of the central nervous system include Arnold-Chiari malformation (a variety of brain stem and spinal cord abnormalities), hydrocephalus, macrocephaly and Dandy-Walker Syndrome.
- V. **PERINATAL ASPHYXIA AND TRAUMA** - Problems in this category are related to premature birth and difficult labor. Cerebral palsy is one of the conditions that can result from either oxygen deprivation or mechanical trauma. A wide variety of other developmental problems can also result from problems with intracranial hemorrhage, oxygen deprivation or a disorder of cerebral circulation.
- VI. **INFECTIONS OF THE NERVOUS SYSTEM** - Damage to the brain can occur from a wide variety of different kinds of infection (bacteria, viral, fungal, etc.). Examples of significant problems that can affect development include meningitis, cytomegalovirus (CMV), rubella, and polio. Diseases in this category that tend to involve current publicity include the AIDS virus, Creutzfeldt-Jakob Disease, syphilis, and Lyme Disease.
- VII. **AUTOIMMUNE AND POST INFECTIOUS DISEASES** - These result from a failure of the normal balance between the brain and the immune system. Examples include:
- A. ***Rheumatoid Arthritis*** - In addition to the inflammatory changes in their connective tissue, these children may also have other kinds of neurological problems.
  - B. ***Multiple Sclerosis*** - This disease is still not completely understood. It involves a destruction of the myelin sheath and a distribution of lesions that can affect the brain and spinal cord. MS is rare in infants and children, but can be seen more commonly in adolescents. Symptoms include disturbed gait, muscle weakness, and disturbance of vision.
  - C. ***Bell's Palsy*** - The major symptom of this condition is an acute paralysis of the face, often following an infection. I list this disorder because it is an example of a

condition that sounds fairly ominous, but most of these children (80%) recover completely. This condition would not normally be considered to represent any type of significant developmental disability in and of itself.

**VIII. POSTNATAL TRAUMA AND INJURIES BY PHYSICAL AGENTS** – Accidents constitute the major cause of death of children between the ages of five and 19 years. For example, bicycling is responsible for over 20% of all head injuries in children. Examples in this category include:

- A. ***Closed Head Injury*** - More than 90% of major pediatric head injuries are non-penetrating and closed; thus, there is no scalp wound. Significant injuries can include fractures of the skull and extended loss of consciousness.
- B. Other examples include subdural hematoma (collection of bloody fluid between the dura and the arachnoid), spinal cord injuries and injuries to the cranial nerves.

**IX. TOXIC AND NUTRITIONAL DISORDERS** - The brain is sensitive to a wide variety of poisons and toxins. Examples include metals such as lead, arsenic, mercury, and aluminum. Organic toxins would include carbon monoxide, alcohol and a variety of other drugs. Syndromes which can be related to developmental disabilities include:

- A. ***Fetal Alcohol Spectrum Disorder (FASD)*** - If the developing embryo is exposed to significant amounts of alcohol, a wide variety of neurodevelopmental deficits can result. Symptoms can include cognitive delays and numerous physical symptoms. Children with Fetal Alcohol Syndrome (FAS) have growth retardation, intellectual impairment, and a variety of physical symptoms. If the child demonstrates only two of these three criteria, a diagnosis of Fetal Alcohol Effect (FAE) may be made. Symptoms related to FAS/FAE can change over time (e.g., head size), and this can be a difficult diagnosis to make since it is based on both a clinical history and an examination of the physical appearance of the child. Widely varying symptoms have been reported in affected children. However, many individuals with FAS/FAE have difficulty learning from experience (consequences), cannot generalize what they learn in situation A to situation B, and have difficulty applying their knowledge in real life situations. The term FASD is not a clinical diagnosis, but refers to the full range of possible defects that can result from prenatal alcohol exposure. Other medical labels that are emerging in this area include Alcohol-Related Neurodevelopmental Disorders (ARND) and Alcohol-Related Birth Defects (ARBD). Thus, medical nomenclature is still evolving in this area.
- B. ***Lead poisoning*** - Children exposed to overt lead poisoning may show seizures, increased intracranial pressure, ataxia, and cognitive/learning problems.

- X. TUMORS OF THE NERVOUS SYSTEM** - Tumors can occur throughout the brain, causing a wide variety of neurological deficits. Examples include:
- A. ***Tuberous Sclerosis*** - Caused by an autosomal dominant gene, tuberous sclerosis can result in intellectual disability, epilepsy, and skin lesions. However, one-third of these patients can have normal intelligence. A significant proportion of these children can also develop autistic features. Sometimes normal intelligence is seen initially, with the first signs of intellectual deterioration not showing up until between the ages of eight and 14. These children can have tumors in various organs including the brain.
  - B. ***Sturge-Weber Syndrome*** - These children are born with a birthmark on the upper part of the face. Most of these patients develop seizures and there is also a high incidence of cognitive delays. Only five percent of infants born with a port-wine stain on the face actually have Sturge-Weber Syndrome.
- XI. VASCULAR DISORDERS OF THE BRAIN** - A variety of neurological deficits can result from problems affecting the blood vessels of the central nervous system. Most of the problems in this category are the result of a blockage in the blood vessels (and resulting lack of blood supply to the tissue) or to actual hemorrhage.
- XII. SEIZURE DISORDERS** -A seizure is defined as a “sudden, involuntary, time-limited alteration of neurological function caused by the abnormal discharge of neurons in the central nervous system” (David, 2005). Menkes (1995) classifies epileptic conditions according to the following categories:
- A. ***Primary Epilepsies (Idiopathic)*** - These tend to be genetically transmitted and typically do not involve structural lesions. They are more benign because they have a better prognosis for seizure control. Examples include petit mal epilepsy, rolandic epilepsy and childhood epilepsy with occipital spikes.
  - B. ***Secondary (symptomatic) Epilepsies*** - These have anatomic or known biochemical lesions. Examples include Lennox-Gastaut Syndrome and temporal lobe (psychomotor) epilepsy.
  - C. ***Reactive Seizures*** - These represent an abnormal reaction in an otherwise normal brain to physiological stress or insult. Examples include febrile seizures or seizures induced by a toxic substance.
- XIII. DISEASES OF THE MOTOR UNIT** – These kinds of neurological problems occur because of disorders in the motorneuron, its axon, the neuromuscular junction, or the muscle itself. Examples include:

- A. *Spinal Muscular Atrophies* - These result in reduction of muscle power and spontaneous movement, but there is no sensory loss and no intellectual disability. If this disease occurs in infants before six months (Werdnig-Hoffman disease), it is usually fatal by age three. With later onset, the prognosis is more positive.
- B. *Arthrogryposis* - This diagnosis refers to multiple congenital and non-progressive contractures of the joints, and wasting of skeletal muscle. Cerebral mal-development may also occur.
- C. *Myasthenia Gravis* - This is a chronic disease characterized by fatigue in the voluntary muscles. Symptoms in affected children can vary widely.
- D. *Muscular Dystrophy* - A number of diseases are subsumed under this heading. All have significant muscle problems. In Duchenne Muscular Dystrophy, there can be a reduction in IQ (mean IQ of 85) and a possibility of more significant cognitive delays. The course of this illness involves steady deterioration and death often occurs in adolescence. In other types of muscular dystrophy, the IQ may well be normal.

**XIV. NEUROLOGIC MANIFESTATIONS OF DISEASE** - A variety of diseases in the body can affect brain function by interfering with the necessary supply of oxygen and glucose or by interfering with the normal biochemical processes. Examples of disorders in this category include Sickle Cell disease, congenital hypothyroidism, and various kinds of congenital heart disease. Another good example is Williams Syndrome, where children have physical symptoms and intellectual disability associated with elevated calcium levels in their blood.

If you are reviewing a case that appears to involve significant medical, genetic, or neurological disorders that may be causing a developmental disability, it is important to ask the relevant physician to provide a detailed report about this patient. The information you would request would include the following kinds of details:

1. Diagnosis. Ask the physician to explain the meaning of the diagnostic label.
2. Clinical manifestations (including effects on intelligence and development).
3. Types of treatment to help the patient.
4. Prognosis.

By combining this type of medical information with a complete psychological evaluation, the ability to make a valid decision concerning eligibility for services is quite enhanced.

## Summary Points to Remember

- ✓ Persons with the same neurological disorder can have widely differing intellectual and functional limitations.
- ✓ The only way to determine if a person has “a neurological disorder similar to an intellectual disability that requires similar treatment” is to do a comprehensive psychological evaluation in order to specify the intellectual and functional limitations caused by the neurological disease.
- ✓ When reviewing cases with neurological disorders, it is very helpful to get complete medical information that specifies the clinical manifestations, treatment needs, and prognosis.

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## CHAPTER 6

### AUTISM SPECTRUM DISORDER

Thirty years ago, the incidence of autism in the United States was thought to be 2-3 per 10,000. When the DSM-IV came out in 1994, the incidence was listed as 2-5 cases per 10,000 persons. Even by 2004, some authors still noted fairly low rates of 1 per 10,000 (Volkmar and Weisner, 2004). However, most experts now believe that we are seeing a true epidemic of autism that cannot be accounted for by changes in diagnostic guidelines or assessment procedures. The term autism spectrum disorder (ASD) is now an official DSM-5 diagnosis that is being used to refer to the diverse labels and symptoms that were previously subsumed under the umbrella of autism (see formal definition of ASD in Chapter 4). The Centers for Disease Control and Prevention (CDC) estimates that the incidence figure for ASD in the United States is now approximately 1 in 88 persons, with the disorder being 5 times more common in boys than girls. Please see the CDC website for other relevant details and updated information in this regard. Most of the difficult to call cases in terms of eligibility decisions that will provide a challenge to Montana DDP professionals and policy makers will be related to either ASD or dual diagnoses encompassing mental health issues (see chapter 7). Therefore, I have decided to devote a full chapter to topics related to autism spectrum disorder. Since the diagnosis of ASD is usually made in childhood, I will emphasize topics related to children in this chapter.

A reliable diagnosis of autism spectrum disorder can now be made as early as 1 year when a comprehensive evaluation (including use of the Toddler Module of the *ADOS-2*) is carried out by experienced clinicians. No single symptom or behavior is sufficient to make a diagnosis of autism. Autism spectrum disorder represents a complex pattern of symptoms that can involve many of the following kinds of difficulties:

1. ***Language/Social Communication*** – Young children with ASD generally make only limited use of gestures as a way to communicate. They may talk to themselves and engage in repeating the words, phrases, or sentences that they have heard somewhere else (e.g., on T.V. or in a movie), but it is more difficult for them to initiate communication with another person. They may echo words and phrases (echolalia) but they may not always understand these words or use them in a meaningful way. Their vocal intonation and rhythm may be unusual (e.g., flat, monotone, sing-song). Their use of words tends to be concrete and literal, rather than abstract and conceptual. Language patterns with adults with ASD can be quite varied.
2. ***Social Relationships*** – Children with ASD generally have difficulty making consistent eye contact with others. It can be hard for them to imitate important and relevant actions and behaviors that they see. Their facial expressions may be flat, limited, or not directed towards others. They may not have a social smile. They

may have difficulty reading social cues, especially in terms of what the other person is thinking (i.e., theory of mind) or feeling (i.e., empathy). They may enjoy playing primarily by themselves. Even if they seem to enjoy social interaction at times, they may not know how to initiate it. It can be hard for them to engage in turn-taking. They may use an adult's hand or body as a tool. Their play can be repetitive and rigid to the point where they are very upset if their usual approach is changed, possibly because novelty and change are not easily processed or understood. Persons with ASD have difficulty developing age-appropriate peer relationships, and often have difficulty adjusting their behavior to suit various social contexts.

3. ***Sensory Issues, Restrictive and Repetitive Patterns*** – A child on the autism spectrum may appear to be deaf or to be overly sensitive to sound. They may show repetitive patterns such as walking on tip-toes, flapping their hands, or jumping up and down. They may not show normal responses to pain. They may not like to be touched. They may be preoccupied with light, reflections, or mirrors. They may have obsessive interests that they enjoy pursuing on a repetitive basis for hours (e.g., lining up cars, watching the same movie over and over, reading the same book many times). They may not like certain types of clothes or foods because of sensory processing difficulties. Other sensory-related behaviors could include whirling, spinning, head banging, biting, etc. Additional self-stimulatory behaviors could include sucking or licking objects, sniffing or smelling people or objects, and rocking back and forth in order to stimulate the vestibular sense. With ASD there can also be an insistence on sameness (e.g., being extremely upset by a change in packaging or a different brand of a favorite food), inflexible adherence to routines, and highly restricted interests (e.g., carrying string or yarn everywhere, watching a “Thomas the Tank Engine” video for hours, etc.).
4. ***General Development*** – The development of children with ASD **may** be delayed in areas related to understanding abstractions and concepts, but more advanced in terms of rote skills (e.g., naming pictures, reading sight words, counting, naming letters and numbers, etc.). Children with ASD may have difficulty understanding what they read. They may show skills on occasion that are not practiced or seen on a consistent basis. Their test protocols may show significant discrepancies, with both strengths and weaknesses noted. Strengths may be within normal limits or higher, while the weaknesses may be well below the third percentile. In addition, autism can occur with a wide variety of other conditions, such as Down Syndrome, Tuberous Sclerosis, Cerebral Palsy, and Seizure Disorders. Each person with ASD is totally unique.

There are many myths associated with the field of autism. Some of these are briefly described below, based on the work of Chantal Sicile-Kira (2004):

1. ***The Rain Man Myth*** – Very few persons end up looking or acting like Dustin Hoffman did in “The Rain Man.” People with ASD do not necessarily have extraordinary talents. Everyone who has ASD is not a genius (though some are).

2. ***People With Autism Are “Retarded”*** – Everyone who has ASD does not have an intellectual disability. However, the cognitive development of people with ASD can be difficult to evaluate. It can take a great deal of time to even begin to understand the learning style of a person with ASD in order to know how they learn best.
3. ***Everyone Who Has A Symptom Of ASD Has ASD*** – Children can walk on their tip-toes and not have ASD. They can enjoy rocking back and forth for 45 minutes at a time without having ASD. Unless there are a large number of symptoms that represent the patterns described above, ASD may not be an appropriate diagnosis.
4. ***There Is No cure Or Recovery From ASD*** – We now see research reports of children who receive intensive interventions indicating that they make very significant progress after their diagnosis. People with ASD are now writing books and finding ways to support themselves as independent adults. A positive response to an appropriate intervention should be expected.
5. ***People with ASD Live in Their Own Little World. They Do Not Have Emotions and Do Not Get Attached to Others*** – Persons with autism have been able to date, get married, and have children. They are capable of forming attachments. They obviously do experience emotions. They have a strong interest in the real world around them, but they also have significant challenges in terms of being able to understand certain kinds of information and the social network around them.

