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**Author**

Streissguth, Ann P.

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# **Fetal Alcohol Syndrome: Understanding the Problem; Understanding the Solution; What Indian Communities Can Do**

**ANN P. STREISSGUTH**

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## INTRODUCTION

Fetal Alcohol Syndrome (FAS) has been reported in people of all racial identities. FAS is not an Indian problem per se; it is an alcohol problem. It is an Indian problem only to the extent that Indians have alcohol problems. FAS is a major public health problem in cultures that have problems with alcohol abuse.

Many American Indian/Alaska Native communities have disproportionately high rates of FAS, both on and off reservations, both among children raised in their natural environments and those who have been adopted away and raised out of their communities. FAS is not caused by the environment in which a child is raised after birth, but by the toxic effects of alcohol prior to birth. It has been proposed that cultural, social, environmental, and biological factors may interact to increase the risk of FAS among American Indians/Alaska Natives.<sup>1</sup> This paper focuses on what Indian communities can do to understand and prevent this disabling condition and to help the lives of those affected.

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Ann P. Streissguth is a professor and director of the Fetal Alcohol and Drug Unit, Department of Psychiatry and Behavioral Sciences, University of Washington School of Medicine, Seattle.

In 1890, Crowfoot said,

What is life? It is the flash of a firefly in the night. It is the breath of a buffalo in the wintertime. It is the little shadow which runs across the grass and loses itself in the sunset.<sup>2</sup>

Life is fragile. Life is a sacred trust. It is our sacred trust because we are responsible adults. We are the elders for children everywhere. It is our job to safeguard our children so that they can carry on in our place, so that they can carry on the culture. A people that abandons its children ends up with no culture and no people. Each of us must ask ourselves, "Do we have the courage and the strength to fight for our children?" In the words of another famous American Indian, Sitting Bull, "Let us put our minds together and see what kind of life we can make for our children."<sup>3</sup> That's what we are about when we speak about Fetal Alcohol Syndrome. We're talking about saving our children.

Fetal Alcohol Syndrome (FAS) is a birth defect caused by mothers drinking alcohol during pregnancy. In the past, many women did not know that alcohol could hurt their unborn babies. Many women still do not really understand how damaging alcohol can be. FAS is a birth defect that lasts a lifetime. Even though children with FAS may not look very unusual, they have sustained some degree of prenatal brain damage from alcohol that affects how well they perform and even how they behave. The life history of one Indian boy is poignantly told by his adoptive father, Michael Dorris, who did not know at first that his son had FAS:

My son will forever travel through a moonless night with only the roar of the wind for company. Don't talk to him of mountains, of tropical beaches. Don't ask him to swoon at sunrises or marvel at the filter of light through leaves. He's never had time for such things, and he does not believe in them. He may pass by them close enough to touch on either side, but his hands are stretched forward, grasping for balance instead of pleasure. He doesn't wonder where he came from, where he's going. He doesn't ask who he is, or why. Questions are a luxury, the province of those at a distance from the periodic shock of rain. Gravity presses on Adam so hard against reality that he doesn't feel the points at which he touches it. A drowning man is not separated from the lust for air by a bridge of thought—he is one with it—and my son, conceived and grown in an ethanol bath, lives each day in the act of drowning. For him there is no shore.<sup>4</sup>

FAS robs children of their ability to develop into what could have been their potential had they not been thwarted by prenatal alcohol exposure. Children with FAS will never be what they might have been, had their mothers not been drinking during pregnancy. The sadness of this knowledge is shared by mothers, by families, and by communities. This sadness can motivate change.

One of the biggest single things that each of us can do for our children is to assure that they spend the first nine months of life in an alcohol-free environment. Our children cannot do that alone—it is up to us. Some women never have to think about not drinking during pregnancy. They live in cultures in which alcohol use by women is not generally acceptable or encouraged. These women do not have to make a personal choice not to drink. Such cultures provide a strong, supportive force for women *not* to drink during pregnancy. Such a cultural identity can increase resistance to even the seductive advertising campaigns that promote the idea that drinking is smart and fashionable.

Drinking for pregnant women is never smart or fashionable. Drinking for a pregnant woman is dangerous for her child even at levels that are not dangerous for the mother. Exactly how dangerous it is depends on how much alcohol is consumed, when it is consumed, and the individual characteristics of the mother herself and her fetus. One of the most significant problems among women in the childbearing years is that many have been “partying” for a month or two before discovering that they are pregnant. Thus, they may be drinking during a time when the unborn child is very sensitive to the damaging effects of alcohol. Although stopping drinking any time during pregnancy is better than not stopping at all, the best situation is not to have been drinking at all.

It will take courage to save our children. It will not be easy to identify women in our communities who are still drinking during pregnancy. It will not be easy to find effective methods to help them. It is easier to go home and forget about it, but we must think of our children.

I know one young girl with FAS who has probably done more to prevent Fetal Alcohol Syndrome than anyone else on her reservation. She prevented FAS in her four younger brothers and sisters, and she is happy about that, to the best that she can understand it. Eighteen years ago, her mother brought her, as a newborn baby, to be seen by Dr. David W. Smith at the University

of Washington in Seattle. Dr. Smith told the mother, "Your baby has Fetal Alcohol Syndrome. It is caused by your drinking alcohol during pregnancy. If you continue drinking during all of your pregnancies, you will damage all of the rest of your children." Her mother said that, at first, she was furious and kept right on drinking. But two years later, when she found out that she was pregnant again, she said to herself, "I'll show him!" She put down her unopened beer and did not drink again—ever. Why? Because when she delivered the big healthy baby that came from an alcohol-free pregnancy, she knew that she had never had a healthy baby before. While she is happy for the four beautiful children that she had after she quit drinking, this mother continues to live with her sadness about the reduced quality of life available to her daughter with FAS, as well as the knowledge that she will have to care for this daughter for the rest of her life. But this mother did not let her sadness overwhelm her. She went on to do those things that her alcoholism had prevented her from doing before: She finished high school. She went to college. She became an alcohol counselor. She became a source of strength in her community, helping other women to avoid drinking during pregnancy. Furthermore, through her openness in sharing her experiences, her whole community can see every day the difference between the beautiful, healthy children she produced and the FAS daughter who was robbed of ever achieving her potential. Her community has learned that prevention is important and that it is possible.

## FAS: FACTS AND FIGURES

### **What Is Fetal Alcohol Syndrome (FAS) and What Is Fetal Alcohol Effects (FAE)?**

FAS is a birth defect caused by prenatal alcohol exposure. Unlike club foot or cleft lip and palate, which are major malformations observable at birth, FAS has more subtle physical characteristics but devastating mental consequences. FAS is a medical diagnosis defined by a cluster of three main characteristics: (1) growth deficiency, particularly observable at birth and in the early childhood years; (2) a pattern of minor physical anomalies particularly observable in the face; and (3) some manifestations of Central Nervous System (CNS) dysfunction.<sup>5</sup>

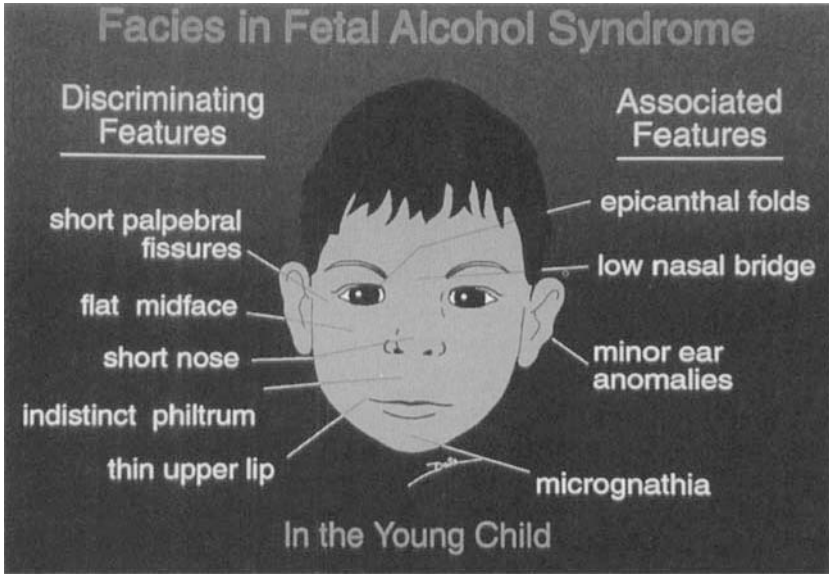


FIGURE 1. Facial features associated with Fetal Alcohol Syndrome. The features on the left are those most frequently seen in patients with FAS. Those on the right are also seen with increased frequency but are not as diagnostically relevant. It is the pattern of characteristics rather than any single anomaly that is diagnostically significant. From Streissguth and Little, 1994.

