FEDERAL PARTNERSHIPS IN ADDRESSING FETAL ALCOHOL SPECTRUM DISORDERS

FY2001 – 2005 Progress Report and FY2006 – 2010 Strategic Plan of the Interagency Coordinating Committee on Fetal Alcohol Syndrome

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ABBREVIATIONS USED IN THIS REPORT

ADD – Administration on Developmental Disabilities
AHRQ - Agency for Heathcare Research & Quality
AI/AN – American Indian and Alaska Native people
ARBD - Alcohol - related birth defects
ARND - Alcohol - related neurodevelopmetal disorders
CDC - Center for Disease Control & Prevention
CIFASD - Collaborative Initiative on Fetal Alcohol Spectrum Disorders
CMHS - Center for Mental Health Services
CSAP - Center for Substance Abuse Prevention
CSAT - Center for Substance Abuse Treatment
DBH – Division of Behavioral Health
DHHS - Department of Health & Human Services
DOJ - Department of Justice
ED - Department of Education
FAE - Fetal Alcohol Effects
FAS - Fetal Alcohol Syndrome
FASD - Fetal Alcohol Spectrum Disorders
FASSNet - Fetal Alcohol Syndrome Surveillance Network
FICC – Federal Interagency Coordinating Council
FY – Fiscal Year
HRSA - Health Resources & Services Administration
ICCFAS - Interagency Coordinating Committee on Fetal Alcohol Syndrome
IDEA – Individuals With Disabilities Education Act
IHS - Indian Health Services
IOM – Institute of Medicine
MCHB - Maternal and Child Health Bureau
MOFAS - Minnesota Organization on Fetal Alcohol Syndrome
NCADI - SAMHSA's National Clearinghouse for Alcohol and Drug Information
NCBDDD – National Center on Birth Defects and Developmental Disabilities
NIAAA - National Institute on Alcohol Abuse and Alcoholism
NICHD - National Institute of Child Health and Human Development
NIH - National Institutes of Health
NIMH – National Institute of Mental Health
NOFAS - National Organization on Fetal Alcohol Syndrome
NTFFAS/FAE - National Task Force on Fetal Alcohol Syndrome and Fetal Alcohol Effect
OJJDP - Office of Juvenile Justice and Delinquency Prevention
OSEP - Office of Special Education Programs
OSERS - Office of Special Education & Rehabilitative Services
RFP – Request for Proposals
SAMHSA - Substance Abuse and Mental Health Services Administration
SIDS – Sudden Infant Death Syndrome
USDA – United States Department of Agriculture
WIC – Women/Infants/Children

FOREWORD

In response to a request from the Congressional Caucus on Fetal Alcohol Spectrum Disorders (FASD), the Interagency Coordinating Committee on Fetal Alcohol Syndrome (ICCFAS) has prepared this report of accomplishments covering FY2001 to 2005 and a Strategic Plan for FY2006-2010.

The request was received from Congressmen Frank Pallone, Jr. and Jim Ramstad in April 2005 and stated:

> *As co-chairs of the Congressional Caucus on Fetal Alcohol Spectrum Disorders, we commend the important work of the Interagency Coordinating Committee on Fetal Alcohol Syndrome (ICCFAS). We recognize the valuable contributions made by the ICCFAS to the federal initiative concerning FASD, as such an effort transcends the mission and resources of any agency.*
>
> *Ever since the inception of the ICCFAS in October 1996, a significant amount of interagency communication and collaboration has taken place to support the mission of preventing and treating fetal alcohol spectrum disorders (FASD). Accordingly, we would like to request that the Committee submit a report to Congress on recent accomplishments and a five-year strategic plan for FY2006-2010. The last time such a report was requested was fiscal year 2001 in the reports accompanying that year's budget for the Department of Health and Human Services.*
>
> *Since the effects of prenatal alcohol exposure in society are so prevalent, we encourage the continued and committed participation of all federal agencies relevant to the fight against FASD. We also encourage the ICCFAS to promote and facilitate the development of new projects, convene meetings, and further coordinate an effective strategy that will guide the Committee and its participants over the next five years.*

We concur with the Congressional Caucus on Fetal Alcohol Spectrum Disorders on the need for a continued Federal commitment to reduce the burden of FASD on society and address the needs of individuals prenatally exposed to alcohol. In addition, we thank the Congressional Caucus on Fetal Alcohol Spectrum Disorders for their interest in the work of the ICCFAS in coordinating increased communication, cooperation, and collaboration among the many Federal entities with programs and activities related to FASD.

INTERAGENCY COORDINATING COMMITTEE ON FETAL ALCOHOL SYNDROME PROGRESS REPORT AND STRATEGIC PLAN FOR FY2006-2010

I. EXECUTIVE SUMMARY

A. Introduction

The mission of the Interagency Coordinating Committee on Fetal Alcohol Syndrome (ICCFAS) is to enhance and increase communication, cooperation, collaboration, and partnerships among disciplines and Federal agencies to address health, education, developmental disabilities, alcohol research, and health and social services and justice issues that are relevant to disorders caused by prenatal alcohol exposure. The vision of ICCFAS is that collaborative partnerships, using the resources of government and other organizations, will reduce the prevalence of individuals affected by prenatal exposure to alcohol and provide appropriate interventions and support to persons affected by Fetal Alcohol Spectrum Disorders (FASD) and their families.

The current membership of the ICCFAS includes representatives from the following organizations:

- Department of Health and Human Services (DHHS);
  - Agency for Heathcare Research and Quality (AHRQ),
  - Centers for Disease Control and Prevention (CDC),
  - Health Resources and Services Administration (HRSA),
  - Indian Health Service (IHS),
  - Substance Abuse and Mental Health Services Administration (SAMHSA),
  - National Institutes of Health (NIH):
    the National Institute of Alcohol Abuse and Alcoholism (NIAAA),
    and the National Institute of Child Health and Human Development (NICHD);
- Department of Education (ED), Office of Special Education and Rehabilitative Services (OSERS);
- and the Department of Justice (DOJ), Office of Juvenile Justice and Delinquency Prevention (OJJDP).

This executive summary of five years of progress and a strategic plan comprises a reasonable reflection of our recent activities, future goals, and plans.

Since its formation in October 1996, in response to recommendations of an expert committee of the Institute of Medicine (IOM), the ICCFAS has promoted increased communication, cooperation and collaboration among the many Federal agencies whose work has bearing on issues related to the prenatal exposure of unborn children to the toxic effects of alcohol. In 2000 the ICCFAS submitted its first five year progress report describing meetings, workshops, conferences, joint activities and the beginnings of FAS-related communication, cooperation, and collaborations among these many

Federal agencies. In addition, numerous selected projects from the individual member organizations were highlighted. The FY2001-2005 ICCFAS Strategic Plan called for an increase in interactions among the ICCFAS member organizations, as well as expansion of selected programs in specific agencies.

Federal Actions Resulted in New Opportunities for Interagency FAS-related Activities.

The ICCFAS capitalized on several FAS-related actions at the Federal level to use as vehicles for increased communication, cooperation, and collaboration and created synergistic outcomes. Several of the unique opportunities that cultivated more interactions among ICCFAS organizations were as follows:

- The establishment of the National Task Force on Fetal Alcohol Syndrome and Fetal Alcohol Effects in 2000 and its inaugural meeting in December 2001;
- Creation of Centers for Excellence on FAS by SAMHSA in late 2001;
- The call to action by the National Organization on Fetal Alcohol Syndrome (NOFAS) on expanding the terminology on alcohol-related birth defects to include other effects that are less severe but more common than FAS and to use the umbrella term, Fetal Alcohol Spectrum Disorders (FASD);
- Re-issuance of the Surgeon General's Advisory on alcohol use during pregnancy in February 2005; and
- The designation of September ninth as National Fetal Alcohol Spectrum Disorders Day, a day for formal annual recognition of and focus on alcohol-related birth defects.

B. Progress Report and Strategic Plan FY2006-2010

OBJECTIVE I. Expanding Communication, Cooperation, and Collaboration among Federal Agencies

Recent Progress

Progress during FY2001-2005 is reflected in the greater than three fold average increase in the number of formal interactions among ICCFAS organizations. In the area of communications there were twice as many shared meetings, workshops, and planning and formal information exchanging sessions. Co-sponsorship of conferences, research programs, observational studies, and outreach activities more than tripled in number compared to the previous five year period. Representatives from ICCFAS member agencies dramatically increased service to each other more than eight fold, as speakers at conferences, meetings, and workshops and in writing articles for newsletters sponsored by others ICCFAS organizations. Likewise, providing assistance as advisors and consultants to fellow members and their agencies was four times more frequently than in the previous reporting period. These advisory and consultant roles were in the form of service on advisory committees, help with preparation of program announcements and requests for applications, review of proposals and assistance in launching outreach programs.

Strategic Plan 2006-2010

One of the guiding principles of the ICCFAS has been to use the diverse missions, strengths, and resources of the various member organizations to advance the effectiveness of the Federal response

to alcohol-related birth defects. During the next five year period, the ICCFAS and its member organizations will continue that tradition and expand even more on its policy of shared leadership through use of subcommittees and working groups led by different agencies to help set direction and apprise the ICCFAS of new opportunities for action in specific areas. Additional agencies whose mission and activities can enhance the Federal effort against alcohol-related birth defects will be asked to join the ICCFAS and/or participate in relevant ICCFAS working groups.

OBJECTIVE II. Documenting Prevalence and Identifying Children with FASD

Recent Progress

CDC introduced improved multi-source surveillance methods to better track the incidence and prevalence of FAS. Feedback from health care providers and others on the practicality of using the 1996 IOM recommended diagnostic criteria for individuals affected by prenatal alcohol exposure prompted a review and proposed improved implementation. In the summer of 2004 CDC and the Task Force, with advice from ICCFAS members, developed and published new guidelines for referral and diagnosis of FAS. In the same time frame, in other publications, CDC-, IHS-, and NIAAA-supported researchers proposed revised procedures, and improved interpretation and quantification of the IOM diagnosis criteria.

Strategic Plan 2006-2010

NIAAA, NICHD, and CDC will continue to fund studies to develop objective tests for prenatal alcohol exposure and early diagnosis of FAS and other negative outcomes of prenatal alcohol exposure. Studies of high risk populations nationally and internationally will continue as they provide unparalleled opportunities to study larger numbers of individuals in the same environment over short periods of time. New surveillance methods, diagnostic tools, cognitive development, factors affecting behavior, and effective coping strategies and mitigating variables will be studied.

OBJECTIVE III: Reducing Drinking During Pregnancy

Recent Progress

Outcomes from research funded by NIAAA and CDC, demonstration projects sponsored by HRSA, and a review and evaluation funded by the AHRQ have resulted in new and revised health care worker-friendly, quick, and reliable screening tools and recommendations for use of such in primary care settings and at prenatal sites. CDC, NIAAA, and NICHD continue to gather information on risky behaviors that increase the likelihood of alcohol exposed pregnancies. SAMHSA has provided funding and advice to States and communities to assist them in developing comprehensive programs for screening for alcohol misuse, early diagnosis of children, and improved services for individuals and families affected by prenatal alcohol exposure. To improve information sharing and enhance problem solving, partnerships have been formed between Federal agencies, State governments and communities, organizations of medical professions, and advocacy groups, and between IHS and Alaska Native communities and Health Canada and Canadian First Nations groups.

Strategic Plan 2006-2010

One of the areas that currently appear ripe for major emphasis during the next five years is reduction of drinking during pregnancy by promotion of universal screening for alcohol misuse by pregnant and non-pregnant women of childbearing age. An increase in risky drinking, revised and improved screening tools, recommendations from expert panels on effectiveness, and major public health campaigns for promotion of healthier life habits suggest that the ICCFAS' and its member organizations' planned promotion of universal screening, intervention, and referral for treatment is timely.

OBJECTIVE IV. Intervening with Children and Families Affected by Prenatal Alcohol Exposure

Recent Progress

Increased awareness of alcohol-related birth defects, recognition of individuals affected by FASD, and guidelines for giving and obtaining better services for individuals and families affected by FASD have been developed for educators, health care providers, juvenile justice and law enforcement personnel, and families by CDC, ED, HRSA, IHS, NIAAA, OJJDP, and SAMHSA. Research and longitudinal observation studies funded by NIAAA, NICHD, and CDC have provided new information on characterizing FASD into adolescence, factors that can mitigate outcomes, and better understanding of the compromised cognitive, behavior, and social functions.

Strategic Plan 2006-2010

During the next five years, major ICCFAS emphases for improving the lives of individuals and families affected by FASD will be led by the ICCFAS working groups on education and juvenile justice. The ED led working group will evaluate current FASD-related materials for educators, identify gaps where additional materials are needed, and promote the use of such materials for the classroom. In addition, the ICCFAS education working group and the Department of Education FASD Work Group will survey and evaluate how children with FASD are currently served in our education systems, whether standard testing procedures adequately identify the disabilities common in persons with FASD, and if new remedial approaches and methods are needed to educate children with the disabilities associated with FASD. The ICCFAS Juvenile Justice working group will continue its campaign to increase awareness and educate justice and law enforcement officials about FASD and the disabilities that result from prenatal alcohol exposure. The Juvenile Justice working group, the Department of Justice, and other ICCFAS member organizations will attempt to gather substantive information on how many individuals with FASD are in the justice system, how we can introduce regular screening for FASD there, how persons with FASD are treated by State and Tribal courts, and how rehabilitative services can be improved for persons with the disabilities associated with FASD. In addition, awareness of FASD will be promoted in national education and juvenile justice forums and venues.

OBJECTIVE V. Increasing Research on the Etiology and Pathogenesis of Alcohol's Prenatal Toxicity

Recent Progress

Recent results from NIAAA- and NICHD- funded research are beginning to clarify neurological mechanisms, mediators, modulators, and specific pathways of alcohol-induced prenatal brain cell

loss, disruption of brain cell migration during development, impairments in learning and memory, reduced brain mass, and visual deficits. Data from research on fetal growth restriction have implicated factors involving disruption of vasodilation mechanisms which results in deficient blood vessel development and poor blood flow in placenta. New data from research using various animal models indicate that prenatal alcohol exposure produces changes in regulatory pathways resulting in altered stress responses and disruption of biorhythms.

Strategic Plan 2006-2010

Development of new therapies and new applications of existing therapies for FASD are dependent on knowledge and understanding of mechanisms of action of alcohol's toxic effects on the developing fetus. NIAAA and NICHD will continue to fund research to elucidate vulnerability and putative protection due to genetic, physiological, metabolic, and nutritional variation. In addition, studies on the effects of different postnatal environments on later outcomes in those prenatally exposed will be encouraged. Funding will continue for community linked studies on clarification of the role of prenatal alcohol exposure in stillbirths and Sudden Infant Death Syndrome (SIDS).

OBJECTIVE VI. Improving Educational Outreach, Training, and Information Dissemination about FASD

Recent Progress

Recent enhanced availability of Internet communication capability was seized upon by all ICCFAS member organizations to increase information dissemination, provide on-line training and educational materials, and quick and easy procedures for requesting more information or advice. SAMHSA's Center of Excellence capitalized on its information technology strengths to develop an unusually extensive on-line searchable collection of FASD-related materials and an interactive Web-based information center.

Strategic Plan 2006-2010

All ICCFAS member organizations will promote the use of the dozens of informative materials, guidelines, and curricula developed in the past few years for the public, community leaders, policy makers and advocacy groups, health care providers and education and justice professionals. We will enhance dissemination of best practices for identifying women at risk for alcohol misuse, and improving intervention and treatment for alcohol use disorders. In addition, we will continue to support FASD-related conferences and workshops to stimulate new research, to promote increased awareness, and to help mobilize States, communities, and other organized groups to improve systems of care for individuals and families affected by FASD.

C. Monitoring Progress

Progress will be monitored and reviewed throughout the year during teleconference calls, regular Internet communications, and documented at semi-annual ICCFAS meetings. In addition to the general memberships' oversight of progress and implementation of the new strategic plan, the ICCFAS working groups will provide specific direction, recommendations, and evaluation of progress made.

II. INTERAGENCY COORDINATING COMMITTEE ON FETAL ALCOHOL SYNDROME PROGRESS REPORT AND STRATEGIC PLAN FY2006-2010

A. Introduction

It is with pleasure that the organizations represented on the Interagency Coordinating Committee on Fetal Alcohol Syndrome (ICCFAS) present a report on progress over the last five years and plans for the next five years which capitalize on the strengths and resources of each agency. The ICCFAS and its members have made significant contributions toward addressing Fetal Alcohol Syndrome (FAS) and related negative effects of prenatal alcohol exposure through public education, training of professionals, pilot prevention and treatment interventions, cutting-edge research, and efforts to facilitate the creation of comprehensive systems of care at the state and community level.

The ICCFAS was created, in October 1996, in response to a report by an expert committee of the Institute of Medicine (IOM). The IOM report, issued in 1996, is titled *Fetal Alcohol Syndrome: Diagnosis, Epidemiology, Prevention, and Treatment* (Stratton et al, 1996). The report recommended that the National Institute on Alcohol Abuse and Alcoholism (NIAAA) chair a Federal effort to coordinate Fetal Alcohol Syndrome (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 is chaired by the Deputy Director of NIAAA.

During its initial four years of existence the ICCFAS made significant progress in gaining the support and continued participation of relevant government agencies. Member agencies expanded their scope of activities relevant to the prevention, treatment, and understanding of FAS and sponsored workshops and conferences to stimulate an exchange of information between subject matter experts and ICCFAS agencies and their public. A report on these activities was presented to Congress in 2000. During 2001-2005 the momentum from this effort was carried to the next level with an increase in the development of significant programs in many of the member organizations.

Mission and Vision of the ICCFAS

The mission of the ICCFAS is to exchange information, develop collaborations and partnerships among Federal agencies to address FAS and related conditions more effectively. The ICCFAS promotes and facilitates the development of projects and programs within and between member agencies to:

1. Prevent at risk drinking and improve the quality of interventions and treatments for all women of childbearing age.
2. Improve health care, education and correctional interventions and services for children and adults affected by prenatal alcohol exposure.
3. Foster basic research to identify mechanisms of alcohol teratogenesis, to improve prevention, and to develop appropriate treatments.

