

## ICCFASD 1996-2000 Annual Report and 2001-2005 Strategic Plan

### PROGRESS REPORT AND FIVE-YEAR STRATEGIC PLAN

In response to requests from the House and Senate Appropriations Committees in the reports accompanying the fiscal year (FY) 2001 budget for the Department of Health and Human Services, the National Institutes of Health (NIH) has prepared this progress report on the Interagency Coordinating Committee on Fetal Alcohol Syndrome.

#### **The Senate language stated:**

*The Committee commends NIAAA for its sponsorship of fetal alcohol syndrome (FAS) research and prevention activities. The Committee recognizes that collaborations between many agencies and organizations are needed to address the multiple issues central to FAS. The Committee is pleased with the membership of the collaborative Interagency Coordinating Committee on Fetal Alcohol Syndrome (ICCFAS) and with the progress of the ICCFAS. The Committee requests that the NIAAA, because of its leadership role in the ICCFAS, be prepared to present an update on the progress of the ICCFAS at next year's hearings.*

As coordinator of the ICCFAS, the NIH National Institute on Alcohol Abuse and Alcoholism (NIAAA) has the responsibility for preparing the report collaboratively with the representatives of member Federal organizations, agencies, and institutes. NIAAA asked each representative to contribute a statement of accomplishments since the last report, current activities, future plans, and efforts to develop projects in partnership with others. This information is compiled and presented in the following report.

The report describes the development of the ICCFAS and provides information on the FAS-related activities of member organizations within six priority areas. It also reports on working group meetings, workshops, and conferences sponsored by the ICCFAS. The purpose of these and future meetings is to develop a common terminology among member organizations, to promote an understanding of the research and service issues and needs that will form the basis of future collaborative efforts, and to exchange the results of programs and projects with members of the academic, health care, education, and justice communities. In addition, the ICCFAS Web site features an overview of the ICCFAS membership, goals and objectives, and important workshops and conferences. The Web site address is <http://www.niaaa.nih.gov/alcohol-health/fetal-alcohol-exposure>.

### **BACKGROUND**

Fetal alcohol syndrome is the "leading cause of preventable birth defects in the United States" (IOM, 1996, p. 7). FAS is caused by maternal alcohol use during pregnancy and is manifested in neurological and motor deficits, mental retardation, learning disabilities, and craniofacial malformations, among other signs and symptoms.

The first clinical description of FAS appeared 25 years ago. Since then, resources at every level of government have been devoted to improving the health care community's understanding of the etiology, diagnosis, treatment, and prevention of FAS. Although these efforts have produced some positive results, FAS remains a substantial public health problem that potentially can be reduced and eliminated.

### **The Incidence and Prevalence of FAS**

Estimates of the prevalence of FAS vary depending on the methodology used. Published estimates vary from 0.67 per 1,000 live births (CDC, 1995) to 1 per 1,000 (Abel, 1995). The Institute of Medicine (IOM) estimates that the prevalence of FAS ranges from 0.6 to 3 cases per 1,000 births, noting that some communities have higher rates than others (IOM, 1996). The prevalence of alcohol-related birth defects (ARBD) and alcohol-related neurobehavioral disorders (ARND) is expected to be significantly greater than the prevalence of FAS. A recent reanalysis of data from an NIAAA-supported study on alcohol and pregnancy in Seattle, Washington, estimated a threefold higher incidence of ARND than FAS, with ARND at 9 cases per 1,000 births.

### **Fetal Alcohol Syndrome as a Public Health Issue**

The economic costs of FAS have been estimated at slightly over \$4 billion for 1998, including both health care costs (\$2.8 billion) and productivity losses (\$1.3 billion) attributable to FAS. Of the \$2.8 billion in estimated health care costs of FAS in 1998, more than 90 percent was accounted for by the costs of providing home and residential care to adults with moderate to severe mental retardation associated with FAS and by the costs of special education for children and adolescents with the range of mental impairments that are associated with FAS. The remaining health care costs were associated with various medical procedures used to treat specific birth defects that are associated with FAS. The estimated value of lost productivity associated with FAS is based on estimates that 52.5 percent of FAS survivors suffer minimal brain dysfunction, 37.5 percent have mild mental retardation, and 2.5 percent have severe mental retardation. On the basis of these estimates, productivity losses suffered by adults with FAS were estimated at \$1.3 billion. (Estimates for 1998 are projections reported by Harwood, 2000. The projections were based on estimates, analyses, and data reported in Harwood et al., 1998.)

Many costs devoted to meeting the needs of children and adults with FAS are not easily identified because (1) the Federal programs that support FAS research and services are administered under the auspices of several departments of the Federal Government and (2) children with FAS often are not distinguished from other program recipients.

### **Creation and Structure of the ICCFAS**

The challenge facing the ICCFAS is to improve communication and cooperation among disciplines that address health, education, developmental disability, alcohol research, and social service issues relevant to FAS and related disorders. The ICCFAS was created in October 1996 in response to a report by an expert committee of the IOM and a subsequent report and

recommendation requested by NIAAA. The IOM report, issued in 1996, is titled Fetal Alcohol Syndrome: Diagnosis, Epidemiology, Prevention, and Treatment.

The report recommended that NIAAA chair a Federal effort to coordinate FAS activities since the responsibility for addressing the many issues relevant to FAS transcends the mission and resources of any single agency or program. The ICCFAS, which is chaired by the Deputy Director of NIAAA and convened and administered by its Office of Collaborative Research, now coordinates a national effort addressing FAS, ARBD, and ARND.

Current membership of the ICCFAS includes representatives from the following agencies:

#### Department of Health and Human Services (DHHS)

- Agency for Healthcare Research and Quality (AHRQ)
- Centers for Disease Control and Prevention (CDC)
- Health Resources and Services Administration (HRSA)
- Indian Health Service (IHS)
- National Institutes of Health (NIH)
  - National Institute on Alcohol Abuse and Alcoholism (NIAAA)
  - National Institute of Child Health and Human Development (NICHD)
- Substance Abuse and Mental Health Services Administration (SAMHSA)

#### Department of Education (ED)

- Office of Special Education and Rehabilitative Services (OSERS)

#### Department of Justice (DOJ)

- Office of Juvenile Justice and Delinquency Prevention (OJJDP)

Other Federal agencies and NIH institutes are invited to participate in working groups and to cosponsor activities of the ICCFAS. Representatives from the National Organization on Fetal Alcohol Syndrome (NOFAS), the FAS Family Resource Institute, the American Indian Rehabilitation Research and Training Center, and FAS organizations at the State level regularly attend meetings.

In its inaugural meeting in 1996, the ICCFAS decided that the first order of business was to develop an understanding of FAS-related programs and services within the Department of Health and Human Services. This approach not only revealed areas of overlap and needs within programs of the Department, but also provided opportunities for the Committee's member organizations to develop collaborations. With this foundation in place, the ICCFAS expanded its membership to include the Departments of Education and Justice, clients of which include children with FAS. Each member organization contributes its perspective on FAS and suggestions for improvements and partnerships. Between 1996 and 1999 each member organization sponsored a meeting during which staff and grantees or contractors presented accomplishments and plans. These meetings revealed resources available for collaboration and suggested areas of health research and services that need attention.

## ICCFAS Objectives

The objectives of the ICCFAS are to exchange information and to coordinate Federal strategies and programs in an effort to address FAS/ARND more effectively on a national level. The Committee will promote and facilitate the development of projects within member organizations and collaborative projects and cooperative programs between member agencies. Specifically, these projects will be designed to:

- Prevent at-risk drinking among all women of childbearing age.
- Disseminate effective techniques for screening and intervening with pregnant women.
- Enhance identification and improve the quality of intervention and treatment of women at risk for an alcohol-exposed pregnancy.
- Improve diagnosis of FAS and alcohol-related neurological disorders.
- Improve health care, education, and correctional interventions for affected children and adults with FAS and other prenatal alcohol-related disorders.
- Foster basic research to identify mechanisms of alcohol teratogenesis, leading to improved interventions and treatments.
- Improve communication among basic research, clinical research, education, and service-provider communities and educate communities and health care professionals.

From 1996 to 2000, the first 4 years after the establishment of the ICCFAS, the member organizations identified high-priority activities that were critical to the population served or to the expansion of their fetal alcohol-related programs. The areas of high priority for the first 4 years were information dissemination and outreach, prevention of drinking during pregnancy, intervening with children affected by prenatal alcohol exposure, improving diagnosis and case identification, and furthering the understanding of the etiology and pathogenesis of FAS and ARND. From 2001 to 2005 member agencies will greatly expand the scope of activities in each of these areas, and the Committee will continue to sponsor workshops and conferences to stimulate research and transfer information to the public and professional groups.

### Coordination with the Department of Education Working Group on FAS/ARND and the National Task Force on FAS/FAE

Among the new activities to be undertaken by the ICCFAS over the next few years will be coordinating with the Department of Education FAS/ARND working group and the congressionally mandated, newly established National Task Force on Fetal Alcohol Syndrome and Fetal Alcohol Effects (FAE). In 1999 ED expressed an interest in ensuring that education and childcare professionals develop a better understanding of FAS/ARND and that they are prepared to participate fully with others in addressing the issues. Thus, the Working Group on FAS/ARND was formed and is administered jointly by the Federal Interagency Coordinating Council (FICC) and the ICCFAS. It has assumed primary responsibility for developing a 1- to 2-year plan of action for intervention with children with FAS aged 0 to 8 years and their families. The working group comprises representatives from the ICCFAS agencies, the mental health field, educators, early childhood school psychologists, counselors, FAS research scientists, and parents of children with FAS/ARND. Other ICCFAS member agencies will continue to be very active in the area of programs for school-aged children. In addition to participating in the identification of methods for the early diagnosis of children with FAS/ARND, over the next 5

years the working group and other ICCFAS member agencies will focus their efforts on the following areas:

- Clarifying ethical and confidentiality issues involved in conducting screening and assessment in schools and other early intervention settings;
- Identifying and refining appropriate intervention strategies to serve children and families with FAS/ARND effectively in school settings and to prevent secondary disabilities; and
- Providing intensive, effective, and ongoing training and technical assistance to teachers and other professionals responsible for the care and education of children.