The CNS effects can include microcephaly (small head) and/or hyperactivity, gross motor delays, perceptual motor problems, attentional deficits, learning and/or memory problems. The facial features include short palpebral fissures (the width of the eye slit); a thin upper lip and smooth and/or long philtrum (the ridges that run between the lips and the nose); and a flat midface. Figure 1 portrays the typical face of a young child with FAS. Other facial features that occur with increased frequency but that are not necessarily diagnostic of FAS are also listed in figure 1. In addition, children with FAS are at increased risk for major congenital malformations such as heart defects, cleft lip and palate, spina bifida, and so forth, but no one malformation is characteristic of FAS. Children with FAS are also at increased risk for otitis media (ear infections) and hearing disorders; for eye problems such as strabismus and myopia (crossed eyes and nearsightedness); and for joint and limb anomalies and misaligned and maloccluded secondary teeth.<sup>6</sup>

The essential aspect of the FAS diagnosis is the presence of this pattern of defects: growth deficiency, minor physical anomalies, and CNS dysfunction, in a child who was known to have been exposed to alcohol in utero. Other children who are exposed heavily to alcohol before birth may have one or two of these three primary features, but not all three. Such children are usually not diagnosed FAS, but rather are termed possible Fetal Alcohol Effects (FAE), which is not a medical diagnosis but a descriptive term to describe observed effects that could have been caused by prenatal alcohol exposure. Children with FAS are not necessarily more severely affected than those with FAE, but they may be. Children with FAE may be in need of the same type of services as those with the full FAS. However, it is often more difficult for children with FAE to get needed services, because they do not have a medical diagnosis.

The diagnosis of FAS is made on the basis of a clinical examination, usually by a dysmorphologist, who is a specialist trained in birth defects syndromes. Many medical geneticists and pediatricians, but not all, are also skilled in FAS identification. Many physicians have had little or no experience with this diagnosis. At this time, there is no laboratory test for FAS as there is for Down Syndrome (in which a chromosomal abnormality can be detected) or phenylketonuria (PKU, in which elevated phenylalanine levels can be detected from a simple and inexpensive neonatal screening test).

It is beneficial for the child and the mother to have Fetal Alcohol Syndrome diagnosed early. Speedy diagnosis of the infant can lead to appropriate treatment for the mother's alcoholism and the child's developmental disabilities. A recent study at a large maternity center in Texas showed that, without emphasis on FAS detection, it is unlikely that FAS patients will be routinely diagnosed either at birth or in the perinatal period.<sup>7</sup>

*Each community should have a system for effectively screening children at risk for FAS. Such screening programs should begin at birth and continue during the early childhood years. Each community should have a systematic referral network for evaluating children suspected of having FAS and for treating alcoholic mothers at risk for producing children with FAS.*

### **What Causes FAS?**

Alcohol consumption by a pregnant woman is the cause of FAS. Despite the fact that alcohol is used frequently in our society for

many social and ceremonial occasions, it is well recognized as a teratogenic drug—a drug that causes birth defects from prenatal exposure. Since the birth defects caused by alcohol primarily affect the brain, they are observed primarily through brain-related behaviors. This makes these defects even less conspicuous at birth. Children with FAS often go undiagnosed in their communities, particularly when they do not have major physical malformations. This means that their special needs often are unmet.

Like all teratogenic drugs, alcohol acts in a “dose-dependent” fashion. This means that, in general, the more a mother drinks, the worse the effects are on her child. However, like other teratogens, alcohol does not affect everyone equally. Some mothers are more sensitive than others to the teratogenic effects of alcohol. This explains why one mother will have an affected child at levels of alcohol use that do not produce an FAS child from another mother. Likewise, children have varying levels of sensitivity to fetal alcohol effects. That explains why we can see different degrees of fetal alcohol effects in nonidentical twins of alcoholic mothers. Even though they get the same amount of alcohol in utero, nonidentical twins, who have disparate genetic backgrounds, can have different sensitivities to prenatal alcohol exposure and different degrees of fetal alcohol effects.<sup>8</sup>

When alcohol is consumed by a pregnant woman, it takes only a few minutes for the blood alcohol level of the fetus to reach the blood alcohol level of the mother. The fetus, however, being so tiny and in such a rapid state of development, is much more vulnerable to the effects of alcohol than is the mother. Therefore, levels of alcohol that might not be high enough to cause the mother to feel drunk can still be dangerous for the fetus. That is why we say, “When the mother drinks, the baby drinks, too” (figure 2).

Prenatal alcohol affects whatever is developing in the fetus. Physical anomalies are related to exposure during the first trimester. Body weight is more affected by drinking during late pregnancy. But the brain, which is the most vulnerable organ in the body to the prenatal effects of alcohol, is developing throughout pregnancy. There is no safe time during pregnancy to drink.

Different patterns of alcohol use can also have different effects on the fetus. Drinking binges (three to five drinks at a time), even if they occur only infrequently, are especially dangerous to the fetus. However, there is no indication that any level or pattern of



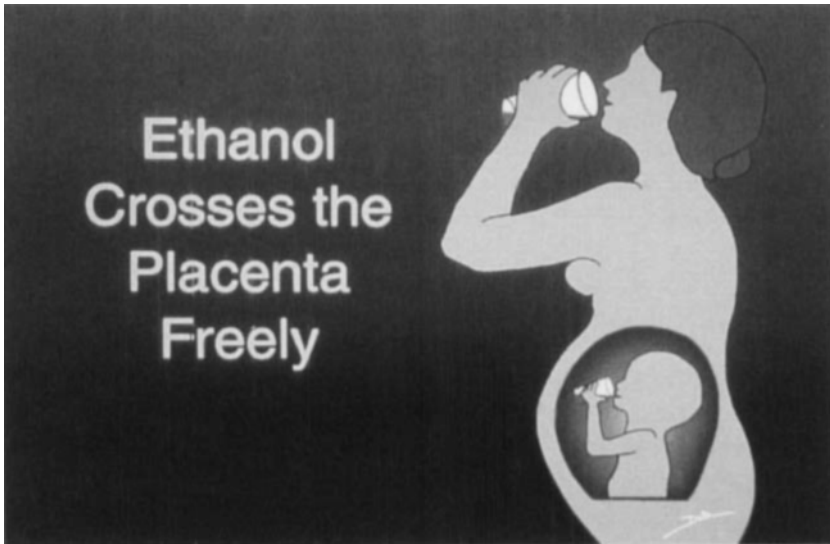


FIGURE 2. When a pregnant woman drinks alcohol, so does her baby. Alcohol readily crosses the placenta and, within minutes, the fetus has the same blood alcohol level as the mother. From Streissguth and Little, 1994.

alcohol exposure is entirely safe. See “Unit 5: Alcohol, Pregnancy, and the Fetal Alcohol Syndrome: Second Edition” for further documentation on FAS and effects of prenatal alcohol exposure on the fetus.<sup>9</sup>

*The best advice is not to drink alcohol during pregnancy. Although FAS is caused by heavy or binge patterns of drinking, even moderate or “social” levels of drinking can cause more subtle effects, including lowered birth weight and learning problems.*<sup>10</sup>

### **Is FAS Inherited?**

No, a mother with FAS will not pass it on to her children unless she herself also drinks during pregnancy. We do, however, see families in which several generations of women have FAS or FAE. This happens when women with FAS/FAE become alcoholic and continue to drink alcohol during their pregnancies. Children with FAS/FAE are themselves at increased risk for alcoholism because they have at least one alcoholic relative (their mother). Although the proportion of children with FAS/FAE who become alcoholic is unknown, we have certainly observed alcoholism in a number

of patients with FAS and FAE, and it often presents special treatment problems due to their developmental disabilities.<sup>11</sup>

A father with FAS will not pass FAS on to his children either. The father's drinking does not cause FAS, but studies are underway now to determine whether a father's drinking can be dangerous to his children in some other way. It is easier for a mother not to drink during pregnancy if she is supported by a husband who is not drinking. In this way, both partners are preparing wisely for their role as parents.

