Fetal alcohol syndrome/effects| Straight talk on the syndrome

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FETAL ALCOHOL SYNDROME/EFFECTS:

STRAIGHT TALK ON THE SYNDROME

Running Head: FAS/ARBD

by

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presented in partial fulfillment

of the requirements for

the degree of Education Specialist

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Approved By

[Signatures and dates]
This paper focuses on Fetal Alcohol Syndrome and Fetal Alcohol Effects. It explains why Fetal Alcohol Effects is now referred to as Alcohol Related Birth Defects (ARBD) in the research literature. The author concentrates on a brief review of the literature published from 1990 to 1995. The cause, history, physical and behavioral characteristics, life-long needs, intervention and implications for counseling needs are discussed. An annotated bibliography is included which details several sources that contain helpful suggestions in parenting, teaching, counseling or working with individuals affected by ARBD.
INTRODUCTION

If there was a way to prevent the most common cause of mental retardation in humans, one might expect that the entire world community would be in agreement and take all necessary steps to prevent any more children being born with this affliction. Sadly, that is not the case. The number one cause of mental retardation is Fetal Alcohol Syndrome (FAS). The drug that causes the damage is alcohol—a drug that is legal and accepted socially in most countries of the world; a drug that may even have certain health benefits if taken in moderation (University of California 1995).

The Harvard Mental Health Letter (Grinspoon, ed., 1990; annotated by Hales & Hales, 1993) states:

FAS and FAE [Fetal Alcohol Effects] are widespread problems affecting as many as 80,000 children born each year. Retarded growth, physical deformities, and brain function abnormalities are the most serious manifestations of the problem. Learning disabilities including low IQ, poor judgement, inability [or reduced ability] to perceive cause and effect and lack of moral understanding are a few of the difficulties encountered. Long-term special education, vocational training, medical treatment, and speech therapy are only a few of the special services required by children and adults with
FAS/FAE. Women with FAS or FAE often give birth to children with FAS or FAE because of alcohol use during pregnancy. No known level of alcohol consumption is safe during pregnancy. Often children of alcoholic mothers end up in foster care or other placements due to the drinking mothers' inability to care for their children.

The above, in a few words, is an overall description of the problem.

This author has lived and worked among a high risk for fetal alcohol exposure population for the last twenty years. Over the years, I have been an early home interventionist for developmentally disabled and at risk children and their parents for three years, an elementary school counselor for three years. I am currently working as a mental health counselor specializing in sexual abuse treatment, domestic abuse intervention and treatment, adult survivor of trauma treatment and family preservation activities. During this time, I have become more and more aware of the negative consequences of fetal alcohol exposure. I was touched, educated and motivated by Dorris' book, The Broken Cord, (1989) to become a part of the community that wanted to prevent any more affected children being born. At the same time, I am very aware of the many diagnosed and undiagnosed individuals who are in need of life long-services, support and protection. One of my observations is that many adults
who may be affected do not share the opinion that they need services, support and protection. They do not accept supervision and guidance (i.e., societal rules) as do other developmentally disabled adults (e.g., group home, sheltered workshop participants). Adults who may be FAS/ARBD tend to:
  (a) have more children starting at an earlier age (five to eight children is not uncommon), (b) tend not to parent well, with their children often becoming wards of the court, (c) usually have an alcohol problem themselves and very possibly fetally expose another generation of children, (d) resist intervention, (e) and do not respond to time-limited intervention with long-term positive behavior changes. In other words, during the time period we work with them and provide guidance, structure, educate them regarding parenting, adaptive living skills, provide counseling, and so forth, most do okay. But when the interventionists are no longer making regular home visits or the children are no longer wards of the court, the family tends to fall apart again. Drinking often starts again and the children again become wards of the court and the cycle starts all over.

Even before anyone had heard of FAS, there were families in the community that fit this pattern. Now with more knowledge, it appears that FAS, untreated, is definitely a multigenerational disorder—each generation more profoundly affected than the previous one.
This paper will address how alcohol can cause damage to an unborn fetus, describe the range, diversity and uniqueness of damage fetal alcohol exposure can cause, address the many costs of FAS/E, prevention, and give information surrounding the diagnosis and life-long prognosis for those affected. It will describe typical characteristics associated with FAS/E during childhood, adolescence and adulthood. It will also address the historical perspective of FAS/E, suggest intervention strategies and techniques for maximizing affected people's potential, and discuss general counseling issues surrounding fetal alcohol exposure.

DESCRIPTION AND TERMS

In order to receive the medical diagnosis of FAS, a person must have each of the three following characteristics: (a) growth deficiency—low weight and/or short length at birth and continuing during childhood; (b) a characteristic pattern of facial features and other physical abnormalities; and (c) central nervous system dysfunction—which may be manifested as microcephaly (i.e., small head circumference) and/or neurobehavioral dysfunctions like hyperactivity, motor problems, attention deficits, and cognitive disabilities ranging from mental retardation to varied learning difficulties. Generally there must also be strong evidence of maternal drinking during pregnancy (Burgess & Streissguth, 1992 & 1990).
The characteristic pattern of facial features and other physical abnormalities include short palpebral fissures or small eyes, especially in relation to the distance between the eyes, a long, smooth philtrum, a thin upper lip, flat midfacial region, short nose, small chin, minor abnormalities of the outer ear, epicanthal folds (Burgess & Streissguth, 1990; Giunta & Streissguth, 1988), head circumference that is below the normal range, and joint abnormalities. Not all of these characteristics need to be present for a positive diagnosis, but the more a person has, the more likely the characteristics are caused from fetal alcohol exposure.

Fetal Alcohol Effects (FAE) is a term that has been popularly used to describe a person who has a history of fetal alcohol exposure, does not have all the physical signs necessary to be diagnosed as FAS, but does exhibit behavioral and social characteristics identified with FAS. Burgess & Streissguth (1990) state that it is important to "note that FAE is not a less severe form of FAS; it simply means that the child did not suffer all the physical abnormalities. The cognitive and behavioral characteristics of FAE are similar to those observed in FAS" (p. 4-5).