The National Task Force is administered by the Centers for Disease Control and Prevention and 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 National Task Force is also 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 interventions for children with FAS/FAE and their families. The National Task Force on FAS/FAE was chartered by the Secretary of DHHS as a Federal Advisory Committee and held its first meeting in December 2000.

Whereas the membership of the ICCFAS includes only representatives of Federal Government agencies and institutes, the National Task Force membership includes community researchers and clinicians and other interest group representatives. The chair of the ICCFAS is a mandated member of the National Task Force and will ensure coordination with ICCFAS activities.

### ICCFAS Progress In Developing Collaborative Programs

Since 1996 individual agencies have made substantial progress in expanding or adapting existing programs to address FAS/ARND. New initiatives have been developed by some agencies, and others have made progress by expanding the awareness of the professional groups and communities they serve. ICCFAS organizations have worked together to cosponsor projects, have participated in the development of plans, and have reviewed progress made on initiatives of member organizations. In some cases, complementary initiatives have been developed. In other instances, the programs of a member organization that have the potential to address issues related to FAS are being used as a foundation for action. The following outlines the accomplishments of the ICCFAS and its member organizations and future plans and needs in six activity areas: Workshops and Conferences, Intervening with Children and Families Affected by Prenatal Alcohol Exposure, Improving Methods for Diagnosis and Case Identification, Increasing Research on Etiology and Pathogenesis, Information Dissemination, and Prevention of Drinking During Pregnancy. It is clear that the activities in each area are highly dependent on and overlap accomplishments and plans in other areas. For example, the Four-State Consortium and Alaska FAS Project supported by SAMHSA will have strong elements under both prevention of FAS and intervention with affected children. This is viewed as a strength in that it can facilitate the exchange of information and results among persons working on several different issues related to the overall objectives of the ICCFAS.

#### Workshops and Conferences

To develop a common understanding of the status of areas critical to addressing FAS, the ICCFAS has sponsored the following workshops and working group meetings since 1997. For most, reports have been developed and widely circulated. All have resulted in an increase in research and demonstration projects in the topic areas. Workshops have been well attended by research scientists and representatives from family support organizations, States, and advocacy groups. More than 25 academic institutions have been represented in the various meetings and workshops of the ICCFAS. Several ICCFAS organizations have issued requests for grant applications related to their mission following a conference.

### Accomplishments

- Alternative Perspectives on the State of the Art of Diagnosis of FAS, Alcohol-Related Neurological Disorders, and Alcohol-Related Birth Defects (April 7, 1997)
- Measuring Alcohol Consumption Among Pregnant and Childbearing-Age Women in Clinical Studies and Surveys (June 24, 1997)
- Prevention of Risk Drinking in Pregnancy (April 23-24, 1998; formal report available)
- Intervening With Children Affected by Prenatal Alcohol Exposure (September 10-11, 1998; report is available)
- Early Childhood Neurobehavioral Assessment for the Differential Diagnosis of Fetal Alcohol Syndrome and Alcohol-Related Neurological Disorders (March 8-10, 2000; report available)

### Future Plans and Needs

Having sponsored five introductory workshops examining the state of the art of diagnosis of FAS and ARBD, prevention of risk drinking during pregnancy, and intervention with children affected by prenatal alcohol exposure, by FY 2005 the ICCFAS will host workshops to share research findings and to facilitate the practical application of the latest research findings. Three of those planned workshops have the following themes:

- School-Based Interventions for Children Affected by Prenatal Alcohol Exposure
- Effective Treatment Strategies for Alcohol-Abusing and High-Risk Women of Childbearing Age
- Progress on Strategies to Prevent At-Risk Drinking in Women of Childbearing Age

### Intervening with Children and Families Affected by Prenatal Alcohol Exposure

Developmental problems in children exposed to maternal alcohol use are often not acknowledged except in the most extreme cases. It follows that the many affected individuals who are not correctly diagnosed do not receive appropriate interventions and treatment for their alcohol-related disabilities. For those children who are correctly diagnosed, there is a need for targeted efforts directed at secondary disabilities to prevent some of the more negative outcomes reported to be associated with FAS.

Research has demonstrated that among groups of high-risk children, adequate education and training, together with protection from negative child-rearing environments and attention to predictable crises at various developmental stages, can make the difference between achieving a reasonable degree of independence and life satisfaction and a lifetime of severe disability. Given the complexity of the challenges confronting alcohol-affected children and their families, there is

a critical need for a well-organized strategy to improve early case identification and interventions to mitigate the effects of prenatal alcohol exposure. The ICCFAS has identified several key gaps in the scientific knowledge base and in the existing service delivery system that must be addressed within the context of such a strategy.

## Accomplishments

- A monograph of the proceedings and presentations of the ICCFAS Special Focus Session titled "Intervening With Children Affected by Prenatal Alcohol Exposure" was developed. This is one of the most extensive collections of presentations specifically addressing the topic of intervening with children affected by in utero alcohol exposure. Topics of scientific papers range from pharmacotherapy in children with FAS to social skills and motor skills training. This monograph was distributed widely to member agencies as well as to university research programs, parent groups, and professional medical associations.
- As indicated above, ED is chairing a collaborative working group jointly sponsored by the FICC and the ICCFAS and focused on educational interventions for children ages 0 to 8 with FAS and their families. The working group is in the process of developing an action plan that will result in the development and dissemination of national guidelines for identifying and intervening with children with FAS/FAE and their families in school settings.
- ED has funded two projects in Alaska for training special educators and related service personnel to serve children with disabilities. One project will provide master's level preparation to students to serve infants and toddlers with autism, FAS, and severe disabilities and their families in rural Alaska. The other project will recruit and train rural underrepresented Alaska Natives to provide effective early childhood services and local rural leadership in policy and programming decisions in early childhood systems. Coursework will include study in autism, FAS, and speech and language delays.
- Supported by OJJDP, the Consortium on Children, Families, and the Law is conducting research and convening a study group on the topic of children with disabilities, including FAS, in the juvenile justice system. This project will explore (1) the characteristics of education programs most likely to be effective for these youth; (2) identification of current programs with these characteristics; (3) models for community-based systems that can successfully reintegrate youth with disabilities with their families, schools, and communities after their release from juvenile justice facilities; and (4) ways in which these education programs and community-based systems can be enhanced to maximize delinquency prevention.
- OJJDP, in collaboration with ED's Office of Special Education and Rehabilitative Services, provided funding in FY 1999 to establish a Center for Students with Disabilities in the Juvenile Justice System. The Center, being implemented by the University of Maryland, will provide guidance and assistance to States, schools, justice programs, families, and communities with the design, implementation, and evaluation of comprehensive educational programs for students with disabilities (including FAS/FAE) who are in or at risk of entering the juvenile justice system.
- NIAAA is supporting research to characterize specific impairments in learning and memory, executive functioning, attention, motor control, visual spatial functioning, and psychosocial behavior and to identify anatomical correlates of these neurobehavioral deficits found in FAS, ARND, and ARBD. By understanding the areas of the brain that are affected and how these brain changes affect behavior, researchers can work more effectively to design means of intervention.
- NIAAA will continue to support pre-clinical studies that evaluate potential pharmacological agents for preventing FAS/ARND or treating the deficits in affected children. NIAAA will also

continue support of a project that is examining the effects of therapeutic motor training to improve brain function in an animal model of prenatal alcohol induced injury.

NICHHD is also spearheading an NIH-wide effort to evaluate the appropriate use of pharmacological compounds in children, relying on the Institute's Pediatric Pharmacology Research Units and similar efforts supported by other institutes. Pharmacological approaches in children have to be carefully considered, especially for those with organic brain deficits (such as children with FAS) that may cause unusual and idiosyncratic reactions to neuroactive compounds. Certain stimulants that have proven to be particularly useful for treating children with attentional and hyperactivity disorders are being evaluated for children exposed prenatally to alcohol.

- Effective intervention-whether behavioral, educational, or pharmacological-is greatly facilitated by early and accurate diagnosis. NICHHD supports a broad range of studies on children with developmental problems. Not surprisingly, the most effective approaches have proven to be those that are tailored to particular strengths and weaknesses of the affected child. Current research focuses on two issues that are particularly difficult for children with cognitive and behavioral deficits: generalization (the transfer of learning from the classroom to real-life situations) and attention problems. Behavioral researchers are developing strategies that are useful for parents, family, and teachers as well as for the affected individual. One promising approach uses computers to provide personalized instruction and training.
- Since OSERS and OJJDP have been working collaboratively to develop programs for students with disabilities in the juvenile justice system, a joint working group meeting featuring the projects of both organizations is being planned. OSERS data for 1997-1998 indicate that 17,279 students with disabilities were being served in correctional facilities (this is not the total involved in the justice system). Of that total, 45 percent are classified as having a learning disability and 42 percent as emotionally disturbed. Most children with FAS/ARND are unable to function adaptively in their communities, and their behavioral problems and failures in the educational system often lead them into the justice system.
- The SAMHSA initiative, "Coordinated Prevention Services to Children of Substance-Abusing Parents and Their Families," will determine the most effective prevention interventions for children of substance-abusing parents in order to enhance protective factors and reduce children's risk of becoming substance abusers and/or developing other problems. The target population for this project includes children with FAS or ARBD.
- Because of the dramatic impact of the early years of childhood on the rest of life, SAMHSA's "Starting Early, Starting Smart" grant program examines the effectiveness of integrating substance abuse and mental health services into primary care service settings (public and private health care programs) and into early childhood service settings (early learning programs, child care programs, preschools, etc.) for children ages 0 to 7 and their families. Early childhood research and reports from the field agree that these settings are in dire need of assistance in delivering these very specialized services, as staff and the young children and families they serve are experiencing increasing challenges. This initiative is a public-private partnership funded by SAMHSA's three Centers and The Casey Family Program, a private nonprofit operating foundation. In FY 2000 \$5.5 million in Federal funds supported applied research in 11 sites (child care, Head Start, or primary care clinics and a data coordinating center).
- SAMHSA supports the Women, Co-Occurring Disorders, and Violence Study. The primary goal of the program is to generate knowledge about the development of an integrated services

approach for women with co-occurring disorders and their children. This comprehensive approach serves to prevent the birth of alcohol and drug exposed infants and ensures that children with special needs (i.e., FAS/FAE) receive appropriate services.

