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# **American Indians' Knowledge about Fetal Alcohol Syndrome: An Exploratory Study**

**MYRA SHOSTAK AND LESTER B. BROWN**

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## INTRODUCTION

The purpose of this study was to determine the kinds and amounts of information possessed by urban American Indians in Southern California regarding the effects of alcohol on the developing fetus. The identification of the nature and extent of American Indians' knowledge regarding FAS may assist in developing future prevention efforts.

Since ancient times, a relationship has been noted between alcohol use by pregnant women and the occurrence of deformities in their offspring.<sup>1</sup> However, it was not until 1973 that the pattern of facial characteristics, growth deficiencies, and developmental delays often observed in children of chronic alcoholic mothers was identified as fetal alcohol syndrome (FAS).<sup>2</sup> Subsequent research established alcohol as a teratogen, a substance "capable of producing death, malformations, growth deficiency, or CNS dysfunction depending on the dose and timing of prenatal exposure and the individual genetic endowment of mother and child."<sup>3</sup>

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FAS has been called "an equal opportunity affliction."<sup>4</sup> Children with this syndrome have been identified among all socioeconomic groups and all nationalities. During the 1970s, as recognition of this problem grew worldwide, an awareness began to develop among Southwestern American Indians tribes in the United States.<sup>5</sup> In 1979, the Indian Children's Program of the Indian Health Service established the Fetal Alcohol Syndrome Project in order to assess the incidence of FAS among Southwestern tribes and to provide educational, preventive, and diagnostic services to these communities.<sup>6</sup> This project, as well as subsequent programs in Arizona<sup>7</sup> and in the Northern Plains,<sup>8</sup> identified FAS as a significant and growing problem among many of the tribes studied.

Since 1979, the Indian Health Service has established several programs focusing on the education of clinicians and prevention specialists and the development of primary, secondary, and tertiary prevention programs.<sup>9</sup>

#### LITERATURE REVIEW

FAS is a preventable tragedy. If a pregnant woman abstains from alcohol throughout her pregnancy, her child will not develop FAS. The human costs of FAS in terms of pain and suffering are inestimable. The annual financial cost of treating children with this syndrome has been estimated conservatively at \$74.6 million.<sup>10</sup> The lifetime costs of caring for a child with FAS is about \$1 million.<sup>11</sup> The National Indian FAS Prevention Program cost approximately \$300,000.<sup>12</sup> The designers of this program advise that, "if the damage associated with only one FAS child has been prevented and the special needs and costs associated with the problems of such a child have been eliminated, the program has more than paid for itself."<sup>13</sup>

In ancient times, a relationship was often noted between alcohol use by pregnant women and the occurrence of deformities in their offspring.<sup>14</sup> Bridal couples in ancient Carthage were prohibited from drinking on their wedding night for fear of having a deformed infant. A report to the British House of Commons in 1834 stated that the babies of alcoholic mothers often appeared starved, shriveled, and imperfect. In an 1899 study of alcoholic women in a Liverpool jail, Sullivan reported a high correlation between alcohol use and perinatal mortality.<sup>15</sup> In spite of these observations, the problems of children of alcoholic mothers were

usually attributed to poor nutrition and disruptive home environments. Government reports and books on pregnancy that were published as late as the 1950s indicated that the ingestion of alcohol did not harm the developing fetus.<sup>16</sup>

In 1968, Lemoine's observations of one hundred children of alcoholic mothers were published in a French medical journal. Lemoine noted that these children all had similar facial characteristics, growth deficiencies, and psychomotor disturbances, which could be attributed to their mothers' use of alcohol during pregnancy.<sup>17</sup> In 1973, researchers described a similar pattern of malformations in children of chronic alcoholic mothers and identified this disorder as fetal alcohol syndrome.<sup>18</sup> Their work focused attention on the toxicity of alcohol and encouraged international research into the effects of alcohol on the fetus.<sup>19</sup>

Alcohol is now recognized as a teratogenic drug.<sup>20</sup> A teratogen is an agent "capable of producing death, malformations, growth deficiency, or CNS dysfunction depending on the dose and timing of prenatal exposure and the individual genetic endowment of mother and child."<sup>21</sup> Research indicates that alcohol "readily crosses the placenta so that fetal blood alcohol levels approximate those of the mothers."<sup>22</sup> The term fetal alcohol syndrome (FAS) refers to the pattern of physical malformations and behavioral and growth disturbances produced in infants by the mothers' ingestion of alcohol during pregnancy.

