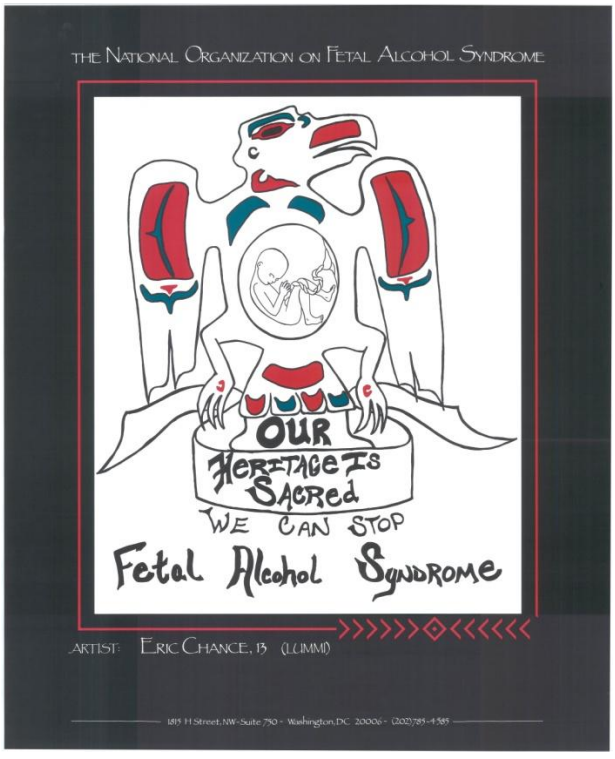
Native American
Fetal Alcohol Spectrum Disorders
Collaborative



An initiative of the National Organization on Fetal Alcohol Syndrome and the National Indian Health Board

Introduction

The Native American Fetal Alcohol Spectrum Disorders Collaborative is an initiative in development by the National Organization on Fetal Alcohol Syndrome (NOFAS) and the National Indian Health Board (NIHB). The Collaborative's mission is to prevent Fetal Alcohol Spectrum Disorders (FASD) among American Indians and Alaska Natives (AI/ANs) and to improve outcomes for AI/AN children and adults living with FASD.

Although FASD affects all populations, some Tribes have experienced higher than average prevalence rates. Fortunately, many Tribes have been far more proactive and innovative than other communities in addressing the problem. The Collaborative will serve as a resource for Tribes and AI/AN organizations addressing FASD in clinical, educational, judicial, and community-wide settings.

Project Development

The project's first year will be dedicated to a Tribally-engaged planning period designed to inform the Collaborative through the direct input of Tribal stakeholders and the target communities. Planning will begin with a comprehensive environmental scan of past and current FASD-related AI/AN initiatives and published findings to ensure that Native voices are fully engaged in the formation of the Collaborative. In order to achieve this, NOFAS and NIHB will convene a National Advisory Committee that includes representatives from six geographic areas within Indian Country with the highest FASD prevalence rates. The Advisory Committee will assist the Collaborative in planning and organizing regional Talking Circles to collect recommendations from affected communities regarding issues to be addressed, successful and culturally-driven approaches in education and training, and the development or adaptation of culturally appropriate resource materials.

Talking Circles are a deeply rooted practice among American Indians that afford an open, non-judgmental environment for sharing and listening. Reflections from the Circles will shape a formal year one needs assessment that will include a more comprehensive overview of the existing state of FASD and guide the Collaborative' s proposed strategies and path toward improvement.

Future activities will be determined from initial consultations, the environmental scan, perspectives gathered from the Talking Circles, and Advisory Committee deliberations. Such activities could include a train-the-trainers initiative, clinical demonstration sites, multi-media public awareness campaigns, online interactive curricula, conferences or meetings, a comprehensive report on the state of FASD among AI/AN populations, mini-grants to Tribes, a patient registry, and prevalence and economic studies.

NIHB will devote a segment of a future National Tribal Public Health Summit to FASD and the Collaborative, and will approach other key organizations such as the National Indian Child Welfare Association and the National Indian Education Association as prospective partners.

This formative period is critical to justifying the Collaborative's mission and objectives and ensuring the commitment of its programmatic and funding partners.

Fetal Alcohol Spectrum Disorders

FASD[1] 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. FASD is not a diagnostic term. Under the FASD umbrella, individuals can be diagnosed with Fetal Alcohol Syndrome (FAS), Partial Fetal Alcohol Syndrome (PFAS), or Neurobehavioral Disorder Associated with Prenatal Alcohol Exposure (NDPAE). Each diagnosis can include significant medical and mental health problems.