- SAMHSA's Welfare Reform and Substance Abuse Prevention for Parenting Adolescents Program is designed to help determine whether the provision of comprehensive substance abuse prevention interventions directed at adolescent parents has positive outcomes in specific areas, including alcohol, tobacco, and drug use; academic performance; subsequent pregnancies; and parenting and life skills. The knowledge gained from this program will help prevent substance abuse in the target population and thereby help prevent FAS/FAE.
- CDC cosponsored a national conference on FAS titled "Getting to Standards of Care for Fetal Alcohol Syndrome: Defining Best Practices" in Atlanta, Georgia, in April 2001. The conference targeted health professionals, mental health and social service providers, educators, parents, and others. The aim of the conference was to raise awareness about FAS/FAE and promote development and implementation of effective interventions for individuals with FAS and their families.
- OJJDP's "Safe Start" demonstration initiative seeks to reduce the impact of family and community violence on young children from birth to age 6. (Violence in this context refers not only to domestic violence, but to abuse, neglect, maltreatment, and violent crime.) Goals include increasing access to quality prevention programs and improving identification, referral, and intervention for children and families in need of services, including those affected by FAS. Communities selected for grant awards under this initiative are charged with creating or enhancing comprehensive service delivery systems, incorporating service providers in the fields of early childhood education/development, primary health care, mental health, family support/strengthening, domestic violence, substance abuse prevention and treatment, crisis intervention, child welfare, and law enforcement.
- SAMHSA is funding the "The Comprehensive, Integrated Approach to Fetal Alcohol Syndrome: Prevention, Intervention, and Service Delivery for the State of Alaska" to support a comprehensive, integrated approach to eliminate or reduce FAS within Alaska. This 5-year demonstration program will provide Alaska with a clear understanding of the prevalence of FAS, data on the effects of the State's prevention efforts, and clear direction on how to improve prevention and treatment services. Specifically, the project seeks to determine the most effective, integrated prevention and treatment models to (1) prevent alcohol use and abuse by all women of childbearing age within Alaska; (2) prevent, delay, and/or reduce substance abuse in those individuals who have FAS/FAE; and (3) improve the quality of life for those individuals already affected by prenatal exposure to alcohol by minimizing secondary disabilities and maximizing their individual potential.

## Future Plans and Needs

To expand the range of high quality services available to children and families with FAS, ARND, and ARBD, the ICCFAS has formulated the following objectives for FY 2001-2005: (1) identify methods for the early screening and diagnosis of children with FAS/FAE; (2) investigate specific impairments associated with FAS, ARND, and ARBD, particularly impairments in attention, language, sensory integration, and other behavioral problems; (3) elucidate the role of the postnatal environment in modifying the effects of fetal alcohol exposure; (4) develop and disseminate clinical practice guidelines for intervening and following up with children and families affected by FAS, ARND, and ARBD; (5) identify program design and evaluation

enhancements and other strategies to improve access to high quality services; (6) evaluate the effectiveness of educational interventions on children with FAS, ARND, and ARBD; and (7) develop state-of-the-art professional training programs and other programs that will help bridge the gap from research to practice. To achieve these objectives the Committee has planned the following activities:

- ED and the ICCFAS to sponsor workshops for educational psychologists and other professionals to examine and recommend age specific and appropriate screening instruments for use in schools and other early intervention settings.
- NIAAA to continue supporting and seek to expand research to identify and correlate specific brain structures affected by ARND and the functional and neurobehavioral deficits found in affected children, with the aim of contributing to more effective interventions. The Institute will ensure that the observations and recommendations published in the conference report "Early Childhood Neurobehavioral Assessment for the Differential Diagnosis of FAS and ARND" lead to additional research on the differential diagnosis of FAS/ARND, which will inform the development of effective interventions in educational and early childcare settings.
- The ICCFAS and ED Working Group on FAS/ARND to identify or develop and disseminate practice guidelines for teachers and providers of early childcare services who work with fetal alcohol-exposed children.
- CDC to fund programs to develop, implement, and evaluate materials to educate parents and professionals working in public health service agencies, social service agencies, and schools about FAS and how to secure access to diagnostic and treatment services for affected children and their families.
- CDC to fund a collaborative research consortium for identifying, developing, and evaluating effective strategies for intervening with children and adolescents with FAS and ARND that can be integrated into existing public health service systems.
- OJJDP to sponsor research designed to study FAS and FAE as risk factors for delinquency. In its FY 2001 Proposed Comprehensive Plan, OJJDP proposes to support a study to assess the rate of FAS/FAE among youth within the juvenile justice system, determine what services are available, and develop screening and individualized case management and planning to better serve youth affected by FAS/FAE.
- Participating agencies to collaboratively develop educational materials on FAS/FAE that are accurate, accessible, and specialized for various groups or cultures, to include fathers, teen parents, and extended families.
- The ICCFAS to develop a guide to Federal resources and initiatives.
- ED Working Group on FAS/ARND to explore and address the ethical, legal, and confidentiality issues associated with FAS/ARND and to develop guidelines for communicating with parents about pertinent issues, especially stigma and denial issues.
- NICHD to continue and disseminate results from the National Longitudinal Study of Adolescent Health and other studies to facilitate the identification of new intervention strategies.
- SAMHSA to continue funding "Coordinated Prevention Services to Children of Substance-Abusing Parents and Their Families," which provides a bridge to services for families at greatest risk for FAS.
- SAMHSA to expand the "Starting Early, Starting Smart" grant program to include more elementary and middle schools (continuing a program expansion that began in FY 2000). The program examines the effectiveness of integrating substance abuse and mental health services into primary care service settings.

- The ICCFAS to provide updates on research evaluating potential pharmacological agents for the treatment of disabilities related to FAS/ARND.
- The ICCFAS to sponsor a workshop to provide an update on effective interventions for children with FAS/FAE, as well as sessions at national and regional professional meetings.

### Improving Methods for Diagnosis and Case Identification

Although a clear diagnosis of FAS or ARND greatly facilitates the management and treatment of developmental disorders, this does not occur for a significant number of children exposed to alcohol in utero. In the absence of maternal disclosure, the diagnosis is difficult due to the lack of a biological marker, nonspecific and often subtle symptomatology, differences in the severity and timing of the insult, individual differences in response and resiliency, and the overall complexity and plasticity of brain development. The diagnosis is further complicated by legal and privacy issues, as well as lack of awareness among some health care providers.

One of the problems inherent in diagnosing and screening children for FAS is that cases are identified primarily through referral from health care providers. This is believed to lead to marked underreporting. A second issue is that there are small numbers of same age children with FAS in any one city. This makes it difficult to characterize the neurobehavioral effects and deficits that result at specific age levels.

Because school systems benefit from the early identification of children with special education needs, NIAAA is developing and refining procedures for accurately screening large numbers of children within a primary school or health care setting for FAS. This will permit establishment of age specific cohorts of FAS cases for subsequent studies and for intervention and treatment trials.

Systems for national and State-based surveillance of FAS must continue to be refined and expanded to describe the scope of the problem and to track the impact of prevention efforts. CDC has conducted FAS surveillance activities since 1979 using hospital discharge data systems, and is currently engaged in developing multiple-source, State-based systems using computerized data entry and case designation. The goal of this program, the Fetal Alcohol Syndrome Surveillance Network (FASSNET), is to develop a model system that can be replicated in State health departments around the country.

### Accomplishments

- The ICCFAS convened a workshop that brought together the neurodevelopmental experts and neurobehavioral researchers studying the effects of a number of high-risk teratogenic agents to review the state of the art in age-specific assessment techniques as they might be applied to specific patterns of impairment. The National Institute of Neurological Disorders and Stroke, NIH, joined ICCFAS organizations in sponsoring this event. The primary focus was on the neurobehavioral assessment of children exposed prenatally to alcohol as the example teratogen. Although the distinctive FAS facial features and mental retardation that may be caused by heavy prenatal drinking have captured public attention, this workshop focused on the need to determine the neurobehavioral deficits that distinguish prenatal exposure from attention deficit/hyperactivity disorder, autism, lead exposure, and other disorders.

Characterizing the distinguishing neurological effects that might result from moderate drinking, in the absence of full-blown FAS or ARND, is of considerable interest, as this might lead to earlier and more effective interventions with infants and reduce the considerable estimated socioeconomic impact of the problem.

- To make rapid progress in developing cohorts of same-age children with FAS for future studies, multidisciplinary NIAAA teams that include clinicians and biomedical and behavioral research scientists from a number of academic institutions in the United States have been collaborating with South African and Russian colleagues. In one South African community two waves of screening revealed that the prevalence of FAS in first graders was 46 to 75 per 1,000, many times higher than that in the United States. Neurobehavioral studies of this cohort are resulting in informative data on the pattern of deficits at this age level. Studies of the social, physiological, and genetic maternal risk factors were also conducted. Some publications have resulted from this effort and others are in progress. The South Africa study, which is being performed in preparation for other active surveillance efforts in the United States, is supported by the NIH Office of Research on Minority Health and NIAAA. An Indian Health Service grantee worked with community representatives to design a prevention effort.