There are some disorders that look like autism spectrum disorder, but they are not. When a professional is trying to make a diagnosis of autism spectrum disorder, they may need to rule out a wide variety of other conditions that include the following:

1. **Aphasia** – This is a speech and language disorder caused by a brain injury that makes it difficult for the person to communicate with verbal language. However, difficulties with social skills and restrictive and repetitive behaviors are not part of aphasia.
2. **Landau-Kleffner Syndrome (LKS)** – This is a rare condition where children experience typical development followed by significant regression. However, LKS can be detected through an EEG, so it is thought to be a different syndrome from ASD.
3. **Intellectual Disability** – Children with an intellectual disability or cognitive delay are generally delayed in all areas of development, whereas children with ASD more typically show a pattern of strengths and weaknesses. However, in cases of more severe autism, a child may exhibit generalized developmental delay.

4. **Non-Verbal Learning Disorders (NLD)** – Persons with NLD may have average verbal intelligence, while also having difficulties with socializing and some sensory differences. However, they generally do not display the restrictive and repetitive behavior patterns and interests typically seen in autism spectrum disorder.
5. **Obsessive-Compulsive Disorder (OCD)** – Children with OCD do not have the usual types of social or communication problems seen in ASD.
6. **Schizophrenia** – Schizophrenia typically occurs in adolescence or young adulthood and is marked by hallucinations and delusions rather than the ASD symptoms described at the beginning of this chapter which begin during the early developmental period.
7. **Reactive Attachment Disorder** – Children with attachment disorder can have significant difficulties relating to others, but this is due to a history of abuse and neglect rather than a neurological disorder. Generally, both the history and symptom presentation seen in children with attachment disorder are different from the usual pattern seen in children with autism.
8. **Speech and Language Disorder** – Children with speech and language disorders are very motivated to communicate and will try a wide variety of non-verbal communication skills, such as pointing, gestures, or signs to get across their meaning and intent. DSM-5 now describes a Social (Pragmatic) Communication Disorder in its Communication Disorders section (see pages 47-49). Persons with this disorder have significant difficulty with the social use of language (as in ASD), but they do not have restricted/repetitive patterns of behavior, interests, or activities.
9. **Sensory Impairment** – Young children who are deaf or blind may show some early symptoms that look like ASD. For example, young deaf children may not be socially responsive, and blind children may engage in rocking as a form of self-stimulation. However, these symptoms generally decrease over time following appropriate interventions.
10. **Social Phobia** – Children with social phobia may be quite limited in terms of social interaction outside of their immediate family, but they generally are capable of good social and communication skills with people they know well, and they do not show restrictive and repetitive behavior patterns.

The above summary was adapted from Carolyn Thorwarth Bruey’s book, “Demystifying Autism Spectrum Disorders: A Guide for Parents and Professionals” (discussed in Karen Siff Exkorn’s “Autism Source Book” – 2005).

There is now a large amount of research devoted to understanding the causes of autism. We know that autism is not caused by parental rejection, lack of love, or inadequate parenting skills. Some of the most likely causes of autism are described in the table below, which was originally adapted (and later expanded) from Janzen (1999), David (2005), and Cain et al (2006):

## Some of the Conditions Implicated as Possible Causes of Autism

### Genetic

- A. Chromosomal Factors: Siblings of persons with autism have a 3 to 7% chance of having autism. If one identical twin has an ASD, there is a 36% (Williams, 2004) to 90% (Exkorn, 2005) chance that the other twin will also have an ASD. The risk for identical twins rises to 93% if milder variants such as Asperger's Disorder are included (Cain et al, 2006).
- B. Spontaneous Mutations: Spontaneous mutations can occur which cause problematic cognitive and neurological development. These recently discovered mutations are much more common in autism/autism spectrum disorder compared to a healthy control group. Thus, experts estimate that there may be 100 different genes involved in the syndrome of ASD. A given individual might have mutations in only one or a few of these genes. In these types of cases, parents do not have to fear a greater risk of recurrence in subsequent pregnancies (Sebat et al, 2007).
- C. Some syndromes can be associated with autism (Tuberous Sclerosis, Fragile X Syndrome, Down Syndrome, Phenylketonuria).

### Prenatal

Examples: 1<sup>st</sup> and 2<sup>nd</sup> trimester bleeding, "suboptimal" pregnancy, congenital infections (rubella, CMV, herpes), exposure to alcohol and drugs, immune disorders and inflammatory disease

### Perinatal

Examples: Hyperbilirubinemia, Hypoglycemia, Respiratory Distress

### Postnatal

- A. Metabolic Imbalances (e.g., thyroid disease)
- B. Exposure to Environmental Chemicals (e.g., lead and other toxic chemicals)
- C. Severe Viral Infections (e.g., encephalitis, spinal meningitis)
- D. Traumatic Brain Injury (e.g. severe car accident)

The bottom line on autism spectrum disorder is that there is no bottom line. Intelligence can range from severe intellectual disability to gifted cognitive abilities. Social skills can be extremely limited on one end of the continuum, to being odd, awkward, or insensitive on the other. People with ASD can be non-verbal or quite verbal. They can have poor motor skills or well-developed motor skills. In terms of sensory stimulation, they can be either hyposensitive or hypersensitive, or both within the same person. As noted above, this tells us that there are probably many different causes to the complex disorder that we call ASD. The prognosis for each person is unique to them. We are still a long way from unraveling this mystery.

Now that we have a better understanding of autism spectrum disorder, I would like to briefly discuss some of the challenges that are noted with this population in terms of eligibility for

services for developmental disabilities. First of all, as stated previously, Autism Spectrum Disorder is now the official diagnosis for DSM-5. However, it seems obvious that many individuals who were previously diagnosed as having Asperger's disorder, high functioning autism, or PDD-NOS were never thought of as having a developmental disability. Many of these individuals are attending college, are self-supporting, and are highly skilled in some or even many areas. For purposes of determination of eligibility for development disabilities services, the pertinent severity levels in the DSM-5 are Level 2 (requiring substantial support) and Level 3 (requiring very substantial support). Therefore, these guidelines will be incorporated into the decision making process described further in Chapter 9.

A list of helpful websites for additional information on autism is contained in Appendix G.

## **Summary Points to Remember**

- ✓ The CDC estimates that the incidence of autism in the U.S. is 1 in 88 persons.
- ✓ Autism Spectrum Disorder (ASD) is now an official diagnosis in DSM-5.
- ✓ ASD is five times more common in boys than girls.
- ✓ Autism spectrum disorder involves persistent deficits in social communication along with restricted and repetitive behaviors, interests, or activities.
- ✓ There are many myths associated with autism. One is that persons with autism live in "their own little world" and are totally unable to relate to other people.
- ✓ In order to make a diagnosis of autism, it can be important to rule out a variety of conditions, such as a communication disorder, a sensory impairment, or a mental health disorder.
- ✓ There is no one cause of autism. A variety of possible causal agents have been identified (e.g., viral infections, genetic factors, neurological conditions).
- ✓ The bottom line on autism spectrum disorder is that there is no bottom line. Thus, the disorder can range from mild to severe, and can encompass a wide variety of symptoms.
- ✓ All persons with an autism spectrum disorder as defined by DSM-5 are not developmentally disabled. To meet Montana eligibility guidelines for developmental disabilities an autistic person must have a significant impairment of intellectual functioning and be designated either Level 2 or Level 3 in terms of severity ratings in DSM-5 (See Chapter 9 and Appendix I for further discussion).

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# CHAPTER 7

## ISSUES IN DUAL DIAGNOSIS (DEVELOPMENTAL DISABILITIES AND PSYCHIATRIC DISORDERS)

The term "dual diagnosis" is subject to both misinterpretation and misinformation. Historically, we have tended to believe that a person who was developmentally disabled might be expected to have associated "behavior problems" that were thought to be secondary to their developmental disability. However, many of these individuals were never evaluated to see if they might be depressed, have an anxiety disorder, be experiencing hallucinations, etc. As one person said, "It's as if they think that just because your development is delayed, you can't get depressed".

Secondly, the term "dual diagnosis" has been used in a variety of ways in the literature. These include the following:

1. Mental illness and developmental disabilities.
2. A psychiatric disorder combined with substance abuse.
3. Having a physical disability and any other disability.
4. Some other combination of diagnoses (e.g., being a psychopath and a schizophrenic).
5. Some clinicians use the term comorbidity as an alternative to dual diagnosis. An example of comorbidities could involve intellectual disability, severe depression, and a seizure disorder all co-existing in the same person.

We will be using only the first category described above for this chapter on dual diagnosis. Let us begin our discussion of this topic by looking at some of the statistics regarding mental health difficulties in the so-called "normal" population in the United States. The following statistics have been noted in the literature (Hayes and Smith, 2005):

1. Throughout a lifetime, each of us has about a 50-50 chance of struggling with suicidal thoughts at a moderate to severe level for at least two weeks.
2. Almost 100% of all the people on the planet will at some point in their life contemplate killing themselves.
3. Approximately 20% of persons in the U.S. will experience a diagnosable mental illness during any given year (Hughes, 2006).
4. About 50% of all adults will have a major psychiatric disorder at some point in their lives.
5. 50% of all marriages end in divorce.

6. In summary, mental health difficulties appear to be present in most “normal” people at some time in our lives.

Estimates regarding the prevalence of mental health diagnoses being combined with developmental disabilities have shown a great deal of variability in the literature. Reported incidence figures have ranged from 10% to 80% (Williams, 2004), but the most common findings reveal percentages of about 14% - 23%, which is fairly similar to the general population estimate of 16% (Deb, Thomas, and Bright, 2001). However, the frequency of schizophrenia in the developmentally disabled population is at least ten times higher than a general norm group (4.4% vs .4%) and the incidence of a phobic disorder is about four times the rate for the general population (4.4% vs. 1.1%) according to Deb et al, 2001. It is also interesting to note that children with developmental disabilities are thought to have about three times as much psychiatric disturbance as children of average intelligence (Bouras, 1999). Historically, there has been a definite tendency to under diagnose mental health disorders in persons with developmental disabilities. However, as we shall see, even well-informed mental health clinicians can still have difficulty trying to utilize diagnostic criteria and assessment procedures that were originally designed for patients who did not have developmental disabilities.

Given the rather alarming mental health statistics noted above for normal persons, the findings regarding the high percentage of psychiatric symptoms in persons with developmental disabilities should come as no surprise. Because these persons may have cognitive limitations or other disabilities that may restrict their problem-solving skills, they are likely subject to even greater stresses. The “stress-vulnerability model” (Hughes, 2006) is a theory which hypothesizes that mental illness is caused by a combination of biological vulnerability and exposure to stress. Some of the stresses associated with developmental disabilities have been well described by Gilson and Levitas (1987) and Hughes (2006). They include the following:

### **Stresses in Persons with Developmental Disabilities**

1. Being labeled.
2. Sibling conflicts.
3. Peer conflicts, teasing, and rejection.
4. Frustration with school performance.
5. Frustration with sexual and dating opportunities.
6. Out-of-home placement.
7. Aging, illness or death of parents.
8. Other emotional losses (e.g., moving away from friends).
9. Medical illnesses.
10. Limited finances.
11. Increased rates of abuse and neglect.
12. Segregation and limited social support.

Many of the cases typically referred to as "dual diagnosis" involve persons who have highly problematic behavior patterns. A good example would include a person who is both intellectually disabled and schizophrenic. Mental health service programs may feel that they can do little to help this kind of person because the cognitive limitations prohibit the use of their usual treatment modalities (e.g., individual psychotherapy, group therapy). On the other hand, service providers who work with persons with developmental disabilities may have little or no experience dealing with the symptoms of psychosis. The total disability in this type of case tends to be greater than the simple sum of the two individual disabilities. It is easy for these kinds of persons to "fall through the cracks" because they really do not fit easily into either major service system.

If we take only one mental health disorder as an example, we can learn a great deal from looking at the diagnosis of depression. At any one point in time, about 6% of the U.S. population suffers from major depression. Millions of Americans are treated for depression each year. In my experience, there is little doubt that persons with developmental disabilities have rates of depression that are at least equal to or greater than those seen in the so-called normal population. Unfortunately, many of these persons have never been diagnosed to be depressed and they have never received treatment. Most studies now indicate that intellectually disabled people are at a greater than average risk of developing psychiatric disorders. However, these diagnoses can be difficult to make for persons who are functioning in the severe to profound range of disability. In our example of depression, clinicians generally rely on the patient's self-report to clarify mood, thoughts of death or suicide, and diminished ability to think or concentrate. While some symptoms of depression can be observed, some may be masked or hard to infer from direct observation only. This is a major challenge for professionals in this field.

Following is a list of the most basic categories of mental disorders. Individuals with any indication of special needs in these areas should be referred for additional evaluation:

### **Basic Categories of Mental Disorders**

1. Disorders usually first diagnosed in childhood:
  - A. Autism
  - B. ADHD
  - C. Tic Disorders
  - D. Reactive Attachment Disorder
2. Depression.
3. Anxiety disorders.
4. Preoccupation with physical complaints.
5. Sexual and gender identity disorders.
6. Eating disorders.
7. Sleep disorders.
8. Impulse-control disorders.
9. Adjustment disorders following significant stress (new symptoms related to depression, anxiety, or disturbance of behavior).
10. Substance abuse.
11. Dementia or mental deterioration of any kind.
12. Psychotic disorders involving delusions or hallucinations.

The above categories of mental disorders can be reviewed in more detail in the DSM-5. I think that the following definition of mental illness by the Medical Society of the State of New York (MSSNY) provides a good practical way to think about the clinical significance of a mental disorder:

*“Mental illness is a substantial disorder of thought, mood, perception, orientation, or memory which grossly impairs judgment, behavior, capacity to recognize reality, or ability to meet the ordinary demands of life.”*

As we noted previously with autism spectrum disorder, there are also many myths associated with schizophrenia (Olson, Hellings, and Black, 2003). These include the beliefs that people with schizophrenia are always dangerous to others, or that schizophrenia is caused by poor parenting. Neither idea has any basis in fact. A person with schizophrenia can become violent, but so can people who are not psychotic. Because identical twins do not always both have schizophrenia, environmental stresses seem to play a role in the development of the disease, but poor parenting is not thought to be part of the etiology. Schizophrenia is viewed as a type of brain disease. It is not a “split personality” (myth 3). People with a split personality would normally be diagnosed to have a dissociative identity disorder (formerly called multiple personality disorder). Finally, we should also note that a person who does not speak can still have a psychotic disorder. Examples of behaviors that could indicate this would include the person nodding as if they are talking to someone, wrapping one’s head or covering one’s eyes or ears as if to keep out voices or other sensations, or wanting to sleep with weapons such as knives, sticks, or a baseball bat to protect themselves from nonexistent threats. Lastly, a person can have hallucinations or delusions and not be schizophrenic. These symptoms could potentially be due to a substance-induced psychotic disorder, a mood disorder, a brief psychotic disorder, or other possibilities.

