

**Fetal Alcohol Syndrome and Associated Disabilities:**  
A Training Manual to Aid in Vocational Rehabilitation  
and Other Non-medical Services

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## FOREWORD

This training manual is a compilation of many years of research and experience in the fields of fetal alcohol syndrome (FAS) and vocational rehabilitation (VR). It is a revised and expanded version of *Fetal Alcohol Syndrome: A Manual to Aid in Vocational Rehabilitation and Other Non-Medical Services*. FAS is both a complicated condition and a simple one if the reader will remember that the primary condition associated with FAS is permanent brain damage. Due to the complexities of this field, however, the training of others in FAS is not a task to be taken lightly. This manual does not fully include the guidance and feedback given by professional trainers. Therefore, this manual was intended for use by non-medical service providers in training workshops by properly trained professionals.

Since this manual was written, the American Indian Rehabilitation Research and Training Center has closed. For additional information, contact the authors at their addresses shown below.

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**Fetal Alcohol Syndrome and Associated  
Disabilities: A Training Manual to Aid in Vocational  
Rehabilitation and Other Non-medical Services**

*“Let us put our heads together and see what kind of life  
we can make for our children.”*

–Sitting Bull

**A RACE AT RISK?**

A series of publications in the late 1980s (e.g., Dorris, 1989; Streissguth, LaDue & Randels, 1988; Streissguth, Aase, Clarren, Randels, LaDue & Smith, 1991; Abel & Sokol, 1987) raised awareness of the extent of FAS in American Indian and Alaska Native communities. At that time, the highest known rate of FAS in the world was in the Copper River region of the Alaskan interior, prompting Chuck Knopf, former clinical supervisor at the Fairbanks Regional Center for Alcohol and Other Addictions, to observe that "We are not just talking about a generation at risk; we are talking about a race at risk" (quoted by Backover, 1991, p.3). One of the earliest comprehensive attempts to compare the prevalence of FAS in different ethnic and racial groups in the 1980s found that the rate for American Indians and Alaska Natives was far higher (at 2.9 per thousand) than for any other group (Chavez, Cordero & Becerra, 1988). FAS was identified as among the half dozen conditions that American Indians experience at alarming rates when compared with the general population (U.S. General Accounting Office, 1993). The best data for 1990 for American Indians and Alaska Natives showed a rate of FAS that was more than 10 times the rate for the total population (Boufford, 1997). More recent data (1993), while less reliable, indicate even higher rates for American Indians and Alaska Natives

(Boufford, 1997). The latest estimate for the U.S. is a FAS rate of 1.95 per 1,000 live births, although estimates run as high as 3.0 per 1,000 -- about 12,000 babies a year (Center on Addiction and Substance Abuse, 1996, p. 53.). Epidemiological surveillance efforts by the Centers for Disease Control (2002) seem to indicate that FAS is higher in frequency among American Indians and Alaska Natives than among other races and ethnic groups (3.2 per thousand). As a result of these findings, as well as Michael Dorris's account (1989) of his attempt to parent an adopted American Indian boy with FAS, American Indian and Alaska Native communities have been in the vanguard of attempts to deal with this serious issue. In response to a pilot project conducted by the Indian Health Service (IHS) in the Southwest in the early 1980s, less than ten years after FAS was defined in the medical literature, the IHS created the National Indian Fetal Alcohol Syndrome Prevention Program (Prugh, 1985). Unfortunately, the problem persists, and people born with FAS before anyone knew what it was are now adults, and many of them need help to become productive citizens. The effect of their needs is proportionately large in American Indian and Alaska Native communities because they are often small, and isolated, as well as because the rate of FAS is likely to be higher than in other communities. Therefore, FAS is a community issue as well as an individual issue in those communities.

Since FAS was first defined as a medical syndrome in 1973, the extent of knowledge in the field has expanded dramatically. The highest incidence rates yet reported are associated with certain American Indian reservations and Canadian reserves, although the incidence rates in other American Indian communities are less than the national average (Stratton, Howe, & Battaglia, 1996, pp. 83–89). Until six years ago, the most recent reliable data (for the year 1990) for American Indians and Alaska Natives showed a rate of FAS that, at 5.2 per 1,000 was more than 10 times the rate for the total population (Boufford, 1997). More recent data (1993), while less reliable, indicated even higher rates for American Indians and Alaska Natives (Boufford, 1997). Since

then, controlled surveys in four states (Alaska, Arizona, Colorado, and New York) have indicated a prevalence rate of 3.2 per 1,000 for American Indians, compared with an overall rate of 0.4 per 1,000 (Centers for Disease Control, 2002). A recent estimate for the U.S. is a FAS rate of 1.95 per 1,000 live births, although estimates run as high as 3.0 per 1,000 -- about 12,000 babies a year (Center on Addiction and Substance Abuse, 1996, p. 53.).

As American Indian and Alaska Native adults who can compete in the modern labor market leave their communities for higher paying jobs elsewhere, the number of adults who have fetal alcohol syndrome (FAS) or alcohol-related neurodevelopmental disorders (ARND) in these communities may become more inflated, and may become a more noticeable and significant problem requiring attention. People who are diagnosed with FAS/ARND are at high risk for mental retardation, learning disabilities, attention deficit disorder, and other disabilities.

In purely biological terms, American Indians and Alaska Natives are no more susceptible to FAS than people of any other race. However, for a variety of historical, social, economic, and political reasons, some small American Indian and Alaska Native communities, which may include the last native speakers of certain tribal languages, may not survive, and FAS could be a factor because of the effect it can have on family health and welfare. FAS is, first and foremost, a public health issue reaching across generations.

#### **STEPS TOWARDS HEALING AND WHOLENESS**

*Self-determination* has been a phrase to live by in Native communities since the Indian Self-Determination Act was passed in 1975. It is a marvelous concept and one to be embraced. But . . . What if you are a child, adolescent, or adult with prenatal exposure to alcohol? Self-determination can, if preventive steps are not taken, turn into self-termination. We embrace person-centered planning. However, this is not the same as person-dictated planning. American Indians and Alaska Natives place a high value on family and



community, and each has its place in the planning process. Thus, planning is collective as well as person-centered.

The purpose of this training manual is to provide vocational rehabilitation (VR) counselors, school counselors and other non-medical service providers with background information and tools as an adjunct to training. With this information, trainees will be better equipped to participate in planning more effective services for people with fetal alcohol syndrome (FAS) and related conditions, to fulfill educational or employment goals and to reach their full potential. This manual is intended to aid the trainee in the following areas:

- Understanding what fetal alcohol syndrome is and what it is not (Section I). This section of the manual presents the current definitions of FAS and ARND. Included in this section are a summary of the diagnostic process and an outline of the embryological origins of FAS.
- Recognizing and assessing primary and secondary disabilities associated with FAS/ARND (Section II). This section explores the common primary and secondary disabilities or conditions associated with FAS and ARND as well as their impact on long-term functioning and vocational placements.
- Screening for FAS or ARND (Section III). The third section explores the common tools used in the functional assessment of people with FAS and ARND. One of the items, the Fetal Alcohol Exposure Risk Assessment For Adolescents And Adults, is intended to help the vocational high school counselor screen for FAS/ARND and, if appropriate refer for a diagnostic evaluation or further testing.
- Developing an individualized plan for employment, education, services, or programs (Section IV). The fourth section is a practical guide for using the material gained through assessment and screening of the client to write a viable, appropriate, and practical individualized plan [(Individualized Education Plan (IEP), Individualized Service Plan (ISP), or Individualized Plan for Employment (IPE)]. Three case studies are provided to help

illustrate the points outlined above. Trainees are asked to use the knowledge gained to outline an appropriate plan for each of these case studies.

- Designing and aiding the implementation of an individualized plan (Section V). The fifth section shows trainees how to design and aid the implementation of an individualized plan. A fourth case study is provided to give trainees practice with this process.
- Evaluating how a plan is working and make adjustments (Section VI). This final section aids the trainee in learning how to provide ongoing program evaluation and implementing any needed changes.

# I. UNDERSTANDING WHAT FETAL ALCOHOL SYNDROME IS AND WHAT IT IS NOT

## TERMINOLOGY

*Fetal alcohol syndrome (FAS)* was first defined as a medical syndrome in 1973 by researchers at the University of Washington in Seattle (Jones & Smith, 1973; Aase, 1981; Little, Asker, Sampson, & Renwick, 1986). A syndrome is a constellation of features related to a common etiology, in this case prenatal alcohol exposure. All of the following items are required for the diagnosis of FAS (Astley & Clarren, 1997):

1. Confirmation of maternal alcohol exposure
2. Evidence of a characteristic pattern of facial anomalies
3. Evidence of growth retardation
4. Evidence of central nervous system (CNS) dysfunction

Other diagnostic categories addressing the existence of alcohol-related CNS damage occur in the absence of either facial abnormalities or marked growth deficiencies (Astley & Clarren, 1997; Stratton et al., 1996):

1. Partial FAS with confirmed maternal alcohol exposure
2. Atypical FAS
3. FAS without confirmed maternal alcohol exposure
4. Alcohol-related birth defects (ARBD), or Sentinel physical findings (a combination of key physical findings highly sensitive and specific to in utero alcohol exposure).
5. Fetal alcohol related conditions (FARC), including
  - a) Alcohol-related neurodevelopmental disorder (ARND)
  - b) Static encephalopathy (any unchanging physical abnormality in the brain)

c) Neurobehavioral disorder

It is in the fifth category (FARC) that the majority of clients affected by prenatal alcohol exposure are likely to fall. The three subcategories of FARC overlap considerably, and in this manual we will make no attempt to distinguish between them. *Alcohol-related neurodevelopmental disorder (ARND)* may be defined as follows:

*A history of maternal alcohol exposure, along with CNS abnormalities characteristic of FAS, and/or evidence of a complex pattern of behavior or cognitive abnormalities that are inconsistent with developmental level and cannot be explained by familial background or environment alone, such as learning difficulties, deficits in school performance, poor impulse control, problems in social perception, deficits in higher level receptive and expressive language, poor capacity for abstraction or metacognition, specific deficits in mathematical skills, or problems in memory, attention, or judgment (Stratton et al., 1996, p. 5).*

This category is similar to static encephalopathy (Astley & Clarren, 1997, p. 16), fetal alcohol-related conditions (FARC), or the previously used term, fetal alcohol effects (FAE). In this manual, we will use ARND and FAE interchangeably to encompass all those persons prenatally affected by alcohol who do not meet the dysmorphic criteria for FAS.

## DIAGNOSIS

Diagnosis is made by an expert trained in the assessment of birth defects. This can include specially trained physicians such as dysmorphologists, geneticists, pediatricians, neurologists, and obstetricians-gynecologists. Diagnosis should not be made by nurses, psychologists, teachers, vocational or school counselors, or physicians who do not have the training and experience required, because the diagnosis must differentiate

between FAS and certain genetic disorders that look similar to it, such as Fragile-X syndrome, Aarskog syndrome, Noonan syndrome, and Fetal Hydantoin Syndrome (Astley & Clarren, 1997, p. 2).

For many people, a diagnosis of FAS stigmatizes the birth mother. Therefore, diagnosis is a serious matter, and should be made by a *team* including, but not limited to, the dysmorphologist, an educational expert, a family or community advocate, a psychologist, a social worker, an occupational therapist, a speech and language expert, a public health nurse, and a VR counselor, if the client or student is an adolescent or adult. Each member of the team contributes significant input and, after diagnosis, serves as an advocate, support, and educational resource for the family. This is particularly important when it comes time for implementation of an individualized service, education, or employment plan.

This team model has been designed and implemented through the University of Washington in Seattle by Dr. Sterling Clarren and Dr. Susan Astley. This team approach is the center of a network of similar clinics being operated around the state of Washington and the United States (Clarren & Astley, 1997). This model is particularly helpful in that it accesses and utilizes resources currently in place in each community. It can also be an excellent guide for identifying where there are service gaps and providing information to community leaders about the best possible method to plug these gaps.

Diagnosis is based on an assessment of the factors outlined above (Astley & Clarren, 1997). In the Astley and Clarren system, each factor is ranked on a 4-point Likert scale and placed on a four-by-four grid (see below, p.59, Figure 3 for an illustration of this). The rank of each area is determined in conjunction with a diagnostic team and standard scores for each area. For example, growth is based on height and weight. Genetic factors, such as parental height, should be considered when determining if a client is truly growth deficient. Weight is adjusted for gender and age and then, based on the standard scores, a number is

assigned and placed into the grid. Weight is assessed over the life span of the client. The lower the overall pattern of weight, the higher the score on the grid, e.g., a client who was below the 5th percentile at birth and remains growth deficient would receive a score of 4 on the grid.

Facial abnormalities are assessed through measurements and comparison of the philtrum/upper lip area to a standardized chart. The length of the eye slit (palpebral fissure) and the distance between the eyes is measured. The smaller the eyes and the greater the distance between the eyes, the higher the score for the eye measurement. However, some ethnic groups may have different population standards for palpebral fissures (Stratton et al., 1996, p. 72), and the standards for American Indians and Alaska Natives are not well known. The eye measurement is figured in with the level of abnormality of the philtrum/upper lip area and assigned a score. This score is placed on the grid. Epicanthal folds are another facial feature that used to be considered characteristic of FAS, but this feature occurs naturally without FAS in American Indians and Alaska Natives, so its utility as a diagnostic feature has been questioned (Abel, 1998, pp. 77-78).

Evidence of brain (CNS) damage can include lower IQ scores, a small head (microcephaly), or testing results. IQ scores lower than 60, abnormalities on a brain scan or other objective tests, or a persistent pattern of neurologic findings, such as microcephaly or a diagnosed seizure disorder, would rate the client a score of 4 on brain damage.

To obtain a 4 on the grid for alcohol exposure, the client's mother or another reliable informant must confirm maternal prenatal use and report exposure that would produce a blood alcohol concentration greater than 100 mg% weekly, early in the pregnancy (Astley & Clarren, 1997). Lower frequency and amounts would result in a lower score on the grid. A rank of 2 means alcohol exposure unknown, and a rank of 1 means confirmed *absence* of gestational alcohol exposure.

Fours or threes in all of the above categories are required to receive a diagnosis of FAS. There are 256 different diagnostic codes based on this grid system. To be considered for a diagnosis of ARND, there must be evidence of both alcohol exposure and brain damage, e.g. through behavior or testing scores. As other developmental disabilities, personality disorders, and psychiatric disorders can also produce signs of brain damage, ARND cannot be considered a possibility without confirmed prenatal alcohol exposure.

In addition to the four factors outlined above, pre and postnatal trauma other than exposure to alcohol must be taken into account. For example, if a client has been sexually abused, this must be taken as a possible factor in rating the amount and type of CNS damage. If the mother was in a serious car accident prior to the client's birth, this must be taken into account in assessing the physical findings and brain damage. There are many of these factors, some of which will become clear in reading the case studies included in this manual. The Astley-Clarren grid can also be used as a screening and referral tool (see the section on Assessment for more information on this process).

### **Does It Help to Obtain a Diagnostic Examination?**

Streissguth (1994) suggests that a diagnostic examination answers several important questions for a family, and often for the person with FAS/ARND as well:

1. Understanding the cause of an adolescent's disability is usually a tremendous relief for the parents, whose child-rearing techniques were often blamed (perhaps incorrectly) for the adolescent's problems. As Julie Gelo (1996) put it, the diagnosis of her children with FAS helped her realize that "I'm not crazy." She added, "I was not the only parent who felt like they were beating their head against the wall – why weren't the parenting tactics working with these children when they had worked just fine with our other children?"
2. Understanding that an adolescent's developmental disabilities have a

biological origin can help a family sort out their expectations and develop a reasonable plan of action for the adolescent.

3. The diagnosis can be very helpful to the person with FAS/ARND, who has often wondered why they were not like everyone else, or why they were having such a hard time meeting expectations.
4. With a diagnosis, “Service doors crack open... When our children received their diagnosis, it opened many doors for additional funding and services that they would not have qualified for otherwise” (Gelo, 1996). The diagnosis can be particularly important in qualifying for developmental disabilities services.
5. Although a diagnosis of FAS/ARND may not be, by itself, sufficient to qualify an adolescent for special education, according to Gelo the diagnosis and accompanying recommendations “have enabled us to get the children an Individualized Education Plan at their schools. It has helped us work with educators as a team for the best interest of each individual child.” (Eligibility criteria for special education differ from one state to the next. In some states, the CNS dysfunction required as part of the diagnosis of FAS/ARND is enough to qualify a child for special education.)
6. A diagnosis maybe “very useful in setting up necessary medical management” for persons with FAS/ARND (Gelo, 1996), from medication management to referrals for additional services such as speech therapy. Speech therapy can include services for expressive language disorders, auditory processing difficulties, etc.

“In short,” Streissguth concludes, “understanding the cause helps everyone work toward effective interventions”(p. 73). Of course, in American Indian and Alaska Native communities, the “family” may be an extended family, including clan relatives. Diane Malbin has said that a diagnosis can help the person with FAS/ARND shift awareness from thinking that “I *am* the problem” to an awareness that “I *have* a problem.” She then added,



*After all, children with FAS, like the rest of us, have the need to make sense of their own behavior. In the absence of a diagnosis, well-meant interventions and therapies can be horribly inappropriate.* (Streissguth & Kanter, 1997, p. 205)

As a practical matter, however, Streissguth, et al. (1996) have shown that an early diagnosis of FAS/ARND is one of the most powerful factors associated with the *lack* of secondary “disabilities” (behavioral problems) later in life (pp. 25-28).

### EMBRYOLOGY

*Birth defects associated with FAS can vary, depending on when during gestation the fetus is exposed and how long the exposure continues.*

*Coles, 1994, p. 22*

The auditory, vestibular, ocular, CNS, and craniofacial systems are tied together embryologically, anatomically, and functionally. Congenital anomalies in one system are generally associated with anomalies in the other systems (Church & Kaltenbach, 1997). Alcohol is a powerful teratogenic (birth defect causing) drug. Organs form during the first 6 to 12 weeks after implantation of an embryo, so that exposure to any teratogen (such as alcohol) during that time can lead to gross structural malformations and other alcohol-related birth defects (ARBD), including the facial features characteristic of FAS. Brain development occurs throughout gestation and past birth (Figure 1). At any point during gestation, after implantation has occurred, the brain can be adversely affected by maternal alcohol consumption. Embryonic cells can be killed by maternally consumed alcohol, and neuronal cell populations may be particularly vulnerable. The brain damage associated with prenatal alcohol exposure is often due to the disruption of brain cell migration as the brain develops. Gross brain structures may be significantly reduced in size, resulting in microcephaly or the reduction in size of specific parts of the brain. Alcohol

can impair development of the corpus callosum, the band of connecting tissue between the right and left hemispheres. Ocular and auditory defects are also common. In fact, the presence of a congenital eye anomaly is usually thought to indicate the presence of an inner ear anomaly (Church & Kaltenbach, 1997). For these reasons, hearing and visual impairments are common in people with FAS. The face is also developing at this time, so that daily consumption or heavy binge drinking can impact fetal development, resulting in the classic face seen in FAS and used as part of the diagnostic criteria on the Astley-Clarren grid (see Section III). However, exposure of the fetus to alcohol does not always produce detectable effects.

**Figure 1. Vulnerability of Organ Systems during fetal development (Coles 1994, p. 23)**



1996) and are involved in the CNS dysfunction that is part of the definition of FAS and ARND.

Most fetal growth occurs in the third trimester. Alcohol consumed in the last trimester can lead to decreased fetal growth, brain damage, or more subtle physical problems. No amount of alcohol has been determined to be safe, and after implantation has occurred, no time during pregnancy is free from risk if alcohol is used by pregnant women.

## II. PRIMARY AND SECONDARY DISABILITIES ASSOCIATED WITH FAS AND ARND

### TERMINOLOGY

Brain damage caused by prenatal alcohol exposure cannot be cured, nor can the brain cells killed by alcohol be replaced. The effects of the brain damage can be reduced, and to some extent the brain can be rebuilt by constant repetition to develop new links between cells (synaptogenesis). However, the extent of brain repair in individuals with FAS/ARND has not been adequately studied. Current experience indicates that even with early intervention, brain damage and its associated behaviors are likely to persist across the life span.

This primary condition (brain damage) affects the individual's ability to function. The extent of these effects is determined by how much and when the mother drank during her pregnancy, and by individual characteristics. Associated with this primary condition, there may be comorbidity or co-occurring health conditions, as well as secondary conditions. For example, attention deficit hyperactivity disorder (ADHD) is often associated with FAS. It is a distinct disability that may co-occur with FAS but is not necessarily caused by FAS.

### **Primary Disability**

The VR system generally defines primary disability as the one that has the most functional limitations in terms of employment outcome. This means that the primary disability is relative to employment outcome and the person's previous work history. The primary disability is not necessarily the most severe disability, although it usually is.

A primary disability may also be thought of as a disability that one is born with (Streissguth, 1997). In the case of FAS, the primary disability results from brain damage and, as such, cannot be cured. FAS is generally considered a medical condition (coded as 760.71 in the ICD-9 CM system), and is not recognized per se as a disability. However, FAS may result in one or more recognized disabilities, such as mental retardation, or learning disability. But the word “primary” is relative: Medical people tend to understand primary as referring to the cause (e.g., prenatal alcohol exposure), whereas professionals in VR are more likely to understand primary as referring to the most functionally limiting in terms of employment outcome (e.g., attention deficit disorder).

#### **DISABILITIES COMMONLY ASSOCIATED WITH FAS/ARND**

Although people with FAS/ARND often have many disabilities, quantitative studies of comorbidity are few. People with FAS or ARND usually have at least one other disability. Having one disorder does not rule out the possibility of another. In the experience of the authors, and by many anecdotal reports available, multiple diagnoses appear to be the norm rather than the exception. In our research, we found an average of about 4 disabilities per American Indian/Alaska Native with FAS or ARND. In our data, the most common disabilities associated with people who have FAS or ARND were mental retardation, attention deficit hyperactivity disorder, depression (various types), learning disorders, and developmental delay: language deficits (Schacht, 2003). A study of 145 persons with FAS/ARND in Alaska (Colberg, 1997) showed that 41% of them had speech or language delay, 35% had fine or gross motor delay, 28% had short attention span or attention deficit disorder (ADD), and 20% had learning disability or mental retardation. Most of these 145 people (83%) were Alaska Natives. Multiple disabilities were common. In another study in Alaska of 36 children with FAS, 34% had a speech impairment, 20% had mental retardation, 20% had learning disabilities, 14% had “pre-school disabilities” (developmental delays), 6% had serious emotional disturbance, and

6% had multiple disabilities (Gessner, Bischoff, Perham-Hester, Chandler, & Middaugh, 1998). The critical thing to ask is this: are these really independent disorders, each with its own unique organic cause and its own unique treatment strategy, or are they linked by a common etiology (fetal exposure to alcohol) requiring a comprehensive integrated treatment strategy? If the latter, does a comprehensive, integrated rehabilitation plan make more sense than a piecemeal approach that treats each disability separately? While FASD is not necessarily a causal agent in the disorders listed, it can change the clinical presentation and articulation of symptoms by the patient.

