

**Determining Eligibility
for Services to Persons
With Developmental
Disabilities in Montana:
A Staff Reference Manual
(5th Edition – 2011)**

By William Cook, Ph.D.

TABLE OF CONTENTS

	<u>Page No.</u>
Preface	1
CHAPTER 1: Labeling, Classification, and Historical Issues Regarding Mental Measurements and Psychological Testing	3
CHAPTER 2: What is a Developmental Delay?	7
CHAPTER 3: Description of Psychological Test Instruments	9
CHAPTER 4: Clinical Definitions of Disabilities	23
CHAPTER 5: Neurological Disorders	30
CHAPTER 6: Autism Spectrum Disorders	37
CHAPTER 7: Issues in Dual Diagnosis (Developmental Disabilities & Psychiatric Disorders)	44
CHAPTER 8: Techniques to Enhance the Referral Process	52
CHAPTER 9: Making the Eligibility Decision	55
APPENDIX A: Definitions for Statistical Measures and Terms	60
APPENDIX B: Table of Percentile Ranks	65
APPENDIX C: Table of Percentile Ranks for Subtest Scores	66
APPENDIX D: Classification of I.Q. Test Scores	67
APPENDIX E: American Association on Intellectual and Developmental Disabilities (AAIDD) – 2002 Definition of Mental Retardation and Related Materials	68
APPENDIX F: State of Montana Definition of a Developmental Disability	75
APPENDIX G: List of Web Sites for Autism Information	76
APPENDIX H: Federal Definition of a Developmental Disability	77
APPENDIX I: Understanding the Meaning of the Term “Untestable”	78
APPENDIX J: Eligibility Determination Form (Adults)	81
APPENDIX K: Eligibility Determination Form (Children)	88
APPENDIX L: Case Studies	95

PREFACE

This book is the fifth edition of a training manual that was first written and used in workshops in 1989. The current revision involves only minor changes needed to update the 2007 version, primarily in regard to the issue of a client being deemed “untestable” (see page 2). It is hoped that the current manual will 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 (e.g., DSM-IV-TR 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. Provide a working understanding of autism spectrum disorder.
8. Improve our knowledge of dual diagnosis issues.
9. Complete a clinical decision-making worksheet in order to determine whether or not a prospective client meets Montana guidelines regarding eligibility for services to persons with developmental disabilities.

As I noted in 1996, these kinds of goals are ambitious. To achieve them, the interested reader should attend a training workshop and be willing to read and study the manual in detail. After directed effort, a motivated workshop participant should be able to accomplish the above goals.

The development of the clinical decision-making process for determining eligibility has been the result of much collaboration. I would like to thank all of the people across the state of Montana who contacted me with their suggestions and feedback for the Clinical Decision-Making Worksheets. Peggy Moses was particularly helpful on several occasions. Special thanks also go to Perry Jones, who has provided much needed technical and programmatic support for this project. Our e-mails could fill a second manual, and they would likely make interesting reading regarding some of the

many challenges that are seen in the area of determining eligibility. Finally, I want to thank Denise Watkins, who was responsible for all of the typing, graphics, and formatting of this manuscript. Her outstanding skills, unending patience, and much-needed creativity were invaluable. Without Denise this reference manual would not exist. Many, many thanks!

Since the 2007 edition of this manual, people across the state of Montana have reported an increase in the number of clients who have been found to be “untestable” when referred for psychological evaluations. One factor in this regard may be the increasing number of children on the autism spectrum, since these clients present significant challenges to clinicians attempting to use a standardized testing format. The 2011 revision of this manual was undertaken primarily to resolve this issue. Accordingly, Appendix I was added to the manual in order to provide an in-depth understanding of the meaning of the term “untestable”. Appendix I helps us to see that being “untestable” is not the end of a testing process, but rather the beginning of an alternative assessment approach utilizing a variety of informal and less standardized measures that still provide a good picture of the client’s skills and abilities across a wide variety of areas. Psychologists can be asked to use informal procedures to take the place of standardized tests, or they can be utilized to review assessment and program data that has already been gathered in order to answer basic questions regarding eligibility for services (e.g., see Chapter 9, and pages 4-5 of Appendices J and K). New protocols for incorporating non-standardized testing information into the Eligibility Determination forms have now been written for both children and adults (see Appendices J and K). Finally, three revised standardized assessment instruments are now described in Chapter 3 (i.e., *WAIS-IV*, *DAS-II*, *CTONI-2*).

I hope the current revisions help to resolve the dilemma of clients being “untestable”. There is no one, perfect way to resolve these kinds of challenges. Each case is unique. Five editions of this manual now give us a clear perspective that determining eligibility is a process, and the journey goes on and on.

Finally, please remember that it was never intended for you to memorize this manual. I hope you will keep it on your desk (or on your computer) 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 below.

William Cook, Ph.D.
T-214 Fort Missoula
Missoula, MT 59804
E-mail: drbillcook@gmail.com

July 1, 2011

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 developmental disabilities 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 2007, we are still struggling to find appropriate ways to deal with definitions and nomenclature for persons who have disabilities.

Many 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.
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, government must put some limits on who gets special services and who does not. At that point, Quality Improvement Specialists 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 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.

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:

$$\text{I.Q.} = \frac{\text{MA}}{\text{CA}} \times 100$$

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.

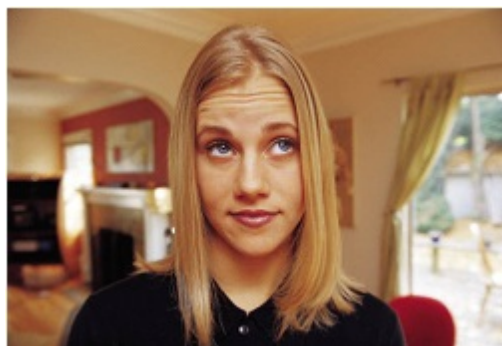
Some theories have attempted to portray intelligence as primarily a unitary phenomenon (a general factor of intelligence), while others have emphasized very specific factor analyses in order to identify specific intellectual skills such as verbal fluency, quantitative reasoning, speed of reactions, and 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 I.Q. scores. Genetically related individuals raised apart have highly correlated I.Q.'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 I.Q. 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 I.Q. scores was due to genetic factors. Of even more interest is the current thinking that environmental conditions can affect I.Q. scores by about 20-25 points. Thus, a young child functioning in the mildly mentally retarded 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 I.Q. 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 Native American client 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 I.Q. 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 on 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 and teaching.
- ✓ Intelligence tests should be as culture fair as possible, though this can be an elusive goal in some circumstances.

References

Bouras, N. (Ed.). (1999). Psychiatric and Behavioural Disorders in Developmental Disabilities and Mental Retardation. Cambridge, UK: Cambridge University Press.

Cook, J.W., & Wollerhseim, J.P. (1976). The effect of labeling of special education students on the perception of contact versus no-contact normal peers. Journal of Special Education, 10 (2), 187-198.

Cook, J.W. (1976). A factorial study of the effects of labeling, appearance and behavior on adolescents' perception of the mentally retarded. Unpublished doctoral dissertation, University of Montana.

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 is significant. 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 guidelines specify what cut-off points can be useful for determining when a particular milestone is significantly slow or delayed:

<p>A. Gross Motor Skills:</p> <ul style="list-style-type: none"><input type="checkbox"/> 1. Child is not able to sit independently by nine months.<input type="checkbox"/> 2. Child is not walking independently by 19 months of age.<input type="checkbox"/> 3. Motor assessment standard scores of 75 or lower.
<p>B. Speech and Language Skills:</p> <ul style="list-style-type: none"><input type="checkbox"/> 1. The child is not talking at all by age two.<input type="checkbox"/> 2. There are no sentences by age three.<input type="checkbox"/> 3. Communication assessment standard scores of 75 or lower.
<p>C. Cognitive Development:</p> <ul style="list-style-type: none"><input type="checkbox"/> 1. Child has I.Q. scores on a standardized test of intelligence that are 75 or lower.
<p>D. Self Help Skills:</p> <ul style="list-style-type: none"><input type="checkbox"/> 1. Not able to feed self with spoon and fork by age three.<input type="checkbox"/> 2. Not toilet trained by age four.<input type="checkbox"/> 3. Not able to dress self by age five.<input type="checkbox"/> 4. Adaptive behavior assessment standard scores of 75 or lower.
<p>E. Social Skills:</p> <ul style="list-style-type: none"><input type="checkbox"/> 1. Lack of interest in social relationships by age two.<input type="checkbox"/> 2. Inability to make friends within peer group by age six.<input type="checkbox"/> 3. Social skills assessment standard scores of 75 or lower.
<p>F. Educational Skills:</p> <ul style="list-style-type: none"><input type="checkbox"/> 1. Child's grade level performance is delayed by at least three years in reading, arithmetic, and written language after age 10 (fourth grade).<input type="checkbox"/> 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. For an adult to meet the standard of demonstrating a significant developmental delay that is manifest before age 18, there should be checks indicating delays in all or nearly all of the above areas. 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 I.Q. scores can be fairly confusing. Appendix D shows the cut-off points for both I.Q. scores and percentile ranks for the various categories of cognitive development. Thus, an I.Q. score of 90-109 is average, while an I.Q. 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 I.Q. score in a psychological evaluation report, you can look it up in Appendix D and determine its meaning.

Summary Points to Remember

- ✓ The developmental history for persons who are eligible for services because of developmental disabilities will normally show significant delays in most skill areas (with the possible exception of motor skills).
- ✓ A developmental disability is a generalized delay in development.
- ✓ Based on the classification table from Appendix D, an I.Q. score of 92 is average, while an I.Q. 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 client.