There has been a recent change in labeling by the researchers and professionals in the field of FAS. They are starting to use the term "Alcohol/Drug Related Birth Defect (ARBD)" instead of the term FAE (Gordis, 1992; Rathbun,
From the beginning of research the criteria for diagnosing FAS has remained very narrow (refer to the three criteria in previous paragraph). This narrow diagnostic criteria is a "double-edged sword" according to Malbin (1993). It does provide a clear and easily identifiable picture for people with FAS which leads to good research and intervention for them but doesn't address those without the full syndrome who have organic brain damage from fetal alcohol exposure.

Pioneer researchers described those having several signs of FAS but not enough to confirm the diagnosis as having "possible fetal alcohol effects" (Aase, 1994, p. 8). "Possible" was soon dropped and FAE became a diagnosis in itself. Researchers were uncomfortable with this because the observed abnormalities could be from causes other than fetal alcohol exposure. At this point it is very difficult to prove scientifically how the abnormalities originated. In 1989, Sokol and Clarren published an article that cautioned against diagnosing FAE and suggested the term, Alcohol Related Birth Defects (ARBD). Aase (1994) states "until a precise and unequivocal standard for diagnosis becomes available, the wisest course would be to provide a purely descriptive diagnosis for children who do not meet the [narrow] criteria for FAS" (p. 8). The descriptive diagnosis could include stating that the person was exposed to alcohol in utero, plus the other signs seen in the
person. It seems that Aase is suggesting that unless a person fits the criteria for a diagnosis of full FAS, there should be only a description of problems.

Jones, a pioneer researcher, wrote an article (n.d.) where he stated "in that a specific behavioral phenotype unique to children prenatally exposed to alcohol has not yet been delineated, developmental and behavioral problems in phenotypically-normal children whose mothers consumed alcohol during pregnancy should not be attributed to alcohol" (p. 8).

Malbin (1993) presents another point of view for those who do not exhibit all the physical signs of fetal alcohol exposure, and in which the diagnostician may or may not have access to the mother's drinking history. Malbin points out that these people may be left without a diagnosis, without the understanding that they have organic brain damage and without the intervention they need to maximize success. The term FAE and ARBD will be used interchangeably in this paper because, in the current literature, the issue is not settled and both terms are used.

**SPECIAL NEEDS**

A person with full Fetal Alcohol Syndrome who has mental retardation generally has lifetime special services available to her or him. These services include special education throughout her or his school years, adult developmentally disabled services such as being eligible for
group home or semi-independent living, structured recreational activities, sheltered workshop or supported employment (Jones, n.d.). This is the kind of life-long structure that a majority of fetally exposed individuals need, but don't get if they don't qualify for developmentally disabled services.

People diagnosed with FAE often do not qualify for special services and yet they also struggle with the consequences of fetal alcohol exposure in many aspects of their lives. They have a physically invisible handicap. There is organic brain damage, but because they look "normal", their problem behavior is seen as willful. Those with FAS who look "normal" and have an IQ within normal limits often are not recognized as having a disability (Malbin, 1993).

With fetal alcohol exposure, a person's IQ is not the most important determining factor in whether the person is in need of special services. A study with 61 adolescents and adults who had previously been diagnosed as having FAS (70%) or FAE (30%) revealed that the average IQ for the FAS sample was 66, and for the FAE sample was 73, but the range for the full sample was very broad: from 20 to 105. Other results came out of this study in that, the average reading, spelling and math performance levels of these patients were 4th grade, 3rd grade, and 2nd grade, respectively. The Vineland Adaptive Behavior Scales (VABS), revealed that the
average level of general adaptive functioning was 7 years, 5 months (emphasis added) although the median age of those tested was 16 years, 5 months. There was no indication of a general improvement in IQ, achievement or adaptive living scores as patients got older (Streissguth, LaDue & Randels, 1987). LaDue (personal communication, November 7, 1990) stressed the significance of the results from the above study which used the VABS because in essence, what society is dealing with is a seven to ten year old functioning in an adult body, that often looks "normal". LaDue's strong warning continues to be one of the most important reasons why our society needs to deal directly with adults who are affected by ARBD and treat FAS/E or ARBD as the life-long disability that it is (Streissguth, Aase, Clarren, Randels, LaDue & Smith, 1991).

COST

FAS/E is not confined in its effects to a certain culture, region of a particular country, a "type" of individual or "others" (Aase, 1994, p.8). Streissguth (1983) lists cases of FAS being reported in the medical literature of many countries including Germany, France, Sweden, British Columbia and the Yukon Territory in Canada, Ireland, Finland, Hungary, Japan, South Africa, Australia and England as well as the United States. Of the identifiable causes of mental retardation only FAS is preventable. There never has been a child with FAS/E born
to a woman who does not drink any alcohol during her pregnancy.

There is a wide range of damage that fetal alcohol exposure causes. The diversity and uniqueness of the damage to each exposed individual is part of what makes this a difficult condition to diagnose and implement appropriate, effective intervention techniques (Malbin, 1993). It is evident society pays a huge price in higher neonatal care costs, foster care, lack of adoptive homes for the older children who are affected, the school system impact, the adult developmentally disabled system, the legal system impact and highest of all—lost human potential (Bloss, 1994; Streissguth, et al, 1991).

A mother telling her story in *Fantastic Antone Succeeds!* (Lutke, 1993) describes the human cost.

Prenatal alcohol abuse for my children and for thousands and thousands of other children has created profoundly life-altering neurological handicaps. But most of the damage is invisible. Without special help, my children do not have the ability to follow society's rules, especially the unwritten ones. They do not have the ability to conceptualize, comprehend, generalize, sort out, retain, and apply abstract information.