### **Learning Disabilities (NEW)**

The term “learning disability” was apparently first used and defined by Kirk (1962, cited in Streissguth, Bookstein, Sampson, & Barr, 1993, p.144). The term referred to a discrepancy between a child’s apparent capacity to learn and his or her level of achievement. A review of the LD classifications for 49 of 50 states revealed that 28 of the states included IQ/Achievement discrepancy criteria in their LD guidelines (Ibid., citing Frankenberger & Harper, 1987). However, the National Joint Committee for Learning Disabilities (NJCLD)(1981; 1985) preferred a slightly different definition:

*‘Learning disabilities’ is a generic term that refers to a heterogeneous group of disorders manifested by significant difficulties in the acquisition and use of listening, speaking, reading, writing, reasoning or mathematical abilities. These disorders are intrinsic to the individual and presumed to be due to central nervous system dysfunction. Even though a learning disability may occur concomitantly with other handicapping conditions (e.g., sensory impairment, mental retardation, social and emotional disturbance) or environmental influences (e.g., cultural differences, insufficient/inappropriate instruction, psychogenic factors), it is not the direct result of those conditions or influences. (as cited in Streissguth et al., 1993; see also NJCLD, 1985).*

Thus there are two different views of LD: one that defines it in terms of a *difference* between IQ and achievement, and another that defines it as being below normal on *both* indices. A more recent definition of LD, by the Interagency Committee on Learning Disabilities (ICLD) (1989), does not mention IQ as a defining characteristic:

*Learning disabilities is a generic term that refers to a heterogeneous group of disorders manifested by significant difficulties in the acquisition and use of listening, speaking, reading, writing, reasoning, or mathematical abilities, or of social skills. These disorders are intrinsic to the individual and presumed to be due to central nervous system dysfunction. Even though a learning disability may occur concomitantly with other handicapping conditions (e.g., sensory impairment, mental retardation, social and emotional disturbance), with socioenvironmental influences (e.g., cultural differences, insufficient or inappropriate instruction, psychogenic factors) and especially attention deficit disorder, all of which may cause learning problems, a learning disability is not the direct result of those conditions or influences.*

The DSM-IV uses the term “Learning Disorder (*formerly Academic Skills Disorders*)”, that seems to follow the NJCLD definition:

*Learning Disorders are diagnosed when the individual’s achievement on individually administered, standardized tests in reading, mathematics, or written expression is substantially below that expected for age, schooling, and level of intelligence. The learning problems significantly interfere with academic achievement or activities of daily living that require reading, mathematical, or writing skills. A variety of statistical approaches can be used to establish that a discrepancy is significant. **Substantially below** is usually defined as a discrepancy of more than 2 standard deviations between achievement and IQ. A smaller discrepancy between achievement and IQ (i.e., between 1 and 2 standard deviations)*



*is sometimes used, especially in cases where an individual's performance on an IQ test may have been compromised by an associated disorder in cognitive processing, a comorbid mental disorder or a general medical condition, or the individual's ethnic or cultural background. If a sensory deficit is present, the learning difficulties must be in excess of those usually associated with the deficit. Learning Disorders may persist into adulthood.*

*Demoralization, low self-esteem, and deficits in social skills may be associated with Learning Disorders...Adults with Learning Disorders may have significant difficulties with employment or social adjustment. Many individuals (10%-25%) with Conduct Disorder, Oppositional Defiant Disorder, Attention-Deficit/Hyperactivity Disorder, Major Depressive Disorder, or Dysthymic Disorder also have Learning Disorders... There may be underlying abnormalities in cognitive processing (e.g., deficits in visual perception, linguistic processes, attention or memory, or a combination of these) that often precede or are associated with Learning Disorders. Standardized tests to measure these processes are generally less reliable and valid than other psychoeducational tests...Learning Disorders are...frequently found in association with a variety of general medical conditions (e.g., lead poisoning, fetal alcohol syndrome, or fragile X syndrome.) (DSM-IV pp.46-47, emphasis added in last sentence.)*

This approach to learning disabilities resulted in the definition of the following Learning Disorders:

- 315.00 Reading Disorder
- 315.1 Mathematics Disorder
- 315.2 Disorder of Written Expression
- 315.9 Learning Disorder Not Otherwise Specified

The last category might include problems in *all three areas* that together

significantly interfere with academic achievement even though tests measuring each individual skill is not substantially below that expected given the person's chronological age, measured intelligence, and age-appropriate education (DSM-IV, p.53).

Sometimes cultural or ethnic differences in learning patterns can be mistaken for a learning disorder, but the DSM-IV definition of learning disorders excludes this possibility:

*Learning Disorders must be differentiated from **normal variations in academic attainment** and from scholastic difficulties due to **lack of opportunity, poor teaching, or cultural factors.** (p. 47, emphasis in original.)*

A culturally competent diagnostician will not diagnose a learning disorder on this basis (pp 47-48). All of these factors must be taken into account when making a diagnosis or providing treatment.

### **IDEA Definition**

One other definition of importance is provided in the Individuals with Disabilities Education Act (IDEA). The federal government defines learning disabilities in Public Law 94-142, as amended by Public Law 101-76 (IDEA):

*Specific learning disability means a disorder in one or more of the basic psychological processes involved in understanding or in using language, spoken or written, which may manifest itself in an imperfect ability to listen, think, speak, read, write, spell, or to do mathematical calculations. The term includes such conditions as perceptual handicaps, brain injury, minimal brain dysfunction, dyslexia, and developmental aphasia. The term does not include children who have problems that are primarily the result of visual, hearing, or motor disabilities, or mental retardation, emotional disturbance, or of environmental, cultural, or economic disadvantage.*

This definition resembles the ICLD definition given above in that it does not

refer to a discrepancy between IQ and achievement. Thus, the differences in the 1980s definitions of the NJCLD and ICLD are perpetuated in the differences between the DSM-IV and IDEA of the 1990s, and these differences are also perpetuated among the states. According to Jean Lokerson (1992, p. 99),

*Although the definition in federal law governs the identification of and services to children with learning disabilities (LD), there are variations between states and among school systems. In an attempt to clarify the identification, some states specify an intelligence range. Others add a concept of a discrepancy between potential and achievement, sometimes quantifying the discrepancy using test scores. These slightly different "yardsticks" are indicative of a lack of clear consensus about exactly what learning disabilities are.*

Streissguth, et al. (1993, 145, 147-152) were able to show that prenatal exposure to alcohol statistically predicts the NJCLD type of LD that has evolved into the DSM-IV definition, but not Kirk's type of LD, which has evolved into the IDEA definition. According to Johnson (1999, p.22), other more anecdotal sources seem to distinguish the learning problems associated with FAS/ARND from those associated with LD (Burgess & Streissguth, 1992; Kleinfeld, 1993; Morse 1993), "presumably on the basis of the differing neurological etiologies of the learning problems." Johnson (1999, pp.23f.) has developed a parallel list of learning problems in children with FAS/FAE and children with Learning Disabilities, shown below as Table 1. In general, the learning problems of children with FAS/ARND may be more intractable than in students with learning disabilities (shown in table by "\*"). Differences in the table are highlighted in *italics*. The point here is that LD *with* FAS/ARND is not necessarily the same as LD *without* FAS/ARND, and that treatment strategies that work with the latter may not work as well with the former.

<b>Table 1. Learning Problems in Children with FAS/FAE, and with Learning Disabilities</b>	
<b>Children with FAS/FAE</b>	<b>Children with LD</b>
IQ range 20-130	IQ range same as normal population
*Slow development of early language, including articulation	<i>May have</i> slow development of early language, including articulation
*Problems with sound/symbol relationships & phonological awareness	Problems with sound/symbol relationships & phonological awareness
*Problems with storage and retrieval of information	Problems with storage and retrieval of <i>linguistic</i> information
*Slow to process language	<i>May be</i> slow to process language
*Problems with spelling, reading, writing, and math	Problems with spelling, reading, writing, and <i>sometimes</i> math
*Difficulty with abstract relationships	<i>May have</i> difficulty with abstract relationships
*May be able to decode but struggle with comprehension	May be able to decode but struggle with comprehension
*Poor cognitive processing, <i>especially executive and strategic processes</i>	<i>May have</i> poor cognitive processing
(Not known)	<i>May have reversals in reading and writing</i>
*Impulsive; lack of awareness of consequences	<i>May be</i> impulsive; <i>may show</i> lack of awareness of consequences
*Problems organizing ideas, things, time	Problems organizing ideas, things, time
*Poor short and/or long term memory	Poor short and/or long term memory
*Poor sequencing, especially instructions	Poor sequencing, especially instructions
*Problems generalizing from one activity or situation to another	Problems generalizing from one activity or situation to another
*Transitions between activities are often difficult, <i>and may cause child to withdraw or be disruptive</i>	Transitions between activities <i>may be</i> difficult
*Poor communication skills, especially pragmatics of language	<i>May have</i> poor communication skills, especially pragmatics of language
*Variability; marked difference between “good days” and “bad days”	<i>May show</i> variability; marked difference between “good days” and “bad days”
*At risk for developing secondary problems such as depression, anxiety, substance abuse, <i>trouble with the law</i>	At risk for developing secondary problems such as depression, anxiety, substance abuse

Barbara Morse (1993, p.32) expressed learning disabilities in terms of information processing deficits:

*Information processing deficits were first defined in the 1960s to represent learning disabilities in four domains: input, integration, memory, and output. Input represents the recording of information from the senses. Memory represents the storage of information for later use. Integration is the process of interpreting the input. Output requires appropriate use of language and motor skills. Many people have a learning disability in one or two areas; children with FAS seem to have processing deficits in all areas.*

Dodd, Fischer, Ostwald and Rose (1992) reviewed LD issues with respect to the vocational readiness of American Indian adolescents. They assessed the skills and interests of American Indian adolescents who had been identified with LD that could be used to seek and maintain employment, and obtained work samples and vocational interest data from American Indian adults with LD who were attending a tribal college that provided services for American Indians with disabilities. Their recommendations included teaching specific vocational and job-seeking skills to American Indian students with LD (pp. 62-63).

The course of LD disorders can be mild to severe. Some children with learning disorders or those with intensive, early, and appropriate interventions can make progress. For some people, these are permanent disorders affecting their academic, vocational, and social functioning throughout life. A school psychologist, clinical psychologist, psychiatrist, or other qualified specialist can make this diagnosis. If there is a head trauma or other medical problem (such as encephalitis), a physician should be on the diagnostic team (LaDue, n.d., 199).

- A study of 145 FAS/ARND cases in Alaska (Colberg, 1997) showed that 41% of the cases had speech or language delay, 28% had short attention span or attention deficit disorder (ADD), and 20% had learning disability

or mental retardation. Most of these 145 cases (83%) were Alaska Natives. Multiple disabilities were common.

- In another study in Alaska of 36 children with FAS, 34% had a speech impairment, 20% had learning disabilities (Gessner, Bischoff, Perham-Hester, Chandler, & Middaugh, 1998).

A somewhat more indirect measure of learning disabilities is “Disrupted school experience”(DSE), one of the “secondary disabilities” of FAS/FAE defined by Streissguth, Barr, Kogan & Bookstein (1996, p.37-41). Persons who were ever suspended from school, expelled from school, or dropped out of school were considered to have DSE. Among male teenagers, at least 70% had had DSE. Among female teenagers, 40% of those with FAS had DSE, compared with 50% of those with FAE. But among adults, the results by sex were reversed: More females than males had DSE. For both teenagers and adults, persons with “FAE” had more DSE (>70%) than persons with FAS (42% [males], 52% [females]). In this study, 40% of the clients with FAS/FAE were known to have been in special education, more than 60% had received remedial intervention for reading, more than 60% for arithmetic, about 45% for written language, and about 42% for speech problems.

Closely related to the Learning Disorders in the DSM-IV are the Communication Disorders, including

- 315.31 Expressive Language Disorder
- 315.31 Mixed Receptive-Expressive Language Disorder.

Codes for the two disorders are the same, but the DSM-IV distinguishes between their diagnostic features (DSM-IV pp. 55-60).

### **Depression (NEW)**

Connor and Kasari (2000) found that prenatal alcohol exposure, maternal depression, and child gender seemed to be highly associated with child depressive symptoms. Girls who had higher levels of prenatal alcohol exposure

and whose mothers acknowledged higher levels of depression endorsed the highest number of depressive symptoms. Connor (personal communication, June 25, 2001) added,

*Usually the psychiatric literature notes that maternal alcohol consumption is correlated with mood disorder in children. They interpret this to mean that living with an alcoholic mother increases stress associated with succumbing to the disorder. They do not look at the possibility that children of alcoholic women may also have prenatal alcohol exposure in their histories.*

Depression is far more common in children and adolescents than is typically acknowledged. It is a disorder characterized by a depressed mood most of the time. Adolescents and adults often present as being irritable. Other signs of depression include a loss of interest in activities, sleeping too much, losing or gaining weight, feelings of low self-worth and self-esteem, and difficulties concentrating and paying attention may also be seen. People with FAS/ARND (especially if undiagnosed) are particularly susceptible to feelings of low self-worth and self-esteem because of their disabilities. They may blame themselves for their disability-related problems, not knowing what is wrong. Adolescents and adults with depression may be aggressive and angry. Suicidal thoughts and attempts can also occur.

This is a serious disorder that can occur throughout life and can be related to losses in the person's life. It may also have a genetic component in how much at risk a person is to experience depression. There are many types of medication available to treat depression. Psychotherapy can also be useful. A psychologist, psychiatrist, or other qualified health professional should make this diagnosis (LaDue, n.d., 198f.) In a large (n=415) clinical sample of adolescents and adults with FAS or FAE, 42% of the teenagers and 52% of the adults with FAS/FAE were reported to have depression problems. In addition, 43% had made suicide threats, and 23% had made suicide attempts (Streissguth, Barr, Kogan, & Bookstein, 1996, 35).

### **Mental Retardation (NEW)**

The concept of mental retardation (MR) has evolved considerably over the past 100 years, as things we thought we knew about MR have been exposed as stereotypes, and new understandings about the potential and abilities of persons with MR have been revealed. Even basic issues of definition have undergone significant change (Crane, 2002).

According to the *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV)*, Mental retardation (MR) is characterized “by significantly sub-average intellectual functioning (an IQ of approximately 70 or below) with onset before age 18 years and concurrent deficits or impairments in adaptive functioning” (DSM-IV: American Psychiatric Association, 1994, p. 37). Subcategories differentiated by IQ scores include (DSM-IV, p. 40)

• 317 Mild MR	IQ Level 50-55 to approximately 70
• 318.0 Moderate Retardation	IQ Level 35-40 to 50-55
• 318.1 Severe MR	IQ Level 20-25 to 35-40
• 318.2 Profound MR	IQ Level Below 20 or 25
• 319 MR, Severity Unspecified	

The dividing line between categories is given as a range because IQ scores may involve a measurement error of approximately 5 points. IQ scores are supposed to be unaffected by culture or language, but this assumption has been challenged (see Beiser & Gotowiec, 2000, for a review of the literature and new research). This is an important issue for American Indians and Alaska Natives, because their children have lower average IQ scores than their dominant-culture counterparts. Explanations of this difference refer to differences in Socio-Economic Status (SES), cultural differences, stressful life events, and pre-and perinatal biological factors. Beiser and Gotowiec noted that “Low SES reliably predicts low IQ scores” (p. 238). Native versus non-Native IQ score differences were more pronounced for verbal than for performance



subscales. The authors' concluding discussion began with the observation that "Failure to distinguish between IQ scores and the complex construct of 'intelligence' has kindled a great deal of controversy" (p. 247). Their study found that Native children's verbal IQ scores were nearly 1.5 standard deviations lower than non-Native children's. The most significant control variables explaining this difference were SES, maternal pre- and perinatal health, differences in English language skills, and parents' "cultural attitudes." They conclude with the observation that

*The study results support the contention of no less an authority than Binet that the IQ test does not measure anything innate or permanent. In another of his tenets about testing, Binet stated that low IQ scores do not necessarily signify innate incapacity... The results of the current study... support the idea that environmental circumstances exert profound effects on IQ score, verbal performance in particular. (pp.251-252)*

But while it may be true that the IQ scores of American Indians and Alaska Natives with FAS/ARND may appear to be lower than they actually are, this does not necessarily mean that they are less impaired. What it does mean is that an assessment of the severity of cognitive impairment should not be based solely on IQ tests.

The most common "predisposing factor" for mental retardation cited by the DSM-IV is "early alterations of embryonic development," which account for about 30% of the cases of MR. This factor includes "prenatal damage due to toxins (e.g., maternal alcohol consumption...)" (DSM-IV, p. 43). Thus, prenatal alcohol exposure is recognized as one of the major predisposing factors in MR.

The IQ issue is important because an IQ of 70 or less is often used as the primary criterion for eligibility for developmental disabilities (DD) services. DD eligibility is one of the most powerful factors protecting a person with FAS/ARND from the development of secondary disabilities (Streissguth et al., 1996, pp. 25-28).

"Borderline Intellectual Functioning" (DSM-IV Code V62.89) describes

an IQ range that is higher than that for Mental Retardation (generally 71-84). Because of the measurement error, the DSM-IV observes that “Differentiating Mild Mental Retardation from Borderline Intellectual Functioning requires careful consideration of all available information” (p.45), and “is especially difficult when the coexistence of certain mental disorders (e.g., schizophrenia) is involved” (p. 684). It may therefore be the case that FAS/ARND is one of those mental disorders that makes such differentiating difficult.

FAS is the leading known cause of mental retardation, surpassing both Spina Bifida and Down’s Syndrome (Cook, et. al., 1990, p. 17; Streissguth, Aase, Clarren, Randels, LaDue, & Smith, 1991; National Institute on Alcohol Abuse and Alcoholism [NIAAA], 1993; Abel & Sokol, 1987). However, in a large clinical sample, only 27% of FAS patients and 9% of “FAE” patients had an IQ of 70 or less (Streissguth, Barr, Kogan & Bookstein, 1996, 20). Other studies include:

- A study of 145 FAS/ARND cases in Alaska (Colberg, 1997) showed that 20% had learning disability or mental retardation. Most of these 145 cases (83%) were Alaska Natives. Multiple disabilities were common.
- In another study in Alaska of 36 children with FAS, 20% had mental retardation (Gessner, Bischoff, Perham-Hester, Chandler, & Middaugh, 1998).

### **Receptive-Expressive Language Disorder (NEW)**

Receptive-Expressive Language Disorder is based on standardized test scores (e.g. IQ test scores), as well as on behavior (DSM-IV, p. 58-61). It is characterized by delays and impairment in receptive language skills where the child has difficulty “translating” language into usable information and expressive language skills where the child has a limited vocabulary, difficulty producing words and using sentences, and not using tenses correctly. Onset is generally before the age of 4. However, this disorder can occur if there is some type of physical trauma later in childhood, e.g. a head injury. With intervention,

some children can develop normal language. This may not occur in children with significant brain damage. If the disorder is severe enough, it may lead to a learning disorder.

The DSM-IV description of the diagnostic features of Mixed Receptive-Expressive Language Disorder includes the following (pp.58, 59):

*The essential feature of Mixed Receptive-Expressive Language Disorder is an impairment in both receptive and expressive language development as demonstrated by scores on standardized individually administered measures of both receptive and expressive language development that are substantially below those obtained from standardized measures of non-verbal intellectual capacity (Criterion A). ...The language difficulties interfere with academic or occupational achievement or with social communication (Criterion B), and the symptoms do not meet the criteria for Pervasive Developmental Disorder (Criterion C).*

*...Because the development of expressive language in childhood relies on the acquisition of receptive skills, a pure receptive language disorder (analogous to a Wernicke's aphasia in adults) is virtually never seen.*

Associated features and disorders include (p.59):

*Conversational skills (e.g., taking turns, maintaining a topic) are often quite poor or inappropriate. Deficits in various areas of sensory information processing are common, especially in temporal auditory processing (e.g., processing rate, association of sounds and symbols, sequence of words and memory, attention to and discrimination of sounds). ...Phonological disorder, **Learning Disorders**, and deficits in speech perception are often present and accompanied by memory impairments. Other associated disorders are **Attention-Deficit/Hyperactivity Disorder**, **Developmental Coordination Disorder**, and **Enuresis**. [Bold emphasis added.]*

Other related disorders may include Central Auditory Processing Disorder (CAPD), and serous otitis media.

The DSM-IV (p.59) adds this note on specific culture and gender features:

*Assessments of the development of communication abilities must take into account the individual's cultural and language content, particularly for individuals growing up in bilingual environments. The standardized measures of language development and of nonverbal intellectual capacity must be relevant for the cultural and linguistic group.*

A school psychologist, clinical psychologist, psychiatrist, or other qualified specialist should make this diagnosis. If there is a head injury or other medical problem (e.g. encephalitis), a physician should be on the diagnostic team.

Language disorders can impact a person's performance across many aspects of life, and certainly vocational development is no exception. Persons with FAS/ARND may be talkative, but what they say can sometimes seem inappropriate or out of place. They have been described as "talking too much and too fast, but having little to say" (Streissguth, LaDue, & Randels, 1988, p. 31). The capacity for verbal output may exceed their ability to process verbal output: They may find it difficult to absorb and recall a simple list of instructions. However, "careful observation and testing may be able to illustrate high levels of competence in non-language based problem solving (e.g. Block Design on the WISC-R) and may help to differentiate the language disabled student from the child with Fetal Alcohol Syndrome" (Wegmann, Colfax, Gray, & Reed, 1998, p. 31).

### **Central Auditory Processing Disorder**

Children with FAS may be at elevated risk for Central Auditory Processing Disorder (CAPD) (Barker, personal communication), which affects the way the brain processes the sound that the ears hear. According to Kaufman (2003),

*A CAPD is a receptive language disorder. It refers to difficulties in*

*the decoding and storing of auditory information (typically incoming verbal messages). This type of receptive language disorder is a result of genetic factors and/or early otitis media though causal factors may not be able to be found.*

According to Paton (n.d.a), CAPD can also be caused by an insufficient number of nerve cells:

*The auditory system must convey the speech sounds (they are not yet identified as words) without distortion up to the cortex of the brain. Here the temporal lobe organizes them into words and the information is routed to other centers of thought, action, sight, and so on.*

*For all these jobs to be done we need several conditions. There must be enough nerve fibers to share the work and no cell loss from such conditions as lack of oxygen at birth or failure of development embryologically. Also, the nerves must all transmit at normal speed, not slower in spots as when the brain is swollen (this can happen with head injuries or strokes and, some people believe, with certain allergies). The brain must be able to produce proper amounts of chemical neurotransmitters for the nerves to carry their messages*

Since alcohol is a known teratogen that can kill nerve cells, it is not surprising that an association between FAS and CAPD has been suggested (Conry 1996, Language Development, p.2).

Learning disorders can be caused by difficulties in sensory input, such as Central Auditory Processing Disorder (CAPD) (Paton, n.d.a; n.d.b):

*A CAPD is a physical hearing impairment, but one which does not show up as a hearing loss on routine screenings or an audiogram. Instead, it affects the hearing system beyond the ear, whose job it is to separate a meaningful message from non-essential background sound and deliver that information with good clarity to the intellectual centers of the brain (the central nervous system) [n.d.b].*

There is currently some debate about exactly what CAPD is, what causes it, and how it is related to other language and learning disorders, and how special education services might be affected (Durkel, 2001). The American Speech-Language-Hearing Association (ASHA) defined CAPD this way (ASHA, n.d.):

*A central auditory processing disorder (CAPD) occurs when auditory centers of the brain are affected by injury, disease, tumor, heredity or unknown causes. CAPD does not necessarily involve (although it may) hearing loss. Central auditory processing involves sound localization and lateralization, auditory discrimination, auditory pattern recognition, the temporal aspects of sounds, and the ability to deal with degraded and competing acoustic signals. Therefore, a deficiency in one or more of the above listed behaviors may constitute a central auditory processing disorder. CAPD is often associated with Attention Deficit disorder (ADD) or Attention Deficit Hyperactivity Disorder (ADHD).*

Malbin (1993) has suggested that slow processing of auditory or visual stimuli may result in slow cognitive pace, meaning that persons with FAS/ARND may need longer to process information than other people (Johnson, 1999, 29). Malbin has sometimes spoken of children with FAS/ARND as “ten second children in a one second world” as a way of expressing their slower processing speed (Personal communication, September 27, 2002).

