Introduction

Fetal alcohol syndrome (FAS) is a national tragedy affecting tens of thousands of babies born each year in the United States. First identified in the U.S. in 1973, it is the leading known cause of mental retardation and birth defects in this country. [1]

FAS is defined as a pattern of neurological, behavioral, and cognitive deficits that interfere with growth, learning, and socialization. Caused solely by a mother's drinking alcoholic beverages during pregnancy, it is 100% preventable.

The term FAS is used in this document to refer to the full spectrum of prenatal exposure to alcohol, encompassing the various terms used to describe the condition even when the characteristic facial features of FAS are absent: alcohol-related neurodevelopmental disorders (ARND), alcohol related birth defects (ARBD), and the more common term, fetal alcohol effects (FAE). Regardless of which term is used, the reality is the same—lifelong, irreversible brain damage caused by alcohol use during pregnancy.

The Center for Substance Abuse Prevention (CSAP) provides national leadership in the development of policies, programs, and services to prevent underage alcohol and tobacco use, illicit drug use, and the abuse of alcohol and other drugs. The two primary strategies being used by CSAP to address the problem of FAS are (1) identifying, supporting, and promoting effective substance abuse prevention practices; and (2) building capacity of States, communities, and other groups to apply such practices effectively.

In fall 2001, CSAP was charged with the development and administration of the FAS Center for Excellence, a congressional mandate. This effort was put in place to identify best practices in FAS prevention and services for persons with FAS. In order to support the objectives of the Center for Excellence, CSAP has initiated several efforts, including the funding of seven FAS prevention and treatment programs.

This document has been developed for the first meeting of all the FAS grantees in Sedona, Arizona, in April, 2002. By sharing information among projects and comparing salient project characteristics, we hope to begin working toward developing a common research methodology. Collectively, these projects have the greatest potential to provide scientifically based evidence on what prevention and treatment approaches are most successful.

We invite you to read this document to become familiar with current innovative approaches being tested to prevent FAS.

Deborah Stone, Ph.D.
Project Officer, FAS Center for Excellence
Center for Substance Abuse Prevention

Description of FAS and Program Evolution

In this section, the FAS facts are identified, followed by discussions of the challenges to preventing the condition, Federal efforts to prevent FAS, and the role of the FAS Center for Excellence in supporting prevention projects.

FAS FACTS

Definition. FAS is a pattern of neurological, behavioral, and cognitive deficits that interferes with growth, learning, and socialization. [2]

Cause. FAS is caused solely by a mother's drinking alcoholic beverages during pregnancy. [3]

Discovery. FAS first was identified in the scientific literature in the U.S. in 1973. [4]

Harm. AOf all the substances of abuse, including heroin, cocaine, and marijuana, alcohol produces by far the most serious neurobehavioral effects in the fetus.@ [5]

Incidence. Estimates for FAS vary between 0.5 and 3 per 1,000 live births in the U.S., with some communities having substantially higher rates than others (e.g., some American Indian communities have rates as much as 33 times higher than the general population). [6]

Economic costs. Costs associated with FAS have been estimated to range from $1.4[7] to $5 million per affected person, excluding the cost of incarceration.[8]

Awareness. Although more than two thousand scientific reports have been published about the harmful effects of alcohol on the fetus, only 73% of the females and 55% of males in 1990 had ever heard of FAS, and fewer yet had an accurate understanding of the condition. [9] Further, it is helpful to remember that 1990 was a time of heightened awareness about FAS with the publication of the book, *The Broken Cord*, by Michael Doris.

Risk Behavior. More than half of women age 15 B 44 drank while pregnant according to a national survey. [10] The rate of binge drinking (i.e., five or more drinks on any one occasion) as well as frequent drinking (seven or more drinks per week or five or more on any one occasion) among pregnant women increased fourfold between 1991 and 1995. [11] The most recent statistics show minimal decreases in binge drinking between 1995 and 1999 (down to 2.7% from 2.9%) and in frequent drinking (down to 3.3% from 3.5%). [12]

CHALLENGES TO PREVENTING FAS

Prevention of FAS is a complex issue that resists simple solutions. Some progress has been made in changing the behavior of moderate or social drinkers, but heavy drinkers have proven harder to reach. They often are addicted to alcohol and come from communities where alcohol and other drug abuse is endemic.

FAS prevention is even more challenging since alcohol produces many of its most serious effects early in the first trimester when many women do not know they are pregnant. Further, there is no definitive information about the quantity of alcohol that produces negative effects, and some heavy drinkers do not give birth to FAS children. Despite these unique challenges, FAS prevention efforts are absolutely necessary. The fundamental message to be conveyed to women of childbearing age is: If you drink, do not become pregnant; if you are pregnant, do not drink.

Service providers can play a critical role in preventing and treating FAS. Educators, health care professionals, social service workers, and criminal justice personnel need to be able to recognize individuals with FAS, since they behave in ways that are clearly different from persons with other types of disabilities or psychiatric conditions. All too often, the condition is not recognized and persons with FAS undergo repeated, expensive interventions that are ineffective. With early diagnosis and a coordinated service approach, the lives of persons with FAS can be improved and the overall costs of care can be reduced.

COORDINATED FEDERAL EFFORTS TO PREVENT FAS

In 1996, the **Interagency Coordinating Committee on Fetal Alcohol Syndrome,** led by Faye Calhoun, Ph.D., of the National Institute of Alcoholism and Alcohol Abuse**,** was created**.** This Committee was formed to improve cooperation among disciplines that address health, education, developmental disability, alcohol research, and social services relevant to FAS and related disorders. Current membership includes the Department of Health and Human Services (DHHS), the Department of Education (ED), the Department of Justice (DOJ), and several sub-agencies under these Departments.