But the more profound tragedy for all these children, and certainly for mine, is that their
neurologically dictated social behavior appears to be—in the eye of the beholder—deliberate and willful misbehavior....This view of alcohol-affected children sets up, both the children and ourselves as parents, for long-term failure as we try to accomplish the impossible (p.72-73).

The published monetary estimates of the lifetime cost of FAS/ARBD have varied. Early studies cited in Bloss's article (1994) stated that the cost of FAS in the United States had been estimated at $321 million per year for only some of the disabilities associated with FAS. There is an estimate that one individual will have lifetime costs ranging from $596,000 to $1.4 million (Streissguth, et al, 1991). It is very difficult to assign a concise monetary figure to Alcohol Related Birth Defects because of the range of damage. What can be said is that there is a higher cost of maintaining an affected person over a lifetime versus a person who was not fetally exposed to alcohol, even if everything else in these two hypothetical individuals' lives were exactly the same.

**DIAGNOSIS**

Diagnosis of FAS is made by gathering a combination of body measurements, a social history of the person's behavior, learning, etc., and if possible a history of the birth mother's drinking pattern and amount during pregnancy. A dismorphologist, a medical doctor with advanced training
to diagnose birth defects, is the person best qualified to make the diagnosis of FAS/ARBD. However, because there are very few dismorphologists practicing in the United States, any medical doctor, with special training, can adequately diagnose FAS. It is possible for the trained medical doctor to diagnose the clear cases of FAS and refer those that are suspected of having ARBD to a dismorphologist.

Many doctors have been reluctant to diagnose because there is no cure for FAS/ARBD. One of the concerns is that after the person has been diagnosed—then what? A Special Education teacher with many years experience voiced her concern regarding diagnosis. She said:

How much harm will come out of diagnosing a child with FAS/E if they do not receive proper education and care after the diagnosis? These children don't need just a label. Our school district doesn't want to make more services available because the budget is stretched as it is (Dannette O'Connor, personal communication, March, 1990).

She felt very strongly that children should not be diagnosed.

In the literature, there are more references demonstrating that the person and her or his family manages the disability better when the person knows there is a reason for the problems she or he is dealing with (Engelmann, 1993; Malbin, 1993; Streissguth, et al, 1991).
In the video, What's Wrong With My Child? (1990) a young woman with FAS talked about how it helped her to know why she had learning problems. Her adoptive parents were able to get her birth mother's alcohol history when she was carrying their daughter. The young woman wrote a letter to her birth mother as part of therapy expressing her anger, hurt and then acceptance of her mother's addiction. Both the adoptive parents and the young woman were doing better as a family after the young woman was diagnosed.

When a person has FAS and exhibits most of the physical characteristics of the syndrome, there is a temptation for the lay person to make an "informal" diagnosis (Groves, 1993). As FAS becomes more well-known, more people make "informal" diagnoses. This is not a good thing. Those who work in the education and human services fields must be very cautious. It is important to leave the diagnosis up to trained medical professionals. The advice that is current (e.g. Barbara O'Hara, personal communication, March, 1995; Malbin, 1993) is to "act as if" when there is not a diagnosis, but under no circumstances label a person FAS/E without having the person seen by a trained physician. Even then, the diagnosis is to be used only to better intervene, manage and structure the affected person's environment so she or he can maximize her or his potential.

The information most valuable in diagnosing a person is the maternal alcohol in-take history while pregnant.
Because alcohol crosses the placenta and is a drying agent, it will damage whatever cell growth is happening at the time. Sometimes the fetus is not exposed to enough alcohol to create all the physical characteristics. However, research, (Enloe, Jr., 1980) has shown that there are cell changes, even if the changes are not visible.

**HISTORY**

That a pregnant mother could damage her unborn child is not a new idea. In many articles on FAS there are historical references cited which warn of the dangers of fetal alcohol exposure. In the Old Testament book of Judges 13:3-4 an angel visits a woman to tell her she will bear a child and warns her "Behold, thou shalt conceive and bear a son: and now drink no wine or strong drink" (cited in Ahneman, 1993). The statement: "Alcohol should be barred to any man or woman who is intending to create children" and "Children should not be made in bodies saturated with drunkenness," are attributed to Plato in an article on FAS in the *Prevention Works Newsletter* (1994).

In England during the 1720s, there was a surplus of grain. The grain was turned into inexpensive gin (Gibbons, 1992) rather than stored to protect it from rats. During this period, noted as the "gin epidemic," a great number of women drank. It was suggested by the British College of Physicians during this period, that prenatal alcohol consumption was the cause of a decline in the birth rate and
an increase in "weak, feeble and distempered children" (Dartmouth, 1982). It was reported to the British Parliament in 1834, that infants born to alcoholic women have a "starved, shriveled and imperfect look" (Dartmouth, 1982).

In 1899, William Sullivan is credited with the first scientific confirmation of effects of prenatal alcohol exposure. He did a study on the female "drunkards" in the Liverpool jail and found that they had a stillborn and infant death rate 2 to 2 1/2 times greater than that of children born to their "sober relatives" (Sullivan, 1899; California Urban Indian Health Council, n.d.).

One can see from the above examples, that the observation that alcohol consumption by a pregnant woman could have negative effects on the child is not new. Even with this "folk" knowledge, it wasn't until 1968 that the scientific and medical community began once again to notice and study prenatal effects of alcohol on children. In France, a medical doctor, Lemoine, (1968), and colleagues described the similar characteristics of 127 children born to chronic alcoholics. The French findings were largely ignored.

In the United States, Jones and Smith coined the term Fetal Alcohol Syndrome in 1973 (Jones, 1973; Prevention Works, 1994). Though this started professional interest in FAS, Streissguth, another University of Washington FAS
research pioneer, described the difficulties of getting the medical and professional community at large to take the concerns of FAS researchers seriously (Streissguth, personal communication, November 7, 1990). Public concern and scientific interest in FAS/E, as a permanent life-long preventable disability, has increased during the last ten years. By 1991, over 2,000 articles have been published concerning FAS/E or ARBD (Streissguth, et al, 1991).