*Good parenting begins before birth. The parents and the family should provide a safe, nurturing environment in which it is easier for a woman not to drink alcohol, smoke cigarettes, or take drugs during pregnancy in order to produce a healthy child for the next generation.*

### **How Common Is FAS?**

The prevalence of FAS in any society depends on the drinking habits of women of childbearing age. If women do not drink during pregnancy, there is no FAS. Overall, the incidence rate of FAS is probably between one and three per thousand. But in some Indian communities, the incidence rate is much higher.

Several studies have been carried out in American Indian/Canadian Indian populations. May and colleagues found great variability in the prevalence of FAS among different tribes of the southwestern United States.<sup>12</sup> On one reservation, about one in seven hundred births resulted in a child with FAS. On another reservation, children were at significantly higher risk, about one child with FAS in one hundred births. These studies undoubtedly underestimate the true prevalence, because they were based on a community screening and referral network; they did not include children who died or were not in the community at the time the studies were carried out, or who, for one reason or another, were not referred through the screening program or refused to be evaluated.

May and colleagues found other important tribal differences in FAS which they related to community attitudes toward alcohol. On some reservations, the children with FAS were born primarily to a small number of women who were somewhat isolated from the community and who each produced a number of affected children. On other reservations, children with FAS were produced by a much larger number of women, and these women were more likely to be involved in the mainstream culture.

May and colleagues found not only that the rate of FAS/FAE increased between 1967 and 1982 but that the rate was closely related to per capita payments. One small reservation produced fourteen children with FAS/FAE during years of regular per capita payments from royalties; only one such child was produced after per capita payments were discontinued. Unfortunately, no subsequent prevalence studies on this population have been undertaken.

The prevalence patterns of FAS followed trends for the prevalence of alcohol-related problems in general. Tribes with a loose, band-level social organization had a higher prevalence of FAS, while the more highly structured tribes had the fewest drinking mothers and the lowest prevalence of fetal alcohol damage.<sup>13</sup> An important aspect of this early study was the documentation that, among those mothers who had affected children, 25 percent had produced more than one child with FAS/FAE. Early identification of babies with FAS can serve as a deterrent against further FAS, if the mother is given proper assistance.

In a small Canadian Indian community, Robinson and colleagues carried out a systematic evaluation of every child and every mother.<sup>14</sup> One in eight children were identified as having the full FAS; twenty-two out of the 116 children examined had FAS/FAE. These children were born to fourteen of the forty-five mothers who were using alcohol during pregnancy. No children with FAS/FAE were born to the forty-seven women in the community who were not drinking during pregnancy. Five of the mothers in this community accounted for 54 percent of the children with FAS. Early identification of these children with FAS could have targeted these mothers for help after their first FAS child was born.

When children with FAS/FAE were compared with another group of children from the same community who were matched for age and sex but did not have FAS/FAE, the children with FAS/FAE performed significantly more poorly on tests of general intelligence. Almost 20 percent of the children in this community had FAS/FAE, and two-thirds of these were mentally retarded. These statistics demonstrate the devastating impact of female alcohol abuse in this small, isolated community of approximately 350 Native American people. Can a culture withstand such an onslaught?

*Prevalence studies of FAS/FAE in American and Canadian Indian communities demonstrate the tremendous importance of preventing*

*FAS/FAE. They also suggest that special attention should be devoted to women who have already produced a child with FAS, since they are at highest risk for having another affected child. Prevention of FAS in a future pregnancy is an important reason for an early diagnosis of FAS in babies.*

### **What Kinds of Problems Do Children with FAS Have?**

The developmental course of babies with FAS may include developmental delays, but this is not always the case. They are, however, at higher than normal risk for sucking and feeding problems and for sleep disorders.<sup>15</sup> Otitis media and failure to thrive are also frequently noted during infancy. About 70–80 percent of young children with FAS are hyperactive, but a few are hypoactive.<sup>16</sup> Some children with FAS/FAE also evidence language and perceptual-motor problems during the preschool years. With the onset of school, attention deficits and behavioral problems often emerge, and academic problems are noted.<sup>17</sup>

Deficits in intellectual functioning have been reported frequently in groups of children with FAS/FAE who were given standardized IQ tests. As a group, patients with the full FAS have a lower IQ score than those with FAE.<sup>18</sup> The Wechsler IQ tests yield both a verbal (VIQ) and a performance IQ score (PIQ); it is interesting to note that 95 percent of these adolescent and adult patients with FAS/FAE had a VIQ lower than the PIQ.<sup>19</sup> The PIQ tasks involve arranging block designs, putting together puzzles, coding data, and finding missing elements in pictures. The VIQ tasks include vocabulary, abstract thinking, general comprehension, memory for digits, and general information level. This finding was not limited to the Indian patients in the sample but typified most of the patients with FAS/FAE, regardless of social background, level of IQ, or socioeconomic status. In our clinical experience with patients with FAS/FAE, their VIQ (rather than their PIQ) appears to be a better indicator of their specialized needs. Patients who have been denied special services due to a high PIQ have often done quite poorly, because the expectations were inappropriately high.

Although the average IQ scores of children with FAS is in the mentally retarded range (around 68 to 70), it is a mistake to think that all children with FAS are mentally retarded. Almost half are not technically mentally retarded and thus are ineligible for the special services that are more readily available for persons with

clear mental retardation. It is important to realize that (a) many patients with FAS may have normal or borderline normal intelligence, and (b) those who are not retarded may still have neuropsychologic and adaptive behavior problems caused by Central Nervous System (CNS) dysfunction stemming from their prenatal alcohol exposure. These latter patients often have more problems, because their facade of normalcy masks cognitive deficits in attention, memory, language, and abstract thinking that make it difficult for them to meet expectations both academically and psychosocially.<sup>20</sup>

Most studies of children with FAS have not singled out American or Canadian Indians or Alaska Natives for special discussion, although large numbers of Indian patients have been included in studies of patients with FAS from the Pacific Northwest and the Southwest U.S.<sup>21</sup>

Two papers and one book, however, have focused specifically on Indian patients with FAS or FAS/FAE.<sup>22</sup> Conry described the neuropsychologic functioning of the twenty-two patients with FAS/FAE identified in the Robinson et al. study of 1987.<sup>23</sup> Streissguth, LaDue, and Randels have written a manual on FAS with special reference to American Indians; specific recommendations for what Indian communities can do have also been published.<sup>24</sup>

Carney and Chermak compared ten American Indian children who had been diagnosed FAS with seventeen non-FAS American Indian children who were progressing normally in school.<sup>25</sup> All children in both groups had been placed in English-speaking adoptive or foster homes between birth and three years of age. All of the children with FAS had been identified early, placed in infant stimulation and preschool programs, and were receiving special educational services in the public schools. No child presented a history of secondary neurologic insult or trauma. Auditory and visual screening preceded the language testing. The children with FAS had IQ scores ranging from 50 to 91, with a mean of 79. The comparison group of Indian children was presumed to be of normal intelligence. On the Test of Language Development (TOLD), children with FAS performed significantly more poorly than the normal Indian comparison group on most aspects of language development, despite early stimulation programs and remedial interventions. This study did not investigate adaptive or psychosocial behavior that might be improved with early identification and appropriate programming. Furthermore,

the study design did not permit evaluation of the early stimulation per se. In this study, younger children with FAS presented with more global language deficits, while those who were older presented with more syntactic deficits. These findings were interpreted as confirming the delayed semantic development and disordered syntactic development among children with FAS reported by Hamilton in a racially mixed group of patients and controls.<sup>26</sup>

*FAS is not specifically an Indian problem, yet many Indian children have FAS/FAE. Children with FAS/FAE have many developmental disabilities, including but not limited to mental retardation. Indian children with FAS are significantly more impaired on neuropsychologic tests and on language development than normal Indian comparison groups. This finding demonstrates again the toll of alcoholism on the health and well-being of American Indian children.*

### **Does FAS Go Away When Children Grow Up?**

No, unfortunately FAS is a lifetime disability. However, the types of problems and physical manifestations may change with age. For example, after children go through puberty, the physical features of FAS may be less distinctive. The faces of the patients may not be as characteristic as they were in early childhood, particularly as the nose and chin lengthen and the features coarsen as adulthood approaches. Growth deficiency, especially for weight, may not be as remarkable as in infancy and childhood, but microcephaly (small head circumference) stays fairly constant across time.<sup>27</sup> The relative difficulty in making the diagnosis after puberty demonstrates the importance of early identification.