In 2000, the **National Task Force on Fetal Alcohol Syndrome** was chartered by the Secretary of DHHS as a Federal Advisory Committee. Led by Louise Floyd, D.S.N, from the National Center on Birth Defects and Developmental Disabilities within the Centers for Disease Control and Prevention and chaired by Ed Riley, Ph.D., this Task Force is a 13-member committee charged with advising all Federal, State, and local agencies and professional groups on FAS and FAE programs, including research on education and public awareness for service providers, school-age children, women at risk, and the general public. The Task Force also is charged with providing advice to these entities on programs and research matters concerning medical diagnosis and interventions for women at risk of an alcohol-exposed pregnancy, as well as for individuals with FAS and their families.

In 2000 the **FAS Center for Excellence** was authorized under Section 519D of the Children's Health Act for a 5-year period. As specified in the legislation, the Center will:

- Study adaptations of innovative clinical interventions and service delivery improvements strategies for children and adults with fetal alcohol syndrome or alcohol-related birth defects and their families
- Identify communities that have exemplary comprehensive systems of care for such individuals so that they can provide technical assistance to other communities attempting to set up similar systems of care
- Provide technical assistance to communities that do not have comprehensive systems of care for such individuals and their families
- Provide training to 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
- Develop innovative techniques for preventing alcohol use by women in childbearing years
- Perform other functions, to the extent authorized by the Secretary after consideration of recommendations made by the National Task Force on Fetal Alcohol Syndrome

In its first year, the Center for Excellence has been focusing its efforts on:

- Forming a Steering Committee to provide guidance to the Center including its first meeting held in February 2002, co-chaired by Faye Calhoun, Ph.D. and Ed Riley, Ph.D.
- Developing a comprehensive database on FAS resources and research
- Conducting a series of regional Town Hall meetings for service providers and parents/caregivers of persons with FAS
- Supporting the development of an FAS Web site and toll-free information hotline

- Providing training and technical assistance to organizations regarding successful FAS prevention and intervention activities

- Providing technical assistance, training, strategic and operational advice, and coordination among the FAS prevention projects

CENTER FOR EXCELLENCECSUPPORT FOR FAS PREVENTION PROJECTS

CSAP funded seven FAS prevention projects in 2000 and 2001. Two projects started in late 2000: Alaska's comprehensive statewide effort, and the Four-State Consortium (formed by Minnesota, Montana, North Dakota, and South Dakota) to improve the science base on diagnosed cases, risk factors, prevalence, and prevention. An additional five Community Initiated Prevention Intervention projects were funded in September 2001. These five projects field test FAS prevention approaches that have been shown to prevent, reduce, or delay alcohol use for groups at risk for having FAS children.

There is great variation between these projects. All seven of these projects will test different prevention interventions. Three of the projects are focused on statewide or multiple county areas, while the four others are focused on a metropolitan area or tribal group. Except for Alaska's 5-year project, all of the projects are funded for three years. The main body of this booklet provides an indepth description for each of these projects.

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Alaska's Statewide Fetal Alcohol Syndrome Five-Year Comprehensive Project

Office of Fetal Alcohol Syndrome
State of Alaska Department of Health and Social Services
Juneau, AK

Grant #9198

OVERVIEW

Alaska's Five-Year Fetal Alcohol Syndrome (FAS) Project is an effort to address issues related to fetal alcohol syndrome and other alcohol-related birth defects (ARBD) throughout Alaska, focusing both on prevention and on improvement of services to individuals and families affected by this disability. Alaska's FAS project is a comprehensive, integrated effort encompassing prevention, intervention, screening and diagnosis and improved service delivery. Four statewide goals have been identified for the five-year project period:

- Prevent all fetal alcohol spectrum disorders (FASD)
- Screen and diagnose children at risk of FASD as early as possible
- Improve lifelong outcomes through improved service delivery to families and individuals affected by FASD
- Document our progress and evaluate program outcomes.

The project is multidisciplinary, culturally appropriate, and community-based. The approach aims to coordinate existing systems and processes that now operate separately; to integrate service delivery and information management systems to the greatest extent possible; and to set up structures that will be self-sustaining into the future.

BACKGROUND

Alaska experiences a high rate of births where the fetus was exposed to alcohol. Current statistics indicate an FAS prevalence rate of 1.4 births per 1,000 live births and a rate of 12.6 births per 1,000 experiencing other alcohol-related birth defects. This same study indicates a prevalence rate for Alaska Natives at 4.8 per 1,000 live births. Alaska is among the leading States in estimates of alcohol-related risk factors and has one of the highest per capita alcohol consumption levels in the NationC30 percent higher than the national average. Alaska also has the highest rate of alcohol-related hospitalizations in the country. In addition, the State is among the top five in the country with the highest prevalence of binge drinking by women of reproductive age, drinking more than 30 drinks per month.

FAS has social costs for Alaska as well. It is estimated that 65 percent of children with FAS are either in State custody and living in foster care or have been in custody and are now in adoptive homes. Only 23 percent of affected children are living at home with one or both biological parents.

FAS and other alcohol-affected children have much greater needs than other children in foster care, including increased need for augmented care rates, adoption subsidies, and special services for respite care, infant learning programs, health care, educational services, and other support. In a report prepared for the Alaska Advisory Board on Alcoholism and Drug Abuse, issued in November 2001, it is estimated that the cumulative costs of medical and residential services for all individuals with FAS in Alaska are reported between $21 and $42 million annually.

MISSION

To prevent all alcohol-related birth defects and to improve the delivery of services to those individuals already affected by fetal alcohol spectrum disorders.