In Russia, data are being collected on groups of similar-age children with neurological deficits in orphanages and boarding schools. Neurobehavioral studies are in progress. Among the benefits of these studies is the development of collaborating teams of scientists and clinicians that can apply techniques and findings to populations in the United States. Dr. Ken Jones, who first outlined the diagnostic criteria for FAS in 1973, is a member of the diagnostic teams in both studies.

- NIAAA will continue to emphasize its research on fetal alcohol exposure and school-age cognitive function. Recent studies under this initiative have identified specific patterns of intellectual impairment in FAS patients, and efforts are being exerted to characterize more carefully the specific deficits associated with lower level prenatal exposure to alcohol, in particular those that are associated with ARND. In a recent 7½-year followup evaluation of 340 Detroit children recruited to overrepresent moderate-to-heavy prenatal alcohol exposure, the investigators have begun to identify a distinct "neurobehavioral profile" associated with this exposure. This profile differs from FAS in that IQ and verbal learning appear to be spared, but resembles FAS in that deficits in focused attention, arithmetic, and working memory are particularly prominent. Preliminary 7½-year followup data also indicate an alcohol-related increased incidence of clinically significant levels of childhood aggression and social problems, after controlling for confounders and current caregiver alcohol use. Because these effects are only partially the result of attention deficits, these data suggest that, in addition to its effects on attention, prenatal alcohol exposure may directly disrupt central nervous system pathways that underlie affective response and emotional regulation.

The investigators are now evaluating the children at age 12. They are further refining the distinctive pattern of alcohol-related attention deficits seen at 7½ years and examining the relation between prenatal alcohol and socioemotional function using a new test battery focusing on social judgment, social competence, and emotionality; a clinical assessment of psychopathology; and adolescent alcohol and drug use. They are further focusing on dose-response relations, threshold, pattern of pregnancy drinking associated with developmental deficit, and the importance of the observed deficits for the day-to-day function of the individual

child. The data to be generated from this study have the potential to help refine the diagnosis of ARND and to contribute to the design of interventions specifically targeted to alcohol-exposed children.

- To further evaluate the neurodevelopmental consequences of heavy, as distinguished from moderate, alcohol exposure in pregnancy, a parallel prospective study has been initiated in South Africa, where alcohol ingestion levels far exceed those typically seen in the United States. Given the high levels of alcohol use, active interventions for their drinking problems are undertaken with the women; however, despite this effort, many women continue to drink heavily. Neurodevelopmental findings in the children exposed to these high levels of alcohol should aid in further refining the knowledge base on the specific nature of the deficits and lead to the identification and application of more effective interventions.
- CDC will continue developing its collaborative FASSNET study with five State-based cooperative agreement recipients. The program is the largest FAS-focused, population-based case-finding and surveillance program in the United States. The 5-year project is in its third year of developing a model FAS surveillance system for State health departments. The methodology for the system has been established along with uniform case definitions, electronic data entry forms, and provider education materials. Abstraction of possible cases from a variety of existing data sources has been under way for approximately a year, with more than 1,000 records abstracted for identifying potential cases. Preliminary data analyses began in September 2000. A committee of grantees and internationally recognized dysmorphologists has worked to develop a surveillance case definition based on recommendations and the clinical criteria outlined in the IOM report. The surveillance case definition will improve reporting and provide a method for the consistent application of the case definition to monitor trends in the occurrence of FAS.
- IHS is a cosponsor with the University of Washington Fetal Alcohol and Drug Unit of four 3-day training sessions on FAS. The training is provided to American Indians and Alaska Natives or those working with American Indian and Alaska Native communities. Each of the four training sessions is designed to accommodate six trainees selected by IHS. The training is open to professionals (e.g., physicians, psychiatrists, psychologists, social workers, nurses, teachers, lawyers, judges) as well as advocates and parent activists. The 3-day curriculum includes (1) preventing and overcoming secondary disabilities in people with FAS across the life span; (2) preventing FAS with the birth to 3 advocacy model for working with very high-risk mothers and their families; and (3) demonstrations of a multidisciplinary FAS diagnostic clinic and its relevance for community interventions, parent advocacy, and prevention.
- Practitioners at all stages of the juvenile justice system, from arrest to aftercare, need information regarding appropriate, practical, and well-validated assessment instruments. In FY 2000 OJJDP funded a focus group to examine issues related to screening and assessment. This group, convened by the National GAINS Center for People with Co-Occurring Disorders in the Justice System and comprising both researchers and practitioners, is reviewing current literature on screening and assessment, identifying key clinical issues, examining current practices, and proposing model approaches.
- NICHD has also been collaborating with ED, the National Center for Health Statistics, and other agencies to develop health measures for the Early Childhood Longitudinal Study, Year 2000 Birth Cohort study (ECLS-B), a nationally representative sample of births to be followed beginning in year 2000. The ECLS-B study will ask recent mothers about alcohol consumption before, during, and after pregnancy, as well as drinking problems of parents. This information, paired with other characteristics of the mother and father, will make it possible to understand the consequences

of alcohol consumption on the health, development, and growth trajectories of children and help identify mediating effects.

- NIAAA grantees are collaborating with investigators in several sites in the United States to conduct a study of the prevalence of FAS among children. Trained school nurses will collect growth parameters of 3- to 7-year-old children, and all children meeting certain criteria will be selected for further physical examination and neuropsychological testing. Similar to the collaborative prevalence studies being conducted in South Africa, interviews will be administered to mothers of the identified children to gather information on demographics, environment, and frequency, volume, and patterns of alcohol consumption.

### Future Plans and Needs

In FY 2001-2005 the ICCFAS will focus its diagnosis and case-identification efforts on the following areas: (1) developing and refining procedures for accurately screening large numbers of children within a primary school or health care setting for FAS; (2) assessing the characteristics and clinical expression of FAS, ARND, and ARBD across the life span; and (3) identifying potential structural or functional brain abnormalities and how they may correlate with cognitive and behavioral features of FAS, ARBD, and ARND. To achieve these objectives the following activities are planned:

- NIAAA and CDC to continue studies in foreign countries involving large populations of children with FAS in preparation for other active surveillance efforts in the United States.
- CDC and NIAAA to collaborate on training health care providers at five CDC grantee sites to improve case-identification and referral. NIAAA is developing provider-training packets for three specific target groups, one of which is pediatricians. State-based surveillance systems will monitor trends in case-finding and referral, providing data for evaluation of the training program.
- NIAAA grantees to continue their collaboration with investigators and clinicians in cities in the United States to conduct a study of the prevalence of FAS among children. The neurobehavioral data from these studies and the information on demographics and habits from the maternal interviews will contribute to the future development of intervention and prevention programs.
- IHS to work with the NIAAA-supported FAS Epidemiology Research II Project in the Aberdeen IHS Area to assist in the followup care of the fetal alcohol-exposed children identified by the project.
- NIAAA to continue studies examining correlation of neurocognitive deficits found in FAS with specific neuroanatomic abnormalities as determined by noninvasive imaging techniques such as magnetic resonance imaging.

### Increasing Research on Etiology and Pathogenesis

Of all the substances of abuse, including heroin, cocaine, and marijuana, alcohol produces by far the most serious neurobehavioral effects in the fetus. Although many of the effects of prenatal exposure to alcohol have been well described, much remains to be learned about the mechanisms by which alcohol produces those effects. In addition to the need to identify the specific neurobiologic mechanisms by which alcohol acts on the developing fetus, there is a need for more research on the duration and dose of exposure required to cause adverse fetal outcomes, differences in individual vulnerability to prenatal exposure to alcohol, gestational age-related variability in fetal alcohol effects, and the range of deficits that may be caused by prenatal

alcohol exposure. Animal research on the effects of postnatal and postweaning experiences on developmental outcome will have particular relevance for the development of treatment strategies for children with FAS and other alcohol-related birth defects. It is expected that further investigation of the etiology and pathogenesis of alcohol-related developmental disorders will ultimately reveal methods to reverse or attenuate the effects of alcohol in utero.

## Accomplishments

- NIAAA funded 91 FAS-related grants in 1999, the majority of which focus on elucidating the mechanisms by which alcohol disrupts normal brain development and body growth and on identifying the critical periods during gestation when the fetus is most vulnerable to injury. This research has yielded significant results in the areas of craniofacial dysmorphology, abnormal brain growth and tissue differentiation, growth retardation, and other abnormal organ system development. For example, evidence has emerged that alcohol may interfere with multiple cellular functions in the developing brain, including cellular proliferation, cell survival and programmed death, and cellular migration. Some studies are now beginning to test growth factors and other compounds for their potential to block or reverse the effects of alcohol on the developing fetus.
- NIAAA-supported research in FY 2000 has demonstrated that certain long-chain alcohols can block the harmful effects of short-chain alcohols, including beverage alcohol, on nerve cell growth and development. Beverage alcohol can disrupt the process by which neurons find and attach themselves to other cells in the developing brain. This process, called cell-cell adhesion, occurs because of molecular tags on the cells that tell the neurons where to attach. Researchers at Harvard have found that low concentrations of ethanol (beverage alcohol) inhibit cell-cell adhesion mediated by a certain protein (L1) in cultured cells. Results indicate that inhibition of cell-cell adhesion by ethanol may play a role in the development of FAS. The finding that certain long-chain alcohols can block the effects of beverage alcohol on cell-cell adhesion may provide important leads to the identification of effective therapies.
- NICHD is sponsoring research efforts within the Neonatal Intensive Care Unit (NICU) Network to study the safety and efficacy of new treatment and management strategies for neonatal disorders and medical complications frequently seen in premature and low-birth-weight infants. The Maternal Lifestyles Study within this program is investigating the development and family outcomes associated with in utero exposure to polysubstance abuse among 1,400 mother-infant pairs. In another network, the Maternal Fetal Medicine Units will be continuing to research ways to improve the management of pregnancy and prevent specific obstetric problems, including those that may be related to alcohol exposure.
- NICHD is sponsoring a project to perform neuropsychological and educational followups in a large cohort of children with FAS/FAE.