There are a number of behavioral characteristics that raise the suspicion that a person with a developmental disability could also have a mental disorder. These are listed below, as described by Cain et al (2006):

1. Behavior disturbances that occur across all settings.
2. Behavioral disturbances that do not respond to well-designed consistent behavioral interventions.
3. Behavior disturbances that are associated with concurrent changes in sleep, appetite, sexual activity, and/or daily functioning.
4. Evidence of hyper-arousal with increased autonomic activity (e.g., tremors, fast pulse, sweating) accompanying the behavior of concern.

Personality disorders represent another category of psychological dysfunction that can be difficult to understand. A personality disorder is defined as “an enduring pattern of inner experience and behavior that deviates markedly from the expectations of the person’s culture, is pervasive and inflexible, has an onset in adolescence or early adulthood, is stable over time, and leads to distress or impairment” (DSM-5). These disorders can involve symptoms that are

similar to other major psychiatric disorders (e.g., paranoid or suspicious thinking, odd beliefs, unusual perceptual experiences, etc.). However, the personality disorders which are similar to or mimic the more serious psychiatric disorders (e.g., Paranoid Personality Disorder, Schizoid Personality Disorder, Schizotypal Personality Disorder, Obsessive-Compulsive Personality Disorder) are generally less severe in terms of their symptom presentation. The most common personality disorders in persons with a developmental disability are avoidant, antisocial, paranoid, dependent, and borderline (Cain et al, 2006). The table on the following page lists all of the personality disorders in DSM-5.

### **DSM-5 Personality Disorders**

Paranoid Personality Disorder  
Schizoid Personality Disorder  
Schizotypal Personality Disorder  
Anti-Social Personality Disorder  
Borderline Personality Disorder  
Histrionic Personality Disorder  
Narcissistic Personality Disorder  
Avoidant Personality Disorder  
Dependent Personality Disorder  
Obsessive-Compulsive Personality Disorder  
Personality change due to another medical condition  
Other specified personality disorder and unspecified  
personality disorder

As a general rule, clinicians have historically noted that it is difficult to change a personality. These kinds of traits tend to be ingrained in day-to-day behavior patterns. However, in the last ten years we have seen some success with very intensive and comprehensive treatment programs that help persons with Borderline Personality Disorder to utilize a new model for evaluating and monitoring their own behavior and thought patterns that is called Dialectical Behavior Therapy (DBT). In my experience, DBT typically requires relatively high levels of conceptual abilities and this tends to represent a poor match in relation to the cognitive resources of most clients with a developmental disability. However, a treatment manual for persons with intellectual disabilities and borderline personality disorder is now being developed (Cain et al, 2006).

Interventions for persons with developmental disabilities who also have mental health diagnoses should emphasize concrete techniques. These include behavior therapy or cognitive-behavior therapy. It is generally quite helpful to include caretakers in therapy so that a consistent “therapeutic milieu” is available to assist the patient during the real life situations where problems are occurring. Psychotropic medications can certainly be effective, but these should generally be combined with counseling/psychotherapy and monitored carefully. As Menolascino

and Potter (1989) cautioned, the goal of psychotropic medication should be "to assist the patient in moving forward toward meaningful interpersonal engagements in the least restrictive of physical settings - a goal that cannot be accomplished in the presence of semi-sedation." Please see Cain et al (2006) for a good summary of psychotropic medication issues related to dual diagnosis. Family therapy, parent training approaches, and individual therapy are examples of additional treatment techniques that can be utilized with or without psychotropic medication to form an overall coordinated treatment program. More information on treatment suggestions for specific mental health diagnoses in developmentally disabled individuals can be found in a recent "Dual Diagnosis Primer" (Hughes, 2006). Other resources are also available from the National Association for the Dually Diagnosed (NADD) at 110 Prince Street, Kingston, NY 12401 (phone: 1-800-331-5362).

Please keep in mind that the concepts discussed in this chapter are closely related to the medical model. Traditional assessment and treatment procedures in the United States are based on this model. However, it is not the only model available. Other models could be called "strength-based holistic approaches" or approaches that tend to emphasize the person in the context of their culture (Fadiman, 1997; Gaw, 2000).

Although the diagnostic and treatment issues related to dual diagnosis can be very complicated, it is important to remember that guidelines for determining eligibility for services to persons with a developmental disability remain the same. The person's history should be of some assistance in determining which problem came first in the sequence, i.e., psychiatric/emotional difficulties or the developmental disability. A simple case would involve a person who is slow in their development and obviously developmentally disabled. Over time, they develop secondary emotional difficulties as they try to cope with stressful life events. These individuals would certainly be eligible for all services appropriate to persons with developmental disabilities.

The more complicated case involves a person who exhibits a major psychiatric disorder early in life, while simultaneously developing normally in terms of cognition, language, motor skills, etc. Examples of these disorders might include bipolar disorder or a severe attachment disorder. Over time, these mental and emotional difficulties may make it impossible for the child to benefit from education, instruction, or environmental stimulation. Slowly, their IQ scores and developmental indices may drop. In these cases, it would appear that the psychiatric diagnosis is the primary problem, and the later delays in development are a secondary manifestation. It is also possible that the person may have normal or near-normal intelligence, but not do well in a testing environment due to their emotional difficulties. In these kinds of cases, it is important to rely on a skillful psychological evaluation, a detailed social and medical history, and careful clinical judgment to make an appropriate decision concerning eligibility for services. Fortunately, we are now seeing the availability of several scales and interview formats that can be useful for clients with combined mental disorders and developmental disabilities. One of the best known of these is the Mini Psychiatric Assessment Schedule for Adults with Development Disability (Mini PAS-ADD) developed by Prosser et al, 1998. Ten other assessment tools in this area are discussed in Cain et al (2006). Finally, the National Association for the Dually Diagnosed (NADD) has developed an adaptation of the DSM-IV-TR that was designed to

facilitate a more accurate mental health diagnosis for people with an intellectual disability. This book is called Diagnostic Manual-Intellectual Disability (see 2007 reference under Fletcher). I would assume that this will be updated in relation to DSM-5 at some future point.

When making an eligibility determination for developmental disabilities services, the following points need to be emphasized:

1. If the person has a diagnosed mental illness, then the psychological evaluation report should indicate when discussing the validity of the reported test results that the behaviors associated with the person's mental disorder (e.g., inattention, lack of motivation, disruptive behaviors, etc.) did not adversely affect the outcome of the testing process (see Appendix J).
2. If a person with a diagnosed mental illness is referred for an independent psychological evaluation, then the psychologist should be specifically asked whether or not the mental illness was thought to have affected the IQ scores (see Appendix J).
3. If the person has a dual diagnosis of an intellectual disability and a mental illness, then this person can be deemed eligible for developmental disabilities services as long as number 1 and/or number 2 above have been satisfied.



4.

## Summary Points to Remember

- ✓ Although used in different ways by different people, our focus on dual diagnosis is related to developmental disabilities combined with psychiatric disorders.
- ✓ The incidence of mental health problems in the so-called normal population is quite high. Sixteen percent of the general population has a mental health disorder at any one point in time.
- ✓ Estimates regarding the prevalence of mental health diagnoses being combined with developmental disabilities generally fall in the range from 14% - 23%.
- ✓ The frequency of schizophrenia in the developmentally disabled population is at least ten times higher than a general norm group (4.4% vs .4%).
- ✓ The incidence of a phobic disorder in clients with developmental disabilities is about four times the rate for the general population (4.4% vs. 1.1%).
- ✓ The incidence of developmental disabilities being combined with psychiatric disorders in children is about three times what would be expected in the normal population.
- ✓ The stress of a developmental disability can lead to a psychiatric disorder.
- ✓ A personality disorder may use a label that is similar to a major psychiatric disorder (e.g., paranoid personality disorder, schizoid personality disorder, obsessive-compulsive personality disorder), but the symptoms used to define a personality disorder are less severe than the symptoms of a full-blown DSM-5 psychiatric disorder.
- ✓ For a person who may have a dual diagnosis, the guidelines for determining eligibility for services to persons with a developmental disability remain the same as for any other applicant. The most important guidelines for eligibility decision-making related to mental health disorders are listed in the three points at the end of this chapter.

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## CHAPTER 8

### TECHNIQUES TO ENHANCE THE REFERRAL PROCESS

One of the most important variables in being able to provide quality services to persons with developmental disabilities involves establishing a close working relationship between agency/community service providers and professionals who have specialized expertise and experience working with persons with a developmental disability. Some professionals will be interested in working with these clients, while others will not. I recommend that providers establish a personal relationship with physicians, psychologists, speech and language pathologists, physical therapists, occupational therapists, and other professionals in order to enhance communication and improve the overall quality of care and treatment.

In this chapter, we will focus primarily on ways to work effectively with a psychologist. A psychological evaluation is not a general "check up" such as one might receive in a yearly physical examination. Rather, it is more like going in to see a medical doctor in order to find out what is causing the pain in your neck or leg. In other words, you have specific questions that you want to get answered. Thus, you need to know why you are referring a person and be very clear and specific in posing these questions to the psychologist. A similar process can be used for physicians. You could think of it as learning the art of being able to ask the right questions. The three steps in this process are identified in the next section.

#### 1. Why are you referring this person? - General orientation

##### EXAMPLES:

- A. It was recommended by the habilitation team because of questions about the person's emotional status (e.g., is the person experiencing a psychotic disorder?).
- B. The person has not had an evaluation in 15 years and there is a need to have more current psychological information in the chart as far as cognitive functioning is concerned.
- C. Parents are requesting an evaluation because they think their son is not appropriately placed in services.
- D. The primary care physician is requesting an evaluation because she wonders if there might be some organic impairment or deterioration in the past three years.
- E. Specific stress issues have been identified in this person's life and these suggest a need for a psychological evaluation (e.g., mother died).

**2. What broad diagnostic questions do you want answered in proceeding with a determination that a person has a developmental disability?**

EXAMPLES:

- A. Is this person intellectually disabled?
- B. Do the person's symptoms fit on the autism spectrum?
- C. Does this person have a neurological condition similar to an intellectual disability which might make him/her eligible for services to persons with developmental disabilities?
- D. Does this person have a mental health disorder (specify in relation to depression, anxiety, PTSD, etc.)?
- F. What is this person's level of adaptive behavior functioning?
- G. Does the person, due to substantial disability require treatment/services similar to those needed by intellectually disabled persons?

**3. What specific issues do you want to see evaluated? Is there any specific information that you are requesting? Do you want treatment suggestions?**

EXAMPLES:

- A. What is the level of severity of this person's autism spectrum disorder according to DSM-5 guidelines?
- B. What suggestions could be considered for behavioral intervention programs to decrease the specified target behaviors (e.g., head banging) with this person?
- C. Is psychotherapy indicated to help this person with her apparent depression?
- D. Is this client being served in the least restrictive treatment alternative in terms of his residential or vocational placement?
- E. What would be appropriate vocational programs goals to consider for this person?
- F. Please provide the standard scores and their 95% confidence interval for all tests administered.
- G. If there is a fairly high likelihood that the person being referred will be "untestable", you can request that the psychologist attempt informal procedures if possible and not stop the evaluation if standardized assessment devices cannot be administered (see Appendix K).

**Note:** For children or adults who are already receiving services, the psychologist can be asked to review the informal assessments and program data that are currently available in order to answer the above questions or the questions on parts 4-5 of the Eligibility Determination Forms (see Appendices L and M).

## Summary Points to Remember

- ✓ It is very helpful to establish a personal relationship with professionals who have specialized expertise and experience working with persons with a developmental disability.
- ✓ Before you request a psychological evaluation, you need to specify what questions you want to have answered by the psychologist.
- ✓ The three-step process for enhancing the referral process is as follows:
  1. What is the general reason for referring this client?
  2. What broad diagnostic questions do you want answered?
  3. What specific issues do you want to see evaluated?



4.

# CHAPTER 9

## MAKING THE ELIGIBILITY DECISION

This chapter represents the culmination of the entire Manual. Now it is time to make the eligibility decision.

The Department in consideration of: 1) the parameters established by the relevant legal authorities, 2) the professional knowledge base in the field of developmental disabilities, and 3) the experience and practice in the delivery of developmental disabilities services in Montana and elsewhere, has determined that a person must meet all of the following criteria in order to be found eligible for the receipt of state sponsored developmental disabilities services:

- A. The person has an IQ score of approximately 70 or less.
- B. The person has an adaptive behavior composite score of approximately 70 or less.
- C. The effect of the person's developmental disability involves functional limitations in three or more areas of a major life activity.
- D. The disability originated before the person attained age 18.
- E. The disability is expected to continue indefinitely.<sup>1</sup>
- F. The disability meets the definitions and requirements delineated in Appendix I for substantial disability and treatment needs.<sup>2</sup>

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These criteria are further detailed in Appendix I.

<sup>1</sup>To verify this criterion, it may be important to investigate 2 specific phenomena. One involves inconsistent IQ scores reported over time (e.g., scores above and below 70). The other possibility involves reports where the psychologist states that the obtained results are not thought to be a valid sample of the client's true intellectual potential. Both of these types of examples may require independent psychological evaluations to help sort out the possible subtle and complex variables involved in a particular case.

<sup>2</sup>Specific examples of treatment needs typically required by a person with an intellectual disability would include placement in a sheltered workshop, supported employment in the community, group homes, or supported living in semi-independent home settings.

There are three steps involved in the eligibility decision process:

**STEP 1:** The first step in making the eligibility decision is to gather the appropriate information. Guidelines in this regard are listed below for both adults and children.

**Part A – Adults:** Guidelines for assessment procedures necessary to determine eligibility for services to adults with developmental disabilities (defined as age 16 and over):

1. A current or recent assessment of intelligence using a standardized individual test designed to measure intellectual functioning. The IQ test should be administered by a licensed psychologist. A “recent” test is generally one that has been administered within three years. However, there are no rigid rules in this regard. Exceptions are possible when:
  - A. The original scores are low (e.g., below 60).
  - B. The person’s functioning level has not changed.
  - C. The evaluating clinician states that the earlier scores are still valid.
2. A current or recent assessment of adaptive behavior. Adaptive behavior for adults is measured using the *Vineland-II Adaptive Behavior Scales*.
3. A current or recent assessment of educational achievement which utilizes standardized tests to identify academic skills in reading, arithmetic and written language. This step is optional for adults. It can be helpful if the person has functional academic skills and there is a pattern of variable test scores (significant strengths and weaknesses) across the other cognitive and adaptive skills being assessed.
4. A comprehensive history should be compiled by gathering relevant records and by interviewing parents/caretakers and the adult applicant. This could be done by a social worker, an Intake Coordinator, Case Manager, Case Manager Supervisor/Director of Case Management Services, or a Quality Improvement Specialist (QIS). If parents are not available, other records (including social history) should be utilized. The historical information will be used to document the following:
  - A. Developmental history
  - B. Medical history
  - C. Educational history
  - D. Social history
  - E. Mental health history
  - F. Other relevant historical records (e.g., past employment, past placement in services for persons with developmental disabilities, etc.)