The vision of the Interagency Coordinating Committee on Fetal Alcohol Syndrome is that a collaborative partnership using the resources of government agencies and other organizations will:

1. Reduce the prevalence of children affected by prenatal exposure to alcohol;
2. Provide appropriate interventions and support to persons affected by Fetal Alcohol Spectrum Disorders (FASD) and their families; and
3. Build sustainable approaches within existing systems to properly address the disorders.

Progress in Terminology Development

Fetal Alcohol Syndrome (FAS) is the term coined by Jones and Smith in a 1973 publication describing the teratogenic effects of alcohol in children of alcoholic mothers in the U.S. Since that time significant resources and attention at many levels of government have been devoted to improving diagnosis, treatment, and prevention of FAS and increasing understanding of alcohol teratogenesis. Over the past two decades 90 – 100 articles per year have been published on basic, biomedical, and psychosocial studies of this fetal developmental disorder. Early research efforts were focused on one of the most well known consequences of prenatal alcohol exposure, FAS. This devastating birth defect is characterized by craniofacial malformations, neurological and motor deficits, intrauterine growth retardation, learning disabilities, and limited behavioral and social skills.

In recent years we have come to understand not only that the teratological effects of alcohol cover a broad range of human structures and functions, but also that there is great variability in the severity of the deficits. The scope of disabilities and malformation varies and depends on such exposure factors as the amount of alcohol, frequency of exposure, stage of development when alcohol is present, individual differences in sensitivity, and probably variation in both maternal and fetal alcohol metabolism. FAS remains one of the most serious known consequences of heavy drinking during pregnancy. Research is beginning to address other possible consequences of prenatal alcohol exposure such as stillbirth and sudden infant death syndrome (SIDS).

In 2004 representatives from ICCFAS agencies responded to a call from the National Organization on Fetal Alcohol Syndrome (NOFAS), the nation's leading non-profit organization dedicated to preventing the detrimental effects of prenatal alcohol exposure. The purpose of the meeting was to bring together Federal representatives, research scientists, and other interested parties to define a term to include comprehensively the various outcomes of prenatal exposure to alcohol. The umbrella term "Fetal Alcohol Spectrum Disorders (FASD)" is now used to characterize the full range of prenatal alcohol damage varying from mild to severe and encompassing a broad array of physical defects and cognitive, behavioral, and emotional deficits. It refers to conditions such as:

- Fetal alcohol syndrome (FAS), including partial FAS
- Fetal alcohol effects (FAE)
- Alcohol-related neurodevelopmental disorder (ARND)
- Alcohol-related birth defects (ARBD)

The expressions, "FAS," "FASD," and "results of prenatal exposure to alcohol," are used variably throughout this report as deemed appropriate to the context of the item or sentence.

Current Estimates of Prevalence

Estimates of prevalence of FAS vary widely depending on the epidemiological methodology used, the assessment tool used for the diagnosis, the population studied, and the age of the individuals at

assessment. Considering data from many different kinds of studies, a good general estimate of the prevalence rate of FAS is 2 cases per 1,000 individuals in the U.S. (Abel, 1995; May and Gossage, 2001; Meany et al, 2003). Moreover, other FASD, such as ARND and ARBD, are expected to be significantly more frequent than FAS but are more difficult to diagnose. Recent estimates of the prevalence of FAS, ARND, and ARBD are 10 cases per 1,000 children (Sampson et al, 1997; May and Gossage, 2001) or 40,000 born per year. For more details see Part III, Section A, Item 1.

Cost to Society

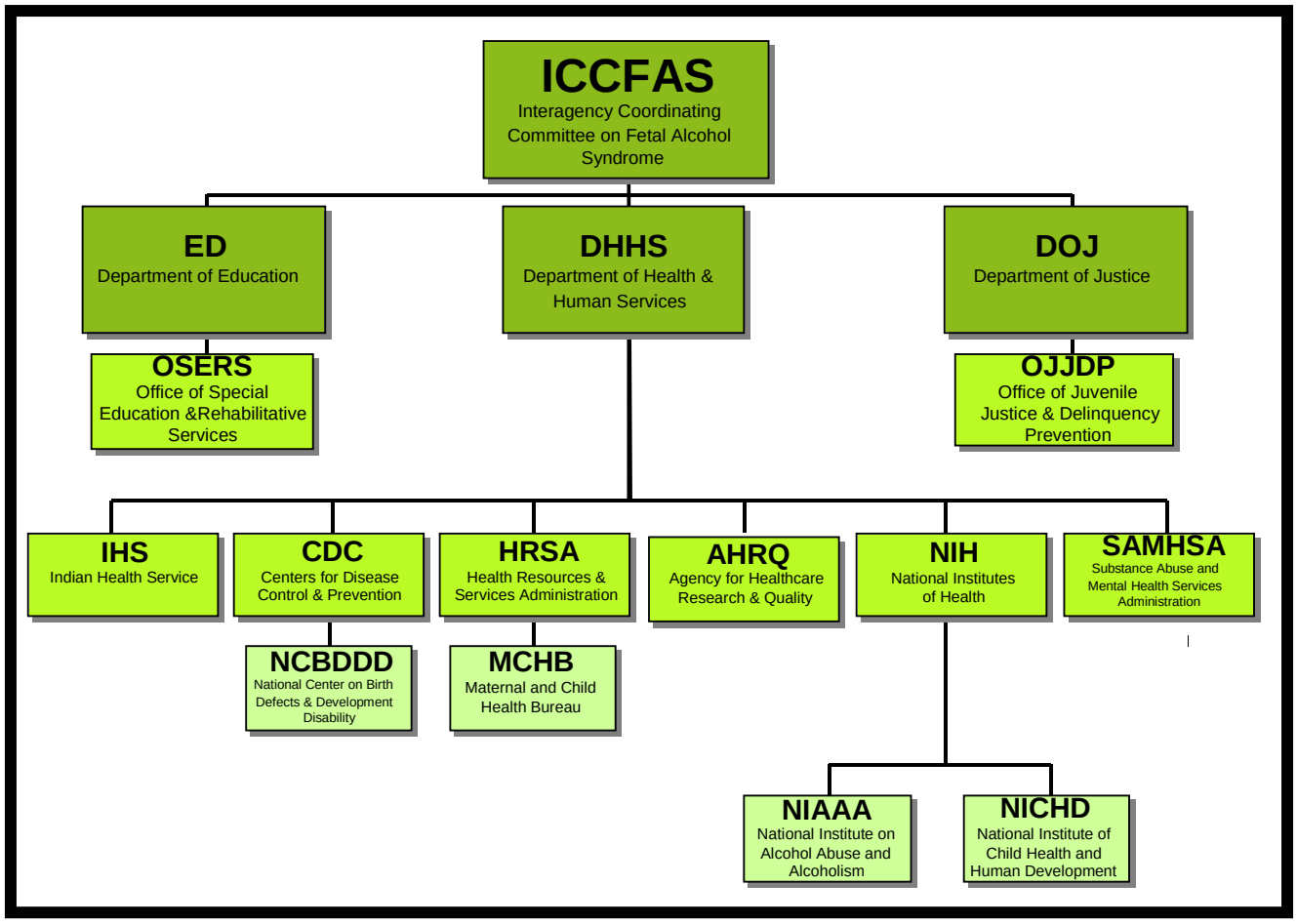
Assuming a prevalence rate of 2 cases per 1000 live births, the economic cost of FAS in 2002 in the U.S. was estimated to be $3.6 billion for medical care and residential and social services for individuals to age 65 (Lupton, Burd and Harwood, 2004). Lost productivity - due to the increased incidence of brain dysfunction and mental retardation in adults in this population - adds another $1.3 billion in 1998 dollars (Harwood, 2000). Cognitive, behavioral, emotional, and social problems in children with FASD often lead to mental disabilities, substance abuse problems, struggles in school, and involvement with the corrections systems. Lifetime costs of FAS alone are estimated at $2 million (in 2002 dollars) per individual, not including costs to society such as incarceration, burden on families, and poor quality of life (Harwood and Napolitano, 1985; Lupton et al, 2004). For more details see Part III, Section A, Item 1.

Evidence of the Potential for an Increase in Prevalence

Like U.S. national trends, binge and heavy drinking by women of childbearing age are on the rise. Data from the 2000 National Alcohol Survey indicate that previous year alcohol consumption would classify 30 percent of women of childbearing age as engaging in risky drinking (Nayak and Kaskutas, 2004). Furthermore, in 2001-2002 more than 5 percent of U.S. women of childbearing age met DSM-IV diagnostic criteria for alcohol abuse or dependence (Grant et al, 2004; Hasin and Grant, 2004). Despite warning labels, public service announcements, and dozens of articles each year about the risk of fetal damage due to alcohol exposure, 12.5 percent of pregnant women reported some use of alcohol in 2001 (Floyd and Sidhu, 2004). Most alcohol use during pregnancy is low to moderate but we know of no safe level of consumption during pregnancy. For more details see Part III, Section A, Item 1.

Structure of the ICCFAS

The challenge facing the ICCFAS is to improve communication and cooperation among disciplines that address health, education, developmental disability, research, justice, and social service issues relevant to FAS and related disorders. Current membership of the ICCFAS includes representatives from the Department of Health and Human Services (DHHS), the Department of Education (ED), and the Department of Justice (DOJ) (see organizational chart below). Names and contact information of agency representatives to the ICCFAS are listed in the Part II, Section C.



Noteworthy Actions at the Federal Level Advancing the Fight against Fetal Alcohol Damage

Re-Issuance of the Surgeon General's Advisory

On February 21, 2005, the U.S. Surgeon General updated the 1981 warning about alcohol use during pregnancy. Dr. Carmona advised that: 1) a woman should not drink alcohol during pregnancy; 2) a pregnant woman who has already consumed alcohol during her pregnancy should stop in order to minimize further risk of fetal alcohol damage; 3) a woman who is considering becoming pregnant should abstain from alcohol; 4) recognizing that nearly half of all births in the United States are unplanned, women of childbearing age should consult their physicians and take steps to reduce the possibility of prenatal alcohol exposure; and 5) health professionals should routinely inquire about alcohol consumption by women of childbearing age, inform them of the risks of alcohol consumption during pregnancy, and advise them not to drink alcoholic beverages during pregnancy.

Creation of the Center for Excellence on FASD by the Substance Abuse and Mental Health Services Administration (SAMHSA)

Under the Children's Health Act of 2000 (H.R. 4365, section 519D) Congress mandated the creation of "Centers of Excellence on services for individuals with fetal alcohol syndrome and alcohol-related birth defects and treatment for individuals with such conditions and their families." In response to the congressional mandate, in June 2001 SAMHSA established a Center for Excellence to promote comprehensive systems of care, provide information and technical assistance to States and communities, provide training, and develop prevention and intervention techniques.

Establishment of the National Task Force on FAS/FAE

The National Task Force was established in 2000 to provide recommendations to organizations at the Federal, State and local levels. The Task Force, which held its first meeting in December of 2001, is a chartered advisory group administered and managed by the Fetal Alcohol Syndrome Prevention Team of the National Center for Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention. The membership includes research scientists, persons with FASD, advocacy group representation and public members. The convener and chair of the ICCFAS is a standing member of the Task Force. For more details and the recommendations of the Task Force see Part III, Section C.

Designation by Congress of September 9 as "National Fetal Alcohol Spectrum Disorders Awareness Day"

On May 12, 2005, the Senate passed the resolution designating September 9 for formal recognition of FASD and prevention of alcohol-related birth defects. The ninth day of the ninth month is symbolic for the nine months of pregnancy. This special designation will provide an opportunity for ICCFAS member agencies to focus on disseminating information on FASD and prevention of FASD and to join with other organizations in this effort.

B. Progress Report and Strategic Plans

Examples of progress under each overall goal will be cited. Strategic and joint goals and action items for the next five years have been developed with the following assumptions:

1. There will be modest increases in agency budgets over the next 5 years and additional support to address FASD will require modifications to existing programs.
2. Funding for agency programs to address FASD will continue at least at the current levels.
3. States will continue to develop interest in building FASD into their systems of health, education and justice.

OBJECTIVE I. Support Communication, Cooperation, and Collaboration among Federal Agencies

Communication, collaboration, and cooperation are fostered and promoted among ICCFAS members through meetings, informal discussions, and the overall exchange of ideas and updates of new findings and activities in conversations and electronic missives. Strategies on how activities in different agencies can complement each other and how synergy can be achieved are the primary focus of these exchanges. Leveraging the work of member organizations through more collaborative and cooperative activities will remain a key strategy. The member organizations have diverse missions and unique strengths. Some generate new knowledge through research funding. Other agencies fund translational research and that feeds back to promote basic research. Others promote and assist in the development and improvement of health care delivery services by States and community organizations.

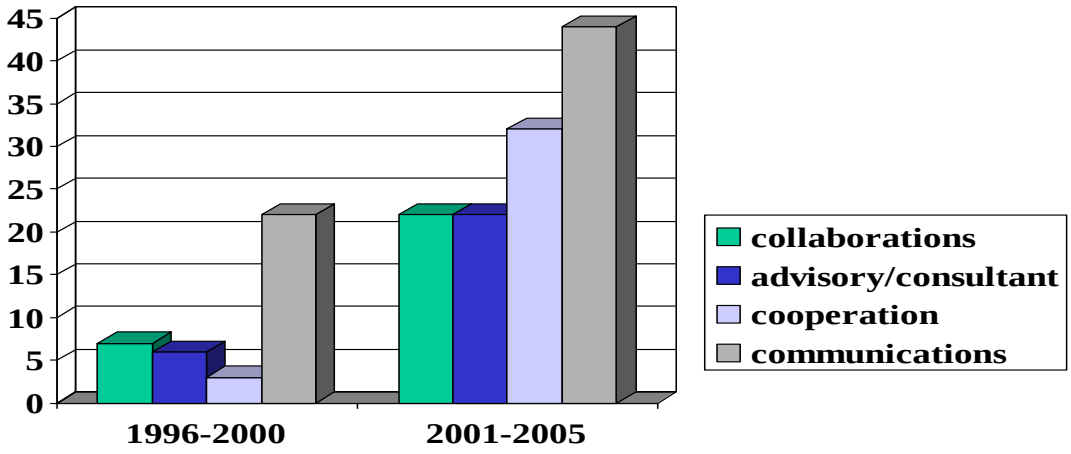
Examples of Progress

- The ICCFAS has fostered communication and exchange of ideas, cooperation, and collaboration during the regular meetings of the Committee, through workshops and meetings sponsored by the ICCFAS or its member organizations, and by joint attendance at such. In the past 5 years the ICCFAS has met 10 times to exchange ideas and plan for future collaborations. These meetings have been characterized by presentations of selected progress reports highlighting the activities, program, and resources of the different Federal organizations. (For a list of sponsored workshops, symposia, and conferences see Part III, Section A, Item 3.b.vi.)
- ICCFAS members have served in a variety of roles with respect to SAMHSA's FASD Center for Excellence: as formal advisors at Center Steering Committee meetings; as collaborators and reviewers of RFP's; and as speakers and trainers at State and community workshops and town hall meetings. The Deputy Director for NIAAA serves as the primary Federal advisor to the Steering Committee for the Center.
- ICCFAS members have cooperated with the Task Force by advising on the new guidelines developed for diagnosis and referral of FAS, providing presentations at meetings and assisting in the development and promotion of the Surgeon General's 2005 Advisory on Alcohol Use in Pregnancy.
- The ICCFAS membership and the Department of Education (ED) Work Group on FAS/ARND sponsored a FAS workshop at a National Childhood Early Interventions Meeting. The ED representative to the ICCFAS leads the ICCFAS subgroup on Education.

Members of this subgroup include ICCFAS members, educators, educational psychologists, research scientists, and others. Members of the subgroup provide recommendations to the ICCFAS for improving the education of children affected by FASD. (See Part II, Section D Item 1.)

- The ICCFAS Work Group on FASD and Juvenile Justice and Delinquency Prevention is chaired by the Justice Department representative to the ICCFAS. This subgroup of the ICCFAS is focusing on developing guidelines and curricula about FASD for training juvenile justice, legal, and law enforcement professionals. (See Part II, Section D, Item 3.)
- A March 2001 workshop, "The Identification and Treatment of Alcohol Use Disorders among Women of Childbearing Age," was sponsored by NIAAA and the NIH Office of Research on Women's Health and included service providers from SAMHSA. The panel assembled for this workshop was charged with identifying best practices for screening and treatment of women of childbearing age who have alcohol use disorders. This group comprised of treatment researchers, clinical specialists, and service providers made several recommendations to the ICCFAS based on gaps in knowledge and barriers to effective approaches to screening, intervention, and treatment of women of children bearing age with alcohol dependence, alcohol abuse, and those who engage in other risky drinking behaviors. See Part II, Section D, Item 2 for their recommendations.
- ICCFAS organizations had many opportunities for increased communication about FASD-related matters during the past five years. Seizing on these opportunities resulted in twice as many formal communication sessions as in the previous five year period. In addition, formal collaborations, consultant activities, and cooperative efforts were four times as frequent in the past five year period as in the previous five year period. See chart below.

In the Past Five Years Formal Interactions Among ICCFAS Member Organizations Have Increased Dramatically.



Collaborations – co-sponsorship of conferences, research programs, observational studies, and outreach activities
Advisory/consultant – serve on advisory committees, help with preparation of program announcements (RFP's) and review of proposals, assist with launch of outreach programs
Cooperation – serve others by speaking at meetings, writing articles for newsletters, etc.
Communication – shared meetings, workshops, planning sessions of work groups, information sharing within the ICCFAS and between the ICCFAS and the Task Force

Plans for increased cooperation among agencies, FY2006-2010

The concept of distributed leadership will be used to increase cooperation and collaboration within the ICCFAS agencies on projects of mutual interest. Working groups allow the membership of the ICCFAS to work with a lead agency and some outside experts to plan and develop actions on a specific issue. There are other agencies within the Federal government whose missions and programs could assist in preventing FASD or addressing the needs of children affected by FASD. Further, research on FASD has progressed to the extent that collaboration with other NIH research institutes is needed.