KEY STAKEHOLDERS

Key stakeholders include tribal organizations, State agencies, community service providers and parents/caregiver such as:

Alaska Federation of Natives
Office of the Governor
Alaska Court System
Department of Corrections
Department of Education and Early Development
Division of Public Health
Division of Juvenile Justice
Division of Public Assistance
Division of Alcoholism and Drug Abuse
Division of Family and Youth Services
Division of Mental Health and Developmental Disabilities
Alaska Mental Health Board
Governor's Council on Disabilities and Special Education
Department of Health and Social Services
Advisory Board on Alcoholism and Drug Abuse
Alaska Native Health Corporations
University of Alaska Anchorage
Community non-profit organizations
FAS parent support groups

GOVERNANCE

The Office of FAS is located within the Office of the Commissioner of the Alaska Department of Health and Social Services. The Program Manager reports directly to the Commissioner of Health and Social Services, with guidance from a 21-member statewide FAS Steering Committee that meets twice yearly in person, and regularly throughout the year via teleconference and work group meetings.

First Year Budget: $5.8 million per year

INTERVENTION ACTIVITIES

The project has three statewide strategies: FAS prevention (keeping FAS/ARBD from occurring whenever possible); screening and diagnosis (determining incidence and prevalence of the disorder in Alaska); and service delivery (improving the health and social functioning of children, youth, and adults with the disorder).

Prevention

Among the project's prevention activities is the development of multimedia, multistrategy public education campaign to be distributed through statewide TV, radio, and newspapers. The campaign will include different approaches based on target audiences to meet the needs of cultural, age, gender, and geographic diversity. In addition, the project is funding community-based FAS Innovative Grant programs aimed at prevention of FASD through public education, interventions with high-risk women, policy changes related to prenatal care, and changing public attitudes about drinking and pregnancy.

Screening and Diagnosis

Among screening and diagnosis activities is the development of the statewide FAS Community Diagnostic Team Network. To date the statewide diagnostic network includes 14 communities, with one additional community receiving training in September 2002. Currently, more than 20 Alaskan medical doctors and 100 other service providers including advocates, psychologists, speech therapists, health aides, nurses, child protection workers, mental health counselors, school counselors, and others have received training at the University of Washington in the 4-Digit Diagnostic Code process.

A project to screen all children entering the State's child protective services is in the planning stages, with a summer 2002 start date. Once screened, appropriate diagnostic referrals will be made. Another pending project is to train an FAS diagnostic team within our State mental health hospital (Alaska Psychiatric Institute), to provide diagnostic services for those hospitalized or entering our correctional system.

Service Delivery

A number of improved services delivery projects are underway, including the development of an Alaska-specific training curriculum for use with all State services providers. The curriculum will be developed in three phases: FAS 101; how does this disability impact functionality; and discipline-specific intervention models. Our initial partners in this endeavor include child protective services, public assistance, juvenile justice, corrections, educators, residential care providers, and rural human service providers. In addition, we have funded an FAS Education Specialist within the Department of Education and Early Development, who is providing training, support, and resources for teachers across Alaska in how to improve student learning when FASD is an issue. A number of projects are also developing to improve services to those individuals who enter our criminal justice system who have FASD, both youth and adults. We are supporting a case manager for the newly developing Family Drug Court, reaching mothers with alcohol abuse problems who enter the CPS system, and working with the Anchorage Mental Health Court to facilitate adult diagnostic services before sentencing, when appropriate.

EVALUATION ACTIVITIES

The project is developing an FAS information and evaluation center, through which all FAS/ARBD-related data and evaluation efforts will be reported, coordinated, analyzed, and disseminated. The plan is to develop collection and evaluation mechanisms that are appropriate and culturally competent for a variety of target audiences. The project will develop a manual as a tool to replicate the project in other States and communities. Through this effort we are conducting a statewide survey to assess knowledge, attitudes, beliefs, and behaviors of the general public, health care providers, substance abuse counselors, educators, social workers, and corrections personnel. In addition we are collecting diagnostic data from our Community Diagnostic Teams and working closely with the FAS Surveillance Project, funded by the Federal Centers for Disease Control.

The project has developed a multidisciplinary evaluation team model and an integrated assessment, approved by the Alaska FAS Steering Committee. A comprehensive evaluation plan has been reviewed by the University of Alaska Institutional Review Board which has been approved by CSAP. The plan includes a review of prevention activities; programs working with high-risk women; educational services to individuals with FASD; and FASD screening and diagnosis at the community level. All evaluation efforts will provide overall evaluations of the project, as well as ongoing, continuous improvement efforts to help grantees and communities make necessary project adjustments as they progress in their activities.

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Effectiveness of a Culturally Focused Skills Enhancement Approach to Reduce Alcohol Use in Native Women

College of Public Health
University of Arizona
Tucson, AZ

Grant #9428

OVERVIEW

The University of Arizona College of Public Health is implementing and evaluating the effectiveness of a culturally based, cognitive/behavioral intervention to reduce alcohol use among adult Native American women of childbearing age. This 3-year study will compare the effectiveness of a skills training approach with an education-only approach with 280 Pasqua Yaqui women.

BACKGROUND

The rate of birth defects among Native Americans in Arizona is documented as the highest among any ethnic group. According to the 1990 report from the Arizona Birth Defects Monitoring Program, Native Americans have a rate of 25.69 per 10,000 live births and fetal deaths.

The Native American women in this project are members of the Pascua Yaqui Tribe of Arizona, a Federally recognized American Indian community of about 12,400 members living in pueblos and communities, with about 6,000 in the Tucson area. It is estimated that 30 to 40 percent of the total Pascua Yaqui population and 15 to 20 percent of pregnant Yaqui women are chemically dependent. Since alcohol abuse often is associated with any type of chemical dependency, this means between 15 and 20 percent of children born each year to Yaqui women are at risk for alcohol-related birth defects, including fetal alcohol syndrome (FAS).

MISSION

To reduce alcohol use and prevent FAS births among Pascua Yaqui women of childbearing age.