- G. Summary of assessment interview data - This can be extremely helpful, especially in cases where written records are unavailable. Examples would include having Developmental Disabilities Program staff (see # 4 above) interview parents, siblings, past teachers, neighbors or friends of the applicant. This may provide the evidence necessary to document that the disability did indeed begin before age 18 as shown by enrollment in self-contained special education classes at a particular age, history of delayed development, lack of independence in specific activities, etc.
5. A current general medical examination. (Optional-use if questions concerning medical/neurological issues are unresolved).
  6. Review of current status and needs. Information gathered in this step would include:
    - A. Current residential placement and needs
    - B. Current employment placement and needs
    - C. Other current needs or problems (social, emotional, medical, psychological, legal, case-management, etc.)
  7. If an interview of the adult is conducted, this is a good time to observe communication skills, general knowledge, and the person's ability to provide a coherent history. This is also an opportunity to screen the person's overall functioning level (e.g., read a paragraph, write a paragraph, perform arithmetic problems, have the person tell the story of her life, have the person tell about a recent movie she has seen, have the person give the current day and date, ask the person to give his age and birthday, etc.).
  8. Finally, a determination needs to be made if the person has need of specialized services similar to that required by persons with intellectual disabilities.

**Summary:** When gathering the above information, it is important to remember that the final decision will be based on both quantitative data (e.g., test scores) and qualitative data (e.g., direct interviews, historical records).

**Part B-Children:** Guidelines for assessment procedures necessary to determine eligibility for services to children with developmental disabilities (ages 6-15):

1. A current or recent assessment of intelligence using a standardized individual test designed to measure intellectual functioning. The IQ test should be administered by a licensed psychologist or school psychologist. A “recent” test is generally one that has been administered within 1-2 years for younger children (e.g., 3-5). For children ages 6-15, a three year standard may be appropriate. Because of their limited predictive validity, try not to use preschool test results (e.g., ages 0-5) for close to call cases. The flexible guidelines for defining a “recent” test that

were delineated for adults on the previous page can also be applied to children (e.g., exceptions to the rule are possible when the original scores are very low, functioning level has not changed, or the evaluating clinician states that the earlier scores are still valid).

2. A current or recent standardized assessment of adaptive behavior, which as stated in Part A-4 above will typically be the Vineland-II according to Developmental Disabilities Program (DDP) policy.
3. A current or recent assessment of educational achievement which utilizes standardized tests to identify academic skills in reading, arithmetic and written language. This type of testing is optional and not required to make an eligibility determination decision unless there is significant scatter in cognitive abilities and adaptive skills and the person is thought to have significant strengths in academic functioning.
4. A comprehensive history should be compiled based on relevant information and records. Information may be directly obtained from parents and other appropriate persons. The historical information will be used to document the following:
  - A. Developmental history
  - B. Medical history
  - C. Educational history
  - D. Social history
  - E. Mental health history
  - F. Other relevant records (e.g., progress in home stimulation programs, past placement in services for children with developmental disabilities)
  - G. Summary of assessment interview data - This step can be useful in gathering informal, qualitative data and behavioral observations regarding the child's general functioning. Examples would include interviewing parents/caretakers, siblings, teachers, or daycare providers. This may provide the evidence necessary to determine if the child is significantly delayed in development, needs further assessment, has made recent progress, etc.
5. A current general medical examination (optional-use if questions concerning medical/neurological issues are unresolved).
6. Review of current status and needs. Information gathered in this step will include:
  - A. Current residential placement and needs
  - B. Current educational placement and needs
  - C. Current needs for home-based intervention programs

- D. Other current needs or problems (e.g., behavior management, case-management needs, etc.)

If the information in Step 1 is complete, go to Step 3. If inconsistencies or questions remain, go to Step 2.

**STEP 2:** If questions still remain, utilize the three-step referral process (see Chapter 8). Provide all records and adaptive behavior information to the psychologist (and/or physician if necessary). Clearly specify what questions you want answered. The psychologist will also need to be given copies of Appendices I and J so that he/she can plan their evaluation appropriately and know what information will be required by Montana Developmental Disabilities Program staff in the final written report.

**STEP 3:** Once all of the necessary information has been gathered, then it should be summarized on the appropriate Eligibility Determination Form. Forms for adults are included in Appendix L. Forms for children are included in Appendix M.

By proceeding through each step of the Eligibility Determination Form, a valid decision concerning eligibility should result. However, it is important to remember that no human decision-making process is perfect or flawless. The following guidelines may be helpful:

1. If more information is still needed, delay the decision until all relevant and available records are gathered.
2. Second opinions can be very helpful, especially in “close to call” cases. This can be done by requesting a psychological evaluation, obtaining an independent paper/records review by a designated Developmental Disabilities Program (DDP) consultant, or by having a Quality Improvement Specialist (QIS) or other regional DDP staff person visit or observe the person in their home, school, or work place.
3. If service options outside the Developmental Disabilities Program seem more appropriate or less restrictive (e.g., vocational rehabilitation through the Rehabilitation Services Division, mental health services, etc.), then these can be recommended at the end of the forms in Appendices L and M. A follow-up decision concerning eligibility for services to persons with developmental disabilities can always be made later if the initial recommendations for other service options are not successful.
4. The Eligibility Determination Form is designed specifically to implement the procedures and criteria set out in this Manual.
5. The Eligibility Determination Form provides for a decision focused on a real person (not a “number” or a “statistic”). In order to make this kind of decision, it is important to

consider the following:

- A. Incorporate and integrate older test data with current test results in order to provide a complete picture of a person's functioning level where necessary.
- B. Utilize both formal test results and informal clinical data. The child's developmental history is important. If a 38-year-old adult has never worked competitively, this is important. Terms like "significant" or "substantial disability" cannot be precisely defined. This can only be decided on the basis of reviewing all the data.
- C. If a psychologist provides an age-equivalent or grade-equivalent score, or only a range of scores for their test results, ask for the specific standard scores in all areas evaluated (see #2 in Appendix J).
- D. In considering strengths and positive findings, any one strength obviously does not invalidate a legitimate developmental disability. What do the preponderance of the data indicate? Is the child basically delayed in development or functioning at an age-appropriate level in most areas? Is the adult capable of caring for himself/herself, or not? These are the kinds of basic questions that need to be addressed.

The eligibility determination process for the State of Montana provides a number of steps that involve checks and balances, opportunities for independent evaluations, second opinions, administrative reviews, appeals for a fair hearing, and other due process considerations (see Appendix N). The purpose of this Manual is to present the eligibility determination process for developmental disabilities services. I hope it accomplishes this goal and fosters a more uniform application of the process for making eligibility decisions in the State of Montana. I also hope that I have clarified some of the important issues in this regard. There is a major need to bring good old common sense to this endeavor. Decisions that are based on a complete and competent review of all relevant data for each unique individual represent the current state of the art in this area. Thus, there is both art and science in this process. Hopefully, we can reach a point where there is a good balance between the two.

## Summary Points to Remember

- ✓ The following three steps constitute the eligibility decision-making process:
  1. Gather all of the appropriate historical information and current records.
  2. If questions still remain, utilize the three-step referral process from Chapter 8.
  3. Complete the Eligibility Determination Form appropriate for either adults (Appendix L) or children (Appendix M).
  
- ✓ The Montana definition of an intellectual disability is **NOT** based on DSM-5, but rather is based on this Manual, which in turn is based on an existing state statutory definition of intellectual disability, federal law, AAIDD guidelines, and professional knowledge and expertise.
  
- ✓ The final eligibility decision represents a judgment that inevitably will require a combination of common sense, science, and the current state of the art. It will not be perfect. When this decision is informed by an individualized assessment of the person and a complete review of all relevant data, then an optimal determination should be forthcoming.
  
- ✓ Montana has a number of checks and balances in its eligibility decision making procedures that provide for important due process considerations (see Appendix N).



# APPENDIX A

## DEFINITIONS FOR STATISTICAL MEASURES AND TERMS

The following terms represent the most commonly used statistical measures in psychological test reports. You can use them to understand the data and quantitative findings provided by psychological tests.

**Age Equivalent Score** - This provides a rough estimate of the developmental age at which the person is functioning in a particular area. For example, an age equivalent score of eight years seven months in reading would suggest that the client is reading like other persons who are at this age level. This type of score is never as precise as a statistical measure, such as an IQ score or a percentile rank.

**Correlation** - Correlation is a term that is used in our general language as well as having a precise mathematical definition. When used by psychologists, it typically means that two scores tend to be very similar (e.g., an IQ score of 67 and an achievement standard score of 68 are closely correlated). Mathematically, a correlation score has a more precise meaning in which scores can range from -1 to +1. The following table explains the meaning of various correlations:

.80 to 1.00 - very high correlation  
.60 to .79 - substantial correlation  
.40 to .59 - moderate correlation  
.20 to .39 - little correlation  
.01 to .19 - practically no correlation

A correlation of .50 indicates that 25 percent of the variation in one score is directly associated with variation in a second score ( $.50 \times .50 = .25$ ). A small  $r$  is often used as the symbol of a correlation coefficient if mathematical terms are being employed. A negative correlation (e.g., -.35) means that the scores vary in an opposite manner. Thus, as one score gets larger, we would expect that the other score will get smaller (or vice versa).

**Grade Equivalent Score** - This provides an estimate of how the client's performance would compare to students in a graded school system. For example, a grade equivalent score of 6.4 would be approximately similar to the performance of students in the fourth month of their sixth grade year. Again, this score provides a less precise piece of information than standard scores based on the normal curve.

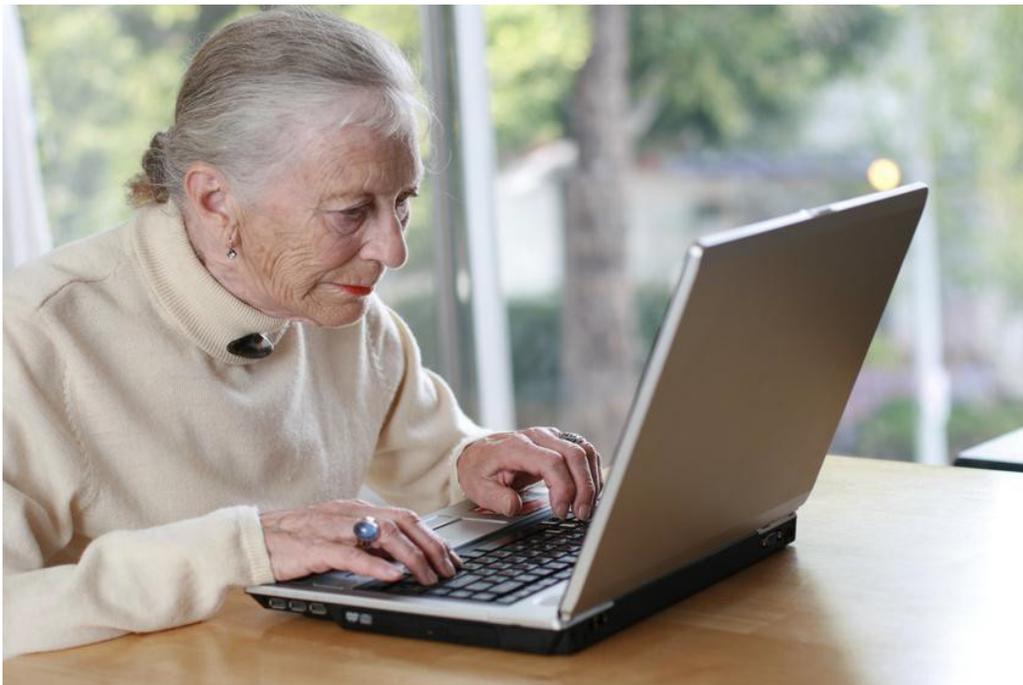
**Mean** (commonly noted as  $\bar{X}$ ) - The mean is an arithmetic average. Thus, it is simply the total of all scores divided by the number of scores. The mean for any test is the average score obtained by adding all the scores from a given population and dividing by the number of persons tested.

**Median** - The median is the middle score in a sample of data points. To find the median, one needs to organize scores from lowest to highest in a table. The median score is the score in the middle such that 50 percent of the scores in the distribution would fall below it, while 50 percent would also be higher.

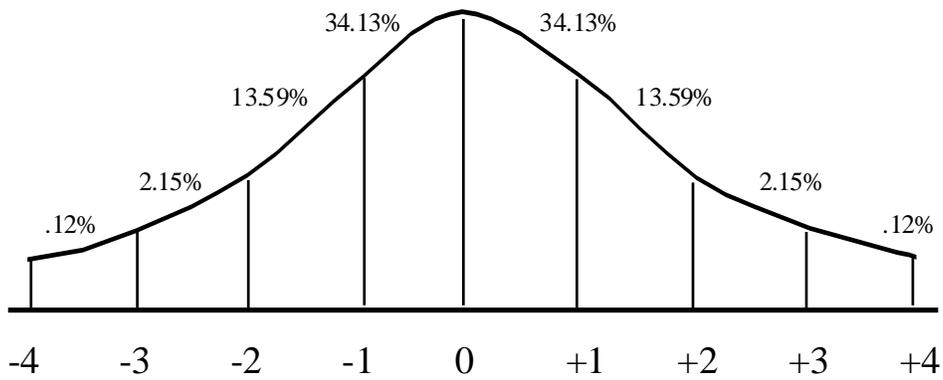
**Mental Age** - This provides an estimate of the person's developmental functioning in terms of cognitive abilities. For example, a mental age of four years six months suggests that the person's cognitive development is similar to that seen in a child who is 4 ½. Since it is basically an age equivalent score (see above), it is relatively imprecise.

**Mode** - The mode is a measure of central tendency that represents the most frequent score seen in a sample of scores.

**Normal Curve** - The normal curve is a symmetrical, bell shaped curve which is based upon a mathematical formula. 95.44 percent of any population will fall within  $\pm 2$  standard deviations of the mean. 99.74 percent of any population will fall within  $\pm 3$  standard deviations of the mean. A picture of the normal curve is provided on the following page. It shows the relationship between the normal curve and other statistical terms (percentile, T-scores, IQ scores, and subtest scaled scores).