ACTION PLANS AND RESPONSIBLE ORGANIZATIONS

- Maintain two existing ICCFAS working groups and add a third:
  1. The Department of Education led group on the identification and education of children with FASD in schools will continue
  2. The Department of Justice led working group concentrating on juvenile justice issues will continue.
  3. ICCFAS will establish a new working group on reducing alcohol misuse and intervening and treating women of childbearing age.
- Invite other Federal agencies to participate in ICCFAS meetings and working groups. These include the Bureau of Justice Assistance, Department of Justice; the Department of Agriculture, Division of Nutrition; and the Administration on Developmental Disabilities. (NIAAA)
- NIH Institutes whose missions include research on developmental disabilities and approaches to addressing these will be consulted by NICHD and NIAAA. These include the National Institute on Mental Health and the National Institute on Neurological Diseases and Stroke. During the previous reporting period these Institutes participated in a workshop on determining the differential diagnosis of FAS. Additional collaborations will be pursued. (NIAAA, NICHD)
- ICCFAS agencies will periodically cosponsor and participate in workshops and conferences focused on summarizing current evidence, identifying gaps in knowledge, and cross-cutting issues of concern in the reduction of drinking in pregnancy, identification and prevention of FASD, improving the quality of life for persons and families affected by FASD, and increased understanding of alcohol teratogenesis. (ICCFAS agencies)
- Prevalence of mental health problems among women who misuse alcohol during pregnancy is very high. In order to expand our efforts in addressing such comorbidity the National Institute of Mental Health will be asked to participate in the ICCFAS. (ICCFAS, NIAAA)
- ICCFAS will meet twice each year as a group to reinforce and increase collegiality and to facilitate the sharing of ideas that provide advice to each other on major projects and programs. (ICCFAS, NIAAA)

OBJECTIVE II. Document the Prevalence and Identify Children with FASD

The FY2001-2005 strategic plan identified the need for epidemiological studies, surveillance, monitoring of cases, and characterization of individuals negatively affected by prenatal alcohol

exposure. This included a need for developing and refining methods and procedures for accurately screening large numbers of children, assessing the characteristics and clinical expression of FAS and ARND across the lifespan, and identifying facial anomalies and how they may correlate with cognitive and behavioral features of FAS and ARND.

Examples of Progress and Responsible Organizations

- The FAS Surveillance Network (FASSNet), an improved multi-source record passive surveillance system, was developed for identifying children with FAS in different populations. Results indicate an overall 3-year FAS prevalence rate of 0.3 to 0.4 per 1000 live-born infants in the test States of Arizona, Colorado, and New York, but a rate of 1.5 in Alaska, due primarily to a high rate among American Indians and Alaska Natives people (AI/AN). These prevalence rates are higher than CDC rates published in the 1990's and that is probably due to better ascertainment by this multi-source method. (CDC)
- A continuing study of more than 400 individuals who had prenatal alcohol exposure through heavy maternal drinking has revealed long term negative effects of this exposure on social development during the adolescent and young adult years. Current data also demonstrate mitigation of these adverse life outcomes by early diagnosis and good stable environments. (NIAAA, CDC, IHS)
- The maintenance of a multi-disciplinary and multi-national team of clinicians and scientists to study FASD nationally and in six foreign countries each with a higher prevalence of FAS than the United States has resulted in the development of prospective methods to estimate the prevalence of FAS, an increased understanding of the maternal risk factors (including genetics and metabolism) for having an child affected by FASD and improved documentation of the cognitive deficits in children affected by FASD. (NIAAA)
- Prevention and surveillance methods have been improved through collaborations in South Africa and Denmark. (CDC)
- Alaska has increased reporting of births affected by alcohol to its Birth Defects Registry as a result of its new comprehensive diagnostic services developed under the Alaska Statewide Fetal Alcohol Syndrome Five-Year Comprehensive Project. (SAMHSA)
- New comprehensive guidelines have been developed and published for referral and diagnosis of FAS to educate the medical and allied health fields about FAS. (CDC)
- Revised procedures for using IOM guidelines for early screening and diagnosis of children with FAS have been developed and evaluated. The results of such procedures have been published. (IHS, CDC, NIAAA)
- NICHD researchers have published easy to use scales of normal neurobehavioral characteristics of neonates. These scales have been developed to allow identification of at-risk newborns and may be a useful adjunct to other tools in the development of multiple parameter schemes for improved identification of FASD at birth. (NICHD)
- Researchers recently reported preliminary results indicating that children with heavy prenatal alcohol exposure can be distinguished from non-exposed children with greater than 90 percent accuracy using freedom from distractibility and attention problem scales of commonly available neurobehavioral assessment tools. (NIAAA)
- Preliminary data have identified and validated some fatty acid ethyl ether ester metabolites as having high potential for use of meconium (first stool) based biomarkers for fetal alcohol exposure. Clinically useful application is being investigated and additional research has been

funded that seeks to find other quantitative biomarkers for prenatal alcohol exposure. (NIAAA, CDC)

- 3-D facial imaging studies and MRI studies are underway to determine the full range of structural defects in FASD and their relationship to changes in neurobehavioral development. (NIAAA)

Plans to Improve Surveillance and Identification

Research results indicate that early identification of children affected by FASD with support to families and an educational intervention is critical to preventing the secondary disabilities which can occur with FASD. Enhanced methods for identification and improved surveillance methods are needed so that States can target areas of high risk and provide the necessary services.

Action Plans and Responsible Organizations

- Integrate programs for the surveillance of FASD with those for other developmental disabilities. (CDC)
- Support research on the characteristics and clinical expression of FASD across the lifespan and validate diagnostic tools in different ethnic populations. (NIAAA)
- Gather data on the prevalence of individuals with FASD in the justice system. (DOJ, SAMHSA)
- Collect surveillance information regarding how American Indian and Alaska Native people address juvenile offenders affected by FASD in tribal courts. (IHS)
- Continue to support research to improve preliminary screening, diagnosis, and procedures to develop objective markers of exposure. (NIAAA, NICHD, CDC)
- Convene a workshop or conference to review progress made implementing updates of the diagnostic guidelines. Distribute the results to appropriate providers. (CDC)
- Encourage research for the development of objective biomarkers of prenatal exposure based on recent advances in diagnostic imaging and new biotechnologies, such as, genomic, proteomic, and metabolomic schemes. (NIAAA)
- Continue to collaborate on methods to identify less severe forms of FASD. (ICCFAS, CDC, NIAAA, ED)
- Encourage increased used of uniform FAS assessment tools within Native American populations. (IHS, CDC)
- Integrate FAS evaluation into existing systems for assessing developmentally delayed children. (ED, DOJ)
- Support studies on FASD-related secondary disabilities, including comorbid substance abuse and other mental health problems in persons affected by prenatal alcohol exposure. (NIAAA)
- Explore screening mechanisms and algorithm development to identify multiple informative factors to predict overall risk. (SAMHSA)

OBJECTIVE III. Reduce Drinking During Pregnancy

FASD is 100 percent preventable. Decreasing drinking during pregnancy was one of the key objectives of the FY2001-2005 strategic plan. During the last 5 years there was a significant increase

in the number of projects funded by ICCFAS members for dissemination of information, improvement of services, and research on prevention of drinking during pregnancy.

Examples of Progress and Responsible Organizations

- Studies show that screening and brief intervention or motivational interviewing substantially reduce women's preconception and prenatal drinking levels. Some studies have focused on low and moderate-income women at high risk for alcohol abuse. CDC's Project CHOICES (**C**hanging **H**igh-Risk Alc**O**hol Use and **I**ncreasing **C**ontraception **E**ffectiveness **S**tudy) has focused on high-risk sexually active college-age women engaging in risky drinking and not practicing effective contraception. (NIAAA, CDC)
- Methods that are brief, valid, and efficient to screen women for alcohol use at primary care settings and in prenatal visits have been developed, have been shown to increase overall screening, and are being implemented in clinics. (SAMHSA, NIAAA, HRSA/MCHB)
- Screening and, when appropriate, referral for further evaluation and treatment, of women of childbearing age, during the National Alcohol Screening Day for public awareness about alcohol's effects, has grown from approximately 400 in 2001 to more than 8,000 screened in 2004. (NIAAA, SAMHSA)
- ICCFAS and the Task Force are coordinating a year long effort for highlighting the Surgeon General's 2005 advisory against drinking during pregnancy. The advisory is being highlighted in newsletters, on Web sites, in announcements to stakeholders at meetings, and in published letters, articles, and brief notices throughout the year. (ICCFAS member organizations)
- In spring 2004, the U.S. Prevention Services Task Force (USPSTF) recommended screening and behavioral counseling interventions to reduce alcohol misuse by adults, including pregnant women, in primary care settings. (AHRQ)
- The National Longitudinal Study of Adolescent Health increases understanding about the determinants and consequences of heavy alcohol consumption and other high-risk behaviors among women of childbearing age. New reports from this study indicate that ambivalence toward pregnancy in adolescent girls in grades 9 through 11 has been shown to be predictive of the occurrence of pregnancy. Thus defining a potentially high-risk population. (NICHD)

Plans to Decrease the Prevalence of FASD through Prevention, Intervention, and Treatment of Alcohol Misuse by Women of Childbearing Age

Although significant progress has been made during the past 5 years, additional work is still needed in collaboration with States and communities. The findings from research conducted by NIAAA and CDC and demonstration projects sponsored by HRSA/MCHB indicate that there are reasonable and feasible approaches that might be implemented. A large body of knowledge has emerged on the success of screening and brief interventions in health care settings.

Action Plans and Responsible Organizations

- Support research studies to increase understanding of the mechanisms for behavior change to enhance progress in prevention and intervention studies and improve treatment approaches for alcohol use disorders. (NIAAA)
- Improve access to care for alcohol-abusing and high-risk women of childbearing age. (SAMHSA, HRSA)

- Continue monitoring and reporting the prevalence of alcohol misuse by women of childbearing age. (CDC, NIAAA)
- Maintain high visibility of the impact of alcohol misuse - including FASD - among women of childbearing age. (SAMHSA, HRSA, CDC)
- Promote universal screening for alcohol use disorders by health care providers. (NIAAA, SAMHSA, HRSA, CDC, IHS)
- Evaluate and promote best practices, especially use of newly developed or revised alcohol abuse and dependence assessment tools. (CDC, HRSA, ICCFAS, IHS, SAMHSA, NIAAA)
- Support studies of new methods to motivate pregnant and non-pregnant women of childbearing age to reduce their alcohol consumption. (NIAAA, CDC)
- Continue to support epidemiological research on co-occurrence of alcohol use disorders and other mental health problems in women of childbearing age. (NIAAA)
- Support studies on reduction of risky alcohol use in adolescents in both the short term and in changing the trajectory away from unhealthy use throughout life. (NICHD, NIAAA, OJJDP)

OBJECTIVE III and OBJECTIVE IV, Combined Programs. Reduce Drinking During Pregnancy and Intervene with Children Affected by FASD and Their Families

The FY2001-2005 ICCFAS strategic plan included several projects having substantial overlap in prevention of drinking during pregnancy and intervention with children and families affected by the detrimental effects of prenatal alcohol exposure. These more comprehensive programs have made significant progress to achieve ICCFAS objectives.

Examples of Progress and Responsible Organizations

- ICCFAS member agencies have provided funding to States to assist them in developing comprehensive programs for prevention, early diagnosis, and improved services to individuals and families affected by FASD. (HRSA/MCHB, SAMHSA, CDC)
- Federal agencies, organizations of medical professionals, State governments and community groups have formed partnerships to expand the knowledge base on prevention and intervention systems and identify ways to improve through shared solutions. Alaskan and Canadian First Nations groups have also formed such partnerships. (CDC, SAMHSA, IHS)
- Through a Statewide Fetal Alcohol Syndrome Five-Year Comprehensive Project, Alaska has not only developed new prevention programs, but also has developed the most comprehensive FASD diagnostic services in the country. Diagnostic services are linked to the State's birth defects registry, and identified individuals and families are referred for needed treatment and services. (SAMHSA)
- ICCFAS member organizations have funded conferences to present overall best practices for screening for alcohol use in pregnancy and conferences for identifying effective intervention models and therapies for individuals with FAS/FASD. (AHRQ, CDC, IHS and SAMHSA, ICCFAS and NIAAA)
- Education of women in recovery to increase their awareness about FASD and encourage screening of their children has been piloted thrice as part of an innovative women's summit model, "Women in Recovery Summits." (SAMHSA)

Plans to Increase Effectiveness through Combined Programs

Activities combining prevention and intervention strategies frequently have resulted in synergy and improved overall outcome in many settings. To promote and increase the number of combined programs and to expand and improve the response of service systems, partnerships have been formed between Federal agencies, organizations of medical professionals, and local governments.

ACTION PLANS AND RESPONSIBLE ORGANIZATIONS

- Encourage, support, and advise State level programs and community based organizations to integrate comprehensive systems of coordinated services for the prevention, identification, and treatment of FASD into their existing delivery systems. (HRSA, SAMHSA)
- Support Tribal projects to reduce the level of FAS through development of effective programs and multidisciplinary collaborative partnerships. (IHS, SAMHSA)
- Encourage projects to identify and monitor high-risk women of child bearing age who may have been prenatally exposed to alcohol. (SAMHSA, IHS, OJJDP)
- Expand programs aimed at reducing the impact of family and community violence (including abuse and neglect) on young children through increasing access to quality prevention programs and identification, referral, and intervention for children and families in need of services. Because of the strong relationship between alcohol use disorders and violence many of the families served by such programs will have children with one of the FASD or be at risk for future alcohol exposed pregnancies. (SAMHSA, OJJDP)
- Address mental health conditions that co-exist with alcohol use disorders in women of childbearing age through fostering interactions between alcohol treatment and mental health providers. (SAMHSA)
- Support FASD consultation and services for American Indian and Alaska Natives and other specific communities through agreements with appropriate regional specialists. (IHS)
- Continue to sponsor activities for women in recovery who have children with FASD to share experiences and discuss with experts the difficulty of recovery, understanding FASD, the impact of FASD on families, and how to get help. (SAMHSA)
- Increase support for FASD-related research on health promotion, disease prevention, and health disparities that is jointly conducted by communities and researchers. (AHRQ, CDC, NIAAA, NICHD)
- Explore screening mechanisms and algorithm development to identify multiple informative factors to predict overall risk. (SAMHSA)

OBJECTIVE IV. Intervene with Children and Families Affected by Prenatal Alcohol Exposure

Another goal of the FY2001-2005 Strategic Plan was to expand the range of high-quality services available to children and families affected by prenatal alcohol exposure. The plan identified several areas for development that the ICCFAS agencies have pursued through new and existing programs.

Examples of Progress and Responsible Organizations

- Basic research using animal models is being funded to explore potential medications and nutritional supplements that may improve developmental outcomes in children with FASD. For example, postnatal choline supplements to rats prenatally exposed to alcohol have been shown to improve learning and memory problems. (NIAAA, NICHD)
- Head Start programs in American Indian and Native Alaskan (AI/NA) communities include a mental health curriculum and mental health screening and consultation. IHS and Tribal behavioral health staff provide classroom observation for Head Start programs to identify children with emotional or behavioral problems for early intervention. (IHS)
- Promising preliminary data have shown that a computerized virtual reality Safety Skills Training Program on home fire safety can help children practice corrective safety actions and better understand cause and effect, often a problem in children with a FASD. (NIAAA)
- ICCFAS agencies have developed information programs and training on FASD for professionals and general public and have held workshops and programs for their constituents on FASD issues and on improving lives of individuals and families affected by prenatal alcohol exposure. (IHS, CDC, SAMHSA)
- Individuals with FAS and ARND have both cognitive and social skills deficits. Preliminary results from a recent research study demonstrate a significant relationship between poor social functioning and some of the cognitive skills (planning, decision making, and verbal fluency) that are weak in individuals with FASD. To be effective, social skills training programs must be tailored to the cognitive skills of the persons to be trained. (NIAAA)
- Educational curricula and guides have been developed for school staff and law enforcement personnel and for parents and families, including information on how to secure access to appropriate services for children with a FASD and their families. (ED, IHS, OJJDP, NIAAA, HRSA, CDC)
- Several ICCFAS organizations have funded new programs to improve access to State and community systems that assist families in need. (SAMHSA, IHS, OJJDP)
- ICCFAS organizations have funded several projects that are developing educational and psychosocial interventions aimed at improving developmental outcomes, reducing secondary disabilities of individuals with a FASD, and improving the lives of families affected by prenatal alcohol exposure. (CDC, IHS, NIAAA)
- Specific behavioral impairments associated with a FASD (e.g., hyper-reactivity to stress) have been investigated and the potential for mitigation through enriched postnatal environments is being explored. (NIAAA)

Plans To Improve the Lives /Mitigate the Effects of Prenatal Alcohol Exposure on Individuals and Their Families

Recent progress in understanding brain plasticity and in the enumeration of the disabilities produced by prenatal alcohol exposure provide new opportunities to mitigate the life outcomes of FASD and improve the quality of life for children and families affected by prenatal alcohol exposure. Some ICCFAS member organizations have recently begun to make progress in promoting integrated systems of care that support a synergistic comprehensive approach. Much work lies ahead on the application of new approaches to these problems.

Action Plans and Responsible Organizations

- Continue to support research and monitoring studies to identify, characterize, and delineate specific impairments associated with FASD. (NIAAA, CDC)
- Coordinate activities across agencies to meet the needs of children with a FASD. (ICCFAS)
- Disseminate findings of research on potential therapies to mitigate the deficits resulting from prenatal alcohol exposure and improve the functioning of persons with FASD. (NIAAA, NICHD, CDC, IHS)
- Identify program designs and strategies that improve access to high-quality services (SAMHSA, ED/OSERS, OJJDP).
- Conduct studies to clarify the role of the postnatal environment in modifying the life outcomes of prenatal alcohol exposure. (NIAAA, CDC, NICHD)
- Monitor the implementation of approaches to addressing FASD in educational and justice systems and provide advice for improvements. (OJJDP, OSERS, SAMHSA, NIAAA)
- Create links between the juvenile justice, child welfare, and education systems to address need of youth with FASD. (DOJ/OJJDP, ED/OSERS, SAMHSA)

OBJECTIVE V. Increase Research on Etiology and Pathogenesis

Goals of the 2001-2005 ICCFAS Strategic Plan included expanding and supporting basic and clinical research to advance understanding of the etiology and pathogenesis of prenatal exposure to alcohol by supporting basic studies and exploring the applicability of recent developments in biotechnology for studies of FASD.