In 1980, the Fetal Alcohol Study Group of the Research Society on Alcoholics established the minimal criteria required to diagnose FAS. These criteria are "prenatal and/or postnatal growth retardation (weight, length, or height below the tenth percentile, when corrected for gestational age); CNS involvement (including neurological abnormality, developmental delay, behavior dysfunction or deficit, intellectual impairment and/or structural abnormalities, such as microcephaly [head circumference below the third percentile] or brain malformations found on imaging studies or autopsy); and a characteristic face, currently qualitatively described as including short palpebral fissures, an elongated mid-face, a long and flattened philtrum, thin upper lip, and flattened maxilla."<sup>23</sup> Children who have been affected by alcohol exposure in utero but who do not meet all three diagnostic criteria for FAS are considered to have fetal alcohol effects (FAE), or alcohol-related birth defects (ARBD).<sup>24</sup>

Children with FAS are viewed as multihandicapped.<sup>25</sup> Congenital malformations observed include heart defects, genito-

urinary tract malformations, spina bifida, microcephaly, facial dysmorphism, and various skeletal anomalies. The facial dysmorphism often contributes to numerous dental problems which, in turn, contribute to feeding and speech problems. In infancy, weak sucking ability, heightened sensitivity to sound, irritability, tremulousness, seizures, sleeping problems, decreased alertness, and a general failure to thrive have been noted.<sup>26</sup> An increased rate of both life-threatening and minor infections and various immunologic abnormalities in both infants and older children suggests that alcohol may have a long-lasting effect on the immune system.<sup>27</sup> Research suggests a possible increased rate of malignant tumors among children prenatally exposed to alcohol.<sup>28</sup> A high incidence of hearing and visual disorders, as well as speech and language difficulties, have been observed in children with FAS.<sup>29</sup>

Central nervous system effects include mental retardation, hyperactivity, poor impulse control, perceptual and motor problems, delayed fine and gross motor development, problems with generalizations and abstract thinking, poor problem-solving skills, poor social adaptation, and attention and memory difficulties.<sup>30</sup> The average IQ of children with FAS is around 68, but the range of scores is wide, with a few scores occasionally falling into the normal range.<sup>31</sup> A correlation has been observed between increased severity of physical problems and decreased intellectual abilities.<sup>32</sup> FAS is now considered to be "the leading known cause of mental retardation in the United States, surpassing Down's syndrome and spina bifida."<sup>33</sup>

Follow-up studies of children diagnosed with FAS indicate that this syndrome persists throughout childhood and into adulthood.<sup>34</sup> Although some improvements in IQ scores have been observed over time, children with the most severe growth and dysmorphic characteristics have IQ scores that remain stable.<sup>35</sup> A follow-up study of sixty-one adolescents and adults between the ages of twelve and forty who previously had been diagnosed with FAS/FAE (fetal alcohol effects) noted improvements in the areas of facial dysmorphism and weight.<sup>36</sup> However, these individuals continued to be microcephalic and short in stature. The average IQ score was 68, with a range of 20 to 105. None of the individuals diagnosed with FAS had IQ scores over 90. Performance on tests of reading, math, and spelling was at an elementary school level, with math being the area that presented the greatest difficulty. Communication deficits observed included perseveration and ecolalia. Test scores were higher on perfor-

mance tasks than on verbal tasks. Maladaptive behaviors included attention deficits, dependency, lack of social inhibition, and impulsivity. Problems were noted with judgment, comprehension, and abstraction. Individuals often did not consider the consequences of their behavior, were unaware of subtle social cues, were uncritically trusting of strangers, and had difficulty forming friendships. These maladaptive behaviors and problems were observed in individuals with normal as well as subnormal IQs. Among adolescents, the behavioral problems were more frequent and severe than those experienced by adolescents with Down's syndrome. In general, these individuals were "functioning at a level of adaptation that is more characteristic of younger children . . . . Patients with FAS/FAE were most disabled in the area of socialization skills."<sup>37</sup> Chaotic home environments, multiple foster care placements, and absence of early diagnosis are cited as possible contributory factors to these problems. Streissguth and her colleagues suggest that further research is needed to identify environmental factors that influence the development of these children. Kleinfeld states that, although FAS involves permanent damage to the brain and CNS, it is not yet known "what will happen to children who have the benefits of early diagnosis, early intervention, loving and informed parents, and appropriate education,"<sup>38</sup> and she cites the need for further research into these questions.

Morse proposes that the application of an information-processing framework provides a new and constructive way to understand the behavior of children with FAS.<sup>39</sup> This framework states that information processing occurs in the areas of input, integration, memory, and output. Deficits in any of these areas contribute to learning disabilities. Individuals with learning disabilities have been observed to have deficits in one or two of these areas; however, Morse suggests that children with FAS may have information processing deficits in all four areas. This conceptual framework provides an explanation for many of the cognitive and behavioral problems that have been noted in these children and can be utilized in the development of new educational and therapeutic techniques.