Most of the patients with FAS described in the medical literature have been young children. However, in 1985, a ten-year follow-up of the first eleven children diagnosed with FAS was published.<sup>28</sup> Two out of the original eleven children were dead at follow-up, and one could not be located. Half of the remaining eight were clearly mentally retarded and seemed to be appropriately cared for at home and at school. These mentally retarded patients were regarded as disabled, and their caregivers and schools were knowledgeable about their FAS diagnosis.

The other four patients, however, all of whom had IQ scores in the "borderline" range (between 70 and 85), were not generally recognized as having FAS, were not identified as disabled, and were all having difficulty in school, where they were expected to

be learning at a normal rate. One dropped out of school in the fifth grade; one left school in middle school and had a baby. The major psychosocial problems observed in this small group of children with FAS prompted a larger and more comprehensive study of older patients with this disorder.

The first major study of the long-term consequences was published in 1991 by Streissguth et al. on sixty-one patients who ranged in age from twelve to forty years.<sup>29</sup> Their average age was around seventeen years. Seventy-four percent of the sample were American Indian, because the study involved a follow-up of many patients originally examined in the FAS prevalence study conducted on several Indian reservations in the Southwest. The group also involved patients referred clinically for evaluation of FAS in the Pacific Northwest. A disproportionate number of the latter were nonreservation Indians often in adoptive or foster homes. All of the patients were diagnosed by one of a small group of dysmorphologists highly experienced in FAS.

Unlike previous studies of younger children with FAS which have dealt only with IQ and achievement scores, this study carried out systematic evaluations of the patients' level of adaptive functioning, using the Vineland Adaptive Behavior Scale (VABS), which is administered to the patient's caregiver. Although this subgroup of patients had an average chronological age of seventeen years, their average age of adaptive functioning was at a seven-year level. Of the three domains making up the VABS adaptive behavior score, these patients performed best on daily living skills (at an average nine-year level) and most poorly on socialization skills (at approximately the six-year level). Communication skills were at the seven- to eight-year level. Although one or two patients had age-appropriate daily living skills, none were age-appropriate in terms of socialization or communication skills.

When we separated out only those patients with FAS/FAE who were not technically retarded, the items that distinguished them from age-appropriate behaviors were failure to consider consequences of action, lack of appropriate initiative, unresponsiveness to subtle social cues, and lack of reciprocal friendships. Thus, many of the adaptive behaviors normally acquired during the adolescent period were not acquired by these patients with FAS/FAE. Although it is possible that some of the adaptive behavior deficits could have resulted from disruptive postnatal environments, only about 12 percent of the patients were living with one or both biologic parents at the time of assessment.

While it is known that abusive and neglectful environments can have long-term negative consequences to children, accurate data on early abuse and neglect are very difficult to obtain historically. One recent study of adolescents and adults with FAS/FAE (which included 77 percent American Indians) found that child neglect had been reported in 86 percent of the cases, physical abuse in 52 percent, and sexual abuse in 35 percent.<sup>30</sup> In an earlier report from this same study, it was found that maternal rights had been terminated in more than one-third of patients with FAS/FAE.<sup>31</sup> Reservation Indians with FAS/FAE were much less likely to have been removed from their biologic families for abuse and neglect than were patients in urban settings (15 percent vs. 52 percent).

*Fetal Alcohol Syndrome is a life-long disability; children do not outgrow FAS, but their problems change with age. Early identification of children with FAS/FAE is important for both prevention and intervention. Since most of the adolescents and adults studied to date did not have the advantage of an early diagnosis, it is possible that improved adaptive functioning could be brought about by early identification and appropriate interventions.*

### **Can FAS Be Prevented?**

Yes, FAS can be prevented; the prevention is both simple and complex. The simple part is that, if no more women drank alcohol during pregnancy, there would be no more children born with FAS/FAE. The complexity is in bringing this about in a society that encourages alcohol use through cultural stereotypes and aggressive advertising aimed at minorities and at young women of childbearing age. FAS/FAE can certainly be prevented. How to do it is the problem and the challenge.

First, we must be clear about the message. The best message for preventing FAS and alcohol damage to the fetus is the recommendation of the Surgeon General of the United States: "The Surgeon General advises women who are pregnant (or considering pregnancy) not to drink alcoholic beverages and to be aware of the alcoholic content of foods and drugs."<sup>32</sup> Statements like, "It's OK to drink a little; just don't overdo it" are particularly damaging, because they are interpreted by mothers with alcohol problems as license to drink as usual. The abstinence message, presented in a nonjudgmental, supportive manner, provides a clear and comfortable framework for the mother (and her spouse and family) to alter their habits as needed in preparing for a healthy baby.



Because alcohol passes through the milk as well, abstinence during breastfeeding is also recommended.<sup>33</sup>

A problem arises when a woman finds out she is pregnant after some level of drinking. For such women, it is important to point out the evidence that suggests that stopping drinking at any time during pregnancy is better than not stopping at all.<sup>34</sup> While the most desirable goal is complete abstinence—and certainly this is the appropriate public health message—cutting down alcohol consumption significantly is better than continuing heavy drinking.

Now let us consider strategies for prevention. I recommend the “3-P Program” for preventing fetal alcohol damage:

Public Awareness  
Professional Education  
Provision of Services

*Public Awareness* means that the whole community must understand that women should not drink during pregnancy. Public awareness means that communities must come to recognize that some of the children with whom they are having trouble are the products of prenatal alcohol damage. The recognition that some of the adolescents and young adults in trouble may have FAS/FAE is a potent force for community understanding of the long-term consequences of FAS and for the development of effective plans for prevention. Public awareness means that the community must eventually come to realize that combating fetal alcohol damage means combating alcoholism. Saving the children must be a tribal priority, from the tribal council to the grandmothers, from school children to elders, from young couples to old uncles. Everyone must understand that drinking during pregnancy hurts the children. Then everyone can work together to develop effective strategies for coping with the problem. A booklet produced by the Center for Science in the Public Interest provides many specific suggestions that could be adapted for Indian communities.<sup>35</sup>

*Professional Education* means that all professionals in the community must understand the impact of alcohol on the children. This includes the teachers, the school psychologists, the social workers, the community health nurses, the doctors, the alcoholism counselors, the mental health specialists, the job training specialists, the probation officers, the Child Protective Ser-

vices personnel, the tribal judges, and the religious and spiritual leaders. All of these professionals need to know what children and adults with FAS look like, how they act, what kind of problems they have, and what kind of help they need to become productive members of society within the limitations of their disabilities. The motivation to prevent FAS arises from the knowledge of its devastating consequences to the health of the community's children and to the vitality of the tribal culture.

The higher fertility rate of American Indian women (compared to white or Black women), the lower age of Indian mothers (one in five is under twenty years of age), and the higher school dropout rate of Indian mothers are all factors that emphasize the importance of educating young school-age American Indian/Alaska Native children regarding not drinking during pregnancy.<sup>36</sup>

*Provision of Services* means that each community must decide how to provide two different kinds of services to prevent FAS: first, adequate treatment services for pregnant, alcohol-abusing women must be provided.<sup>37</sup> Many women will need more than a single reminder to break long-standing patterns of alcohol abuse. Incarceration is not an effective long-term solution. Communities need coordinated services for alcohol-abusing women, including specialized alcohol counseling for women, women's support groups, and culturally relevant activities to replace the social activities that may have been focused around drinking. Inpatient treatment programs that permit children to accompany their mothers are desperately needed.