**ALCOHOL AS A TERATOFEN**

A teratogen is a substance known to cause adverse effects on offspring as a result of gestational exposure. Teratogenic endpoints include death, malformation, growth deficiency, and functional effects (Michaelis & Michaelis, 1994; Streissguth & LaDue, 1987). In layperson's terms, consuming alcohol, a teratogen, when pregnant means that the alcohol will cross the placental barrier and will likely cause damage to the developing fetus or embryo.

An excellent article by Enloe, Jr. (1980) clearly explains how alcohol affects developing human cells. It describes how alcohol has the ability to "behave like a liquid sponge" and absorb portions of water. He states, "They [children fetally exposed to alcohol] simply do not have the same amount of brain tissues as do normal children because alcohol has withdrawn some of the fluid from the developing brain cells and the cells have died or remain functionless." (p. 13). Alcohol can also interfere with the
proper "wiring" (Michaelis & Michaelis, 1994) of developing neurons and may account for diagnosed individuals describing themselves as having:

"a brain like Swiss Cheese"; "a man with a mind like a steele sieve"; a man who felt like he was "in a room with doors leading off of it, and sometimes the doors were all closed"; or the adolescent who drew a picture of himself in a jail cell, his arm extended beyond the bars, holding a broomstick stretched toward the key to his cell, saying, "The broomstick is just an inch too short. Happens all the time." (Malbin, 1993, p. 12).

The kind of and extent of damage done to a developing fetus exposed to alcohol cannot be standardized at this time. There are many factors that influence the outcome for each individual fetus (Malbin, 1993; Michaelis & Michaelis, 1994). Factors that need to be considered include: the mother's physical health, her eating habits, her pattern of drinking, both the mother's and fetus' liver efficiency (Enloe, Jr., 1980), age of the mother, timing of the alcohol insult, fetal susceptibility, whether other drugs were being used (Burgess & Streissguth, 1990), and genetic sensitivity (Michaelis & Michaelis, 1994; Prevention Works, 1994).

Osborn, Harris & Weinberg (1993) expand on what alcohol does when it crosses the placenta. They argue that the alcohol content is particularly high in the fetus' amniotic
fluid, placenta, liver, pancreas, kidney, lung, thymus, heart and brain. The fetus' ability to metabolize alcohol is different than that of the mother because of the deficiency of the hepatic enzyme alcohol dehydrogenase, the primary enzymatic pathway for alcohol metabolism. Thus the fetus has to rely on passive diffusion across the placenta and the mother's elimination of the alcohol. This results in alcohol concentration in the amniotic fluid even after it has been eliminated from the mother's blood (Osborn, et al, 1993). According to Osborn, Harris & Weinberg, the fetus stays drunk longer than the mother!

Studies suggest that first trimester exposure is associated with organ and musculoskeletal anomalies, and that second and third trimester exposures are associated with overall growth, intellectual and behavioral problems (Coles 1994; Engelmann, 1993; Osborn, et al, 1993).

For the individual affected by ARBD, perhaps it is not so important to determine when the alcoholic exposure happened in gestation, but to establish that the individual was fetally exposed and then set about intervening and structuring her or his environment so that she or he can experience maximum success. It is enough to know that the organic damage cannot be "undone." We all must learn different ways of accomplishing success and accept individual differences and limitations without judging the individual as inadequate (Malbin, 1993).
Frequently the question about the birth father's contribution to FAS/E is raised. The research literature has not yet established a direct link to the child having FAS if the birth father was drinking at the time of conception (Cicero, 1994; Prevention Works, 1994). One study cited found that chronic alcohol consumption in the male made conception less likely because the male's sperm is adversely affected (Prevention Works, 1994). Cicero (1994) did a study with laboratory rats indicating that adolescent male rats can impair the cognitive ability of their offspring by a short period of heavy drinking before conception. It was in the male rat offspring specifically, that there were abnormalities in the learning and hormonal levels. In their combined study, Cicero and Wozniak "think their animal experiments indicate that alcohol can exert a mutagenic effect on the sperm of a prospective father and thereby affect his future offspring" (cited in Horgan, 1990, p. 23). It is reported that studies of male rodents also show that alcohol affects offspring's immune system as well (Harbison, 1989). Streissguth, et al (1991) suggest "that both the maternal and the paternal drinking history should be routinely obtained during any workup of patients of any age with developmental disabilities, attentional defects, and/or conduct disorders" (p. 1967).

Animal studies allow for controls that are impossible in research with humans. However, the symptoms found in
animal models are remarkably similar to those observed in humans. Structural malformations, smaller birthweights, growth retardation, brain abnormalities, functional deficits, and similar internal organ damage are some of the similarities (Becker, Randall, Sola, Saulnier & Weathersby, 1994; Cicero, 1994).

Whether an alcoholic birth father contributes to his child's disability through the conception process is an unanswered question. What can be stated is that it is common sense that a father can help his pregnant partner not drink if he is supportive and sober while she is pregnant (Jones, n.d.). This is one of the best roles a father can play in prevention of FAS/E.

Because brain cells continue to develop and mature even after birth, alcohol exposure can still cause damage to brain cells even after birth (Dartmouth Medical School, 1982). Stories of mothers (usually practicing alcoholics) giving their newborn infants alcohol in a bottle because it made them sleep better were common some years ago. Even more widespread was the advice that a nursing mother drink a beer to help her let down her milk. This advice was given by well meaning mother's helpers, The LaLeche League and medical doctors (Leerhsen & Schaefer, 1989). With public education and more awareness, these are not common practices today.
CHARACTERISTICS

When discussing the typical characteristics of a person affected by FAS/E, it is important to remember that, unlike other syndromes, each person displays a variable combination and severity of symptoms, so that, although commonalities exist, each person with FAS/E is also unique (Osborn, et al, 1993). This uniqueness tends to be a hallmark of fetal alcohol exposure. The FAS Coordinator for the State of Washington was quoted as saying, "The one thing we can say about individuals with FAS and FAE is that no two are the same" (Malbin, 1993, p. 9).