Human and animal studies indicate that the fetus is vulnerable to alcohol damage throughout pregnancy and that "the type and severity of the damage depends on the timing of the alcohol insult as well as dose and the peak blood alcohol concentration."<sup>40</sup> Developing organs, especially the brain, are particularly vulner-

able to alcohol damage during the first trimester.<sup>41</sup> Drinking during this period is also associated with increased risk of low birth weight; small head circumference and length (below the tenth percentile); and head and facial abnormalities.<sup>42</sup> Throughout the second trimester, there is an increased risk of miscarriage.<sup>43</sup> One study noted that this risk was double among pregnant women who consumed one to two drinks daily as compared to abstainers.<sup>44</sup> Another study estimated that more than 25 percent of women who consume alcohol at least twice a week are likely to abort with a minimum dose of one ounce of alcohol (two drinks) at each drinking episode.<sup>45</sup> High blood alcohol concentrations interfere with the rapid brain growth and neurophysiologic organization that occur during the third trimester, resulting in impaired central nervous system development and limited cognitive and behavioral abilities.<sup>46</sup> An increased rate of stillbirths has also been noted in some but not all studies. One report indicated that, among women who had at least three drinks a day, the stillbirth rate was two and one-half times higher than among women who consumed lower amounts of alcohol.<sup>47</sup>

A considerable amount of research has focused on the relationship between the type and severity of damage and the dose of alcohol consumed. Measurement of alcohol intake is a difficult process, especially during pregnancy, which is a time when women often alter their consumption patterns.<sup>48</sup> Also, these measurements depend on reports by pregnant women who may be reluctant to disclose actual intake levels because of denial, guilt, or fear. Finally, remembered frequency may differ from actual frequency of drinking.<sup>49</sup> Animal studies suggest that peak blood alcohol concentration, rather than the dose of alcohol itself, is the critical factor in fetal development. Blood alcohol concentration is higher after binge drinking, especially if drinking occurs with an empty stomach.<sup>50</sup> At the present time, what levels of alcohol intake result in what degree of developmental problems is unknown.<sup>51</sup> The complicated nature of fetal development has led some researchers to state, "It is probable that there is no single dose-response relationship for ethanol teratogenesis, but rather that each abnormal outcome in brain structure or function, morphology, and growth has its own dose-response and gestational timing parameters."<sup>52</sup>

The effects of exposure to alcohol in utero are now conceptualized as existing on a continuum.<sup>53</sup> Individuals who have FAS are at one end of this continuum. Those who have been affected by

alcohol exposure in utero but do not meet the three diagnostic criteria for FAS fall somewhere along the remainder of this continuum, depending on the severity of the effect. It is estimated that FAE occurs three to four times as frequently as FAS.<sup>54</sup>

### INCIDENCE RATES

In 1990, estimates of the incidence of FAS nationally and internationally varied from 1/600 live births in Sweden to 1/1,000 live births in France to 1/750 live births in Seattle, Washington. Figures compiled from twenty studies conducted in Australia, North America, and Europe suggested a worldwide incidence of 1.9/1,000 live births.<sup>55</sup> The Harvard Mental Health Letter<sup>56</sup> stated that, according to the best available information at that time, 5,000 to 10,000 children with FAS are born annually in the United States. The Department of Health and Human Services placed this figure between 1,800 and 2,400.<sup>57</sup> A more recent conservative estimate, based on prospective rather than a combination of prospective and retrospective studies, indicates a rate of 0.33 cases per 1,000 in the Western world.<sup>58</sup> These researchers state that, according to their calculations, around 1,200 children are born with FAS annually in the United States. However, others believe these figures are too low and cite the difficulty of diagnosing FAS accurately at birth because of ambiguity and the fact that certain features are not observable until later in infancy and/or childhood.<sup>59</sup> Streissguth found that one of the largest obstetrical services in the United States has reported a 100 percent failure rate in diagnosing FAS at time of delivery and substantiates this latter claim.<sup>60</sup>

During the 1970s, experienced clinicians working with American Indians identified FAS as a serious and increasing problem among the Southwestern tribes of the United States. In 1979, the Indian Children's Program of the Indian Health Service established a Fetal Alcohol Syndrome Project in order to assess the incidence of FAS among American Indians on selected Southwest reservations during the years 1968–1982.<sup>61</sup> Researchers discovered a significant variation in the incidence of FAS on the reservations studied, ranging from 1/690 live births among Navajo tribes, to 1/495 live births among Pueblo tribes, to 1/102 live births among Plains tribes. They found that 25 percent of all mothers who had given birth to one child with FAS subsequently had other FAS or FAE babies, with an average of 1.3 affected

children per mother. Of additional concern was the observation that, among the Pueblo and Navajo tribes, there was a significantly higher incidence of FAS/FAE in the years 1978–1982 than in the years 1969–1977.