Women who have just delivered a child with FAS are at highest risk for delivering another. Diagnosis of babies with FAS leads to identification of the highest risk mothers. Advocacy-oriented follow-up is needed after delivery as well as before. The birth of one affected child is an excellent time to begin efforts to prevent another disabled child from being born. Both alcoholism treatment and birth control are important issues, but, for these to be effective, many additional problems may have to be addressed, including stable housing, protection from abusive relationships, financial security, and ongoing medical care. In our work with the highest risk women, who are abusing alcohol and drugs during pregnancy, we find that those who receive little or no prenatal care are often themselves developmentally disabled and unable to care for themselves adequately.<sup>38</sup> Many are from alcohol-abusing homes. Delivery of an alcohol- or

drug-affected baby offers a unique opportunity for intervention to break the cycle.

The second type of community service needed to prevent FAS/FAE is an evaluation of persons of all ages with respect to FAS/FAE, so that their needs can be adequately met. Babies with FAS may be at risk for abuse and neglect. Children with FAS may be at risk for dropping out of school, leaving home early, and living without appropriate supervision. In this unprotected environment, they can be easily victimized and led into alcohol and drug abuse, trouble with the law, and unwanted pregnancies. Early identification of children with FAS can allow communities to build protective networks for these vulnerable young people to prevent them from drinking during pregnancy and producing another generation of children with FAS/FAE.

Two books discuss effective community strategies for preventing FAS. One deals specifically with American Indian communities.<sup>39</sup>

*FAS is preventable. FAS prevention is as simple as getting women to stop drinking during pregnancy and as complex as changing community attitudes about drinking and alcohol abuse.*

## PREVENTING FAS: WHAT INDIAN COMMUNITIES CAN DO

### **Preventing FAS Means Dealing with Community Alcoholism**

Since FAS is a product of community alcoholism, it is impossible to deal with one without the other. Communities that are in denial about their alcoholism will not likely be willing to work to prevent FAS. On the other hand, protecting the community's children through preventing FAS can be an effective strategy for arousing community action against alcoholism in general.

Even though fewer Indians report using alcohol than their non-Indian counterparts some Indian peoples are wracked with alcohol problems.<sup>40</sup> Not only do Indians suffer from more cirrhosis of the liver, alcohol deaths, and alcohol-related morbidity and mortality than non-Indians, but these problems impact the health status of Indian women.<sup>41</sup> A recent report from the state of California shows that access to prenatal care is lower for Indians than non-Indians, and the rates of low birth weight and infant mortality are higher than for the total population. About 33

percent of deaths among Indian women are alcohol related compared to 4.3 percent for California women of all races.<sup>42</sup>

Like the giant river that commences with a tiny mountain stream, a community's efforts to cope with alcohol may arise from small and humble beginnings. In a compelling video, *Honor for All*, produced by the Alkali Lake band of Canadian Indians, one sees how the seeds of the idea to attack community alcoholism first grew in the mind of one woman and then her family.<sup>43</sup> One sees how, with the support of an alcoholism worker from a neighboring community, this family was able to enlist recruits from many community families, obtain leadership through participation in tribal politics, utilize available police enforcement from the wider community, sabotage the bootleggers, encourage sobriety, utilize inpatient alcoholism treatment for hard-core alcoholics, and, over a period of a dozen years, pull the community into sobriety. Although FAS is never mentioned in this video, it is obvious that any program that produces 95 percent sobriety in a community that had been 95 percent alcoholic, would surely benefit the children. The encouraging epilogue to this story is that this community is not unique.

An Aleut village in Alaska reported a similar experience to me as it worked its way up from alcoholism to sobriety over a fifteen-year period.<sup>44</sup> One alcoholic mother who had produced a child with FAS gave birth to a normal child six years later, after she had stopped drinking. She said she never could have done it alone—that it was her village that had helped her. In fact, her community was so shocked by the knowledge that this child had been damaged by his mother's drinking and could not learn like other Aleut children that the people took responsibility for repeatedly sending the mother off for residential treatment when her drinking was out of control. When, in a period of sobriety, she produced a normal child, the village rejoiced.

Community informants confirmed, however, that the answer lay not in what they did for this one mother but rather in what they did to build a concept of wellness in the community. Such efforts nurtured and fostered individual growth and supported individual abstinence, as the village itself grew and overcame its alcoholism and other alcohol-related problems. Three factors were identified as bringing about the change: (1) the community's acceptance of responsibility for change; (2) the proper training of key community members, and (3) assistance from outside alcoholism experts in bringing about change.

The key members of the village team in the fight against alcoholism were the village public safety officer (the VPSO), the village alcohol counselor, the community health nurse, and the community health aide. The VPSO said that change involved village awareness that alcoholism was not acceptable and that the consequences of alcoholism would not be tolerated. Drunk and disorderly behavior were particularly targeted. Wives began expecting more responsible behavior from their husbands. Nonusers among the youth used peer pressure against the users. Recalcitrant alcoholics were sent for treatment. The community members said, "When one person gets well, it plants the seeds of wellness in others." When those who were sober started taking over positions of responsibility in the community, things began to change. Gradually, "the sober outnumbered the drunk."

The community members felt that the key was in the community's accepting the responsibility to change themselves. They said as long as they left the responsibility with the outside experts, they could not change. They saw the move toward wellness as deriving from the combined forces of responsibility from within the village and the availability and utilization of experts from outside the village.<sup>45</sup>

*A single community, acting on its own volition (but using state and federal resources through key public health and safety workers), can use local action to bring about significant community change from alcoholism to sobriety. The prevention of FAS and FAE is a natural consequence of reducing community alcoholism.*

### **FAS Prevention Requires Specific Community Actions**

The Tuba City FAS Prevention Project is a model program for a community project specifically focused on FAS prevention, which, in turn, contributed to a decrease in alcoholism in the community.<sup>46</sup> Begun in 1988 by an IHS physician, a Navajo-speaking prevention worker, and a Navajo-speaking clerk, this program utilized a three-pronged approach to FAS prevention. It involved community, family, and individually based therapeutic techniques. The essential components of the program included community awareness, education of pregnant women about FAS, screening of high-risk pregnant women who were drinking heavily during pregnancy and those who had produced previous children with FAS/FAE, and the referral of such women for empathic case management and support. Clients received counseling, per-

sonal support, and social services. Diagnostic clinics were held every few months to examine children born to high-risk mothers.

In the first eighteen months of this program, 1,147 employees from the Navajo and Hopi tribal agencies and schools were trained in FAS recognition and awareness. More than two thousand community members participated in ongoing presentations and activities about FAS, either in the Navajo language or bilingual. Newspaper articles, including an interview with a mother who stopped drinking during pregnancy, reached an estimated thirty thousand people.

A total of thirty-nine high-risk mothers were identified. Of the thirty-two who remained in the area at the end of the eighteen-month period, 56 percent were abstinent, 13 percent were drinking less, and 31 percent were still drinking as heavily as before. At the end of the eighteen-month period, 21 percent were pregnant, 10 percent were using birth control, 15 percent had had voluntary tubal ligations, and 36 percent were at risk for another pregnancy.

Of the thirty-one identified women, eleven had children with FAS or FAE, including two who were "possible" FAS/FAE and were awaiting a dysmorphology exam. Three of these children with FAS/FAE were delivered during the eighteen-month program; the other eight were identified among existing children of the thirty-one women in the program. Thus, approximately one-third of the high-risk drinking women identified in the program had actually had a child with FAS/FAE—indicating the effectiveness of the program in screening women with risky drinking habits. Even though intervention was too late for the current pregnancy, these mothers were identified as in special need of either continued alcohol treatment, more effective birth control, or both. It is clear that these women must be a high priority for supportive postnatal follow-up and advocacy.

Three mothers of children with FAS were able to produce subsequent normal children after being identified by the program and provided with appropriate alcoholism treatment.<sup>47</sup> Key elements in this success were (1) diagnosis of the affected child; (2) nonblaming treatment of the mother; and (3) provision of adequate services for her rehabilitation.<sup>48</sup>

What factors contributed to the success of the program? Some clients stated that they agreed to participate because the program was designated as a prevention program rather than as an alcoholism or a social work program. Another key element was the status of the program staff as trusted community

residents. Another is the family-oriented approach, which recognized that alcohol abuse is highly concentrated in some families.