## Future Plans and Needs

To advance understanding of the etiology and pathogenesis of prenatal exposure to alcohol:

- NIAAA and NICHD to support and expand research on the mechanisms that underlie alcohol-derived injury in the developing fetus and child. Research projects involving children who were exposed to alcohol at moderate to high levels are to be continued and expanded to new neurobehavioral and cognitive issues. Also to be continued are NIAAA studies of the correlation

of neurocognitive deficits in FAS and specific neuroanatomic deficits in other children prenatally exposed to alcohol as determined by noninvasive imaging technologies such as magnetic resonance imaging.

- NIAAA to expand the study of various factors that serve as mediators of alcohol-induced fetal injury. A broad range of NIAAA research activities will be continued, including research on the role of various trophic growth factors in fetal alcohol injury. For example, one study is examining the effect of alcohol on the vitamin A derivative retinoic acid, which is a regulator of cell growth. The involvement of other growth factors such as nerve growth factor and the neurotransmitters serotonin and glutamate will continue to be explored, as will the role of reactive oxygen species.
- NICHD to continue supporting an animal model study addressing whether dietary iron levels increase the vulnerability of the developing brain to alcohol exposure.
- NICHD to continue its research efforts within the NICU Network to investigate the safety and efficacy of new treatment and management strategies for neonatal disorders frequently seen in premature and low-birth-weight infants. The Institute will also continue the Maternal Lifestyles Study to examine the development and family outcomes associated with in utero exposure to polysubstance abuse.
- In FY 2001 NICHD and NIAAA to sponsor a workshop examining the possible relationship of maternal drinking to alcohol-related neurological disorders and sudden infant death syndrome among American Indians and Alaska Natives.
- NIAAA to continue its investigation of factors that cause children of some alcohol-consuming women to be vulnerable to FAS while others remain unaffected.

### Information Dissemination

A successful national strategy to reduce the incidence and impact of alcohol-related congenital disorders will include activities to significantly increase information dissemination and outreach to patient groups, academics, professional organizations, health care providers, State directors of special education, State lead agencies for early intervention, and the general public. Although the ICCFAS has made some progress toward the elimination of the redundancy and fragmentation that previously characterized the Federal response to FAS/FAE, much remains to be done. For example, there is a need for agencies to collaborate in the development of public health messages that will be relevant to the culturally diverse communities that are affected by maternal drinking and in the evaluation of the impact of those messages on maternal drinking behavior within those communities.

A successful communications strategy will also address the need for agencies with many of the same clients to share sensitive information and be aware of all the ethical and legal implications that attend this issue. Most important, over the next 5 years the ICCFAS will focus increasing attention on evaluating the impact of its information dissemination activities on the knowledge, attitudes, and behavior of specific target audiences. It is expected that improved outcome evaluation will yield important answers to the apparent resistance to current public education efforts of the small but significant minority of women who continue to drink heavily during pregnancy. Continuous improvement in communications strategies will also provide the key to bridging the gap from research to practice among professionals who serve children.

### Accomplishments

- NIAAA began hosting the ICCFAS Web site in 2001. The site features information on the membership of the Committee, its goals and objectives, coordination with other organizations, and workshops and conferences. It also includes important workshop and conference reports and links to other reliable sources of information. The Web site address is [www.niaaa.nih.gov/research-major-initiatives/fetal-alcohol-spectrum-disorders](http://www.niaaa.nih.gov/research-major-initiatives/fetal-alcohol-spectrum-disorders).
- AHRQ, in partnership with the American Medical Association and the American Association of Health Plans Foundation, has established the National Guidelines Clearinghouse, which is a publicly available database of evidence-based clinical guidelines and related documents that provides Internet users with free online access to guidelines on a wide array of clinical topics. These guidelines can be used as is or customized to meet users' specific needs. Currently there are nine treatment guidelines that address FAS from sources such as the American Psychiatric Association, Canadian Task Force on Preventive Health Care, Kaiser Permanente Health Plan, Inc., and the American Diabetes Association. The Web address for this site is [www.guideline.gov](http://www.guideline.gov).
- AHRQ manages Put Prevention Into Practice (PIIP), a program developed in 1994 by the DHHS Office of Disease Prevention and Health Promotion to improve implementation of the recommendations of the U.S. Preventive Services Task Force (USPSTF). The PIIP tools enable doctors and other health care providers to (1) determine which services their patients should receive; (2) facilitate the implementation of the delivery of clinical preventive services; and (3) make it easier for patients to understand and keep track of their preventive care. Issues related to preventing FAS (such as screening and counseling) can be found in the *PIIP Clinician's Handbook of Preventive Services*, Chapter 53. All PIIP materials are available in print and online. AHRQ also manages the USPSTF mentioned above. Specific recommendations (on which PIIP recommendations are based) can be found in the Report of the U.S. Preventive Services Task Force, *Guide to Clinical Preventive Services*, Chapter 52. These recommendations will be updated in the third edition of this report, which is due to be published in 2002.
- NIAAA is collaborating on a pilot project with NOFAS. The organizations are developing an FAS initiative for the District of Columbia. This project will use the media to reach high-risk women and to communicate FAS information to minority populations. Research is in progress on message concepts and the most effective channels to reach the target audience. NIAAA will evaluate the effort so that the pilot will provide data that can be used in other communities.
- SAMHSA's National Clearinghouse for Alcohol and Drug Information has a wealth of information and materials concerning alcohol and other substance abuse prevention during pregnancy. These materials can be accessed on the Web at [www.health.org](http://www.health.org). Many of these documents were developed by or in collaboration with NIAAA. There will be increased use of this resource by member organizations, and some of these publications will serve as a foundation for the development of materials targeting specific patient populations.
- IHS is developing a new guidebook for parents and caregivers of children and adolescents with FAS. This book will substantially update a previous publication first prepared in 1986, with a second edition in 1988. The new guidebook was completed in FY 1999, and it will be disseminated throughout the IHS health care delivery system and to American Indian and Alaska Native communities. It specifically addresses issues related to FAS diagnosis and treatment and followup services for children fetally exposed to alcohol.
- NIAAA has published yearly updates of its bibliography on alcohol and pregnancy. The bibliography is compiled using records from the Alcohol and Alcohol Problems Science database, commonly called ETOH. It is online on NIAAA's Web site at [http:// etoh.niaaa.nih.gov](http://etoh.niaaa.nih.gov). Although the database is available to all, the bibliography is published as a service to FAS researchers who meet yearly in conjunction with the Research Society on Alcoholism. The bibliography covers

material entered into the ETOH during the previous year. Publications of NIAAA-supported research are numerous.

- NIAAA has developed two training booklets for clinicians: *Prevention of Fetal Alcohol Exposure and Treatment of At-Risk Drinking*, for clinicians who work primarily with women, and *Identification and Care of Fetal Alcohol-Exposed Children*, for clinicians who work primarily with children. NIAAA also has developed a women's self-help workbook on risky drinking behaviors. All booklets are being focus-tested with groups of physicians and patients in inner-city clinics that have high-risk clientele. CDC and NIAAA will collaborate to improve diagnosis and casefinding through the piloting of NIAAA-produced education and training materials at CDC FAS Surveillance Program sites. CDC and the cooperative agreement grantees will provide technical assistance in program development and evaluation of materials directed to providers involved in the diagnosis of FAS.
- IHS is working with the Association of American Indian Physicians (AAIP) to make screening forms accessible through the Internet at AAIP's Web site ([www.aaip.com/index.html](http://www.aaip.com/index.html)). This screening guide contains the only self-administered questionnaire (SAQ) for substance abuse screening specifically developed and tested among Alaska Native and American Indian women. The purpose of the training guide is to (1) prepare prenatal care providers to screen pregnant women for substance use (including alcohol) using the SAQ, and (2) mobilize community resources in developing a systematic approach to counseling and treatment of women who score positive at screening.
- HRSA's Maternal and Child Health Bureau funded a project through Boston University's Fetal Alcohol Education Program to increase awareness and improve prevention efforts for FAS and FAE by inserting educational articles into national professional maternal and child health newsletters and by developing and distributing a State-by-State resource directory that includes information ranging from the availability of women's treatment to programs serving children with FAS/FAE. The directory has been widely disseminated to national organizations, State health departments, and other interested agencies.
- CDC conducted a qualitative study on health communications aimed at reducing alcohol-exposed pregnancies by targeting high-risk women before conception. The study targeted African American women and resulted in a number of focus group-tested health education products, including brochures, posters, and public service announcements. These are available by contacting Karrien Williams of the CDC FAS Prevention Office (770-488-7370).
- CDC, in partnership with the Association of Retarded Citizens (ARC), produced a public information brochure targeting childbearing-age women who are pregnant, planning a pregnancy, or at risk of becoming pregnant and alerting them to the adverse consequences of drinking during pregnancy. This brochure is available by contacting the ARC National Headquarters (301-565-3842) or any local ARC chapter in the community.
- CDC has published a number of articles during the past year documenting the problem of alcohol use among childbearing-age women, including those who are pregnant.
- IHS is continuing to develop content for information dissemination and outreach. Ideas include education activities, a Web page, and updating the IHS primary care provider training courses. For example, a guide, *Screening American Indian/Alaska Native Women for Substance Use During Pregnancy* (1997), was developed through an interagency agreement between IHS and CDC and became available in 1999 on the IHS Web site. It is being distributed to IHS tribal and urban Indian prenatal health clinics.
- NIAAA is in the final stages of developing an American Indian-focused version of its highly successful FAS patient brochure. Focus testing has recently been completed on this brochure. The English-language brochure, *Drinking and Your Pregnancy*, and Spanish-language brochure,

La bebeda y su embarazo, have already been disseminated (250,000 copies), and both versions are available, full text and graphics, on NIAAA's home page ([www.niaaa.nih.gov](http://www.niaaa.nih.gov)). The National Association of Government Communicators Blue Pencil competition awarded the English-language version of this brochure first prize in the brochure for a lay audience category in 1998. Under the auspices of the U.S.-South Africa Bi-National Commission, a version of this brochure was produced collaboratively with South African community representatives in the Afrikaans language. Twenty-five thousand copies were made available, and several hundred were presented to the mayor of a high-risk community by the U.S. Surgeon General.