KEY STAKEHOLDERS

The project works closely with the Pascua Yaqui Tribe Health Department, which currently is funded by the U.S. Substance Abuse and Mental Health Services Administration for a treatment enhancement project. The Pascua Yaqui Health Department works closely with tribal agencies and community representatives to address domestic violence and improve children's services across departments.

The Pascua Yaqui Tribal Council, of which five members are assigned as advisors to the Health Department, oversees and provides consultants to the project. In addition, the project receives cultural guidance from the Community Advisory Committee, a group of interested community members and Pascua Yaqui health professionals, and relies upon the Curriculum Development Workgroup, the Community Outreach Liaison, and other counselors and interviewers.

GOVERNANCE

The University of Arizona College of Public Health, a research institution with extensive experience in grants, cooperative agreements, and contracts, is collaborating with the Pascua Yaqui Tribe of Arizona Health Department and has subcontracted with them to provide most aspects of this project. The Community Advisory Committee meets regularly to oversee the cultural aspects of the project and curriculum development.

First Year Budget: $465,210

INTERVENTION ACTIVITIES

At least 280 participants are randomly assigned to either an intervention (skills training) group or an attention placebo (education) group. Both types of groups consist of twelve 2-hour sessions that occur once a week over a 12-week period.

The goal of the skills training sessions is to develop support among women and foster learning skills to assist them to resist and decrease alcohol use. These skills may also help them deal with uncomfortable social situations that create negative emotional reactions that may lead to substance use. The curriculum used in the skills training session is designed to improve general and culture-specific social competence, coping, and alcohol resistance skills. It also focuses on the relationships between alcohol use/abuse and trauma, stress, and depression in women's lives, as well as the impact of cumulative intergenerational stressors related to genocide, racism, poverty, death, and alcoholism.

The skills training session interventions are based on a cultural foundation of ceremony, honor, and talking circles. Talking circles are ceremonies in which one person sets the theme as a sacred token, such as a special rock or eagle feather, is passed from person to person. Participants who hold the token speak from their hearts with honesty and integrity, sharing their feelings about the theme and what is important to them.

In contrast, the educational group sessions provide information regarding substance use and the effects of abuse, child management, and other important issues determined by the Curriculum Development Workgroup.

The participants in both interventions complete intensive indepth interviews and a battery of standardized questionnaires before they are assigned to a group. Every three months after the initial assessment, participants repeat an abbreviated interview and the battery of questionnaires. Participants obtain gift certificates for completing the assessments and each of the 12 group sessions.

EVALUATION ACTIVITIES

Process and outcome measures examine the fidelity of the group processes, intervention dosage, degree to which alcohol use is reduced, acquisition of alcohol resistance skills, and the strength of associations between psychosocial variables and alcohol use. Long-term outcome measures include assessing issues related to the prevalence of FAS, such as healthy birth weights for children born to mothers who participated in the skills group versus the education group. If the skills training intervention approach is successful, the Pascua Yaqui Health Department will continue to fund skills training sessions, and perhaps the evaluation component.

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Four-State Consortium on Fetal Alcohol Syndrome/Fetal Alcohol Effects

Center for Disabilities
Department of Pediatrics
School of Medicine
University of South Dakota
Sioux Falls, SD 57105

Grant #5 KD1 SP09199-02

OVERVIEW

The Four-State Consortium on Fetal Alcohol Syndrome/Fetal Alcohol Effects (FAS/FAE)—composed of Minnesota, Montana, North Dakota, and South DakotaC improves data collection systems to understand the extent of the problem; identifies female populations in the region at risk for giving birth to children with FAS; evaluates and implements prevention programs; and evaluates the effectiveness of a multi-State effort to prevent FAS/FAE.

BACKGROUND

According to surveys, a child with FAS is born every other day in the region including Minnesota, Montana, North Dakota, and South Dakota. Using a conservative FAS incidence rate of 2 per 1,000 births, there were an estimated 187 FAS births in the four-State region in 1995. However, many more children are born with FAE, alcohol-related birth defects, and alcohol-related neurodevelopmental disorders. Using a conservative incidence rate of 12 per 1,000 births, there were 1,120 children born with these conditions in 1995. National studies cite two factors about the region that create increased risk for FAS births: the rural nature of the States, and the large numbers of American Indian reservations (33 in the region).

MISSION

To build the capacity in the States of Minnesota, Montana, North Dakota and South Dakota through the establishment of the Four-State Consortium to reduce the risk factors that result in children being born affected by fetal alcohol syndrome or fetal alcohol effects.

KEY STAKEHOLDERS

Stakeholders include a number of State agencies across the region as well as Native American organizations, including the Federal Indian Health Service offices at national, regional and local levels.

GOVERNANCE

The cooperative agreement is administered through the University of South Dakota. The Four-State Consortium Advisory Council, the Consortium Steering Committee, and individual State Advisory Committees advise the project. Membership within these groups include health and social service professionals and people representing American Indian and other minority populations. Other contributing governing organizations include a task force for research/data collection. In addition, each State has a consortium implementation agency:

Minnesota C Minnesota Organization on Fetal Alcohol Syndrome, a nonprofit member of the National Organization on FAS with years of experience in FAS prevention

Montana C Montana Department of Public Health and Human Services, the agency charged with programs and services safeguarding the health and welfare of Montanans

North Dakota C Fetal Alcohol Syndrome Center, School of Medicine, University of North Dakota, the lead agency for prevention and treatment services for people affected by prenatal alcohol exposure

South Dakota C Center for Disabilities, School of Medicine, University of South Dakota, a leader in using partnerships to provide services within the State and to assist people with disabilities to lead better lives. It has led FAS prevention, intervention, and treatment efforts and serves as the fiscal and administrative agent for the cooperative agreement.