When a pregnant woman consumes alcohol, the alcohol crosses the placenta into the blood supply of her developing baby. Alcohol is a neurotoxin to a growing embryo or fetus that interferes with normal prenatal human development and can cause brain and spinal cord damage, other physical birth defects, a characteristic set of facial malformations, and from mild to severe, lifelong intellectual disabilities.

Of all the substances of abuse, including marijuana, cocaine and heroin, alcohol produces by far the most serious neurobehavioral effects on the embryo or fetus.[2]

FASD is known as a "hidden disability" because some individuals are not diagnosed until adolescence, adulthood, or not at all. Although the birth defects are permanent, early diagnosis and appropriate treatment can prevent the secondary disabilities associated with FASD that place a significant burden on the individual, their family, and community.

For the individuals with the disorder who are not identified and treated, the risk of secondary disabilities is staggering. Ninety percent have mental health disorders, 60% have disrupted school experience, 60% over the age of 12 have been in trouble with the law, and 50% above the age of 12 have been confined for mental health problems, alcohol or illicit drug problems, or incarcerated for a crime.[3]

Fortunately, therapeutic rehabilitation for women of childbearing age who have difficulty abstaining from alcohol when pregnant or are experiencing an alcohol use disorder, and interventions that prevent the secondary disabilities in individuals with FASD, are both effective when accessible and properly implemented in a timely manner. Moreover, FASD itself is completely, 100% preventable when professionals, policymakers, and populations at-large

[1] From 1973, when the disorder was discovered in U.S. medical literature, the primary term used to describe alcohol-related birth defects was Fetal Alcohol Syndrome. In 2004, the term Fetal Alcohol Spectrum Disorders was defined and adopted as a better description of the range of diagnoses associated with prenatal alcohol exposure. Fetal Alcohol Syndrome remains in use as a diagnosis under the FASD umbrella. (NOFAS FASD Terminology Summit, 2004)

[2] Institute of Medicine, Fetal Alcohol Syndrome: Diagnosis, Epidemiology, Prevention, and Treatment, 1996.

[3] Understanding the Occurrence of Secondary Disabilities in Clients with Fetal Alcohol Syndrome, 1996.

understand the risk and actively address the needs of pregnant women and the individuals prenatally exposed to alcohol.

Statement of Need

Native American cultures possess a rich history, tradition, and spirituality. There are 566 federally recognized Tribes across the United States, each with its own distinctive identity. Some AI/AN populations experience significant alcohol problems and other health disparities.

The underlying causes of these health disparities are complex. A legacy of oppression, displacement and loss of self-determination, and other trauma are factors in many problems, including alcohol abuse. Alcoholism poses one of the most significant public health problems for Native Americans, who are five times more likely than whites to die of alcohol-related causes, including liver disease, and experience higher rates of drunk driving and alcohol-related deaths than the general population.[4] Excessive alcohol consumption is the leading cause of preventable deaths among American Indians and Alaska Natives, according to a report issued by the Centers for Disease Control and Prevention and the Indian Health Service. The report, the first of its kind, says that alcohol-related deaths account for 11.7 percent of all deaths among American Indians and Alaska Natives – nearly twice that of the general population.[5]

While FASD is a health concern among all populations that consume alcohol, from 1981 to 1991 the recorded prevalence of FAS among AI/ANs stood at 31 per 10,000 births compared to 2.1 in the overall U.S. population.[6] A 2007 study reported the prevalence of FAS in Alaska to be 1.5 per 1,000 live births, but 5.6 among AI/ANs. Prominent researcher Dr. Phil May has studied the prevalence of FAS and FASD among AI/ANs populations and the general public for 30 years. His most recent findings, published in the November 2014 edition of *Pediatrics*, measure the rate of FASD among school-aged children in the United States at one in 50, if not higher[7], making FASD nearly 20% more widespread than autism.

Many Tribes have long recognized the consequences of alcohol consumption, including FASD, and have established programs to treat individuals with alcohol use disorders. Unfortunately, only a few Tribes have implemented FASD prevention or treatment initiatives, sometimes due to insufficient resources but more often because of a lack of familiarity with validated clinical practices, access to culturally appropriate materials, or proper training. The Native American FASD Collaborative will be a state-of-the-art resource dedicated solely to FASD and to overcoming these limitations.