The facial characteristics that are used to diagnose FAS in very young children may continue to be prominent until the onset of adolescence when they tend to soften. However the growth deficiencies persist throughout adolescence and adulthood (Osborn, et al, 1993). Much has been written on the physical characteristics of FAS. There is the minimum criteria needed to diagnose FAS that involves physical features. In addition, children often have problems with their heart, liver, kidney, eyes, ears and immune system (Aase, 1994; Prevention Works, 1994). A description of babies with FAS is as follows: "often tremulous, has poor muscle tone, disrupted sleep/wake cycles, and often exhibit 'failure to thrive' characteristics. This is indicative of central nervous system damage" (Streissguth, LaDue & Randels, 1986 p. 10).
For a more detailed discussion of the possible physical characteristics and problems associated with FAS, the reader is referred to the article, *Fetal Alcohol Syndrome: Review of the Literature with Implications for Physical Therapists*, by Osborn, Harris & Weinberg (1993).

In adolescence and adulthood, the person with FAS may gain weight, but will usually retain the short stature. After the permanent teeth come in, there are often observable dental anomalies such as malaligned and malformed teeth (Streissguth, LaDue & Randels, 1986). Other possible physical characteristics of adolescence and adulthood are abnormalities of the philtrum, teeth, lips, eyes, head shape, fingers, nose, ears, palm, back/neck/spine and midface (Streissguth, LaDue & Randels, 1986).

There is a range for intellectual functioning for people with FAS/ARBD. The range on an IQ test is from normal to severely retarded. One difference is that often people with FAS/ARBD are seen as "smarter" than they are. Streissguth, et al, (1986) described preschool children with FAS as seeming alert, outgoing, excessively friendly, and more interested in people than objects. They may talk a lot and ask a lot of questions, but their speech often lacks richness of thought and grammatical complexity.

The Vineland Adaptive Behavior Scales (VABS) have been used by researchers to determine that people with FAS/ARBD are not like other people with other forms of developmental
disability, such as Down's Syndrome. As a group, with or without accompanying low IQ, 58% of the diagnosed adolescents and adults in a study were identified on the VABS as having maladaptive behavior scores in the 'significant' range. Streissguth (1994) states that this is a much higher proportion of patients with severe behavior problems compared with people with Down's Syndrome.

For most people affected with FAS/ARBD their special education/academic needs are generated by their individual behavioral characteristics. Even though every person with FAS/ARBD is an individual, many share a common behavioral profile. Parts of this profile may be greater or lesser than other, but there is commonality.

In newborns, there tend to be the following behavioral characteristics: feeding problems, irritability, disturbances in the sleep/wake cycle, display less interest and ability to bond with caregivers (Aase, 1994; Streissguth, LaDue & Randels, 1986), sensory hypersensitivity, and eating problems which may be because of neuromuscular delays (Weiner & Morse, 1994).

In preschool age children there tend to be the following behavioral characteristics: delay in developmental milestones, short attention span, often very active, higher verbal ability than comprehension, often lack a fear of strangers (Aase, 1994; Streissguth, LaDue & Randels, 1986), poor balance and coordination (Becker, et
al, 1994), learning difficulties which may be associated with organizational and processing deficits in the areas of information input, output, integration, and memory, learning may occur in spurts (Weiner & Morse, 1994).

In school age children there tend to be the following behavioral characteristics: often very active, often very affectionate, distractable, poor attention span, poor short-term memory, inadequate communication skills, often need special education help in spite of an IQ within normal range, impulsivity, difficulty with social interactions (Aase, 1994; Streissguth, LaDue & Randels, 1986), as they grow older the impulsivity and activity may become restlessness or a tendency to leave a situation when things don't go their way, poor judgement, which is actually an inability to predict the consequences of their behavior, there may be lying and stealing with little remorse and the tendency to not learn from past negative consequences (Burgess & Streissguth, 1992).

In adolescence there tend to be the following behavioral characteristics: impulsivity, social interaction difficulties, easily led and influenced, poor judgement, trouble with abstract thinking, limited problem-solving skills, often drop out of or are expelled from school (Aase, 1994; Streissguth, LaDue & Randels, 1986), usually normal physical development of sexuality which may cause problems, may have more depression, anxiety and the feeling of being
different, definite deficits in functional or adaptive living skills (Burgess & Streissguth, 1992).

In adulthood, there tend to be the following behavioral characteristics: difficulty finding and holding jobs because of their unreliability, lack of social skills, often functional illiteracy, lack of strong, stable peer social support and are at above average risk for becoming involved in drug abuse and criminal behavior (Aase, 1994).

Malbin (1993) has grouped behavioral characteristics that describe the pre-adolescent up into adulthood. She cites a model by Morse that identifies three areas where most people with FAS/ARBD have trouble. The three areas include: (a) Difficulty translating information from one sense or modality into appropriate behavior. For example, translating hearing into doing, thinking into saying, reading into speaking, feelings into words or gaps in links such as difficulty translating information from one sense into appropriate behavior (i.e., able to 'talk the talk, but not walk the walk') inconsistent mastery, and spotty memory. (b) Difficulty generalizing information. Links are not automatically formed. Learning happens in isolated clumps and may be unconnected or loosely connected to other experiences, thoughts, or emotions. There are gaps in association such as learning information in isolated pieces, inflexibility of thought, and difficulty predicting outcomes. (c) There is difficulty perceiving similarities
and differences. Without the ability to generalize and make associations, a person's capacity to compare and contrast, see whole patterns, sequence, predict, and judge is affected. There are gaps in comparing and contrasting such as (a) difficulty distinguishing fantasy from reality, (b) difficulty distinguishing between friends and strangers, (c) trouble evaluating differences in environments, (d) difficulty making associations and integrating behaviors, (e) difficulty with abstractions such as math, money, and time, (f) There is behavior that is socially inappropriate and intrusive (Malbin, 1993).