First Year Budget: $2,652,000

INTERVENTION ACTIVITIES

The Consortium activities to prevent FAS are divided into three basic categories:

! Development and evaluation of the formation of a Four-State Consortium on the prevention of FAS/FAE—The Consortium will utilize process and outcome measures to determine the effectiveness of working as a consortium to decrease the prevalence of FAS/FAE across the four States. This will be accomplished through the following activities:

- C Establish Consortium Advisory Council, Steering Committee, and State Advisory Committees to advise and guide the Consortium
- C Collect information on successes and barriers encountered through the use of Significant Event Tracking Forms
- C Complete interviews and satisfaction surveys with participants to gather antidotal information

- Data Collection Improvement Efforts—The Consortium will improve data collection by systematizing information gathered concerning the prevalence of FAS and FAE to determine high-risk areas and populations. Activities that will assist the Consortium to meet this objective include:

  - Increase and systemize data collection to create information for planning and conducting prevention, diagnosis, and service efforts
  - Increase the number of women identified as high risk for pregnancies that result in births of individuals with FAS
  - Collect information on common elements across the four States through the use of common instruments
  - Complete chart reviews to assess standard characteristics in persons who potentially may have FAS

- Prevention Efforts—The Consortium will implement and test a science-based intervention model for women considered high risk to abuse alcohol during their childbearing years. Activities that support this objective include:

  - Development and implementation of a structured home visitation/extended case management program
  - An individualized risk reduction intervention design based on a logic model in conjunction with the home visitation program
  - Utilization of local community resources and supports facilitated by a support specialist assigned to women considered high risk to abuse alcohol
  - Specific prevention interventions designed to be culturally appropriate
  - Curriculum based on motivational interviewing theory and techniques used to maximize domain factors in logic model.

EVALUATION ACTIVITIES

One major evaluation activity is to document and describe the partnership dynamics of the Consortium, which researchers hope may one day serve as a national model. The evaluation design will describe patterns of interaction, barriers to cooperation, attitudes about the Consortium, levels of agreement on important topics, joint projects, and accomplishments of the Consortium. The inter-relationships between the Four-State Consortium Advisory Council and the advisory committees from each State also will be examined.

The assessment of the intervention activities will utilize a wide range of evaluation designs. One method will include an evaluation of the effectiveness of an extended case management model with high-risk women that is scientifically based and culturally appropriate versus a comparison group.

The Consortium also is collecting and evaluating information that currently does not exist in one central location, or at all. It is analyzing data through specific interventions that use a variety of measurement and analysis tools. Two common instruments will be used across the Consortium: FAS Data Entry Form and the Prenatal Questionnaire.

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Rural Prevention of Fetal Alcohol Syndrome and Fetal Alcohol Effects

Bluegrass Prevention Center
Bluegrass Regional Mental Health-Mental Retardation Board, Inc.
Lexington, KY

Grant #9403

OVERVIEW

The Bluegrass Prevention Center is evaluating the effectiveness of a multi-component fetal alcohol syndrome (FAS)/fetal alcohol effects (FAE) prevention approach in rural communities in 13 central Kentucky counties. The 3-year study will test a multi-component strategy focusing on health care provider interventions with pregnant women, an awareness campaign, and training on diagnosis and early intervention through family care practices and early childhood service providers.

BACKGROUND

According to a small survey in rural Kentucky conducted by the Bluegrass Prevention Center, only 15 percent of men and women respondents correctly answered that no amount of alcohol is safe to drink while pregnant. A majority of respondents believed that Alow birth weight@ was the most common effect of drinking during pregnancy rather than the correct response, Apermanent brain damage.@ Some women respondents believed Alow birth weight@ meant an Aeasy birth," an understanding that health professionals believe may actually promote alcohol use during pregnancy with the hope of an easy delivery.

In addition, Kentucky has the highest infant mortality rate due to birth defects of any State in the Nation. Further, birth defects are the leading cause of years of potential life lost in the State, and contribute significantly to childhood morbidity and long-term disability.

MISSION

To reduce FAS/FAE births by educating county health department staff who deal with pregnant women; developing a community awareness campaign; and providing training to pediatric, foster care, and early childhood service workers on diagnosis and early intervention.

KEY STAKEHOLDERS

The key stakeholders of the project include national advocacy organizations, State health agencies, education boards, medical centers, and FAS organizations. Stakeholders include:

ARC, a national organization for people with mental retardation and other developmental disabilities and their families
National Organization on Fetal Alcohol Syndrome
FAS Community Resource Center
Health Departments in 13 rural Kentucky counties
Head Start programs in 13 rural Kentucky counties Community-Based Services (foster care) programs in 13 rural Kentucky counties
Perinatal Recovery, Infant Development and Education Program
KY F.A.S.
Family Resource/Youth Service Centers in 13 rural Kentucky counties
Lexington March of Dimes
Lincoln County Board of Education
Madison County Community Partnership
Kentucky Volunteers of America
Community newspapers
Several family medical practices

GOVERNANCE

The project is governed by the Bluegrass Regional Mental Health-Mental Retardation Board, which originally was established in 1966 to provide an avenue for de-institutionalization of State psychiatric patients. It now is considered one of the largest nonprofit community mental health centers in the country. In 1975, Bluegrass added substance abuse prevention and intervention services and now employs more than 1,200 staff in 17 counties. Its prevention centers provide programs based on sound research and current effective practices using competent, certified personnel.

First Year Budget: $436,874

INTERVENTION ACTIVITIES

The Bluegrass Prevention Center is implementing a multi-component, community-based prevention effort, within which are three intervention components:

- Health Care Provider Interventions—County health departments in Central Kentucky average 30 new pregnant patients per month. The first component of the project is to increase health care providers= communication with pregnant women about FAS/FAE. Research has shown that during pregnancy, women can be highly motivated to stop drinking for the sake of their unborn children, especially through health provider efforts. Research also has shown that health care providers often are uncomfortable discussing alcohol-related problems with their patients, and report a need for additional training to screen and manage these cases.