- CDC, in collaboration with the Oklahoma State Department of Health, developed and tested a reproductive health education curriculum targeting women in alcohol and drug treatment centers. "Making Positive Health Decisions" consists of 10 lessons lasting a minimum of 1 hour per session. These lessons may be incorporated into inpatient and outpatient recovery programs. The curriculum became available from the Maternal and Infant Health Service, Oklahoma State Department of Health, in FY 1999 and was disseminated to all State-funded alcohol and drug treatment centers in Oklahoma and to others upon request from the Oklahoma State Department of Health.

### **Future Plans and Needs**

To enhance the dissemination of information and to implement programs of outreach to the community, the ICCFAS has identified the following objectives for FY 2001-2005:

- Collaborate with the National Task Force on FAS/FAE charged with advising Federal, State, and local prevention, treatment, and research programs, including those involving education and public awareness for relevant service providers, school-age children, women at risk for giving birth to children with FAS and FAE, and the general public. A key objective of the National Task Force is to increase access to high-quality services for individuals with FAS and FAE and their families. All ICCFAS member agencies are committed to ensuring that the recommendations of the National Task Force inform policymaking processes, both at the level of the ICCFAS and at the individual agency level.
- In addition, member agencies will form partnerships to:
  - Provide health care workers, other professionals, and health care provider organizations with information on best practices for screening and intervening with women and children;
  - Increase the visibility of public health messages regarding FAS and alcohol abuse during pregnancy; and
  - Enhance outreach to alcohol-dependent and high-risk women of childbearing age.

The Committee has planned the following related activities to achieve these objectives.

### **To provide health care, education, and criminal justice professionals and provider organizations with information on best practices for screening and intervening with women and children:**

- Develop and test curricula and screening tools for juvenile justice professionals, including juvenile court judges, probation officers, juvenile detention and corrections staff, and others

who work in the juvenile justice system. (OJJDP, NIAAA, Minnesota criminal justice professionals, MOFAS)

- Increase by 50 percent the distribution of existing guidelines for FAS screening and intervention (e.g., educational materials and provider training manual developed by American Indian Rehabilitation Research and Training Center).
- Develop and test curricula for educating parents, educators, and public health service providers about FAS and how to access diagnostic and treatment services for children affected. (CDC, NIAAA, and ED)
- Sponsor FAS sessions at professional and clinical conferences and meetings.
- Develop a guide to Federal resources and initiatives targeting service providers. (ED)
- Develop a training curriculum for health care professionals to facilitate and ensure the use of NIAAA publications: Personal Steps to a Healthy Choice; Identification of At-Risk Drinking and Intervention with Women of Childbearing Age, and Identification and Care of Fetal Alcohol-Exposed Children. The curriculum will be pilot tested in several communities and then distributed to health care providers and health care organizations. (NIAAA)
- Develop, evaluate, and disseminate an Internet-based education module for health care providers on identifying and intervening with women at risk for an alcohol-exposed pregnancy. (CDC)
- Collaborate to use existing technical assistance and dissemination networks and clearinghouses for FAS, ARND, and ARBD.
- Assess the need for and scope of a FAS/FAE National Training and Technical Assistance Center and Clearinghouse; plan and establish.

**To increase the visibility of public health messages regarding FAS and alcohol use during pregnancy:**

- Coordinate a national campaign on FAS in conjunction with the National Task Force on FAS/FAE. (CDC)
- Develop and organize one national and three regional conferences for parents and caregivers working with young children.
- Through the FAS initiative for the District of Columbia, launch a media campaign targeting the African American community. (NOFAS, NIAAA)
- Fund university-based pilot studies of targeted campaigns aimed at reducing alcohol use during pregnancy. (CDC)
- Cosponsor the fourth annual National Alcohol Screening Day and increase the number of prenatal and gynecology sites participating. (CSAT, NIAAA)
- Pilot test "Understanding Alcohol," a 1-week curriculum designed to allow seventh and eighth graders to separate myths from facts about the use and abuse of alcohol, including a review of the impact of prenatal alcohol exposure. (NIAAA)
- Develop an "Understanding Alcohol" curriculum for children in grades 6 and 9 through 12. (NIAAA)
- Expand the nurse home visitation program supported by OJJDP and DHHS, and send intervention and public awareness posters to those sites.

**To enhance outreach to alcohol-dependent and high-risk women of childbearing age:**

- In collaboration with the Association of Schools of Public Health, fund research and development projects aimed at developing effective intervention strategies for preventing alcohol-exposed pregnancies in culturally diverse and adolescent populations. (CDC)
- Distribute *Personal Steps to a Healthy Choice*, a self-help workbook newly developed by NIAAA for women, to a minimum of 200 prenatal care sites. The workbook facilitates intervention of health care practitioners with pregnant and preconceptional women who need to decrease their level of drinking. (NIAAA)

## **Prevention of Drinking During Pregnancy**

Alcohol consumption patterns among women in the general U.S. population provide a context for discussing the drinking behavior of pregnant women. Approximately 60 percent of adult women in the United States drink alcohol at least occasionally. Of these, the large majority consume small to moderate amounts without adverse social, behavioral, or health consequences. "Approximately 4 percent of all women would be considered to have either an alcohol abuse or alcohol dependence disorder, as defined by the fourth edition of the *Diagnostic and Statistical Manual of Mental Disorders*" (IOM, 1996, p. 8).

Available data indicate substantially lower rates of both drinking (approximately 20 percent according to national surveys) and heavy drinking (less than 1 percent) among pregnant women relative to nonpregnant women of childbearing age. Although these percentages are small in relative terms, the large absolute numbers of women who continue to engage in high-risk drinking during pregnancy point to an urgent need to understand the personal and environmental correlates of heavy maternal drinking. Furthermore, although researchers have seen some encouraging changes in drinking patterns during pregnancy over the years, "there is no substantive evidence of any change in drinking behavior among women who drink more heavily or abuse alcohol, either in terms of proportions of heavy drinkers at the time of conception or in terms of consumption levels during pregnancy" (IOM, 1996, p. 105).

The lack of substantial evidence of any change in drinking behavior among women who drink more heavily or abuse alcohol during pregnancy points to a need to reevaluate the scope and quality of prevention research. Population-based surveys such as the Behavioral Risk Factors Surveillance System (BRFSS) and SAMHSA's National Household Survey on Drug Abuse have alerted the Nation to the prevalence rates and trends in harmful alcohol consumption among childbearing-age women (pregnant and nonpregnant). These studies have also characterized women at risk by comparing them to nondrinking women in order to guide researchers in targeting public health interventions more effectively. There is a need for additional studies such as CDC's Project CHOICES epidemiological survey to provide greater depth of understanding of specific alcohol use patterns, reproductive history and health status, and other risk predictors of women most likely to have an alcohol-exposed pregnancy. Moreover, findings from recent research on drinking among women in general should be applied to better understand drinking behavior among pregnant women.

## **Accomplishments**

- NIAAA distributed the ICCFAS working group report, titled *Prevention of Risk Drinking in Pregnancy*, to health care organizations and academic groups for use in in-service training of chemical-dependency specialists, health educators, and clinicians at Kaiser Permanente in California. NIAAA grantees are exploring the feasibility of incorporating screening for risk drinking into prenatal clinics within a health maintenance organization.
- CDC has continued to monitor alcohol use among childbearing-age women and produce prevalence reports appearing in *Morbidity and Mortality Weekly Report* and peer-reviewed journals that have gained the attention of the media and raised renewed awareness of this public health issue.
- SAMHSA is providing funding for the Four-State Consortium on Fetal Alcohol Syndrome and Fetal Alcohol Effects, a cooperative agreement that will facilitate collaboration between FAS/FAE coordinating agencies and service providers in South Dakota, North Dakota, Minnesota, and Montana and that will include strong linkages with the American Indian community. The goals of the cooperative agreement are to (1) develop an information base to systematize data collection on the incidence and prevalence of FAS and FAE to determine high-risk areas and populations, and (2) implement and test universal, selective, and scientifically defensible interventions in high-risk areas and populations to prevent, reduce, and/or delay substance abuse. Much of the initial work will focus on coordinating the development of an information system with data related to the incidence and prevalence of FAS/FAE and population characteristics. In subsequent years the project will aim to improve prevention and intervention services and outcomes for all people living in the four-State area, with special emphasis on women of childbearing age and pregnant women, persons already affected by FAS/FAE, and others living in areas with high incidence and prevalence of FAS/FAE.
- OJJDP, together with the Bureau of Justice Assistance and the Executive Office for Weed and Seed, is currently funding a replication of the well-tested model of nurse home visitation for at-risk first-time mothers and their children. During their home visits with mothers, nurses address high-risk drinking and prenatal alcohol exposure, along with other maternal and child health issues. Through OJJDP, the DHHS is funding an evaluation of this replication study. The six replication sites include Pinellas County (St. Petersburg), Florida; Oklahoma City/County, Oklahoma; Fresno County (Fresno), California; Los Angeles County, California; St. Louis, Missouri; and Alameda County (Oakland), California.
- NIAAA and NICHD are involved in a collaborative project on FAS as part of the District of Columbia initiative to prevent infant mortality. The project involves three hospital sites within the District of Columbia that are involved in prenatal health care and delivery and two public prenatal health clinics. A major goal of the D.C. Initiative on FAS is to create an effective and user-friendly prenatal screening tool for measuring the consumption of alcohol by pregnant women. Several different questionnaires on alcohol consumption are currently available, but none are routinely used to screen all women in the prenatal clinic setting. Thus, reliable statistics on pregnant women who use or abuse alcohol are not generated by most current prenatal medical facilities. A unique feature of the D.C. Initiative screen is the use of the audio and computer-assisted self-administration method (ACASI), with which a woman can complete the questionnaire in privacy and by self-administration. The ACASI method has been shown to increase the reliability of respondents' answers to sensitive questions. The system's implementation of self-administration will benefit busy health care workers in clinical settings and will further encourage the questionnaire's utilization in clinical settings. More accurate data on prenatal consumption of alcohol within a population, combined with reliable demographics and understanding of drinking patterns (with whom, when, why, for example), will greatly enhance health care worker abilities to develop and implement intervention and prevention