It is important to remember that many people with ARBD are not diagnosed as such. They may have been identified as having attention deficit disorder, attachment disorder, learning disabilities, as being oppositional or lazy. Accurate identification is the basis for the development of appropriate parenting and professional strategies. Failure to recognize the organic brain damage that is part of FAS/ARBD may make the problems worse, adding to everyone's frustration (Malbin, 1993).

**INTERVENTION/MANAGEMENT**

Much detail has been written on the educational, environmental, structural and academic interventions that caregivers and professionals have used successfully with people who have fetal alcohol exposure to maximize their success. Several excellent sources have been identified in
Appendix A with a brief annotated bibliography of the identified sources.

One of the first in-depth papers, *A Manual on Adolescents and Adults with Fetal Alcohol Syndrome with Special Reference to American Indians*, for the general public was developed by Streissguth, LaDue & Randels, (1986). It continues to present a comprehensive view of what must be developed and implemented for the life needs of persons seriously affected by FAS/ARBD. Though it is written for the Native American population specifically, the authors' suggestions as to what is needed, especially for the affected adult, can be generalized anywhere. The authors also describe how difficult and expensive it is to set up these life-long interventions and predicted that the situation surrounding care of FAS/ARBD adults would have to reach crisis proportions before solutions would be implemented. This manual and Dorris' book, *The Broken Cord* (1989), have been widely used to educate and alert people to the seriousness of fetal alcohol exposure.

Rathbun (1993) is a nationally known expert on successful interventions for those with FAS/ARBD. She is among many who suggest, "Try differently rather than harder" (O'Hara, personal communication, March, 1995).

Developmental mastery results from learning how to manage one's own weaknesses, and build on strengths....There is no one right way. As with
other physical impairments, professionals and caregivers may not know how to help; people with alcohol related birth defects can be asked for their input, i.e., "When I see you forget something is it okay to point it out?" or "Does it help if I remind you, or does it bother you?"

Open questions allow the person to say what is or isn't comfortable, and what is frustrating—most times it has little to do with the caregiver, unless the caregiver sounds irritated or impatient when memory problems take place (Rathbun, 1993, p. 18).

Immunizing persons with alcohol related birth defects against feelings of chronic inadequacy may be one of the more vital components of learning (Rathbun, 1993). It has been found that people with FAS/E, like other people with disabilities, function better when they are raised in stable, nurturing, structured home and school environments adapted to their needs (Davis, 1994; Malbin, 1993).

**GENERAL COUNSELING STRATEGIES**

Several areas of counseling can be addressed surrounding the issue of FAS. There are the counseling needs of the pregnant alcohol user. Several tools exist for assessing her drinking habits, usually best used by the health care professional in a nonthreatening way. If the tool indicates that she is drinking during pregnancy, the
health care professional can share information as to how alcohol is damaging her developing child, counsel her that stopping alcohol use any time during her pregnancy will better the outcome for the child and refer her to other services if she wants help (Elliott & Johnson, 1983). The birth father should, if at all possible, be involved in all counseling efforts (Cicero, 1994; Jones, n.d.). The reader is referred to an in-depth discussion regarding the assessment measures contained in the article by Russell (1994).

Counseling the birth mother of an affected child involves assessing where she is in accepting the child's diagnosis and her own recovery process. A major issue tends to be a deep grieving process which may be complicated by internalized shame. The birth mothers often receive little positive support and don't really expect it (Malbin, 1993). This type of grief resurfaces as the child moves into adulthood. All those who have been affected by FAS/ARBD need to grieve their losses and challenges when they feel them, then move on to solutions (Engelmann, 1993). If the child has been adopted, the grieving issues will be similar for the entire family. It is important for the family to move through the grieving and acceptance process. Because immediate family is often the best advocacy "agency" for the affected person, appropriate treatment and structure can be addressed and developed. The assumption of willful
misconduct by the affected person diminishes which changes the approach to teaching and structuring the environment differently for more success (Rathbun, 1993). Dealing with the grief surrounding FAS/E gives a chance for caregivers to increase more positive parenting skills which can benefit all the children in the family and gives the caregivers an opportunity to seek out support for themselves.

Counseling the affected person can carry its own challenges. Bergstein (personal communication, April 4, 1995), a counselor who specializes in sexual abuse treatment for victims under 18 gives the following advice:

My experience of working with children with moderate to severe FAS has led me to not introduce much variety. Do the same thing—consistency, consistency, consistency! Limit their options. I’m much more directive and problem/solution oriented with breaks for fun like art. The kids will have periods of grasping a recovery issue and then lose it. I keep in mind that these kids tend to learn in a circular manner so we come back to issues and check in. My experience is that two weeks after the counseling relationship is concluded, the kid may have forgotten much of what we have worked on. I’ve learned to let go of any expectations and then I’ll get blown away by the one miraculous thing they do.
Malbin (1993) and Rathbun (1993) have had similar observations regarding counseling. Malbin suggests keeping treatment plans simple and concrete, providing structure, not strict control, using strengths and interests to teach and process issues, walking clients through transitions, paying close attention to follow through, and role-playing as helpful techniques when counseling affected individuals.