Masis and May point out that, although fewer Navajo women are drinkers compared to women in the overall U.S. population, the abusive drinking is concentrated in a minority of families that suffer from a multitude of other social problems.<sup>49</sup> Furthermore, they note that most of the thirty-nine mothers in the program were known to be adult children of alcoholics and also had spouses or in-laws or both who were heavy drinkers. This finding indicates the multiple factors contributing to alcoholism among women and the importance of a multifaceted, multidisciplinary, inter-generational approach to treatment.

Masis and May also point out that the effectiveness of the program depends not only on knowledge, case finding, and treatment efforts inside and outside the clinic and hospital, but also on the involvement of multiple constituencies in the community. This program serves as a model demonstration project for Indian communities wishing to take responsibility for their own FAS prevention efforts. Unfortunately, the program was more difficult to keep running than anyone realized, and, sadly, five years after its onset, it was closed.<sup>50</sup>

Changing Indian Health Service (IHS) staff and tribal leaders can disrupt the continuity of programs that depend heavily on dedicated and highly trained personnel. An innovative concept developed by Dr. Patricia Tswelnaldin to train Indian certified alcohol and chemical dependency counselors as FAS experts has recently been described.<sup>51</sup> This program assures that Indian professionals, who have a high likelihood of remaining on the reservation, will be knowledgeable advocates at the local level for FAS prevention and intervention.

A recently created computer program to facilitate screening for prenatal risk factors at the Albuquerque Public Health Service Hospital may be another useful model to assure ongoing programs in the face of changing professional personnel.<sup>52</sup> The Pregnancy Information Program (PIP) is a patient-interactive computer program designed to assess behavioral risks and to provide health education to pregnant women. More than 95 percent of the 265 American Indian women who completed the PIP rated it favorably. Compared to information in the medical records or obtained through urine screens, the PIP produced more quantifiable data on alcohol and drug use during pregnancy.

Other models and ideas are also available for preventing FAS. On the Lummi Reservation in Washington State, an "Indian Aunt" program was developed with a small grant from the March of Dimes, which provided funding for a respected Lummi woman to work both individually and collectively with all pregnant women in the community around alcohol issues. A variety of projects were undertaken, including educational activities about FAS; weekly group meetings in which the women could provide support for each other in their efforts to achieve sobriety; and individual interventions with mothers at particularly high risk.

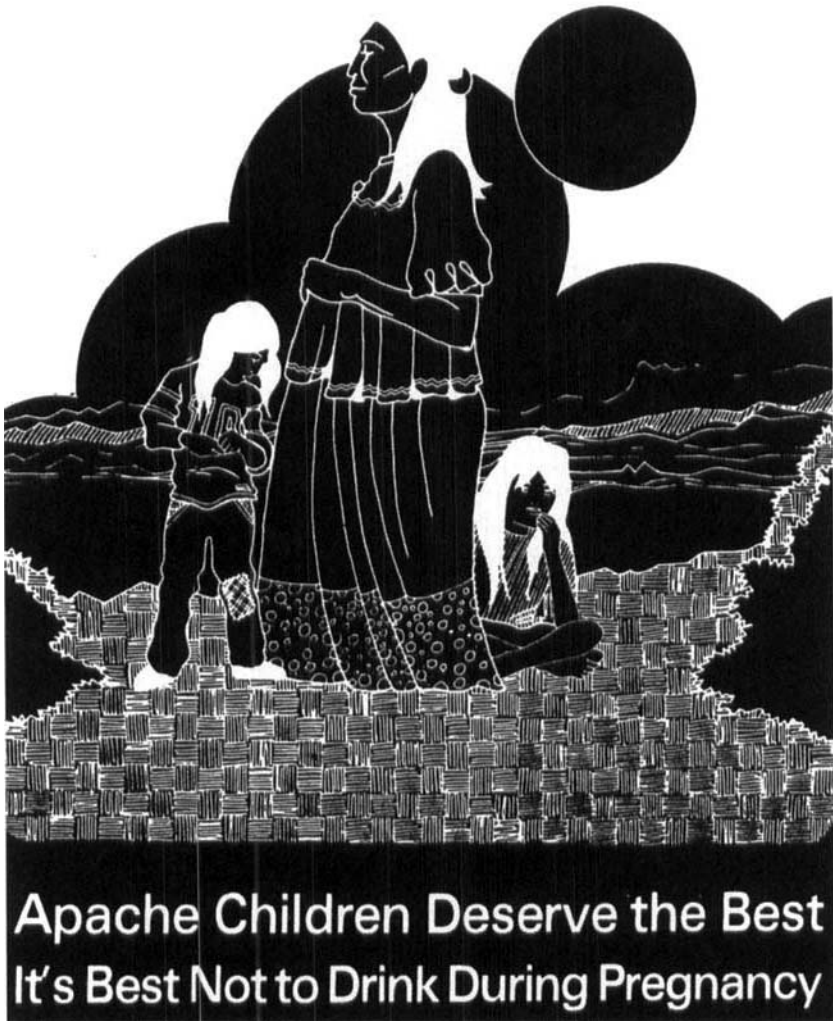
On the Yakima Reservation in Washington State, the Robert Wood Johnson Foundation funded an FAS prevention project to create a "safe house." Here community members could escape the problems associated with alcohol abuse in their own homes and could obtain help in overcoming alcohol abuse during pregnancy or in the postpartum period. Peer counselors were available on an individual basis for support and advocacy.

In Alaska, direct legislative funding through IHS provided a "prematernal home" in Anchorage to which pregnant Alaska Native women from throughout the state could be brought, to focus on an alcohol-free pregnancy and to plan for continuing abstinence during breastfeeding and future pregnancies. Since the needs of pregnant alcoholic mothers were so different from those of other high-risk pregnant women receiving residential care during pregnancy in Anchorage (such as those with diabetes), this program was less effective in shared quarters.<sup>53</sup>

Whatever the nature of the interventions, it seems likely that those that are culturally relevant will be the most effective. More than ten years ago on the White Mountain Apache Reservation in Arizona, tribal members made posters, "Apache Children Deserve the Best" (see figure 3), which were utilized throughout the reservation. A song, "FAS Child," was written in a jazzy beat to appeal to teenagers. Sung by a young Apache woman, it was played repeatedly on the local radio station. The song depicted the selfishness of a young couple who "partied" during their pregnancy, instead of nurturing their unborn child, and were left with the sadness of having produced a child with FAS.

An FAS prevention program was initiated at the Fort Belknap Service Unit in Montana by one woman who took it upon herself to do what she could to prevent this tragic birth defect.<sup>54</sup> Some of her most successful encounters were in the local taverns, where bartenders, after learning about FAS through her slide show,





*FIGURE 3. An FAS prevention poster produced by the White Mountain Apache to protect their children.*

agreed to serve free nonalcoholic drinks to pregnant clients and to display posters about the dangers of drinking during pregnancy.

Finally, another innovative FAS prevention program was initiated as part of a family-oriented, Indian residential alcoholism treatment program (NARA) in Portland, Oregon.<sup>55</sup> Here, the addition of a staff member identified as an FAS specialist created five more FAS services not previously available: (1) weekly FAS/fetal drug education classes; (2) pregnancy testing, counseling, and referral for all female clients; (3) assessments for all alcohol- or drug-affected children identified by NARA or referring agencies; (4) provision of specialized services; and (5) provision of a safe and accepting environment in which parents could explore and grieve about their roles in prenatal substance abuse. This innovative program provides an important glimpse at prenatal substance abuse among Indian women in a residential alcohol treatment facility.

Of the approximately two hundred women clients seen during a two-year period in the above program, more than 95 percent reported moderate to heavy prenatal substance abuse with at least one pregnancy. More than 80 percent had lost custody of children at some point in their addiction, and 40 percent reported significant neonatal and early childhood problems in their children, including premature delivery, low birth weight, failure to thrive, respiratory and cardiac problems, hyperactivity, developmental delays, incomplete ear or hard palate formation, and diagnosis of FAS and other alcohol-related birth defects. The FAS specialist and the primary counselors encouraged female clients to deal with the resulting grief, guilt, and shame. They felt that "working their twelve-step program" provided the clients the needed support to break through denial and deal honestly with these effects of their disease.

