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# **Fetal Alcohol Spectrum Disorders in Indian Country**

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## **Site Visit Final Report Executive Summary**

A Report from the  
Substance Abuse and Mental Health Services Administration  
**Fetal Alcohol Spectrum Disorders  
Center for Excellence**

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U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES  
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SAMHSA  
Fetal Alcohol Spectrum Disorders  
Center for Excellence

### EXECUTIVE SUMMARY

As part of its outreach efforts in Indian Country, the Substance Abuse and Mental Health Services Administration (SAMHSA) Fetal Alcohol Spectrum Disorders (FASD) Center for Excellence sponsored site visits in 2002. Two consultants interviewed representatives from 10 tribal groups and 5 health centers in July, August, and September. The sites included 10 reservations and 5 urban Indian Community Health Centers.

### Fetal Alcohol Spectrum Disorders

“Fetal Alcohol Spectrum Disorders (FASD)” is an umbrella term describing the range of effects that can occur in an individual whose mother drank alcohol during pregnancy. These effects may include physical, mental, behavioral, and/or learning disabilities with possible lifelong implications. The term FASD is not intended for use as a clinical diagnosis.

FASD refers to several conditions, such as fetal alcohol syndrome (FAS), alcohol-related birth defects (ARBD), and alcohol-related neurodevelopmental disorder (ARND):

- FAS describes a distinct pattern of growth retardation, central nervous system dysfunction, and facial anomalies.
- ARBD refers to organ dysfunction and musculoskeletal damage.
- ARND refers to central nervous system defects and behavior problems or cognitive deficits.

FASD is 100 percent preventable. Prenatal alcohol exposure is the most preventable cause of developmental disabilities and mental retardation. Because researchers have not identified a safe amount of alcohol use during pregnancy, abstinence is recommended. However, approximately 1 in 10 U.S. women drinks alcohol while pregnant. Women who give birth to children with FASD are usually heavy drinkers, binge drinkers (four or more drinks on one occasion), or both. But adverse outcomes also occur in the children of women who drink moderate amounts of alcohol.

Nearly 40,000 babies are born each year with FASD, accounting for about 1 percent of all live births. Statistics on the incidence of FASD among American Indians/Alaska Natives are limited. The rate is estimated to be three times that among non-Natives.

Children with FASD experience lifelong difficulties and disabilities, such as:

- Decreased intellectual functioning
- Deficits in verbal learning, spatial memory, and reasoning
- Cognitive motor deficits
- Slowed reaction time
- Balance problems
- Substance abuse and mental health problems
- Disrupted school experience
- Trouble with the law and incarceration
- Inappropriate sexual behavior
- Dependent living

- Problems with employment

### Health Care and FASD in Indian Country

Indian Country is not homogeneous. There are 558 federally or State-recognized sovereign tribal nations. Each has a distinct culture, history, customs, and traditional beliefs. However, some similarities exist among many tribes:

- Rural setting
- Limited access to health care
- Presence of a dominant culture

The Bureau of Indian Affairs (BIA) initially provided health care to American Indians/Alaska Natives, but it was inadequate. To improve services, the Transfer Act of 1954 assigned responsibility for health care to the Public Health Service (PHS) within the U.S. Department of Health and Human Services (HHS). A new agency, the Indian Health Service (IHS), was created within PHS to address the needs of Native Americans. One of the major accomplishments of IHS was to build hospitals and clinics to serve American Indian/Alaska Native communities.

The Federal Government's goal to support tribal self-determination led to the Indian Self Determination and Education Assistance Act of 1975 (P.L. 93-638). Since then, many tribes have slowly taken over the operation of their own health care programs. About 15 years ago, Title III of the Act enacted the Tribal Self-Governance Demonstration Project, now known as self-governance compacting. Tribes can negotiate a compact with the Federal Government that defines the government-to-government relationship.

Historically, IHS provided services, training, and education for FASD, which was a line item in the budget for tribal alcohol treatment and prevention programs. Most tribes had a designated FASD coordinator who directed and managed awareness and prevention programs in their community. Since self-governance compacting, IHS no longer provides specific funds or services for FASD. FASD was dropped as a line item of IHS funding to the tribes involved in compacting.

Today, most FASD programs in Indian Country have been terminated. Most tribes provide limited services for FASD or none at all. Services for children are provided primarily through State early intervention programs or Federal programs, such as Head Start. Services for affected adults do not exist unless the adult is severely disabled.

The Head Start program has recently become a source of major concern in Indian Country. Proposed changes to Head Start will place the program under the auspices of States and tribes. With budget cuts, compacting, and other actions in response to the Self-Determination Act, FASD does not often come to the attention of the tribes that would be responsible for Head Start.

Currently, Head Start programs in Native American communities are the primary programs that identify children with FASD and other special needs. If the Head Start programs become the responsibility of the States and tribes, most likely fewer children with FASD will be identified. This change will be a considerable setback for the tribes.

### FASD Center for Excellence

SAMHSA's two key strategies for preventing and treating FASD are to identify, support, and promote effective prevention practices and to build capacity of States, communities, and other groups to apply such practices. As part of these strategies, SAMHSA operates the FASD Center for Excellence. The Center was created as part of the Children's Health Act of 2000 and was launched in September 2001. The Center has six legislative mandates:

1. Study adaptations of innovative clinical interventions and service delivery improvement strategies for children and adults with fetal alcohol syndrome or alcohol-related birth defects and their families.
2. Identify communities that have an exemplary comprehensive system of care for such individuals so that they can provide technical assistance to other communities attempting to set up such a system of care.
3. Provide technical assistance to communities who do not have a comprehensive system of care for such individuals and their families.
4. Train community leaders, mental health and substance abuse professionals, families, law enforcement personnel, judges, health professionals, persons working in financial assistance programs, social service personnel, child welfare professionals, and other service providers on the implications of fetal alcohol syndrome and alcohol-related birth defects and the early identification of and referral for such conditions.
5. Develop innovative techniques for preventing alcohol use by women in childbearing years.
6. Perform other functions, to the extent authorized by the Secretary after consideration of recommendations made by the National Task Force on Fetal Alcohol Syndrome.