PREVENTION

While this paper focuses on what FAS/ARBD is, it must include a brief discussion about prevention. Since this is the only birth defect that is totally preventable, great effort has been poured into prevention. Peterson & Lowe (1992) contend in their article that an important group of women have been missed by the current prevention efforts. These are women for whom abstinence is difficult, but who are not physically addicted. Nevertheless, there has been an increase in community education and concern. In 1995, it is unusual for this author to find anyone in the communities where she works who is not aware that pregnant women drinking alcohol is bad for the developing child. There are, however, still many women who are drinking, even after they know they are pregnant. It appears that these women have lost the choice as to whether to drink or not—they are suffering the disease of alcoholism (Engelmann, 1993). "Just put them in jail till they give birth," is a popular first response. This is not an easy thing to do. The
threat of punishment has not been very effective with people who have lost the choice of whether to drink (Sockwell, 1993). Then there is the issue of singling out only pregnant women and punishing them for their drinking. This flies in the face of the fourteenth amendment right to equal protection under the law (Sockwell, 1993). It seems the way to prevent pregnant alcoholic women drinking alcohol is not a settled issue.

Prevention activities targeted at young people, a general public awareness campaign, and educating doctors to screen their pregnant patients for drinking habits are more successful. One example is a study done in California among sixty-two high risk women which showed that all the women in the study had knowledge that alcohol and drugs can physically harm the fetus; the majority had detailed information regarding birth defects, low birth weight, and fetal alcohol syndrome. Their main sources of education/information were television and their physician (Hussong, Bird, & Murphy, 1994).

Prevention is too much for any one agency. For example, one local FAS/E Task Force in Northeastern Montana made up of both professionals and community members has been meeting for four years. Even with the combined effort of the task force, there is a need for more prevention activities and public awareness, more support for caregivers, more special services needed for affected people
of all ages, the need for more education for the school systems, the criminal justice system, the social services system, more treatment options for pregnant women who have children, and the education of the medical profession. This task force is trying to accomplish these tasks while facing the obstacles of inadequate time, energy, money and sometimes support. Everyone who is a part of the task force believes that the work must continue. If the efforts of the task force prevent just one woman from drinking while pregnant, then all the efforts will have been well worth the struggle.

According to McCreary (1993), national health goals endorsed by Congress call for reducing the incidence of fetal alcohol syndrome by 90 percent by the year 2000. This is a lofty goal, because Congress has been reluctant to allocate adequate funds to accomplish this goal. One can only guess what the current Congress will do regarding preventing FAS/ARBD. There is much left to be done in the area of prevention, much left to be done with newborns, preschool and young children and adolescents.

**GOALS**

LaDue, (personal communication, November 7, 1990; Streissguth, LaDue & Randels, 1986) set out her recommendations for each age group. Her overall goal is to ensure that affected individuals receive proper health care, educational services, birth control information and safe
long-term residential placement. What follows is her "wish list" for all people who are affected by fetal alcohol exposure.

For Birth to Five Years:

A case manager/coordinator of services; placement of child in preschool; respite care for caregivers; early diagnosis; early intervention with parents or caregivers; education of caregivers regarding physical/psychosocial needs of the affected infant/child.

For Six Years to Eleven Years:

Safe, stable, structured residential placement; careful monitoring of health issues; appropriate educational placement; evaluation of adaptive living behavior; clear, concrete and immediate consequences for inappropriate behaviors; respite care for caregivers; a case manager; use of visual cues; behavior shaping using very concrete techniques.

For Twelve Years to Seventeen Years:

Emphasis on special needs/problems of this population including: most reach academic ceiling; sexual difficulties—either easily exploited or engaging in inappropriate sexual behavior; depression; pregnancy or fathering a child; loss of residential placement. For intervention during this period Dr. LaDue includes education of caregivers and affected child regarding sexual development and birth control programs; implementing
planning for adult residential/vocational training and placement; appropriate mental health intervention if needed; respite care for caregivers; continued safe, stable residential placement; the education focus would switch from academic to daily living and vocational skills; careful monitoring of social activities and structuring of leisure time. (LaDue, Streissguth & Randels, 1992).

**For Adulthood (18+):**

Safe, stable residential placement; economic support and protection; specialized vocational training and job placement; medical care; appropriate mental health services; guardianship for funds; client advocates to help ensure the above occur; protection from social/sexual exploitation. (LaDue, Streissguth & Randels, 1992).

**CONCLUSION**

There is hope. LaDue's "wish list" still holds much relevance in today's society. We, as a nation, need to stand together and realize that FAS/ARBD can be prevented if women and men don't drink alcohol before conceiving a child and women do not consume alcohol while pregnant. We, as a nation, also need to recognize that we have affected people of all ages among us, and they have special life-long needs. I wrote the following after attending the Every Third Child...A Seminar on Prevention Through Education, Diagnosis, and Treatment of Fetal Alcohol Syndrome Specifically as it to the Native American Conference in
Denver, Colorado in 1990: "Early diagnosis is important so an effective long range intervention plan can be developed. This disability cannot be taken away, but affected people who have the above (meaning Dr. LaDue's Wish List) starting early in life do much better."

There are success stories in the literature; and I'm sure in many communities in the world. For preschool and school age children, there has been progress in recognizing their unique needs (i.e., the saying, "Try differently, not harder.") I am concerned that the unique life-long need for support, services, guidance and structure has not been recognized for adults who are affected by ARBD but don't fit into the developmentally disabled system. They very well may be the key to preventing another generation of children being born fetally exposed to alcohol.

The work goes on!
APPENDIX A

ANNOTATED BIBLIOGRAPHY


This book offers the practical wisdom of parents, teachers, and therapists on raising and educating children with FAS/E. Parents describe how they organize their family life and deal with the schools. Teachers offer descriptions of classrooms where children with FAS/E thrive. This book emphasized the message that the future of children with FAS/E is more hopeful than existing stereotypes portray (Hales & Hales, 1993 p. 351).