### **Attention Deficit Hyperactivity Disorder (NEW)**

Attention Deficit Hyperactivity Disorder (ADHD) is a diagnosis that is commonly given to adolescents with FAS/ARND (Coles, 2001). In fact, some have suggested that ADHD is a core feature of FAS (Kopera-Frye et al., 1997, and Oesterheld & Wilson, 1997, cited in Coles, Platzman, Lynch & Freides,

2002). It is characterized by an inability to concentrate or pay attention. A higher level of physical activity is also seen in adolescents with ADHD than their age-mates. The difficulties in attending to information, along with the higher level of activity must cause problems in social, school, or work functioning in order for the adolescent to receive this diagnosis. Abnormal impulsivity, being “fidgety” to an abnormal degree, and abnormal impatience are among the commonly seen behaviors in adolescents with ADHD. Medication is often used and can be helpful, as is clear, concise and consistent structure. These problems must be present prior to the age of 7 for this to be considered an accurate diagnosis. A psychologist, psychiatrist, pediatrician, or other qualified health professional should make this diagnosis (LaDue, 2002, pp. 233-234; DSM-IV).

The DSM-IV devotes significant space to this disorder (pp.78-85). They distinguish two main varieties of the disorder, one with hyperactivity (ADHD) and one without hyperactivity (ADD):

- 314.00 Attention-Deficit/Hyperactivity Disorder, Predominantly Inattentive Type [ADD]
- 314.01 Attention-Deficit/Hyperactivity Disorder, Predominantly Hyperactive-Impulsive Type [ADHD]
- 314.01 Attention-Deficit/Hyperactivity Disorder, Combined type

The diagnostic criteria include 9 symptoms of “inattention,” 6 symptoms of “hyperactivity”, and 3 symptoms of “impulsivity.” The diagnosis of ADD requires the persistence of at least 6 of the 9 symptoms of inattention for at least 6 months. The diagnosis of ADHD requires at least 6 of the 9 symptoms of hyperactivity and impulsivity. The diagnosis for the Combined Type is made if the requirements for both inattention and hyperactivity-impulsivity are met.

In a large (n = 415) clinical sample, 61% of the teenagers and 42% of the adults with FAS or FAE had attention deficit problems (Streissguth, Barr, Kogan, & Bookstein, 1996, 35). In addition, 70% of the teenagers and 68% of the adults had “repeated attention problems” (p.38). In addition, a study of 145

FAS/ARND cases in Alaska (Colberg, 1997) showed that 28% had short attention span or attention deficit disorder (ADD). Most of these 145 cases (83%) were Alaska Natives. Multiple disabilities were common.

However, AD(H)D and FAS are diagnosed in different ways. ADHD is not usually diagnosed by neurocognitive tests of attention, but instead relies on clinical observation and parent and teacher reports. Seldom is any attempt made at a differential diagnosis in comparison with FAS. Coles (2001) made a controlled clinical study of children, some diagnosed with FAS/ARND, and some diagnosed with AD(H)D. She found that

- Prenatal alcohol exposure was not associated with ADHD as it is usually defined;
- The performance pattern was not the same for children with ADHD as those with FAS/ARND: Those in the ADHD group had difficulty in selective and sustained attention and were more impulsive, whereas those in the FAS/ARND group had more difficulty learning new material and in utilizing flexibility in problem-solving.

Coles concluded (p.201),

*These results call into question the assumption that behavior seen in children with FAS results from the same neurocognitive deficits as those seen in children diagnosed with ADHD. Our comparison of these groups of children showed that even though their impairment on tests of global intelligence was similar, little similarity existed in their pattern of responses. Further, their behavior problems also differed...Although similar to some findings..., these results are inconsistent with reports that have identified deficits in focusing and sustaining attention in alcohol-exposed longitudinal samples... and ADHDlike behavior among FAS-FAE patients...*

Thus, while people with FAS/ARND may manifest behaviors similar to those of people with ADHD, closer analysis of dimensions of attention measured by



Coles such as Focus, Shift, Sustain, and Encode may provide the basis for a differential diagnosis of these conditions. In a subsequent study, Coles, Platzman, Lynch and Freides (2002) examined the “Sustain” function in greater detail and found that the differences between adolescents with ADHD and those with FAS/ARND were mainly in visual modalities.

To summarize, many individuals with FAS/ARND have ADHD symptoms. However, according to Coles, the attention problems of children with ADHD and children with FASD differ. In addition, children with FAS/ARND have more problems with social-communication, sensory integration, and fine and gross motor skills than those with ADHD. (LaDue, 2002, p. 234)

In conclusion, although a useful differential diagnosis between FAS/ARND and AD(H)D has not yet been established, it must be remembered in the meantime that some persons casually diagnosed with ADHD might actually have FAS/ARND, and that interventions designed for persons with ADHD may not work as well for persons with FAS. In summary,

*For those with ADHD, some special education and vocational services might be available, but most individuals with FASD are far more disabled throughout their lifespan than those with ADHD alone.* (LaDue, 2002, p. 230).

### **Oppositional Defiant Disorder (ODD) (NEW)**

LaDue (2002) included ODD as one of the “Diagnoses commonly associated with Fetal Alcohol Syndrome and Fetal Alcohol Related Conditions.” She observed that

*Children with FASD may become frustrated and irritated when over stimulated. They may be disturbed when they cannot understand what is being asked of them. Children with FASD often do not have the behavioral repertoire to respond with a variety of options. In situations where they have to generate their own answers or responses rather than*

*having information given to them in simple and understandable ways, they are likely to be even more aggravated. (pp. 238-239).*

This may result in the symptoms of ODD in the years between 8 years of age and early adolescence (DSM-IV, p. 92). The DSM-IV notes that

*Attention-Deficit/Hyperactivity Disorder is common in children with Oppositional Defiant Disorder. Learning Disorders and Communication Disorders also tend to be associated with Oppositional Defiant Disorder...*

*Oppositional behaviors must also be distinguished from the disruptive behavior resulting from inattention and impulsivity in **Attention-Deficit/Hyperactivity Disorder**. When the two disorders co-occur, both diagnoses should be made... Oppositional Defiant Disorder must also be distinguished from a failure to follow directions that is the result of **impaired language comprehension** (e.g., hearing loss, Mixed Receptive-Expressive Language Disorder)... A diagnosis of Oppositional Defiant Disorder should be considered only if the behaviors occur more frequently and have more serious consequences than is typically observed in other individuals of comparable developmental stage and lead to significant impairment in social, academic, or occupational functioning (pp. 92-93, emphasis in original).*

The diagnosis of ODD requires that the symptoms persist for at least 6 months and is characterized by the frequent occurrence of at least four of eight problem behaviors, which include

1. losing temper;
2. arguing with adults;
3. actively defying or refusing to comply with the requests or rules of adults;
4. deliberately doing things that will annoy other people;
5. blaming others for his or her own mistakes or misbehavior;
6. being touchy or easily annoyed by others;

7. being angry and resentful; and
8. being spiteful or vindictive (DSM-IV, p. 91).

What is interesting about this list is how much it involves subjective impressions of the person's intentions and motivations, which may be misinterpreted. As Diane Malbin (n.d.) observed,

*The belief that many primary learning and behavioral characteristics that may reflect the underlying neuropathology associated with FAS are the result of willful, volitional or intentional behaviors often leads to punishment of these symptoms. Inadvertently, this may in turn result in the development of an array of secondary defensive behaviors. ... The key to prevention is linking the idea of brain dysfunction with presenting behaviors, reframing perceptions, and moving from punishment to support. The shift is from seeing a child as one who "won't" do something to one who possibly "can't".*

Thus, some behaviors that may *seem to be* oppositional and defiant may instead be coping manifestations of a neurological disorder. Therefore, special care needs to be taken to avoid misdiagnosis of this condition.

#### **OTHER COMORBID MEDICAL CONDITIONS AFFECTING DISABILITIES**

Children with FAS are reported to have high rates of visual and hearing problems (Stratton, Howe & Battaglia, 1996, 157). The development of the brain is closely tied in the developing embryo to the development of the sense organs, especially hearing and seeing. Because of this, developmental anomalies in these sensory systems are common, and if present they may result in Learning or Communication Disorders (see above).

#### **Hearing Impairments and Otitis media**

Alcohol-related birth defects may include conductive hearing loss or neurosensory hearing loss (Stratton, Howe & Battaglia, 1996, pp. 4-5).

*Increased frequencies of both conductive and neurosensory hearing*

*problems are found in children with FAS...a history of recurrent otitis media or delays in speech should also alert the clinician to the possibility of hearing loss* (p. 157).

The frequency of *recurrent serous otitis media* (middle ear infection) is reported to be higher among children with FAS, and appears to be associated with Eustachian tube dysfunction secondary to embryonic malformations of the first and second branchial arches (Church, 1987; Church & Gerkin, 1988). In fact, Johnson (1979) suggested that continuing otitis media be included as a possible manifestation of FAS, and similarly, FAS should be added to the differential diagnosis of persistent otitis media during infancy. Otitis media, particularly recurrent *serous* (with secretion) otitis media, deserves attention “because of the particularly high prevalence of the disease and associated disabilities among American Indians” (U.S. Congress, Office of Technology Assessment, 1990; as cited in Mendola, Buck, & Starr, 1994, p. 37). Otitis media is associated with disabilities such as hearing deficits, reading disorders, language delays, and poorly defined long-term outcomes (Zinkus, Gottlieb & Schapiro, 1978; as cited in Mendola, Buck, & Starr, 1994).

Church, Eldis, Blakley, and Bawle (1997) cited a study reporting a high incidence (29%) of hearing impairment due to sensori-neural hearing loss (SNHL) in a group of 14 children with FAS. Their own study of 22 FAS patients showed that 27% had mild SNHL, 82% had receptive language deficits, and 73% had expressive language scores more than one standard deviation below the norm for their chronological ages. They concluded that “virtually every FAS patient with a language disorder also had a hearing disorder and vice versa” (p. 231).

### **Visual Impairments**

Alcohol-related birth defects may include small optic globes (short palpebral fissures, a defining feature of the “FAS face”), strabismus, retinal vascular anomalies, and refractive problems secondary to small globes

(Stratton, Howe & Battaglia, 1996, 4-5). They also note that

*Visual acuity may be compromised by the short distance from the lens to the retina (small optic globes) or the shape of the lens. ...retinal abnormalities may be found...* (p. 157). In addition to these defects of the eye

itself, analogous to the outer, middle and inner ear, there may also be impairment of intermediate visual processing equivalent to CAPD. Thus, Connor, Streissguth, Sampson, Bookstein and Barr (1999) found that

*In relation to the comparison group, patients with FAS/FAE exhibited substantial deficits in both auditory and visual attention...*

As previously indicated, Coles et al. (2002) found that one important difference between people with FAS and people with ADHD but not FAS was mainly in visual modalities. FAS can co-occur with dyslexia (Dyer, Alberts, & Niemann, 1997, p. 59), but whether they are functionally linked or not, is not known.

### **Summary**

In summary, people who have FAS/ARND are at elevated risk for speech or language disorders, learning disabilities, hearing impairment, mental retardation, attention deficit disorders (ADD), depression, and other disabilities. Of course, not all persons with FAS/ARND will have *all* of those disabilities, but multiple disabilities are common. These disabilities in a person with FAS/ARND often differ in details from the way these disabilities are expressed in persons who do not have FAS/ARND (Wegmann et al., 1998, p. 31). These unique qualities are only beginning to be understood.

### **SECONDARY DISABILITIES/CONDITIONS**

In VR, a secondary disability is any disability that limits the person's functioning in terms of employment outcome, but is not the primary disability. In the literature on FAS, secondary *conditions* are sometimes referred to as "secondary disabilities." They are considered secondary because they develop as the result of a primary condition, i.e., alcohol-induced damage to the brain of

the fetus. In VR literature, these secondary disabilities are more likely to be considered as secondary conditions or functional limitations. These are discussed in more detail in the following sections.

The term “secondary conditions” was coined in 1988 (Marge, 1988) to refer to the additional disabilities (or conditions) that may result from the acquisition of a primary disability (or condition). Several factors help identify a secondary disability/condition:

1. It is associated with and arises from the increased risks created by the primary disability (or condition).
2. It may be just as limiting as the primary disability (or condition) in negatively impacting daily functioning.
3. The secondary disability (or condition) occurs after the acquisition of the primary disability (or condition)—there is usually a lag time or latency period between the recognition of the primary and secondary conditions. In the case of FAS/ARND, the secondary disabilities (or conditions) are often the first recognized.

This dual terminology (disabilities vs. conditions) is the result of evolving ideas within the professions. A secondary disability is distinguished from a “co-morbid” or co-occurring health condition. Streissguth and her colleagues at the University of Washington have used the term “secondary disability” in this context. However, over the past decade or so a number of scientists at the Centers for Disease Control have indicated that interest in this area should not be restricted to secondary disabilities alone but should encompass all health complications that may arise because of the increased risks to health created by the primary disability. Therefore, it has been argued that a better term is “secondary *conditions*” to cover all health complications. At first, this term was intended to refer to physical and mental health issues. Now it also includes behaviors, events, and so forth. Restricted usage of the

term “disability” is common in VR, in which the secondary disabilities discussed in the FAS literature would more likely be recognized as secondary conditions.

Thus, “secondary conditions” is the term used in this manual to distinguish a broad array of physical, medical, behavioral, social, emotional, or familial conditions and limitations to which someone with a primary diagnosis is vulnerable by virtue of that primary condition.

These secondary conditions are extremely important because they are what attract attention and demand treatment or remediation. Individuals with FAS/ARND are at high risk for these secondary conditions, which can be associated with functional limitations. Secondary conditions due to alcohol-related brain damage may include but are not limited to memory problems, difficulties with abstracting abilities, impulsivity, a lack of understanding of cause and effect, poor judgment, and being easily influenced. Psychiatric problems, loss of residential placement, educational and vocational concerns, legal issues, in both civil and criminal cases, psychosocial problems, and substance abuse are frequently reported in the FAS literature as secondary disabilities associated with prenatal alcohol exposure. For people with FAS/ARND, it is the secondary conditions that most negatively impact gainful employment. Although FAS cannot be cured, ***these secondary conditions can often be treated and remediated.***

According to Streissguth, Barr, Kogan and Bookstein (1996), the six main secondary disabilities associated with FAS are mental health problems, disrupted school experience, trouble with the law, confinement, inappropriate sexual behavior, and alcohol/drug problems. Two additional secondary disabilities were defined for adults: dependent living, and problems with employment. This last "secondary disability" is a special concern in this manual.

This difference in terminology between secondary disabilities and secondary conditions makes it appear as if the fields of FAS research, on the

one hand, and special education and VR on the other hand, often speak different languages. In reality, the fields are far closer than one might think, as we hope to show, and the differences are due at least in part to an evolving terminology. For this training manual, the following terminology is used:

**Primary Condition:** This is a condition that one is born with that cannot be changed (e.g., FAS or cerebral palsy).

**Primary Disability:** This is the disability that is most limits the person's functioning in terms of employment outcome (e.g. mental retardation).

**Secondary Condition:** This is a condition that one is not born with, but that develops as a product of a primary condition and one's environment. This term is similar to functional limitation.

**Secondary Disability:** A secondary disability is a barrier to vocational or educational progress, but is not the primary disability.

### **Mental Health Problems**

The first secondary "disability" described by Streissguth et al. (1996, pp. 34-36) was mental health problems. These were defined as "(a) ever having on e of a list of mental health problems, or (b) gone to a psychiatrist, psychotherapist, or counselor for mental health problems, or (c) ever having been a client in a psychiatric or mental health hospital (p.30). The most common mental health problems were attention deficit problems (61%), and depression ("over half the adults," p. 35), which were addressed in this manual in a previous section.

### **Disrupted School Experience**

The second primary "disability" described by Streissguth et al. (1996)



was disrupted school experience, defined as "ever being suspended or expelled from school, or as having dropped out of school" (p. 30). The most frequent "learning problems" identified were repeated "attention problems (70%) and repeatedly incomplete school work (55-60%)"(p. 38). Repeated behavior problems were also a factor. Two of the most important such problems were "getting along with peers" (50-60%), and "disruptive in class" (42-60%, both problems varying by age). Other repeated behavioral problems occurring in more than 30 of the sample included disobeying school rules, talking back to teachers, and fighting (p. 39). Social skills deficits among children prenatally affected by alcohol have also been noted by Thomas, Kelly, Mattson, and Riley (1998), who concluded that "social deficits in children with FAS are beyond what can be explained by low IQ scores and indicate that there may be arrested, and not simply delayed, development of social abilities in children with FAS."

Streissguth et al. (1996) also found that 40% of their FAS/FAE sample "were known to have been in special education" (p.40), and about two thirds of the sample had attended a resource room in connection with an early intervention program (p.40). The most common types of remedial interventions these students received were reading and arithmetic (60-65% each), followed by written language and speech (more than 40%), social skills and counseling (about 35%), and life skills (30%) (p.41).

### **Trouble with the Law**

One of the "secondary disabilities" identified by Streissguth, et al. (1996, 42-45) was *Trouble with the Law* (TWL). In their large clinical sample (n = 412), the percentages ranged from about 40% of adolescent and adult females, to 70+% of adult males. Legal proceedings with adolescents and adults with FAS/ARND are a frequent occurrence (LaDue & Dunne, 1997; Boland, Burrill, Duwyn & Karp, 1998; Conry & Fast, 2000; Fast, Conry & Loock, 1999). Many of these problems happened due to the impulsivity, lack of ability to connect cause and effect, difficulty learning from past experiences, and being easily

influenced by their peers. These behaviors and problems are commonly associated with the brain damage, particularly in the frontal lobes, secondary to prenatal alcohol exposure.

The first offenses of people with FAS/ARND are often minor, such as shoplifting, or malicious mischief. However, there are other circumstances where, due to their being easily led, they become "involved" with gangs, at least as fringe members who do the bidding of other members. In a few cases, this has led to situations of violence, grand larceny, auto theft, and other serious problems. It is important to note, however, that this is not the norm. About 15% of the adolescents and adults in a large clinical sample of people with FAS/FAE had committed sexual assault (Streissguth et al., 1996, 43). We will consider strategies for intervention with the legal system in a later section.

### **Confinement**

Confinement, while not itself a disability, is indicative of a serious problem. It was defined as being incarcerated for a crime (35%), or ever having been in a mental hospital ("23% of the clients over 12 years of age"), or ever having been in an alcohol/drug inpatient program (15%)(p.46). The confinement rate for adults 21 years of age or older was higher for clients with FAE (70-75%) than for clients with FAS(!)(45-50%)(p.46).

### **Inappropriate Sexual Behavior**

Another of the "secondary disabilities" defined by Streissguth et al. (1996) was Inappropriate Sexual Behavior (ISB), which is defined as ever having been sentenced to a sexual offender's treatment program, or having been reported to have "repeated" problems with one or more of 10 inappropriate sexual behaviors, the most common of which were, in descending order of frequency, (a) sexual advances; (b) sexual touching; (c) promiscuity; (d) exposure; and (e) compulsions. These sexual problems occur due to people with FAS/ARND not fully understanding sexual/personal boundaries. Combine this

with impulsivity and a lower level of maturity and an increasing sex drive and it is not surprising that this is a significant area of concern. Adolescents and adults with FAS/ARND often relate better to younger people, sometimes children. The person with FAS/ARND may fail to recognize what is appropriate behavior and express their sexual needs/feelings with younger people. Of course this, in turn, can lead to Trouble with the Law (see above).

In addition, without being in a safe living situation, a high number of adolescents and adults with FAS/ARND have, themselves, been sexually abused. Early childhood trauma, particularly without therapy, is frequently expressed in sexual issues as the person grows older. Inappropriate touching and comments are the most commonly seen sexual issues in this population. Generally, these are incidents are of an opportunistic nature rather than being predatory. However, there are times when sexual assault does occur.

It is not possible to make blanket statements about any particular population. However, this is one area where prevention is highly possible. As people with FAS/ARND grow older, if they have been sexually abused, it is important that they receive appropriate therapy.

### **Alcohol and Drug Problems**

This secondary "disability" was defined by Streissguth, et al. (1996) for clients "who have ever had alcohol abuse problems, drug abuse problems, or have ever been in alcohol or drug abuse treatment (inpatient or outpatient) (p.51). The rate was much higher for adult clients with FAE (50-70%) than for adult clients with FAS (30-40%)(p.51).

### **Dependent Living**

For adults with FAS/FAE, another secondary "disability" is dependent living, defined in terms of two sets of criteria, both of which had to be met for the person to be considered dependent. The first set of criteria consisted of 12 activities of daily living. Being unable to manage his or her own money, one of

the activities of daily living, automatically was considered a sign of dependence (Streissguth et al., 1996, p.56). A person who was independent in at least 9 of the 12 activities of daily living (ADL), including money management, was considered independent. The ADL most often requiring help or supervision were money management (>80%), making decisions (ca. 78%), getting social services (70%), getting medical care (ca. 67%), interpersonal relationships (ca. 57%), and grocery shopping (ca. 52%)(p.57). The second set of criteria revolved around whether one was dependent on a caregiver or other support person to organize his/her life. About 80% of individuals with FAS/FAE in Streissguth et al.(1996)'s sample were considered dependent (p.56).

### **Summary**

Whatever one might call the conditions, disabilities or behaviors described above, it is clear that the central nervous system impairments that are part of the definition of FAS/ARND have a series of behavioral consequences that limit the ability of persons with FAS/ARND to function in society without strategic support services. The research of Streissguth et al. (1996) shows that these behavioral consequences are diminished, on average, when a diagnosis of FAS/FAE is made before the age of 6, earning the distinction of a "Universal Protective Factor"(p.28). However, there is also much that can be done if the diagnosis is made at later ages, as we will make clear in subsequent sections.

### **FUNCTIONAL LIMITATIONS (*REVISED*)**

A barrier or deficit that interferes with some predetermined standard of functioning is called a "functional limitation." Functional assessment has occupied a very important role in the field of vocational rehabilitation for many years, and plays a central role in the daily work of rehabilitation professionals (Livneh & Male, 1993). In VR programs, the standard is past, current, or potential successful vocational performance. The entire development of a VR

case hinges on the proper identification of functional limitations at the outset. Functional limitations are a key concept in VR because the services provided under the IPE are directed explicitly at the remediation of these limitations. Functional limitation statements provide a basis for explaining why an individual needs services, why specific services are planned, and how these services are expected to contribute to the individual's rehabilitation. Similarly, in an educational context, the standard might be past, current, or potential successful *educational* performance. This information is to be used to describe the client when determining eligibility, planning services (such as the IPE), and describing improvement in functioning at closure or at annual performance evaluations.

Before looking at specific functional limitations, however, it is important to consider the words we use. When describing functional limitations, loaded words should be avoided. For example, consider the word "lazy." This is a loaded word because it implies something about the person's motivational state that may not be true, especially if the person has memory problems, or is depressed. Or consider the word "uncaring": If the person has trouble linking words with feelings, it might seem as if they don't care. Or consider the word "irresponsible." Behavior that seems irresponsible can result from a disparity between the person's chronological age and their functional age. For example, we hold an adult responsible for many things that we do not hold children responsible for. But what if someone who is 20 years old can only function at the level of a 12-year-old, because of a cognitive impairment?

Important functional limitations may be hidden from view, and may not be obvious on first presentation. People with FAS/ARND may present a complex portrait of competencies and delays. It is not uncommon to encounter a mix of abilities and lags in any one person. The profile of maturation and strengths varies significantly between people with FAS and ARND. The following text box ("*Is it that the person won't, or is it that the person can't?*") and Table 2 on behavior and neuropathology, with the accompanying chart

(Figure 1) is intended to provide a visual cue for gaps that may be masked by abilities (for example, emotional *immaturity* may be hidden by strong expressive language skills.) The chronological age of the hypothetical individual in Figure 1 was 18. In this case, Expressive language (bottom bar), and physical maturity (middle) may give one a first impression of normal development. It is only later that one might find out that social skills, emotional maturity, and comprehension are at the 6 - 7 year old level.

**Is it that the person won't?**

**or**

**Is it that the person can't?**

by Diane Malbin

<http://www.come-over.to/FAS/cantwont.htm>

Beliefs dictate behaviors. The belief that many primary learning and behavioral characteristics that may reflect the underlying neuropathology associated with FAS are the result of willful, volitional or intentional behaviors often leads to punishment of these symptoms. Inadvertently, this may in turn result in the development of an array of secondary defensive behaviors. The chronic lack of a good 'fit' between the needs of those with FAS and their environments may lead to tertiary characteristics of school failure, mental health problems, running away, or trouble with the law. These are all believed to be preventable. The key to prevention is linking the idea of brain dysfunction with presenting behaviors, reframing perceptions, and moving from punishment to support. The shift is from seeing a child as one who "won't" do something to one who possibly "can't" (Table 2).