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 I.Q., a Verbal I.Q., and a Full Scale I.Q. 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 I.Q. score or a Performance I.Q. score. Rather, it uses four Index scores and a Full Scale I.Q. 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 client’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 I.Q. Score – As a global summary, the Full Scale I.Q. Score provides a measure of the client’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 I.Q. 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 I.Q. 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 I.Q. 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-III noted above, except that the item content is geared towards children in the 6-16 year range. Like the *WAIS-III*, 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-III*. The other index scores are also very similar (Verbal Comprehension, Working Memory, Processing Speed) to the index scores described above for the *WAIS-III*. 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 - Third Edition (WPPSI-III)*. The *WPPSI-III* provides a measure of intelligence for children in the age range from two years, six months up to seven years, three months. The *WPPSI-III* provides the same general type of information noted with the other Wechsler scales described above (Verbal, Performance, and Full Scale I.Q. scores all based on a mean of 100 and a standard deviation of 15). In addition, it provides a measure of General Language development as a separate standard score.
- 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 client'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 I.Q. 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 - Non-Verbal

- A. *Comprehensive Test of Non-verbal 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.

- 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 client 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 II, 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), and the Battelle Developmental Inventory - Second Edition. 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 client's eligibility for services in the area of developmental disabilities unless a client 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 I 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 client 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 client demonstrates low average or borderline deficits, then further diagnostic testing would certainly be indicated to provide a more comprehensive assessment. If a client has a long history of significant developmental delays (e.g., I.Q. scores of 50-55), then it might be appropriate to use a *KBIT-2* just to confirm that the client is still functioning at the same basic level.

- C. *Wechsler Abbreviated Scale of Intelligence (WASI)*. The purpose of the *WASI* 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 89. 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*. Again, the *WASI* could be useful for clients who are thought to have intellectual abilities that are average (or above), or cognitively delayed at a moderate level or lower. The *WASI* is not able to 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 individuals 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 individuals. 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 client'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 client.
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 a 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 C 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 B 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 client'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 I.Q. scores from the cognitive testing in order to see if consistent delays are noted in both areas. It also has subtest scores for the Subdomain areas called v-scale scores that 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. This format can be helpful in cases that might involve factors such as reading difficulties, cognitive limitations, or caregiver bias. If these issues are not thought to be 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 late 2007, the *Vineland-II* will also provide an Expanded Interview form, which should yield 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 clients 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.

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 - Second Edition (WIAT-II). The WIAT-II is appropriate for persons in the age range from 4 to 85. The WIAT-II was designed to provide direct comparisons with all of the various Wechsler intelligence scales. The WIAT-II samples oral expression, written comprehension, and basic academic skills related to reading, arithmetic, and written language.
- D. Wide Range Achievement Test - 3 (WRAT-3). The WRAT-3 provides a quick screening for identifying achievement skills for reading sight words, spelling from dictation, and doing arithmetic computation. The test administration takes 15-30 minutes and is appropriate for persons in the age range from 5 to 75.
- 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 (ADOS)*. The *ADOS* was published in 2001 by Dr. Catherine Lord. It allows clinicians to assess and diagnose autism or pervasive developmental disorder across ages (toddlers to adults), developmental levels, and language skills (no speech to reciprocal conversational skills). Administration test time is 35-40 minutes. The *ADOS* 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* to be the state-of-the-art assessment instrument for autism.
- D. *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.).
- E. The *Childhood Autism Rating Scales (CARS)*. The *CARS* provides a rating of a child's behavior 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. Again, this scale should be used in conjunction with other procedures in an overall comprehensive evaluation of the child.

- F. 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.
- G. 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. The scales are based on DSM-IV categories.
- H. 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.
- I. Gilliam 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.
- J. 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.

IX. New Developments – Without trying to look into a crystal ball, it seems possible that the next few years will result in a decrease in our emphasis on standardized testing, particularly in the public school system. There are movements currently under way that are designed to use alternatives to standardized tests, especially for students with a learning disability. An example of one of the best known alternatives is “Response to Intervention” (RTI). RTI could be viewed as a diagnostic prescriptive approach that is basically designed to avoid labeling a student as having a learning disability. Thus, if a student has academic delays, they would be given one or more research-validated interventions. Progress would then be carefully monitored in order to see if the student is able to catch up to their peers. If the student is not able to make grade level progress (especially at the level of improvement suggested by the research findings), then this could be viewed as de facto evidence of a learning disability. There are some nice advantages to the RTI approach. First of all, schools are able to intervene early with children who are struggling in school. In addition, RTI can document which types of instructional strategies are most effective with a specific student. The 2004 IDEA legislation allows schools to use some of their federal funds to support students with special needs before they are identified as learning disabled. RTI is one model that will be utilized in this process. Some school districts may decide to implement RTI for some of their students, but my understanding is that they will not be forced to do so by either the state or federal government. At this point, it appears that assessment procedures used to identify students who have cognitive delay, autism, or preschool developmental delays will basically stay the same as they are now (generally relying on standardized testing procedures wherever possible).



Summary Points to Remember

- ✓ The tests described in this chapter are not a list of approved tests.
- ✓ Clinicians use clinical judgment to determine which test is appropriate for each particular client.
- ✓ 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.
- ✓ Screening measures should normally not be used to make a diagnosis unless a client is “untestable” (See Appendix I).



CHAPTER 4

CLINICAL DEFINITIONS OF DISABILITIES

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

- I. **MENTAL RETARDATION** – Diagnostic and Statistical Manual of Mental Disorders - Fourth Edition - Text Revision (DSM-IV-TR). The DSM-IV-TR establishes three criteria for mental retardation as follows:
- A. Significantly sub-average general intellectual functioning (an I.Q. of approximately 70 or below on an individually administered I.Q. test). The level of severity for each diagnosis is listed in the table below.
 - B. Concurrent deficits or impairments in present adaptive functioning (the person's effectiveness in meeting the standards accepted for his or her age by his or her cultural group) in at least two of the following areas: communication, self care, home living, social/interpersonal skills, use of community resources, self direction, functional academic skills, work, leisure, health, and safety.
 - C. Onset before age 18. (See Appendix H for federal definition, which extends the age to 22).

Level of Severity of Mental Retardation	I.Q. Levels
Mild Mental Retardation	50-55 to approximately 70
Moderate Mental Retardation	35-40 to 50-55
Severe Mental Retardation	20-25 to 35-40
Profound Mental Retardation	Below 20 or 25
Mental Retardation, Severity Unspecified	This diagnosis is used when there is a strong presumption of mental retardation but the person's intelligence is untestable by standardized tests. See Appendix I for more information on the meaning of the term "untestable".



CAUTIONARY NOTE: There is a measurement error of approximately five points in assessing I.Q. Thus, a person can be diagnosed to be mentally retarded with an I.Q. score as high as 75 if they have significant deficits in adaptive behavior. On the other hand, mental retardation would not be an appropriate diagnosis for an individual with an I.Q. score lower than 70 if there are no significant impairments in adaptive behavior.

By way of comparison, the American Association on Mental Retardation (AAMR) established their most recent definition of mental retardation in 2002. Please see Appendix E for a complete review of AAMR's position on this issue. Their definition is similar to the DSM-IV-TR diagnosis (but without specifying I.Q. score cut-off points). Finally, it is also interesting to note that in 2007 AAMR changed its name to the American Association on Intellectual and Developmental Disabilities (AAIDD).

II. **PERVASIVE DEVELOPMENTAL DISORDERS** - These are characterized by severe and pervasive impairments in several areas of development. The DSM-IV-TR categories are listed below:

- A. ***Autistic Disorder*** - These individuals have a qualitative impairment in social interaction, a significant impairment in communication, and restricted, repetitive and stereotyped patterns of behavior, interests, and activities. The developmental delays and abnormal functioning are noticeable prior to age three. See Chapter 6 for a full description of this topic.
- B. ***Rett's Disorder*** - These children have normal prenatal and perinatal development, apparently normal psycho-motor development through the first five months after birth, and normal head circumference at birth. Later, they show a deceleration of head growth between ages five and 48 months, a loss of previously acquired purposeful hand skills between age five and 30 months (with a subsequent development of stereotypic hand movements), a loss of social engagement early in the course (although often social interaction develops later), the appearance of poorly coordinated gait or trunk movements, and severely impaired expressive and receptive language development with severe psychomotor retardation. Rett's Disorder has been diagnosed only in females and the characteristic pattern of head growth deceleration is one of the primary diagnostic criterion.
- C. ***Childhood Disintegrative Disorder*** - The essential feature of this disorder is a marked regression in multiple areas of functioning following a period of at least two years of apparently normal development. Thus, during the first two years, these children show age appropriate verbal and non-verbal communication, social relationships, play, and adaptive behavior. Later, they show significant delays in development (language, social, bowel or bladder control, motor skills). These children also show abnormalities of functioning in other areas (social interaction, communication, or stereotypic behavior patterns). This condition has also been named Heller's Syndrome, dementia infantilis, or disintegrative psychosis.
- D. ***Asperger's Disorder*** - Children with Asperger's Disorder are similar to autistic children, except that there is no significant generalized delay in language. Thus, these children will typically show normal cognitive development, normal language, and normal self help skills, while having a significant impairment in social interaction and a pattern of restricted, repetitive and stereotypic behaviors.

E. ***Pervasive Developmental Disorder, not otherwise specified (including atypical autism)*** - The DSM-IV-TR guidelines now clarify that this category can only be used when there is a severe and pervasive impairment in the development of reciprocal social interaction along with the following criteria:

1. Significant impairment in verbal or non-verbal communication, or
2. Presence of stereotyped behavior, interests, and activities, and
3. Does not meet full criteria for any of the other Pervasive Developmental Disorders described above.