The Center maintains a comprehensive database on FASD resources and research, a Web site, and a toll-free information line. In addition, the Center has conducted 15 regional Town Hall meetings for service providers, persons with FASD, parents, and caregivers to gather information on problems and needs.

In response to its second mandate, the Center has been creating a national inventory of FASD-specific programs. An inventory of this nature has never been created before. When it is completed, it will provide critical program referral information.

### Site Visit Methodology

Project consultants conducted site visits to 10 tribal reservations and 5 urban Indian Community Health Centers. The consultants thought that spending time in the community and visiting different departments would be the best way to gather information. However, it can be difficult to obtain a representative sample. Using the 2000 Census figures, the consultants identified the top 10 American Indian tribal groups and chose a tribe to represent each group (e.g., the 10 Apache tribes were represented by the Mescalero tribe).

The 10 reservation tribes selected were:

- Eastern Cherokee
- Oneida Wisconsin
- Choctaw
- Red Cliff Band Chippewa

- Blackfeet
- Rosebud Lakota Sioux
- Mescalero Apache
- Pueblo of Jemez
- Navajo
- Tohono O'Odham

In selecting the urban Indian Community Health Centers, the consultants used the 2000 Census figures to identify cities with a large American Indian/Alaska Native population. They also sought geographic diversity. They selected New York City, Minneapolis, Tulsa, Phoenix, and Anchorage. The consultants contacted the recognized urban Indian Community Health Center to identify available FASD services and programs.

Two interviewers divided the site visits and telephoned each assigned site to arrange the visit. The interviewers discussed the purpose of the visit, the FASD Center for Excellence and its mandates, and the commitments of SAMHSA and the FASD Center to Indian Country. For site visits to reservations, the interviewers subsequently contacted the programs and departments of interest, such as:

- Alcohol and drug
- Behavioral health and mental health
- Treatment
- Women and children
- Head Start and early intervention
- School districts and education
- Social services
- Clinics, hospitals, and Community Health Representatives (CHRs)
- Criminal justice system

For site visits to community health centers, the interviewers called the executive director or clinical director to schedule the visit. They also identified the staff and departments that could help provide a comprehensive review of FASD services. The consultants used a form to standardize data collection. Visits to reservations lasted from three-quarters of a day to a day and a half. The visits to urban health centers lasted approximately a half-day.

### Findings

All sites were extremely cooperative, and several people came in on their day off to meet with the interview team. All the visits involved interviewees from different departments or programs. Tribal staff usually gave the consultants a facility tour. At one site, the consultants were given a tour of the town that included highlights of the reservation. Many of the individuals interviewed had some historical perspective of FASD services that had been provided by IHS.

The data collected from the sites will be added to an overall national database and provide the beginnings of a database for Indian Country. This database will be broadened as additional information is gathered about the services offered by tribes and urban centers not listed in this survey.

It is important to remember that each tribe is different, just as each region of the country is different. In addition to the differences, some similarities exist across the 15 sites. Site visit findings include:

- Only one tribe has a paid FASD coordinator. This coordinator primarily provides community education and prevention and is the only person to cover 14 million acres.
- Only one of the cities surveyed has an FASD clinical coordinator working at a regional medical center to coordinate diagnostic teams in the State but not to coordinate services.
- Early intervention programs, Head Start, or local school districts provide most of the services for children with special needs.
- No tribe provides coordinated services for FASD.
- FASD services are not programmatically supported within IHS or any of the tribes except the Diné. Before self-governance compacting, IHS provided quality training, workshops, and assessment and diagnostic clinics. Today, IHS now offers little in FASD prevention and services support. Therefore, the Native American communities visited for this report have limited information about FASD and how to prevent it.
- Prevention programs or community awareness programs are person specific, not program specific. Several tribal behavioral health or medical service providers said they had FASD prevention programs in the past that were started by one individual in a health, social service, or education agency who was concerned about FASD. When that individual left or moved to another department, the program was not maintained because of lack of interest.
- Coordination among tribal departments or between IHS, BIA, and tribal facilities is minimal. In one community where all three entities had a social service department, none of the individual departments was familiar with the activities of the others.
- Most tribal social service departments are not aware of what is happening in early intervention and Head Start programs.
- Unless there is significant physical or cognitive impairment, most children with FASD are not identified until they reach Head Start.
- Some clinics do not ask about drinking during pregnancy or current drinking unless there is an obvious problem. None of the clinics or behavioral health departments in the surveyed communities uses a standard protocol to determine the level of maternal drinking.
- No services are available for adults with FASD unless they are so impaired that they cannot care for themselves.
- Adolescents receive services in the court systems, and their symptoms are often misdiagnosed as ADHD or a conduct disorder.
- A strong need exists to assist the tribes in coordinating prevention and direct service efforts.
- Community FASD prevention efforts are minimal. In several communities, diabetes information was very apparent, with billboards about diabetes, but nothing about FASD.
- Most sites had elements of good programs (e.g., individuals trained in FASD) but did not have the infrastructure to sustain programs after IHS support ceased.

These findings indicate that a sustained, coordinated effort is needed to foster the development of FASD prevention and interventions in Indian Country.