People with FAS/FAE may present a complex portrait of competencies and delays. It is not uncommon to encounter a mix of abilities and lags in any one person. The profile of maturation and strengths varies significantly between people with FAS/FAE. This chart is intended to provide a visual cue for gaps which may be masked by abilities (i.e., emotional immaturity may be hidden by strong expressive language skills.)

It is when the expectation that a person is "on time" when they are actually developmentally much younger that conflict develops. "Why don't you act your age!" and "Grow up" are common comments which reflect frustration where immaturity has not been recognized as part of a normal variability in development. One parent said her feeling about her child changed after she was reminded to "Think younger." A gradual catch up is noted in young adults with FAS/FAE. Rather than being able to leave home at 18, a more realistic timeline may be 25 to 30. Ask yourself what responsibilities would be reasonable to expect from a 10 year old when confronted by a tall, verbal 16 year old with FAS or ARND. Adjust expectations accordingly. If what you're trying doesn't work, don't try harder, try *different*.

(Adapted from: Research findings of Streissguth, Clarren et al. by Diane Malbin 1994)

(<http://www.come-over.to/FAS/timeline.htm>)

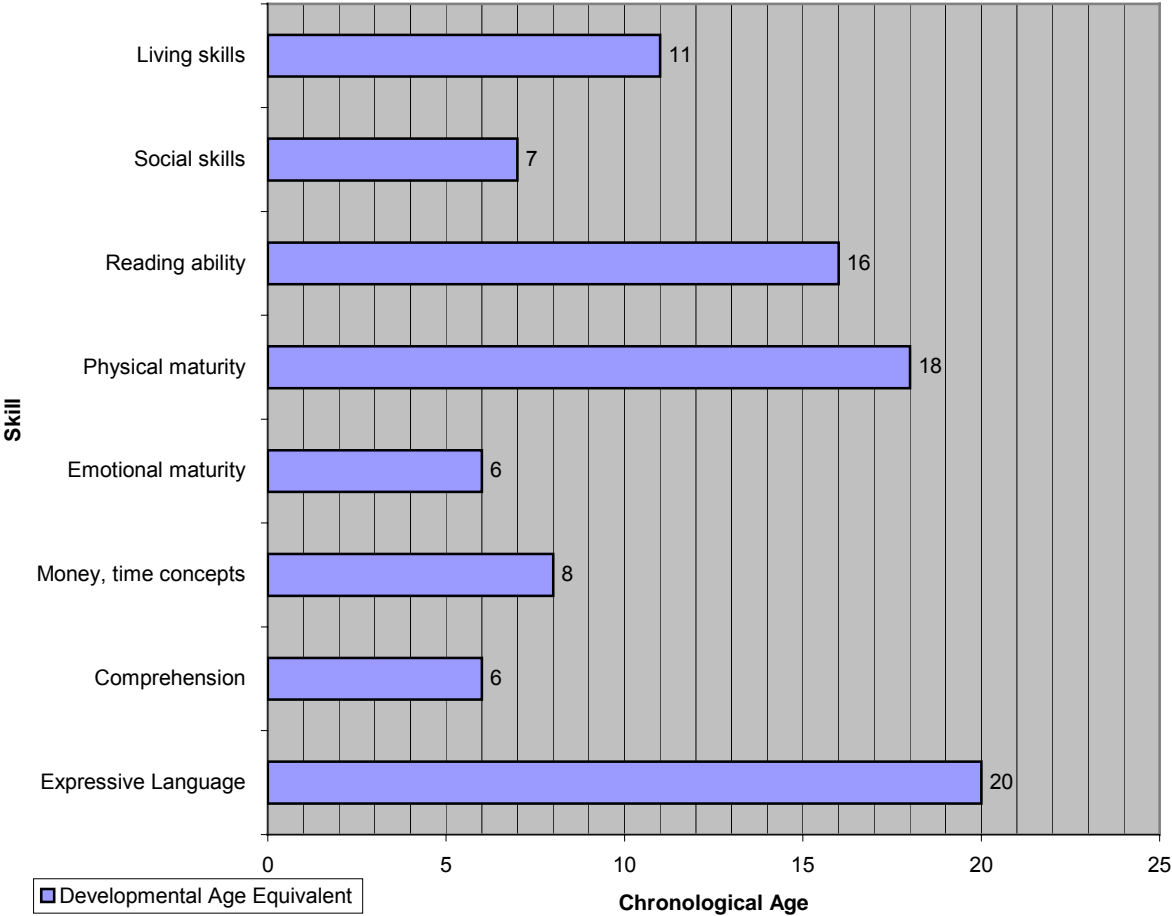
**Table 2. Observed behavior and neuropathology**

<b>Primary Characteristics: Neuropathology</b>	<b>Standard Interpretation (May Lead to Punishment)</b>	<b>Secondary Defenses or Characteristics</b>
Memory problems	Could remember if they he/she tried	Fear, self protection
Inconsistent performance	Not trying on "off" days	Anxiety
Forgetful	Willful	Frustration
Poor short term (auditory) memory	Not listening, paying attention	Anger, avoidance
Remembers some things, not others	Seen as lazy	Confusion, depression
"Gaps": Talks the talk, doesn't Walk the walk: disconnections	Willfully disobedient	More defensiveness
Can't link words with feelings	Seen as uncaring	Shut down, confusion
Forgets words, ideas	Doesn't try, could do it	FRUSTRATION!!!!
Decodes, doesn't comprehend	Manipulative	Inferiority, fear, masking
Difficulty forming associations	Does it 'on purpose'	Internalizes negatives
Doesn't see similarities differences	"Should" know better!	Isolated, fearful
May not generalize or apply rules in new settings	"Trying to make me mad"	Masks mistakes, lies
Difficulty with abstractions: money, math, time	Has to know times tables!	Avoids homework
Poor planning, sequencing initiating, following through	Punished for not doing tasks	Feels blindsided, may not understand
Difficulty understanding danger	Psychopathology	May shut down
Impulsive, suggestible	Daredevil, sociopath	Behaves accordingly
Can't see consequences	No conscience, punished	Blames others
Fatigue	Passive resistive	Irritability to rage
Long response time	Trying to be controlling	Gives up or acts out
Acts young for age	Too dependent, irresponsible	Overwhelmed
Socially "inappropriate"	Poor values, insensitive	Gravitates to "comfort" friends
Perseverative	Controlling, wants own way	Rigid, resistive
Oversensitive	Hypochondriac	Discomfort, distress, whiny
No response, flat affect	Doesn't care	Lacks language to communicate clearly

(Diane Malbin, <http://www.come-over.to/FAS/cantwont.htm>)



Figure 1. Adaptive Behavior Profile of Person with FAS



Livneh and Male (1993) have suggested that all functional limitations fall into one of six "realms", and Table 3 (adapted from pp.46-48) shows the correspondence between those realms and the kinds of functional limitations often observed in persons with FAS.

**Table 3. Livneh & Male's Realms of Functional Limitation**

"Realm"	Likely Categories of Functional Limitations for people with FAS/ARND
1. Physical-Structural	[Not common]
2. Physical-Neurological	Sensory Limitations; Restricted Environment Debilitation or Exertion Limitation;
3. Cognitive-Processing	Invisible Limitations; Mental Limitations; Educational Skills
4. Cognitive-Affective	Dysfunctional Behavior (Emotional); Consciousness Limitation; Motivity Limitation
5. Social-Structural	Communication Limitations
6. Social-Affective	Substance Dependency; Communication Limitations

1. Physical-Structural limitations are the result of body parts that are missing, deformed or damaged. Some individuals with alcohol-related birth defects (ARBD), such as heart abnormalities, scoliosis, etc. may have this type of limitation. Heart defects are estimated to occur in about 18% of persons with FAS/ARND.
2. Physical-Neurological limitations are those affecting mobility, manipulation, speech, and hearing, seeing, and other sensory functioning.
3. Cognitive Processing limitations are due to brain dysfunction, and include **Mental Retardation** and substance abuse. This category of functional limitations is quite common in persons with FAS.
4. Cognitive-Affective limitations relate to judgment, decision-making, motivation, concentration, and staying on task are also quite common in

persons with FAS. Impulsivity is one indicator of this type of limitation.

5. Social Structural limitations include impaired ability to communicate through normal channels (e.g., speech impairment). Although people with FAS may be very talkative, and may hear sound normally, their ability to process speech may be impaired (e.g., by CAPD), and they commonly miss subtle social cues
6. Social Affective limitations include difficulty forming or maintaining meaningful, rewarding or safe interpersonal relationships. This also is quite common among persons with FAS, and can present problems in the workplace.

This summary shows that persons with FAS may have functional limitations in almost every realm. These functional limitations are not independent disabilities that can be treated without regard to the other limitations. Rather, an integrated approach that treats the entire spectrum of their limitations is needed.

While there is no standard list of Functional Limitations, the following pages contain information on some functional limitation categories used in some states that may apply to a person with FAS. Specific information about functional limitations that are common among individuals with FAS or ARND is summarized, along with codes used in the VR system in Arizona (similar systems are in use in other states). **An asterisk indicates a functional limitation that identifies a client as severely impaired when both the limitation exists and the individual needs multiple services over an extended period of time** [Note: Bulleted capital letters in outline indicate selected items drawn from Arizona's more comprehensive list].

<b>General limitation</b>	<b>Specific Examples that may apply for persons with FAS/ARND</b>
Communication Limitations, e.g.:	<ul style="list-style-type: none"> <li>• Cannot read or speak English [<i>Note: this assumes an English-speaking home and school environment. Not to be used alone.</i>]</li> <li>• Lacks communication skills (e.g., deaf person with no knowledge of sign language). People with FAS/ARND have difficulty processing verbal input, so have them repeat back in their own words their understanding of what was just said to see if they processed the information. If they cannot do this, they may lack communication skills or have a speech or language impairment.</li> <li>• Has poor or no interactive skills with other people.</li> </ul>
Sensory Limitations, e.g.:	<ul style="list-style-type: none"> <li>• Cannot tolerate loud noises.</li> </ul>
Dysfunctional Behavior (Emotional), e.g.:	<p>Disabilities, and their impact, can often lead to emotional or affective concerns such as a lack of confidence, changes in self-esteem after becoming disabled or recognizing the presence of a disability in one's self, and emotional stress caused by the consequences of the disability. The functional limitations should be identified and steps to ameliorate or decrease these problems should be included in the IEP/IPE. [<i>When these limitations are the basis of VR intervention they should be identified and considered to be "based on the individual's disability."</i>] Limitations in this category [Dysfunctional Behavior (Emotional)] include those listed below:</p> <ul style="list-style-type: none"> <li>• Lacks confidence in ability to work and to (re)enter the labor market.</li> <li>• Unable to deal with the facts of disablement as they relate to taking responsibility for a new life.</li> <li>• Suffers from violent mood swings.</li> <li>• Has difficulty controlling his or her temper.</li> <li>• Has fears or phobias affecting his or her ability to work or live independently.</li> <li>• Suffers from extreme passivity.</li> <li>• Does not relate normally with people (poor social and interpersonal skills).</li> <li>• Is abusive to self or others.</li> <li>• Has a low energy level.</li> <li>• Has unrealistic view of self.</li> <li>• Has unrealistic view of the world of work.</li> <li>• Is not in touch with reality.</li> <li>• Has little or no sense of personal identity.</li> <li>• Has low self-esteem.</li> <li>• Is awkward in social settings.</li> <li>• Has not learned basic social or survival skills.</li> <li>• Cannot handle stress as it relates to everyday living.</li> </ul>
Invisible Limitations, e.g.:	<ul style="list-style-type: none"> <li>• Lacks vocational skills [<i>cannot be used alone</i>].</li> <li>• Lacks work habits (does not know how to work).</li> <li>• Has knowledge or training in a specific vocational area but lacks the performance skills for job placement.</li> </ul>

<b>General limitation</b>	<b>Specific Examples that may apply for persons with FAS/ARND</b>
Restricted Environment, e.g.:	<ul style="list-style-type: none"> <li>• Must be in a controlled environment.</li> <li>• Must avoid an environment with excess noise.</li> <li>• Must be able to move about freely (cannot stay in one position for long periods of time).</li> </ul>
Mental Limitations, e.g.:	<p>The limitations in this category encompass intellectual capacity and achievement. Deficits in these areas can seriously impact the client's ability to learn, recall, process, and use information in a positive fashion. Individualized plans should address the possible or actual limitations the client has in each of the following areas and provide for services to reduce the negative impact of such deficits. Limitations in this category include those listed below:</p> <ul style="list-style-type: none"> <li>• Impaired ability to learn in one or more areas.</li> <li>• Impaired ability to understand in one or more areas.</li> <li>• Impaired reasoning ability.</li> <li>• Difficulty processing new information.</li> <li>• Unable to remember information.</li> <li>• Unable to make change [money].</li> <li>• Unable to learn basic social or survival skills.</li> <li>• Can only follow 1 or 2 step directions.</li> <li>• Requires ongoing and supportive supervision.</li> <li>• *Lack of ability to work independently (and multiple services are needed over an extended period of time). Documentation of the effects of the impairment can be made by medical, psychological, or vocational evidence.</li> </ul>
Substance Dependency, e.g.:	<ul style="list-style-type: none"> <li>• Physical dependency (addiction) to drugs.</li> </ul>
Consciousness Limitation, e.g.:	<ul style="list-style-type: none"> <li>• Has periods of involuntary inattentiveness.</li> </ul>
Debilitation or Exertion Limitation, e.g.:	<ul style="list-style-type: none"> <li>• *Lack of ability to work independently (and multiple services are needed over an extended period of time). Documentation of the effects of the impairment can be made by medical, psychological, or vocational evidence.</li> </ul>
Motivity Limitation, e.g.:	<ul style="list-style-type: none"> <li>• Cannot sit still (hyperactive) or rocks back and forth.</li> <li>• Has impaired motor functioning due to medication.</li> <li>• Movement speed is restricted to noncompetitive level.</li> </ul>
Educational Skills (in English), e.g.:	<ul style="list-style-type: none"> <li>• Does not read.</li> <li>• Has survival skills in reading (2nd grade and below).</li> <li>• Reads and understands basic instructions only (3rd grade - 5th grade).</li> <li>• Does not have usable writing skills.</li> <li>• Has limited writing skills (3rd grade - 5th grade).</li> <li>• Does not add or subtract.</li> </ul>

Listed below are other attributes that may functionally limit the client's employability due to others' perceptions and concerns. These may not actually restrict the client's ability to work or function, but nonetheless may constitute employment limitations requiring special counseling or intervention and placement assistance. Eligibility for VR services is NEVER based upon the following:

- Unstable or nonexistent work history
- Criminal record
- Minority group identification
- Socioeconomic identification
- Socially unacceptable appearance, e.g. poor hygiene

These additional attributes are commonly observed in clients with FAS or ARND. They are also items that may be functionally limiting, *but only because others consider them as such*. In VR, they might be considered as secondary conditions imposed by persons who are not aware of the client's disabilities.

A client may present with only a few functional limitations. However, in reality, many may exist. It is these deficits that vocational programs must adequately address to aid in acquiring and maintaining gainful employment for clients with FAS/ARND. One way to measure functional limitations is by means of an Adaptive Behavior assessment.

### **THE NEED FOR VOCATIONAL REHABILITATION**

People who have FAS/ARND are at high risk for problems with employment (PWE) and for being unable to live independently when they become adults. These are two of the secondary disabilities defined by Streissguth et al. (1996) on the basis of 90 cases (actual sample size may be slightly less for some categories). A majority, 79% of the men and women in

their sample had a history of PWE. The researchers defined PWE using a number of criteria, including: (a) having financial support other than their own earnings, (b) earning less than \$280 per week, (c) being in a sheltered workshop, (d) working half time or less, or (e) having had more than three jobs over the past two years. Each of these was regarded as red flags indicating PWE. Even though low IQ was not an explicit factor, every person with FAS/ARND who had an IQ of 70 or below also had PWE. Among those defined as having PWE, almost two-thirds had problems holding a job, half had trouble getting hired, half had experienced being fired, and almost one third had lost a job without understanding why. The most common on-the-job problem was being easily frustrated (65%), followed by poor task comprehension (57%), poor judgment (55%), and social problems (54%). At least one of these (poor task comprehension) may indicate poor job placement.

Streissguth and Barr (1998) conducted a similar study of the American Indians in their data, consisting of 53 Native Americans who were 14 to 51 years old. Twenty-four (24) of these were at least 21 years old. In this sample, 87% had PWE. However, 83% had been employed for wages. Holding a job for more than 2 years was rare; most held their job for between 4 and 24 months. The same problems were observed as for the general population, but with percentages 5–10 points greater. Virtually all adult clients in this sample had an unstable relationship to the work environment.

### **III. SCREENING AND FUNCTIONAL ASSESSMENT**

Screening is an important issue in the training of service providers, to assist them in the identification of disorders that may significantly affect outcomes, so that more effective rehabilitation plans can be developed. Screening is a "brief assessment procedure designed to identify [people] who should receive more intensive diagnosis or assessment" (Meisels & Provence, 1989, as cited in American Academy of Pediatrics [1994]). Screening is

therefore a means to an end, such as referral for assessment to enhance rehabilitation outcomes. Screening is especially important when prior identification is unlikely or problematic for some reason. The job of screening, then, is to provide a quick and easy method that can be widely used to identify individuals at risk for the target condition (such as FAS, LD or depression), while minimizing the number of false negatives (cases that escape detection). The job of *diagnosis*, on the other hand, is to weed out the false positives. According to Glascoe and Shapiro (2000b), “Good screens are right 70 to 80 per cent of the time,” but with FAS, this is too optimistic. For example, consider one of the few screening instruments for FAS that has been fully published (Burd, Cox, Poitra, Wentz, Ebertowski, Martsof, Kerbeshian, & Klug, 1999).

**Screening is a  
means to an end**

**A positive screen is  
not a diagnosis!**

Of 65 children receiving positive screens, 45 were seen for evaluation, and of these only 6 were diagnosed with FAS (p.332-333). In other words, this screen was right only 13% (6/45) of the time. In Glascoe and Shapiro’s terms, there are no known good screening instruments for FAS. For this reason, it is very important to remember that a positive screen is not the same as a diagnosis!

Screening for FAS and ARND is something any trained professional can do. A number of tools are discussed in this section. None of them have been validated specifically for American Indians.

### **The FASNET Assessment Tool**

The FASNET Assessment Tool for Use With Adults (Berg, Kinsey, Lutke, & Wheway, 1995) was developed to help parents and professionals (a) acquire a comprehensive and non-medical method of assessing whether prenatal alcohol exposure is a factor in difficulties any particular individual might be displaying; (b) determine if a diagnostic evaluation is warranted; (c) help provide



information to the family physician; (d) translate medical jargon into lay terms; and (e) facilitate understanding and communication between parents, caregivers, and providers.

An advantage of the FASNET is that it is a screening instrument specifically designed and scored for FAS screening by nonprofessionals. The areas covered by the FASNET include a history of prenatal alcohol exposure; developmental history; school history; physical findings; communication and language usage; social skills; overall behavior; attention, activity, and impulsivity; memory; cognition; safety issues; and mental health issues. This checklist has 265 items; a score of more than 50% indicates the need for a physician referral in order to assess the *possibility* that alcohol-related birth defects are playing a part in the developmental or behavioral problems of this child. However, this scoring threshold has not been clinically evaluated to minimize false positives and false negatives, so the validity and reliability of this instrument are unknown. The checklists on safety issues and mental health issues are provided, but are not used in the scoring. A different FASNET assessment tool has been designed for teenagers, ages 14–18.

### **Astley-Clarren Grid**

This grid (Figure 2) was developed by Drs. Susan Astley and Sterling Clarren (1997) to aid in diagnosis, as described previously in the section, Diagnosis. When used for screening, this grid should include information from the areas of growth deficiency, facial features, brain dysfunction, and gestational alcohol. In screening, we attempt to rate the level of risk for each of these four risk factors on a scale from 1 (no risk) to 4 (high risk). Counselors doing the screening should base the information on either standard scores or their best guess. If there is a question about the presence of any one area, the *lower* risk level should be marked with a referral for further assessment.

For example, if there is a “moderate” growth deficiency, that cell is marked with a 3, an X, or a check ✓ (Figure 3). The 3 indicated in the left margin of the corresponding row translates to the 3 written below the column, as shown in Figure 3. In this sample case, the individual is rated as having “moderate” facial features associated with prenatal alcohol exposure, “definite” brain dysfunction, and “high risk” for gestational alcohol. When the grid has been filled in (Figure 4, top rows), this can be converted to a numeric four-digit code (bottom row) and used as part of the referral information provided to the dysmorphologist and other providers.

*Figure 3. The Astley-Clarren Grid.*

Rating	Growth Deficiency	FAS Facial Features	Brain Dysfunction	Gestational Alcohol
(4)	significant	severe	definite	high risk
(3)	moderate	moderate	probable	some risk
(2)	mild	mild	possible	unknown
(1)	none	absent	unlikely	no risk

Figure 2. Sample Case Using the Astley-Clarren Grid.

Rating	Growth deficiency	FAS Facial Features	Brain Dysfunction	Gestational Alcohol
(4)			✓	✓
(3)	✓	✓		
(2)				
(1)				
<i>Sample Case =</i>	3	3	4	4

Even though this is the same grid system that Astley and Clarren use for diagnosis, its use by counselors who have not been trained in diagnosis is only guesswork. The Astley-Clarren grid is being used, in this context, only for screening purposes. If there is definite (4) or postulated (3) prenatal alcohol exposure, along with any of the limitations previously described, it is important to refer the client for a more extensive diagnostic evaluation. One of the reasons for this is that certain other conditions with similar characteristics must be *ruled out*. Another reason is that determination of the level of severity of some of the features requires advanced knowledge that most counselors do not have. Only a dysmorphologist, geneticist, or specially trained physician can accurately determine the severity of facial features and brain dysfunction, and the degree of growth retardation. However, this grid can be used by non-specialists as a way of organizing information to determine whether or not a referral is warranted.

### **Rating the Facial Features**

As explained in the section, Diagnosis, assessment of FAS facial characteristics is based on (a) a thin upper lip, (b) a smooth philtrum (upper lip area), and (c) small eyes that appear to be widely spaced. In a diagnostic evaluation, these features are measured and evaluated in a complex process (Astley & Clarren, 1997, pp. 23–26), because the degree to which each feature is expressed varies from severe (extreme classic form) to absent. These features are best evaluated with a full-face photo taken between the ages of 2 and 12 with a neutral facial expression, as smiles and other facial expressions can distort these features. Family standards, especially for a thin upper lip, should be taken into consideration, as normal upper lip thinness varies from one family and race to another. For screening purposes, one should take as much care as is feasible to avoid over-diagnosing. To receive a 4 rating, all three facial features must be unmistakably present in severe form. To receive a 3 rating, two of the three must be present in severe form, and the third must be present in moderate form.

### **Rating Growth Deficiency**

Growth deficiency must take family norms into account, as well as age-appropriate standards, gender, and postnatal environmental influences. Records of an individual's growth history are very important because by adulthood, infant growth deficiencies may be obscured by environmental influences. Thus, for diagnostic evaluation, rating growth deficiency can be quite complex (Astley & Clarren, 1997, pp. 19–22). For a 4 rating, there should be evidence of severe growth retardation in both height and weight after controlling for parental height and postnatal environmental influences. For a 3 rating, at least one of the two should be severe and the other should be moderate.