programs for pregnant women who are consuming alcohol, which is the ultimate goal of the D.C. Initiative on FAS. Publications are in progress.

- The CDC-funded Project CHOICES multisite study completed an epidemiological survey identifying a group of community-based settings in which the rate of women at risk for an alcohol-exposed pregnancy was seven times higher than that in the general population. Approximately 2,700 surveys were completed specifically addressing both alcohol and contraceptive behavior in preconceptional women. Settings included a jail, a university-based gynecology clinic, primary care centers providing services to women, alcohol and drug treatment centers, and a media-recruited group of risk drinkers. A brief treatment model for changing risky drinking and ineffective contraceptive behavior was successfully piloted in these settings.
- In 2001, CDC funded a Project CHOICES multisite study for a randomized controlled trial of the efficacy of the motivational intervention developed during phase I. Additional community-based clinics were incorporated in the study, including Women, Infants, and Children (WIC) and sexually transmitted diseases (STD) clinics. The study is slated for completion in 2003. If found efficacious, dissemination efforts will be developed for FY 2005-2008.
- Advertising influences children's perceptions of commonly accepted social values and behaviors. Whereas early research found no direct relationship between alcohol advertising and its consumption by youth, many young people today have greater recognition of some alcohol beverage brand names than of former U.S. Presidents. SAMHSA's Center for Substance Abuse Prevention is conducting two research activities with NIAAA. In the Effects of Alcohol Advertising on Underage Drinking Study, which is determining whether alcohol advertising affects initiation of drinking and consumption patterns among youth, grantees are exploring relationships between exposure to advertising, alcohol expectancies and other mediating variables (e.g., personality or family norms), and actual alcohol consumption by youth. The second effort, Prevention of Alcohol-Related Problems Among College Students, focuses on environmental interventions to change external factors that promote or inhibit college drinking; individual-focused interventions to influence knowledge, attitudes, and skills that affect drinking behavior; and multicomponent interventions that include both approaches.
- NIAAA and the NIH Office of Research on Women's Health cosponsored a Request for Applications (RFA) on the prevention of FAS. This RFA encouraged several approaches including community-based research. Seven high-quality grant applications were funded. The ICCFAS devoted a meeting to bring these and selected CDC grantees together to present their plans and to encourage them to collaborate to strengthen the quality of their projects.
- The HRSA Maternal and Child Health Bureau conducted an FY 1999 new grant competition that resulted in the funding of four 3-year applications. Grants were provided to programs with a direct service prenatal clinic population to test methods to motivate providers to systematically screen for alcohol use during pregnancy, provide information on associated risks, and refer for interventions if needed. Funded projects in Massachusetts, Puerto Rico, Illinois, and Nebraska link community efforts with the State Maternal and Child Health Title V Office to enhance program effectiveness and to disseminate results. Project efforts target a diverse care system including those who serve public and private clinics and clinics for American Indians.
- Since 1997, HRSA's Maternal and Child Health Bureau has provided technical assistance to Healthy Start (HS) communities on the topic of prenatal screening for alcohol and illicit substance use. During the needs assessment, HS grantees frequently request training on how to improve screening for substance use by perinatal providers. To date, over 40 HS communities have received such training.

- SAMHSA has awarded State Incentive Grants for Community-Based Action to Governor's offices in 25 States to support statewide planning for coordinated substance abuse prevention services. A full 85 percent of these funds will be directed to community-based substance abuse prevention programs. In addition, SAMHSA has awarded five grants for Regional Centers for the Application of Prevention Technologies. These grants support State and community efforts to implement well-grounded, research-based, effective substance abuse prevention strategies.
- CDC collaborated with the American College of *Obstetrics and Gynecology* (ACOG) to complete the analysis of a survey of obstetricians/gynecologists addressing their knowledge, attitudes, and practices regarding prenatal alcohol, tobacco, and other drug use. Some of the study results and implications have been published jointly by CDC and ACOG in ACOG's official journal, *Obstetrics and Gynecology*. A report has been prepared on the tobacco and other drug use information obtained from the survey and submitted for publication.
- NIAAA and SAMHSA collaborated with the National Mental Health Screening Project to sponsor an annual National Alcohol Screening Day held in April 1999 and in April 2000. Other sponsors included NOFAS, the American Medical Association, and 15 other prominent organizations. Two thousand sites participated, and a special effort was made to encourage participation of prenatal clinics. IHS facilitated participation of some of its hospital and clinic facilities.
- Several demographic studies undertaken by NICHD will contribute to an improved understanding of the determinants and consequences of heavy alcohol consumption and other high-risk behaviors among women of childbearing age. NICHD recently funded a new wave of the National Longitudinal Study of Adolescent Health. This comprehensive study of health and health-risk behaviors, originally conducted in 1994-1996, was extended in the year 2000 to examine health behaviors among young adults 18 to 24 years of age. The early adult years are characterized by a high prevalence of alcohol consumption, binge drinking, and high rates of unintended pregnancy—all factors critical to the risk and prevention of FAS. The study will provide rich prospective data that will enable researchers to understand better the individual and social factors that contribute to an elevated risk of FAS, potentially leading to the identification of new intervention strategies. The study will also examine a broad range of other health-risk behaviors, including smoking, drug use, and violence, and health-protective behaviors, such as healthy eating and physical exercise, among pregnant and nonpregnant women in the early adult years.
- To provide additional information about substance use and abuse, SAMHSA has expanded the sample size of the annual National Household Survey on Drug Abuse (NHSDA) from 18,000 to 70,000 interviews each year through 2010. The NHSDA explores the relationship between pregnancy among females aged 15 to 44 and three measures of drug use: past-month illicit drug use, binge alcohol use (drinking five or more drinks on the same occasion on at least one day during the past 30 days), and past-month cigarette use.
- SAMHSA will continue its program "Girl Power!", a multiphase national public education campaign developed by SAMHSA and sponsored by the Secretary of DHHS to help encourage and empower 9- to 14-year-old girls to make the most of their lives. During its first phase, which focused on preventing the abuse of alcohol, tobacco, and other drugs, "Girl Power!" combined strong "no-use" messages with an emphasis on providing opportunities for girls to build skills and self-confidence in academics, arts, sports, and other endeavors. The "Girl Power!" campaign takes a comprehensive approach, addressing not only a range of health issues but also the erosion of self-confidence, motivation, and opportunity that is all too typical for many girls during the transitional period of 9 to 14 years of age. According to the NHSDA, girls are particularly vulnerable to initiating substance use during this same period. SAMHSA supports

programs that develop "Girl Power!" activities and curricula to prevent alcohol, tobacco, and drug abuse. The prevention messages of this campaign target teen pregnancy as well as alcohol and drug use. As a result, the "Girl Power!" campaign serves to prevent FAS/FAE.

- Dr. Linda Teplin of Northwestern University, with support from the National Institute of Mental Health and OJJDP, is conducting a large-scale, longitudinal study of alcohol and other substance abuse and mental illness among detained juveniles in Cook County, Illinois. The study's goals are to determine the extent of alcohol, drug, and mental disorders in this population; identify the factors that determine which juveniles receive needed services; and explore developmental patterns of drug and alcohol use, violence, and HIV/AIDS risk behaviors. Researchers are collecting urine samples from the juveniles within 48 hours of arrest, allowing them to identify most substances being used at the time of arrest. Preliminary data suggest that approximately a quarter of the research participants meet criteria for alcohol abuse or dependence, with rates being roughly equal for males and females. Because 79 percent of the participants report being sexually active, there is a substantial risk in this population for alcohol-affected pregnancy.
- In FY 2000 OJJDP issued two program announcements for gender-specific programs for girls in the juvenile justice system. The first, the Girls Study Group, will develop the research foundation that communities need to make sound decisions on how best to prevent and reduce delinquency and violence by girls. The Study Group will establish the theoretical and empirical basis for disseminating or testing prevention and intervention strategies for girls, and will disseminate information on effective and promising strategies that are developmentally and culturally appropriate. The second effort, the National Girls Institute, will advance the understanding and application of promising prevention, intervention, treatment, education, detention, and aftercare programs and services for delinquent and at-risk girls. The Institute will accomplish its mission through a broad range of activities, including program development and enhancement, research activities, training and technical assistance, information dissemination, collaboration with Federal and private agencies, and policy development.
- The children of substance-abusing parents (COSAPs) face significantly higher-than-average risk for early substance use, the development of substance dependence, and a range of collateral physical and mental health problems (e.g., FAS/FAE). In FY 1998 SAMHSA initiated a program that currently supports 15 grants that are testing the effectiveness of prevention models for COSAPs, ages 6 to 8, 9 to 11, and 12 to 14, and their siblings, whose parents are in or have attended substance abuse treatment programs.
- Alcohol abuse not only causes FAS, but studies show that it is frequently implicated in adolescent traffic deaths, suicides, homicides, and other fatal injuries. SAMHSA's Center for Substance Abuse Treatment and NIAAA are collaborating to fund research that will contribute to the identification of efficacious treatment interventions and services for adolescent alcohol abusers and alcoholics. Two types of studies have been funded: (1) a theory-driven investigation that is based on experimental design; and (2) inquiries that assess practice-as-usual in health service settings.