Examples of Progress and Responsible Organizations

- Between FY2000 and FY2004 NIAAA increased its funding for basic and clinical research studies on the etiology and pathogenesis of FASD by over 40 percent. This funded research has yielded convincing evidence that alcohol-induced premature cell death in animal models of FAS involves the generation of free radicals. Such data may facilitate design of specific inhibitors to prevent alcohol-induced cell death. (NIAAA)
- Several studies implicate the importance of excitatory amino acid neurotransmitter receptor systems in prenatal alcohol-induced impairments in learning and memory, in reduced brain mass, and in impaired visual plasticity. (NIAAA)
- There are preliminary data demonstrating that inhibition of a nitric oxide-based vasodilation mechanism may be involved in alcohol-induced fetal growth restriction via disruption of fetal blood flow regulation and blood vessel development. (NICHD)
- The results of CDC and IHS funded projects suggested a relationship between sudden infant death syndrome (SIDS) and heavy prenatal alcohol exposure. Four cooperative agreements were funded to create a network for the development of community-linked studies to investigate the role of prenatal alcohol exposure in the risk for adverse pregnancy outcomes such as stillbirth, FAS, and SIDS, and to further research on the mechanism of their relationship. (NIAAA, NICHD)
- Innovative imaging technologies are being used to study the nature of brain damage in FAS. (NIAAA)

- Molecular and cellular changes associated with alcohol exposure during embryonic development are being detailed in studies using new animal models. (NIAAA, NICHD)
- Disruption of various regulatory pathways by alcohol exposure during development has been demonstrated in a number of animal studies. Research is being funded to explore in animal models the mechanism of disruptions associated with a variety of abnormalities, including altered stress response, abnormal birth weight, neurological development and craniofacial defects. (NIAAA)
- Researchers have shown that alcohol-induced inhibition of a specific cell adhesion molecule, which guides and stimulates migrating nerve cells, is correlated with cell death and reduced growth in early development, and two small protein molecules, brain peptides, have been discovered which can prevent the alcohol-related effects. (NIAAA, NICHD)
- New data showed that prenatal alcohol exposure disrupts diurnal rhythms. Such disruption may result in timing of linked physiological processes and cascades no longer being optimized. (NIAAA)

Plans to Increase Understanding of the Mechanisms of Action of Alcohol on the Developing Fetus That May Lead to the Development of Therapies to Address Specific Deficits

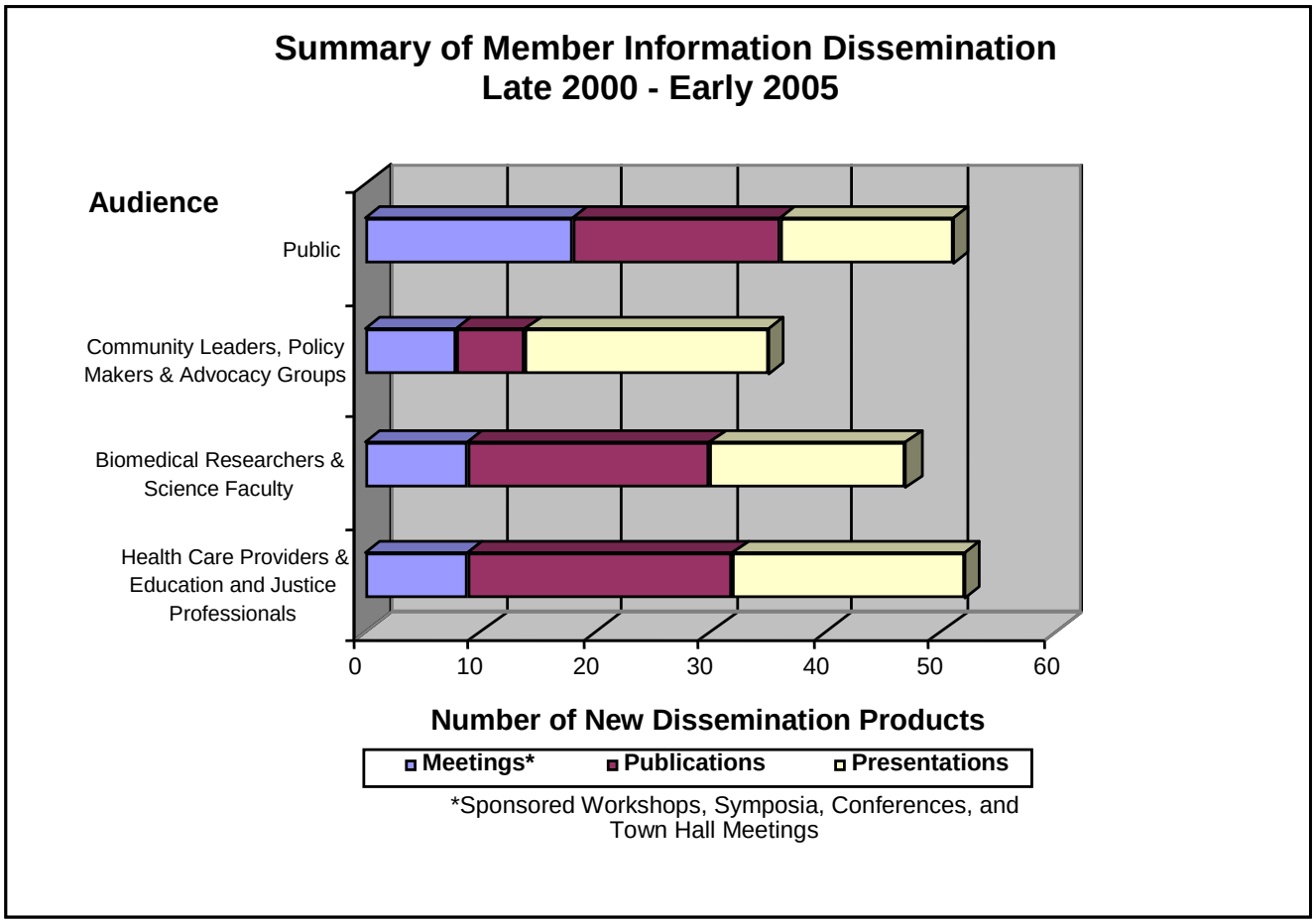
Much remains to be learned about the environmental and physiological bases of variable vulnerability and risk for FAS. In addition, greater characterization of mechanisms involved in alcohol-induced fetal brain damage may assist in the design of useful diagnostics and therapies. Several goals and objectives are proposed for ongoing research and future research on the etiology and pathogenesis of FASD that utilize new research tools to address gaps in our knowledge.

Action Plans and Responsible Organizations

- Fund studies investigating differential FASD vulnerability and putative protection due to differences in genetic, physiological, metabolic, and nutrient and other health factors. (NIAAA, NICHD)
- Conduct community linked studies to elucidate the relationship between prenatal alcohol exposure and stillbirths and SIDS, as well, as studies of the basic physiological and biochemical substrates involved. (NIAAA, NICHD)
- Continue support for studies aimed at identification of relevant postnatal factors and mechanisms that affect the lifelong outcomes of FASD-related disabilities and increased risk for alcohol use disorders, depression, and other mental health problems. (NIAAA)
- Encourage longitudinal studies in humans and animals that explore long term effects, plasticity, and mechanisms of prenatal disruption of basic physiological processes (stress responses, diurnal rhythms, immune system function, sleep architecture, and reproductive, sensory, and cardiovascular function). (NIAAA, NICHD)
- Provide continued funding for projects studying maternal and in-utero risk factors (genetic, metabolic, etc) that may promote or protect from the negative effects of alcohol consumption in pregnancy. (NIAAA, NICHD)

OBJECTIVE VI. Increase Educational Outreach, Training, and Information Dissemination

A goal of the FY2001-2005 Strategic Plan was to educate and train professionals whose activities can reduce prenatal alcohol exposure and mitigate the everyday difficulties faced by the families and persons affected by prenatal alcohol exposure. ICCFAS members have been very active during the last 5 years developing new information products through sponsored workshops, conferences, and numerous publications and presentations. Outreach has been to professionals in education, health care and the justice system as well as to the public. The following graph summaries the audiences reached through ICCFAS sponsored information dissemination efforts.



Selected Specific Examples of Progress and Responsible Organizations

- In the past 5 years the Internet has expanded as a means of information dissemination, with the ICCFAS members enhancing the visibility of FASD issues through their Web sites; making electronic information more readily available to the public, communities, and a variety of professionals; and enhancing access to informational brochures, CD's, videos, posters, and other media. (ICCFAS members)
- The SAMHSA FASD Center for Excellence has convened 15 town hall meetings nationwide, including one for Native Americans. The Center operates an Information Resource Center that includes a toll-free telephone line, viewing library, and Web site. The Center also

developed a Web-enabled searchable database for FASD literature, publications, and other materials for professionals and the public. (SAMHSA)

- Information kits have been developed about the dangers of alcohol misuse, in English and Spanish versions, for distribution during National Alcohol Screening Day (NASD) in April. Kits with special materials focusing on women and pregnancy are prepared for primary care sites. (NIAAA and SAMHSA)
- The SAMHSA Fetal Alcohol Spectrum Disorder Materials Development Center, launched in FY2001, focuses on message and material development. New documents are disseminated through the National Clearinghouse for Alcohol and Drug Information, the SAMHSA FASD Center for Excellence Web site, and through professional conference presentations. Materials were also developed for elementary school teachers and administrators to improve their ability to teach children with FASD and for community-based public education programs. (SAMHSA)
- Boston University FAS education center, through a project funded by HRSA/MCHB, inserted educational articles into national professional maternal and child health newsletters and developed and distributed 500 copies of a State-by-State resource directory that includes information on FAS/FAE services. The directory is also available on the NOFAS Web site. (HRSA/MCHB)
- "Play It Smart. Alcohol and Pregnancy Don't Mix," a multi-media campaign to increase public awareness, was developed and tested in the Washington, D.C. area. The campaign and lessons learned may serve as a model for such information dissemination programs in other cities. (NIAAA)
- Nearly 200 training sessions for almost 10,000 participants in 32 States, District of Columbia, Canada, Japan and the United Kingdom have been held on a broad spectrum of FASD relevant medical and social issues for a variety of professional medical, social, and justice workers, service providers, and individuals with FASD and their families since 2001. (SAMHSA)
- Grants have been awarded to establish four regional training centers for education and training of medical and allied health students and practitioners about FAS. (CDC)
- A comprehensive training program for service providers of American Indian and Alaska Native clients with FASD and their families has been established through the University of Washington where 64 health care providers were trained between 1998 and 2004. Funding for this service continues in FY2005. (IHS)
- Development of community based curricula and training programs on intervention strategies for Latina women at high risk for alcohol-exposed pregnancies have been developed and are currently being evaluated. (CDC)

Finally, many sharable educational resources have been developed through ICCFAS member programs and are now available through the Internet. These sharable resources are summarized in the following table:

Sharable Educational Resources Developed by ICCFAS Members: 2000 to Early 2005

Audience	Resource	ICCFAS Member Sponsor(s)
American Indian tribal courts, health care and social workers, and the tribal community	Focuses on increasing awareness of FASD and describes medical and psychological aspects, encourages a cooperative approach to referring and responding to persons with a FASD within the community, www.nijc.org	CDC
Families affected by FASD, health care and community providers	National & State Resource Directory for FASD; includes information ranging from availability of women's treatment to programs serving children with a FASD, www.nofas.org or at legal issues at http://depts.washington.edu/fadu/	HRSA/MCHB
Families affected by FASD, health care and community providers	General information about FAS on CD-ROM and Web site. Includes learning module on primary and secondary characteristics, video and still images, and diagnostic process. www.academicedge.com	NIAAA
Families affected by FASD, health care and community providers	General information about FASD, components of care for children with these conditions, and advocating for services and supports, www.thearc.org/fasproject/thecurriculum.htm	CDC
Families affected by FASD and community providers	A Practical Native American Guide for Caregivers of Children, Adolescents, and Adults With Fetal Alcohol Syndrome and Alcohol Related Conditions, http://www.ihs.gov/MedicalPrograms/Behavioral	IHS
General public, professionals, families and caregivers	FASD-The Basics, downloadable online slide show for self-study or use in presentations http://www.fascenter.samhsa.gov/whatsnew/FASDTheBasic.cfm	SAMHSA
Justice system officials and legal professionals	Screening and Assessing Mental Health and Substance Use Disorders Among Youth in the Juvenile Justice System: A Resource Guide for Practitioners, http://www.ncjrs.org/pdffiles1/ojjdp/204956.pdf	OJJDP
Justice system officials and legal professionals	*Tools for Success: Working With Youth With Fetal Alcohol Syndrome and Effects in the Juvenile Justice System. Resource Guide* http://www.mofas.org/	NIAAA, OJJDP
Medical and allied health professionals	*Fetal Alcohol Syndrome: Guidelines for Referral and Diagnosis*, http://www.cdc.gov/ncbddd/fas/	CDC
Medical and allied health professionals	A Social Work Curriculum for the Prevention and Treatment of Alcohol Use Disorders, http://www.niaaa.nih.gov/publications/social/Module10KFetaExposure/Module10K.html	NIAAA
Medical and allied health professionals	*A Clinical Guide for Obstetric and Pediatric Providers*, comprehensive overview, screening, treatment, strategies for referral and list of resources, http://www.vida-health.com	NIAAA
Schoolchildren	Science curriculum module with FASD focus, for classroom grades 5-12 - Better Safe Than Sorry, http://www.niaaa.nih.gov/publications/Science/curriculum.html	NIAAA
School teachers and parents of schoolchildren with FASD	Describes core deficits of children with a FASD , ways to recognize the condition, effective teaching and parenting skills, resource guide, www.doublearc.org	CDC
School teachers and other education staff	Fetal Alcohol Spectrum Disorders: A Toolbox for Educators, guide with a behavioral and learning profile of students with a FASD, as well as effective teaching strategies, available early 2006 at http://www.niaaa.nih.gov/publications/publications.htm	NIAAA
State trainers for school system-based training for parents	Includes review of characteristics of children with a FAS; secondary disabilities; needed services; family stressors and coping strategies; what schools can do to help, www.edc.org	CDC
Women in substance abuse programs	*Recovering Hope: Mothers Speak Out About Fetal Alcohol Spectrum Disorders*, video of mothers sharing experiences, http://www.fascenter.samhsa.gov/resource/index.cfm	SAMHSA

Plans to Increase Efforts to Educate and Provide Information

During the last 5 years tremendous progress was made in increasing awareness among health care professionals, State agency coordinators, legislators, and the public. As shown in the progress report all agencies participated in this effort. Yet, there remains a need to reach obstetricians, who often advise patients about consuming alcohol while relying on information from outdated texts, and pediatricians, nurses, and social workers, who might assist in the early identification of children affected by FASD. The need to provide information to juvenile justice professionals and childhood and early start educators is great.

ACTION PLANS AND RESPONSIBLE ORGANIZATIONS

- Increase use and dissemination of recently developed materials and curricula related to FASD developed by or sponsored by ICCFAS organizations. (all ICCFAS agencies)
- Enhance distribution and use of the existing training tools and evaluate whether there are any gaps in the battery of materials that are now available. (SAMHSA, CDC, OSEP)
- Increase activities to publicize of the availability of FASD information to the public. (SAMHSA)
- Enhance dissemination of information on established best practices for identifying women at risk for alcohol misuse and improving intervention and treatment for alcohol use disorders. (CDC, NIAAA, HRSA, IHS, SAMHSA)
- Promote and support FASD-related workshops and symposia at national conferences to inform justice and education personnel, clinical professionals and service providers, and biomedical researchers. (ICCFAS, CDC, NIAAA, NICHD, IHS, OJJDP, OSEP, SAMHSA)

IMPLEMENTATION AND MONITORING OF PROGRESS

As stated in the section above, work groups will be used to implement and monitor progress towards goals related to education, justice and addressing the needs of women of childbearing age who are at risk of having a child affected by FASD. These working groups began to meet to develop implementation plans for the actions identified. Monitoring of progress will be accomplished both within the working groups and by the overall ICCFAS. Action items not covered by the working groups will be monitored by the overall ICCFAS in meetings to be held at least two times per year.

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D. Recommendations from ICCFAS Work Groups

1. Education ICCFAS Work Group and Recommendations

In early 2000 the Education ICCFAS Work Group emphasized the need for better identification of methods for the early diagnosis of children with FAS/ARND and suggested that the ICCFAS member organizations focus their efforts on:

1. Providing intensive, effective, and ongoing training and technical assistance to teachers and other professionals responsible for the care and education of children;

2. Identifying and refining appropriate intervention strategies to serve children and families with FAS/ARND effectively in school settings and to prevent secondary disabilities; and

3. Clarifying ethical and confidentiality issues involved in conducting screening and assessment in schools and other early intervention settings.

4. Continuation of collaboration between the ICCFAS and the Federal Interagency Coordinating Council (FICC) to promote early identification of children with FASD and

5. Expansion of the age of identification of FASD from early childhood to 21 years old;

6. Coordination of funding across agencies to encourage working together to meet the needs of children with diagnoses of FASD, and families of those children, to conduct research, and to disseminate findings;

7. That the FICC and ICCFAS conduct longitudinal studies of children with FASD and their families;

8. That the working group facilitate the formation of partnerships between families and educational professionals in planning for the education of children with FASD; and

9. That FAS should be added as a qualifying condition for children under IDEA's *other health-impaired* category if this category remains after reauthorization of the law.

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2. Recommendations to the ICCFAS for Best Practices for Identifying, Intervening with and Treating Women with Alcohol Use Disorders

ICCFAS priorities on best practices for identifying, intervening with and treating women of childbearing age who abuse or are addicted to alcohol have been guided by participants attending workshops and conferences sponsored by the ICCFAS, NIAAA, and the NIH Office of Women's Health. They recommended the following priorities for future research.

1. Examine effective approaches to the treatment of pregnant women, including a comparison of the efficacy of specialized programs for pregnant women and non-specialized programs which enroll pregnant women.
2. Compare the relative efficacy of single gender and mixed gender treatment programs.
3. Expand research on the use of brief interventions with women, with special emphasis on identifying ways to increase health care providers' awareness and commitment to screening and intervening with women of childbearing age.
4. Investigate effective approaches to identifying and treating co-existing mental health disorders among women.
5. Identify methods to improve referral processes, including the development of standardized criteria for referral to specialized alcohol treatment and exploration of innovative approaches to improving patient compliance.