## Rating Gestational Alcohol

Typical questions regarding gestational alcohol are included in the FASNET General Information section (Berg et al., 1995; see also Wegmann et al., 1998). Other good questions can be found in Streissguth (1997, Figure 2.2, p. 21). To obtain a 4 on the grid for alcohol exposure, the client's mother or another reliable informant must confirm maternal prenatal use and report exposure that would produce a blood alcohol concentration greater than 100 mg% weekly, early on in the pregnancy (Astley & Clarren, 1997). Lower frequency and amounts would result in a lower score on the grid. A rating of 3 is given when drinking occurred during gestation in frequencies and volumes less than that for a rating of 4 *and* the source of the report is the birth mother, a direct observer, or some other reliable source. A rating of 2 means "alcohol exposure unknown," whereas a rank of 1 means "confirmed *absence* of gestational alcohol exposure."

## Rating Brain Dysfunction

A number of instruments are presented here for evaluating brain dysfunction. A 4 rating requires one of the following:

1. Evidence of mental retardation (MR) (a diagnosis of MR, or IQ < 60(!) (Astley & Clarren, 1997, p.27).
2. Structural anomalies of the brain on CT/MRI, such as partial or complete agenesis of the corpus callosum or cerebellar hypoplasia.
3. Microcephaly (unusually small head circumference for age or gender).
4. Neurological hard or soft signs (as age appropriate), such as impaired fine motor skills, neurosensory hearing loss, poor tandem gait, or poor eye-hand coordination if extra-neurological causes for these signs can be ruled out.

If evidence for the above is lacking, the instruments described in the following pages can help decide whether to rate brain dysfunction as a 1, 2, or 3 in the Astley-Clarren system.

### **Functional Indicators of Organic Brain Dysfunction**

Wegmann et al. (1997) have also published a checklist of functional indicators of organic brain dysfunction for adolescents and adults based on Astley and Clarren (1997, p. 8). This two-page checklist contains 55 items in eight categories that are to be answered *Yes*, *No*, *Unknown*, or *Too Young to Assess*. A sufficient number of these items serves to support a category 3 classification in the grid for brain dysfunction. However, as Astley and Clarren note, “to date, criteria for the number of deficiencies that must be present to warrant a Category 3 classification have not been established” (p. 27).

### **Fetal Alcohol Behaviors Scale (FABS)**

The variables in this checklist have been defined by Streissguth, Bookstein, Barr, Press, and Sampson (1998). The 36 items involved are a condensed version of their earlier 68-item Personal Behaviors Checklist (PBC). Thus, the items are weighted heavily toward the Brain Dysfunction component of FAS, and only indirectly to the factors of facial dysmorphology, growth retardation, or maternal alcohol consumption. In addition, since the checklist is based on personal behaviors, it is heavily weighted with secondary disabilities associated with FAS, rather than primary features of FAS itself. Nevertheless, it is a screening tool that can be interpreted for FAS/ARND screening in a straightforward manner. As with most checklists, each item usually invites a *Yes* or *No* response. On average, they report that it takes about 5 minutes to complete. The FABS is inexpensive to administer and score, and the summary score appears to be independent of age, sex, race, IQ, and FAS versus FAE. It shows promise of being a suitable screening tool when combined with a few

other relevant questions, making it potentially very useful as a screening device. Unfortunately, the FABS is not available to the public at this time, except by special arrangement with the authors. Because the questions are so heavily weighted for secondary disabilities, there is a higher risk of false negatives (i.e., persons with FAS who are not exhibiting secondary disabilities.)

The items are intended to be asked of the person's caretaker. According to the authors, a Yes on 15 or more of the 36 FABS items indicates that the person is at risk for FAS or ARND, and that a more thorough assessment and diagnosis is needed. When the same items were administered on a normal population, most had no more than 10 Yes responses. Its maximum usefulness applies across various groups from age 2 through age 35.

### **Fetal Alcohol Exposure Risk Assessment For Adolescents And Adults**

The items in this screening instrument (Appendix A) are closely related to the criteria used to define FAS. The items are intended to be obtained mostly from existing case history files. When no information exists in the files with respect to a particular item, it may be left blank. If appropriate, other information sources can be sought. This screening instrument has not yet been validated by field-testing. No scoring system to minimize false positive and false negatives has yet been established, and this instrument is still experimental. Each of the four diagnostic areas is rated on a four point Likert scale. If these ratings are added together, the minimum score, 4, would be an indication that FAS/ARND is extremely unlikely. The maximum score, 16, would be an indication that FAS is very likely, but that a referral for evaluation should still be made to make sure that the symptoms are not related to some other cause. Since this instrument is organized by categories similar to the Astley-Clarren grid, a score of 12 or more would serve to support a strong recommendation for referral for evaluation. In this sense, it is a tool that can be used for FAS/ARND screening on an experimental basis. The authors invite those who might use this instrument to share their results with us so that a

better scoring system for referral that minimizes false negatives and false positives can be established.

### **Adaptive Behavior Assessment**

Adaptive behaviors are everyday skills such as walking, talking, getting dressed, going to school and work, preparing a meal, cleaning the house, and so forth. They are skills that a person learns in the process of adapting to his or her surroundings. As Figure 4 showed, normal development in one area does not necessarily imply normal development in other areas. Adaptive behavior assessments are a very important tool to help us detect hidden areas of disability that might compromise, if undetected, the success of employment.

Because adaptive behaviors are for the most part developmental, it is possible to describe a person's adaptive behavior as an age-equivalent score. An average five-year-old, for example, would be expected to have adaptive behaviors similar to those of other five-year-olds.

Behavior problems, often called maladaptive behaviors, are those that interfere with everyday activities. Good adaptive behavior and a lack of behavior problems promote independence at home, at school, and in the community. Behavior problems are far more difficult to quantify than adaptive behaviors because they are not developmental and their expression varies from day to day and from setting to setting. Behavior problems do not increase or decrease steadily with age. Nevertheless, they can be reliably measured.

The purpose of measuring adaptive and maladaptive behavior is usually either for diagnosis or for program planning. The diagnosis of mental retardation, as an example, requires deficits in both cognitive ability and adaptive behavior, occurring before age 18. Adaptive behavior assessment is also used to determine the type and amount of special assistance that people with disabilities may need. This assistance might be in the form of special education and vocational training for young people, and supported work or special living arrangements such as personal care attendants, group homes, or



nursing homes for adults. Adaptive behavior assessments are often used in preschool and special education programs for determining eligibility, for program planning, and for assessing outcomes.

**The Vineland Adaptive Behavior Scales**

The Vineland Adaptive Behavior Scales (VABS), a revision of the original Vineland Social Maturity Scale, are distinguished by their heritage as well as by good norms and psychometrics (Sparrow, Balla, & Cicchetti, 1984). The VABS assesses personal and social skills, with norms up to age 18. Two interview editions, one with 577 items, the other with 279 items, gather information through semi-structured interviews with a parent or caregiver. Both include a Motor Skills Domain for children less than 6 years old and an optional Maladaptive Behavior Domain for children 5 to 18. There is also a 244-item Classroom Edition completed by a teacher.

The VABS is administered by a psychologist, social worker, or other professional with a graduate degree and training in interview techniques. Although the assessment booklets are straightforward and well organized, the interview process is complex and time consuming. Completion of the VABS is accomplished through asking general questions with additional probing as needed. The

respondent is not asked the questions directly nor allowed to read the actual questions.

A similarly administered behavior section contains a list of 27 minor maladaptive behaviors,

Adaptive Behavior Assessments		
For example, here is a summary of Matthew B.'s Vineland, assessed at the age of 19. This chart shows that in Communication and Daily Living skills, he was 5 - 7 years behind, and that in terms of socialization skills, he was functioning at less than half his chronological age. This demonstrates a significant functional limitation in the "Social-Affective" realm.		
Vineland Adaptive Behavior Scales (VABS)		
	SS	AE
<b>Communication</b>	92	12.5 years
<b>Daily Living Skills</b>	103	14.0 years
<b>Socialization Skills</b>	58	6.8 years
<b>Adaptive Behavior Composite</b>	84	11.2 years
<b>Maladaptive Level</b>	<i>Significant</i>	

e.g. sucking the thumb or fingers. Nine more serious behaviors, not normed for individuals with disabilities, can be scored by both frequency and severity (Hill, 1998). The VABS covers five areas: communication skills, daily living skills, socialization, motor skills, and maladaptive behaviors. The motor skills domain is only for children under 6 years of age. The communication domain includes receptive, expressive, and written communication skills. Daily living skills encompass personal, domestic, and community interactions. The socialization domain includes interpersonal relationships, play and leisure time, and coping skills.

All of these are scored and the average of these scores is used as the Adaptive Behavior Composite. These scores are translated into standard scores and into age equivalents. This gives a comparison of the client's skills to their age mates.

Streissguth, Clarren, and Jones' 1985 study (as cited in Streissguth 1994) reported the following adaptive living deficits seen in individuals with FAS or FAE with an average chronological age of 17: an average overall level of adaptive functioning of age 7; performance at an average age of 9 years old in daily living skills based on the Vineland Adaptive Behavior Scale (VABS); performance at an average 6-year-old level in socialization skills; and significant communication deficits. (p.77). In the same article, Streissguth reports that:

*...even patients with FAS or fetal alcohol effects (FAE) who were not technically retarded were frequently characterized on the VABS by such items as failing to consider consequences of their actions, lacking appropriate initiative, being unresponsive to subtle cues, and lacking reciprocal friendships (p. 78).*

The Adaptive Behavior Composite score can be used to screen for FAS: A composite score of less than 65 indicates that the person may be at risk for FAS/ARND (Streissguth et al., 1996, p. 26) and that referral for FAS/ARND diagnosis is warranted. However, some children with a higher composite score

can have FAS/ARND, especially if there is evidence of maternal alcohol consumption during the pregnancy.

The Maladaptive Behavior Scale concerns specific behaviors that are often correlated with organic brain damage or psychiatric disorders. It should be noted that, once again, the areas covered on the VABS correlate well to those on the FASNET, the Astley-Clarren grid, and the information needed for the VR assessment.

### **The Scales of Independent Behavior, Revised**

The Scales of Independent Behavior, Revised (SIB-R; revised in 1996) is distinguished by several features. It contains an excellent behavior problem scale in addition to its adaptive behavior assessment. It also provides a unique score that reflects overall independence based on adaptive and maladaptive behavior combined. It has norms that extend beyond adolescence—from 3 months to more than 80 years, which makes it more suitable for adult populations than the Vineland. It can be administered either as a questionnaire or as a carefully structured interview, with special materials to aid the interview process. It has a short form, a short form for children, and a short form adapted for individuals who are blind (Hill, 1998a).

The SIB-R's 259 adaptive behavior items comprise 14 subscales grouped into four clusters: Motor Skills, Social Interaction and Communication Skills, Personal Living Skills, and Community Living Skills. Each SIB-R adaptive behavior item is a statement of a task (for example: washes, rinses, and dries hair). A respondent rates the individual being assessed each task, using a scale from 0 to 3:

0. Never or rarely performs the task (even if asked).
1. Does the task, but not well, or about one-fourth of the time (may need to be asked).

2. Does the task fairly well, or about three-fourths of the time (may need to be asked).
3. Does the task very well always or almost always (without being asked).

This scale assesses the quality of performance and the individual's motivation. That is, even though someone may be able to perform a task, he or she may not do so independently, either because he does not realize that it is necessary to do so, because he refuses to (a behavior problem), or because processing/performing the task is so difficult that the benefits of completing the task are not worth the great effort. For the person with FAS/ARND, this ability to perform should be considered in the context of the person's neurological impairment, which may make the task more difficult than for people without this impairment (see section on Functional Limitations, Table 2 by Diane Malbin). Independence is also affected by environmental pressures to perform; the results of the SIB-R must be read in this context.

The SIB-R measures independence—not just adaptive behavior. Children and adults with developmental disabilities often need special assistance at home, at school, or at work. The SIB-R assesses adaptive and maladaptive behavior to determine the type and amount of special assistance that people with disabilities may need. This assistance might be in the form of special education and vocational training for young people, and supported work or special living arrangements such as personal care attendants, group homes, or nursing homes for adults.

The SIB-R is widely used in special education programs for diagnosis and for determining eligibility, for program planning, and for assessing outcomes. A new SIB-R checklist booklet can be completed by a teacher, psychologist, or social worker directly, or with the help of special interview materials that involve parents. The SIB-R was designed to be an integral part of interdisciplinary planning. Its contents provide an excellent outline for team

discussion, often eliciting information and opinions that parents might not otherwise bring up on their own.

*Independence* is the ability to do things on one's own without getting into trouble. This means not only the ability to perform a task, but also knowing when to do it and having the willingness to do it. Behavior problems interfere with independence, requiring special supervision or restrictions of some kind, and additional assistance with behaving more appropriately. The SIB-R can measure overall independence because, unlike other adaptive behavior scales, it includes a highly reliable measure of behavior problems. Independence is reflected in a Support Score, ranging from 0 to 100, that indicates the service intensity required by an individual, considering both adaptive and maladaptive behavior. A severely handicapped student with many serious problem behaviors would require intensive supervision (a Support Score below 20). An adult without disabilities, and with no behavior problems, can live independently without supervision (a Support Score of about 90 or more).

The Support Score was developed with the knowledge that neither adaptive behavior nor problem behavior alone can predict "difficulty." An individual may require close supervision or intense assistance because he or she is severely disabled (limited adaptive behavior) or simply because he or she is young. Someone with advanced adaptive skills may require even closer supervision (e.g. a higher teacher-student ratio in the classroom) because of serious problem behaviors.

The Support Score was derived to reflect the level of care, supervision, or training needed by individuals at home or in educational and human service programs. Although not a simple formula, the Support Score is a weighted combination of approximately 70% adaptive behavior and 30% maladaptive behavior. This score is able to differentiate not only level of placement, such as regular classroom or special classroom, but also level of success within a classroom or a group home, and even one's rank among one's peers (Hill, 1998b). The primary concern with the SIB-R is that no scoring system is known

specifically for persons with FAS/ARND, so that its use for screening must be considered experimental. However, the results may be quite useful for VR counselors and other professionals apart from the issue of FAS/ARND screening.

## SCREENING AND ASSESSMENT OF CO-OCCURRING DISABILITIES(NEW)

### **Mental Retardation (NEW)**

As stated in the previous section, according to the DSM-IV, MR is characterized by (a) onset before age 18; (b) significantly sub-average intellectual functioning (an IQ of approximately 70 or below); (c) concurrent deficits or impairments in adaptive functioning (DSM-IV, p. 37). Although a counselor cannot make this *diagnosis* without special training, he/she can obtain any existing records of IQ and adaptive behavior, and if those records appear to meet the criteria, an appropriate referral for diagnosis should be made. If the person suspected of FAS/ARND has not had an IQ test or adaptive behavior assessment, the counselor can seek to obtain these results, knowing that they will be needed for appropriate service planning.

### **Learning Disabilities (NEW)**

As the previous section on LD indicated, a diagnosis of LD is a complex matter, and must be made by a specialist. However, any counselor can screen for LD using the simple instrument in Appendix B This instrument has been validated (State of Washington, 1998), and was found to have an overall correct classification rate of 72% for LD (p. 14). However, this does not make much sense, because they also report about 30% false positives, and 30% false negatives (p. 15), which would seem to imply a correct classification rate of 40%. This is good, but certainly indicates that a screening instrument cannot substitute for a diagnostic assessment.

## **Mood disorders (NEW)**

A standard screening instrument for depression is the Beck Depression Inventory, revised (BDI-II) (Beck, 1996)

**BDI-II, Beck depression inventory : manual**, by [Aaron T. Beck](#)

- **Publisher:** Psychological Corp. ; Harcourt Brace; 2nd ed. edition



## IV. DEVELOPING AN INDIVIDUALIZED PLAN

This section introduces information that can be used as is, or that can be modified, in writing an individualized plan such as an Individualized Educational Program (IEP), Individualized Service Plan (ISP), or Individualized Plan For Employment (IPE). This information may also be helpful for providing suggestions in program implementation.

An individualized plan has the following purposes:

- Identify individual strengths and deficits of any particular client or student.
- Establish goals consistent with his or her interests and abilities, vocational training, and past work experience (if any).
- Develop a plan to address the deficits and develop the strengths.
- Implement this plan in a timely fashion.
- Produce measurable outcomes that assess the success of the plan.

### PERSON-CENTERED PLANNING

*Many people are familiar with the planning processes agencies use in serving individuals with disabilities. Whole life planning is separate from developing an agency service plan, such as an Individual Education Plan (IEP), Individual Service Plan (ISP), Individual Written Rehabilitation Plan (IWRP) or any variation on these processes. The whole life plan is the **person's** plan, not a school's or an agency's plan. The Individual does not **participate** in whole life planning; he or she **controls** it.*

(Butterworth, Gold, Hagner, Marrone, & van Gelder, n.d., §2, p.4)

Person-centered planning (PCP) refers to several approaches to organizing and guiding individual and community change in collaboration with individuals with disabilities, their families, and their friends. Family-centered planning (FCP) refers to principles designed to lead to partnership and collaboration between parents and professionals to ensure the best possible supports and services for a child with a disability and the child's entire family. Some examples of approaches that use the principles of person-centered planning or family-centered planning are whole life planning, personal futures planning, making action plans (MAPS), planning alternative tomorrows with hope (PATH), individual family service plan (IFSP), and essential lifestyles planning (Marone, Hoff, & Helm, 1997). Although individually distinctive, the foundations for these approaches are based on the PCP/FCP principles of *community presence, choice, competence, respect, and community participation*. The steps involved in PCP begin by gathering background information:

1. Develop a history or personal life story of the focus person. This is accomplished by everyone sharing past events in the person's life. The focus person's parents and family may share the largest amount of this information. Things such as background, critical events, medical issues, major developments, important relationships, and so forth, may be shared.
2. Describe the quality of the focus person's life. This may be accomplished by exploring community participation, community presence, choices or rights, respect, and competence.
3. Identify the personal preferences of the focus person—things the focus person enjoys doing and things that are undesirable to the person.

After the background information has been gathered, the next steps relate to the planning meeting.

4. Review the personal profile. The group at this point has the opportunity to make additional comments and observations, as well as adding test results.
5. Review trends in the environment. Identify ongoing events that are likely to affect the focus person's life.
6. Share visions for the future. Through brainstorming, participants are challenged to imagine ways to increase opportunities.
7. Identify obstacles and opportunities—things that could make the vision a reality.
8. Identify strategies and action steps for implementing the vision.
9. Get started; identify action steps that can be completed within a short time.
10. Identify the need for service delivery to be more responsive to individual needs.

### **Identifying Data**

This section of the individualized plan should provide a minimal amount of identifying data, such as date of birth, gender, race or cultural status, and marital status. The referent should be identified and the concerns of the referent, along with any identified by the client.

## **Diagnoses**

This section should simply list any known diagnoses that the client or the evaluator may wish to have ruled out, as well as suspected diagnoses at referral. This includes any relevant medical diagnoses, as well as any professional assessment of disabilities such as learning disabilities, ADD, mental retardation, hearing impairment, visual impairment, and so forth, along with a DSM-IV multi-axial assessment, if available. In addition, screening results [such as the FASNET assessment tool, FABS, and Fetal Alcohol Exposure Risk Assessment For Adolescents And Adults (Appendix A)] should be included. Any information on the Astley-Clarren grid should be provided, along with an indication of whether the information was provided as part of a diagnosis or a screening.

## **Background Information**

This section should include information of the kinds indicated for person-centered planning (personal life story, quality of life assessment, personal preferences), the history contained in the FASNET assessment tool, and any other relevant history. Legal issues, medications, past employment history, relevant medical history, substance abuse history, and legal issues should be covered in this section. This section should include a description of the client's overall appearance, general affect, and ability to attend and follow directions, as well as any observable deficits, such as language problems, memory problems, or high or low activity levels.

## **Assessment Instruments Administered and Results**

This section should provide a listing of any assessment tools (apart from those already used in diagnosis) administered (e.g., IQ, VABS, SIB-R,

achievement tests, aptitude tests, career planning results) and the client's or student's scores or performance on these tools. A narrative description of the client's strengths and deficits, based on each tool, is included. The date of administration of each assessment tool should also be included, as scores may change with age. Many commonly used tests have not been validated specifically for American Indians and Alaska Natives and some are more culture-bound than others. Information about ethnic background should be included in order to keep these test results in perspective and to address possible cultural issues.

### **Planning Considerations**

In this section, planning considerations suggested in the PCP approach should be summarized. These include environmental trends (ongoing events that are likely to affect the focus person's life), visions for the future (brainstorming), obstacles, and opportunities. Environmental trends might include changes in eligibility for services, transition from one status to another (e.g., school to work transition), expiration of support services, and so forth. Changes in family relationships involving parents, significant others, siblings, or children should also be reviewed. Visions for the future might include career opportunities and vocational planning, desired place of residence (such as reservation, American Indian community, urban area), desired residential setting (living independently, with family members, or in a suitable residential facility), and desired natural support networks (such as family, Indian organizations, or religious organizations).

### **Summary and Recommendations**

This section is a summation of the information in the previous sections. A review of the client's concerns and needs is included. In addition, this section provides recommendations to (a) address the deficits noted, (b)

identify resources in the community for vocational training and placement, and (c) make further referrals and evaluations if warranted.

This section should be clear, concise, and practical. It is intended to be the road map for providers, caregivers, and vocational training people to work from when developing and implementing an individualized plan. Specific names of programs and providers should be included if at all possible.

### **CASE STUDIES**

We are now ready to use this information to consider an actual case study. Certain aspects of each case have been changed to preserve anonymity. Each case study is based on an individual of American Indian birth or heritage. The purpose of this case study is to illustrate some of the concerns facing American Indians with FAS/ARND. Trainees are asked to discuss this case in a small professionally diverse group and to respond to the questions listed at the end of the case. The answers are then discussed with the trainer.

#### **Exercise: Case Study #1: Andrea K.**

Andrea K. is a 14-year-old girl of Native and African-American descent. She was born to a 19-year-old woman who was living on a small rural reservation. Mrs. K. had a history of substance abuse going back at least 5 years. She traveled back and forth to the nearest urban center, about 50 miles away, where she was involved in prostitution and other criminal activity. It is believed that Andrea is the child of one of Mrs. K.'s customers.

Mrs. K. often left her daughter with family members, many of whom were also involved in substance use. It is documented that she was physically and sexually abused multiple times by multiple people before the age of 5. During one of her outings on the street when Mrs. K. had Andrea with her, she was arrested for prostitution and Andrea was placed into nonrelative, non-Native foster care with a single woman and her 10-year-old daughter.

After Mrs. K. was released from jail, she attempted to regain custody of her daughter. She was ordered by the court to get a psychological evaluation, complete substance abuse treatment, and refrain from any participation in prostitution. Mrs. K. tried several times to complete what had

been required but was unable to successfully maintain her sobriety. When Andrea was 7 years old, her mother was diagnosed with HIV/AIDS. She committed suicide by overdose within a month of receiving her diagnosis.

Andrea had been in foster care for 2 years by the time of her mother's suicide. The foster mother asked to adopt Andrea and the tribe wherein Andrea was enrolled agreed. This was accomplished within the next year. Shortly after the adoption was completed, her adoptive mother, Mrs. J., remarried. In the 2 years that she had been with Mrs. J., Andrea displayed significant sexually aggressive behavior, impulsivity, lying, stealing, and violent outbursts. Andrea was able to bond with her adoptive sister and father but not her adoptive mother. This became a source of tension in the family.

Andrea entered school and was placed into a class for children who were severely behaviorally disturbed. She was able to maintain her behavior while in the classroom and actually did fairly well on her school work, achieving B's and C's. However, during recess and at home, Andrea's behavior would rapidly deteriorate to the point where her adoptive family began to fear for their own safety. Andrea was placed in therapy but refused to cooperate. Several attempts were made to find a medication that would help but Andrea refused to take these. She molested at least 6 younger children.

The family requested and received a full-time in-home aide to help with Andrea. Andrea's behavior at home was aggressive toward the aides, resulting in rapid staff turn-over. By the time she was 12, her behavior was such that the adoptive mother refused to keep her in the home anymore, contacted the tribe, and asked that the adoption be declared a failure.