May attributes this variation in the incidence of FAS among tribes to differences in the social organization of the tribes studied.<sup>62</sup> Tribes characterized by loose, small-group organization allow more individuation of behavior and tend to produce higher rates of deviant behavior. This type of organization is characteristic of the Plains tribes, which had an extremely high rate of FAS. Plains women who drink are not as subject to negative sanctions as women in other tribes. Tribes organized in larger groups have a more rigid social structure, reinforce conformity, and produce less deviance. Navajo and Pueblo tribes are organized according to this pattern. Drinking is rare and unacceptable among Navajo and Pueblo women who are over twenty-five and have passed the age of experimentation. When older women do abuse alcohol, they are frequently ostracized from mainstream tribal society—a practice that appears to maintain their abusive drinking and may explain the birth of several children with FAS to a single mother.<sup>63</sup>

Since May published his initial findings regarding the prevalence of FAS among American Indians on selected Southwest reservations, additional prevalence studies have been conducted and have found a prevalence rate in 1982 for FAS to be 1.3/1,000 for children under the age of fifteen. The prevalence rate for FAS among children aged four years and under was 2.7/1,000, and the combined rate for FAS/FAE among this age group was 3.7/1,000. These figures indicate that the incidence of FAS/FAE is on the increase in this population.<sup>64</sup>

A pilot FAS surveillance conducted by the Indian Health Service between the years 1987 and 1990 in four American Indian communities on the Northern Plains yielded a confirmed incidence rate of 3.9/1,000.<sup>65</sup> However, the authors suggest that, because of certain methodological problems, this estimate is probably low; they project a rate of at least 8.5/1,000, which is twenty-six times higher than the confirmed incidence rate.

The failure to use race-related normative data in the diagnosis of FAS among American Indians has also been cited as a factor that may contribute to inflated incidence rates. “For example, two of the most common facial features associated with FAS are epicanthic folds and short palpebral fissures. Native Americans have a genetic trait for epicanthic folds. The presence of such folds

makes measurements of other facial features, e.g., palpebral fissure size, problematic."<sup>66</sup> Because of the absence of standard growth charts for American Indians, examiners rely on the use of standard growth charts for Caucasian children. There is a possibility that significant differences exist between the birth and growth weights of American Indians and Caucasian infants. A significant difference has been observed between the birth weights of African-American and Caucasian infants, with a trend among African-American infants toward lower birth weights. If a similar trend exists for American Indians, this would affect the diagnosis of FAS and the accuracy of incidence rates.<sup>67</sup>

The absence of accurate incidence rates of FAS among American Indians was recognized in bill H.R. 1322, which was presented to the U.S. House of Representatives by Representative Campbell of Colorado on 7 March 1992. This bill called for an annual report to Congress that would include "the incidence of FAS/FAE babies born for all births by reservation and urban based sites," as well as "the prevalence of FAS/FAE affected Indian persons in Indian Communities."<sup>68</sup> This bill has been stalled in the budget committee of the House since its presentation (personal communication, secretary to Representative Rohrabacher, July 1993).

#### PREVENTION AND TREATMENT PROGRAMS IN AMERICAN INDIAN COMMUNITIES

Even in the absence of accurate statistics, researchers agree that FAS is a significant problem among American Indians. It also has generated significant interest in American Indian communities, where children are viewed as special gifts.<sup>69</sup> During the years 1979–1982, the Fetal Alcohol Syndrome Project of the Indian Health Service educated clinicians regarding the recognition, diagnosis, and treatment of FAS/FAE. The project developed a team of prevention specialists who distributed information about FAS/FAE to their communities and trained community members to assist in prevention efforts and to recognize and refer affected children. A library of educational materials was established for community members and health personnel. Treatment clinics were instituted as places for families to receive counseling regarding future pregnancies and the care of affected children.<sup>70</sup>

This pilot project focused national attention on the significance of FAS and led to the establishment of the National Indian Fetal

Alcohol Syndrome Prevention Program in 1983. This program was funded by the Indian Health Service through the All Indian Pueblo Council.<sup>71</sup> The goal of the program was "to provide native communities throughout the United States with the knowledge, skills, and strategies to initiate primary, secondary, and tertiary prevention measures on their own."<sup>72</sup> In order to achieve this goal, the staff of the program reviewed established FAS prevention education programs, developed Native American FAS prevention materials, trained IHS area FAS resource personnel, trained local personnel to pursue FAS prevention, monitored FAS prevention education programs, provided technical assistance to FAS prevention educators, and assessed the outcomes of prevention education.<sup>73</sup>

Evaluation of prevention education indicated that, among children in grades 5 through high school, there was a statistically significant knowledge gain among four of the eight groups tested and some knowledge gain in all groups. Among community groups, there was a statistically significant increase in knowledge in ten of the fourteen training sessions. Retests of these same populations from two to four months later indicated that a substantial amount of information was retained in each group, with the scores being statistically significant in three of the six groups tested. Additionally, test scores of students who had not been involved in the prevention education were higher than the pretest scores of students who had participated in the program, suggesting that a communitywide prevention campaign that occurred after the program may have disseminated information successfully and that "there may have been some general diffusion of knowledge among peers."<sup>74</sup> The researchers point out that these findings clearly indicate the effectiveness of macro-level FAS prevention programs.