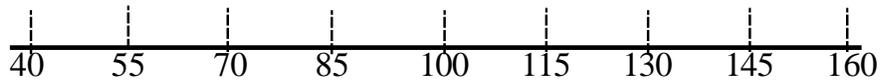


## Standard Deviations

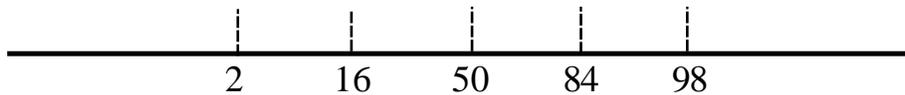


## I.Q. Scores

(or any other standard score with a mean of 100 and a standard deviation of 15)

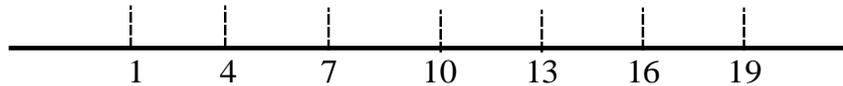


## Percentile Ranks

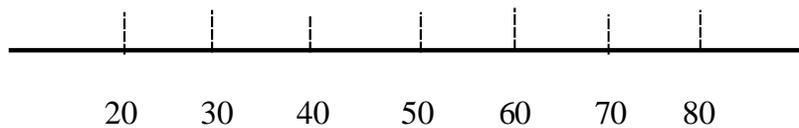


## Subtest Scaled Scores

(with a mean of 10 and a standard deviation of 3)



## T-Scores



**Percentile Rank** - A given percentile score tells you what percentage of persons would score lower and what percentage would score higher than a given score. For example, a percentile rank of 36 indicates that 36 percent of the population would score lower, while 64 would score higher.

**Raw Score** - A raw score is the total number of correct answers for a given subtest. It is a score that has no real meaning, since it does not allow us to compare that person's performance with any standard or norm group. For example, a person could get a raw score of 15 on a test where there are 30 items and this could be an excellent performance for a given age group that would put him in the top three percent for his age, but one would not know this based on looking only at the raw score. To be meaningful, raw scores need to be changed into some type of standard score.

**Reliability** - Reliability tells us the extent to which a person will tend to obtain the same test score on a repeated basis, no matter who gives the test or when it is given.

**Scaled Score** - A scaled score is basically a standard score that is applied to a subtest, which represents one part of the overall test. Thus, on the various *Wechsler* scales, each subtest has a mean scaled score of 10 and a standard deviation of three. Here again, the most important thing about a scaled score is that it allows us to make a ready comparison with the norm group. Appendix C provides a table of percentile ranks for the various scaled scores of a test like the *WAIS-IV*, which uses a scaled score of 10 and a standard deviation of three.

**Standard Deviation** - This is a statistical term arrived at by a rather complicated formula in order to tell you how scores are grouped in a data sample. The smaller the standard deviation, the closer these scores are grouped around a mean or average point. The larger the standard deviation, the more that the scores are "spread out" or scattered randomly. Psychometric and intelligence tests are carefully constructed in order to create a small standard deviation so that scores are tightly grouped in relation to the mean. The standard deviation is probably best understood by looking at the normal curve illustrated on the previous page.

**Standard Error of Measurement** (SEm) - This is an additional statistical term that tells us about the reliability of a test. It helps us determine how much we would expect a person's score to vary if he were tested frequently. Statistically, the chances are two out of three that a person's "true" score will fall within  $\pm 1$  SEm. The chances are 95 percent that it will fall within  $\pm 2$  SEm. For adults tested on the *Wechsler Adult Intelligence Scale-4th Edition*, the SEM for the Full Scale IQ score is about 2-2.5 points (the range is 1.90 to 2.58). Thus, if we round this off to 2.5, then we would expect that an IQ score of 69 would fall between 66.5 and 71.5 two-thirds of the time. We would expect that it would fall between 64 and 74 ninety-five percent of the time if the person were retested on future occasions. This tells us that the *WAIS-IV* is a reliable test since very similar scores will tend to occur over time. However, it is not perfect. Scores at different times with different clinicians will change. The SEM varies for each test and on the basis of age. IQ scores for most intelligence tests have a SEM of 2-5 points.

**Standard Score** - A standard score represents a statistical transformation of a raw score such that it does have meaning in comparison to a norm group. Standard scores can be readily compared with each other because they tell us where the person falls on the normal curve or give us a percentile rank for where the person performs in relation to their age peers. Most IQ tests use a standard score of 100, with a standard deviation of 15. Appendix B provides a table of percentile ranks for standard scores which do have a mean of 100 and a standard deviation of 15. Other tests might have different standard scores (e.g., mean of 50 and a standard deviation of 10), but these would be interpreted in the same way, i.e., by looking at a table of percentile ranks for that particular standard score in order to know whether it is falling in the middle or at some extreme point.

**T-Score** - This is a type of subtest scaled score that has a mean of 50 and a standard deviation of 10. It is used for the MMPI-2 and some other tests.

**Validity** - Validity indicators tell us whether or not the test is sampling what we want it to measure. Does it predict how a person will function in society? Does it predict how a person will perform in school? There are a large number of validity measures that can be evaluated for each test.



## APPENDIX B TABLE OF PERCENTILE RANKS

(Can be used for any test that has standard scores

with a mean of 100 and a standard deviation of 15).

Standard Score	Percentile	Standard Score	Percentile	Standard Score	Percentile
46	.03	76	5	106	66
47	.04	77	6	107	68
48	.05	78	7	108	70
49	.06	79	8	109	73
50	.07	80	9	110	75
51	.08	81	10	111	77
52	.09	82	12	112	79
53	.1	83	13	113	81
54	.2	84	14	114	83
55	.3	85	16	115	84
56	.4	86	18	116	86
57	.5	87	19	117	87
58	.6	88	21	118	88
59	.7	89	23	119	90
60	.8	90	25	120	91
61	.9	91	27	121	92
62	1	92	30	122	93
63	1	93	32	123	94
64	1	94	34	124	95
65	1	95	37	125	95
66	1	96	39	126	96
67	1	97	42	127	96
68	2	98	45	128	97
69	2	99	47	129	97
70	2	100	50	130	98
71	3	101	53	131	98
72	3	102	55	132	98
73	4	103	58	133	99
74	4	104	61		
75	5	105	63		

## APPENDIX C

### TABLE OF PERCENTILE RANKS FOR SUBTEST SCALED SCORES

(Can be used for any subtest score having a mean of 10 and a standard deviation of 3)

Scaled Score	Percentile Rank
19	99.9
18	99.6
17	99
16	98
15	95
14	91
13	84
12	75
11	63
10	50
9	37
8	25
7	16
6	9
5	5
4	2
3	1
2	0.4
1	0.1

## APPENDIX D

### *CLASSIFICATION OF IQ TEST SCORES\**

Classification	IQ Score Range	Percentile Rank Range
Very Superior (Gifted)	130 and Above	98 (top 2%)
Superior	120-129	91-97
High Average	110-119	75-90
Average	90-109	25-74
Low Average	80-89	9-24
Borderline	70-79	2-8
Extremely Low**	69 and below	2 <sup>nd</sup> Percentile and lower

\*Various tests may have slightly different classification systems, but the above table is consistent with the various *Wechsler* scales.

\*\*Scores in this category will typically result in an Intellectual Disability diagnosis, with mild, moderate, severe, or profound levels being identified (see pages 33-36 in DSM-5). However, if significant subtest or composite score discrepancies (i.e., statistically significant differences) are present, then the Full Scale IQ score should always be interpreted with caution.



# APPENDIX E

## AMERICAN ASSOCIATION ON INTELLECTUAL AND DEVELOPMENTAL DISABILITIES (AAIDD)

**Definition of Intellectual Disability:** Intellectual disability is a disability characterized by significant limitations in both intellectual functioning and in adaptive behavior, which covers many everyday social and practical skills. This disability originates before the age of 18.

**Intellectual Functioning:** Intellectual functioning—also called intelligence—refers to general mental capacity, such as learning, reasoning, problem solving, and so on. One way to measure intellectual functioning is an IQ test. Generally, an IQ test score of around 70 or as high as 75 indicates a limitation in intellectual functioning.

**Adaptive Behavior:** Adaptive behavior is the collection of conceptual, social, and practical skills that are learned and performed by people in their everyday lives.

- ✓ Conceptual skills—language and literacy; money, time, and number concepts; and self-direction.
- ✓ Social skills—interpersonal skills, social responsibility, self-esteem, gullibility, naïveté (i.e., wariness), social problem solving, and the ability to follow rules/obey laws and to avoid being victimized.
- ✓ Practical skills—activities of daily living (personal care), occupational skills, healthcare, travel/transportation, schedules/routines, safety, use of money, use of the telephone.

Standardized tests can also determine limitations in adaptive behavior.

**Age of Onset:** This condition is one of several developmental disabilities—that is, there is evidence of the disability during the developmental period, which in the US is operationalized as before the age of 18.

**Additional Considerations:** But in defining and assessing intellectual disability, the AAIDD stresses that additional factors must be taken into account, such as the community environment typical of the individual’s peers and culture. Professionals should also consider linguistic diversity and cultural differences in the way people communicate, move, and behave.

Finally, assessments must also assume that limitations in individuals often coexist with strengths, and that a person’s level of life functioning will improve if appropriate personalized supports are provided over a sustained period.

Only on the basis of such many-sided evaluations can professionals determine whether an individual has intellectual disability and tailor individualized support plans.

For readers interested in developing a greater understanding of the AAIDD definition, please consult their website and review their 6 pages of frequently asked questions (FAQ).



## APPENDIX F

### STATE OF MONTANA DEFINITION OF A DEVELOPMENTAL DISABILITY

The current definition of a "developmental disability" in the State of Montana (following changes made by the 63<sup>rd</sup> legislature:2013-2014) is provided below:

*"Developmental disabilities" means disabilities attributable to intellectual disability, cerebral palsy, epilepsy, autism, or any other neurologically disabling condition closely related to intellectual disability and requiring treatment similar to that required by intellectually disabled individuals if the disability originated before the individual attained age 18, has continued or can be expected to continue indefinitely, and results in the person having a substantial disability.*

**Reference:** Montana Code Annotated, 53-20-202(3), MCA



# APPENDIX G

## WEBSITES FOR AUTISM INFORMATION

### [Autism Research Institute](#)

4182 Adams Avenue  
San Diego, CA 92116 619-  
281-7165  
619-563-6840 fax

### [Autism Society of America](#)

7910 Woodmont Avenue, Suite 300  
Bethesda, MD 20814  
800-328-8476  
301-657-0881  
301-675-0869 fax

### [Center for Study of Autism](#)

P.O. Box 4538  
Salem, OR 97302  
503-363-9110 voice/fax)

### [Autism Speaks](#)

### **Diet Information Resources**

[Kinnikinnick.com](#)  
[Miss Robens.com](#)

### **National Information Center for Children**

### **and Youths with Disabilities**

[nichcy@aed.org](mailto:nichcy@aed.org)

P.O. Box 1492  
Washington, DC 20012  
304-525-8014  
304-525-8026 Fax

### [TEACCH](#)

### [UC Davis Mind Institute](#)

Then click on Products  
Then click on Autism Distance Education  
Parent Training (ADEPT)

### [Autism Internet Modules](#)

Screening Across the Lifespan for Autism  
Spectrum Disorders

### **Montana Autism Education Project**

Website by Doug Doty of the Montana  
Office of Public Instruction  
Wide Variety of Topics  
[opi.mt.gov/users/dougdoty](http://opi.mt.gov/users/dougdoty)

### **The National Professional Development Center on Autism Spectrum Disorder**

Emphasizes Evidence Based Practices for  
Children and Youth with ASD  
[autismpdc.fpg.unc](http://autismpdc.fpg.unc.edu)

### [Project SPIES for Parents](#)

SPIES = Strategies for Preschool  
Intervention in Everyday Settings

### [National Institutes for Health](#)

Autism Spectrum Disorder

## APPENDIX H

### <sup>3</sup>FEDERAL DEFINITION OF A DEVELOPMENTAL DISABILITY

The term "developmental disability" means a severe, chronic disability of a person 5 years of age or older which:

- A. is attributable to a mental or physical impairment or combination of mental and physical impairments;
- B. is manifested before the person attains age twenty-two;
- C. is likely to continue indefinitely;
- D. results in substantial functional limitations in three or more of the following areas of major life activity:
  - i. self-care,
  - ii. receptive and expressive language,
  - iii. learning,
  - iv. mobility,
  - v. self-direction,
  - vi. capacity for independent living, and
  - vii. economic self-sufficiency; and
- E. reflects the person's need for a combination and sequence of special, interdisciplinary, or generic care, treatment, or other services which are of lifelong or extended duration and are individually planned and coordinated.

The term developmentally disabled when applied to infants and young children means persons from birth to age five, inclusive, who have substantial developmental delay or specific congenital or acquired conditions with a high probability of resulting in developmental disabilities if services are not provided.

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<sup>3</sup> Based on the Developmental Disabilities Assistance and Bill of Rights Act of 2000.

# APPENDIX I

## OPERATIONAL ELIGIBILITY CRITERIA FOR MONTANA

### DEVELOPMENTAL DISABILITIES SERVICES (DDS)

- I. Developmental disability determination criteria for an intellectual disability are provided in this first section. These are also the general developmental disability criteria that are applied to all other diagnoses and conditions:
- A. The person has an IQ score of 70 or below. If a person is diagnosed with an intellectual disability based on an IQ greater than 70, the psychologist should provide a specific rationale as to why the person is being considered intellectually disabled (e.g., based on the 95% confidence interval related to 2 standard errors of measurement for a particular test).
  - B. The person has an Adaptive Behavior Composite score of 70 or less. Here again, the psychologist should provide a specific rationale as to why the person is considered intellectually disabled if the composite score for the adaptive behavior measure is greater than 70.
  - C. The effect of the person's intellectual disability needs to result in functional limitations in three or more of the following areas of a major life activity:
    - 1. Self care
    - 2. Receptive and expressive language
    - 3. Learning
    - 4. Mobility
    - 5. Self-direction
    - 6. Capacity for independent living
    - 7. Economic self-sufficiency
  - D. There must be documentation that the developmental disability originated before the person turned age 18.
  - E. There must be a statement that the developmental disability has continued or can be expected to continue indefinitely.
  - F. The person must be in need of treatment required by intellectually disabled persons. In accordance with the federal definition of a developmental disability, this treatment reflects the person's need for a combination and sequence of special, interdisciplinary, or generic care, treatment, or other services which are of lifelong or extended duration and are individually planned and coordinated.

- G. For persons from birth to age 5, inclusive, who have substantial developmental delay or specific congenital or acquired conditions with a high probability of resulting in developmental disabilities if services are not provided, medical records and documentation from the child's physician will be used to make the eligibility determination.

## II. Determining Eligibility In Relation To Autism:

In order to determine developmental disability eligibility in relation to autism spectrum disorder, a person must be determined to meet letter A or letter B, and letter C as described below:

- A. Level 2 guidelines (requiring substantial support) for both social communication and restricted, repetitive behaviors.
- B. Level 3 guidelines (requiring very substantial support) for both social communication and restricted, repetitive behaviors.
- C. Significant impairment of intellectual functioning that is similar to an intellectual disability and requires similar treatment. Level 2 and Level 3 descriptors are clearly delineated on page 52 of the DSM-5 manual.