Andrea was placed into a group home where she was the youngest child. She received 24-hour-a-day monitoring and structure. Her adoptive father and sister continued visitation but her adoptive mother refused to do so. Andrea's violent behavior continued and she assaulted both the house staff and other group home residents. She refused to participate in therapy, her hygiene deteriorated to the point where Andrea was refusing to bathe, and she began to express having had hallucinations.

The group home staff believed that they could not provide adequate care for Andrea and she was transferred to a long-term child assessment and treatment facility. She has resided in this facility for 8 months and attempts are now being made to place Andrea back in the community. Andrea, while in the hospital, became more compliant with medication and was prescribed Tegretol and Paxil. Her violent behavior has decreased to some degree but she still displays sexually inappropriate behavior and refuses therapy. Andrea, at the age of 14, was 5' 3" tall and weighed 145 pounds.

Andrea was assessed at age 14 at the time of her hospital admission.

Wechsler Intelligence Scale for Children (WISC-III)	
Subscale	Score
VIQ	85
PIQ	101
FSIQ	96

Wide Range Achievement Test-3 (WRAT-3)		
	SS	GE
Reading	98	8th
Spelling	94	7th
Arithmetic	75	4th

Vineland Adaptive Behavior Scales (VABS)		
	SS	AE
Communication	80	9.0 years
Daily Living Skills	95	12.8 years
Socialization Skills	50	5.5 years
Adaptive Behavior Composite	71	8.9 years

Questions:

1. Based on the Astley-Clarren diagnostic grid, what 4-digit code best fits this data? What further information, if any, would be required to make a diagnosis?
2. What disabilities does Andrea probably have? Are any additional assessments needed to identify her disabilities?
3. What are the predominant issues that are of concern in making Andrea's transition from the hospital back to the school and community?
4. If Andrea were to be returned to the school system, what types of professionals should be involved on her IEP team?



5. What types of services will Andrea need in the near future and for her long-term functioning? What types of professionals should be involved?

## **SPECIAL CONSIDERATIONS FOR DIFFERENT INDIVIDUALIZED PLANS**

Different agencies use different kinds of individualized plans. As was pointed out in the previous section, the problem with these is that too often they are the *agency's* plan, rather than the *individual's* plan. Most agencies now at least pay lip service to the importance of *consumer-driven* planning-- that is, planning should be done "by" and "with" rather than "for" the individual without their full participation and consent. In all the plans discussed below, we advocate this full participation and consent, along the lines of person-centered planning.

While individualized plans have many common features, they have distinctive characteristics, too. We will proceed chronologically by age of first use, because each may build on the one before. Thus, we begin with a discussion of Individualized Service Plans (ISPs), which may be formulated as early as the preschool years. Individualized Education Plans (IEPs) are discussed next, because they are formulated during childhood or adolescence. Individualized Plans for Employment (IPEs) are discussed last because they are usually developed later.

### **ISP: Special Considerations**

An individualized service plan (ISP) is developed annually and is reviewed biannually, quarterly, or as needed for individuals who have been deemed eligible for services from the Department of Economic Security (DES), Division of Developmental Disabilities (DDD). The ISP is a written statement, developed by an interdisciplinary team (ISP team), of services to be provided and goals and objectives to be attained for a person with developmental disabilities. The ISP directs the provision of safe, secure, and dependable

active treatment in areas that are necessary for individuals to achieve full social inclusion, independence, and personal and economic well-being.

The ISP team must include, but is not limited to, the eligible individual, his or her parent or guardian, if any, and the DES/DDD support coordinator. The team should also include friends, teachers, physicians, therapists, vocational counselors, direct care providers, and others, as the team deems necessary. The following items are the responsibility of the DDD support coordinator:

- Identify team members and schedule meetings of the interdisciplinary team.
- Notify team members and facilitate meetings (unless contrary to the wishes of the individual or his or her family).
- Write the ISP based on consensus reached during the team meeting.
- Distribute copies of the completed ISP to the team members.

The need for service provision is determined by the ISP team based on formal and informal evaluations and assessments, the preferences of the individual and family or responsible person, and a written statement of the person's goals and desired future. The annual ISP paperwork should include the following sections (Division of Developmental Disabilities, 1993, Chapter 800, pg. 800 - 825):

- ISP Cover Sheet (DD-214)
- Service Plan (DD-215)
- Summary of Professional Evaluations (DD-216)
- Team Assessment Summary (DD-217)
- Preferences and Vision of the Future (DD-218)
- Long Term Goal and Implementation of Goal (DD-219)

- Team Agreements and Assignments (DD-219)
- Support Information (DD-220-1)

The progression of the ISP paperwork is designed to establish the need for services (resources or supports) based on information derived from the functional statements of need, the long-term goal(s), and the objectives. Thus, services are provided in accordance with the individual's needs and objectives to achieve the long-term goal set forth at the planning meeting. For example, if a team identified employment as a goal, an individualized goal would be established based on the current need for skills. The needs would then be addressed by an employment-related program (ERP), which is a service provided by the Division of Developmental Disabilities to facilitate the attainment of prevocational skills necessary to function in a work setting. These skills would then be translated into measurable objectives that allow for individualized teaching strategies and review of progress made by the individual toward the goal. The objectives are then reviewed and modified, during subsequent ISP meetings, until the skills are attained. At this point, a referral would be made to Rehabilitation Services Administration (RSA) to provide an appropriate vocational placement and related services, such as job coaching.

### **Exercise: Case Study #2: Gerry G.**

Gerry G. is a 17-year-old male of Native descent. He was the only child born to a man and a woman, both of whom were described as alcoholic and both of whom were killed in a single car crash when Gerry was 3 years old. He was placed in an adoptive home with five other younger adoptive siblings. Gerry had a history of mild behavioral problems that were managed by his parents using schedules, clear, concrete, and immediate positive and negative consequences, and a level system where Gerry could earn his privileges.

Gerry was in special education programs and did well in these because the same type of structure was used in both his home and his school environment. He participated in Special Olympic programs and, overall, was

doing well until the age of 13, when his behavior began to deteriorate. At this time, two of Gerry's younger female siblings disclosed that he had sexually molested them several times in the past 6 months. Gerry also began to show severely violent behavior and to act out in school. His foster family, in order to protect his siblings, had Gerry placed into a group home.

He resided in this group home with constant supervision and monitoring, and his sexually aggressive behavior was contained. However, his acting out in school, poor impulse control, lying, stealing, and instigating behavior, while it decreased, still remained of concern. Gerry was placed in therapy for sexually aggressive youths and participated, albeit reluctantly. He was able to be transitioned to a foster home with a single male and one other boy. However, the foster father in this home did not provide adequate supervision and structure. Due to serious concerns about Gerry's safety, he was returned to his original group home.

Gerry has had two legal charges placed against him, one for setting a fire to a garbage can at his group home and another for painting gang-related graffiti on a store near his group home. He served 3 months in detention for the first charge and has yet to be sentenced on the second. Gerry is approaching his eighteenth birthday. He has not had any reported sexual offending in the past 3 years, and since the store vandalism 2 months ago, he has not displayed any physically or verbally aggressive behavior. Therapy has continued and, at this point, Gerry is a far more active participant.

A physical examination and a psychological evaluation were done when Gerry turned 17 to help in transitioning to adult services. Gerry measured 5' 8" and 135 pounds at age 17. He has an odd appearance to his face, a frequent source of teasing by the other residents in his group home. (Testing at age 17.)

Wechsler Adult Intelligence Scale-III (WAIS-III)	
Subscale	Score
VIQ	45
PIQ	62
FSIQ	56

Wide Range Achievement Test-3 (WRAT-3)		
	SS	GE
Reading	60	4
Spelling	50	<3
Arithmetic	45	<3

Vineland Adaptive Behavior Scales (VABS)		
	SS	AE
Communication	65	7.2 years
Daily Living Skills	76	8.1 years
Socialization Skills	55	6.5 years
Adaptive Behavior Composite	62	7.2 years

#### Questions:

1. Plot Gerry's scores on the grid and identify what additional data might be needed to make an accurate diagnosis for FAS/ARND.
2. What disabilities is Gerry known to have? Are there other disabilities he should be assessed for?
3. What type of therapy has Gerry most likely been involved in? What type of approaches might be most useful?
4. What type of vocational rehabilitation and other services is Gerry likely to need?
5. Is he a viable candidate for independent living? Tell what your answer is based on.
6. Is Gerry still a risk to the community? If so, what areas, and what services, if any, might be needed to reduce this risk?

### **IEP: Special Considerations**

An individualized education plan (IEP) is a written statement for each student with a disability that includes, among other things, the following items:

1. A statement of the student's present levels of educational performance, including how the student's disability affects the student's involvement and progress in the general curriculum.
2. A statement of measurable annual goals, including benchmarks or short-term objectives, and how the student's progress towards these goals will be measured.
3. A statement of the services and supplementary aids to be provided to the student, or on behalf of the student, and a statement of the program modifications or supports for school personnel that will be provided for the student.
4. A statement of the extent, if any, to which the student will *not* participate with children without disabilities in the regular class and in other activities.
5. A statement about transition services, including the following:
  - (a) Beginning at age 14, and updated annually, a statement of the transition service needs of the student under the applicable components of the student's IEP that focuses on the student's courses of study (such as participation in a vocational education program).
  - (b) Beginning at age 16 (or younger, if determined appropriate by the IEP team), a statement of needed transition services for the student,

including, when appropriate, a statement of the interagency responsibilities or any needed linkages.

The initial evaluation [see (a) above] is conducted by an IEP team, which is composed of the following people (Individuals with Disabilities Education Act Amendments, 1997, section d.1.B.):

1. The parents of the student with a disability.
2. At least one regular education teacher of the student (if the student is, or may be, participating in the regular education environment).
3. At least one special education teacher, or where appropriate, at least one special education provider for the student.
4. A representative of the local educational agency who is qualified to provide, or supervise the provision of, specially designed instruction to meet the unique needs of children with disabilities.
5. An individual who can interpret the instructional implications of evaluation results, who may be a member of the team as described in 2 through 6.
6. At the discretion of the parent or the agency, other individuals who have knowledge or special expertise regarding the student, including related services personnel as appropriate (e.g., VR counselor).
7. Whenever appropriate, the student with a disability.

The interests of the IEP team, with respect to transition planning, converge with the interests of the VR system, and provide a mechanism *where the two systems can work together effectively!* Each IEP is developed by the IEP team, which must consider the following issues:



1. The strengths of the student and the concerns of the individual and his or her parents for enhancing the education of their child.
2. The results of the initial evaluation or most recent evaluation of the student.
3. Strategies, when appropriate, including positive behavioral interventions and supports to address that behavior, in the case of a student whose behavior impedes his or her learning or that of others.
4. All resources available in the area from individuals, team members, and relevant agencies.

The multidisciplinary IEP team, including a VR counselor, is very similar to the kind of diagnostic team mentioned earlier. In fact, it is recommended that there be considerable overlap between the two, if they are not completely the same.

### **IPE: Special considerations**

Based on the information provided in the previous sections of this manual, it is apparent that individuals with FAS/ARND may have significant barriers to obtaining and maintaining meaningful employment. Therefore, information regarding long-term expectations, including vocational implications for adults, is much needed. It is very important that these individuals receive vocational services by qualified vocational rehabilitation counselors versed in the specific and unique effects of FASD on learning and performance (Wilton, 1998). For example, because of the inconsistent learning patterns commonly associated with this condition, performance on standard vocational assessment tools may be inaccurate, or at the very least, only representative of the day the assessment was administered.

Two other effects of FAS/ARND that merit attention are the inconsistent

learning patterns and the spotty memory that can be exhibited by many individuals with this diagnosis. Difficulties with learning may be associated with organizational and processing deficits in the areas of information input, output, integration, and memory (Weiner & Morse, 1994). Although a task may appear to be mastered one day, the following day, or the following week, that same task may very well need to be re-taught. This is a re-occurring pattern. These findings indicate that individuals with FAS/ARND may have significant barriers to obtaining and maintaining meaningful employment.

An individualized plan for employment (IPE), formerly an individualized written rehabilitation plan (IWRP), contains documents in the client's file that are the official record of the intake, application, assessment, eligibility for services, and plan of services for the client. Of these, references to the IPE usually refer to the plan of services for the client, which must include the following items:

1. A specific vocational goal, such as auto mechanic, bookkeeper, counselor, nurse, artist, or janitor.
2. Types of services, names of providers, and duration of service for each one. Each service necessary to correct, ameliorate, or circumvent functional limitations and to help obtain the job goal should be specifically identified. The planned beginning and ending dates for each service must also be stated. Vital services needed to achieve the vocational goal should be listed even if VR will not be paying for it or arranging it.
3. Criteria for measuring and documenting progress, including the client's responsibilities (intermediate objectives), should be established. It is important to recognize that the client is not merely a passive recipient of services, but is an active participant in the process of vocational

rehabilitation. It is also a good idea to specify criteria for recognizing when a service has been completed or is no longer needed.

4. The individual or organization responsible for providing or paying for each service. The payer can be VR, another agency, or even the client, if he or she can afford it.

VR services can provide selected vocationally and educationally related services to youths over 16 years of age who are currently enrolled in school. To provide these services, a written cooperative agreement between the local education agency (LEA) and VR is necessary. This cooperative agreement must state specifically which services the school is unable to provide that may be required in the student's IEP, that are within the scope of VR services, and are not available as a similar benefit from a third resource [AZDES 4-3-03.C, 1982].

### **Specific VR Services for persons with LD and FAS/ARND**

Research on the VR services provided to persons with LD may also apply to some extent to persons with FAS/ARND. In an analysis of services for 659 American Indians and Alaska Natives (AI/AN) with LD in the VR system in 1998, the most common services provided were Assessment (14%), Transportation (14%), Job-Finding (15%) and Job Placement (15%). Some individuals received more than one of these services. Furthermore, VR clients with LD who received assessment services were more likely to be closed rehabilitated than AI/AN clients who did not receive assessment services (Schacht, 2003, p. 46). Since only 15% received assessment services, it seems clear that these services need to be included more often in the IPE of AI/AN with LD.

The IPE should pay special attention to two functional limitations typical of persons with FAS/ARND: (a) difficulty with interpersonal relationships and social skills and (b) learning style differences, including a lack of

understanding of cause and effect (see Section on Functional Limitations). Dealing effectively with these functional limitations requires a structured, organized, slower paced environment. Integration into a new work environment typically requires communication skills, facility with social interaction, and impulsivity control--which are often a source of difficulty for people who have FAS/ARND. For these reasons, social skills training and job coaching are frequently needed. Streissguth (1997, p. 198) recommended that

*social skills training and continuing job coaching are frequently needed. Even when people with FAS/FAE have job training, actually finding a job; getting matched with the right job; and obtaining appropriate and ongoing help, supervision, and support on the job all present problems.*

These two broadly defined effects of FASD—difficulty with interpersonal relationships and social skills; and learning style (which includes a lack of understanding of cause and effect)—are due to organic brain damage, and may result in a negative impact on job development, placement, and the successful maintenance of employment.

It is well documented that individuals diagnosed with FAS/ARND have difficulty with interpersonal relationships stemming from inadequate communication skills, impulsivity and difficulty with social interactions (Aase, 1994). Unfortunately, integration into a new work setting requires all of those skills. Schein (as cited in Millington, Butterworth, Fesko, & McCarthy, 1998) noted that organizational socialization is the “price” of membership the new worker must be willing to pay in order to stay employed. New employees must assimilate to the job site and quickly adapt to co-workers’ and employers’ expectations. Much of this process relies on an individual’s ability to read subtle social cues and adapt, based on successful processing of those cues. People with FAS/ARND often fail in the workplace because of the social aspect of work.

Learning style is another obstacle to employment for individuals with FAS. Problems with an individual’s learning style can often be due to organic

brain differences. Magnetic Resonance Imaging (MRI) has shown significant differences in the brain volume, and structure of the brains of certain individuals with FAS or prenatal exposure to alcohol (Mattson, Jernigan, & Riley, 1994). These differences in the brain result in differences in learning styles as well as memory deficits. Professionals have spent much effort formulating educational strategies that may be effective with individuals with these types of organic brain differences (e.g. Doctor 1994). Individuals with FAS/ARND learn best with multi-modality instruction. The same concept taught in several different ways (i.e., reading about a task, hearing about a task, and being shown a task) will have a better chance of being integrated into that individual's repertoire of skills.

### **Supported Employment**

Supported employment as a Federal program was first defined in the Developmental Disabilities Act in 1984. It defined supported employment as paid employment, rather than volunteer work or unpaid training or "work activity." It was designed for persons with developmental disabilities for whom competitive employment at or above the minimum wage is unlikely. Supported employment under this Act is for people with severe disabilities who were not previously considered as having employment potential—for example, who were denied eligibility for state vocational rehabilitation services (Butterworth, Gold, Hagner, Marrone, & Van Gelder, n.d., p. 1.5).

A very similar definition was adopted two years later in the Rehabilitation Act Amendments of 1986, with the key addition of the specific inclusion of people with chronic mental illness. It was defined as competitive work, in integrated work settings, for individuals with severe handicaps for whom employment has not occurred or has been interrupted or intermittent, who need ongoing support services, including transitional employment for persons with chronic mental illness (p.1.6). People with FAS/ARND often need

supported employment services, so it is a good idea to include this possibility in planning.

### **Mentoring and Apprenticeships**

Mentoring or apprenticing is often an effective way to teach an individual with FAS/ARND a new job or job skill. Streissguth (1997) related an example:

*Riley had a special skill in his “back pocket,” having learned printing in junior high school. When he graduated from high school, he started out working in fast-food chains, like the rest of his friends. He had failed repeatedly in these jobs and become discouraged when a friend remembered that Riley had printing skills and told him about an apprenticeship opportunity. The kindly owner of a small printing company let him serve an apprenticeship for several years, then hired him to work in the print shop. The predictable nature of the work, the patience and kindness of the master printer, and the relaxed pace of the shop all combined in a successful employment experience for Riley for many years. (pp. 194-195)*

The above example shows how a structured work environment with a slower, relaxed pace can facilitate the success of an individual with FAS/ARND. The apprenticeship program served as a comprehensive “job coaching” plan where Riley learned at his own pace. He was hired on two years later, presumably after mastering the requirements of the job.

### **Malbin's Guidelines for Vocational Development and Job Placement**

Vocational development and job placement for individuals affected by FAS/ARND should be based on Diane Malbin’s (1994) guidelines for supporting individuals with FAS/ARND. These guidelines are practical suggestions based on current research and her years of working with individuals affected by FAS/ARND. They can be a useful frame of reference for the vocational counselor, and encompass implementation as well as vocational development.

Therefore, some of the guidelines will be introduced here, and the remainder will be introduced in the section below on implementation. The relevant guidelines can be summarized as follows:

1. Identify strengths, skills, and interests. Of course, this is, or should be, standard operating procedure in any vocational planning.
2. Help develop skills for expression of feelings.
3. Provide specific support for social skill development.
4. Understand the various forms of communication.
5. Encourage safe, multi-sensory exploration.
6. Evaluate elements of environments and modify them as needed. It is generally a good idea to anticipate the kind of work environment that is normally involved for a particular vocational goal, to anticipate any handicapping elements that might interfere with successful work adjustment. It is usually best to make reasonable accommodations before they become a problem.

Suggestions #2 - 5 can be viewed as appropriate for pre-employment training services that may be needed to help the client become job-ready. By integrating these guidelines into the job placement process, the vocational counselor can gain an in-depth understanding of the individual she is serving. In addition, the counselor can begin to view individual jobs and work environments within the context of FAS/ARND. The result will usually be a better worker-environment fit.

Indeed, these can be written into the Individualized Plan for Employment (IPE). These guidelines will facilitate the process O'Brien and Lovett (as cited in Parker & Szymanski, 1998) suggest:

*While planning job search strategies with a client, placement professionals may engage in person-centered planning approaches that focus on the needs of the client first and also solicit input from family and friends.*

This of course is in keeping with the suggestions regarding person-centered planning earlier in this chapter.

**Exercise: Case Study #3: Matthew B.**

Matthew B. is a 20-year-old male of Native descent who was born to a 16-year-old girl who consumed at least 6–10 cans of beer a day throughout much of her pregnancy. This had been her pattern of alcohol consumption since the age of 9. Matthew's mother, due to her age, emotional problems, and heavy alcohol use, was unable to care for him. She had left him at home alone and unattended for several days. The neighbors became worried about the baby and the Child Protective Services agency was called.

Matthew was placed in foster care at the age of 17 months. The neighbor, a young married Caucasian woman who made the initial call to CPS, took Matthew as a foster child 1 month later. His birth mother gave her consent for this placement, and voluntarily relinquished her maternal rights 6 months later. Matthew was adopted by his foster family in an open adoption. He has had sporadic contact with his biological mother up to the present. His rate of visitation depends on her level of alcohol use and Matthew's ability to handle his birth mother's erratic behavior.

Matthew's family originally lived in a small rural community. His adoptive parents divorced when he was 5. He, his mother, and her biological daughter, an infant of 2 months, moved to a large urban center. The mother remarried 2 years later and the family has remained in the urban area, indeed in the same home, for the past 13 years.

Matthew, from the time of his birth, showed developmental delays. He was longer than normal at birth but markedly underweight. His biological father was later determined to be 6' 5" tall and his birth mother was 5' 1". Matthew, throughout his developmental history, continued to be above average for height but below the 5th percentile for weight. He showed significant developmental delays in walking, talking, and toilet training. Much of this was thought, originally, to be related to the repeated physical neglect he experienced in his birth home.

Matthew was placed by his adoptive mother in preschool at the age of 3. While his home environment was calm, well structured, and predictable, the preschool he had been placed in did not have these qualities. Matthew was unable to function in this environment. Because of difficulties related to his behavior, it was necessary for him to remain at home with his mother until age 6 when he began kindergarten.



Upon entering first grade, Matthew's challenging behaviors and various successful interventions (scheduling, specific structure, adapting the classroom) were shared with the administrative and teaching staff at the elementary school he was to attend. A psychological and adaptive behavior assessment was done. As a result of this evaluation, Matthew was placed in a self-contained special education class. He was maintained in self-contained classes until the seventh grade when he was mainstreamed into regular classes with the exception of math and language arts. Despite remediation attempts in these subjects, Matthew had great difficulties with abstract concepts and tasks. He is, however, musical and artistic and has good visual spatial skills.

Matthew's social skills have been poor and he has had psychiatric and behavioral difficulties as well. The latter have included impulsivity, psychotic episodes, perseverative behavior, anger outbursts, and severe social withdrawal. He was diagnosed as having Asberger's disorder (DSM IV code 299.80), and placed on a series of medications including Cylert, Ritalin, and Imipramine in conjunction with an antipsychotic agent.

Matthew graduated from high school at the age of 18. He was placed in a Department of VR program and trained in computer data entry and processing. After successfully completing his training, he was placed in a small accounting firm where it is his job to input a variety of data. His data entry program is such that he receives automated quality control feedback on a continuous basis.

He works 5 hours per day or more if he is able. His supervisor works in the same area and allows Matthew up to 10 minutes per hour of break time. Matthew has been in this placement for nearly 2 years.

He is currently living in an adult DD home with four other young men. He is still on his medication and still showing serious signs of social withdrawal. He has overnight visitation with his family twice a month.

Matthew's IQ, academic achievement, and adaptive behavior scores are listed below. (Testing at age 19.)

Wechsler Adult Intelligence Scale-III (WAIS-III)	
Subscale	Score
VIQ	62
PIQ	103
FSIQ	68

Wide Range Achievement Test-3 (WRAT-3)		
	S	E
Reading	89	10
Spelling	74	8
Arithmetic	63	7

Vineland Adaptive Behavior Scales (VABS)		
	SS	AE
Communication	92	12.5 years
Daily Living Skills	103	14.0 years
Socialization Skills	58	6.8 years
Adaptive Behavior Composite	84	11.2 years
Maladaptive Level	<i>Significant</i>	

Questions:

1. What are the factors presented that would suggest Matthew does or does not have FAS/ARND?
2. What are Matthew's areas of skills or strengths?
3. What disabilities should Matthew be tested for?
4. What long-term interventions might be considered to aid Matthew?
5. What, if any, further assessments should be done with Matthew?
6. What goals for employment should be considered?