III. **ATTENTION DEFICIT HYPERACTIVITY DISORDER (ADHD)** – These children have significant symptoms of inattention and hyperactivity/impulsivity. The symptoms need to be noted before age seven and must result in some impairment in two or more settings (e.g., school, home, or work). There must also be clear evidence of clinically-significant impairment in social, academic, or occupational functioning. These children can be diagnosed according to whether or not they have the combined type, the predominantly inattentive type, or the predominantly hyperactive-impulsive type. In and of itself, ADHD would not typically be considered to be a developmental disability.

IV. **LEARNING DISABILITIES** - Children 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, measured intelligence, and grade level in school. The DSM-IV-TR defines learning disabilities as "learning disorders" and specifies them in areas related to reading, mathematics or written expression. Typically, in diagnosing a learning disability it is important to determine that these are not due to physical handicaps, visual or hearing impairments, mental retardation, emotional disturbance, environmental deprivation, or cultural factors. DSM-IV-TR guidelines suggest that the discrepancy between I.Q. and achievement should be two standard deviations unless the individual's performance on the I.Q. test is thought to be lowered or compromised by an associated disorder in cognitive processing (e.g., memory deficits, visual-motor deficits, etc.). In the typical case, persons with learning disabilities have an I.Q. within normal limits and are not developmentally disabled.

V. **BORDERLINE INTELLECTUAL FUNCTIONING** - Although DSM-IV-TR no longer considers this to be a "mental disorder", it is now deemed to be a "condition that may be a focus of clinical attention." This category can be used when clients achieve I.Q. scores in the 71 - 84 range. Statistically, a large number of people in the population fall into the borderline range of intellectual functioning (13 percent). Most of these individuals would not be eligible for services to developmentally disabled persons, but those on the lower end of the scale should receive a careful review of all the available information to make sure that a misdiagnosis has not occurred such that the person should have been more appropriately diagnosed to be mentally retarded or developmentally disabled on the basis of all the relevant criteria. Finally, you will see different scores used as the benchmarks for the "borderline" category. This is because most tests classify the borderline range as involving I.Q. scores of 70-79, which is different than the current DSM-IV-TR criteria noted above.

- VI. CEREBRAL PALSY** – 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 postnatal 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 mental retardation. I.Q. scores can be quite variable, depending on the degree of CNS impairment. Here again, it is important to look at functional impairment and whether or not the person is significantly handicapped in terms of adaptive behavior and needs the kinds of intensive services required by other developmentally disabled persons.
- VII. EPILEPSY (SEIZURE DISORDER)** – 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 usually reflect 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 occur, though they will not be discussed here (See page 34 in Chapter 5). The bulk of the evidence available supports the view that seizures per se are not a major contributor to mental retardation. There is no evidence that persons with petit mal seizures have I.Q.'s that are in any way different from the normal population. Therefore, the assessment of functional impairment is again crucial with clients who have epilepsy.
- VIII. OTHER CONDITIONS** – There are a large number of other conditions, other than mental illness, which are closely related to mental retardation because there may be 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. If the prospective client with an "other neurological condition" is judged not able to work and has severe deficits in adaptive behavior, they are very likely good candidates to be considered for services to persons with developmental disabilities. This cannot be determined by looking at a single diagnostic label or test score, but rather at the person's overall functioning level. More detailed information on this topic is contained in Chapter 5.

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 mental retardation is not a diagnosis that can be reliably made in young children. Also, we know that mental retardation as a diagnosis does not carry the inevitable prognosis that it will be permanent. Some young children may appear to be slow in development, but they may make significant progress to the point where they are no longer disabled as they grow older.
- B. ***Elderly*** - In general, the same standards for diagnosing a developmental disability in an elderly 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, 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.
- X. **DUAL DIAGNOSIS** - This is a term used to identify persons who have both a developmental disability and a significant form of mental illness. I think it is still important to ensure that all criteria used for identifying persons with developmental disabilities are met. Clinical psychologists working with these patients should be asked to clarify the meaning of any diagnostic terms used to describe a psychiatric disturbance. They should also be requested to provide treatment suggestions for the IP team process. The topic of dual diagnosis is covered in detail in Chapter 7.

PLEASE NOTE: The diagnostic guidelines provided by the DSM-IV-TR manual allow the clinician to use up to five axes to describe a person's functioning across a variety of areas. The five axes are listed and described below:

- AXIS I: Clinical Disorders
Other conditions that may be a focus of clinical attention
- AXIS II: Personality Disorders*
Mental retardation
- AXIS III: General Medical Conditions
- AXIS IV: Psychosocial and Environmental Problems (e.g., educational problems, occupational problems, housing problems, economic problems, problems related to interaction with the legal system/crime, etc.).
- AXIS V: Global Assessment of Functioning. This is a rating from 0 to 100. The higher the score, the more positive is the individual's overall functioning level. Scores of 80 or higher are generally considered to be within the normal range because they involve only transient or expectable reactions to psychosocial stressors.

Relevant state and federal guidelines are provided in Appendices F and H. Service providers should check with the Developmental Disabilities Program (DDP) for the State of Montana in order to be completely sure which guidelines may apply in any given situation (e.g., nursing home placement, Intensive Family Education and Support, regular DDP services, etc.).

*Please see Chapter 7 for a discussion of important topics related to personality disorders.



How Do Clinical Diagnoses Relate to State and Federal Laws?

When we look at the pertinent state and federal laws affecting eligibility for services to persons with developmental disabilities, it seems rather clear that there is room for interpretation. In my opinion, it is difficult (if not impossible) for the appropriate laws to be specific enough to cover all of the complicated individual differences seen in real human beings. The Montana definition (see Appendix F) seems to imply that a person with cerebral palsy or epilepsy is eligible for services even if they might have normal intellectual ability. It seems unlikely that this was the intent of the state legislature. Closer inspection of the state law reveals that the disability must constitute a "substantial handicap" to the individual and this is usually interpreted as meaning that the person requires direct assistance in activities of daily living (eating, dressing, bathing, shopping, etc.). Thus, the intent of the law seems to be that services should be provided for persons who are not able to care for themselves. In addition, the Montana law regarding a "substantial handicap" is interpreted by state officials as meaning that there must be substantial deficits in cognitive/intellectual functioning and related limitations in applicable adaptive skill areas. Finally, the state law indicates that the prospective candidate for services to developmentally disabled persons must require treatment similar to that required by mentally retarded individuals. This means that a person with severe cerebral palsy who is attending college and maintaining passing grades is not eligible for services legally mandated for individuals with developmental disabilities in the State of Montana.

The state and federal laws are linked to conditions that are "closely related to mental retardation" and this seems to indicate that the diagnosis of mental retardation (which is generally fairly well defined) is a kind of benchmark against which other disabilities should be compared to see if they in fact constitute a substantial handicap. Faced with these kinds of issues, it seems appropriate to develop a uniform process for determining eligibility across the State of Montana. This is the purpose of the Clinical Decision-Making Worksheet provided in Appendices J (adults) and K (children).

Summary Points To Remember

- ✓ Specific terms in the field of developmental disabilities can have different definitions. For example, mental retardation is defined somewhat differently, depending on whether one uses DSM-IV-TR or AAIDD guidelines.
- ✓ In the absence of other qualifying data, ADHD would not generally 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.
- ✓ For clinicians who decide to use it, the DSM-IV manual allows the clinician to use up to five axes to provide a comprehensive description of a person's functioning (rather than a single diagnosis).
- ✓ A person with cerebral palsy or epilepsy who does not have a "substantial handicap" is probably not eligible for services for persons with a developmental disability.

References

Diagnostic and Statistical Manual of Mental Disorders - 4th Edition - Text Revision (DSM-IV-TR). (2000). Arlington, VA: American Psychiatric Association.

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 mental retardation and require similar treatment. For a given disease, the actual symptoms experienced by a given person may vary rather dramatically. For example, 50% of the patients affected by some diseases (e.g., homocystinuria) may be mentally retarded, 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 mental retardation. If these children are identified and given early treatment (restricting the dietary intake of phenylalanine), they generally have normal I.Q.s, 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 mental retardation and physical disabilities. As noted above, I.Q. scores can be quite variable with these patients.
 - C. ***Lowe Syndrome*** - This disorder results in severe mental retardation and other 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 I.Q. scores are either normal (mean I.Q. of 96 in one study) or near normal (I.Q.s 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 mental retardation 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 I.Q. 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 INFECTIONOUS 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 Syndrome (FAS)*** - If the developing embryo is exposed to significant amounts of alcohol, Fetal Alcohol Syndrome can result. Symptoms can include mental retardation and a variety of physical symptoms. Children with the full syndrome 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 of the cases of 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.
- 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 mental retardation, 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 mental retardation. 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 motoneuron, 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 retardation. 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 maldevelopment 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 I.Q. (mean I.Q. of 85) and a possibility of mental retardation. The course of this illness involves steady deterioration and death often occurs in adolescence. In other types of muscular dystrophy, the I.Q. 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 and mental retardation 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 functional limitations.
- ✓ The only way to determine if a person has “a neurological disorder similar to mental retardation that requires similar treatment” is to do a comprehensive psychological evaluation in order to specify the 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.

References

David, R.B. (2005). Child and Adolescent Neurology (2nd ed.). Malden, MA: Blackwell Publishings, Ltd.

Menkes, J.H. (1995). Textbook of Child Neurology (5th ed.). Baltimore, MD: Williams and Wilkins.