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3. ICCFAS Juvenile Justice Working Group Recommendations

In December 2001, OJJDP convened the first meeting of the Juvenile Justice Working Group (JJ Working Group), a subcommittee of the ICCFAS. Among the priorities the JJ Working Group recommended to the ICCFAS are:

1. Conduct prevalence studies to provide clear evidence of the numbers of youth with FASD in the justice system and the prevalence of FAS among juvenile sex offenders.

2. Develop a resource guide on FASD for juvenile justice system professionals.

3. Develop, validate, and implement a curriculum for training juvenile justice, legal and law enforcement professionals in issues related to FASD.

4. Create linkages between the juvenile justice, child welfare, and education systems to address the needs of youth with FASD.

5. Collect information regarding how Native American and Alaskan Native people deal with juvenile offenders with FASD in tribal courts.

6. Develop a model describing how State and local juvenile justice systems should respond to youth with FASD and their families. The model could be created through consensus panel or national conference.

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III. APPENDICES

Appendix A. Detailed Information

1. Background on FASD

a. History of FASD

This mini literature review provides an update of recent information. It is meant to be neither comprehensive nor exhaustive but contains some highlights from recently published reports and some historical references required to put the new information in context.

Early literary references indicate that society recognized long ago the detrimental effects of maternal alcohol abuse on children. Notes from England and Scotland appeared in the medical literature just before the beginning of the 20th century (Templeman, 1892 and Sullivan, 1899, referenced in Burd and Wilson, 2004). About 60 years later more detailed medical reports emerged from France. In her 1957 thesis Jaqueline Rouquette described physical and psychological development of young children of alcoholics (Lemoine, 2003). Eleven years later, very definitive medical information on developmental abnormalities in children of alcoholics was published by Lemoine and colleagues (Lemoine et al, 1968, 2003). Although their description of the unusual characteristics of 127 children of alcoholic mothers in France was clinically detailed and comprehensive, the medical community in the U.S. initially paid little attention. However, in 1973 Jones and colleagues described a specific pattern of malformation in eight cases in the U.S. and coined the term Fetal Alcohol Syndrome (FAS) (Jones et al, 1973; Jones and Smith, 1973). Prenatal and postnatal growth retardation had previously been described by Ulleland (1972) in six of those patients who were offspring of mothers with chronic alcoholism. Much interest and many resources have since been devoted to this devastating fetal developmental disorder. From 1981 to 2004, 90-100 articles per year on this subject have been published in the biomedical, basic research, and psychosocial literature.

Early efforts were focused on one of the most well known consequences of prenatal alcohol exposure, Fetal Alcohol Syndrome (FAS). This devastating birth defect is characterized by craniofacial malformations, neurological and motor deficits, intrauterine growth retardation, learning disabilities, and limited behavioral and social skills. More recently we have come to understand not only that the teratological effects of alcohol cover a broad range of human structures and functions, but also that there is great variability in the severity of the deficits. The scope of disabilities and malformation varies and depends on such exposure factors as the amount of alcohol, frequency of exposure, stage of development when alcohol is present, individual differences in sensitivity, and probably variation in both maternal and fetal alcohol metabolism.

FAS is one of the most serious consequences of heavy drinking during pregnancy. However, the full range of prenatal alcohol damage varies from mild to severe and encompasses a broad array of physical defects and cognitive, behavioral, and emotional deficits which are recognized under the umbrella term, Fetal Alcohol Spectrum Disorders (FASD). The Institute of Medicine (IOM)

diagnostic categories (Stratton et al, 1996), FAS and partial FAS, and the clinical conditions, alcohol-related birth defects (ARBD), (malformations of ocular, cardiac, urogenital or skeletal system), and alcohol-related neurodevelopmental disorder (ARND), (clinically significant cognitive or behavioral problems), as well as the general term, fetal alcohol effects (FAE), are all included in FASD. Several recent review articles provide an excellent overview of the medical aspects of prenatal alcohol exposure (Warren and Foudin, 2001; Lockhart, 2001; Coles, 2003; Sokol et al, 2003; Kvigne et al, 2004).

FASD remains a substantial public health, medical, and educational problem despite major research efforts to clarify the mechanisms of alcohol's teratological effects, increased efforts at prevention, continual studies on how to address the medical problems resulting from prenatal alcohol exposure, attempts to improve service delivery to high-risk mothers, and treatment for individuals affected by prenatal alcohol exposure. This is distressing since the incidence and severity of FASD can potentially be reduced or eliminated. Early detection and intervention are essential to attain positive outcomes for individuals who manifest signs of FASD, but this is difficult to achieve due to diagnostic uncertainties, inadequate information on prenatal alcohol exposure history, and lack of appropriate services.

b. Incidence and Prevalence of FASD

Estimates of the prevalence of FAS vary widely depending on the epidemiological methodology used, the assessment tool used for the diagnosis, the population studied, and the age of the individuals at assessment. The 1996 IOM report estimated the prevalence of FAS to be 0.5 to 3 per 1,000 births (Stratton et al, 1996). May and Gossage summarized data and strengths and weaknesses of various methodologies from many different types of studies in their 2001 review (May and Gossage, 2001). They noted that the lowest U.S. estimates (0.2 to 0.7 per 1,000 births) come from passive surveillance systems which examine birth registries, hospital records, etc. Screening and diagnosing FAS in infancy is more difficult and it would be expected that rates based on evaluation in early school grades would be higher. Meaney and colleagues (2003) report FAS prevalence estimates of 0.3 per 1,000 live births vs. 0.9 per 1,000 six year olds in the same geographic population in Colorado.

Although certain to be underestimates of the true prevalence of FAS (May and Gossage, 2001; Fox and Druschel, 2003), passive surveillance based estimates may be the only feasible way to track population trends and evaluate the effects of population wide prevention measures. A newer Centers for Disease Control (CDC) supported State-based surveillance system - Fetal Alcohol Syndrome Surveillance Network (FASSNet) (Hymbaugh et al, 2002) - uses a standardized methodology, draws data from multiple different records, and is expected to provide more reliable estimates (CDC, 2002b; Meany, et al, 2003; Fox and Druschel, 2003). Estimates from the FASSNet system, 0.2 to 1.5 per 1,000 live births in four different areas of the United States (CDC 2004a), are higher than CDC reported data using earlier passive surveillance methods (reviewed in May and Gossage, 2001), probably due to better ascertainment.

Clinic-based studies produce mid-range estimates, 1.95 per 1,000 U.S. births (true mean from 12 different studies, Abel, 1995). Active case assessment approaches yield the highest estimates, e.g., 3.1 per 1,000 first graders in one county in Washington State (Clarren et al, 2001). Data from active case assessment approaches, where a segment of a population or community is screened for all

possible cases, may be more reliable, but this approach is very time consuming and expensive. Estimates based on data from active case assessment indicate large differences in the prevalence of FAS in various populations, especially in those expected to be at high risk. May and Gossage (2001) estimated that the overall U.S. prevalence of FAS in the 1980's and 1990's was 0.5 to 2.0 cases per 1,000 live births.

In a 1995 update on the incidence of FAS, Abel presented convincing evidence that low socio-economic level is a major factor associated with estimates of the prevalence of FAS (Abel, 1995). Since then higher FAS incidence and prevalence have been demonstrated in many lower income communities around the world. Estimates of prevalence based on 1,000 live births are 2.29 in some low income inner-city African American communities (summarized in Abel, 1995); 1.9 in African Americans in nine counties in Western New York State (Meany et al, 2003); 1.87 in the indigenous population in the Northern Tip of Australia (Harris and Buchens, 2003), 4.1 in Alaska Natives (Wells, 2003), and average of 9 from many studies in Northern Plains American Indians (Duimstra et al, 1993; May and Gossage, 2001). Estimates based on active case assessments are 4.3 per 1,000 kindergarten students at the Turtle Mountain School in North Dakota (Poitra et al, 2003) and in even higher in first graders in poor communities in South Africa, 46 to 75 per 1,000 in the wine growing region of the Western Cape Province (May et al, 2000; Riley, et al 2003) and 19 per 1,000 in four non-wine growing communities around Johannesburg (CDC, 2003b). Note that these are community specific estimates. For example, estimates of FAS in different American Indian Communities vary more than ten-fold (May and Gossage, 2001; May et al, 2002; Poitra et al, 2003), and currently, there are no accurate national statistics for FAS in Indian Country (the more than 500 federally recognized tribes within the U.S.).

Considering the data summarized here, the limitations of various methods of estimation, large prevalence differences in rates among populations, and age-based variation in reliability of screening and diagnosis, 2 cases per 1,000 is a reasonable estimate for the prevalence of FAS in the U.S.

Other prenatal alcohol-related conditions, such as fetal alcohol effects (FAE), alcohol-related neurodevelopmental disorder (ARND), and alcohol-related birth defects (ARBD) are expected to be significantly more frequent than FAS but are more difficult to diagnose. "True ARND," defined as showing continuing patterns of alcohol-related neurobehavioral deficits, was measured in children in a longitudinal study on alcohol and pregnancy in Seattle, Washington. Neurobehavioral assessments of children heavily exposed prenatally to alcohol were made at five time points between 1 day and 7 years of age. The data indicated that the number of cases of FAS and ARND was threefold higher than the number of FAS cases alone. These results suggest an estimated incidence of FAS and ARND at 9 cases per 1,000 births in this birth cohort from an Health Maintenance Organization and teaching hospital in Seattle (Sampson et al, 1997). Others have estimated the prevalence of FAS, ARBD, and ARND at 10 per 1,000 live births (May and Gossage, 2001).

Since children with less severe forms of FASD are likely to profit significantly from treatment interventions (pharmacological, nutritional, social skills training, or behavioral, occupational, or physical therapy), a major goal is to develop more efficient assessment tools to monitor the prevalence of these conditions, identify children so afflicted, and provide appropriate interventions to improve their quality of life and reduce the burden on society. Additional difficulties in obtaining reliable estimates of FASD in all populations are the scarcity of an object marker for prenatal alcohol exposure, the reluctance of mothers to admit abusing alcohol during pregnancy, the scarcity of

trained dysmorphologists to identify children affected with FAS at birth, and the lack of specific neurocognitive or behavioral tests to identify individuals affected by FASD throughout the lifespan.

c. Fetal Alcohol Syndrome as a Public Health Issue

Assuming a prevalence rate of 2 cases per 1000 live births, the economic cost of FAS in the U.S. was estimated to be $3.6 billion for the year 2002 for medical care and residential and social services for individuals to age 65. This figure, $3.6 billion per year, is the median inflation adjusted average cost based on estimates published by several different groups during the past two decades. Apparent lack of agreement among the original estimates can be explained by variation in assumed prevalence rates, what has been included in cost components, whether estimates are limited to costs for individuals under age 21 years, dates on which costs are based, and whether the estimated cost of lost productivity was included. Lupton, Byrd and Harwood (2004) summarized multiple reports after adjusting them for inflation to 2002 dollars and normalizing them to a prevalence rate of 2 cases per 1000. They also included costs of medical care and residential and social services to age 65. Their adjusted cost estimates from five of these six well documented studies varied from $2.3 billion to $6.0 billion for 2002 with a median estimate of $3.6 billion. This figure does not include the cost for loss of productivity. An earlier calculation reported by Harwood (2000) provided an estimated loss of productivity in the US due to FAS at $1.3 billion in 1998. This estimate was based on productivity losses due to the increased incidence of brain dysfunction and mental retardation in adults in this population. In addition to estimating the total annual cost to the nation, another approach to presenting cost is to look at the lifetime cost of caring for each child born with FAS. If Harwood and Napolitano's figures are adjusted to 2002 dollars, the U.S. estimated lifetime costs are $2 million per individual (Harwood and Napolitano, 1985; Lupton et al, 2004) for medical care services ($1.6 million) and loss of productivity ($0.4 million). Accordingly $932,000 would have to have been deposited in 2002 at an interest rate of 3 percent for each child born with FAS to cover the expected lifetime costs.

The dollar costs reported are expected to be underestimates of the true costs. Many of the costs devoted to meeting the needs of children and adults with FAS are not easily identified because (1) the Federal programs that support FAS 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. Furthermore, the estimates do not include the cost of special education or expected additional costs for juvenile or criminal justice, substance abuse treatment, mental health care, or vocational services. In addition, all of the estimated dollars here are based on FAS alone. There are no data on the cost of other more frequent but less extreme problems, such as ARBD and ARND, arising from prenatal alcohol exposure.

d. National Trends in Alcohol Consumption and Data on Drinking During Pregnancy

Alcohol consumption by women of childbearing age in the U.S. mirrors national trends. Recent data from the National Institute on Alcohol Abuse and Alcoholism (NIAAA) National Epidemiological Survey on Alcohol and Related Conditions (NESARC) indicate that almost 49 percent of U.S. adults abstain from alcohol use or drink fewer than 12 drinks per year. Another 22 percent are light or occasional drinkers. Unfortunately, however, binge drinking is on the rise. The

NESARC data show that 29 percent of U.S. adults are "risky drinkers" who regularly or occasionally exceed guidelines for safe alcohol consumption. Risky drinkers in the U.S. include not only the 8 percent of U.S. adults who meet standard diagnostic criteria (DSM-IV) (American Psychiatric Association, 1994) for alcohol abuse and dependence (Grant et al, 2004), but also individuals who engage in binge drinking and heavy regular consumption.

Heavy episodic drinking is more common in young adults. The 2003 data from the Substance Abuse and Mental Health Services Administration (SAMHSA) National Survey on Drug Use and Health (NSDUH) indicate rates of binge drinking in the previous month at 41.6 percent for 18-25 yr olds vs. 21.0 percent for persons aged 26 or older (SAMHSA, 2004). NESARC data indicate that 21 percent of 18-29 yrs old engaged in heavy drinking more than once per month in 2001-2002 (Dawson, et al 2004).

Heavy alcohol use is lower among women but data from the 2000 National Alcohol Survey indicate that alcohol consumption in the previous month and in the previous year would classify 7 percent and 30 percent, respectively, of women of child bearing age (age 18-39 yrs.) as engaging in risky drinking (Nayak and Kaskutas, 2004). In 2001-2002 more than 5 percent of U.S. women of childbearing age met DSM-IV criteria for alcohol abuse or dependence (Grant et al, 2004; Hasin and Grant, 2004).

Despite warning labels, public service announcements, and dozens of articles each year about the risk of fetal damage due to alcohol exposure, 12.5 percent of pregnant women reported some use of alcohol in 2001 (Floyd and Sidhu, 2004). National surveys indicate that although rates of drinking during pregnancy changed little between 1991 and 2001, there has been a trend of increased binge and frequent drinking by pregnant women (Floyd and Sidhu, 2004). While in general drinking is lower in pregnant than non-pregnant women (Ebrahim et al, 1999; Floyd and Sidhu, 2004), the 2002 CDC Behavior Risk Factor Surveillance System (BRFSS) data indicate that 10 percent of pregnant women reported consumption of alcohol in the previous month and 2 percent reported binge drinking or frequent alcohol use. Similar data were reported from the 2002 National Survey on Drug Use and Health (NSDUH): 9.1 percent of pregnant women (ages 15-44) reported some alcohol consumption and 3.1 percent reported binge drinking or heavier alcohol use in the previous month. NSDUH data reveal that women in the first trimester of pregnancy, a period before many women might know they are pregnant, reported greater prior month consumption and binge drinking or heavier use (17.3 percent and 8.9 percent, respectively) (SAMHSA, 2004). It may be that more than 10 percent of fetuses in the U.S. are exposed to alcohol at some time during the pregnancy.

Although most women stop drinking once they know that they are pregnant, many continue to drink during pregnancy on an occasional, binge or frequent basis. In 2002, 5.3 percent of women in the third trimester of pregnancy reported some drinking in the prior month (SAMHSA, 2004). Consistent with national survey data, one third to one half of pregnant women assessed in a clinical setting who reported drinking in the first trimester continued to drink after recognition of pregnancy or beyond first trimester (Lucas et al, 2003; O'Connor and Whaley, 2004; Chasnoff et al, 2005). A majority of these women were light occasional drinkers, but there is no level of alcohol exposure that has been demonstrated to be safe in pregnancy.

Alcohol use during pregnancy varies among different communities. Reports from many clinical settings indicate greater use of alcohol in pregnancy than that reported from national surveys. O'Connor and Whaley (2004) have recently reported a 24 percent post conception incidence of alcohol use in low-income women in Women/Infants/Children (WIC) programs in California. Rodan et al (2004) reported 18 percent alcohol use by pregnant low income women in Washington, D.C. Moderate to heavy use in the first trimester was reported by 30 percent of pregnant low income African American women in Pittsburgh (Lucas et al, 2003); and 27 percent and 52 percent, respectively, of women in a public hospital and a private hospital in Atlanta reported alcohol use in the first trimester (Drews et al, 2003). In four demographically and racially diverse populations of mostly Medicaid eligible women, Chasnoff and colleagues (2005) reported that the percentage of women who drank alcohol after learning they were pregnant varied significantly among the four populations: 6, 8, 9, and 37 percent. The highest rate of post conception drinking reported from this study was in a predominantly white rural community.

e. Prevention of Drinking During Pregnancy

Reduction and eventual elimination of drinking during pregnancy requires preventive interventions at all levels: universal population wide approaches to promote awareness and healthy lifestyles, selective screening, counseling, and intervention for those identified as at risk, and indicated special treatment for those at highest risk. Universal strategies to reduce overall alcohol use disorders in the general population are the focus the NIAAA underage drinking initiative, the NIAAA and SAMHSA National Alcohol Screening Day, and the alcohol information awareness programs of many different Federal, State, community, and private organizations. We need to promote screening of all patients for alcohol use as part of general U.S. health promotion. In general, in primary care settings physicians screen more for tobacco use than alcohol use. Much remains to be done to stimulate physicians to increase health promotion and discussion of alcohol use by their patients. A fairly successful vigorous campaign changed attitudes toward tobacco use in the U.S. A similar cultural change in attitudes toward the acceptability of alcohol misuse, in general, and any alcohol use is pregnancy is a major goal.

The 2005 Surgeon General's new advisory on alcohol consumption during pregnancy urges all women who are pregnant, are planning a pregnancy, or at risk of becoming pregnant to abstain from drinking alcohol (CDC, 2005). All ICCFAS member organizations have joined with the Task Force in a year long campaign to promote the Surgeon General's Advisory in order to increase awareness of the dangers of alcohol consumption during pregnancy.