In 1988, a trilevel prevention program was established at the Tuba City, Arizona, Indian Medical Center under the auspices of the Indian Health Service.<sup>75</sup> Although primary, secondary, and tertiary prevention was undertaken, the major focus of the program was the tertiary level. The goal of primary prevention was increased community knowledge and awareness of FAS. At the tertiary level, women were given counseling, personal support, social and medical services. Follow-up of thirty-one women referred to the program indicated that, after eighteen months, seventeen of them were abstaining from alcohol. Among twenty-one pregnant women, nineteen were abstaining from alcohol by

the third trimester of pregnancy. The researchers emphasize that there was a high rate of participation in this program and that several women indicated that this might have occurred because the program was presented as a prevention rather than an alcoholism or social work program. Masis and May also point out that alcoholic women are often ostracized in their communities, tend to have several FAS/FAE children, and are at high risk of premature death. In their follow-up study of adolescents and adults with FAS/FAE, Streissguth and her colleagues found that, of fifty-one mothers on whom information was available, 69 percent were deceased.<sup>76</sup> Another study noted that 23 percent of American Indian mothers of children with FAS/FAE had died by the time FAS screening occurred.<sup>77</sup> In addition to the benefits that accrue to children from FAS prevention efforts, there is also the possibility that these programs will reduce the premature death rate among alcoholic mothers.

Extensive training of American Indians about FAS/FAE has been successfully implemented in California,<sup>78</sup> but no studies have been conducted to assess the level of knowledge about FAS among American Indians in the state. To date, more than ten thousand individuals have received localized training on the prevention of FAS/FAE and other alcohol-related issues.<sup>79</sup>

The need for additional prevention and treatment programs for American Indians was addressed in the proposed legislation presented to the House of Representatives in 1992. H.R. 1322 called for the establishment of a FAS/FAE Task Force "to examine the needs of Indian communities, current Federal resources, and to develop an annual plan for the prevention, intervention, treatment, and aftercare for those affected by FAS and FAE in Indian communities."<sup>80</sup> As indicated earlier, this bill has been stalled in the budget committee of the House since its presentation. In 1994, the Comprehensive Fetal Alcohol Syndrome Prevention Act was presented to the Senate and House, but it is not yet law.<sup>81</sup>

## METHODOLOGY

This study was descriptive in design. The research instruments were constructed to provide information about certain characteristics of the population being studied. This design was chosen because it enabled the collection of a wide variety of specific data about the information that American Indians possess regarding

the effects of alcohol on the developing fetus. Although numerous prevention programs have been implemented, minimal research has been conducted to evaluate the outcomes of these programs. Therefore, this study necessitated the development of an original approach to this task.

The population consisted of seventy-six American Indian adults in an urban area. Some subjects were undergraduate and graduate students at a California university. Other subjects were residents of a facility that provides alcoholism treatment to American Indians and Alaska Natives. Some study participants were members of the Native American Church. Additional study participants were recipients of a monthly newsletter published by an American Indian clinic.

A two-part, fifty-three-item, self-administered survey was utilized for data collection. Part 1 of the survey consisted of thirty-one statements about alcohol consumption during the prenatal period, the effects of alcohol on the fetus, and expectations for the future and the strengths of children with FAS. Fourteen statements dealt with alcohol consumption during the prenatal period and focused on issues of timing, frequency, amount and type of alcohol, and additional risk factors such as smoking, malnutrition, and use of other drugs. The nine statements concerned with the effects of alcohol on the fetus were based on the criteria required to diagnose FAS that were established in 1980 by the Fetal Alcohol Study Group of the Research Society on Alcoholics. These statements focused on growth retardation, facial features, and central nervous system effects. The eight statements that addressed expectations for the future and the strengths of children with FAS focused on the permanency of the syndrome, positive qualities, growth potential, and importance of early intervention. Subjects were asked to indicate whether they thought each statement was probably true, probably false, or they did not know. The remainder of the survey consisted of twenty-two questions dealing with demographic information, as well as information regarding participation in FAS prevention and education programs and patterns of alcohol consumption.

The self-administered surveys, informed consent forms, and cover letters were given to potential respondents from the various settings used. Self-addressed, stamped envelopes were included for the return of the consent forms and surveys. The brochures provided to each respondent, after they completed the survey and as a requirement of the university's Human Subjects Committee,

contained information regarding the effects of alcohol on the fetus and FAS, as well as the names, addresses, and phone numbers of agencies that provide evaluation, referral, and counseling services to American Indian children and their families. Informed consent forms, surveys, brochures, and survey answer sheets were also available in an office in the Department of Social Work.

Descriptive statistics and the Statistical Package for the Social Sciences (SPSS) were used to conduct the data analysis for this study. Descriptive statistics were used to calculate percentages, means, and standard deviations. Chronbach's alpha statistic was employed to determine the internal reliability of the research instrument. The t-test was used to evaluate differences on selected variables among the following groups: subjects who had children and those who did not have children, subjects with tribal membership and those without tribal membership, male and female subjects, and subjects who had taken a FAS education course and those who had not taken this type of course. One-way analysis of variance (ANOVA) tests were conducted to compare the service center members, university students, and church members on selected variables. Correlations were calculated between the following variables: subject's scores on each section of the survey, number of children, subject's age, years of education, years on the reservation, years in Los Angeles, how often the subject drinks, and the amount the subject drinks. The utilization of these statistics allowed for a comprehensive analysis of the data.