Menkes, J.H., Sarnat, H.B., and Maria, B.L. (Eds.). (2000). Child Neurology (7th ed.). Philadelphia, PA: Lippincott, Williams, and Wilkins.



CHAPTER 6

AUTISM SPECTRUM DISORDERS

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 individuals. 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 not an official diagnosis, but it is now being used to refer to the diverse labels and symptoms currently being subsumed under the umbrella of autism (see descriptions for autistic disorder, pervasive developmental disorder - not otherwise specified, and Asperger's Disorder 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 166 individuals, though recent reports from the CDC indicate an even higher figure of 1 in 150 American children from a sample of 14 communities through the U.S. 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 next chapter). Therefore, I have decided to devote a full chapter to topics related to autism spectrum disorder. Since the diagnosis of autism is usually made in childhood, I will emphasize topics related to children in this chapter.

A reliable diagnosis of autism can now be made at 30 months, while screening can take place by around 18 months. 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:

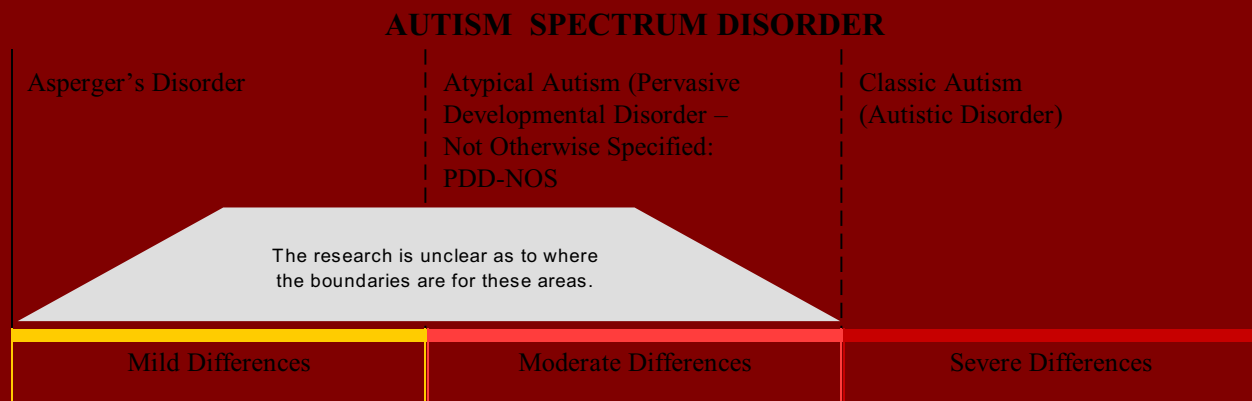
1. ***Language/Social Communication*** – Young children with ASD generally make only limited use of gestures as a way to communicate. They may talk to themselves and engage in repeating the words, phrases, or sentences that they have heard somewhere else (e.g., on T.V. or in a movie), but it is more difficult for them to initiate communication with another person. They may echo words and phrases (echolalia) but they do not seem to understand these words, nor do they 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 or feeling). 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 routine is changed, possibly because novelty and change are not easily processed or understood. Persons with ASD have difficulty developing age-appropriate peer relationships.

3. **Sensory Issues** – 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.

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.

One of the most difficult aspects of understanding autism spectrum disorder is that there are several different diagnostic labels being used in the professional literature. In addition, these terms may be used in different ways by different experts and professionals. Following is a diagram to try to help shed some light on this difficulty:



The above diagram illustrates that the symptoms of autism occur on a spectrum that can range from relatively mild symptoms to very severe symptoms. There is no one type of autism and the severity of symptom presentation varies dramatically. Affected individuals can be intellectually gifted (at least in some specific areas) or they may be severely disabled. 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.

As the above diagram shows, there is no clear consensus in terms of what constitutes high-functioning autism, or whether or not Asperger's Disorder should definitely be considered a form of autism (most experts say "yes"). If a given individual were evaluated by several different professionals, the same person might be diagnosed with autism spectrum disorder (ASD), Asperger's Disorder, PDD-NOS, or autistic disorder. If the experts are not in agreement, it is no wonder that parents and other professionals are easily confused by these kinds of issues.

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 individuals 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 is not mentally retarded. The cognitive development of people with ASD is very difficult to evaluate. It can take a great deal of time to even understand a given ASD person's learning style 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 a pattern, 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. **Mental Retardation** – Children with mental retardation 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 severe autism, there may be a 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 typically seen in autism spectrum disorder.
5. **Obsessive-Compulsive Disorder (OCD)** – Children with OCD do not have the 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.
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.
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 communication with people they know well, and they do not show restrictive and repetitive behavior patterns.

The above summary comes 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 adapted primarily from Janzen (1999), David (2005), and Cain et al (2006):

Some of the Conditions Implicated as Possible Causes of Autism	
Genetic	
A.	<u>Chromosomal Factors</u> : Siblings of individuals 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.	<u>Spontaneous Mutations</u> : 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 st and 2 nd trimester bleeding, "suboptimal" pregnancy, congenital infections (rubella, CMV, herpes), exposure to alcohol and drugs
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 retardation 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 individual. 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 individual is unique to them. We are still a long way from unraveling this mystery.

Now that we at least 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. Let me give a simple example. Let us assume that a client presents with a Full Scale I.Q. score of 82 and a diagnosis of pervasive developmental disorder - not otherwise specified (PDD-NOS). In reading the report of the psychologist, the individual is referred to as having autism spectrum disorder. There is no measure of adaptive behavior in the psychologist's report, so this is obtained through a *Vineland - II (Survey Interview Form)*. When this information is compiled, the individual is shown to have an Adaptive Behavior Composite of 57. Is this person eligible for DD services? Obviously, there is no simple answer to this question, but as we will see in the coming chapters, it would appear that this individual's adaptive behavior deficits represent a "substantial handicap" as noted in the state of Montana definition of a developmental disability. In addition, since autism is also mentioned in the state definition, the person might be viewed as being eligible based on the ASD diagnosis. Finally, the individual could possibly meet the intent of the 2002 AAMR definition of mental retardation because of significant deficits in adaptive behavior related to conceptual, social, and practical adaptive skills. Thus, those of us who are determining eligibility for persons with autism/autism spectrum disorder need to be experts in terms of understanding state and federal laws, have a good clinical understanding of autism, and be familiar with accepted assessment guidelines for this population. If an evaluating clinician states that this client has a substantial disability, he/she could indeed be eligible for services through DDP, even though their I.Q. score is higher than the usual cut-off score. We will address this issue 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 166 individuals.
- ✓ Autism Spectrum Disorder (ASD) is not yet an official diagnosis.
- ✓ A person with Autism Spectrum Disorder could potentially be given several different diagnoses.
- ✓ Autism involves a pervasive pattern of significant impairment in social interaction, communication, and restricted, repetitive and stereotyped behaviors, interests, and 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.
- ✓ A person with autism whose I.Q. score is higher than the usual cut-off score could still be eligible for services to persons with a developmental disability if they have a "substantial handicap."

References

Cain, N.N., Holt, G., Davidson, P.W., and Bouras, N. (2006). Training Handbook of Mental Disorders in Individuals with Intellectual Disability. New York: NADD Press.

David, R.B. (2005). Child and Adolescent Neurology (2nd ed.). Malden, MA: Blackwell Publishings, Ltd.

Exkorn, K.S. (2005). The Autism Source Book: Everything You Need to Know About Diagnosis, Treatment, Coping, and Healing. New York: Regan (an Imprint of Harper Collins Publishers)

Janzen, J.E. (1999). Autism: Facts and Strategies for Parents. San Antonio, TX: Therapy Skill Builders (a Harcourt Health Sciences Company).

Sebat, J. Along with 31 colleagues. (2007). Strong Association of DeNovo Copy Number Mutations with Autism. Science Express (www.scienceexpress.org) March 15, 2007.

Sicile-Kira, C. (2004). Autism Spectrum Disorders: The Complete Guide to Understanding Autism, Asperger's Syndrome, Pervasive Developmental Disorder, and Other ASD's. New York: A Perigee Book.

Volkmar, F.I. and Wiesner, L.A. (2004). Health Care for Children on the Autism Spectrum: A Guide to Medical, Nutritional, and Behavior Issues. Bethesda, MD: Woodbine House, Inc.

Williams, W.L. (Ed.). (2004). Developmental Disabilities: Etiology, Assessment, Intervention, and Integration. Reno, NV: Context Press.



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 you're mentally retarded, 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 comorbidity could involve mental retardation, severe depression, and a seizure disorder all co-existing in the same individual.

We will be using only the first category for possible dual diagnoses described above, i.e., mental illness and developmental disabilities. 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 individuals 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 of us 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 very 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 in 2007 can still have difficulties 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. Although 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 Individuals with Developmental Disabilities

1. Being labeled mentally retarded.
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 mentally retarded 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 sum of the two individual disabilities. It is easy for these kinds of clients 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 individual have never been diagnosed to be depressed and they have never received treatment. Most studies now indicate that mentally retarded people are at a greater than average risk of developing psychiatric disorders. However, these diagnoses can be difficult to make in clients 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. Clients 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 DSM-IV-TR (2000). 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 have 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. Lastly, a person can have hallucinations or delusions and not be schizophrenic. Some of these symptoms could 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 client 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 a 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 individual’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-IV-TR, 2000). Personality disorders are listed under Axis II of the DSM-IV-TR. These 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 less severe in terms of their symptoms. Thus, these cases do not meet DSM-IV-TR criteria for a full-blown Axis I disorder. 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.