Data from the BRFSS indicate that in 2002 nearly 55 percent of women (18-44 yrs old) who might become pregnant reported drinking alcohol, and more than 12 percent reported binge drinking during the 30 days preceding the interview(CDC, 2004b). Because almost 50 percent of all pregnancies in the U.S. are unplanned, some recent prevention efforts, such as CDC's Project BALANCE (**B**irth Control and **AL**cohol **A**wareness: **N**egotiating **C**hoices **E**ffectively) and Project CHOICES, aim to identify and intervene with women at risk for an alcohol exposed pregnancy prior to their becoming pregnant (CDC, 2003; Floyd and Sidhu, 2004).

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.

f. Clinic and Community Based Screening, Treatment, and Referral

A major objective of screening efforts is to identify predictors of health hazards during pregnancy. One barrier to universal screening of women has been male oriented alcohol abuse and alcohol dependence screening tools. The use of these to screen women for alcohol use disorders during pregnancy did not prove very effective (Chang, 2001). Screening for alcohol use in pregnancy is essential for reduction of drinking during pregnancy and subsequent prevention of all of the FASD. Identifying and offering treatment to women at highest risk for negative birth outcomes due to alcohol use can have positive results for the pregnancy, the mother, and the child.

Significant progress has been made in the past several years on development, validation, and use of more sensitive screening to identify women at risk for negative birth outcomes due to alcohol misuse (Chang, 2001; Chang, 2004/2005; Chasnoff et al, 2005). Some of the assessment tools useful in obstetrical practices, however, are not sufficiently sensitive to identify women who do not meet clinical diagnostic criteria for alcohol abuse or dependence but do have a risky pattern of drinking. In the past 5 years published reports note modification of some existing tools and creation of new screening tools to identify pregnant women at risk for negative birth outcomes (Dawson et al, 2001; Thornberry et al, 2002; Chasnoff et al, 2005). Data from the 2000 National Alcohol Survey indicate that alcohol consumption in the previous month and in the previous year would classify 7 percent and 30 percent, respectively, of women of child bearing age (age 18-39 yrs.) as engaging in risky drinking (Nayak and Kaskutas, 2004). Data from Goransson and colleagues (2003) in Sweden indicate that information on risky drinking during the previous year is an important parameter for successful screening of women for alcohol misuse during pregnancy.

A majority of respondents to the survey of Diekman et al. (2000) identified several barriers affecting alcohol use assessment in obstetrical clinical practice: time limitation, patient sensitivity, and need for additional training to enhance ascertainment skills. To reduce the burden of assessment in prenatal care settings, several brief self-administered questionnaires have been developed (Bull et al, 1999, Thornberry et al, 2002, Bradley et al, 2003, Kennedy et al, 2004). Increased screening resulted (Rodan et al, 2004; Kennedy et al, 2004) and reported alcohol use was higher (Whaley and O'Connor, 2003; Rodan et al, 2004). Patient sensitivity was identified as the major barrier to referral for additional services in antenatal clinics in Sweden despite recognition by midwives of substance use disorders in pregnant women (Goransson et al, 2004).

There has been some success with brief intervention and motivational therapy to decrease alcohol use in pregnancy but studies show that after pregnancy most heavy alcohol consumers revert back to alcohol misuse (Kraemer, 2004). Furthermore, recent pilot data from Midanik et al, 2004 indicate that a majority of women assessed positive for risk during pregnancy were not asked about alcohol use during the year following delivery. Physicians need to be encouraged to continue to assess alcohol use postpartum, especially in view of the fact that having had one child affected by prenatal alcohol exposure is a known risk factor for additional negative birth outcomes (Astley et al, 2000a; Astley et al, 2000b).

Comprehensive site programs such as the Alcohol Screening and Assessment Program (ASAP) funded by the Maternal and Child Health Bureau at the Health Resources & Services Administration (HRSA) combine staff training, screening, brief intervention, and patient education during an office visit. To maximize use, the site staff customized the assessment tools and protocols to their specific settings. This resulted in increased use due to greater comfort of the site staff with the program (Kennedy et al, 2004).

2. Background Information on the ICCFAS

a. Creation and Structure of the ICCFAS

The challenge facing the ICCFAS is to improve communication and cooperation among disciplines that address health, education, developmental disabilities, 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* (Stratton et al, 1996).

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 is chaired by the Deputy Director of NIAAA and coordinates efforts among Federal organizations addressing issues associated with conditions caused by prenatal exposure to alcohol, now collectively called FASD (which includes FAS, FAE, ARBD, and ARND).

Current membership of the ICCFAS includes representatives from the following agencies: The 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)'s Maternal and Child Health Bureau (MCHB); Indian Health Service (IHS); National Institutes of Health (NIH): National Institute on Alcohol Abuse and Alcoholism (NIAAA), and 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); and Department of Justice (DOJ), Office of Juvenile Justice and Delinquency Prevention (OJJDP). Other Federal agencies and NIH institutes have often been invited to participate in working groups and to cosponsor activities of the ICCFAS.

The missions and FASD orientation of the regular current member organizations follow:

The Agency for Healthcare Research and Quality (**AHRQ**) promotes health care quality improvement by conducting and supporting health services research that develops and presents scientific evidence regarding all aspects of health care. Health services research includes (1) addressing issues of organization, delivery, financing, utilization, patient and provider behavior, quality, outcomes, effectiveness and cost, (2) evaluating both clinical services and the system in which these services are provided (3) providing information about the cost of care, as well as its

effectiveness, outcomes, efficiency, and quality (4) supporting studies of the structure, process, and effects of health services for individuals and populations and (5) addressing both basic and applied research questions, including fundamental aspects of both individual and system behavior and the application of interventions in practice settings. The vision of the AHRQ is to foster health care research that helps the American health care system to provide access to high-quality, cost-effective services; to be accountable and responsive to consumers and purchasers; and to improve health status and quality of life. The Agency's mission is to improve the outcomes and quality of health care services, to reduce their costs, to improve patient safety, and to broaden access to effective services. AHRQ fulfills its mission by establishing a broad base of scientific research and promoting improvements in clinical and health system practices, including the prevention of diseases and other health conditions.

The mission of the Centers for Disease Control and Prevention (**CDC**) is to promote health and quality of life by preventing and controlling disease, injury, and disability. CDC has been involved in FAS-related activities since 1991. The goals of the Fetal Alcohol Syndrome Prevention Team, which is part of CDC's National Center on Birth Defects and Developmental Disabilities, are to prevent FAS and other alcohol-related disorders, ameliorate these conditions among those affected, and provide education and support to the families, caregivers, and healthcare providers of individuals affected. CDC achieves these goals by developing systems to monitor prenatal alcohol exposures and outcomes, conducting epidemiologic studies to identify maternal risk factors associated with giving birth to a child with FAS, and conducting public health research and program implementation in prevention and intervention.

The Health Resources and Services Administration's (**HRSA**) mission is to improve and expand access to quality health care for all. Within HRSA, the Maternal and Child Health Bureau (**MCHB**) provides national leadership and works in partnership with States, communities, public-private groups, and families to strengthen maternal and child health (MCH) infrastructure, ensure the availability and use of medical homes, and build knowledge and human resources to ensure continued improvement in the health, safety, and well-being of the MCH population. MCHB provides leadership to improve access to comprehensive, culturally sensitive, quality health care for all pregnant women, infants, children, and adolescents and their families, including women of reproductive age, fathers, and children with special health care needs.

The mission of the Indian Health Service (**IHS**), in partnership with American Indian and Alaska Native people (AI/AN), is to raise the physical, mental, social, and spiritual health of AI/AN communities to the highest level possible. The goal is to ensure that comprehensive, culturally acceptable personal and public health services are available and accessible to American Indian and Alaska Native people. The foundation is to uphold the Federal Government's obligation to promote healthy American Indian and Alaska Native people, communities, and cultures and to honor and protect the inherent sovereign rights of tribes. IHS currently provides health services, either directly or through tribal contracts and compacts, to approximately 1.5 million American Indians and Alaska Natives. About one-third of IHS programs are carried out by tribes and tribal organizations. In addition, IHS supports urban Indian health projects from New York City to San Diego, from Flagstaff to Detroit. Current IHS FASD activities relate to the IHS mission and goals in that IHS is working to ensure that comprehensive and culturally appropriate health services are available and accessible for individuals diagnosed with FASD across the lifespan, as well as their families. The ultimate goal is to reduce the FASD disparities in Indian Country and to elevate the physical, mental, social and spiritual health of those individuals diagnosed with FASD to the highest level possible.

NIAAA supports and conducts research focused on improving the treatment and prevention of alcoholism and alcohol-related problems to reduce the enormous health, social, and economic consequences of this disease. NIAAA's mission is to support and promote the best scientific research on alcohol and health to the benefit of all. NIAAA believes that the most effective way to achieve its mission is through the use of multidisciplinary and transdisciplinary approaches to increase understanding of normal and abnormal biological functions and behaviors relating to alcohol use; to improve the diagnosis, prevention, and treatment of alcohol use disorders and pathological consequences of such; and to enhance quality health care. Several goals of the NIAAA Strategic Plan for FY2001-FY2005 have subcomponents directly related to research on FASD: identification of science-based prevention interventions; discovery of treatments to accelerate recovery of organ function or mitigate the consequences of alcohol-induced injury; and further delineation of biological mechanisms associated with excessive alcohol consumption. In addition, the NIAAA research portfolio on prevention of alcohol use disorders supports prevention research studies specifically aimed at reduction of drinking in nonpregnant and pregnant women of childbearing age.

The mission of the National Institute of Child Health and Human Development (**NICHD**) is to ensure that every person is born healthy and wanted, that women suffer no harmful effects from reproductive processes, and that all children have the chance to achieve their full potential for healthy and productive lives, free from disease or disability and to ensure the health, productivity, independence, and well-being of all people through optimal rehabilitation. NICHD supports research aimed at understanding the pathophysiology of FAS, developing treatments for children with developmental disabilities including those associated with FAS, and understanding risk behaviors (e.g., drinking alcohol) in women of childbearing age.

The vision of the Substance Abuse and Mental Health Services Administration (**SAMHSA**) is a life in the community for everyone. SAMHSA's mission is to build resilience and facilitate recovery for people with or at risk for substance abuse and mental illness. SAMHSA is achieving its vision through a mission that is both action-oriented and measurable. In collaboration with States, national and local community-based and faith-based organizations, and public and private sector providers SAMHSA is working to ensure that people with or at risk for a mental or addictive disorder have the opportunity for a fulfilling life that includes a job, a home, and meaningful relationships with family and friends. These goals are addressed through grants and contracts that translate research to practice - bringing new science-based knowledge to community-based services for people with or at risk for mental and substance abuse disorders. The results are being measured in significant improvements in how the Nation responds to substance abuse and mental illnesses. The vision and goals of SAMHSA's FASD programs are to reduce cases of FASD, increase functioning of persons who have FASD, and improve quality of life for individuals and families affected by prenatal alcohol exposure. Specific goals are to facilitate the development of FASD prevention, treatment, and care as a specialty field and to facilitate the development of FASD prevention, treatment and care systems at the State and community level.

The Department of Education (**ED**) mission is to strengthen the Federal commitment to ensuring access to equal educational opportunity for every individual and to supplement and complement the efforts of States, local school systems and other instrumentalities of the States, the private sector, public and private nonprofit educational research institutions, community-based organizations, parents, and students to improve the quality of education. The Department encourages the

increased involvement of the public, parents, and students in Federal education programs and promotes improvements in the quality and usefulness of education through federally supported research, evaluation, and sharing of information. The Department seeks to improve the coordination of Federal education programs; improve the management of Federal education activities; and increase the accountability of Federal education programs to the President, the Congress, and the public. The mission of the Office of Special Education and Rehabilitative Services (OSERS) within the Department of Education is to provide leadership to achieve full integration and participation in society of people with disabilities by ensuring equal opportunity and access to, and excellence in, education, employment, and community living. In implementing this mission, OSERS supports programs that help educate children and youth with disabilities, provides for the rehabilitation of youth and adults with disabilities and supports research to improve the lives of individuals with disabilities. FASD-related activities are consistent with and can be infused into each of the stated mission elements.

The Office of Juvenile Justice and Delinquency Prevention (**OJJDP**) in the US Department of Justice provides national leadership, coordination, and resources to prevent and respond to juvenile delinquency and victimization. OJJDP supports States and communities in their efforts to develop and implement effective and coordinated prevention and intervention programs and to improve the juvenile justice system so that it protects public safety, holds offenders accountable, and provides treatment and rehabilitative services tailored to the needs of juveniles and their families. As a result of their unique neurodevelopmental deficits, youth with FASD are at high risk for entering the juvenile justice system. In addition, because standard juvenile justice interventions and sanctions are not designed to accommodate the unique strengths and weaknesses of individuals with FASD, recidivism rates are likely to be higher than for youth in the juvenile justice system who are not affected by prenatal alcohol exposure. Unfortunately, few, if any, juvenile justice settings screen for FASD, so the exact percentage of youth in the juvenile justice system affected by prenatal alcohol exposure is currently unknown. To fulfill its mission with regard to youth with FASD, OJJDP seeks to train justice system professionals, develop policies and protocols for screening and assessment, and support States and communities in providing individualized treatment and rehabilitative services.

b. ICCFAS Objectives

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

1. Prevent at-risk drinking among all women of childbearing age.
2. Disseminate effective techniques for screening and intervening with pregnant women.
3. Enhance identification and improve the quality of intervention and treatment of women at risk for an alcohol-exposed pregnancy.
4. Improve diagnosis of FAS and alcohol-related neurological disorders.
5. Improve health care, education, and correctional interventions for children and adults with FAS and other prenatal alcohol-related disorders.

6. Foster basic research to identify mechanisms of alcohol teratogenesis, leading to improved interventions and treatments.
7. 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, intervention with children affected by prenatal alcohol exposure, improving diagnosis and case identification, and furthering understanding of the etiology and pathogenesis of FAS and ARND. From 2001 to 2005, member agencies expanded the scope of activities in each of these areas and continued to sponsor workshops, symposia, and conferences to stimulate research and exchange information between professional groups and the public.

c. Meetings of the ICCFAS

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.

The ICCFAS Executive Committee held meetings in early 2000 dedicated to preparing the last progress report, establishing a new strategic plan, and developing plans to implement the objectives in the new strategic plan. Six public meetings were then held during 2001-2003, with different ICCFAS member organizations hosting the meetings. These open meetings included grantees, contractors, Federal colleagues of ICCFAS Executive Committee members, advocacy groups and other members of the public. 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 attended. The meetings included reports on the current FAS-related activities of the ICCFAS member organizations and new data or overviews of special programs on specific topics presented by special guest speakers. The meeting topics included screening of pregnant women for alcohol consumption, FAS and juvenile justice systems, progress on understanding the mechanisms of alcohol teratogenesis, development of the SAMHSA FASD Center for Excellence, communication strategies and education awareness projects, and community-based prevention programs. In 2004 and early 2005 the ICCFAS Executive Committee held several meetings focused on review of progress made in the previous 5 years, development of a new strategic plan, and plans for implementation of the FY2006-2010 strategic plan.

i. ICCFAS and Member Organization Sponsored Workshops and Conferences

Soon after its inception the ICCFAS sponsored a series of planning workshops to develop a common understanding of the status of areas critical to addressing FAS and to assist the committee in setting priorities and developing goals. From 1997 to 2000 the ICCFAS sponsored numerous workshops examining the state of the art of diagnosis of FAS and ARBD, measurement of alcohol consumption in clinical studies vs. surveys, prevention of risk drinking during pregnancy, intervention with children affected by prenatal alcohol exposure, and neurobehavioral assessment of differential diagnosis of FAS and ARND.

In 2001 ICCFAS sponsored two planning workshops to develop a common understanding of the status of areas critical to addressing FAS and to assist the committee in setting priorities and developing goals. The first of these workshops, "FAS Workshop," was sponsored by **ED ICCFAS Work Group on FAS/ARND,** at the National Childhood Early Interventions Meeting, in Washington DC, January 2001. The workshop participants discussed alternative models for screening and referring children in early education and child care settings; the need for national standards for determining eligibility criteria for specialized education services for children with developmental disabilities; and community approaches to strengthening advocacy for children and families affected by fetal alcohol exposure.

The second planning workshop of 2001, "The Identification and Treatment of Alcohol Use Disorders among Women of Childbearing Age," Bethesda, MD, March 13-14, 2001, was cosponsored by the **NIAAA**, and the NIH Office of Research on Women's Health, an included participation by service providers from **SAMHSA**. Participants identified critical gaps in knowledge concerning effective approaches to treatment for women of reproductive age with alcohol use disorders and recommended priorities for future research. These recommendations to the ICCFAS include examining effectiveness of different approaches, such as comparing specialized programs for pregnant women and programs to increase health care provider participation; investigating approaches to the problem of co-morbid conditions; and identifying effective standardized methods for referral to specialized treatment programs.

In FY2001 the focus of workshops and conferences hosted by the **ICCFAS** and member organizations shifted from ICCFAS planning activities toward information sharing and exchange and facilitation of the practical application of the latest research findings. From 2001 to the present, ICCFAS member organizations have sponsored 44 workshops, symposia, and conferences to disseminate and exchange information with health care providers, biomedical researchers, science faculty, justice professions, community leaders, policymakers, advocacy groups, and the general public. These are listed in Part III, Section A, Item 3.b.vi.

ii. Development of Overall Goals: Recommendations from ICCFAS Working Groups

Goals, direction, and priorities of the ICCFAS are developed in close collaboration and coordinated with the Working Groups within the ICCFAS. These working groups meet regularly and often host planning workshops bringing together outside experts to provide an update of the current state of knowledge and activities of interest, to identify gaps in knowledge and services and their delivery, and to apprise the committee of existing opportunities for advancement.