  This component includes extensive training for health care provider on screening tools and how to discuss substance abuse issues with patients. It also includes an onsite case manager to provide one-on-one counseling, referral, and advocacy; screening and discussion of FAS risks led by nurse, midwife, or physician at the first prenatal care visit; and 25-minute one-on-one sessions specific to FAS/FAE, tobacco, and other drug use, led by the case manager during the second or third prenatal visit.

- Community Awareness Campaign—The second component will entail several activities including a community assessment survey conducted across all study groups. The survey will measure existing knowledge, attitudes, and misperceptions about substance use during pregnancy. In addition, it will ask about awareness of local resources for treatment and counseling, and FAS in general. The 2-year campaign will focus on the risks and dangers of substance use during pregnancy, local resources for treatment and counseling, and general information about FAS/FAE.

- Diagnosis and Early Intervention—To strengthen the community's ability to identify FAS/FAE children, the third component is skill-based training that focuses on diagnosis and early intervention through pediatric staff, foster care case workers, and early childhood service providers such as Head Start and the First Steps early intervention programs. Pediatricians will be trained in screening and diagnosis, and early childhood service providers will be trained in identification, referral, and intervention for children with FAS/FAE and their families.

EVALUATION ACTIVITIES

The project is evaluating the effects of the multi-component approach on each single activity and the community. All three interventions are being implemented in several counties designated as County Group A. Each of the other interventions is implemented separately in a county group with a similar population (County Groups B, C, and D). These county groups will demonstrate the effectiveness of each single strategy in a rural community. A fifth county group will not implement any activity and will serve as a control (County Group E).

Researchers will analyze outcomes by the intervention(s) taking place in the community. This will enable them to determine the extent of the Aripple@ effect of each intervention. They expect that the effectiveness of the multi-component approach will demonstrate better outcome evaluations in County Group A compared to those for each single-strategy county group. In addition, knowledge gained through the project will add to Abest practices@ of how to intervene through various human service providers. Researchers hope the study will answers such questions as, Awill a community awareness campaign cause pediatricians to feel more comfortable using FAS/FAE as a diagnosis?@

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Baby First Partnership Project

Governor's Institute on Alcohol and Substance Abuse, Inc.
Research Triangle Park, NC

Grant #9375

OVERVIEW

The Baby First Partnership Project is evaluating two alcohol abuse interventions in Wake County, North Carolina to prevent the birth of children with fetal alcohol syndrome/fetal alcohol effects (FAS/FAE). The 3-year study will implement and test interventions that educate health care providers about FAS screening and assist in preventing women who are at risk for using alcohol during pregnancy from giving birth to infants with FAS/FAE.

BACKGROUND

The North Carolina Birth Defects Monitoring Program reports that no more than five FAS babies per year have been registered over the last 5 years. However, using a conservative estimate of 1 FAS child per 1,000 births, there should be 107 FAS babies born in the State each year. In the Triangle area alone, it has been estimated that 36 babies with FAS per 17,774 live births are born per year in seven hospitals. State Medicaid data show that a total of 87 patients under the age of 21 were diagnosed with FAS in 1998 and 70 patients in 1999. Thus, the syndrome is clearly under-recognized.

MISSION

To improve health care services to women at risk of delivering babies with FAS, to provide support and mentoring services, and to educate health care providers about prevention and screening for women at risk.

KEY STAKEHOLDERS

The Baby First Partnership Project works closely with the Health Department within Wake County Human Services, which includes the State-recognized Step by Step Partnership to Prevent Perinatal Substance Abuse (SBS). The Department provides substance abuse screening, diagnosis, and outpatient treatment for pregnant and postpartum women. An estimated 2,000 women are screened there for alcohol and other drugs each year, and about 10 percent are referred to the SBS program. Moreover, the majority of women enrolled in the SBS program are referred because they or their babies tested positive on an alcohol screening test.

Healthy Mothers, Healthy Babies Coalition of Wake County's (HMHB) mission is to improve the health and well-being of families and to reduce infant mortality and morbidity through partnerships, capacity building, awareness-raising, and service accessibility. The prevention of tobacco, alcohol, and other drug use/abuse are programming priorities. Sixty percent of their initiatives are focused at the community level, and 40% of services are provided directly to families. The Coalition collaborates with the Baby First Partnership Project and the SBS program to prevent alcohol use during pregnancy by educating health care providers in Wake County about prevention and FAS/FAE screening.

The North Carolina Fetal Alcohol Council, charged with educating the public and policymakers about FAS, serves as an advisory board to the project and provides expertise on the effects of the condition on children, families, and society.

Other stakeholders include:

Auger Communications
CARElina Medical Associates, Wake Area Health Education Center
Duke Child Development Unit, Duke University Medical Center
Substance Abuse Services Section, Division of Mental Health, Developmental Disabilities and Substance Abuse Services, North Carolina Department of Health and Human Services
Innovation Research & Training, Inc.

GOVERNANCE

The project is governed by the Governor's Institute on Alcohol and Substance Abuse, a nonprofit organization dedicated to promoting the well-being of all North Carolina citizens by improved education, research, and communication about substance abuse among health care professionals and their communities. Since its establishment in 1991, the Institute has worked to bring together diverse stakeholders to implement programs to improve the quality and effectiveness of substance abuse prevention and treatment throughout the State.

First Year Budget: $495,685

INTERVENTION ACTIVITIES

The Baby First Partnership Project is implementing two health interventions: one targeting health care providers, the other reaching out to women at risk for having babies with FAS. These interventions are conducted through a collaboration of community-based agencies, educational organizations, health care staff, and human service providers within Wake County.

- Health Care Providers Intervention—The first activity is to implement a program educating health care providers (HCPs), including primary care physicians and their staff, about prevention and screening for FAS. The project provides HCPs with a screening tool to be administered to all women of childbearing age to determine their risk. The project also provides educational brochures to be distributed to their clients with information on community treatment, support services, and resources.