DSM-IV-TR 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 Disorder NOS (Not Otherwise Specified)

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 clients with Borderline Personality Disorder to utilize a new model for evaluating and monitoring their own behavior and thought patterns (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 individuals with intellectual disabilities and borderline personality disorder is now being developed (Cain et al, 2006).

Interventions for individuals 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 client'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 clients would certainly be eligible for all services appropriate to persons with developmental disabilities.

The more complicated case involves a person who appears to have 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 I.Q. 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 client 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).



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 involve a term 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 Axis I DSM-IV-TR psychiatric disorder.
- ✓ Even if there is a dual diagnosis, the guidelines for determining eligibility for services to persons with a developmental disability remain the same.

References

- Cain, N.N., Holt, G., Davidson, P.W., and Bouras, N. (2006). Training Handbook of Mental Disorders in Individuals with Intellectual Disability. New York: NADD Press.
- Deb, S., Thomas, M., and Bright, C. (2001). Mental disorder in adults with intellectual disability. Journal of Intellectual Disability Research, 45, Part 6, 495-505.
- Fadiman, A. (1997). The spirit catches you and you fall down: A Hmong child, her American doctors, and the collision of two cultures. New York: Farrar, Straus and Giroux.
- Gaw, A.C. (2001). Cross-cultural psychiatry. Washington, DC: American Psychiatric Publishing, Inc.
- Gilson, S.F., & Levitas, A.S. (1987). Psychosocial Crises in the Lives of Mentally Retarded People. Psychiatric Aspects of Mental Retardation Reviews, 6, (No. 6), 27-31.

Hayes, S.C. & Smith, S. (2005). Get Out of Your Mind and Into Your Life: The New Acceptance and Commitment Therapy. Oakland, CA: New Harbinger Press.

Hughes, E.E. (2006). The Dual Diagnosis Primer: A training manual for family members, case managers, advocates, guardians, and direct support professionals. New York: NADD Press.

Menolascino, F.J. & Potter, J. F. (1989). Mental illness in the elderly mentally retarded. Journal of Applied Gerontology, 8, 192-202.

Naiditch, Z., Marlin, M., & Mayer, S. (1988). Abuse of dually diagnosed persons in institutions: Injuries, alleged abuse, restraint and seclusion of dually diagnosed persons in DMH/DD-operated facilities. (Filed with the Circuit Court). Chicago: Protection and advocacy.

Olson, K.M., Hellings, J.A., & Black, P.A. (2003). Dual Diagnosis: Schizophrenia and other Psychotic Disorders and Developmental Disabilities. Baltimore, MD: Paul H. Brookes Publishing Co.

Prosser, H., Moss, S., Costello, H., Simpson, N., Patel, P., and Rowe, S. (1998). Reliability and Validity of the Mini PAS-ADD for assessing psychiatric disorders in adults with intellectual disability. Journal of Intellectual Disability Research, 42, 264-72.

Williams, W.L. (Ed.). (2004). Developmental Disabilities: Etiology, Assessment, Intervention, and Integration. Reno, NV: Context Press.



CHAPTER 8

TECHNIQUES TO ENHANCE THE REFERRAL PROCESS

One of the most important variables in being able to provide quality services to clients 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 the remainder of 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. In order to accomplish this goal, you need to know why you are referring the client and be very clear and specific in addressing 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 client? - General orientation

EXAMPLES:

- A. It was recommended by the habilitation team because of questions about the client's emotional status.
- B. The client has not had an evaluation in 15 years and there is a need to have more current psychological information in the chart.
- C. Parents are requesting an evaluation because they think their son does not belong in a sheltered workshop.
- 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 client's life and these suggest a need for a psychological evaluation (e.g., mother died).

2. What broad diagnostic questions do you want answered?

EXAMPLES:

- A. Is this person mentally retarded, cognitively delayed, intellectually disabled?
- B. Does this client have a developmental disability?
- C. Does this client fit on the autism spectrum?
- D. Does this client have a neurological condition similar to mental retardation which might make him/her eligible for services to persons with developmental disabilities?

- E. Does this client have a mental health disorder (specify in relation to depression, anxiety, PTSD, etc.)?
- F. Does this client have an emotional problem which, along with a developmental disability, would fit the designation of a "dual diagnosis"?
- G. What is this client's level of adaptive behavior functioning?

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. Can this client be toilet trained? What procedures would be most helpful in this regard?
- B. What suggestions could be considered for behavioral intervention programs to decrease the specified target behaviors (e.g., head banging) with this client?
- C. Is psychotherapy indicated to help this client 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 or goals to consider for this client?
- 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 client 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 are not able to be administered (see Appendix I).

Since the purpose of this manual is to enhance our ability to determine eligibility under the State of Montana definition of developmental disabilities, I will close this chapter with just a few more questions for referral sources which could be helpful in making an eligibility decision. These questions were adapted from a letter developed by Larry Lovelace back in 1996.

1. As best you can determine, did this person's disability originate before the age of 18?
2. Does this person's disability constitute a substantial handicap (generally defined as ability to live independently and be able to support oneself financially through competitive employment)?
3. Is this person's handicap likely to continue indefinitely?
4. Would treatment similar to that provided to individuals who are developmentally disabled be appropriate for this person?
5. According to Montana Code Annotated (53-20-102), Montana's definition of developmental disability states that: ***"Developmental disability" means a disability that is attributable to mental retardation, cerebral palsy, epilepsy, autism, or any other neurologically handicapping condition closely related to mental retardation and that requires treatment similar to that required by mentally retarded individuals. A developmental disability is a disability that originated before the individual attained age 18, that has continued or can***

be expected to continue indefinitely, and that constitutes a substantial handicap of the individual. In your professional opinion, is this person eligible for services under the state of Montana definition for developmental disability services? Please state your rationale.

Note: For children or adult clients 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 pages 4-5 of the Eligibility Determination Forms (see Appendices J and K).

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?
- ✓ Referral sources can be asked to give their professional opinion about whether or not a person meets Montana's definition of developmental disabilities (see Appendix F).



CHAPTER 9

MAKING THE ELIGIBILITY DECISION

This chapter represents the culmination of the entire manual. Now it is time to make the eligibility decision. There are three steps involved in this 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 (age 18 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., <60).
 - B. The client’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. At this time, adaptive behavior for adults will typically be measured using the *Vineland Adaptive Behavior Scales (2nd Edition) – Vineland II*. However, other instruments can also be used (see Chapter 3).
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 client has functional academic skills.
4. A comprehensive history should be compiled by gathering relevant records and by interviewing parents and the prospective adult client. 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.)

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.)

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). When you interview the adult client, this is a good time to observe communication skills, general knowledge, and the client's ability to provide a coherent history. This is also an opportunity to screen the client's overall functioning level (e.g., read a paragraph, write a paragraph, perform arithmetic problems, have client tell the story of her life, have client tell about a recent movie she has seen, have the client give the current day and date, ask the client to give his age and birthday, etc.). Finally, you should assess the client's interest in service options available to persons with a developmental disability.

Part B-Children: Guidelines for assessment procedures necessary to determine eligibility for services to children with developmental disabilities (ages 6-17):

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., 6-9). For children ages 10-16, a three year standard may be appropriate. Try not to use preschool test results (e.g., ages 0-5). The flexible guidelines 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 assessment of adaptive behavior using a standardized, comprehensive instrument.
3. A current or recent assessment of educational achievement which utilizes standardized tests to identify academic skills in reading, arithmetic and written language.
4. A comprehensive history should be compiled by interviewing parents and gathering relevant records. 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).
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 and what information you want included in the final evaluation 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 J. Forms for children are included in Appendix K.

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. If a review by a supervisor or special consultant is necessary, this option is available. Tim Plaska and Connie Orr are both available for this purpose.
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 I and J. A later follow-up decision concerning eligibility for services to persons with developmental disabilities can always be made later if the initial recommendations are not being successful.

4. The Eligibility Determination Form was designed specifically in relation to the Montana statute regarding developmental disabilities (Appendix F). If other laws apply to a particular case (e.g., see Appendix H), please carefully review the specific guidelines that are applicable.
5. The Eligibility Determination Form provides for a flexible decision appropriate for a real person (not a “number” or a “statistic”). In order to make this kind of decision, you may need 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 person has never worked competitively, this is important. Terms like “significant” or “substantial disability” cannot be precisely defined. You need to decide on the basis of reviewing all the data.
 - C. If a psychologist provides an age-equivalent or grade-equivalent score, or a range of scores, ask for the specific standard scores in all areas evaluated.
 - 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 individual capable of caring for himself/herself, or not? These are the kinds of basic questions that need to be addressed.

I will close this chapter with a few additional comments regarding the State of Montana definition of a developmental disability. Cary Lund, an attorney for the Montana Developmental Disabilities Program, suggested that the following points may provide important clarification regarding eligibility determination for services to persons with a developmental disability:

1. The state definition is somewhat vague. It is based on the concepts and ways of thinking that were prevalent in the 1970's.
2. The State of Montana has enacted legal agreements with the federal government regarding its various waiver programs. The specific agreement relevant to our discussion is that the procedures and clinical decision-making worksheets contained in this manual were approved by the federal government and the state of Montana is thereby obligated to follow these procedures for all waiver programs.
3. The 2007 legislature made slight wording changes applicable in the commitment of persons to the Montana Developmental Center (MDC). These changes, amended into 53-20-102, MCA, clarify the intent of the legislature regarding the criteria providing that a condition requires treatment similar to that required for mental retardation, and applies this statement to all the stated conditions inclusive of epilepsy, cerebral palsy, and autism, and not just to “any other neurologically disabling condition.” Thus, one could make the case that the

parallel nature of the two definitions (community services and commitment to MDC) could guide the interpretation of the remaining ambiguity regarding community services (53-20-202, MCA).