## RESULTS

About two-thirds of the subjects (68.4 percent) were female; the median age of the sample was twenty-seven years. The majority of the subjects (69.7 percent) were single. Eighty-eight percent had at least a high school diploma, with 22.3 percent also having a college degree. Twelve subjects (16 percent) reported having lived on a reservation. Eight of these twelve subjects (75.0 percent) had lived on a reservation during their childhood, and ten of the twelve subjects (83.3 percent) had grown up on the reservation. There was a considerable range in the amount of time subjects had lived in Los Angeles, with 28.9 percent having lived there less than five years and 47.3 percent having been in the Los Angeles area more than twenty years.

Thirty-six percent of the subjects had children, but only two subjects had a child with FAS. Two subjects reported that they personally had FAS, and nine subjects (11.8 percent) indicated that at least one relative had FAS. Only nine subjects indicated that they had participated in a FAS prevention or education program. Although FAS education and prevention is part of the curriculum at the treatment setting, eight residents indicated that they had not participated in this type of program. However, for the purpose of data analysis, these eight subjects were considered as having had FAS prevention education, and their number was added to the nine subjects who had responded affirmatively to this question. This resulted in seventeen subjects (22 percent) who had participated in a FAS prevention program.

Three-quarters of the subjects (76.3 percent) drank alcoholic beverages. Only 14.5 percent reported drinking three or more times per week. Of those who drank, thirty-four of fifty-eight (58.6 percent) drank three or more glasses at one time.

Subjects were presented with thirty-one statements about alcohol consumption during the prenatal period, the effects of alcohol on the fetus, and expectations for the future and the strengths of children with FAS. These categories shall be referred to as "Prenatal Period," "Effects of Alcohol," and "Expectations for the Future," respectively.

The mean correct responses for the Prenatal Period section was 87.1 percent; the mean correct responses for the Effects of Alcohol section was 74.1 percent; the mean correct responses for the Expectations for the Future section was 59.9 percent. Internal reliability was moderate, with Chronbach's alpha levels ranging from  $r = .55$  to  $.68$ .

Eleven of the fourteen Prenatal Period items were answered correctly by at least 80.0 percent of the subjects. Fewer correct answers pertaining to the Effects of Alcohol or Expectations for the Future were given by more than 80.0 percent of the subjects. Less than one-third of the subjects correctly answered that "children with FAS can usually spend more time working on a task than children without FAS" (false) (30.3 percent); "children with FAS are often very outgoing and friendly" (true) (7.9 percent); and "children with FAS are often very generous toward others" (true) (17.1 percent).

All subjects correctly answered that "when a pregnant woman drinks alcohol, so does her unborn baby" (true) (100.0 percent)" and "drinking during pregnancy may affect the growth of an

unborn baby's body" (true) (100.0 percent). Analysis indicates that 98.7 percent of the subjects correctly answered that "drinking during pregnancy may affect the development of the unborn baby's brain" (true); 97.4 percent correctly answered that "drinking alcohol may harm an unborn baby at any time during pregnancy" (true); and 97.4 percent correctly answered that "a baby born with FAS will outgrow this problem over time" (false).

As mentioned before, twenty-seven of the seventy-six subjects (35.5 percent) had children. A series of t-tests for independent means compared subjects who had children with those who did not. Subjects with children had significantly more years on the reservation than subjects without children (3.8 years v. 1.1 years). This difference was significant,  $t(74) = 2.00, p < .05$ . No other t-test in table 3 was significant at the .05 level.

Fifty of seventy-six subjects (65.8 percent) reported tribal membership. These two groups of subjects were compared with a series of t-tests for independent means. Subjects with tribal membership had significantly more children than subjects without tribal membership (1.2 children v. 0.3 children). This difference was significant at  $p < .05$ . No other comparison was significant at the .05 level.

Female subjects were compared with male subjects on selected variables with the use of t-tests for independent means. Female subjects had a significantly higher mean correct percentage for the Expectations for the Future statements (63.9 percent correct v. 51.2 percent correct). This difference was significant,  $p < .01$ . No other t-test was found to be significant.

Seventeen subjects (22.4 percent) had participated in a FAS prevention or education program. Through the use of t-tests for independent means, these subjects were compared to those who had not participated in this type of program. Subjects who had taken part in a FAS prevention or education course had significantly higher scores on the Effects of Alcohol statements (85.1 percent correct v. 70.9 percent correct). This difference was significant. Prevention program participants also had significantly more children (1.9 children v. 0.5 children),  $p < .001$ .

Three groups of subjects were compared using one-way analysis of variance tests. These groups were university students ( $n = 46, 60.5$  percent); Eagle Lodge members ( $n = 11, 14.5$  percent); and church members ( $n = 17, 22.4$  percent). University students had significantly fewer children than either the Eagle Lodge members or the Community Church members,  $p < .0001$ , and signifi-

cantly greater amounts of education than the other two groups,  $p < .0001$ .