## III. Determining Eligibility In Relation To Cerebral Palsy:

In order to determine developmental disability eligibility in relation to cerebral palsy, a person must be determined to demonstrate significant impairment of intellectual functioning that is similar to an intellectual disability and requires similar treatment.

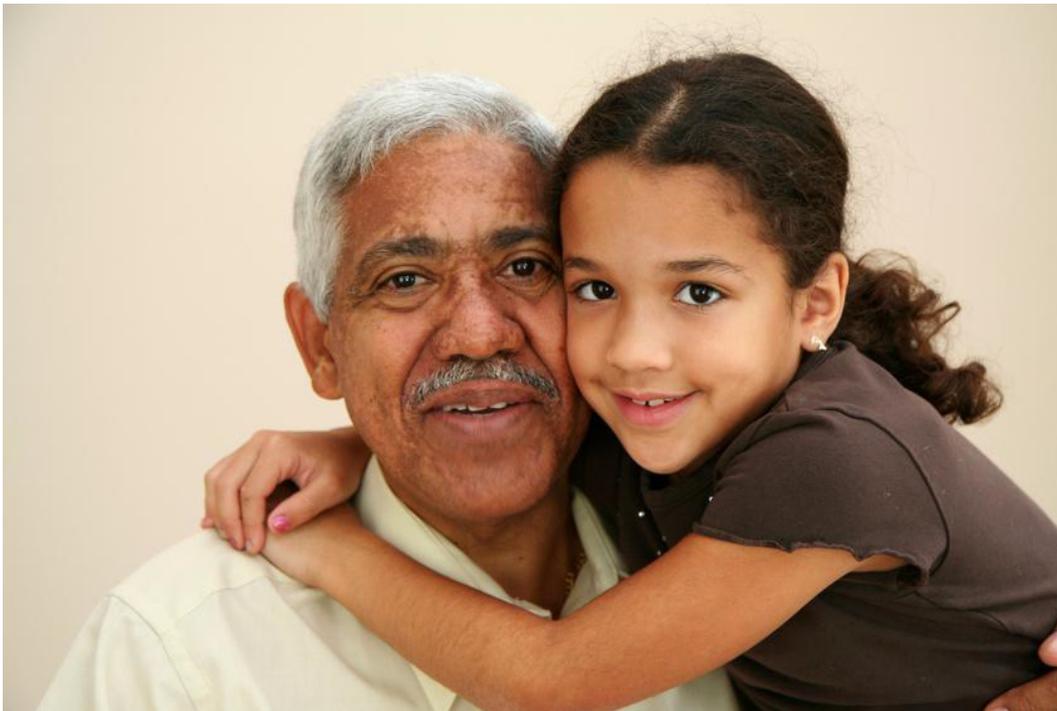
## IV. Determining Eligibility In Relation To Epilepsy:

Most persons with epilepsy do not have a developmental disability. In order to determine developmental disability in relation to epilepsy, a person will typically have uncontrolled seizures and be determined to demonstrate significant impairment of intellectual functioning that is similar to an intellectual disability and requires similar treatment.

## V. Determining Eligibility In Relation To Other Neurological Conditions:

In order to determine developmental disability eligibility in relation to a person with another neurological condition, the person must be determined in accordance with this Manual to have such a condition and to exhibit significant impairment of intellectual functioning that is similar to an intellectual disability and requires similar treatment.

- VI. Determining Eligibility Where There Is An Apparent Combination of Developmental Disabilities and Mental Illness:
- A. A person with an apparent combination of developmental disabilities and mental illness diagnoses may be determined to be eligible for developmental disability services if either number 1 or 2 below are satisfied:
1. The validity section of the person's psychological evaluation report definitively states that the obtained test results were not significantly impacted by behaviors associated with the person's mental disorder (e.g., inattention, lack of motivation, disruptive behaviors, etc.).
  2. If a person with a mental disorder in an appeals process is referred for an independent psychological evaluation, then the psychologist should be specifically asked whether or not the mental illness affected the intelligence test scores and to what extent.
- VII. Substantial Disability - A "substantial disability" as stated in the Montana Code Annotated 53-20-202(3) is defined as meeting the requirements for I-A, I-B, and I-C under the guidelines for an intellectual disability noted above.
- VIII. Defining Treatment Needs - Treatment similar to that required by intellectually disabled persons is described in I-F above.



## **APPENDIX J**

### **REQUIREMENTS FOR PSYCHOLOGICAL EVALUATION REPORTS UTILIZED BY THE MONTANA DEVELOPMENTAL DISABILITIES PROGRAM (DDP) FOR MAKING ELIGIBILITY DECISIONS\***

Psychologists who provide psychological evaluations to assist in the eligibility determination process for persons with a developmental disability will be asked to utilize the following guidelines:

1. Read and make use of the operational definitions and policies delineated in Appendix I.
2. All subtest and composite standard scores should be included in the report, along with a 95% confidence interval for the composite scores (two standard errors of measurement).
3. If a person is diagnosed as having an intellectual disability on the basis of an IQ score above 70, the psychologist should state the specific rationale and justification for making this diagnosis.
4. The Montana Developmental Disabilities Program (DPP) cannot accept either "provisional" or "rule out" diagnoses.
5. A diagnosis of "borderline intellectual functioning" is not sufficient documentation for a determination that a person has a developmental disability.
6. The written report should contain a clear statement indicating whether or not the person meets the operational definitions and policies for a developmental disability described in Appendix I.
7. Although eligibility for Developmental Disabilities Services (DDS) is NOT based on DSM-5 diagnostic criteria for an intellectual disability, it is helpful for the clinician to specify the severity level of the intellectual disability as being mild, moderate, severe, or profound according to DSM-5 guidelines.
8. The clinical report should contain specific examples of the person's functioning level, strengths, and deficits in the conceptual, social, and practical domain areas delineated by DSM-5.
9. For cases of autism spectrum disorder, the psychologist needs to specify whether the

applicant meets Level 1 (requiring support), Level 2 (requiring substantial support), or Level 3 (requiring very substantial support) severity levels for both social communication and restricted, repetitive behaviors according to DSM-5 guidelines. Here again, specific examples of functioning level, strengths, and deficits should be provided for both social communication and the restricted, repetitive behavior categories.

\*These guidelines were adapted, updated, and expanded based on the "Requirements for psychological reports to determine clinical eligibility for the adult or children's DD waiver" utilized by the State of Wyoming.



# APPENDIX K

## UNDERSTANDING THE MEANING OF THE TERM “UNTESTABLE”

**Introduction:** For a person to be evaluated utilizing a standardized test procedure (e.g., the *Wechsler scales*), they need to possess a variety of skills and abilities that include sitting at a table, paying attention, being able to process language in order to respond to questions and directions, cooperating with the examiner, and a general motivation to perform at or near their level of potential. It is not unusual for some children or adults to demonstrate reduced skills in one or more of these areas. To that extent, the standardized test procedures could potentially be somewhat less valid or appropriate for that particular person. This takes one into the art of testing and the need for careful interpretation. However, a small number of applicants are deficient in most or all of the skills necessary for standardized testing. These persons may be "untestable" in relation to standardized tests, but they can still be evaluated and assessed in a variety of other ways as we shall see below.

**Definition:** A person is "untestable" when a psychologist states that the person cannot be evaluated using a standardized testing format. That's all there is to it. In cases where the person has well-documented severe to profound levels of intellectual delays, this judgment could also be made by a professional who is knowledgeable in the field of developmental disabilities. Once this decision is made, then the following process needs to occur:

1. If a person cannot be evaluated using a standardized test format, they can frequently be evaluated by a psychologist using an adapted, non-standardized format that still utilizes a standardized test with various kinds of accommodations. This can provide very useful information. Some of this information is qualitative (e.g., what they could do or not do) and some is quantitative (e.g., making numerical comparisons to a norm group). Another option in this category is to refer to an assessment professional who can evaluate persons with sensory impairments using specialized testing techniques for the blind, hearing impaired, etc.
2. If testing attempts using number 1 above are not successful, a large number of additional valid evaluation procedures are still possible. These would include the following:
  - A. A measure of Adaptive Behavior (e.g., *Vineland-II, Adaptive Behavior Assessment System – II*).
  - B. Informal assessment of play skills related to overall developmental functioning (e.g., *Play Assessment Scale*).

- C. Use of behavior and ability checklists or screening devices to identify skills, strengths, and weaknesses (e.g., Developmental Profile 3, Brigance, Developmental Observation Checklist System (DOCS), Battelle Developmental Inventory – Second Edition).
  - D. Criterion-referenced assessment procedures (e.g., The Carolina, LAP-D, AEPS, etc.).
  - E. Measures of receptive language (e.g., Peabody Picture Vocabulary Test, other picture pointing tasks from standardized test instruments).
  - F. Informal assessment by a teacher or clinician.
  - G. Observation of developmental levels and general functioning in home, school, or work settings.
  - H. Review of portfolios of the person’s previous work or performance in a variety of settings.
  - I. Review of any past records or tests of school achievement (reading, writing, spelling, arithmetic).
  - J. Parent interview regarding skills demonstrated at home.
  - K. Teacher interview regarding skills demonstrated at school.
  - L. Interview with work supervisor regarding skills performed in a work setting.
3. In this clinician’s opinion, virtually all persons can be evaluated using the procedures described in numbers 1 or 2 above. One exception might involve persons who are incarcerated and/or otherwise refuse to give permission for testing, gathering records, or interviewing collateral sources who are knowledgeable about their skills and special needs. Thus, even if a person were in a coma and not conscious, they could still be evaluated using checklists, caregiver interview data, etc. Therefore, being “untestable” is not the end of the process, but rather the beginning of an alternative assessment approach utilizing the guidelines described above. In most cases, this kind of data will be sufficient for determining a person's eligibility for program services.
4. Children under the age of eight can currently be evaluated in a variety of flexible ways to determine if they are “at risk” for a developmental disability. Therefore, the term “untestable” would normally be used only in cases where the applicant is six years of age or older. Examples of the use of alternative assessments and the consideration of other relevant evidence follow in Section 5 below.

5. Case examples related to eligibility reviews:
  - A. Sixteen year-old Joey is being considered for adult Developmental Disabilities Services (DDS). A psychologist states that Joey is "untestable" because he functions far below the level of adult tests such as the *Wechsler Scales*. Other assessment procedures are then used and they reveal a *Vineland-II* Composite Score of 23, as well as 2 year, 3 month level cognitive skills on the *Brigance*, and teacher interview data indicating Joey has a vocabulary of about ten words, cannot be left unsupervised, and still has toilet accidents. Joey is then deemed eligible for DDS.
  - B. Ten year-old Celeste has been referred for DDS. Celeste has been in three residential services placements for children with an emotional disturbance. The latest psychological evaluation states that Celeste was untestable because she was aggressive to the clinician and threw test materials around the room and at the examiner. Previous records indicate that Celeste was found to have IQ scores of 85-95 at ages five and eight. Celeste is then referred for mental health services and a cognitive evaluation by a psychologist who is experienced in using adapted testing with accommodations for children with mental health difficulties. The purpose of the testing is to rule out any type of cognitive delay. By playing games with Celeste and giving her primary reinforcement (e.g., food and sodas) for cooperative behaviors, the psychologist obtains a Verbal IQ score of 89, a Performance IQ score of 93, and a Full Scale IQ score of 90. Adaptive behavior assessment results reveal a *Vineland-II* Composite score of 77. The Psychologist diagnoses Celeste with Oppositional Defiant Disorder and ADHD, but states that she is not cognitively delayed. Celeste is subsequently found to be ineligible for DDS.
  - C. Ronald has been served in Part C services since age two. At age five, he was diagnosed with severe autism, but no developmental testing was done. At age eight, the school psychologist states that Ronald is not able to socially engage with another person at a level sufficient enough to complete standardized testing. Recent records in the file indicate that Ronald has a *Vineland-II* Adaptive Behavior Composite Score of 51, a *Peabody Picture Vocabulary Test (PPVT)* standard score of 57, and *Battelle Developmental Inventory* age equivalent scores that are all at or below age three. Ronald is deemed eligible for DDS.
6. **Summary** – The points discussed above clearly illustrate that the term “untestable” does not have to be a significant obstacle when considering eligibility for services. The term has the most meaning when it is applied to persons who cannot be evaluated using standardized assessment techniques because they are too severely or profoundly impaired. However, these persons can still be evaluated using the assessment techniques described in numbers one or two above.

**APPENDIX L**

**ELIGIBILITY DETERMINATION FORM**

***FOR DEVELOPMENTAL DISABILITIES SERVICES  
(PERSONS AGE 16 AND OVER)***

**Eligibility Determination Form for  
Developmental Disabilities Services  
(Persons Age 16 and Over)**

<b>Applicant:</b>	<b>Social Security #:</b>
<b>Date of Birth:</b>	<b>Form Completed By:</b>
<b>Date Form Completed:</b>	<b>Parent/Family Contact:</b>
<b>Chronological Age:</b>	<b>Assigned Case Manager:</b>

**PART 1: Background Information**

**A. Summarize Historical Data (NK = not known, NR = not relevant, give date and all past diagnoses that have been received in each area):**

1. Developmental History:
2. Medical History:
3. Educational History:
4. Social History:
5. Mental Health History:
6. Employment History:
7. Previous Services Received:
8. Past Test Results (note if different from current findings):

**B. Review of Current Status and Needs:**

1. Current residential placement and needs:
2. Current employment placement and needs:
3. Other current needs or special problems (social, emotional, medical, legal, case-management, etc.)

Applicant's Initials: \_\_\_\_\_

## **PART 2: Most Recent Assessment Data \***

**A. Intellectual Functioning:**

Date	Instrument	Ability Area	Standard Score	95% Confidence Interval

**B. Adaptive Behavior:**

Date	Instrument	Ability Area	Standard Score	95% Confidence Interval

**C. Academic Skills:**

Date	Instrument	Ability Area	Standard Score	95% Confidence Interval

**\*If person is untestable according to the guidelines of Appendix K, note this here:  Yes**  
**Please document why the person cannot be evaluated using a standardized testing format.**  
**Then go to part 3.**

Applicant's Initials: \_\_\_\_\_

### **PART 3: Documentation of Assessment Data** **for Persons Who are Untestable**

At the bottom of this page, please summarize any of the following kinds of assessment data that are available:

- A. Results of behavior and ability checklists or screening devices to identify skills, strengths, and weaknesses.
- B. Outcome of criterion-referenced assessment procedures.
- C. Measures of receptive or expressive language scales.
- D. Informal assessment by a Case Manager or clinician.
- E. Observation of developmental levels and general functioning (home, school, work).
- F. Review of portfolios of the person's previous work or performance in a variety of settings.
- G. Review of any past records of school achievement (reading, writing, spelling, arithmetic).
- H. Parent interview regarding skills demonstrated at home.
- I. Teacher interview regarding skills demonstrated at school.
- J. Interview with work supervisor regarding skills in a job setting.