4. Accordingly, we are left with a de facto operational definition of a developmental disability as involving the following components:
 - A. An I.Q. score of approximately 70 or less.
 - B. An adaptive behavior composite score of approximately 70 or less.
 - C. The disability originated before the individual attained age 18.
 - D. The disability is expected to continue indefinitely.

The purpose of this manual is to make your job easier. I hope it does that. I hope that it continues to lead us towards a more uniform process for making eligibility decisions in the State of Montana. I hope that I have clarified some of the important issues in this regard. However, please remember that there will always be “gray” areas. Subjective decisions that are informed by a complete review of all relevant data represent the current state of the art. When in doubt, perhaps we should err on the side of the client who is applying for services. I think this is the best that we can do. I wish you every success in your efforts to achieve this worthy goal.

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 question still remain, utilize the three-step referral process from Chapter 8.
 3. Complete the Eligibility Determination Form appropriate for either adults (Appendix J) or children (Appendix K).
- ✓ The final decision represents a subjective judgment. It will not be perfect. When our decision is informed by a complete review of all relevant data, this is the best that we can do.



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 I.Q. 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 I.Q. 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.

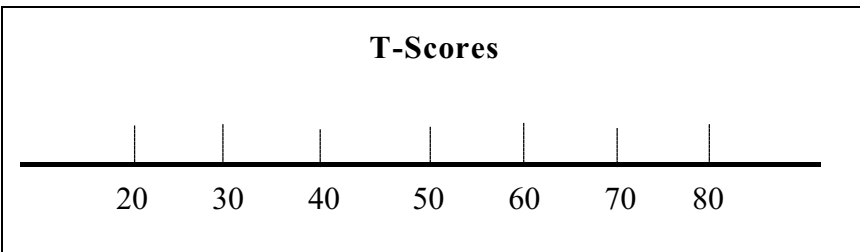
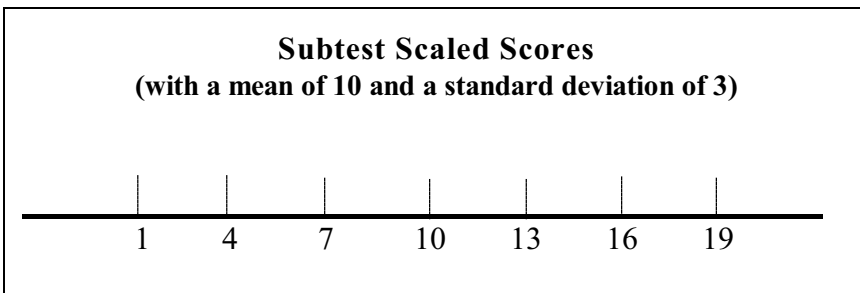
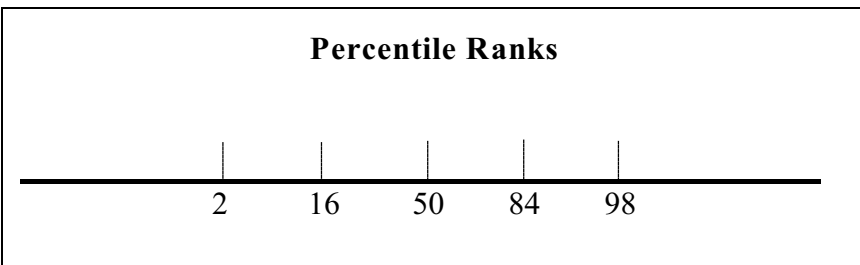
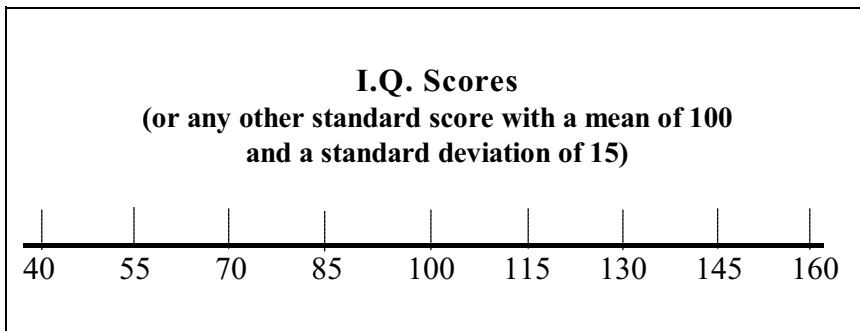
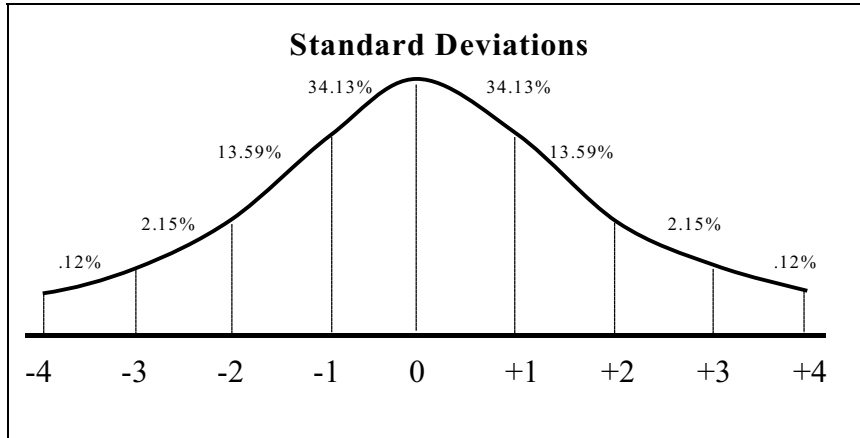
Mental Age - This provides an estimate of the person's developmental functioning in terms of cognitive abilities. For example, a mental age of four years six months suggests that the person's cognitive development is similar to that seen in a child who is 4 ½. Since it is basically an age equivalent 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 +/-2 standard deviations of the mean. 99.74 percent of any population will fall within +/-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, I.Q. scores, and subtest scaled scores).



The normal curve and its relationship to other statistical concepts:



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 client 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 *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-III*, 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 following 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 +/-1 SEM. The chances are 95 percent that it will fall within +/-2 SEM. For adults tested on the *Wechsler Adult Intelligence Scale-3rd Edition*, the SEM for the Full Scale I.Q. 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 I.Q. 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-III* 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. I.Q. 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 I.Q. 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 I.Q. TEST SCORES

Classification	I.Q. 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
Mild Mental Retardation	55-69*	Below 1
Moderate Mental Retardation	40-55*	Below 1
Severe Mental Retardation	25-40*	Below 1
Profound Mental Retardation	Below 25*	Below 1

*These score ranges are approximate and allow for some degree of clinical judgment.



APPENDIX E

AMERICAN ASSOCIATION ON INTELLECTUAL AND DEVELOPMENTAL DISABILITIES (AAIDD)

In 2007, the American Association on Mental Retardation (AAMR) changed its name to AAIDD as noted above. Thus, there can be some confusion about the 2002 AAMR definition of mental retardation, but it is the same association and the same definition with just a new name. In this appendix I will provide the March, 2007 information from AAIDD from their website (www.aaid.org).



Definition of Mental Retardation

Mental retardation is not something you have, like blue eyes, or a bad heart. Nor is it something you are, like short, or thin. It is not a medical disorder, nor a mental disorder. Mental retardation is a particular state of functioning that begins in childhood and is characterized by limitations in both intelligence and adaptive skills. Mental retardation reflects the “fit” between the capabilities of individuals and the structure and expectations of their environment.

The AAMR Definition of Mental Retardation

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

Five Assumptions Essential to the Application of the Definition:

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

Frequently Asked Questions About Mental Retardation and the AAMR Definition

THE AAMR DEFINITION

What is the official AAMR definition of mental retardation? Mental retardation is a disability characterized by significant limitations both in intellectual functioning and in adaptive behavior as expressed in conceptual, social, and practical adaptive skills. This disability originates before the age of 18.

Where can I find the updated AAMR definition of mental retardation? The new 10th edition of *Mental Retardation: Definition, Classification, and Systems of Supports* discusses the updated AAMR definition and classification system in detail. It presents the latest thinking on mental retardation and proposes tools and strategies to determine if an individual has mental retardation. Further, the book suggests what supports can be used to optimize functioning of persons with mental retardation.

What factors must be considered in determining if a person has mental retardation and consequently, developing a support plan for the individual? When using the AAMR definition, classification, and systems of supports, professionals and other team members must:

- Evaluate limitations in present functioning within the context of the individual's age, peers, and culture;
- Take into account the individual's cultural and linguistic differences as well as communication, sensory, motor, and behavioral factors;
- Recognize that limitations often coexist with strengths within an individual;
- Describe limitations so that an individualized plan of needed supports can be developed; and
- Provide appropriate, personalized supports to improve the functioning of a person with mental retardation.

KEY CONCEPTS IN DEFINITION

What is a disability? A disability refers to personal limitations that are of substantial disadvantage to the individual when attempting to function in society. A disability should be considered within the context of the individual's environmental and personal factors, and the need for individualized supports.

What is intelligence? Intelligence refers to a general mental capability. It involves the ability to reason, plan, solve problems, think abstractly, comprehend complex ideas, learn quickly, and learn from experience. Although not perfect, intelligence is represented by Intelligent Quotient (IQ) scores obtained from standardized tests given by a trained professional.