In a follow-up evaluation completed, unfortunately, by only 22 percent of the clients, all evidenced an understanding of FAS, and forty-four of the forty-five recommended abstinence during pregnancy. Twelve of the respondents said they had become pregnant since leaving NARA, and, of those, 50 percent were substance-free. (By comparison, only 13 percent of the respondents reported sobriety during their last pregnancy prior to NARA.) Of the six women pregnant at the time of the survey, all were receiving prenatal care. Of those not pregnant, 72 percent were actively using birth control, of which tubal ligation was the most popular. (Cultural prohibitions against the use of birth control had been an

important topic of discussion in the FAS classes at NARA.) Twenty-eight percent of the women said they had had a previous child diagnosed FAS; 60 percent thought they had had a child with problems due to their drinking. One hundred percent of the respondents felt the classes at NARA should continue.

*These programs serve only as examples of the wide variety of activities that communities can mount to prevent FAS. Other exemplary programs doubtless exist in other areas. In the final analysis, prevention of FAS will require community commitment to the eradication of alcohol abuse. It will also require community action on many fronts for (1) public awareness; (2) professional education; and (3) the provision of services. These actions must be undertaken in the name of the children and for the continuation of the unique culture of each American Indian/Alaska Native community.*

### **Preventing FAS Includes Identifying Children with FAS/FAE**

One of the most effective strategies for preventing FAS is to identify persons with FAS in the community. This works as follows:

- (1) Mothers who have produced children with FAS/FAE are the highest risk women in the community to produce more children with FAS/FAE.
- (2) If these women are identified, the community can make a strenuous effort to intervene and help them to either reduce their alcohol intake or avoid additional pregnancies if they continue to drink. Thus, identifying FAS/FAE can help prevent the birth of additional affected children.
- (3) Once children with FAS/FAE are identified, they can be given more appropriate help and shelter in the community. In this way, they can be prevented from beginning the downward spiral of abusing alcohol and drugs, having babies while drinking, and thus running the risk of producing another generation of children with FAS/FAE. (FAS is not inherited, but children with FAS are themselves at risk for alcohol abuse during pregnancy.)

FAS case-finding techniques can include surveillance programs for high-risk mothers and identification of newborn babies with FAS. Additional case-finding efforts can continue through Headstart and early intervention preschools, especially those targeted for alcohol and drug-abusing mothers. Careful screening

of child protective services caseloads for children with FAS/FAE and of all children in the adoption system can also be an effective strategy for identifying mothers who have already produced a child with FAS/FAE and are at risk for producing another. Likewise, FAS screening programs in conjunction with kindergarten health examinations can be effective in identifying children with FAS/FAE and providing appropriate help to both the children and their mothers.

Identification of individual patients with FAS, particularly older patients with obvious disabilities and community adjustment problems, helps teach the community how devastating the life-long impact of FAS can be. Public awareness can be a major impetus for change, as described above.

Cost-effective FAS screening programs can be modeled after those described by either Robinson and colleagues or May and Hymbaugh.<sup>56</sup> May and Hymbaugh present a detailed description of how a community can go about setting up an FAS prevalence/screening program. Knowing the magnitude of the FAS problem can help mobilize community action, obtain funding for pilot projects, and create an atmosphere for change. An FAS prevalence/screening program can also identify individuals within the community who are alcohol affected and in need of specialized services themselves. Such programs and services can help FAS/FAE children and adults to lead more productive lives and can prevent alcoholism and FAS/FAE in the next generation.

Two new FAS screening and prevalence studies in American Indian communities have recently been described. At the Confederated Tribes of Warm Springs, a survey of drinking practices among 234 females above eighteen years old identified binge drinking as the most common drinking pattern; 60 percent and 85 percent reported experiencing blackouts and hangovers, respectively; 25 percent had attended at least one alcohol treatment program, and 31 percent had reported drinking during the last pregnancy.<sup>57</sup> These data established a baseline for a possible problem with alcohol's impact on children. An FAS screening program was initiated for children meeting the following criteria: (1) mother suspected of alcohol use during pregnancy; (2) child's birth weight less than 3,000 grams; (3) child suspected of developmental delay. A total of 121 children were referred from three community agencies, their records were reviewed, and the twenty-three children meeting two of the three criteria of FAS were scheduled for dysmorphology clinic; nineteen (82 percent) of

these were actually examined. Four children were diagnosed FAS; four were identified as FAE. The minimal prevalence of FAS was 9.2 per 1,000 live births and of FAE 18.4 per 1,000.<sup>58</sup> (No allowances were made for eligible children missed by the screening.)

Three significant benefits to the community were cited as resulting from the screening prevalence study: (1) heightened community awareness about FAS/FAE and further coordination of services for these children and their families; (2) establishment of a cost-effective and efficient methodology and baseline data for further studies to reduce FAS/FAE; and (3) recognition of the need to evaluate the relationship of prenatal alcohol exposure to identification and remediation of developmental delays.<sup>59</sup>

An FAS screening effort in four American Indian communities in the northern Plains was also described recently. Screenings depended on medical records of birth weight less than 3,000 grams and then final dysmorphology examination of children who were suspected of having FAS.<sup>60</sup> Four of the children suspected of having FAS were actually diagnosed FAS (FAS prevalence rate of 8.5 per 1,000 births). However, not all low birth weight babies were screened, and not all children suspected of FAS were brought in for the diagnostic examination (some families were reluctant; other children died before the diagnosis was confirmed). Even the projected rate of 8.5 per 1,000 births (which attempted to compensate for some of the missing data) was thought to be an underestimate. This study demonstrates the difficulty in using medical records data as a starting place for FAS surveillance. The authors recommend institutionalization of FAS surveillance, including self-administered substance abuse questionnaires for the first prenatal visit; systematic follow-up by public health nurses of women at risk for having children with FAS; and community "ownership" of FAS prevention and surveillance.<sup>61</sup>

*FAS case-finding and screening programs serve both to prevent FAS and to increase community awareness. To make this approach work, FAS case-finding must target both the child with FAS/FAE and the child's biological mother. Both the child and the biological mother (even if they no longer live together) may be in need of community intervention services.*

*Culturally specific FAS prevention programs, particularly aimed at pregnant women, have been developed by a number of tribes and Indian groups. The Indian Health Service FAS Information Office can provide listings of available materials and curricula.<sup>62</sup>*

## HELPING PEOPLE WITH FAS: WHAT INDIAN COMMUNITIES CAN DO

This section answers a few questions that are often asked regarding interventions for persons with FAS and help for their caregivers. More detailed suggestions can be found in *A Manual on Adolescents and Adults with Fetal Alcohol Syndrome with Special Reference to American Indians*.<sup>63</sup> Some suggestions from parents and teachers who have worked with children with FAS are available in a recent book.<sup>64</sup>

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

In our opinion, a diagnostic examination answers several important questions for a family, and often for the patient as well. First, understanding the cause of a child's disability is usually a tremendous relief to a family that has frequently thought (or even been told) that the cause of the child's problems was the family's child-rearing techniques. Understanding that a child's developmental disabilities have a biological origin can help a family sort out their expectations and develop a reasonable plan of action for the child. Likewise, the diagnosis can often be helpful to the patients themselves, who have often wondered why they were not like everyone else, or why they were having such a hard time meeting expectations. In short, understanding the cause helps everyone work toward effective interventions. The guidelines provided by May and Hymbaugh and Robinson and colleagues describe effective models of communitywide diagnostic programs.<sup>65</sup> Individual programs for FAS diagnostic evaluations can also be set up in conjunction with a university-affiliated child development or mental retardation program, the state medical genetics officer, or the Indian Health Service. Some states, such as Washington and Alaska, have an FAS coordinator who can help.<sup>66</sup>

### **Is There a Cure for FAS?**

There is no cure for FAS; there is no known treatment that will reverse the damage or undo the disability. That is why prevention by avoiding alcohol during pregnancy remains an important issue always. However, every child should have the right to develop to his own best potential and to lead the most productive life possible, given his own limitations. We do not give up on

children with cerebral palsy; we devise intricate plans to help them with their disability. We do not give up on children who are deaf; we teach them sign language, we fit them with hearing aids, we give them the special help they need to lead as normal a life as possible. The same should be the case for children with FAS. Our goal is to help them develop as far as they can but also, by recognizing their disabilities, to protect and nurture them so they are not overwhelmed by unrealistic expectations.