Native American FASD Collaborative

The Collaborative will make progress toward its overarching goals to prevent alcohol-related birth defects and support individuals living with FASD during the first year planning phase by focusing on four key objectives:

[4] Substance Abuse and Mental Health Services Administration, 2012
[5] Indian Health Service and Centers for Disease Control and Prevention, 2014
[6] (J. Hisnanick, 1992; P. A. May, 1996; J. M. Wallace et al., 2003)
[7] P.A. May et al. *Prevalence and Characteristics of Fetal Alcohol Spectrum Disorders*. Pediatrics 2014; 134:5 855-866

1. Establish an Advisory Committee. The Committee will be comprised of Tribal leaders, activists, professionals, individuals with personal FASD perspective, and representatives of both NOFAS and NIHB.
2. Conduct an FASD environmental scan among AI/AN populations. The scan will establish a baseline of understanding of the problem and needs, document existing programs and data resources available to Indian Country, assess training capacity, and could include a gap analysis to measure the disparity between existing and desired resources and outcomes.
3. Facilitate a minimum of four Talking Circles
4. Create the National Tribal FASD Information, Data, and Resource Clearinghouse. The Clearinghouse will consist of a digital research library accessible by all Tribes through a variety of outreach mechanisms effective for each Tribe.

The qualitative objectives for the Collaborative's second year will be informed by year one planning. The provisional objectives are:

1. Increase the knowledge about FASD and existing interventions and programs among Tribal service providers and public health professionals
2. Increase the number of education or training sessions presented to Tribal professionals
3. Increase the number of trained professionals providing services in Tribal communities
4. Increase the number of Tribes implementing FASD or alcohol screening programs
5. Increase the number of Tribal members receiving alcohol or FASD-related services
6. Document the number of requests for information, trainings, and other quantitative measures, and collect outcomes data.

The objectives will be met by implementing activities using four primary mechanisms, all focused solely on FASD and targeted specifically to AI/AN Tribes and individuals:

Data Clearinghouse – The clearinghouse will provide information and data and respond to requests from AI/AN Tribes, organizations, and individuals for FASD-related materials and resources, and house a comprehensive archive and virtual library—including a website—of research, past and current initiatives, and other materials.

Education and Training – The Collaborative will present training options to service providers and prevention specialists on a range of evidenced-based practices, including alcohol screening and brief intervention, FASD screening and diagnosis, treatment, intervention and wraparound services, public health and health promotion initiatives, education strategies, and other facets of FASD. [Presentations will be led by AI/AN clinical and public health professionals and leading FASD researchers and experts.]

Technical Assistance – The Collaborative will offer technical assistance in support of the implementation of FASD-related practices and strategies. [Guidance will be coordinated by the Collaborative and be provided by experienced clinicians and administrators.]

Policy – The Collaborative will monitor federal, state, and Tribal policies and legislation effecting AI/AN women with an alcohol use disorder and children and adults living with FASD. Issues of interest will include formative research on FASD demographics, access to medical and mental health care, eligibility for disability and education services, provider reimbursement, and other topics. The Advisory Committee will assess policy opportunities and develop a policy agenda.

National Organization on Fetal Alcohol Syndrome (NOFAS)

NOFAS is a 501 (c)3 public health advocacy nonprofit organization based in Washington, D.C. Founded in 1990 as a South Dakota non-profit, NOFAS has worked closely with American Indian and Alaska Native communities over the years to address alcohol-related birth defects. From NOFAS' inception, Indian leaders and activists have been deeply involved in NOFAS' governance and its development and implementation of numerous public health projects in Indian Country, nationally and internationally.

In the early 1990s, NOFAS co-organized a task force among the Sioux Tribes of South Dakota and conducted two national Indian conferences in Minneapolis and Albuquerque. In 1995, NOFAS board member and renowned Native artist Sam English illustrated a popular children's book written by acclaimed author Luci Tapahonso. The Bureau of Indian Affairs strongly promoted the book's use to educate all populations about the dangers of alcohol consumption during pregnancy. The Oneida Nation of Wisconsin reprinted this NOFAS children's book twice as a tremendously generous $80,000 in-kind contribution.

From 2004 through 2007, NOFAS partnered with Cherokee Nation of Oklahoma to conduct FASD trainings for practitioners and a multi-media public awareness campaign. This NOFAS Indian Youth Outreach Project involved training of teenagers as peer educators to make FASD presentations in schools and other settings. NOFAS also collaborated with Mississippi Choctaw, Navajo Nation, Standing Rock Sioux and urban Indians in Portland, Oregon on similar youth initiatives. In 2006, NOFAS worked with the Indian Health Council in Southern California to develop an online FASD training for practitioners as a pilot project and provide professionals with education units as they learn to screen women for alcohol problems and individuals for FASD.