In l999 ED expressed an interest in ensuring that education and childcare professionals develop a better understanding of FAS/ARND and that they were prepared to participate fully with others in addressing the issues. Thus, the Work Group on FAS/ARND was formed. It is led by the ED representative to the ICCFAS and suggests plans of action for intervention with children with FAS and their families. The working group comprises representatives from the ICCFAS agencies, the mental health field, educators, early childhood school psychologists and counselors, FAS research scientists, and parents of children with FAS/ARND. ICCFAS member agencies are active in the area of programs for school-age children. In early 2000 the ICCFAS ED Work Group emphasized the need for better identification of methods for the early diagnosis of children with FAS/ARND. Specifically, the ICCFAS ED Work Group suggested that the working group and ICCFAS member agencies focus their efforts on (a) promotion of early identification of children with FASD through a collaboration between the ICCFAS and the Federal Interagency Coordinating Council (FICC), (b) development of co-funded projects to establish partnerships between educators and families to address the needs of children and families affected by FASD, and (c) inclusion of FAS as a qualifying condition under the reauthorization of the Individuals With Disabilities Education Act (IDEA). Detailed recommendations of the ICCFAS ED Work Group are in the Part II, Section D, Item 1.

A special expert group (from the March 21, 2001 Workshop) charged with identifying best practices for intervening with and treating women of childbearing age who abuse or are dependent on alcohol identified critical gaps in knowledge concerning effective approaches to treatment for women of reproductive age with alcohol use disorders. Their recommendations included the desire to evaluate the need for gender-specific treatment programs, the value of general approaches vs. those specific to pregnant women, healthcare provider awareness and commitment, and the need for treatment of co-occurring mental disorders. More details are listed in the Part II, Section D, Item 2.

In December 2001, **OJJDP** convened the first meeting of the Juvenile Justice Working Group (JJ Working Group), a subcommittee of the ICCFAS. The Working Group includes both Federal and non-Federal members from a variety of disciplines and backgrounds, as well as both adoptive and biological parents of youth with FASD. The subcommittee meets annually to discuss justice issues relevant to FASD and to develop recommendations to the ICCFAS. Between meetings, members communicate by phone, through e-mail, and using an OJJDP-sponsored listserv. The recommendations they have made to the ICCFAS are listed in the Part II, Section D, Item 3.

The National Task Force on FAS/FAE (NTFFAS/FAE) was chartered by the Secretary of DHHS as a Federal Advisory Committee and held its first meeting in December 2000. The purpose of this 13-member committee administered by CDC is to foster coordination among all government agencies, academic bodies, and community groups that conduct or support FAS and FAE research, programs, and surveillance and to otherwise meet the general needs of populations actually or potentially impacted by fetal alcohol syndrome and related disorders. The function of the Task Force includes the charge to advise Federal, State, and local programs, inform research concerning FAS and FAE, and coordinate its efforts with the ICCFAS. Areas for which the Task Force provides advice include programs and research concerning education and public awareness for relevant service providers, school-age children, women at risk, and the general public; medical diagnosis; interventions for women at risk of giving birth to children with FAS and FAE; and beneficial services for individuals with FAS and FAE and their families.

The Task Force membership includes the Chairperson of the ICCFAS, liaison representatives from the American Academy of Pediatrics; American Academy of Family Physicians; American College of Obstetrics and Gynecology; March of Dimes; and the Center for Science in the Public Interest; representatives from advocacy and research organizations such as the Research Society on Alcoholism, the FAS Family Resource Institute, the National Organization on Fetal Alcohol Syndrome, The Arc of the United States, the academic community, and Federal, State and local government agencies and offices, and individuals with FAS and FAE or parents or legal guardians of individuals with FAS and FAE. The Task Force is thus in a unique position to be a conduit for grass roots, community, State, and professional medicinal organizations on the need for action against FASD. In September 2002 the Task Force published (Weber et al, 2002) recommendations for a national agenda on FAS/FAE activities (see Part III, Section C). Some of these recommendations are relevant to the ICCFAS and overlap with recommendations from Work Groups of the ICCFAS.

3. Greater Detail on Recent Progress and Ongoing Activities

OBJECTIVE I. Expanding Communication, Cooperation, and Collaboration among Federal Organizations through the ICCFAS

- The **ICCFAS** has fostered communication and exchange of ideas, cooperation, and collaboration during the regular meetings of the Committee, through workshops and meetings sponsored by the **ICCFAS** or its member organizations, and by joint attendance at such. In the past 5 years the ICCFAS has met 10 times to exchange ideas and plan for future collaborations. These meetings have been characterized by presentations of selected progress reports highlighting the activities, program, and resources of the different Federal organizations.
- During the last 5 years, representatives of the ICCFAS agencies **NIAAA**, **IHS**, and **ED** have served on the **ED** led ICCFAS Work Group on FAS/ARND**.** This group has made recommendations to the **ICCFAS** for development of plans of action for education-based intervention with children with FASD and their families. (See Part II, Section D, Item 1.)
- **OJJDP**, **NIAAA**, and **SAMHSA** representatives to the ICCFAS have served for the last 5 years on the Juvenile Justice Working Group. This ICCFAS subcommittee has helped develop priorities for the ICCFAS and member organizations' legislative and programmatic activities. (See Part II, Section D, Item 3.)
- The National Task Force on Fetal Alcohol Syndrome and Fetal Alcohol Effect held its inaugural meeting on December 14-15, 2000 in Atlanta, Georgia. The Task Force includes representatives from the FAS research, treatment and education communities, advocacy organizations, and three Federal agencies. The Chairperson of the **ICCFAS** has served as a Standing Member of the Task Force.
- The overall goals and objectives of the **ICCFAS** have been developed from the original recommendations of the IOM Committee on FAS, recommendations from the ICCFAS working groups on prevention, education, and juvenile justice, and advice generated at executive committee meetings and in planning workshops with outside experts. There is considerable overlap with the ICCFAS objectives and those published in the 2002 Task Force recommendations for national activities on FAS (Weber et al, 2002). To ensure coordination

between these two groups information on their respective activities has been presented at committee meetings. In addition, the Task Force and ICCFAS convened a joint meeting on December 10-11, 2001 to exchange information and identify areas for future collaboration.

- The **ICCFAS** and many of its member organizations collaborated with the Task Force on several of its recent activities. **CDC, NIAAA, and SAMHSA** collaborated with the NTFFAS/FAE to fulfill a congressional mandate to establish uniform diagnostic criteria for FAS and other prenatal alcohol-related conditions. Work started on the criteria in June 2002 and was completed in July 2004 with the publication of "Fetal Alcohol Syndrome: Guidelines for Referral and Diagnosis" (CDC, 2004c).
- ICCFAS member organizations **CDC, HRSA/MCHB, IHS, NIAAA, NICHD,** and **SAMHSA** worked (2003-2005) with the Task Force to urge the Surgeon General to release a new advisory on alcohol use in pregnancy. The previous advisory was released in 1981. For the advisory, ICCFAS member organizations have provided background information on the scientific and evidence-based knowledge on the dangers of alcohol consumption during pregnancy. In addition, they have provided information to assist in the development of a yearlong coordinated national media campaign to disseminate and reinforce the Surgeon General's Advisory on Alcohol Use in Pregnancy, which was released February 21, 2005.
- **CDC, NIAAA, and SAMHSA** met with FASD clinical and research experts for a summit organized by the National Organization on FAS (NOFAS) to develop a consensus definition of the term FASD. The one-day meeting resulted in the drafting and adoption of a uniform definition of this term used by all the agencies. This contributed toward increased clarity and usage of the term among public health and research partners.
- The **SAMHSA** FAS Center for Excellence supports some activities that transfer research to practice and provide information and assistance to children and families affected by prenatal alcohol exposure. Members of the **ICCFAS** or other representatives from their organizations (Faye Calhoun, **NIAAA**; Marlene EchoHawk and Jon Perez, **IHS**; Louise Floyd, **CDC**; Ellen Hutchins**, HRSA/MCHB;** and Karen Stern, **OJJDP**) have provided advice and guidance to **SAMHSA** on how the SAMHSA FASD Center for Excellence might best pursue its objectives. Dr. Faye Calhoun, Chair of the ICCFAS, served as the primary Federal advisor to the Center for Excellence's Steering Committee.
- A major initiative of the **SAMHSA** FASD Center for Excellence has been to stimulate the interest of States in improving coordination of systems of care to individuals and families affected by prenatal alcohol exposure. As part of this project the Center hosted Building FASD State Systems (BFSS) meetings in 2003, 2004, and 2005. To assist SAMHSA at these meetings, members of the **ICCFAS** (Faye Calhoun and Deidra Roach, **NIAAA**; Louise Floyd, **CDC**; Ellen Hutchins, **HRSA/MCHB**; and Karen Stern, **OJJDP**) helped plan the meetings, gave formal presentations, or served as moderators of discussion panels on such topics as Federal funding opportunities to address FASD.
- From March 2002 through June 2004, the **SAMHSA** FASD Center for Excellence convened 15 town hall meetings nationwide, coordinated with assistance from the National Organization on Fetal Alcohol Syndrome (NOFAS), the FAS Family Resource Institute, and the Alaska Office of FAS. A major goal of these meetings was to hear concerns and recommendations from local citizens that could be used to guide the activities of the Center. Many Federal agencies were represented on VIP panels, including panelists from the

ICCFAS: Faye Calhoun, Deidra Roach, and Kenneth Warren, **NIAAA**; Louise Floyd, **CDC**; Ellen Hutchins, **HRSA/MCHB,** Karen Stern and Donna Ray, **OJJDP**.

- Dr. Faye Calhoun, Deputy Director of NIAAA and Chairperson of the **ICCFAS**, provided the opening address for the first **SAMHSA-**sponsored summer workshop and meeting of teens and young adults affected by prenatal alcohol exposure and their caregivers in Newaygo, MI, August 15-17, 2002. The conference was organized by the Michigan FAS Family Support Group and funded by the **SAMHSA** FASD Center for Excellence; the W.K. Kellogg Foundation; and the Alcohol Research Center of Michigan.
- **OJJDP** has worked closely with **SAMHSA** to ensure that the SAMHSA FASD Center for Excellence's activities address the needs of youth with FASD in or at risk of entering the juvenile justice system. An OJJDP staff member serves as an advisor to the Center Steering Committee. OJJDP assisted in the development and review of two Requests for Proposals (fall 2004) for the Center: one for local community organizations and tribal governments wishing to improve their existing service delivery systems to prevent or treat FASD; the other for juvenile courts wanting to develop and implement policies and procedures to screen, diagnose, and treat juveniles with FASD. OJJDP staff participated in the kickoff meeting for the juvenile court SAMHSA subcontract awardees in spring 2005 by presenting information about OJJDP's interest in the project, the agency's goals for the project sites, and State and local juvenile justice resources that might be helpful to project grantees.

OBJECTIVE II. Documenting Prevalence and Identifying Children with FASD

- FAS is difficult to diagnose accurately in the newborn period, but children with FAS most likely encounter a variety of service providers in early childhood. The FAS Surveillance Network (FASSNet), funded by **CDC** from 1998-2003 cast a broad net and used a multiple source-methodology for FAS case finding and records abstraction. These five State programs (Alaska, Arizona, Colorado, New York, and Wisconsin) combined several data sources within each State to improve the likelihood of finding all children with FAS in different populations across various geographic areas. The FASSNet group's final publication described surveillance of FAS in four States (Alaska, Arizona, Colorado, and New York) among children born from 1995-1997. The overall 3-year prevalence of FAS varied only slightly in three of the four sites, from 0.3 to 0.4 per 1,000 live-born infants; the prevalence in Alaska was 1.5, due primarily to a high rate among American Indians and Alaska Natives (CDC, 2002b). The FASSNet methodology has been streamlined and is being used as a new surveillance system, FASSLink, by the FAS Prevention Project grantees.
- **NIAAA** is funding several long-term studies to follow individuals exposed to alcohol prenatally. One study is a follow-up of a birth cohort of about 500 individuals exposed to alcohol before birth through maternal drinking. The long-term effects of fetal alcohol exposure studied by this project include memory, executive function, information processing, physical size, facial features, alcohol/drug use and abuse and other adverse life outcomes. This rare cohort of individuals offers one of the only a few possibilities of studying long-term effects of fetal alcohol exposure. Recently published results from this study indicate an increase in both heavy drinking and alcohol dependence in 21-year-old adults exposed prenatally to heavy episodic alcohol (Baer et al, 2003). Other recently published data from this longitudinal study show that individuals prenatally exposed to heavy alcohol have an increased adolescent and adulthood incidence of disrupted school experiences, trouble with the law,

confinement, inappropriate sexual behavior, and alcohol and drug problems (Streissguth et al , 2004). In addition, current data indicate that those secondary disabilities and their long-term adverse outcomes can be mitigated by early diagnosis and good stable home environments.

- In another **NIAAA-**funded longitudinal study, a similar opportunity exists to study long-term effects of fetal alcohol exposure in a population first identified 16 years ago. This study has to date characterized these individuals in eight assessments from birth to age 14. The outcomes examined include growth and cognitive and behavioral development. Recently published results from this study show verbal learning and memory deficits associated with first trimester prenatal alcohol exposure in subjects who do not meet diagnostic criteria for FAS (Willford et al, 2004).
- A third ongoing **NIAAA-**sponsored long-term study involves a multisite prevention trial among a group at high risk for maternal drinking and FAS -- American Indians. The research is conducted among four Plains Indian communities, one urban site, and two control sites. The goal is to deliver and study the effectiveness of an FAS prevention program that was designed based on a set of recommendations by the Institute of Medicine. The outcome measures are FAS prevalence rates and adult drinking practices. The study also includes a formative evaluation of specific segments of the prevention package.
- In 2000 **NICHD** funded a third wave of the National Longitudinal Study of Adolescent Health. This comprehensive study examines a broad range of health and health-risk behaviors among young adults 18 to 24 years of age. A high prevalence of alcohol consumption, binge drinking, and unintended pregnancy - all factors contributing to the risk of alcohol-exposed pregnancies - characterize the early adult years. This study has provided rich data that will enable researchers to better understand the individual and social factors that contribute to FASD-relevant risk behaviors, potentially leading to the identification of new prevention strategies. For example, results recently published from an earlier wave of this study indicate that ambivalence toward pregnancy in girls in 9th through 11th grades is predictive of pregnancy subsequently occurring, thus identifying a high-risk group for adolescent pregnancy (Jaccard et al, 2003). Other investigators recently reported that frequency of depressive symptoms in young adults in this sample was associated with heavy drinking but not with low or moderate drinking (Paschall et al, 2005).
- **CDC** and the Foundation for Alcohol Related Research, in collaboration with the National Health Laboratory Services and the University of Witwatersrand (Johannesburg), are working together to develop ongoing surveillance for FAS; estimate the prevalence of FAS in South African provinces; investigate, implement, and evaluate prevention strategies; complete needs assessments detailing the availability and gaps in alcohol prevention and treatment services for women and intervention services for children; and develop local epidemiology capacity through training of key study staff. This project began in 2002 and will continue through 2005. A preliminary report on the data collected finds FAS rates higher than those thus far reported in South Africa. Intervention strategies established through this project are being evaluated currently for replication in other provinces.
- **NICHD** collaborated with **ED**, the **CDC**'s 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 children. The ECLS-B study asked recent mothers about alcohol consumption before, during, and after pregnancy, as well as drinking problems of parents. This information, paired with demographic data and other characteristics about the mother and father, will add to the understanding of

consequences of alcohol consumption on the health, development, and growth of children, and possibly of mediating effects.

- For the past 5 years, Dr. Linda Teplin of Northwestern University, with support from **OJJDP**, NIMH, **SAMHSA**, and **CDC**, as well as several private foundations, has been conducting a large-scale longitudinal study of alcohol, substance use, and mental disorders among detained juveniles in Cook County, Illinois. 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 pregnancies affected by alcohol. Dr. Teplin has recently received permission from Northwestern's Institutional Review Board (IRB) to begin tracking (and potentially assessing) the children born to study participants.
- In 2002 **CDC** established a cooperative agreement with the Danish Medical Research Council to use the Danish National Birth Cohort to examine central nervous system development of children with varying levels of alcohol exposure identified through the Danish National Birth Cohort. The Danish National Birth Cohort is a population-based cohort study of mothers and their children in Denmark. Through a telephone survey, researchers obtained medical information (including alcohol use) from women enrolled in the study prior to pregnancy. Following these women through pregnancy and birth offers the opportunity to also follow their children, who may have been prenatally exposed to alcohol. Medical, behavioral, and intellectual information will be gathered from these children as they become 5 years old. Follow-up exams are underway and the study is scheduled for completion in 2007.
- **CDC** has been monitoring alcohol use among pregnant and nonpregnant women using the Behavioral Risk Factor Surveillance System (BRFSS) since 1991. Ongoing monitoring and reporting of trends in at-risk drinking in women of childbearing age has been effective in keeping this public health concern on the radar screens of clinicians, public health officials, and the public. The most recent trends analyses found that the prevalence of binge drinking in pregnant women reached a high point in 1995 and has not declined since. Binge drinking in nonpregnant women continues to be high also, with 1 in 12 reporting binge drinking in the past month (CDC, 2002a; Floyd and Sidhu, 2004).
- Alaska's Statewide Fetal Alcohol Syndrome Five-Year Comprehensive Project, funded with a 5-year grant awarded through **SAMHSA** in September 2000, has ongoing development of a community-based FASD diagnostic team network. This has resulted in Alaska's having the most comprehensive FASD diagnostic services in the country. After diagnosis, case planning occurs with recommendations for specific services. Alaska has also increased reporting of births affected by alcohol to its Birth Defects Registry. In partnership with the FAS Surveillance Project, the Office of FAS is improving data on FAS prevalence rates.
- In 2003-2004 **CDC** funded seven State-based, 5-year cooperative agreements to develop, implement, and evaluate comprehensive population-based and targeted prevention programs for FAS, including (1) identifying high-prevalence geographic areas and selected subpopulations of childbearing-age women at high risk for an alcohol-exposed pregnancy; (2) establishing or enhancing prenatal and preconceptional intervention programs to serve these populations; and (3) establishing or using existing surveillance and monitoring systems to assess the impact of the prevention programs. Surveillance and monitoring programs were also directed to ensure that children identified with FAS have access to appropriate services

within the community. States funded for this work are Colorado, Michigan, Minnesota, Missouri, South Dakota (in collaboration with North Dakota), Oregon, and Wisconsin.