## **Future Plans and Needs**

In FY 2001-FY 2005 the ICCFAS will focus its prevention activities on four areas: (1) continued monitoring and reporting of the prevalence of alcohol use among childbearing-age women to maintain visibility of this public health problem; (2) improving access to care for alcohol-abusing and high-risk women of childbearing age, with emphasis on special populations (e.g., incarcerated women, women living in shelters). Such studies will address not only the quantity of

services available, but needed improvements in the design and implementation of programs that effectively guide pregnant women to treatment; (3) promotion of universal screening for alcohol abuse by health care providers and of provider participation in a national surveillance system; and (4) enhancing provider assessment and intervention skills. The Committee has planned the following related activities:

- HRSA's Maternal and Child Health Bureau to continue funding through June 2002 four grants designed to motivate providers to screen for perinatal alcohol use.
- ICCFAS to sponsor sessions at annual meetings of health care professional societies and organizations to promote universal screening for alcohol abuse.
- ICCFAS to disseminate results of 14 grants (7 grants cosponsored by NIAAA and NIH's Office of Research on Women's Health, 4 grants awarded by HRSA's Maternal and Child Health Bureau, and 3 grants awarded by CDC) examining the efficacy of a variety of prevention and screening protocols.
- SAMHSA to use new FY 2001 funding to support four to five new cooperative agreements (for 5 years) that will enhance community-initiated programs for the development of innovative prevention programs to reduce the incidence of FAS/ARBD.
- NIAAA and NICHD to conduct phase II of their collaboration to develop an effective and user-friendly prenatal screening tool that measures alcohol consumption by pregnant women. The D.C. Initiative screening tool uses a computer-assisted, self-administration method. The goal is to provide a model for integrating this tool into clinical practice.
- CDC to fund a randomized controlled trial of Project CHOICES motivational intervention for preventing alcohol-exposed pregnancies among high-risk women.
- CDC to use new funding for FY 2001 to expand existing programs and initiate new activities focusing on areas included in the Children's Health Act of 2000, including (1) evaluating intervention programs for children with FAS; (2) expanding intervention studies of women at high risk for having a child with prenatal alcohol exposure to include more American Indians, Alaska Natives, and Hispanics; (3) expanding and improving State surveillance programs for FAS and monitoring prenatal alcohol exposure; and (4) supporting the work of the National Task Force on FAS/FAE.
- SAMHSA to continue community-based action grants to 28 States to support coordinated substance abuse prevention services.
- ICCFAS to formally recommend to national medical societies inclusion of training on screening for alcohol abuse and FAS in physicians' continuing education requirements (e.g., questions on board certification examinations).
- CDC to provide surveillance system grantees in five States (FASSNET) with State-specific analyses of BRFSS data on alcohol use among women of childbearing-age.
- NIAAA to sponsor a workshop on the treatment of women who abuse or are dependent on alcohol.
- SAMSHA to use new funding for FY 2001 to establish an FAS/ARBD Center for Excellence to (1) identify effective science-based practices for the prevention of FAS/ARBD; (2) develop and pilot test adaptations/modifications of those best practices to ensure effectiveness when translated for use by specific populations; (3) coordinate ongoing Center for Substance Abuse Prevention efforts to ensure a learning community among those involved in the current developmental work regarding systems and services designed to prevent FAS/ARBD; (4) design and implement a tracking/management information system that will enable providers to better design and target necessary services; and (5) provide guidance and/or develop appropriate materials and curricula, and devise strategies for their rapid and effective dissemination.

- ICCFAS to conduct sessions on screening for alcohol abuse/dependence at annual meetings of national medical societies.

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## Web Sites

CDC: [www.cdc.gov/ncchd/program/fas/surveillance-fas.htm](http://www.cdc.gov/ncchd/program/fas/surveillance-fas.htm)

ICCFAS: [www.niaaa.nih.gov/research/major-initiatives/fetal-alcohol-spectrum-disorders](http://www.niaaa.nih.gov/research/major-initiatives/fetal-alcohol-spectrum-disorders)

NIAAA: [www.niaaa.nih.gov/](http://www.niaaa.nih.gov/)

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## List of Committee Members

### Chairperson

Mary Dufour, M.D., M.P.H.  
Deputy Director  
National Institute on Alcohol  
Abuse and Alcoholism, NIH  
6000 Executive Boulevard, Suite 400  
Bethesda, Maryland 20892-7003  
Phone: 301-443-3851

Fax: 301-443-7043

E-mail: [mdufour@willco.niaaa.nih.gov](mailto:mdufour@willco.niaaa.nih.gov)

Louise Floyd, R.N., D.S.N.  
Acting Chief, FAS Prevention Branch  
National Center for Birth Defects  
and Developmental Disabilities  
Centers for Disease Control  
and Prevention  
4770 Buford Highway, MSC F49  
Atlanta, Georgia 30033  
Phone: 770-488-7372  
Fax: 770-488-7461  
E-mail: [rfl3@cdc.gov](mailto:rfl3@cdc.gov)

Anita Eichler, M.P.H.  
Associate Administrator  
Alcohol Prevention and Treatment Policy  
SAMHSA  
5600 Fishers Lane, Room 12C-26  
Rockville, Maryland 20857  
Phone: 301-443-1910/7022  
Fax: 301-594-6159

Charlotte Mullican, M.P.H.  
Health Scientist Administrator  
Center for Outcomes and  
Effectiveness Research  
Agency for Healthcare Research  
and Quality  
6010 Executive Boulevard, Suite 300  
Rockville, Maryland 20852  
Phone: 301-594-0382  
Fax: 301-594-3211  
E-mail: [cmullican@ahrq.gov](mailto:cmullican@ahrq.gov)

Karen Stern, Ph.D.  
Social Science Program Specialist  
Office of Juvenile Justice  
and Delinquency Prevention  
810 7th Street, N.W.  
Washington, D.C. 20531  
Phone: 202-514-9395  
Fax: 202-353-9096  
E-mail: [sternk@ojp.usdoj.gov](mailto:sternk@ojp.usdoj.gov)

Phillip Smith, M.D., M.P.H.  
Senior Clinician Consultant  
Indian Health Service  
Parklawn Building, Room 6A-38  
5600 Fishers Lane  
Rockville, Maryland 20857  
Phone: 301-443-6528  
Fax: 301-443-7613  
E-mail: [psmith@hqa.ih.gov](mailto:psmith@hqa.ih.gov)

Faye Calhoun, D.P.A., M.S.  
Associate Director for  
Collaborative Research  
National Institute on Alcohol  
Abuse and Alcoholism, NIH  
6000 Executive Boulevard, Suite 302  
Bethesda, Maryland 20892-7003  
Phone: 301-443-1269  
Fax: 301-480-2358  
E-mail: [fcalhoun@niaaa.nih.gov](mailto:fcalhoun@niaaa.nih.gov)

Ellen Hutchins, Sc.D., M.S.W.  
Chief, Perinatal and Women's  
Health Branch  
Maternal and Child Health Bureau,  
HRSA  
5600 Fishers Lane, Room 11A-05  
Rockville, Maryland 20857  
Phone: 301-443-9534  
Fax: 301-594-0186  
E-mail: [ehutchins@hrsa.gov](mailto:ehutchins@hrsa.gov)

Jan Harlow, Ed.D.  
Education Program Specialist  
Office of Special Education  
and Rehabilitative Services  
U.S. Department of Education  
330 C Street, S.W.  
Washington, D.C. 20202  
Phone: 202-205-8688  
Fax: 202-205-9179  
E-mail: [jan\\_harlow@ed.gov](mailto:jan_harlow@ed.gov)

Lynne Haverkos, Ph.D.  
Child Development and Behavior  
Branch, NICHD

6100 Executive Boulevard, MS 7510  
Room 4B05B  
Bethesda, Maryland 20892-7510  
Phone: 301-435-6881  
E-mail: [haverkol@mail.nih.gov](mailto:haverkol@mail.nih.gov)

Kenneth Warren, Ph.D.  
Director, Office of Scientific Affairs  
National Institute on Alcohol  
Abuse and Alcoholism, NIH  
6000 Executive Boulevard, Room 409  
Bethesda, Maryland 20892  
Phone: 301-443-4375  
Fax: 301-443-6077  
E-mail: [kwarren@willco.niaaa.nih.gov](mailto:kwarren@willco.niaaa.nih.gov)

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**Executive Secretary**

Deidra Roach, M.D.  
Medical Officer  
National Institute on Alcohol  
Abuse and Alcoholism, NIH  
6000 Executive Boulevard, Suite 302  
Bethesda, Maryland 20892-7003  
Phone: 301-443-5820  
Fax: 301-480-2358  
E-mail: [droach@niaaa.nih.gov](mailto:droach@niaaa.nih.gov)