NOFAS assisted the U.S. Substance Abuse and Mental Health Services Administration (SAMHSA) in identifying and convening the expert panel and Native American Advisory Group that developed and published in 2007 the "American Indian/Alaska Native/Native Hawaiian Resource Kit" to help AI/NA/NH communities understand and prevent FASD. The Kit includes Fact Sheet, Information Sheets, How-to-Brochures, Posters and Media and Resource Guides. In 2014, NOFAS also published "Implementing CHOICES in Clinical Settings that Serve American Indian and Alaska Native Women of Childbearing Age" in conjunction with the Centers for Disease Control and Prevention, a report assessing the feasibility of implementing an intervention designed to reduce alcohol consumption among AI/AN women of childbearing age.

National Indian Health Board (NIHB)

The National Health Board (NIHB) is a 501(c) 3 not for profit, charitable organization providing health care advocacy services, facilitates Tribal budget consultation and provides timely information and other services to all Tribal Governments. Whether Tribes operate their own health care delivery systems through contracting and compacting or receive health care directly from the Indian Health Services (IHS), NIHB is their advocate.

NIHB also conducts research, provides policy analysis, program assessment and development, national and regional meeting planning, training, technical assistance, program and project management. These services are provided to Tribes, Area Health Boards, Tribal organizations, federal agencies, and private foundations. The NIHB presents the Tribal perspective while monitoring, reporting on and responding to federal legislation and regulations. It also serves as conduit to open opportunities for the advancement of American Indian and Alaska Native health care with other national and international organizations, foundations corporations and others in its quest to build support for, and advance, Indian health care issues

For more than 40 years, NIHB has continuously played a central role in focusing national attention on Indian health care needs. These efforts continue to gain results and momentum. Since 1972, the NIHB has advised the U.S. Congress, IHS, other federal agencies and private foundations about health disparities and service issues experienced in Indian Country. The future of health care for American Indians and Alaska Natives is intertwined with policy decision at the federal level and changes in mainstream health care management. The NIHB brings to Tribal governments timely information to assist Tribes with effectively making sound health care policy decisions.

NOFAS and NIHB Collaborative Proposal

On behalf of the Collaborative, NOFAS is seeking total funding for the first year in the amount of $250,000 to ensure full implementation of the proposed planning activities. Full funding will assure one full time staff member at both NOFAS and NIHB dedicated to the Collaborative who will be able to successfully achieve the stated first year objectives of, 1) seating the national advisory panel, 2) conducting the environmental scan, 3) convening a minimum of four talking circles in distinct geographic locations, and 4) developing the clearinghouse.

NOFAS will house and manage the clearinghouse and coordinate presentations and trainings, all with input from NIHB. NIHB will take the lead on FASD-related policies and legislation. Technical assistance and the administration of the advisory board will be directed by both NOFAS and NIHB staff.

Evaluation and Sustainability

Success will be measured through both process and outcomes based evaluations. The Collaborative will engage with an independent evaluator to assist in evaluation strategy, including the development and implementation of surveys, instruments, and the collection and analysis of information.

The Collaborative will create a data dashboard to track objectives and other quantitative measures. Outcomes vignettes will illustrate tangible accounts of individuals and Tribes who have benefitted directly from the Collaborative and its resources. A year-end report will describe project successes, lessons learned, challenges and difficulties encountered, and proposed solutions.

The Collaborative's accomplishments and evaluation results will drive future investment. The combined standing of NOFAS and NIHB and the status of FASD as a significant, preventable health concern will make the Collaborative appealing to funders, as will the enormous potential cost savings through the prevention of alcohol dependence[8] and the disabilities associated with FASD.[9]

FASD is a tragic, unnecessary, and pervasive disorder that demands greater public and private attention and investment. AI/AN populations have long been disproportionally affected by alcohol and pregnancy. With critical guidance, coordination, and support from the Collaborative, many Native communities with determination and infrastructure will be positioned to help individuals with FASD live self-directed, fulfilling lives, and to protect future generations from the disorder. The Native American FASD Collaborative is critically necessary and an important investment in future generations. NOFAS and NIHB—on behalf of AIAN Tribes—are ideally positioned to ensure the Collaborative's success.

[8] Alcohol abuse costs the U.S. $224 billion annually. Centers for Disease Control and Prevention, 2012

[9] The lifetime estimated costs for each individual with the full Fetal Alcohol Syndrome is $800,000 to $2.4 million.