**FAS/FAE Information and Resource Packet** (1989). Vermillion: University of South Dakota. Available from University of South Dakota Affiliated Program, USD School of Medicine, University of South Dakota, 414 E. Clark, Vermillion, South Dakota 57069-2390. Tel. 1-605-677-5311 or 1-800-658-3080. Copies available for $5.00 each.

Information in this packet includes education techniques for children, adolescents and adults with FAS/E. All materials can be copied and
distributed freely as there are no copyright restrictions (Hales & Hales, 1993, p. 349).


This booklet was developed to help parents understand their child(ren) affected with FAS. It is formatted in question and answer form and covers the topics of: sleeping, eating, developmental milestones, speech and language, illnesses, sensory, activity levels, learning problems, behavioral concerns, friendships, family relationships, adolescence, parent needs and resources. This would be a good resource for a counselor to have in their library.

**Fetal Alcohol Syndrome/Fetal Alcohol Effects: Strategies for Professionals** (1993). Diane Malbin.

This booklet provides information on FAS and FAE to help support professionals in their work with clients whose lives have been affected by fetal alcohol exposure. This booklet presents a framework for understanding the daily challenges faced by people with FAS/FAE and provides guidelines for educating clients regarding their conditions. Strategies are discussed for working...
with these clients regarding chemical dependency
treatment and recovery.

Handle with Care: Helping Children Prenatally Exposed to
Drugs and Alcohol. (1992). Sylvia F. Villarreal, Lora-Ellen
McKinney & Marcia Quackenbush. Santa Cruz, Calif: ETR
Associates.

This is a valuable resource for school
counselors and educators of children, from
preschool through age ten. There is specific
information about prenatal drug and alcohol
exposure, case studies which give examples of the
broad range of experiences and challenges found
with children born to drug/alcohol involved
parents and profiles good results when these
children receive positive adult care and attention
(Hales & Hales, 1993, p. 351).

A Manual of Adolescents and Adults with Fetal Alcohol
Syndrome, with Special Reference to American Indians, 2d
Randels. Seattle, Wash.: Dept of Psychiatry and Behavioral
Sciences and U.S. Dept. of Health and Human Services.

This work contains recommendations for Tribal
Councils and community leaders, health personnel,
social workers, community personnel, the courts,
teachers and school personnel and caretakers. This can be used as a basic reference manual with information that is relevant to anyone who is interested in FAS/ARBD prevention and intervention.


Diane Davis describes the special needs, behaviors of children diagnosed and background information on alcoholism. The next 124 pages are dedicated to addressing interventions, structure and teaching techniques that have helped to organize and maximize success for children with FAS/ARBD and their caregivers.


An excellent resource for women who worry that their drinking during pregnancy may have affected their children. Written in an easy-to-read style, this illustrated booklet includes information on how
chemical use may affect a child's development during pregnancy and provides facts on what to do and where to go for help. Excellent resource for counselors to use both in prevention and counseling a birth mother.
APPENDIX B

This Appendix lists the assorted material contained in the Educational Resource on Fetal Alcohol Syndrome/Effects given to the University of Montana's Counselor Education Department as part of my project.

The goal of the Educational Resource on Fetal Alcohol Syndrome/Effects is to provide supplemental material for those students who read this paper, thereby allowing them to further educate themselves regarding FAS/E.

The Educational Resource contains the following in order of inclusion:


A Bill of Rights for Children. The Primax Group.

Substance Abuse During Pregnancy. S.F. Wheeler.

Multilevel Intervention for Prevention of Fetal Alcohol Syndrome and Effects of Prenatal Alcohol Exposure. I.E. Smith & C.D. Coles.

Diagnosis and Management of Fetal Alcohol Syndrome. K.L. Jones.

Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Effects (FAE): A Lifespan View, with Implications for Early Intervention. H.C. Olson, D.M. Burgess & A.P. Streissguth.


How Alcohol Affects the Developing Fetus. C.F. Enloe, Jr.


Patients with Fetal Alcohol Syndrome and Their Caretakers. C.T. Giunta & A.P. Streissguth.

Iceberg. Volume 4, No. 4, Fall, 1994.


Fetal Alcohol Syndrome at the Turn of the 20th Century: An Unexpected Explanation of the Kallikak Family. R.J. Karp, Q.H. Qazi, K.A. Moller, W.A. Angelo & J.M. Davis.


Fetal Alcohol Syndrome/Fetal Alcohol Effects: Strategies for Professionals. D. Malbin.

Psychosocial Needs Associated with Fetal Alcohol Syndrome and Fetal Alcohol Effects. R.A. LaDue.

10 Common Misconceptions About Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Effects (FAE).

An Adult Has Been Diagnosed as FAS or FAE--Now What?. Adapted from D. Davis.

Working with Clients Who Have Been Identified as Having FAS/ARBD. D. Malbin.


FAS/FAE Cycle: In the Absence of Identification.

The Montana Fetal Alcohol Syndrome/Effects (FAS/E Program Brochure.

Catalog of Reprints: Native American Issues. B. O'Hara.

The Montana FAS/E Program: Selected Reading List.

Fetal Alcohol Syndrome: The Sobering Facts About the Nation's Number One Preventable Birth Defect. M. Dorris.

Fetal Alcohol Syndrome: A Letter from a 16 Year Old. S. Helbock.

FAS/E Case History I: Male, Age 17, Adopted, Born to Alcoholic Woman, Age 35 at Birth.
FAS/E Case History II: Female, Age 20, Raised by Birth Mom (In Alcohol Recovery for 15 Years), Age 35 at Birth.

A Letter from Dancing Hair and His Birth Mom. Dancing Hair and S. Good Luck.


My Son, A Young Adult with Alcohol Related Birth Defects. C.H. Brice.

Addiction at Birth Marks Her Life: Ann Landers Column. S.V.

Poems by Louella Douglas.

Old Man Coyote and Turtle Woman.


South Dakota University Affiliated Program Fetal Alcohol Syndrome Information Packet.
REFERENCES