- Prevention Advocacy Program—The second activity is to implement an advocacy program for participating women in the SBS program. The advocacy program will be modeled on the 10-year-old, science-based paraprofessional advocacy intervention program at the Fetal Alcohol and Drug Unit at the University of Washington, known as the Parent-Child Assistance Program. It is a complex prevention intervention utilizing paraprofessional staff, who provide guidance and services to women at risk.

  Women paraprofessionals with similar backgrounds and experiences as the clients in the SBS program receive intensive training so they can provide support and mentoring services. The paraprofessionals are then assigned to clients to assist them in identifying and obtaining appropriate services and resources.

EVALUATION ACTIVITIES

Both interventions in the study use random assignment, and researchers will develop a program manual containing all elements necessary for replication. For the health care professional component, researchers are determining the effectiveness of the training, such as whether health care professionals educate patients about FAS, use the screening form, and refer more women at risk for using alcohol during pregnancy to the SBS program.

For the advocacy intervention, researchers are documenting the number and types of services provided to the participating women and determining the effectiveness of the program and its component services in decreasing drinking behaviors during pregnancy.

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Beyond the 7th Generation: A Native American Fetal Alcohol Syndrome/Alcohol-Related Birth Defects Prevention/Intervention Project

American Indian Institute
University of Oklahoma
Norman, OK

Grant # 9401

OVERVIEW

The American Indian Institute at the University of Oklahoma is evaluating the effectiveness of the *7th Generation FAS/FAE Prevention Curriculum* on American Indian youth in several school systems, faith-based organizations, and youth clubs. The three-year study will implement and test the curriculum with 1,500 youths in grades 6 through 12 to determine its effectiveness in preventing, delaying, or reducing problems associated with substance use.

BACKGROUND

Oklahoma has the second highest Native American population in the United States, after California. According to the American Indian Institute, alcohol use by Native Americans affects as much as 50 percent of the population of some reservations. Moreover, Oklahoma is ranked 14th in infant mortality in the country; the State's infant death rate for Native Americans is 6.4 per 1,000 births.

The prevalence of FAS is six times the national average in certain Native American communities; it is five times greater among Native Americans than for African Americans, 100 times greater than for Asians, 35 times greater than for Hispanics, and 33 times greater than for Whites.

MISSION

To implement and test the scientifically developed curriculum, *7th Generation FAS/FAE Prevention Curriculum*, with 1,500 youths in grades 6 through 12 to reduce the likelihood of behaviors that will lead to women giving birth to babies with FAS.

KEY STAKEHOLDERS

The Community Advisory Board, which includes tribal elders, social services professionals, parents, paraprofessionals, and youth, oversees the project. Other stakeholders include:

Oklahoma State Department of Health
Oklahoma Department of Mental Health and Substance Abuse Services
Oklahoma State Department of Health and Human Services
Absentee Shawnee Tribe of Oklahoma
Cherokee Nation
Potawatomi Nation
Sac & Fox Nation
Tecumseh Public Schools
Kansas Public Schools
Leach Public School
Kenwood Public School
Cornerstone Indian Baptist Church
Indian Falls Creek Baptist Assembly
First Indian Baptist Church

GOVERNANCE

The project is governed by the American Indian Institute, College of Continuing Education, University of Oklahoma established in 1951 as a nonprofit Indian service, training, and research organization. The Institute serves American Indian and First Nation communities throughout the United States and Canada by supporting and promoting education, research, health care initiatives, economic development, and political action.

First Year Budget: $497,325

INTERVENTION ACTIVITIES

The project is implemented in classrooms, lunchrooms, and after-school settings such as local youth clubs and faith-based church retreats. This allows for researchers to collect preliminary information as well as follow-up information for comparison. The project's goals are:

- To determine how effective the program is in preventing, delaying, or reducing substance use, particularly alcohol, in the participant group as compared to a control/comparison group in local community settings; and
- To determine how effective the project model is in preventing, delaying, or reducing problems associated with substance use (cognitive, emotional, social, and physical) in the participant group as compared to a control/comparison group in local community settings.

The middle and high school students are predominantly of Native American ethnic heritage, including Cherokee, Potawatomi, Sac & Fox, Absentee Shawnee, and Kickapoo, among others. They live in and around Shawnee and Tecumseh communities in Pottawatomie County, and Kansas, Twin Oaks, and Salina communities in Delaware County, Oklahoma.

Also included are Native American youth representing the 37 Federally recognized tribes in the State and others from tribes throughout the country who attend an annual one-week faith-based retreat at Falls Creek, near Davis in Murray County. Most of these youth are from economically disadvantaged families, are at a high risk of alcohol and other substance abuse, and/or already have been affected by the negative effects of substance abuse.

The curriculum, developed under a previous Center for Substance Abuse Prevention grant in focus groups with input from students and children representing more than 100 tribes, includes videos, interactive lessons, and presentation materials.

The project's title comes in part from the Great Law of the Iroquois: In our every deliberation, we must consider the impact of our decisions on the next seven generations. Native American tradition tells of a time seven generations after the arrival of the Europeans in North America when Native people will have to defend Mother Earth and fight for the future of the creation. Some Native Americans believe that this generation is being born now.

Before receiving the project's curriculum, each of the sixth graders in the study are surveyed, including use of the American Drug and Alcohol Survey, a 20-year-old measurement tool used extensively with Native American and Anglo-American students. These students will be surveyed again in the seventh and eighth grades and will be compared to students who did not receive the curriculum, but also were surveyed. All middle school students will be surveyed to establish whether there are overall changes in the broader social environment.

Sixth graders in the intervention group receive 19 lessons, twice a week in their regular health classes or during lunch hour. High school students will receive instruction in the FAS curriculum twice a week for 4 weeks after school. The church and youth clubs receive instruction on the same schedule.