**Summary:**

## PART 4: Conclusions From Data

### A. Criteria #1: Documentation of Substantial Disability.

1. **Intellectual Functioning** – Do the person's intellectual deficits cause a substantial disability in terms of daily functioning? Yes No  
Summarize Rationale for Decision:
2. **Adaptive Behavior** – Is this person unable to care for himself/herself (self-care, home living, community use, work skills, etc.) without significant support from caregivers? Yes No  
Summarize Rationale for Decision:
3. **Academic Skills** – Is this person unable to perform functional academic skills (e.g., 4th-5th grade level skills or higher)? Yes No  
Summarize Rationale for Decision:
4. **Does the person have a neurological condition related to intellectual disability which requires treatment similar to that required by persons with intellectual disability?**
  - A. Medical diagnosis of cerebral palsy? Yes No
  - B. Diagnosis of Level 2 or Level 3 autism spectrum disorder? Yes No
  - C. Medical diagnosis of uncontrolled seizures? Yes No
  - D. Other neurological condition similar to intellectual disability and similar treatment? (Please name and describe briefly – attach additional supporting documentation as necessary). Yes No requiring

### B. Criteria #2: Documentation of Onset of Disability and Prognosis.

1. **Did the disability originate before age 18?** Yes No Unable to Verify
2. **Has the disability continued or can be expected to continue indefinitely?**  
Yes No No Conclusion Established

## **PART 5: Final Review of Other Data**

### **(Strengths And Possible Inconsistencies):**

1. Has the person ever lived independently for one year without substantial support from caregivers?

Yes No NK\*

2. Has the person ever supported himself/herself on wages earned through employment?

Yes No NK

3. Are any IQ scores in the low average range or higher (80 or above)?

Yes No NK

4. Are any adaptive behavior standard scores in the low average range or higher (80 or above)?

Yes No NK

5. Are any achievement standard scores in the low average range or higher (80 or above)?

Yes No NK

6. Are several subtest scores (3 or more) within the average range (scaled scores of 8 or higher, standard scores of 90 or higher)? If yes, fill in #7.

Yes No NK

7. If the answer to #6 is yes, list the names and scores for all subtests (cognitive, adaptive behavior, academic achievement) that are within the average range:

<u>Date</u>	<u>Name of Test</u>	<u>Name of Subtest</u>	<u>Subtest Score</u>
-------------	---------------------	------------------------	----------------------

8. If the person has a psychiatric disorder (e.g., schizophrenia, major depression), could it have caused lowered IQ and adaptive test scores? If yes, please explain:

Yes No NK

9. Is the person's preference for services opposed to placement in a program appropriate to persons with developmental disabilities? If yes, please specify:

Yes No NK

10. Does the person show service needs that are different from those provided to persons with a developmental disability?

Yes No NK

11. Are there extenuating circumstances operating in this case which were not adequately addressed above? (If yes, please attach supporting documents.)

Yes No NK

12. Have other program options (besides services for persons with developmental disabilities) been attempted without success? If yes, please give specific information:

Yes No NK

\*NK = Not Known

Applicant's Initials: \_\_\_\_\_

## PART 6: Eligibility Decision

According to the 6th Edition of Determining Eligibility for Services to Persons With Developmental Disabilities in Montana, the review of information in this case indicates that:

<input type="checkbox"/> The person <b>is</b> eligible for services funded by the Developmental Disabilities Program.
<input type="checkbox"/> The person is <b>not</b> eligible for services funded by the Developmental Disabilities Program.
The reasons for this decision are:

**Follow-Up Recommendations:** (Please summarize what is being recommended for the individual following this determination of eligibility):

---

Signature of Person Completing Form \_\_\_\_\_ Date \_\_\_\_\_

---

Print Name and Title \_\_\_\_\_

**APPENDIX M**

**ELIGIBILITY DETERMINATION FORM**  
***FOR DEVELOPMENTAL DISABILITIES SERVICES***  
***(CHILDREN AGES 6-15)***

**Eligibility Determination Form for  
Developmental Disabilities Services  
(Children Age 6-15)**

Child's Name: \_\_\_\_\_ Social Security #: \_\_\_\_\_

Date of Birth: \_\_\_\_\_ Form Completed By: \_\_\_\_\_

Date Form Completed: \_\_\_\_\_ Parent/Family Contact: \_\_\_\_\_

Chronological Age: \_\_\_\_\_ Assigned Case Manager: \_\_\_\_\_

**PART 1: Background Information**

**A. Summarize Historical Data (NK = not known, NR = not relevant, give date and all past diagnoses that have been received in each area):**

1. Developmental History:
2. Medical History:
3. Educational History:
4. Social History:
5. Mental Health History:
6. Previous Services Received:
7. Past Test Results (note if different from current findings):

**B. Review of Current Status and Needs:**

1. Current residential placement and needs:
2. Current school placement and needs:
3. Other current needs or special problems (social, emotional, medical, legal, case-management, etc.)

## PART 2: Most Recent Assessment Data \*

**A. Intellectual Functioning:**

Date	Instrument	Ability Area	Standard Score	95% Confidence Interval

**B. Adaptive Behavior:**

Date	Instrument	Ability Area	Standard Score	95% Confidence Interval

**C. Academic Skills:**

Date	Instrument	Ability Area	Standard Score	95% Confidence Interval

**\*If child is untestable according to the guidelines of Appendix K, note this here:  Yes**  
**Please document why the child cannot be evaluated using a standardized testing format.**  
**Then go to part 3.**

## **PART 3: Documentation of Assessment Data for Children Who are Untestable**

At the bottom of this page, please summarize any of the following kinds of assessment data that are available:

- A. Results of behavior and ability checklists or screening devices to identify skills, strengths, and weaknesses.
- B. Results of informal assessment of play skills.
- C. Outcome of criterion-referenced assessment procedures.
- D. Measures of receptive or expressive language scales.
- E. Informal assessment by a teacher, Family Support Specialist, Case Manager or clinician.
- F. Observation of developmental levels and general functioning (home, school, work).
- G. Review of portfolios of the person's previous work or performance in a variety of settings.
- H. Review of any past records of school achievement (reading, writing, spelling, arithmetic).
- I. Parent interview regarding skills demonstrated at home.
- J. Teacher interview regarding skills demonstrated at school.
- K. Interview with work supervisor regarding skills in a job setting.

**Summary:**

## PART 4: Conclusions From Data

A. **Criteria #1: Documentation of Substantial Disability.**

1. **Intellectual Functioning** – Do the child's intellectual deficits cause a substantial disability in terms of daily functioning? Yes No

Summarize Rationale for Decision:

2. **Adaptive Behavior** – Is this child unable to care for himself/herself (self-care, home living, community use, work skills, etc.) without significant support from caregivers?

Yes No

Summarize Rationale for Decision:

3. **Academic Skills** – Is this child unable to perform functional academic skills (e.g., 4th-5th grade level skills or higher)? Yes No

Summarize Rationale for Decision:

4. **Does the person have a neurological condition related to intellectual disability which requires treatment similar to that required by persons with intellectual disability?**

- |   |                              |                                       |
|---|------------------------------|---------------------------------------|
| A. Medical diagnosis of cerebral palsy?   | <input type="checkbox"/> Yes | <input type="checkbox"/> No           |
| B. Diagnosis of Level 2 or Level 3 autism spectrum disorder?  | <input type="checkbox"/> Yes | <input type="checkbox"/> No           |
| C. Medical diagnosis of uncontrolled seizures?  | <input type="checkbox"/> Yes | <input type="checkbox"/> No           |
| D. Other neurological condition similar to intellectual disability and similar treatment? (Please name and describe briefly – attach additional supporting documentation as necessary). | <input type="checkbox"/> Yes | <input type="checkbox"/> No requiring |

B. **Criteria #2: Documentation of Onset of Disability and Prognosis.**

1. **When was the disability first identified (approximate date):**

If unable to verify, please explain:

2. **Has the disability continued or can be expected to continue indefinitely?**

Yes No No Conclusion Established

## **PART 5: Final Review of Other Data**

### **(Strengths And Possible Inconsistencies):**

Yes    No    NK\* 1. Does the child show a significant number age-appropriate behaviors & abilities?

Yes    No    NK\* 2. Are any IQ scores in the low average range or higher (80 or above)?

Yes    No    NK\* 3. Are any adaptive behavior standard scores in the low average range or higher (80 or above)?

Yes    No    NK\* 4. Are any achievement standard scores in the low average range or higher (80 or above)?

Yes    No    NK\* 5. Are several subtest scores (3 or more) within the average range (scaled scores of 8 or higher, standard scores of 90 or higher)? If yes, fill in #6.

Yes    No    NK \*6. If the answer to #5 is yes, list the names and scores for all subtests (cognitive, adaptive behavior, academic achievement) that are within the average range:

Date	Name of Test	Name of Subtest	Subtest Score

Yes    No    NK\* 7. If the child has a psychiatric disorder (e.g., schizophrenia, major depression), could it have caused lowered IQ and adaptive test scores? If yes, please explain:

Yes    No    NK\* 8. Does the person show service needs that are different from those provided to children with a developmental disability?

Yes    No    NK\* 9. Are there extenuating circumstances operating in this case which were not adequately addressed above? (If yes, please attach supporting documents.)

\*NK =Not Known

Applicant's Initials: \_\_\_\_\_

## PART 6: Eligibility Decision

According to the 6th Edition of Determining Eligibility for Services to Persons With Developmental Disabilities in Montana, the review of information in this case indicates that:

- The child **is** eligible for services funded by the Developmental Disabilities Program.
- The child is **not** eligible for services funded by the Developmental Disabilities Program.

The reasons for this decision are:

**Follow-Up Recommendations:** (Please summarize what is being recommended for the child/family

following this determination of eligibility):

---

Signature of Person Completing Form

Date

---

Print Name and Title

# **APPENDIX N**

## **Montana's DDP Eligibility Determination Procedures**

Following is a summary of the eligibility determination process for Developmental Disabilities Services (DDS) in the State of Montana:

1. An Eligibility Specialist (ES) will make an initial decision based on the guidelines in this Manual and completing the appropriate Eligibility Determination Form from either Appendix L or M.
2. The Eligibility Specialist then issues a notice of decision that states the determination that has been made and the basis for the determination. The notice also provides instructions for how a family may contest the determination through the fair hearing process available at the Department Of Public Health And Human Services Office Of Fair Hearings.
3. If the family is not in agreement with the eligibility decision of the Eligibility Specialist, they may submit in writing to the Department Of Public Health And Human Services Office Of Fair Hearings a request for a fair hearing.
4. Once a request for a fair hearing is made, the Developmental Disabilities Program (DDP) will provide the family with an opportunity to participate in an administrative review during which the family will be able to present their reasons for contesting the decision that has been made by the Eligibility Specialist.
5. If the family remains unsatisfied after the administrative review, the matter will continue to fair hearing.
6. The Office Of Fair Hearings can provide information, including reference to the governing administrative rules, concerning the request for and the process of conducting an administrative fair hearing.

## APPENDIX O

### CASE STUDIES

**NOTE:** The following case studies provide some specific examples for using the eligibility determination process described in this Manual.

1. The Case of Michael. Michael was born with hydrocephalus. A scan of his head revealed that he had “no brain” at birth because it was totally compressed like a sponge by the pressure of the fluid in his head cavity. It was also noted that Michael had “no frontal lobes and no corpus collosum.” Over the years, Michael had 14 brain surgeries and six shunt revisions. He was in and out of the hospital until the end of his first year of life. He showed significant motor and language delays of about one year during his first three years of life, and he was served in the Children’s Waiver Services (CWS) program until age 9. At age four, he was given the Stanford-Binet, with the following scores obtained:

#### **Stanford-Binet Intelligence Scale: Fourth Edition – Age 4**

Ability Area	Standard Score	Percentile Rank
Verbal Reasoning	93	33
Abstract/Visual Reasoning	88	23
Quantitative Reasoning	78	8
Short-Term Memory	73	5
TEST COMPOSITE	80	11

\*The Standard Scores for the Ability Areas are based on a mean of 100 and a standard deviation of 16.

At age six, he was given the WISC-III, with the following scores obtained:

#### **WISC-III – Age 6**

Summary Scores	IQ/Index Score	Percentile Rank	95% Confidence Interval
Verbal IQ Score	95	37	89-101
Performance IQ Score	77	6	71-87
Full Scale IQ Score	85	16	80-91
Verbal Comprehension Index	106	66	99-112
Perceptual Organization Index	77	6	71-88
Freedom from Distractibility	72	3	66-85
Processing Speed Index	83	13	76-95

At age six, he was also given the Vineland Adaptive Behavior Scales (1984 version) with the following scores obtained:

**Vineland – Age 6**

Domain	Standard Score	95% Confidence Interval	Percentile Rank
Communication	65	55-75	1
Daily Living Skills	59	49-69	.3
Socialization	61	49-73	.5
Motor Skills	46	30-62	<.1
ADAPTIVE BEHAVIOR COMPOSITE	53	40-60	.1

At age nine, he was given the WISC-IV, with the following scores obtained:

**WISC-IV – Age 9**

Composite Index Scale	Composite Score	Percentile Rank	95% Confidence Interval
Verbal Comprehension (VCI)	102	55	95-109
Perceptual Reasoning (PRI)	90	25	83-98
Working Memory (WMI)	91	27	84-99
Processing Speed (PSI)	94	34	86-104
Full Scale IQ (FSIQ)	93	32	88-98

Finally, at age 9, Michael was also given the ABAS-II, with the following scores obtained:

**ABAS-II – Age 9**

Adaptive Behavior Area	Composite Score	Percentile Rank	95% Confidence Interval
Conceptual	85	16	79-91
Social	89	23	83-95
Practical	74	4	67-81
GENERAL ADAPTIVE COMPOSITE	83	13	77-89

Other information of note includes Michael being significantly under weight and showing growth retardation. He still requires a feeding tube at age 11. Michael has many special needs. The question is: *Does he continue to be eligible for services to persons with a developmental disability in the state of Montana?*

**Eligibility Decision:** Michael showed a high risk for being developmentally disabled as an infant and preschooler. Accordingly, he received appropriate services in Part C and Children's Waiver Services (CWS). However, at age 9, Michael demonstrated evidence of dramatic progress and the decision was that he was no longer eligible for DDP services to children on the basis of a developmental disability. Both IQ scores (e.g., Full Scale IQ = 93) and adaptive behavior scores (e.g., Adaptive Behavior Composite = 83) were well beyond the usual cut-off point for identifying a developmental disability. Therefore, Michael was referred to (and later accepted by) the Physical Disability (PD) waiver program.