### **LEGAL PROCEEDINGS (NEW)**

*"The thought becomes the action...."*

In a sense, legal proceedings are not dissimilar to other kinds of interventions. In general, an unacceptable or undesirable behavior has been identified, information is collected, and plans are made. This is especially the case in the juvenile justice system, which tends to be more treatment oriented, in contrast to the adult justice system, which tends to be more punitive in orientation. Even the adult system, however, becomes more focused on normalization of behavior during the parole phase, after a sentence has been served. So the justice system presents a number of points at which positive interventions can be made. At the time that the person with FAS/ARND first enters the legal system, it is important to educate all parties as to the brain damage and its implications for learning, behavior, and the need for structure. Many attorneys, defense and prosecution attorneys, judges, probation/parole officers, and pre-sentencing officers do not have adequate knowledge of FAS/ARND. If they can be educated to recognize the problems inherent with FAS/ARND, it is possible to use appropriate interventions and possibly reduce the risk of future offending.

A psychological evaluation (or better yet, a neuropsychological evaluation) and, if not already in place, an FAS/ARND diagnostic evaluation

should be completed as early as possible in the legal proceedings, so that subsequent proceedings can be guided by the best available information. For adolescents and adults who have been charged with sexual crimes, a psychosexual evaluation should be part of the overall evaluation. Motivation, past history, amenability to therapy, and structure, within and without the legal system, should be a part of any type of psychological/psychosexual evaluation. It is very important that the evaluator have an adequate awareness of the brain damage and subsequent behavioral implications of FAS/ARND. Without this, critical and possibly mitigating information may not be recognized and presented to the Court.

### **Decline/Remand**

Many states now charge adolescents with a high level offense, negating the "need" for a remand/decline hearing. If this charge is high enough, the juvenile automatically is tried as an adult. In situations where a decline evaluation is done, the personal history, including prenatal substance exposures, legal issues, past abuse, and successful interventions should be thoroughly understood and presented. People with FAS/ARND are often easily victimized. This is a high risk in the adult correctional system and one factor that should to be considered prior to a decision to decline/remand being made.

Once the juvenile is remanded, they are not charged again as a juvenile. However, in some circumstances, where there is open discussion among all parties, e.g. defense, prosecution, and Court officials, the juvenile who has been tried as an adult is still allowed to serve much, if not all, of their time in a juvenile facility. In many cases, this is more appropriate and less of a risk to the adolescent than serving time in an adult facility where, due to their social problems, inability to recognize danger, and overall lower level of abilities, they are easily victimized.

## **Competency/Capacity**

Competency, at the very least, should be where the person truly comprehends the intricacies, subtleties, and implications of their actions. Simply being able to identify people in Court, e.g., pointing out the judge and defense attorney, should not be a basis for finding a person competent, as has been the case in more than one legal situation. People with FAS/ARND are often able to give the correct answer if the question is posed as "Yes/No" but this does not indicate their true understanding of the areas listed above.

It is important in the competency/capacity evaluation and hearings that the defendant's ability to truly recognize what they are charged with and the possible outcomes is assessed. Some evaluators use a checklist type of questionnaire, asking the person to say "Yes" or "No." The defendant often looks competent on such an instrument. However, upon interviewing, it is frequently shown that the defendant, in reality, had little or no sense of what the implications of their actions truly were. Courts should not allow a simple questionnaire or closed questioning in Court to form the sole basis for making a positive competency determination.

## **Trial**

As noted, defense and prosecution attorneys may not have an adequate understanding of FAS/ARND. Having an advocate be part of the legal process from arrest to whatever outcome occurs is important. This is particularly crucial during all Court proceedings. Information in Court should be simplified and, if possible, presented step-by-step with visual aids, rather than in a complex and abstract manner. It should be the advocate's role to consult with the defense attorney, help organize materials on FAS/ARND to be presented to the Court and, if necessary, "translate" legal information to the defendant. Helping the attorney ensure that the defendant truly understands the proceedings and consequences is the goal of such an advocate.

If a probation officer has been assigned, the advocate should provide the same services but be involved to the conclusion of all legal and probation matters. If the juvenile received probation only or detention time and probation, they are often required to attend school, complete UA's, participate in therapy, and refrain from future involvement with troublesome peers. While these are all "reasonable" aspects of probation, they require the juvenile to be able to acquire transportation, structure their own time, remember appointments, and, generally, function at a level that is not obtainable, particularly for adolescents with FAS/ARND.

Often, adolescents with FAS/ARND are not in residential placements where someone can help them organize their lives. They have memory problems and often do not grasp why they should meet with their probation officers. Their choice of friends is often limited, because many higher functioning peers shun them. Their judgment is poor, because they often have little insight into who is or is not an appropriate acquaintance. If the adolescent with FAS/ARND was able to make good choices to begin with, it is not likely they would have been in the legal system!!

The advocate, in conjunction with the probation officer and/or caseworker, can help in:

- finding an appropriate residential program
- ensuring transportation to and from appointments
- finding an appropriate therapist and funds to pay for therapy
- help caregivers provide structure and support to aid in the defendant making better choices in friends; and
- help the probationer enroll in and attend the appropriate educational program and/or appropriate placement structure

Participation in the above, while not eliminating all possible concerns, certainly can aid in reducing them.

## **Incarceration**

The issues of incarceration of the adolescent/young adult with FAS/ARND were touched on briefly, in another section. Throughout this manual, the word "structure" has been used to describe what is one of the most important elements in the life of a person with FAS/ARND.

## **Sentencing**

While FAS/ARND has rarely, if ever, been used as a successful defense, it has been identified as a mitigating factor in the type of sentencing and place of incarceration, if any. In situations where FAS/ARND has been identified as an important factor and this has been presented to the Court, life sentences instead of the death penalty, have been imposed, juveniles tried as adults have been allowed to serve their time in juvenile facilities, mental health ... Courts have been involved, as opposed to criminal proceedings, and defendants have been placed in community protection programs as ... opposed to jail. This has been used ...

The successful aspect of this has come from an advocate, an attorney, and/or the evaluator clearly presenting to the Court the ramifications of the defendant having FAS/ARND. The intent here is not, as often assumed, to eliminate responsibility, but rather, to identify those limitations and deficits, created by prenatal alcohol exposure, that might best be managed through other programs beyond incarceration.

At times, however, there is some benefit in the juvenile serving limited detention time. This can be an effective means of communicating the seriousness of their actions. It can also be used to separate the adolescent from troublesome friends and start a course of clean and sober living. Incarceration, in other cases, is needed if the crimes are serious and/or the defendant is a high

risk to the community. ...a reason for any person with FAS/ARND to serve time. In jail, the days are highly structured. There are often clear and immediate consequences and tightly defined limits and boundaries.

At times, still, the question remains, what will happen once the person returns to the community at large?

It is important that, if incarceration happens, there is still an advocate to aid the person in acquiring educational and vocational services and counseling, as available, while incarcerated. Consultation, if correctional officials are receptive, can be useful in placing the inmate in the most appropriate correctional setting, and minimizing the risk of being victimized.

The structure provided by the correctional system is still needed. The options for community programs and other interventions will be discussed throughout the remainder of this manual.



## V. IMPLEMENTING AN INDIVIDUALIZED PLAN

The purpose of the procedures outlined in this manual is to help the client and his or her providers to have a successful outcome, and to achieve the client's full potential. This is a goal that all parties, especially the client, must endorse and support. In a previous section, steps for the development of an individualized plan for employment (IPE) were outlined. When these steps have been taken, the challenge then becomes one of implementation. From the perspective of vocational rehabilitation (VR), implementation includes provision of services such as assessment, training, transportation, job-finding services, job placement services, etc., as called for by the IPE. For the purposes of VR, implementation of the individualized plan involves translating a generalized set of goals and objectives into a specific job at a specific place with specific people at a specific time. Implementation therefore involves

1. Monitoring and coordination of services
2. Identifying individual or organization responsible for providing or paying for each service specified in the IPE.
3. Measuring and documenting progress, according to criteria specified in the IPE. This includes an evaluation of the goals of each provided service to make sure that the client has achieved these goals in functional terms, in order to recognize when the service has been completed or is no longer needed. [For example, the goal should not merely be "take a computer course" but "learn how to write a letter using Microsoft Word"].
4. Finally, the process of measuring and documenting progress determines when the client is job ready-- i.e., has the knowledge and skills needed to perform the vocational goal.

## **TEAM BUILDING**

Clients with FAS have multiple needs. A case manager should be assigned and the client support team should meet as often as needed but no less than quarterly. These meetings could include, as appropriate, the case manager, mental health therapist, employer or supervisor, social worker, caregiver, client, VR counselor, and job developer or job coach.

The team meeting can be used to assess the appropriateness of the program, to identify concerns early on, to make adjustment as needed, and to ensure that the client is included, as much as reasonable, in program decision and design. Collaboration and communication are the key factors in building a successful team and increasing the chances of a successful outcome for the client.

## **IMPLEMENTING PRE-EMPLOYMENT SERVICES**

### **Assessment**

Assessment as a pre-employment service involves referral to a specialist such as a psychologist, and should include an adaptive behavior assessment, as well as a DSM-IV multi-axial assessment. If FAS or ARND are suspected but have not yet been evaluated, these should be included in the process. Thus, a number of specialists may be required, as an evaluation for FAS/ARND usually requires a trained specialist such as a dysmorphologist. As the assessment is completed and the individualized plan is written, the “whole” of the client and his or her life should remain the central focus throughout the project.

Assessment should identify positives, such as strengths, skills, and interests, as well as common concerns for people with FAS/ARND or LD, such as mental health issues, poor social skills, impulsivity, poor judgment, a lack of abstracting abilities, and poor discrimination and generalization abilities.

These factors often have a profound effect on the client's ability to acquire and retain gainful employment or have a successful educational experience. However, they can meaningfully participate in person-centered planning if members of the team understand how to work with people who have FAS/ARND, and/or LD. A good assessment, along with a well-written individualized plan, provides steps toward change for the client, and perhaps also for the providers.

A functional vocational assessment, also known as a situational assessment, should also be included. This assessment identifies an individual's vocational interests and skills through the performance of job tasks in a variety of actual work environments in the community (Institute for Community Inclusion, n.d., *Glossary of Disability & Employment Terms*; retrieved December 7, 2003, from [http://www.onestops.info/article.php?article\\_id=7](http://www.onestops.info/article.php?article_id=7)). It is very important to not only identify the individual's vocational interests and skills, but also to do so through the performance of job tasks in a variety of actual work environments in the community, and not merely through interviews with a client, or pencil and paper tests. This type of assessment not only identifies the vocational interests and skills of the individual more accurately, but also identifies possible problems in the desired work environment that must be addressed.

## **Training**

Susan Doctor (1994) identified a number of key intervention (i.e., implementation) strategies, including the following:

1. Always provide concrete rather than abstract concepts; lessons taught in context; small steps, taught one at a time; curriculum that is developmentally appropriate; multiple sensory instruction; structure, predictability, routines, and rituals.
2. Always build on individual strengths.

3. Practice, re-teach; practice, re-teach.

The above strategies should be employed by the vocational rehabilitation counselor to facilitate the job placement and training process. When looking at a job type, a particular work environment, or the level of support that may be required to initially integrate a worker into a job site, these strategies prove invaluable. Diane Malbin (1994) suggests that for people with FAS, it may be helpful for training to Help develop skills for expression of feelings.

1. Provide specific support for social skill development.
2. Understand the various forms of communication.
3. Encourage safe, multi-sensory exploration.
4. Include as many sensory modalities as possible to facilitate integration of information and experience.

## **Transportation**

Finding the appropriate job for any client is only one piece of the employment puzzle for people with FAS/ARND. Transportation is one of the supportive services that need to be in place to help the client build toward success.

## **Job-finding services**

## **Job placement services**

### **IDENTIFYING RESOURCES**

Once the person with FAS or LD has been placed in a job, it is important for the placement to get off to a good start. If left to chance, problems may jeopardize the placement. In order to pro-actively improve the prospects for success, advocates might consider the following:

1. Education of the employer about FAS and the type of teaching, structure, supervision, and monitoring that would be helpful.
2. A mentor in the work environment.
3. A money-manager to monitor and protect any of the client's income.

## **STRATEGIES FOR MAXIMIZING SUCCESS**

### **Modifications to the Social and Vocational Environment**

The disabilities associated with FAS and ARND have a physiological basis that is observable as behavioral issues. Therefore, modifications to the social and vocational environment should be made for FAS/ARND as they would for any other physical handicap. According to Malbin (1993,p. 30), who credits Sterling Clarren with the inspiration for these ideas, these modifications could include changes to attitudes, perceptions, physical layout, sensory stimuli, timelines, expectations, and processes, in order to facilitate success:

*The idea is to begin to think about how to modify environments...The goal is not to limit or enable [in the sense of perpetuating unhealthy behaviors] people, nor is it to excuse or avoid. The goal is to support people in achieving appropriate behaviors and successes; the goal is to establish a win-win dynamic. (p.30.)*

Perhaps the five most consistent guiding principles for intervention with persons with FAS/ARND are structure, consistency, brevity, variety, and persistence (Johnson, 1999, p. 27; Tanner-Halverson 1993). Persistence often means repetition: Persons with FAS/ARND often need many more repetitions to learn a new skill than other people. Visual cueing rather than verbal cueing adds "variety." In this section, some specific suggestions will be highlighted to illustrate these general principles (adapted from Tanner-Halverson 1993, 210-221; Kvigne, Struck, Engelhart & West, 1993, and Malbin, "1994" list of 18).

## **Organize the Work Environment**

- Calm and quiet may assist concentration and staying on task. Headphones to block sound or to supply calming music may be helpful.
- Use well defined areas. Things are put away in a certain place, perhaps with a masking tape border to outline the area.
- Remove extraneous materials. Limit the number of objects and displays in room at one time. Use visual displays, then remove them. Keep work areas cleared off, except for materials in use.
- Keep worksheets uncluttered, with lots of white space on the page. Use fewer pictures or problems so the page is not so busy or filled with data.

## **Manage Over-stimulation**

- Anticipate; know danger signs and situations. Build relaxation time into the program. For example, when a client who has FAS starts tapping his/her feet and drumming his/her fingers, she needs to discharge that energy or she can erupt into aggressive behavior. Let her "take a little break now" and speed walk around the building until he/she feels calmed down.
- Teach appropriate ways to respond to overwhelming stimuli. The client can move to another part of the room, ask others to be quiet, or ask permission to leave the group temporarily.

## **Rewards and Discipline**

- Encouragement works better than praise. Say, "I know you can do that... You did that part right! Let's try it again."
- Adapt tasks and materials in terms of frustration tolerance. Shorten the time, number of examples or trials. Simplify material and concepts. When the task

is shortened, the student or client is rewarded with a sense of completion.

### ***Teach Organizational and Analysis Skills***

- Encourage use of a structured checklist of activities.
- Chunk work. Break the work into small pieces. This reduces anxiety, and decreases the tendency to think "I'll never get this all done."
- Use pictorial cues or photographs as reminders of routines. Use pictorial signs for subject areas, special room areas and location signs such as parking area.
- Use Brain Maps. Draw a one-page visualization of a task. It gets the student or client thinking in terms of graphic relationships instead of verbal connections. In the process of creating visuals for their memory map, they are drawing pictures in their brain that will last much longer than words.
- Give direct instruction in thinking skills. Ask the client- How'd you figure that out? What did you do first...? Instructor can model this by thinking out loud so that the student or client hears the instructor's thinking strategies.
- Stop at key points in order to determine the client's understanding.

### ***Teach Generalization***

- Use concrete basic language and simple sentences as much as possible.
- Focus on generalization of skills and behaviors. Generalization is the process of learning a behavior or forming a belief about a specific situation or concept, which can then be applicable to a whole class or ideas, people and/or events. When a task is taught, don't assume that they will automatically know how to generalize the information to new situations. They often will not know how to do that. We have to point out other

situations and get them to actively think about it. When else would you do this? Do you think it would work here? How is that situation similar to this one?

- It also helps to link new learning to prior experience. Fitting information together is the key to successful generalization of knowledge.

### **Managing Impulsivity**

- In group situations, a token such as a “talking stick” can help define who has the “floor,” and whose turn is next.
- Model and rehearse social skills.

### ***Teach social skills***

- How to negotiate to get what you want.
- How to disagree with someone else in an appropriate way.
- How to show someone you like them (appropriately).
- How to accept criticism or negative feedback.
- How to ask for something in a way that will increase the odds you will get it.
- How to get someone's attention in a positive way.
- How to give and take a compliment.
- How to start a conversation.
- How to say no to peer pressure.
- How to act when riding public transportation.
- What to do when you feel scared.

### ***Handling Transitional Periods: Change and Time***

- Explain new situations thoroughly, several times, before they occur.
- Give the worker reminders in advance of activity change, at the end of one activity and the beginning of the next. A predictable tactile signal (e.g., a touch on the shoulder), followed by a simple verbal reminder, may work best.



- Minimize changes in the work routine. Keep to a predictable schedule.
- Use an egg timer to help clearly define the end of an activity

### ***Getting and Maintaining Attention***

- Use the "broken record" technique by repeating the same words over and over again to strengthen the memory. For example, at the end of each session, "What is the last thing we always do?" Reply: "Turn off the lights." People with FAS and related conditions often need more repetitions to learn something than other people do.
- Keep tasks simple and specific. Break any task that takes longer than half an hour into shorter, well-defined components.
- Repeat and restructure continually. Express it different ways, show them through different modalities, including visual, kinesthetic (body movement) and haptic (touch).
- Teach them to ask for repetition of instructions or material in a form other than the one you just used. (Would you write that down for me please? Can we make a diagram?)

### **Interventions for Persons with FAS/ARND and Persons with LD**

According to Johnson (1999, p. 25), students with FAS/ARND and students with LD are both heterogeneous groups, with inter-student and intra-student differences. However, based on her work summarized above in Table 1 (p. 22), she has formulated a series of recommendations summarized and adapted here as Table 4. All items in the table are more important for persons with FAS/ARND than for persons with LD. Differences between columns are highlighted in italics.

**Table 4. Johnson's Recommended Interventions**

Persons with FAS/ARND	Persons with LD
Structure in environment, routines, etc.	Structure in environment, routines, etc.
Consistency in rules, environment, <i>communication.</i>	Consistency in rules, environment
Brevity in communications; <i>make it as concrete as possible.</i>	Brevity in communications. <i>May benefit from concrete presentation.</i>
Variety in communication, using visual and auditory input, singing, and demonstration.	Variety in communication, using visual and auditory input, singing, and demonstration.
Repetition & practice to overlearning.	Repetition & practice to overlearning.
Multisensory teaching & reinforcement.	Multisensory teaching & reinforcement.
Teach to the skill level and need of each worker.	Teach to the skill level and need of each worker.
Adapt environment to minimize distractions.	<i>May be necessary to adapt environment to minimize distractions.</i>
Immediate constructive feedback on successes and errors.	Immediate constructive feedback on successes and errors.

### Facilitating employment success

- Ask professionals to call and confirm appointments in a timely fashion. Difficulty with keeping appointments seems to be a direct manifestation of FAS (Devries & Waller, 1999).
- Position the client directly across from the employer when speaking, looking directly at the speaker so that eye contact can be maintained. If the client comes from a traditional American Indian or Alaska Native background, make sure they understand that maintaining eye contact with a non-Indian employer is expected, and not a sign of disrespect.
- Alert the client or student in advance of activity change: people with FAS

or related conditions often have difficulty with transitions. "We have ten more minutes before lunch. . . We have five more minutes!. . . You should be finishing up."

- Train the student or client to get ready for work the night before, getting clothes laid out, get lunch money ready, and so on.
- Use calendars and assignment books. Teach them how to use them and review their use of them every day for the first two weeks, then once a week.
- Assign short tasks and give explicit, concrete, and carefully defined directions. Instructions or directions like "Go to the Fork in the road. . . Does that ring a bell? Give her the brush off... Let's talk turkey! Why don't you just throw in the towel!" are very confusing, because people with FAS and related conditions often translate language in a very concrete fashion.
- Avoid giving multi-part verbal instructions. People with FAS and related conditions often find it difficult to remember complicated verbal instructions.
- Increase the client's attention by shutting out all unnecessary auditory stimulation that they don't need to hear. Use earphones with no auditory stimuli to screen out extraneous noise.
- Use a "study carrel" type of office space to shut out visual stimulation, reducing distractions.
- Ask the client to repeat back directions in their own words, paraphrasing what was said so that you are sure that the information was processed.
- After the first several items are completed, check back to make sure they

understand the next steps of the task, have not gotten distracted, and have not forgotten how to do the next task.

- People with FAS or related conditions often have significant difficulty dealing with public transportation. Be alert for problems in this area, and help the client or student learn how to deal with them.

Finally, people with FAS or related conditions often benefit significantly from an advocate. The advocate can be a family member, a job coach, or a friend. One of the important advocacy roles is to educate the employer about core disability issues such as those enumerated above. Another important role is to determine when problems are occurring, so that troubleshooting and remediation can prevent termination of employment.

## **VOCATIONAL DEVELOPMENT FOR INDIVIDUALS WITH FAS/ARND**

### **Recommendations for Vocational Counselors**

Rehabilitation counselors should have comprehensive, specific training on the effects of various disabilities throughout their graduate coursework including disability-specific practica. This manual was intended to help supply part of that training.

### **Recommendations for the individual with FAS/ARND and her/his family**

For the individual with FAS/ARND, as with many developmental disabilities, job training should begin early in life. In many cases, the typical school to work transition age of 14-18 is too late. Streissguth (1997) writes of the keys to success

*Training for being a good worker should begin not at age 14 or 18 but when a child is 4-5 years old. Capitalizing on the desire of young children to please the people they like helps them build repetition, order,*

*and organization into their lives. Paying children for performing piecemeal household jobs that are repetitive, cumulative, and easily under their control (e.g. pulling up weeds, picking up pine cones) can help with good work skills. (p.194).*

As each generation passes, and more is understood about the potential effects of prenatal substance abuse, more and more children will be identified and will be eligible to receive early intervention services. These services along with structured educational and environmental modifications beginning early in life can improve the chances of successful work integration dramatically. More study is needed to look at specific interventions that will have the most beneficial impact on later work life. Meanwhile, a number of current programs can help.

Social skills training and job coaching are frequently needed (Streissguth, 1997). Streissguth offers this example:

*Dana, a young man with FAS, had some good “survival skills” but keeping a job wasn’t one of them: “I’ve had lots of jobs, but I have trouble with my memory. I can remember long strings of numbers but still have trouble on the job. I’ve been trying so hard to get along with people and trying to hold a job, but the people are always the problem. I’ve had 20 or 30 jobs—what I’d like is to be able to hold a job. I haven’t succeeded in holding jobs because I can’t find the kind of jobs I like. The kind of jobs I’d like, I’m not trained for. I’ve tried to train myself, on my own, but it’s hard to concentrate—really hard. One time I took a 6-month training program and found a job right away. But usually I get fired pretty quickly. People get really annoyed with me. Sometimes I see some problem that needs fixing or something and I make a suggestion and people really get bent out of shape about that. I just can’t ever seem to pin down what makes them so pissed off. I feel really frustrated.” (p. 198).*

## Job Coaches

A job coach may make the difference between a successful placement and job loss, and can often make a significant difference in the long-term outcome of a placement. A job coach trained to work with persons who have FAS/ARND can be a tremendous asset not only in initial job adjustments, but in the long-term outcome. The sudden withdrawal of a job coach may precipitate readjustment problems. It is often better to wean the client from dependency on the job coach gradually.