A diagnosis helps us recognize that children with FAS have a developmental disability and have special needs. A diagnosis helps us modify our long-range plans and set appropriate short-term goals. This is particularly necessary for children with FAS, because they may not be so physically handicapped or mentally retarded that their disability is obvious. An important goal in raising children with FAS is to help them learn life skills that will contribute to their feelings of personal satisfaction. In particular, we want to avoid producing secondary disabilities in children with FAS. Such secondary disabilities can include early school drop-out, alcohol and drug abuse, mental illness, suicide attempts, joblessness, homelessness, and early and unplanned pregnancies.

### **How Would You Go about Helping a Person with FAS/FAE?**

After an FAS/FAE person has been diagnosed, the next step would be to get a psychological evaluation in order to understand the individual's strengths and weaknesses. Since persons with FAS can have a wide range of IQ scores, from severely mentally retarded to normal intelligence, no single treatment is appropriate. Instead, treatment focuses on determining the extent of the cognitive disability in each child and developing a plan for enhancing each child's development.

Early intervention programs are helpful in providing remedial help with language, motor skills, and interpersonal skills. The learning-to-learn skills that enhance task perseverance, increase attention span, and teach modulated behavior can be especially useful during the preschool years.

During the school-age years, social skills training and adaptive behavior training programs can be useful. By the middle and high school years, a focus on job skills, daily living skills—particularly money management—and early employment experience can be helpful. Healthy recreational and age-appropriate social activi-

ties are also important. Strong bonding with the family can offset disappointments and yearning for peer group acceptance, particularly during the difficult adolescent years.

Because patients with FAS/FAE frequently have behavioral problems, they are often referred to treatment programs. It is beyond the scope of this paper to provide detailed treatment plans, but it is important to consider the mental health needs of patients with FAS/FAE and to consider the mental health needs of their caretakers.<sup>67</sup> In young children with FAS/FAE, behavior management techniques are very effective in helping to reduce “challenging” behaviors that may arise from their prenatal brain damage and can stand in the way of successful living if not dealt with.<sup>68</sup>

In general, we have not observed that the usual modes of play therapy, insight-oriented therapy, or group therapy are particularly effective with patients with FAS/FAE, although no research has been carried out. These patients do, however, respond well to a counselor or advocate who can provide clear feedback on the consequences of their behavior and can offer helpful suggestions. Patients of all ages with FAS/FAE tend to be suggestible and easily influenced by peers. They often mimic maladaptive behaviors of others and develop “symptoms” from those around them. Treatment strategies focusing on age-appropriate techniques for reduction of maladaptive behaviors is the preferred mode. In general, techniques utilizing a positive rather than a negative mode of behavior change seem most effective. There is no research on the efficacy of medications for treating persons with FAS/FAE. Treatment outcome research is urgently needed.

Family support and interventions are also extremely important. Families are often blamed (even by well-meaning professionals) for the behaviors of persons with FAS/FAE. And families have often taken the brunt of their children’s maladaptive behaviors by others who do not understand the basic neuropsychological and information-processing deficits that patients with FAS/FAE may have—even when they appear verbally fluent and have normal intelligence. Families, both biological and adoptive, who have raised other children successfully have often been puzzled at the difficulty they encounter raising children with FAS/FAE. Diagnostic information is often viewed with relief by families and patients alike. The diagnosis should be a first step in developing patterns of interaction based on an understanding of the problem. The diagnosis of FAS is not an end in itself but rather a marker that



more help, protection, and supervision may be needed. An FAS diagnosis is not an excuse for bad behavior but rather a guidepost for how best to evaluate and produce more adaptive behavior.

Although there is little available in the way of clear research results, many communities are developing programs targeting children known to be or suspected of being afflicted with FAS/FAE. Indian communities have been particularly instrumental in moving on this problem, and the strengths and cultural values of Indian peoples seem particularly suited to the needs of Indian children with FAS/FAE.

Parent support groups are instrumental in helping parents understand their needs, organize their behaviors, obtain better services and more understanding for their children, and share their own hopes and disappointments.<sup>69</sup> Community schools should be responsive to the needs of students with FAS/FAE. Alert parents can act as advocates for rallying the support and interest of schools in providing the best learning environment.<sup>70</sup>

Indian Headstart programs are actively developing awareness programs for FAS.<sup>71</sup> Some Indian school districts, such as the Tohono O'Odham in Arizona, have developed specialized programs and guidelines for working with students with FAS/FAE.<sup>72</sup> Some curricula developed for Indian schools in general would seem to be useful in meeting the needs of Indian children with FAS.<sup>73</sup> It is our impression that there continues to be an absence of programs geared toward the adolescent with FAS/FAE, both in the school, in the community, in alcohol and drug treatment and prenatal care programs, and in the juvenile justice and criminal justice system.

## CONCLUSIONS

FAS is a lifelong disability that is totally preventable. If women did not drink alcohol during pregnancy, there would be no more children born with FAS. Preventing FAS, however, is a complicated and challenging process that ultimately requires each community to come to grips with its own alcohol abuse problem. The difficulties of FAS cannot be dealt with by denial any more than they can be dealt with by locking up pregnant women for nine months so they cannot drink.

Responsibility for preventing FAS falls on all of our shoulders. Mothers do not drink in a vacuum; often when they get pregnant,

they are drinking with men. Thus, preventing FAS is also a man's responsibility. Both women and men generally learn their attitudes about alcohol from their parents; preventing FAS is also a parent's responsibility, and a grandparent's. Partying teenagers often drink with their friends; preventing FAS is also the peer group's responsibility. Mothers who give birth to children with FAS often are school drop-outs; it is also the school's responsibility to prevent FAS. Mothers who give birth to children with FAS are often treatment failures from alcohol and drug programs and mental health programs; it is also the responsibility of alcohol and drug treatment programs and mental health programs to prevent FAS. Some people still do not understand that alcohol is bad for the unborn child; it is also the tribal council's responsibility to see that the community is appropriately informed and that appropriate services are available to prevent FAS and to help those with FAS.

Every person in every community has the responsibility to do what he or she can to safeguard the next generation, to prevent FAS, and to help create an environment that will be safe and healthy for our children, both before and after birth. It is respect for life. It is essential for our continuity.

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## NOTES

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62. The Indian Health Service Fetal Alcohol Syndrome Information Office is at Indian Health Service Headquarters West, 300 San Mateo, N.E., Suite 500, Albuquerque, NM 87108. Materials on FAS are available on request. Send requests for information to the attention of Charlene Hill, coordinator, or Lisa Snyder, assistant coordinator, FAS Project. Phone (505) 262-6112.
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### ADDITIONAL RESOURCES

1. A slide-teaching unit on Native American alcohol use is also available as "Unit 10: The Biological Aspects of Alcohol Use" (37 slides with 25 pages of text) from Milner-Fenwick, Inc., 2125 Greenspring Drive, Timonium, MD 21093. Phone (800)432-8433; ask for Bill Hardy, sales representative.

2. An FAS resource guide is available from the Indian Health Service Fetal Alcohol Syndrome Information Office at Indian Health Service Headquarters West, 300 San Mateo, N.E., Suite 500, Albuquerque, NM 87108. Phone (505)262-6112. Send requests to the attention of Charlene Hill, coordinator, or Lisa Snyder, assistant coordinator, FAS project.

3. A new videotape is available: "The Clinical Diagnosis of Fetal Alcohol Syndrome," by Jon M. Aase, M.D. Copyright by Flora and Company Multimedia, P.O. Box 8263, Albuquerque, New Mexico 87198.

4. Reprints and/or subscriptions to *ICEBERG*, an educational newsletter for people concerned about FAS/FAE: P.O. Box 95597, Seattle, WA 98145-2597.

5. NOFAS: National Organization on Fetal Alcohol Syndrome. Contact Patti Munter, executive director, 1815 H Street, N.W., Suite 750, Washington, DC 20006. Phone (202)785-4585.