- 2, **The Case of Joe.** Young Joe showed normal developmental milestones during his first year. At age two, he was thought to be "all boy." By age three he was "into everything and wouldn't mind." At age five, Joe went to kindergarten, but showed significant behavior problems. He was referred for a possible Special Education placement, but his Child Study Team decided that he did not meet Montana guidelines. In fact, most developmental milestones were judged to be grossly within normal limits at age five. However, Joe showed risk factors for ADHD and his behavior was noted to be both impulsive and non-compliant. At age 5, he received a Verbal IQ score of 87, a Performance IQ score of 91, and a Full Scale IQ score of 89. By age seven, Joe was evaluated by his pediatrician and put on stimulant medication for ADHD. At age 12, Joe was re-evaluated by his Child Study Team and found to have a specific learning disability in reading and written language. His math skills were borderline. Cognitive testing at age 13 revealed a Verbal IQ score of 84, Performance IQ score of 87, and Full Scale IQ score of 85 on the WISC-III.

At age 17, Joe was re-evaluated by school personnel in order to transition him into adult services. Referrals were made to both vocational rehabilitation services and the developmental disabilities programs. At age 17, Joe received a Verbal IQ score of 74, a Performance IQ score of 79, and a Full Scale IQ score of 75. His Adaptive Behavior Composite on the Vineland-II was 78. *Is Joe eligible for services to persons with a developmental disability in the state of Montana?*

**Eligibility Decision:** Although Joe's IQ scores have dropped considerably over the last five years, his test scores for both intelligence and adaptive behavior are still higher than the criteria used by DDP to meet the state definition of a developmental disability. It is also interesting to note that neither Joe nor his parents think that he is intellectually disabled.. Accordingly, Joe was referred for Vocational Rehabilitation services.

3. **The Case of Anna.** Anna was born with the umbilical cord wrapped around her neck. She also had to have her tongue clipped. Her mother reports that she crawled, walked, and talked within normal limits compared to her age group. At age seven, Anna was referred to see if she was eligible for services to children with developmental disabilities. At that time, she presented with the following clinical picture:
- A. A seizure disorder that was described as “generalized absence epilepsy.”
  - B. ADHD, combined type.
  - C. Bi-Polar Disorder, type I, mixed episode.
  - D. History of enuresis and encopresis, both of which responded well to a toileting program.
  - E. Rule out learning disability.
  - F. Rule out receptive-expressive language disorder.
  - G. Rule out Tourette’s Disorder.

Anna’s medical records also indicate that her major problems are related to oppositional behaviors and non-compliance, frequent mood swings and temper tantrums, and extreme hyperactivity and short attention span. In addition, her physician reports that Anna’s seizures have not yet been controlled. She has had difficulty tolerating anti-convulsant medication.

During standardized testing on the *WISC-IV* at age seven, Anna earned a Verbal Comprehension Index score of 75 (5<sup>th</sup> percentile), and a Perceptual Reasoning Index score of 88 (14<sup>th</sup> percentile). Her Processing Speed Index Score was 68 (1<sup>st</sup> percentile), while her Working Memory Index score was 72 (3<sup>rd</sup> percentile). The Full Scale IQ score was 77 (6<sup>th</sup> percentile).

On the *Woodcock Johnson - III*, Anna earned a standard score of 57 for Broad Reading, 73 for Broad Math, 57 for Broad Written Language, 88 for Oral Language, and 84 for Academic Knowledge. Anna is said to be a major challenge to her parents. School personnel are considering evaluating her for autism spectrum disorder. She obviously has many special needs. *Is Anna developmentally disabled?*

**Eligibility Decision:** The Eligibility Specialist felt that Anna would probably not meet eligibility guidelines for a developmental disability. However, there was no adaptive behavior data to review on this case. In addition, available medical records did not clarify the impact of Anna’s “uncontrolled” seizures in terms of prognosis, frequency or intensity. Therefore, it was recommended Anna be referred to her neurologist to obtain more information about her epilepsy using Chapter 8 guidelines. It was also recommended that an adaptive behavior assessment be provided before making a formal eligibility decision.

4. **The Case of Susan.** Susan is 27 years of age. She was exposed to drugs and alcohol in utero, and she was a victim of neglect as an infant. She was subsequently adopted by a caring family at nine months of age. She received developmental disabilities children’s

services from the state of Montana until she was six years old. At that time, her ICAP scores were found to be in the 80's to low 90's and a determination was made that she did not have a developmental disability. At age 14, Susan was found to have a Verbal IQ score of 82, a Performance IQ score of 77, and a Full Scale IQ score of 77 on the WISC-III. At age 16, she was given the Wechsler Abbreviated Scale of Intelligence (WASI), which is designed to be a screening test for intelligence. On the WASI, Susan obtained a Verbal IQ score of 88, a Performance IQ score of 89, and a full Scale IQ score of 88. All three of these scores are in the low average range. Also at age 16, Susan was given the WRAT-III, with standard scores reported to be 94 for Reading, 93 for Spelling, and 59 for Arithmetic. Adaptive behavior scores at age 16 on the ICAP were consistently low. Obtained standard scores were 47 for Motor, 50 for Social/Communication, 25 for Personal Living, 28 for Community Living, and 19 for Broad Independence.

The most recent diagnoses for Susan were made by a neuropsychologist and involved the following diagnostic impressions:

1. Asperger's Disorder
2. Bi-Polar Disorder, most recent episode depressed (severe, with psychotic features)
3. Attention Deficit Hyperactivity Disorder (combined type)
4. Specific Learning Disability in Mathematics

At the time Susan was referred for adult services through the Developmental Disabilities Program (DDP), she was placed in an out-of-state residential treatment facility in Colorado. Her reports indicate significant maladaptive behaviors that have included stealing, head banging, safety violations, threats to others, non-compliance, and anger management difficulties. Susan's out-of-state treatment team recommended that she receive 24-hour supervision and support in a structured therapeutic environment. Susan's adoptive parents want her to receive services through DDP. They are pleading for help when Susan returns to live with them in the near future. *Is Susan eligible for services to persons with a developmental disability in the state of Montana?*

**Eligibility Decision:** The Eligibility Specialist felt that a comprehensive adaptive behavior assessment with the Vineland-II (Survey Interview Form) would have been preferable to the obtained results with the ICAP. However, given the available data, the team noted that Susan's IQ and achievement test scores were too high to warrant eligibility for DDP services.

5. **The Case of Nathan.** Nathan was thought to be a normal child from birth to age five. In kindergarten his teacher noted that he sometimes showed "odd" behaviors. He subsequently was socially awkward and had some difficulty establishing and maintaining consistent social relationships. In fourth grade, Nathan was referred to his Child Study Team to determine if he should receive Special Education services. He was not deemed eligible for Special Education, though his team noted that "Nathan has the ability to be successful in school if he would consistently apply himself." Nathan was noted to

daydream frequently and to have difficulty completing assignments. Study skills were noted to be poor. At this time, psychometric scores on the *WISC-III* included a Verbal IQ score of 95, a Performance IQ score of 87, and a Full Scale IQ score of 91.

At age 16, Nathan began using inhalants such as glue, gasoline, and paint thinner. At that time, he showed significant regression and deterioration in all aspects of his behavior and adjustment. He began to experience auditory hallucinations and to have paranoid delusions. Nathan’s treating psychiatrist diagnosed him to have a substance-induced psychotic disorder related to his use of inhalants. However, the psychiatrist also used a “rule out” diagnosis of Schizophrenia, paranoid type. Subsequent psychometric testing by a psychologist resulted in a Verbal IQ score of 72, a Performance IQ score of 65, and Full Scale IQ score of 69. The evaluating psychologist also administered the Survey Interview Form from the *Vineland-II*. Scores obtained on the *Vineland-II* were as follows:

<b>Adaptive Behavior</b>	<b>Composite Score</b>	<b>Percentile Rank</b>	<b>95% Confidence Interval</b>
Communication	74	4	67-81
Daily Living Skills	63	1	56-70
Socialization	65	1	58-72
<b>ADAPTIVE BEHAVIOR COMPOSITE</b>	<b>68</b>	<b>2</b>	<b>62-74</b>

Nathan has now dropped out of school and is no longer capable of meeting normal school academic demands. Nathan’s parents are at their wit’s end. They have consistently administered several anti-psychotic medications prescribed by Nathan’s psychiatrist, but no significant improvement in his mental health status has been forthcoming in the past year. Nathan is now showing significant anger outbursts that involve both verbal threats and some aggressive behaviors that are causing increasing concerns to Nathan’s parents. They feel their son needs 24-hour care and supervision and they would like to have Nathan considered for a group home for young adults with developmental disabilities. *Is Nathan eligible for these kinds of services provided by DDP in the state of Montana?*

**Eligibility Decision:** The Eligibility Specialist who reviewed this case noted the unusual fact that Nathan seemed to be responsible for causing his own disability. However, the ES felt that Nathan was very close to meeting Montana guidelines for a developmental disability. In addition, he also appears to meet guidelines for a traumatic brain injury utilized by the Physically Disabled (PD) waiver program. Ultimately it was decided to refer Nathan for an independent evaluation to review his status in regards to whether he had significant functional limitations in 3 or more areas of a major life activity (see I-C, in Appendix I) and if he had treatment needs similar to those required by a person with an

intellectual disability (see I-F in Appendix D).

6. **The Case of Janet.** Janet was born with the umbilical cord wrapped around her neck and she did require some oxygen to assist her with respiratory distress at birth. She was served in programs for children at risk for a developmental disability in another state. When she moved to Montana at age six, her case manager sent a letter to the local Child and Family Services agency stating that Janet should be included in services for children with a developmental disability in order to maintain the continuity of her programs. The letter included a brief psychologist's report that gave only three scores from the WPPSI-III as follows: Verbal IQ score of 67, Performance IQ score of 69, and Full Scale IQ score of 68. *Should Janet be deemed eligible for services for children with developmental disabilities in the state of Montana?*

**Eligibility Decision:** Despite showing scores consistent with an intellectual disability on an IQ test, the Eligibility Specialist concluded that no eligibility decision could be made until an adaptive behavior assessment for Janet has been provided. If the results of the adaptive behavior assessment were consistent with the intelligence testing, then eligibility for DDP services might well be established.

7. **The Case of Marsha.** Marsha was born full-term with no complications noted. Her developmental milestones were generally ahead of schedule during her preschool years. During her primary and junior high years, she earned nearly straight A's. Her standard scores on group achievement tests were generally at or beyond the 90<sup>th</sup> percentile. At age 14, Marsha began to show deterioration in both her mental and physical functioning. She had difficulty completing school assignments and her physical coordination began to regress. Because Marsha had two known relatives with Huntington's Disease, she was tested for this disorder and the results were positive. By age 17, Marsha was already showing a dramatic decrease in her abilities in virtually all areas. She was referred to a psychologist who diagnosed a "dementia due to Huntington's Disease" (294.1). The psychologist also reported a Verbal IQ score of 65, a Performance IQ score of 72, and a Full Scale IQ score of 69 on the WAIS-III. No adaptive behavior results were provided, but a Quality Improvement Specialist (QIS) assigned to Marsha's case administered a Vineland-II (Survey Interview Form) with Marsha's parents. Obtained results revealed a standard score for Communication of 79, a standard score of 63 for Daily Living Skills, a standard score of 72 for Socialization, and an Adaptive Behavior Composite standard score of 70. Marsha's parents are desperately looking for services that would be helpful for their daughter. *Is Marsha eligible for DDP services in Montana?*

**Eligibility Decision:** The Eligibility Specialist determined that both the current test scores and the progressive nature of Huntington's Disease were sufficient to meet Montana guidelines for a developmental disability. Marsha was referred back to her case manager to seek appropriate services.

8. **The Case of Jack.** Jack was diagnosed with Down Syndrome (Trisomy 21) a few days after his birth. He was involved in Part C programs as an infant and toddler on an "at

risk” basis. At age 3 he was evaluated by a school psychologist who completed a WPPSI-III in which all obtained standard scores were below 60. The Verbal Comprehension Index score was 53 and the Full Scale IQ score was 57. In addition, a Vineland-II Survey Interview Form at age 3 revealed an Adaptive Behavior Composite score of 51, with no significant scatter. At age 7, Jack began having significant cardiac complications based on a congenital heart defect. His parents reapplied for Children’s Waiver Services at this time. No additional formal standardized testing had been completed since age 3 because the school psychologist noted during the IEP process at age 6 that no change in cognitive abilities or adaptive behavior skills had taken place since age 3. Screening with the Brigance Inventory revealed age equivalent scores of 3 or lower in all areas at age 6. *Is Jack eligible for Developmental Disabilities Program (DDP) services?*

**Eligibility Decision:** The Eligibility Specialist noted that Jack’s records were older than the usual guidelines that apply for children (see Chapter 9). However, this was a case where common sense prevailed and the final decision was that Jack obviously continues to be developmentally disabled and is eligible for all DDP services.

9. **The Case of Herman.** At age 17, Herman was referred for consideration of DDS with a DSM-IV diagnosis of an Autistic Disorder (299.00). School testing records revealed a WAIS-IV Full Scale IQ score of 77 and a Vineland-II Adaptive Behavior Composite of 70. The Verbal Comprehension Index score was 105, while the Perceptual Reasoning Index score was 78. The Working Memory Index score was 77, while the Processing Speed Index score was 68. The Eligibility Specialist referred Herman for a psychological evaluation to see if he met DSM-5 guidelines for a Level 2 rating in the areas of social communication and restricted and repetitive behaviors (See DDP policies for autism eligibility in Appendix I). The psychologist in this case was not asked to repeat the recent testing that had been completed by a school psychologist. Results of the independent evaluation revealed a Level 1 severity rating for social communication and a Level 2 rating for restricted and repetitive behaviors. The psychologist noted that Herman was fairly competent in the verbal and social interaction areas (consistent with the previous IQ testing), but did have rigid expectations for inflexible routines and would not let anyone come into his room for fear that they might change or move an object. It was also reported that Herman would cover his ears in public if sounds related to normal traffic were heard. *Does Herman meet Montana guidelines for a developmental disability?*

**Eligibility Decision:** The Eligibility Specialist noted that Herman’s intelligence test scores were above the range that would fit an intellectual disability based on DDP guidelines (see Appendix I). The Eligibility Specialist also stated that the Appendix I requirement for a Level 2 rating for social communication had not been met. The records indicated that Herman’s overall level of functioning was clearly above the level of a person with an intellectual disability, which is the criterion that should be met for autism, cerebral palsy, epilepsy, or other neurological conditions that would qualify for Developmental Disabilities Services (DDS). Therefore, eligibility for these services was denied and Herman was referred for vocational rehabilitation program options.