With regards to the intellectual criterion for the diagnosis of mental retardation, mental retardation is generally thought to be present if an individual has an IQ test score of approximately 70 or below. IQ scores must always be considered in light of the standard error of measurement, appropriateness, and consistency with administration guidelines. Since the standard error of measurement for most IQ tests is approximately 5, the ceiling may go up to 75. This represents a score approximately 2 standard deviations below the mean, considering the standard error of measurement. It is important to remember, however, that an IQ score is only one aspect in determining if a person has mental retardation. Significant limitations in adaptive behavior skills and evidence that the disability was present before age 18 are two additional elements that are critical in determining if a person has mental retardation.

What is Adaptive Behavior? Adaptive behavior represents the conceptual, social, and practical skills that people have learned to be able to function in their everyday lives. Significant limitations in adaptive behavior impact a person's daily life and affect the ability to respond to a particular situation or to the environment.

Limitations in adaptive behavior can be determined by using standardized tests. On these standardized measures, significant limitations in adaptive behavior are operationally defined as performance that is at least 2 standard deviations below the mean of either (a) one of the following three types of adaptive behavior: conceptual, social, or practical, or (b) an overall score on a standardized measure of conceptual, social, and practical skills.

What are some examples of Adaptive Behavior Skills?

Conceptual Skills

- Receptive and expressive language
- Reading and writing
- Money concepts
- Self-directions

Social Skills

- Interpersonal
- Responsibility
- Self-esteem
- Gullibility (likelihood of being tricked or manipulated)
- Naivete
- Follows rules
- Obeys laws
- Avoids victimization

Practical Skills

- Personal activities of daily living such as eating, dressing, mobility and toileting.
- Instrumental activities of daily living such as preparing meals, taking medication, using the telephone, managing money, using transportation, and doing housekeeping activities.
- Occupational skills.
- Maintaining a safe environment.

SUPPORTS AND MENTAL RETARDATION

What are supports? Supports are resources and individual strategies necessary to promote the development, education, interests, and personal well being of a person with mental retardation. Supports can be provided by a parent, friend, teacher, psychologist, doctor, or by any appropriate person or agency.

The concept of supports originated about 15 years ago and has revolutionized the way habilitation and education services are provided to persons with mental retardation. Rather than mold individuals into pre-existing diagnostic categories and force them into existing models of service, the supports approach evaluates the specific needs of the individual and then suggests strategies and services to optimize individual functioning. The supports approach also recognizes that individual needs and circumstances will change over time.

Supports were an innovative aspect of the 1992 AAMR manual and they remain critical in the 2002 system. In 2002, they have been dramatically expanded and improved to reflect significant progress over the last decade.

Why are supports important? Providing individualized supports can improve personal functioning, promote self-determination, and enhance the well being of a person with mental retardation. Supports also leads to community inclusion of persons with intellectual disabilities. Focusing on supports as the way to improve education, employment, recreation, and living environments is an important part of a person-centered approach to providing care to people with mental retardation.

How do you determine what supports are needed? AAMR recommends that an individual's need for supports be analyzed in at least nine key areas such as human development, teaching and education, home living, community living, employment, health and safety, behavior, social, and protection and advocacy.

What are some examples of support areas and support activities?

Human Development Activities

- Providing physical development opportunities that include eye-hand coordination, fine motor skills, and gross motor activities
- Providing cognitive development opportunities such as using words and images to represent the world and reasoning logically about concrete events
- Providing social and emotional developmental activities to foster trust, autonomy, and initiative

Teaching and Education Activities

- Interacting with trainers and teachers and fellow trainees and students
- Participating in making decisions on training and educational activities
- Learning and using problem-solving strategies
- Using technology for learning
- Learning and using functional academics (reading signs, counting change, etc.)
- Learning and using self-determination skills

Home Living Activities

- Using the restroom/toilet
- Laundering and taking care of clothes
- Preparing and eating food
- Housekeeping and cleaning
- Dressing
- Bathing and taking care of personal hygiene and grooming needs
- Operating home appliances and technology
- Participating in leisure activities within the home

Community Living Activities

- Using transportation
- Participating in recreation and leisure activities
- Going to visit friends and family
- Shopping and purchasing goods
- Interacting with community members
- Using public buildings and settings

Employment Activities

- Learning and using specific job skills
- Interacting with co-workers
- Interacting with supervisors
- Completing work-related tasks with speed and quality
- Changing job assignments
- Accessing and obtaining crisis intervention and assistance

Health and Safety Activities

- Accessing and obtaining therapy services
- Taking medication
- Avoiding health and safety hazards
- Communicating with health care providers
- Accessing emergency services
- Maintaining a nutritious diet
- Maintaining physical health
- Maintaining mental health/emotional well-being

Behavioral Activities

- Learning specific skills or behaviors
- Learning and making appropriate decisions
- Accessing and obtaining mental health treatments
- Accessing and obtaining substance abuse treatments
- Incorporating personal preferences into daily activities
- Maintaining socially appropriate behavior in public
- Controlling anger and aggression

Social Activities

- Socializing within the family
- Participating in recreation and leisure activities
- Making appropriate sexual decisions
- Socializing outside the family
- Making and keeping friends
- Communicating with others about personal needs
- Engaging in loving and intimate relationships
- Offering assistance and assisting others

Protection and Advocacy Activities

- Advocating for self and others
- Managing money and personal finances
- Protecting self from exploitation
- Exercising legal rights and responsibilities
- Belonging to and participating in self-advocacy/support organizations
- Obtaining legal services
- Using banks and cashing checks

CAUSES OF MENTAL RETARDATION

What are the causes of Mental Retardation? The causes of mental retardation can be divided into biomedical, social, behavioral, and educational risk factors that interact during the life of an individual and/or across generations from parent to child. Biomedical factors are related to biologic processes, such as genetic disorders or nutrition. Social factors are related to social and family interaction, such as child stimulation and adult responsiveness. Behavioral factors are related to harmful behaviors, such as maternal substance abuse. Educational factors are related to the availability of family and educational supports that promote mental development and increases in adaptive skills. Also, factors present during one generation can influence the outcomes of the next generation. By understanding inter-generational causes, appropriate supports can be used to prevent and reverse the effects of risk factors.

INSIDE AAMR

What is AAMR? Founded in 1876, AAMR is the world's oldest and largest interdisciplinary organization of professionals concerned about mental retardation and related developmental disabilities. With headquarters in Washington, DC, AAMR has a constituency of more than 50,000 people and an active core membership of 7,500 in the United States and in 55 other countries. The mission of AAMR is to promote progressive policies, sound research, effective practices, and universal rights for people with intellectual disabilities.

Has AAMR always had the same definition of mental retardation? No. AAMR has updated the definition of mental retardation ten times since 1908, based on new information, changes in clinical practice, or breakthroughs in scientific research. The 10th edition of *Mental Retardation: Definition, Classification, and Systems of Supports* contains a comprehensive update to the landmark 1992 definition and provides important new information, tools, and strategies for the field and for anyone concerned about people with mental retardation.

What is the reaction of AAMR to the U.S. Supreme Court decision to ban execution of persons with mental retardation? AAMR applauds and fully supports the U.S. Supreme Court decision to stop executing persons with mental retardation. AAMR has always advocated against the death penalty and has long served as *amicus curiae* in Supreme Court cases. In 2001, AAMR and eight other disability organizations presented an *amicus* brief to the U.S. Supreme Court advocating against the death penalty in the Atkins case. James W. Ellis, past president of AAMR, who also argued the case for Atkins says, "The Court has recognized the consensus among the American people, even those who support the death penalty. They are deeply disturbed by the prospect that people with mental retardation could face execution."

Visit www.aamr.org to learn more about AAMR.



APPENDIX F

STATE OF MONTANA DEFINITION OF A DEVELOPMENTAL DISABILITY

The current definition of a "developmental disability" in the State of Montana as of 06/01/07 is listed below:

"Developmental disability" means a disability that is attributable to mental retardation, cerebral palsy, epilepsy, autism, or any other neurologically handicapping condition closely related to mental retardation and that requires treatment similar to that required by mentally retarded individuals. A developmental disability is a disability that originated before the individual attained age 18, that has continued or can be expected to continue indefinitely, and that constitutes a substantial handicap of the individual.

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



APPENDIX G

WEBSITES FOR AUTISM INFORMATION

Autism Research Institute

www.autism.com/autism

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

Autism Society of America

www.autism-society.org

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

Center for Study of Autism

www.autism.org

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

Cure Autism Now (CAN)

www.canfoundation.org

5225 Wilshire Blvd., Suite 226
Los Angeles, CA 90036

MAAP Services, Inc.

www.netnitco.net/users/chart/maap.htm

P.O. Box 524
Crown Point, NY 46307
219-662-1311
219-662-0638 fax

National Information Center for Children and Youths with Disabilities

nichcy@aed.org

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

National Organization for Rare Disorders, Inc. (NORD)

www.nord-rdb.com/orphan

P.O. Box 8923
New Fairfield, CT 06812-8923
800-999-6673
203-746-6518
E-mail: orphan@NORD-RDB.com

TEACCH

www.teacch.com

Diets

www.kinnikinick.com

www.glutenfree.com

www.missroben.com

General Links

www.kathyandcalvin.com

members.aol.com/autism3/links.html

chatautism.com

APPENDIX H

FEDERAL DEFINITION OF A DEVELOPMENTAL DISABILITY¹

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 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; except that such term, when applied to infants and young children means individuals 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.

¹Based on U.S. Public Law 103-230 (1994) and the United States Codes Annotated, Title 42, USCA 6001(8) 1995.

APPENDIX I

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 clients 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. In the remainder of this paper, this issue will be discussed in greater depth.