Selected variables were correlated together and presented in a matrix. The ANOVA did not reveal any significant correlations. These variables were Prenatal Period statements, Effects of Alcohol statements, Expectations for the Future statements, number of children, subject age, years of education, years on the reservation, years in Los Angeles, how often the subject drinks, and the amount the subject drinks. No variable correlated significantly with Prenatal Period statements at the .05 level. The score a subject received on the Effects of Alcohol statements was significantly related to her/his score on the Expectations for the Future statements,  $p < .001$ , and how often the subject drinks,  $p < .05$ . The Effects of Alcohol score was also negatively related to the number of years the subject had lived in Los Angeles,  $p < .05$ .

The number of children the subject had correlated positively with the number of years on the reservation,  $p < .01$ , and with how often the subject drank,  $p < .05$ . The age of the subject was found to be significantly related to the number of children the subject had ( $p < .001$ ); the amount of education the subject had ( $p < .01$ ), and the number of years the subject had lived in Los Angeles ( $p < .01$ ). The subject's level of education also correlated positively with the number of years she/he had lived in Los Angeles,  $p < .01$ . Education level correlated negatively with how often a subject drank ( $p < .05$ ) and the amount the subject drank ( $p < .01$ ).

As would be expected, the number of years the subject had lived in Los Angeles was inversely correlated with the number of years he or she had lived on the reservation,  $p < .01$ . The number of years on the reservation correlated positively with how often the subject drank ( $p < .01$ ) and the amount the subject drank in one sitting ( $p < .01$ ). The number of years the subject had lived in Los Angeles was negatively correlated with how often he/she drank ( $p < .001$ ) and the amount drunk at one time ( $p < .001$ ). Also, as expected, the frequency of drinking was significantly related to the amount the subject drank,  $p < .001$ .

Fifty-two subjects were women. Of the thirty-eight women who drank, thirty-one (59.6 percent) stated that, if they discovered that they were pregnant, they would stop consuming alcohol. One woman (1.9 percent) stated that she would either abstain or reduce the amount she drank while pregnant. The remaining six women (11.0 percent) indicated either an inability to become pregnant or the absence of a serious relationship, or did not

answer this question. Of the fourteen women who did not drink, seven (13.4 percent) indicated that, if they discovered they were pregnant, they would not drink during pregnancy, and seven (13.4 percent) did not answer this question. Twenty-four subjects were men. Of the twenty men who drank, eleven (45.7 percent) stated that, if they thought there were any chance their partner might become pregnant, they and their partner would stop drinking; three (12.5 percent) indicated that they would want their partner to stop drinking; one (4.1 percent) indicated the absence of a relationship; and five (20.8) did not answer the question. The four men (16.6 percent) who did not drink did not answer this question.

University students had significantly fewer children than either the residential facility members or the community church members ( $p < .0001$ ) and significantly higher levels of education than the other two groups ( $p < .0001$ ). The university students were better educated than respondents in the other two groups.

The scores on the Effects of Alcohol section were negatively related to the number of years the subjects had lived in Los Angeles ( $p < .05$ ). This may indicate that people forget this information over time and that it may need to be reinforced periodically.

## SUMMARY

The purpose of this study was to identify the information that American Indians possess regarding the effects of alcohol on the developing fetus. A two-part, fifty-three-item, self-administered survey was completed by seventy-six American Indians in a Southern California urban area. Subjects were requested to indicate whether they thought each statement was probably true, probably false, or they did not know.

Forty-six study participants were undergraduate and graduate students at a Southern California university. Eleven respondents were residents of an American Indian substance abuse facility in Southern California. Seventeen participants were members of a Native American Church in Southern California. Two participants responded to a request that was included in the monthly newsletter published by an American Indian clinic.

Respondents had the highest level of information and were well-informed regarding alcohol consumption during the prena-

tal period (mean correct responses = 87.1 percent). Eleven of the fourteen statements in this section of the survey were responded to correctly by at least 80.0 percent of the subjects. Respondents' level of information was higher than expected. It is possible that these items dealt with information that was emphasized in prevention efforts and in the media. The highly regarded book *The Broken Cord* by Michael Dorris,<sup>82</sup> and the television movie based on this book, may have contributed to this high level of knowledge.

The second highest level of information involved the effects of alcohol on the fetus (mean correct responses = 74.1 percent), followed by statements that addressed expectations for the future and the strengths of children with FAS (mean correct responses = 59.9 percent). Kleinfeld indicates that *The Broken Cord*, the television movie based on the book, and the media have created powerful negative stereotypes about children with FAS. "Our images come from the worst-case scenarios, presented as if they were typical outcomes."<sup>83</sup> The finding that only 7.9 percent of respondents knew that children with FAS are often very outgoing and friendly and that only 17.1 percent knew that these children are often very generous toward others supports the idea of the existence of negative stereotypes. Although parents, teachers, and researchers working with children with FAS have become increasingly aware of the importance of early diagnosis and treatment and have identified techniques that improve the growth and development of these children, this information is just beginning to be communicated to parents, professionals, and the community-at-large. This might account for the low correct response rate on the Expectations for the Future section of the survey.