EVALUATION ACTIVITIES

The evaluation of the project combines qualitative and quantitative methodology to evaluate implementation, compare outcomes, and determine the cost-effectiveness of each venue of implementation. The project uses what is known as a multiple time series design, which means there are multiple measurements of multiple groups before and after the introduction of the intervention.

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Fetal Alcohol Syndrome/Alcohol-Related Birth Defects Prevention: Research to Practice

Fetal Alcohol and Drug Unit
School of Medicine
University of Washington
Seattle, WA

Grant #9423

OVERVIEW

The Fetal Alcohol and Drug Unit at the University of Washington is evaluating a successful substance abuse prevention and intervention program for women at risk for giving birth to infants with fetal alcohol syndrome (FAS) and associated disorders. The 3-year study will use multiple measures to evaluate the program in new settings, including women's use of substance abuse treatment, their reduction in alcohol and drug use, improvements in the access and usage of community services, their use of family planning, and the appropriate placement of exposed children.

BACKGROUND

Researchers at the Fetal Alcohol and Drug Unit already have developed and scientifically tested a substance abuse intervention known as the "Parent-Child Assistance Program (P-CAP)," a paraprofessional advocacy program developed to intervene with women at risk to abuse alcohol and drugs during pregnancy.

This intervention was developed in the early 1990s as the "Birth to 3 Project" under a 4-year CSAP demonstration grant. Intervention activities are conducted by paraprofessional advocates who each work with a caseload of 15 families. Advocates receive initial and ongoing training, and are clinically supervised by a master's level professional in social work, mental health, or chemical dependency treatment. The model uses a case management approach to help mothers reduce the spectrum of risk behaviors associated with substance abuse, and to increase protective factors to enhance the health and social well-being of the mothers and their children. The project received ongoing funding through the State legislature and expanded to four sites in Washington under the new name, Parent-Child Assistance Program. P-CAP has been replicated in the United States at three sites in Minnesota, one site in Ohio, and one in Alaska, and in Canada at two sites in Manitoba and four in Alberta.

The current project focuses on at-risk populations in the Seattle urban area of King County and in the more rural area of Pierce County. Recent data indicate that King County had the greatest number of substance-abusing women giving birth in 1995 (838 women), and Pierce County ranked second in the State (256 women).

MISSION

To enable communities to respond, through long-term advocacy, to the problems of mothers who have abused alcohol and drugs during pregnancy, and to the needs of their children.

KEY STAKEHOLDERS

The project is supported by the Department of Psychiatry and Behavioral Sciences at the University of Washington School of Medicine, and the Tacoma General Hospital. Other stakeholders include:

State of Washington Department of Social and Health Services
Washington State Division of Alcohol and Substance Abuse
Division of Neonatology, Department of Pediatrics, University of Washington Medical Center
Department of Obstetrics and Gynecology, University of Washington Medical Center
FAS Diagnostic and Prevention Network
FAS Interagency Work Group
University of Washington High Risk Infant Follow-up Clinic
Indian Health Service
March of Dimes
FAS Family Resources Institute
Community clinics, treatment centers, and health care providers throughout King and Pierce Counties

GOVERNANCE

The project is governed by the University of Washington School of Medicine. The Fetal Alcohol and Drug Unit has conducted research and clinical interventions with people with substance abuse problems and their families since 1973. Their multidisciplinary research team has published more than 250 papers in peer-reviewed journals on the scientific and clinical aspects of FAS and its associated disorders.

First Year Budget: $1,490,569

INTERVENTION ACTIVITIES

The project focuses on the women at the very highest risk for delivering children with FAS and associated disorders in Washington State, and those who have received little or no prenatal care and who are not connected to community resources. The primary issues are drug and alcohol treatment, family planning, child safety and stability, and the prevention of future alcohol or drug exposed children. The project is field-testing the original P-CAP model with three modifications:

1. Enrolling a more specific sample of mothers who primarily abuse alcohol during pregnancy;
2. Testing a more intensive and focused intervention for a shorter period of time; and
3. Testing the effectiveness of the intervention in a more rural community with a high prevalence of American Indians.

Half of the participants are Seattle (King County) urban residents, and half are residents of Pierce County, including residents of the Muckleshoot and Puyallup Reservations. The project identifies 120 eligible postpartum mothers delivering at two hospitals, and enrolls them while still hospitalized into one of two treatment groups: the adapted 12-month P-CAP intervention (P-CAP12) or the community standard of care (CSC).

Participants are identified and enrolled in the course of a postpartum hospital prevalence study of alcohol/drug use during pregnancy. The Fetal Alcohol and Drug Unit uses a proven one-page screening tool that was developed and tested on the postpartum floors at several urban hospitals.

The project assumes that future alcohol-affected births can be prevented in two ways: by motivating women to abstain from alcohol during their next pregnancy, and educating and encouraging alcohol-abusing women to use reliable birth control methods on a regular basis.

EVALUATION ACTIVITIES

Women will be assessed with a variety of data collection instruments three times over the course of the project: at enrollment after delivery, at the conclusion of the intervention at 12 months, and at follow-up 6 months later. The women will be randomized into either of the two study groups, which should yield comparable results with respect to age, use of street drugs, prescription drug use, and other variables measured at enrollment. Research questions include which intervention is more effective in reducing levels of alcohol and drug abuse and preventing further abuse.

After 12 months of P-CAP12 intervention or CSC, the project will evaluate the utilization of substance abuse treatment, the reduction in maternal alcohol and drug use, and maternal use of effective family planning methods. It will also measure the improved access and successful utilization of appropriate community services for both the mother and her child. Researchers expect the project will maximize primary prevention efforts by targeting limited resources to women at the highest risk of producing children with FAS and associated disorders.

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