Definition: A client is "untestable" when a psychologist states that the client cannot be evaluated using a standardized testing format. That's all there is to it. In cases where the client 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 (home, school, work).
 - 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 potential clients 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 potential client'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 eight years of age and older. This is because the Eligibility Determination Form cannot be completed by authorized Developmental Services Division staff if the applicant's disability prevents the psychologist from administering a standardized IQ test. Alternative assessments and the consideration of other supporting documentation must be used in these cases, serving to corroborate the results of the adaptive behavior assessment. 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 DD services. 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 DD services.
 - B. Ten year-old Celeste has been referred for DD services. 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 I.Q. score of 89, a Performance I.Q. score of 93, and a Full Scale I.Q. 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 mentally retarded or cognitively delayed. Celeste is subsequently found to be ineligible for DD services.

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 DD services.

6. **Summary** – The points discussed above clearly illustrate that the term “untestable” is not a very important or meaningful term when considering clients’ 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 clients and all other clients being considered for eligibility for DDP services can still be evaluated using the assessment techniques described in numbers one or two above.



APPENDIX J

***ELIGIBILITY DETERMINATION FORM
FOR DEVELOPMENTAL DISABILITIES PROGRAM
(ADULTS AGE 18 AND OVER)***

Eligibility Determination Form
for Developmental Disabilities Programs
(Adults Age 18 and Over)

Applicant:	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, NRC = not related to client , give date and all past diagnoses that have been received in each area - use back of this page or attach supporting documents if more space is needed):

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.) _____ _____

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 client is untestable according to the guidelines of Appendix I, note this here: Yes**
Please document why the client cannot be evaluated using a standardized testing format. Then go to page 3.

State of Montana Definition of a Developmental Disability

“Developmental disability” means a disability that is attributable to mental retardation, cerebral palsy, epilepsy, autism, or any other neurologically handicapping condition closely related to mental retardation and that requires treatment similar to that required by mentally retarded individuals. A developmental disability is a disability that originated before the individual attained age 18, that has continued or can be expected to continue indefinitely, and that constitutes a substantial handicap of the individual.

Reference – MCA 53-20-202(3)

PART 4: Conclusions From Data

A. Criteria #1: Documentation of Substantial Disability.

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

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

1.	Did the disability originate before age 18? <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unable to Verify
2.	Has the disability continued or can be expected to continue indefinitely? <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> No Conclusion Established

Applicant's Initials: _____

PART 6: Eligibility Decision

According to the State of Montana's definition of a developmental disability (Criteria 1 and 2), the review of information in this case indicates that:

- The person **is** eligible for services funded by the Developmental Disabilities Program.
- The person is **not** eligible for services funded by the Developmental Disabilities Program.
- The decision is too close to call without review by a supervisor or a special consultant.
- More information is needed. Please specify: _____

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 K

***ELIGIBILITY DETERMINATION FORM
FOR DEVELOPMENTAL DISABILITIES PROGRAM
(CHILDREN AGES 6-17)***

State of Montana

**Eligibility Determination Form
for Developmental Disabilities Programs
(Children Age 6-17)**

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, NRC = not related to client, give date and all past diagnoses that have been received in each area – use the back of this page or attach supporting documents if more space is needed):**

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.)	_____

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

State of Montana Definition of a Developmental Disability

“Developmental disability” means a disability that is attributable to mental retardation, cerebral palsy, epilepsy, autism, or any other neurologically handicapping condition closely related to mental retardation and that requires treatment similar to that required by mentally retarded individuals. A developmental disability is a disability that originated before the individual attained age 18, that has continued or can be expected to continue indefinitely, and that constitutes a substantial handicap of the individual.

Reference – MCA 53-20-202(3)

PART 4: Conclusions From Data

A. Criteria #1: Documentation of Substantial Disability.

1.	<u>Intellectual Functioning</u> – Do the child’s intellectual deficits cause a substantial disability in terms of daily functioning? <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Inconclusive Summarize Rationale for Decision: _____ _____ _____																
2.	<u>Adaptive Behavior</u> – Is this child unable to care for himself/herself (self-care, home living, community use, work skills, etc.) without significant support from caregivers? <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Inconclusive Summarize Rationale for Decision: _____ _____ _____																
3.	<u>Academic Skills</u> – Is this child unable to perform functional academic skills commensurate with his/her age? <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Inconclusive Summarize Rationale for Decision: _____ _____ _____																
4.	Does the person have a neurological condition related to mental retardation which requires treatment similar to that required by individuals with mental retardation? <table style="width: 100%; margin-top: 5px;"> <tr> <td style="width: 20px;">A.</td> <td>Medical diagnosis of cerebral palsy?</td> <td style="text-align: right;"><input type="checkbox"/> Yes</td> <td style="text-align: right;"><input type="checkbox"/> No</td> </tr> <tr> <td>B.</td> <td>Diagnosis of autism?</td> <td style="text-align: right;"><input type="checkbox"/> Yes</td> <td style="text-align: right;"><input type="checkbox"/> No</td> </tr> <tr> <td>C.</td> <td>Medical diagnosis of uncontrolled seizures?</td> <td style="text-align: right;"><input type="checkbox"/> Yes</td> <td style="text-align: right;"><input type="checkbox"/> No</td> </tr> <tr> <td>D.</td> <td>Other neurological condition similar to mental retardation and requiring similar treatment? (Please name and describe briefly – attach additional supporting documentation as necessary).</td> <td style="text-align: right;"><input type="checkbox"/> Yes</td> <td style="text-align: right;"><input type="checkbox"/> No</td> </tr> </table> _____ _____ _____	A.	Medical diagnosis of cerebral palsy?	<input type="checkbox"/> Yes	<input type="checkbox"/> No	B.	Diagnosis of autism?	<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 mental retardation and requiring similar treatment? (Please name and describe briefly – attach additional supporting documentation as necessary).	<input type="checkbox"/> Yes	<input type="checkbox"/> No
A.	Medical diagnosis of cerebral palsy?	<input type="checkbox"/> Yes	<input type="checkbox"/> No														
B.	Diagnosis of autism?	<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 mental retardation and requiring similar treatment? (Please name and describe briefly – attach additional supporting documentation as necessary).	<input type="checkbox"/> Yes	<input type="checkbox"/> No														

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.	Is it expected that the disability will continue indefinitely? <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> No Conclusion Established

PART 6: Eligibility Decision

According to the State of Montana's definition of a developmental disability (Criteria 1 and 2), the review of information in this case indicates that:

<input type="checkbox"/>	The child is eligible for services funded by the Developmental Disabilities Program.
<input type="checkbox"/>	The child is not eligible for services funded by the Developmental Disabilities Program.
<input type="checkbox"/>	The decision is too close to call without review by a supervisor or a special consultant.
<input type="checkbox"/>	More information is needed. Please specify: _____ _____ _____
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 L

CASE STUDIES

NOTE: The following case studies were reviewed by teams of Quality Improvement Specialists meeting at Chico Hot Springs on June 12, 2007. The resulting QIS recommendations are provided after each case.

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 IFES 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	I.Q./Index Score	Percentile Rank	95% Confidence Interval
Verbal I.Q. Score	95	37	89-101
Performance I.Q. Score	77	6	71-87
Full Scale I.Q. 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 I.O. (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 IFES. However, at age 9, Michael demonstrated evidence of dramatic progress and the QIS team felt that he was no longer eligible for DDP services to children on the basis of a developmental disability. Both I.Q. scores (e.g., Full Scale I.Q. = 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 I.Q. score of 87, a Performance I.Q. score of 91, and a Full Scale I.Q. 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 I.Q. score of 84, Performance I.Q. score of 87, and Full Scale I.Q. 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 I.Q. score of 74, a Performance I.Q. score of 79, and a Full Scale I.Q. 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 I.Q. 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 mentally retarded. Accordingly, Joe was referred by the QIS team 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 history:
- 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 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 I.Q. score of 75 (5th percentile), and a Performance I.Q. score of 84 (14th percentile). Her Processing Speed Index Score was 68 (1st percentile). Processing speed on the *WISC-IV* is related to concentration and attention to details. No other scores were reported.

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 QIS team 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. Therefore, the team wisely 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 I.Q. score of 82, a Performance I.Q. score of 77, and a Full Scale I.Q. 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 I.Q. score of 88, a Performance I.Q. score of 89, and a full Scale I.Q. 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 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 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 QIS team felt that a comprehensive adaptive behavior assessment with the Vineland-II (Survey Interview Form) would have been far preferable to the obtained results with the ICAP. However, given the available data, the team noted that Susan's I.Q. 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-IV included a Verbal I.Q. score of 95, a Performance I.Q. score of 87, and a Full Scale I.Q. 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 I.Q. score of 72, a Performance I.Q. score of 65, and Full Scale I.Q. 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:

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

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 QIS team had difficulty with the fact that Nathan seemed to be responsible for causing his own disability. However, the team eventually determined that Nathan does meet Montana guidelines for a developmental disability. Since he also appears to meet guidelines for a traumatic brain injury utilized by the PD waiver program, Nathan and his parents could be given a choice to pursue either service option.

6. **The Case of Janet.** Janet was born with the 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 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 I.Q. score of 67, Performance I.Q. score of 69, and Full Scale I.Q. score of 68. ***Should Janet be deemed eligible for services for children with developmental disabilities in the state of Montana?***

Eligibility Decision: Despite scoring in the mild range of mental retardation on an I.Q. test, the QIS team correctly recommended 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 might well be recommended.

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 90th 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 I.Q. score of 65, a Performance I.Q. score of 72, and a Full Scale I.Q. 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) to 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 QIS team 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. They referred Marsha back to her case manager to seek appropriate services.