Female respondents had a significantly higher mean correct percentage than male respondents for the Expectations for the Future section (63.9 percent correct v. 51.2 percent correct). LaDue notes that "Indian women have traditionally taken on the responsibility for home and family."<sup>84</sup> It is possible that this responsibility has contributed to an increased awareness of the type of information addressed in this section of the survey.

Although FAS education and prevention is part of the curriculum in the substance abuse program, eight residents indicated that they had not participated in a FAS prevention program. Perhaps the program's emphasis on alcoholism treatment contributed to this response pattern. For the purpose of data analysis, these eight respondents were considered as having had FAS

prevention education and were added to the nine respondents who had responded affirmatively to this question, since we knew that these respondents had had training recently as part of their program in substance abuse treatment. When this combined group of seventeen subjects was compared to the fifty-nine subjects who indicated that they had not participated in a FAS prevention program, the results indicated that subjects who received FAS education had significantly higher scores on the Effects of Alcohol questions (85.1 percent correct v. 70.9 percent correct). This indicates that FAS prevention programs do result in increased knowledge levels in certain areas. This finding is consistent with May's and Hymbaugh's evaluation of prevention education programs,<sup>85</sup> which indicated that there was a significant knowledge gain about the effects of alcohol consumption during pregnancy and about FAS among people who participated in these programs. Rural and reservation areas have more noticeable FAS programs than urban Indians might encounter.

### LIMITATIONS

We can assert some findings about the natives surveyed here. However, the three groups of subjects studied did not provide a broad cross-section of American Indians. Because of this methodological limitation, we cannot generalize our findings to a wider population of American Indians.

Students who chose to complete and return the survey may not have been representative of the entire group of American Indian students at the university. This limits our ability to generalize the study's findings to all the American Indian college students at this university or any university.

Sixty-one percent of the respondents were college students. Two subjects indicated that they had FAS. These two demographic characteristics of the sample may have skewed the findings of the study.

The survey instrument was not tested for validity. It is important to know if a research instrument is actually measuring what it is intended to measure. The survey question that was intended to determine whether respondents had participated in FAS prevention or education programs did not always elicit accurate information. Eight of the residents of the substance abuse center who received this information as part of their alcohol treatment

program did not identify it as FAS education. It is possible that other respondents also participated in prevention and education programs that they did not perceive as such.

### RESEARCH RECOMMENDATIONS

Future research should involve a larger sample and a broader cross-section of American Indians. This would increase the ability to generalize the results to the wider population of American Indians. Additional research efforts should include American Indians who are currently residing on reservations and in rural areas.

The Chronbach's alpha statistic indicated that the research instrument was moderately reliable, with Chronbach alpha levels ranging from  $r = .55$  to  $.68$ . Continued refinement of this instrument may increase its reliability. It is interesting to note that, although 97.4 percent of subjects indicated that drinking alcohol may harm an unborn baby at any time during pregnancy, the percentage of correct answers to the three statements about risks of drinking during each specific trimester was somewhat lower. It is possible that these latter statements were confusing and need to be clarified. Tests to determine the validity of the research instrument would also enhance future research efforts.

More detailed questions regarding participation in FAS prevention or education programs might yield more accurate and detailed information regarding the ways in which respondents obtained the knowledge that they have about FAS.

### POLICY AND PRACTICE RECOMMENDATIONS

Even though there is a lack of accurate statistics regarding the incidence of FAS among American Indians, researchers agree that it is a significant problem among this population. Since the identification of this syndrome in 1973 by Jones and Smith,<sup>86</sup> numerous prevention and education programs have been established by national, state, and local agencies. The results of this study—even with its methodological flaws—suggest that these efforts are meeting with some success. It is imperative that our country's resources continue to be channeled into these programs in order to reduce and ultimately eliminate the occurrence of this tragedy.

The National Organization on Fetal Alcohol Syndrome (NOFAS) is a nonprofit organization that was established in 1990 in order to raise public awareness of FAS/FAE. NOFAS focuses its efforts on prevention, intervention, and advocacy. Human service workers should support the efforts of this organization by sharing their time, information, and financial resources.

Social workers and other human service professionals can contribute significantly to the prevention of FAS by advocating for and becoming involved in the education of clients, health and educational professionals, and the community-at-large. According to Wright,

Schools provide an excellent opportunity for intervention. Sex education, family living, and physical education classes should include information on FAS . . . . Women's groups should find FAS a pertinent topic. Workshops and written information could be arranged for the community. Treatment centers for alcoholics are excellent intervention points. Women who receive any kind of treatment for alcohol abuse should be warned about the dangers of FAS.<sup>87</sup>

Human service workers can raise people's awareness of the importance of early diagnosis and treatment of children with FAS; educate teachers and families regarding techniques that improve their growth and development; and thereby contribute to the sense of hope regarding their future. It is in these ways that the well-being of American Indian children, families, and communities will be preserved.

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