According to Butterworth (personal communication, 21 May 2001), *Job coaching is generally a VR purchased service, much like any other service. The mechanism varies from state to state and can vary from case to case. In some cases for supported employment an outcome-based model is used with fixed payments at various benchmark points. Some examples include:*

*Oklahoma: overall fee is established through a bidding process, and accommodates both a standard level of service and a more complex level of service for supported employment. Payments are made at a number of benchmark points (Assessment completed, placement, 4 week retention, stabilization, closure). The benchmarks vary by population (MH, DD).*

*Massachusetts: Pays a fixed amount at 3 benchmark points: Assessment complete, Placement, Job stability. Extended support services can be paid at the point the job retention goal is met at \$26/hour.*

*Most states also fund job coaching (or on-the-job training, really the same thing) at an hourly rate. Massachusetts, as noted above, can combine the two as needed.*

*These services are probably typically provided under the label supported employment, but not always. Supported employment does imply ongoing supports for the life of the job, which requires that funding be handed off at some point to another source (typically after job stabilization and at the point closure occurs). MR/DD or MH agencies*

*are typical sources to pick up funding, but any state level source is fine.*

- [Job coaches and families: Powell, 1987, in Butterworth, et al., (n.d.), Chapter 10 supplement]
- [Rogan, Hagner & Murphy, 1993, in Butterworth notebook, section 8]

## **TROUBLESHOOTING**

One of the most common concerns and problems is setting unreasonable goals and expectations for clients with FAS/ARND. Under favorable circumstances, these clients often have a chatty and gregarious manner, appearing to have not only adequate or above-average verbal skills but also a full comprehension of what is expected of them. The gap between appearance and reality is a common source of frustration and problems between the employer and client with FAS/ARND.

To illustrate how unrealistic expectations can widen the gap between appearance and reality, Dan Dubovsky (1998) has suggested that instead of behavior that is normal, people affected by prenatal alcohol exposure under unfavorable circumstances often appear NURMU, an acronym for Non-compliant, Uncooperative, Resistant, Manipulative, and Unmotivated. His point is that these labels assume a knowledge of the motives of people with FAS or ARND that does not take into account the difficulties with communication and social skills common to this population. If someone doesn't follow directions that others seem to understand, we often jump to the conclusion that they would not do it, rather than consider the possibility that they can not do it because they don't understand or can not remember all the steps. Remembering a list of directions, for example, is something people with FAS often find difficult. In other words, each of these five labels may misrepresent the actual cognitions and behavior motives of the client.

Therefore, when troubleshooting, it is important to look not only at the *person*, but also at the *environment*. For example, a person who uses a wheelchair in a city where there are no curb cuts, and where the entrance to public places requires use of stairways, is said to live in a disabling environment. As a result of the Americans with Disabilities Act, public accommodations must be accessible. Similarly, a person with organic brain dysfunction such as FAS/ARND may find certain environments disabling. Specifically, many persons with FAS/ARND are easily distractible. An environment that many people would find stimulating is instead experienced as quite distracting. A person who has a difficult time completing tasks in a noisy common work area may have far less difficulty completing the same tasks in a quieter environment where there are fewer audio-visual distractions.

The case manager or a job coach can play a crucial role in reducing, if not eliminating, the problems that often result from unrealistic expectations on the part of all involved. For example, giving directions one step at a time is usually more effective than giving complex instructions. Many clients with FAS/ARND have difficulty telling time by a watch with a dial. Having a digital clock, which is easier to read, with a work schedule posted nearby is often useful in keeping the client on task. It is also helpful to convene the interdisciplinary team frequently for accomplishment audits, which help stakeholders keep in touch with their successes and build a sense of pride in their work together.

A pre-employment interview outlining the client's skills and providing information such as the above to the potential employer may reduce unrealistic expectations and promote a more viable work environment. Such an interview will provide both the client and the employer a chance to discuss concerns and establish positive structure from the outset.

Streissguth and Barr (1998) focused their study on the Native Americans in the sample studied by Streissguth, et al. (1996), and both analyzed the employment experiences of the adults in their samples who had FAS or



related conditions. A comparison of their results showed that “lying” on the job was almost twice as frequent among the Native Americans (Streissguth & Barr, 1998), as it was among persons with FAS/ARND in the general population, including Native Americans (Streissguth et al., 1996). Lying is a problematic concept with many persons who have FAS or ARND, who often have difficulty with abstractions. These percentages become more understandable when we add the possibility of cross-cultural misunderstandings. If an employee who has a cognitive impairment as a result of prenatal exposure to alcohol says something that is not “true,” it may be important to find out whether there is intent to deceive, rather than something else. The employer might jump to the conclusion that the employee is dishonest and not trustworthy, and fire the employee. However, a sensitive interview might disclose an entirely different situation, with a different solution. Here is where the client’s interdisciplinary team can find out what really happened, and work out a solution that the employer can live with.

#### **Exercise: Case Study #4: Treena S.**

Treena S. is a 35-year-old female of Native descent who resides with her biological mother, two of her four older siblings, and five nieces and nephews in a small reservation community. Her father died of cancer at the age of 43 when Treena was 3 years old; her mother has not remarried. Treena’s mother, at age 75, is still drinking. She acknowledges having several binges during her early pregnancy. These binges consisted of up to 18 drinks of whiskey over a 3–4 hour period. She was hospitalized multiple times for alcohol poisoning. She denies drinking after the fourth month of her pregnancy, although the accuracy of this report is not known.

Treena is quite growth deficient, being below the 5th percentile for height, weight, and head circumference. She was unable to complete school and has been on Social Security Disability since the age of 18. She has limited verbal and cognitive skills and has deficits in her memory and abstracting abilities. However, her visual skills are good and she has considerable artistic and musical ability. She is also very good with her nieces and nephews.

Treena has not had a significant history of impulsivity or legal concerns but she has been sexually exploited many times, the result being two pregnancies. Both of these pregnancies ended in miscarriages and Treena is now on Depo-Provera for birth control. She began drinking in her early teens and drinks in a binge pattern along with her mother and one of her older siblings. She has been through the tribal alcohol program six times without successful abstinence.

The two older siblings, a brother and sister, who reside with Treena and her mother, both work off the reservation. Neither of them is presently married and both are abstinent from alcohol. Treena’s mother is recently showing signs of Alzheimer’s and chronic liver disease secondary to her long-term alcoholism. Several times in the past 3 months, Treena’s mother has wandered away from the family home and been brought back by other relatives and neighbors living in the immediate vicinity.

Although Treena’s brother and sister would like to continue caring for her, they feel that they cannot provide a home for both her and their ailing mother. The oldest two siblings are living off the reservation and the one who takes Treena on the binges is not considered a viable option for Treena’s placement. After the last incident where Mrs. S. wandered away from home, Treena’s brother and sister consulted a physician and social worker about what options were available in their community.

One of the referrals they received was for a VR program for Treena, one specifically intended to make use of her good artistic and visual spatial skills. An appointment was made and her assessment scores are listed below. Shortly after the referral was made, Treena’s mother’s health deteriorated to the point where she was placed in a nursing home. (Testing at age 35.)

Wechsler Adult Intelligence Scale-III (WAIS-III)	
Subscale	Score
VIQ	62
PIQ	69

Wide Range Achievement Test-3 (WRAT-3)		
	S	G
	S	E
Reading	66	3
Spelling		>

FSIQ	66

	50	3
Arithmetic	> 40	> 3

Vineland Adaptive Behavior Scales (VABS)		
	SS	AE
Communication	55	7.5 years
Daily Living Skills	63	8.1 years
Socialization Skills	50	5.5 years
Adaptive Behavior Composite	56	7.0 years
Maladaptive Behavior	<i>Not Significant</i>	

Questions:

1. Is it likely that Treena has fetal alcohol syndrome? On what are you basing your answer?
2. What disabilities should Treena be assessed for? Is mental retardation likely?
3. Is Treena a more likely candidate for VR or independent living services? If so, in what types of settings and in what types of programs?
4. What are some of the significant secondary disabilities that may impact her gainful employment or independent living?
5. What are the paramount concerns in Treena's life, beyond employment and independent living? What might some of the recommendations be to address these issues?
6. What is Treena's prognosis?

## VI. EVALUATION

The final portion of the process for successfully integrating the client with a disability back into the school or employment world is an ongoing process of reevaluating the individualized plan. Program evaluation should include the following items:

1. Timely completion of special programs.
2. Achievement of goals.
3. Client's improved functioning in the areas assessed by the instruments discussed in this manual.
4. Client's satisfaction with his or her placement.

The interdisciplinary team should meet as needed, once a quarter at the start of the program, and less as the program progresses and supports are established. The client should be included in these meetings as often as possible. Changes to the program should be ongoing to ensure that the client is able to achieve the desired outcome, and is satisfied with the results. If this is not occurring, the team should work together to identify obstacles and to make plans for overcoming these obstacles.

### Exercise #5

Review the case of Matthew (Case 3). What criteria would you use to evaluate his placement? Is this placement meeting his short-term goals but not his long-term goals? Consider the following options:

1. His case can be closed and there is no need for any further support.
2. His case can be closed if certain ongoing supports are assured (identify those supports).

3. His individualized plan for employment (IPE) should be reviewed with Matthew to determine if this placement is meeting his long-term as well as short-term goals.

In summary, this manual emphasizes person-centered planning for American Indians who have FAS or related conditions. This approach involves the use of multidisciplinary teams in diagnosis (Clarren & Astley, 1997) as well as in educational and employment planning, based on the IEP model mandated by the Individuals with Disabilities Education Act (IDEA), as amended in 1997. We feel that this approach works across disciplines and through time to help each client achieve his or her maximum potential.

*No human is worth any less than this!!!*

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Appendix A:

*FETAL ALCOHOL EXPOSURE RISK ASSESSMENT FOR ADOLESCENTS AND  
ADULTS*

**FETAL ALCOHOL EXPOSURE RISK ASSESSMENT FOR ADOLESCENTS AND ADULTS**

Name: \_\_\_\_\_ Date of Exam: \_\_\_\_\_  
 Age: \_\_\_\_\_ Date Of Birth: \_\_\_\_\_ Gender: M F Race/Ethnicity: \_\_\_\_\_  
 Form Completed By: \_\_\_\_\_ Phone #: \_\_\_\_\_

**Sources of Data (please check all that apply)**

Record Review \_\_\_ Date \_\_\_\_\_ Interview of Client \_\_\_\_\_ Date \_\_\_\_\_  
 Interview of Caretaker \_\_\_\_\_ Date \_\_\_\_\_  
 Interview of Parent \_\_\_\_\_ Date \_\_\_\_\_

*(Instructions: Fill out information about the risk factors on the left side of the table and then use that data to summarize the risk of FAS on the right.)*

<p><b>I. Maternal Alcohol Use History During Pregnancy</b></p> <p>Maternal History of Alcoholism: Confirmed: _____ Suspected: _____                  Fetal Exposures to Alcohol: Confirmed: _____ Suspected: _____                  Binge drinking (4 or more drinks per occasion)  <input type="checkbox"/> none      <input type="checkbox"/> 1-2x      <input type="checkbox"/> 3-4x      <input type="checkbox"/> &gt;4x                  Frequency <input type="checkbox"/> none    <input type="checkbox"/> 1-2days/wk    <input type="checkbox"/> 3-4days/wk    <input type="checkbox"/> &gt;4days/wk                  Quantity <input type="checkbox"/> none    <input type="checkbox"/> 1 drink    <input type="checkbox"/> 2-3 drinks    <input type="checkbox"/> 4 or more                  Alcohol use by trimester                      <input type="checkbox"/> first                      <input type="checkbox"/> second    <input type="checkbox"/> third</p>	<p><b>Summary of Alcohol Use During Pregnancy</b></p> <p><input type="checkbox"/> 1. No risk  <input type="checkbox"/> 2. Information not available; Not sure  <input type="checkbox"/> 3. Low risk use  <input type="checkbox"/> 4. High-risk use</p>
<p><b>II. Growth Pattern at age: _____</b> (Use preschool data if possible)</p> <p>Weight _____kg                      <b>Standard Score:</b> _____                  Height _____inches                      <b>Standard Score:</b> _____                  Mother's height _____inches    Father's height _____inches</p>	<p><b>Summary of Growth</b></p> <p><input type="checkbox"/> 1. Normal growth  <input type="checkbox"/> 2. Not Sure  <input type="checkbox"/> 3. Probable growth retardation  <input type="checkbox"/> 4. Definite retardation</p>



## II. Description of Growth Pattern

Growth pattern is “abnormal” if:

- person was in the lowest 5 percentile for height **or** weight in preschool
- person was in the lowest 10 percentile for height **and** weight in preschool
- person is unusually small for his/her age, gender, and family.

## III. Facial Phenotype

- Philtrum smoothness and lip thinness are best assessed from a frontal face photograph taken between the ages of 2 and 12, with a neutral facial expression.
- In the presence of epicanthal folds, the palpebral fissure length may be difficult to ascertain.

## IV. Neurodevelopmental disorders

Neurodevelopmental disorders can be considered “abnormal” if

- head circumference is less than 21 inches (males)/ 20.5 inches (females), or
- mental retardation is present, or
- any of the listed disorders are considered “severe,” or
- there is more than one listed disorder.

## V. Other Physical Abnormalities

There may also be some physical abnormalities associated with fetal alcohol exposure that might indicate a diagnosis of Alcohol-Related Birth Defects (ARBD). These include:

- ◆ **Ophthalmologic** ( In addition to small palpebral fissures and a larger Inner Canthal distance) – Corneal or lens problems; Ptosis; Strabismus; Retinal abnormalities (optic disc abnormalities)
- ◆ **Otologic** – Conductive hearing loss; Sensorineural hearing loss; Posterior rotation of external ear; abnormal frequency or duration of otitis media; abnormalities of the Eustachian tubes

When combined with positive indicators of the four diagnostic categories summarized below, such physical abnormalities provide further support for the need to refer for evaluation of FAS and related conditions.

<b>Summary</b> <i>(please summarize data from the preceding page)</i>					
I.	At-risk maternal alcohol use	<input type="checkbox"/> 4. Certain	<input type="checkbox"/> 3. Probable	<input type="checkbox"/> 2. Not sure	<input type="checkbox"/> 1. none
II.	Growth retardation	<input type="checkbox"/> 4. Certain	<input type="checkbox"/> 3. Probable	<input type="checkbox"/> 2. Not sure	<input type="checkbox"/> 1. none
III.	Facial abnormalities	<input type="checkbox"/> 4. Certain	<input type="checkbox"/> 3. Probable	<input type="checkbox"/> 2. Not sure	<input type="checkbox"/> 1. none
IV.	Neurodevelopmental disorders	<input type="checkbox"/> 4. Certain	<input type="checkbox"/> 3. Probable	<input type="checkbox"/> 2. Not sure	<input type="checkbox"/> 1. none
<p>If I, II, III, &amp; IV are rated 3 or 4 (certain or probable), this person is at risk for Fetal Alcohol Syndrome and should be referred for evaluation of FAS (and to exclude other causes).</p> <p>If IV is rated 3 or 4 (certain or probable), and I is rated 2 or more, this person may be at risk for alcohol-related neurodevelopmental disorder (ARND) and should also be referred for evaluation.</p> <p>Proper diagnosis and disability assessment greatly enhances opportunities for successful outcomes. With both, outcomes become much more manageable. For evaluation of FAS and related conditions in your area, please contact: _____</p>					

**Appendix B:**  
**LEARNING NEEDS SCREENING TOOL**

# LEARNING NEEDS SCREENING TOOL

Interview Date \_\_\_\_\_

BACKGROUND INFORMATION		
NAME	BIRTH DATE	INTERVIEWER NAME
SEX <input type="checkbox"/> Male <input type="checkbox"/> Female	HOUSEHOLD TYPE <input type="checkbox"/> Single parent <input type="checkbox"/> Two parents	COMMUNITY SERVICES OFFICE (CSO)
JAS NUMBER	ETHNICITY <input type="checkbox"/> African American <input type="checkbox"/> Asian <input type="checkbox"/> Caucasian <input type="checkbox"/> Hispanic/Latino <input type="checkbox"/> Native American	
ACES NUMBER	COMPLETED YEARS OF FORMAL EDUCATION	
DEGREE (S) ATTAINED <input type="checkbox"/> High School Diploma <input type="checkbox"/> GED <input type="checkbox"/> Technical/vocational <input type="checkbox"/> AA degree <input type="checkbox"/> Other (specify):		
WHAT KIND OF JOB WOULD YOU LIKE TO GET?		
DO YOU HAVE EXPERIENCE IN THIS FIELD OR A RELATED FIELD?		
WHAT MAKES IT HARD FOR YOU TO GET OR KEEP THIS KIND OF JOB?		
WHAT WOULD HELP?		
<b>BEFORE ANSWERING THE FOLLOWING QUESTIONS, READ THE STATEMENT ALOUD ON THE BACK TO THE CLIENT</b>		
<b>SEE INSTRUCTIONS ON BACK OF THIS PAGE</b>		
YES Section I		
<input type="checkbox"/>	1. Have you had any problems learning in middle school or junior high?	
<input type="checkbox"/>	2. Do you have difficulty working from a test booklet to an answer sheet:	
<input type="checkbox"/>	3. Do you have difficulty or experience problems working with numbers in a column?	
<input type="checkbox"/>	4. Do you have trouble judging distances?	
<input type="checkbox"/>	5. Do any family members have learning problems?	
<b>1 x _____ = _____ = Count the number of "YES'S." Multiply by 1.</b>		
YES Section II		
<input type="checkbox"/>	6. Have you had any problems learning in elementary school?	
<input type="checkbox"/>	7. Do you have difficulty or experience problems mixing mathematical signs (+/x)?	
<b>2 x _____ = _____ = Count the number of "YES'S." Multiply by 2.</b>		
YES Section III		
<input type="checkbox"/>	8. Do you have difficulty or experience problems filling out forms	
<input type="checkbox"/>	9. Did you experience difficulty memorizing numbers?	
<input type="checkbox"/>	10. Do you have difficulty remembers how to spell simple words you know?	
<b>3 x _____ = _____ = Count the number of "YES'S." Multiply by 3.</b>		
YES Section IV		
<input type="checkbox"/>	11. Do you have difficulty or experience problems taking notes?	
<input type="checkbox"/>	12. Do you have difficulty or experience problems adding and subtracting small numbers in your head?	
<input type="checkbox"/>	13. Were you ever in a special program or given extra help in school?	
<b>4 x _____ = _____ = Count the number of "YES'S." Multiply by 4.</b>		
<b>Total: _____ If 12 or more, refer for further assessment.</b>		

## LEARNING NEEDS SCREENING TOOL

BEFORE ASKING THE FOLLOWING QUESTIONS, READ THIS STATEMENT ALOUD TO THE CLIENT:

“The following questions are about your school and life experiences. This information will provide a better understanding of the services you will need to be successfully employed. We’re trying to find out how it was for you (or your family members) back in school or how some of these issues might affect your life now. These questions will help us identify resources that will aid you in self-sufficiency planning with your caseworker.

Ask all questions.

1. Ask the client each question in Sections I, II, III, and IV.
2. Check YES if client answers the question with “yes”
3. In each section, count the number of “yes” answers.
4. Multiply the number of “yes” responses in each section by the number shown in the “Count the number of YES’S” area. For example, multiply the number of Section III “yes,’s” by 3.
5. Record that product after the =sign in that area.
6. Add up the numbers after the =sigh and enter that total in the Total row.
7. **If the Total is 12 or more, the participant may need further assessment and/or referral for employment related accommodation.**



**Appendix :**

***PSYCHOSOCIAL NEEDS ASSOCIATED WITH FETAL  
ALCOHOL SYNDROME***

PSYCHOSOCIAL NEEDS ASSOCIATED WITH FETAL ALCOHOL  
SYNDROME:  
PRACTICAL GUIDELINES FOR PARENTS AND CARETAKERS

Robin A. LaDue, Ph.D.

Fetal Alcohol & Drug Unit

University of Washington, School of Medicine, GG-20

Seattle, Washington 98195

ADOLESCENCE  
AGES 12 - 17 YEARS

Problems and Concerns:

- Academic ceiling is often reached; usually 4th grade for Reading, 3rd grade for Spelling and Arithmetic
- Increasing social difficulties and isolation
- Low motivation
- Egocentric, difficulty comprehending and/or responding to other's feelings, needs, and desires
- Lying, stealing, passivity in responding to requests
- Faulty logic

Problems and Concerns:

- Impulsive, aggressive, unpredictable, & violent behavior
- Involvement in vandalism, other criminal activity
- Pregnancy/fathering a child
- Loss of residential placement
- Low self-esteem and mental health issues
  - \* Depression
  - \* Suicidal ideation and attempts
  - \* Substance abuse
  - \* Sexual/emotional abuse and trauma

Recommendations:

- Change focus from academic skills to vocational and daily living skills
- Continued structuring and monitoring of leisure time and activities
- Involvement in structured social and sport group activities
- Anticipation of transition/crises situations along with appropriate planning

and early interventions

Recommendations:

- Help the patient to make healthy choices and to build on his or her existing skills
- Education of parents, caretakers, and patients regarding sexual development, birth control options, and protection against sexually transmitted diseases (STDs)
- Education of parents, caretakers, and patients to help protect against sexual exploitation
- Implement planning for future residential placement, financial needs, and vocational/educational training

Recommendations:

- Case manager role expands to include acting as a liaison between patient, family, schools, vocational programs, health care providers, and court services, if necessary
- Continued listing of daily chores with increasing responsibility
- Respite care for families
- Caretakers support group

PSYCHOSOCIAL NEEDS ASSOCIATED WITH FETAL ALCOHOL  
SYNDROME:  
PRACTICAL GUIDELINES FOR PARENTS AND CARETAKERS

Robin A. LaDue, Ph.D.

Fetal Alcohol & Drug Unit

University of Washington, School of Medicine, GG-20

Seattle, Washington 98195

ADULTHOOD  
AGES 18 + YEARS

Problems and Concerns:

- Increased expectations of the patient by others
- Increased dissatisfaction towards the patient by others
- Unpredictable and impulsive behavior
- Aggressive and violent behavior
- Depression/Suicidal ideation and attempts
- Poor comprehension of social expectations
- Withdrawal and social isolation

Problems and Concerns:

- Social/sexual/financial exploitation
- Economic support and protection
- Job training and placement
- Medical care
- Birth control/pregnancy/fathering a child
- Child care
- Legal issues, incarceration

Recommendations:

- Guardianship for funds
- Subsidized residential placements, including special moneys for biologic & adoptive parents to help defray costs for special needs
- “Homebuilders” support to help the patient live as independently as possible and to help in teaching parenting skills if the patient has children
- Specialized vocational training and/or job placements

- Medical coupons and care
- Case manager to help patients and families access services
  - \* Drug and alcohol treatment for patient, if needed
  - \* To act as liaison with court and other legal concerns, if necessary
- Patient advocates to ensure the recommendations are acknowledged and implemented

Recommendations:

- Acknowledgment of the patient's limitations, strengths and skills
- Acceptance of the patient's "world"

**Appendix C:**

***ABBREVIATIONS USED IN THIS MANUAL***

## ABBREVIATIONS USED IN THIS MANUAL

<b>ADD</b>	Attention Deficit Disorder
<b>ARND</b>	Alcohol-Related Neurodevelopmental Disorder
<b>DSM-IV</b>	Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition
<b>FABS</b>	Fetal Alcohol Behaviors Scale
<b>FAE</b>	Fetal Alcohol Effects
<b>FARC</b>	Fetal Alcohol Related Conditions
<b>FAS</b>	Fetal Alcohol Syndrome
<b>IEP</b>	Individualized Education Plan
<b>IPE</b>	Individualized Plan for Employment
<b>ISP</b>	Individualized Service Plan
<b>IWRP</b>	Individualized Written Rehabilitation Plan
<b>PCP</b>	Person Centered Planning
<b>PWE</b>	Problems with Employment
<b>SIB-R</b>	Scales of Independent Behavior – Revised
<b>VABS</b>	Vineland Adaptive Behavior Scales
<b>VR</b>	Vocational Rehabilitation