- The IOM committee on FAS developed diagnostic criteria for FAS and alcohol-related effects (Stratton et al 1996). Some have thought that those criteria were severely limiting due to the lack of specific parameters, failure to consider family history, and failure to define ARBD and ARND for clinical use. **NIAAA-**funded researchers have recently published a new report revising the 1996 IOM diagnostic criteria for FASD and clarifying them to facilitate their practical application in clinical pediatric settings (Hoyme et al, 2005).
- Under the new program "State Agencies and Community Organizations Planning and Implementing the FASD Initiative" the **SAMHSA** FASD Center for Excellence recently awarded subcontracts for 20 community-based organizations and 10 State projects. Among these are several initiatives to improve screening and diagnosis of FASD, including testing of various tools. The projects began in late 2004 and early 2005. The first phase of the projects is a planning year, followed by 4 optional years for implementation.
- **IHS** Maternal Child Health coordinators held discussions on FAS August 24 through October 4, 2004 and received comments from health care providers. Needs cited included identification and appropriate intervention for at-risk pregnancies, diagnosis and terminology, multidisciplinary intervention and followup, interdisciplinary communication and information sharing.
- **NIAAA** convened a workshop in 2001 to stimulate research on biological markers that will document exposure to alcohol in neonates or provide definitive evidence of maternal alcohol consumption during pregnancy. Researchers supported by NIAAA have validated a biomarker of fetal exposure to alcohol (Bearer et al, 2003, Bearer et al, 2004/2005). Fatty acid ethyl esters (FAEE), products of non-oxidative metabolism, have been detected in meconium, the first bowel movement of the newborn. With previous methods of measuring FAEE, sensitivity and specificity for detecting any maternal drinking were low. In this study, ethyl oleate indicated maternal alcohol use with sensitivity and specificity greater than 80 percent. NIAAA has partnered with a small business through the Small Business Innovation Research (SBIR) program to develop an assay for FAEE in hair.
- **NIAAA** SBIR program is also supporting the development of a microarray chip than can simultaneously detect changes in a variety of proteins and chemicals in tissues affected by prenatal alcohol exposure. A clinically useful biomarker to detect risk levels of drinking during pregnancy would permit earlier identification and intervention for infants affected by alcohol exposure and will facilitate recognition of women who are likely to drink during their next pregnancy. Biomarkers for FAS could also help to identify potential physiological mechanisms that mediate alcohol teratogenesis.
- As part of the FY 2002 appropriations funding legislation, Congress mandated that **CDC**, in coordination with the National Task Force on FAS/FAE, other federally-funded FAS programs, and appropriate nongovernmental organizations, develop guidelines for the diagnosis of FAS and other negative birth outcomes resulting from prenatal alcohol exposure. Over a 2-year period these groups and a Scientific Working Group convened by CDC met and deliberated on the clinical diagnostic criteria for FAS. *Fetal Alcohol Syndrome: Guidelines for Referral and Diagnosis* was published in July 2004 (CDC, 2004c) and introduced at the National Conference of the National Center on Birth Defects and Developmental Disabilities in

Washington, DC. These guidelines are being disseminated and can be accessed at www.cdc.gov/ncbddd/fas .

- In 2004 **NIAAA** researchers reported that children with heavy prenatal alcohol exposure can be distinguished from nonexposed children with a high degree of accuracy using commonly used measures of attention, specifically the "Freedom from Distractibility Scale" from the WISC-III and the "Attention Problems Scale from the Child Behavior Checklist." Classification accuracy was 91.7 percent overall, with 93.3 percent of the alcohol exposed children and 90 percent of the control children accurately classified (Lee et al, 2004).
- The **IHS** and **CDC** have validated and approved an IHS prenatal health assessment tool to screen for substance use in prenatal clinics. The IHS prenatal assessment is considered to be an excellent screening tool and currently is used in IHS Aberdeen Area and other areas. Aberdeen Area has also created a CD-ROM "Screening Pregnant Women for Substance Use; A Training Guide for Health Care Providers" to assist with use of the screening tool. The IHS prenatal assessment can be found at: http://www.psc.gov/forms/IHS/ihs-866.pdf .
- **NIAAA** established a neurobehavioral assessment core as part of its Collaborative Initiative on FASD (CIFASD) (2003-present). The purpose of the core is to develop a flexible and standardized test battery to assess alcohol-exposed individuals from birth to adulthood. The core test battery will include measures of general cognitive ability, attention, executive functioning, language, visual perception, memory, motor skills, and emotional functioning. It will be evaluated in CIFASD consortium sites in the United States, Russia, South Africa, and Italy to determine its usefulness across diverse cultural and geographic settings. An important goal of this project is to identify assessment tools useful in identifying individuals who lack the classic facial features characteristic of FAS but have significant cognitive and behavioral impairments related to prenatal alcohol exposure. Determining the impact of prenatal alcohol exposure across the lifespan may improve access to services for individuals who "age out" of programs targeting children and adolescents and are subsequently lost to follow-up.
- Currently, there is no specific laboratory marker to indicate fetal alcohol syndrome. Obtaining a reliable marker for fetal alcohol exposure could lead to the identification and treatment of women at risk for having a child with FASD who may not otherwise provide this information because of the stigma associated with prenatal alcohol use. Possible biomarkers include maternal blood and meconium (first stool of the newborn infant) testing. Studies are needed to devise and test sensitive and specific biomarkers to help identify alcohol-exposed pregnancies and newborns exposed to alcohol prenatally. In 2001 **CDC** funded three university-based projects in Ohio, Maryland, and Massachusetts to establish the feasibility and utility of prenatal biomarkers of alcohol use for clinical and surveillance use. These projects will continue to enroll study subjects in 2005 and will complete analysis in 2006.
- Included among the shared core facilities of the **NIAAA** Collaborative Initiative on Fetal Alcohol Spectrum Disorders (CIFASD) (2003-present) consortium is a dysmorphology center staffed by expert diagnosticians to ensure accurate and consistent diagnosis of fetal alcohol spectrum disorders in children from across multiple research sites in very diverse cultural and geographic settings. A key objective of this project is the integration of data from expert physical examinations and 3-D facial imaging studies to determine the full range of structural defects in FASD and their relationship to changes in neurobehavioral development. The center also aims to develop strategies to improve diagnosis of fetal alcohol spectrum disorders in the newborn period.

- The **IHS** Health Manual is currently being updated and stipulates standards and protocols for screening consumers for co-occurring mental and substance use disorders and linking them with integrated treatment strategies. IHS Primary Health Care screening protocols and standards are established at the service unit level to best reflect their particular needs and population. The broader outlines of minimum required elements are published in the IHS Health Manual chapters as well as Joint Commission and Committee on Accreditation and Rehabilitative Facilities (CARF) requirements. The Health Manual information can be accessed and downloaded from the Internet at: http://www.ihs.gov/PublicInfo/Publications/IHSManual/index.asp (Part 3. Professional Services – Mental Health Program, Chapter 14.4 Treatment Process Standards A. Patient Intake & Screening, B. Patient Assessment, & C. Treatment Planning).
- The Education Work Group (**ED/OSEP**) collaborated with ICCFAS and the Federal Interagency Coordinating Council (FICC) to promote early identification of children with FASD. They agreed to expand the age of identification of FASD from early childhood to 21 years old and to explore use of the educational interventions described in Dr. Rochelle Schwartz-Bloom's report, "FAS: A Toolbox for Educators" for teaching students with FAS.

OBJECTIVE III. Prevention of Drinking during Pregnancy

- **NIAAA** and **NICHD** have completed Phase I and Phase II (1999-2004) of the collaborative "DC Initiative on FAS," which was part of the "Initiative to Reduce Infant Mortality in Minority Populations in the District of Columbia." This research project took place at three hospital sites within the District of Columbia (DC) involved in prenatal health care and delivery and two public prenatal health clinics. In Phase I, an audio-computer-assisted self-interview (ACASI) was developed and validated to screen for alcohol use in pregnant women attending prenatal clinics for health care. The computerized user-friendly screening instrument includes questions about alcohol use, smoking, drug use, and medical history. It was favorably reviewed by more than 90 percent of the patients in the study and judged easy to use. The findings have been published (Thornberry, et al, 2002) and the journal *CIN: Computers, Informatics, Nursing* has chosen the publication for Nursing Continuing Education credits.
- In the Phase II of the DC Initiative, "Identifying Risk for Fetal Alcohol Exposure During Preconception and Perinatal Visits for Low-Income Minority Women," participants (n=1064), were low-income African-American and Hispanic women between 18 and 45 years old. They were asked in the primary and prenatal clinic waiting rooms to use the ACASI to answer alcohol-related questions about quantity, frequency, tolerance, worry about drinking and thought or attempts to reduce consumption. To identify heavy and moderate drinking, not just abusive and dependent drinkers, the cutoff used for recommending counseling was lower than in most previously published reports. Health care providers received a printout of the data on the computer screen. Compared to previous year data from the same sites, ACASI screening yielded higher reported prevalence of alcohol use. Women who reported greater alcohol consumption during the ACASI screen were more likely to receive educational brochures and be targeted for brief intervention. These results suggest that, in general, computerized screening in primary care clinics may enhance risk assessment (Rodan et al, 2004). Results have been presented at both the 2004 Annual Meeting of the Research Society

for Alcoholism and the American Public Health Association 132nd Annual Meeting, 2004. Full-length manuscripts are being prepared for publication in peer-reviewed journals.

- The **HRSA's** Maternal and Child Health Bureau funded an initial demonstration project from FY1999-2001, "Improving Screening for Alcohol Use During Pregnancy Among Providers," to programs with direct service prenatal clinic populations. The purpose of the project was to test methods that might motivate providers to systematically screen for alcohol use during pregnancy, provide information on associated risks, and refer for interventions if needed by the client. Four projects were funded in the following States: Massachusetts (Kennedy et al, 2004), Puerto Rico, Illinois, and Nebraska. The projects linked community efforts with the State and Maternal and Child Health Title V Offices to enhance program effectiveness and disseminate results. Project efforts targeted a diverse care system including those who serve public and private clinics and clinics for American Indians. Findings from these projects included the need to change the practice site as little as possible when implementing screening and to train all staff in the clinics. Staff at all four projects indicated that the 4P's and 5P's screens (similar screening tools used in these demonstration projects) were better than other screens they tried. Three of the projects noted that face-to-face screening was best but one project felt that it was better to use a self-administered screen to minimize interviewer bias. Each project identified "lessons learned" that are now being replicated in two States, Massachusetts and Illinois.
- In 2001 **CDC** funded three universities (Nova Southeastern University, University of Texas, and Virginia Commonwealth University) to conduct a randomized controlled trial (RCT) of a dual-focused intervention for prevention of alcohol-exposed pregnancies in high-risk women. This study, Project CHOICES, focuses on preconception women since most women do not realize they are pregnant until the 6th week of pregnancy and many continue to drink heavily resulting in the birth of a child with FASD. An early study of Project CHOICES, which seeks to reduce harmful alcohol use and postpone pregnancy until alcohol use is under control, found it successful in reducing risk for an alcohol-exposed pregnancy in two-thirds of the high-risk women who received the intervention (CDC, 2003a). Data collection for the RCT was completed in fall 2004 with more than 800 women randomized to intervention and standard care groups. Preliminary analyses find higher rates of reduced risk for an alcohol-exposed pregnancy among women who received the more intensive intervention compared to those who only received information and referral that represented the standard of care for the setting. Further analyses and dissemination of the study results and information about the Project CHOICES approach to reducing alcohol-exposed pregnancies will be carried out during 2005.
- **NICHD** has supported a number of behavioral research studies designed to add to our knowledge of risk behaviors (including alcohol use) during adolescence and young adulthood. These studies include investigations of factors contributing to and moderating alcohol use in early adolescence, the influence of parents and peers, and intergenerational transmission of substance use. Other factors being examined are the impact of poverty on health and risk behavior and alcohol use in sexually active minority adolescents. In addition, some funded studies evaluate developmental and psychosocial approaches to models of binge drinking and descriptive studies of problem behaviors (including alcohol use and binge drinking) among middle school students.
- In September 2000, **SAMHSA** awarded a 3-year grant to the Center for Disabilities at the University of South Dakota School of Medicine and Health Sciences for a Four-State

Consortium to build capacity to reduce risk factors associated with FASD. The Four-State Consortium includes Minnesota, Montana, North Dakota, and South Dakota. The primary objectives of this cooperative agreement were to share resources among the four States and to evaluate the effectiveness of resource sharing, to develop an information base to identify populations and areas at high risk, and to implement and test prevention models for women at high risk of abusing alcohol during their childbearing years. Much of the information and results generated from this project were published in the November-December 2003 issue of *Neurotoxicology and Teratology*. Additional ongoing work by the Consortium includes validating a brief instrument on alcohol use that can be completed within 5 minutes, developing clinic procedures for using the revised instrument, training clinics on using the instrument, and making appropriate referrals to community resources based on the results.

- **NIAAA** has supported studies of screening, brief intervention, and motivational interviewing in the prevention of alcohol use during pregnancy. Findings indicate that screening and brief intervention or motivational interviewing substantially reduced women's prenatal drinking levels (Handmaker and Wilbourne, 2001; Fleming et al, 2002; Armstrong et al, 2003). Several such studies target women with low to moderate incomes as well as women from minority groups at high risk for drinking during pregnancy. Screening and brief intervention were demonstrated to have high potential for broad dissemination within prenatal health care systems targeted at moderate- and low-income women. In one study, low-income women who were screened and received brief intervention achieved nearly 100 percent reduction in their alcohol consumption by the third trimester compared to a 90 percent reduction in drinking by women who only received screening for alcohol consumption (O'Connor and Whaley, 2003). Preliminary results from another study demonstrate similar drinking habits between partners but poor agreement between pregnant women and their partners on questions about prenatal alcohol use and its consequences. This suggests that partner involvement may improve a woman's ability to reduce drinking during pregnancy (Chang et al, 2003).
- In spring 2004 the **AHRQ** sponsored U.S. Prevention Services Task Force (USPSTF) released new findings and recommendations based on their recent comprehensive study on evidence for clinical preventive services for alcohol misuse. The USPSTF found good evidence that screening in primary care settings can accurately identify patients whose levels or patterns of alcohol consumption do not meet criteria for alcohol dependence, but place them at risk for increased morbidity and mortality, and good evidence that brief behavioral counseling interventions with follow-up produce small to moderate reductions in alcohol consumption that are sustained over 6- to 12-month periods or longer. "The evidence supports the effectiveness of behavioral counseling interventions among women of childbearing age and recommends screening and behavioral counseling interventions to reduce alcohol misuse by adults, including pregnant women, in primary care settings."
- Beginning in 1997, **HRSA**'s Maternal and Child Health Bureau provided technical assistance through a contract to selected Healthy Start communities on the topic of prenatal screening for alcohol and illicit substance use. On average, 12 sites were funded per year for each of the 8 years of this project. Technical assistance focusing on the use of alcohol and other drugs during pregnancy has been delivered to 60 Healthy Start sites and two sites funded by MCHB to develop strategies for motivating physicians to screen for alcohol use during pregnancy. Within the Healthy Start sites, the goal of the technical assistance has been to develop policies and procedures for integrating substance use screening and assessment into primary prenatal

care and to link the prenatal care sites to substance abuse treatment programs. A recently published paper describes the outcomes of the one-minute screening and standard clinical assessment in four Healthy Start sites. The results indicate that in a demographically diverse, majority Medicaid-eligible population (4865 women) 21 percent of pregnant women drank alcohol in the month prior to knowledge of pregnancy and 11 percent after learning of the pregnancy (Chasnoff et al., 2005). It should be easy for clinics and doctor's offices to integrate this one-minute screen identifying at-risk drinking into prenatal visits throughout pregnancy.

- Each April, to raise public awareness about alcohol's effects on general health, a National Alcohol Screening Day (NASD) is conducted by **NIAAA**, **SAMHSA**, and Screening for Mental Health, Inc. More than 50 public and private partners have been NASD sponsors. A wide variety of colleges, hospitals, businesses, and government agencies host NASD events in campus centers, shopping malls, and other community-based venues. At these screening sites, participants can receive a written questionnaire to identify particular risk for problems with alcohol and can meet with a health professional. In 2004, more than 5000 sites nationwide offered free screenings. Screening at primary care sites has grown from 1173 attendees screened at 365 sites in 2001 to more than 25,000 attendees screened at 2137 primary care sites in 2004. Sixty-two percent of those screened at primary care sites were between the ages of 18 and 44, and 57 percent were women. Among women who were pregnant, breast-feeding, or planning a pregnancy, approximately 12 percent screened positive for problem drinking. All participants were provided with educational materials and referrals for further evaluation or treatment were provided when appropriate.
- In 2001 **CDC** provided 3 years of funding for three university-based projects to design, implement, and evaluate targeted media campaigns aimed at reducing prenatal alcohol use. These sites were St. Louis University (St. Louis, MO), targeting African-American women in St. Louis; University of California, Los Angeles (Los Angeles, CA), targeting various racial and ethnic groups in southern California; and University of Iowa (Iowa City, IA), targeting rural WIC recipients. These campaigns used various implementation strategies and media. The St. Louis campaign conducted a random-digit dial survey to assess FASD knowledge after the campaign. Results did not show an increase in FASD prevention knowledge but they did find that if frequency of messages heard was high, FASD prevention knowledge did improve. Preliminary results from the Iowa campaign suggest that the intervention increased the health literacy of women regarding alcohol and pregnancy and improved women's comfort in discussing the issue. Plans for publication of project findings are underway.
- Between 1999 and 2004 **NIAAA** funded several individual research studies to evaluate proposed methods to prevent drinking during pregnancy, such as brief intervention or motivational enhancement for pregnant women who screened positive for drinking. Recent preliminary results from one of those studies evaluating long-term effects of brief intervention demonstrated that women in an intervention group seen in a large urban obstetrics practice were significantly less likely to report any alcohol use during the prenatal follow-up period than the usual care subjects. However, increased alcohol abstinence rates, less binge drinking, and reductions in daily alcohol intake are not sustained during the postpartum 12 month follow-up period when women may be vulnerable for a subsequent pregnancy (Kraemer, 2004). Thus, additional research is needed to further investigate methods to protect women from alcohol exposure during the first trimester of their next pregnancy. Four NIAAA-supported prevention investigators presented progress on ongoing studies aimed at reducing

the risk of drinking during pregnancy at the December 2003 meeting of the ICCFAS. Complete results of these studies are expected to be published in the near future.

- **NICHD** has contributed to the **NIAAA** program "Leadership to Keep Children Alcohol Free," the Governors' Spouses Initiative on Children and Alcohol, to assist in the identification and prevention of underage drinking. The long-term goals of this initiative, reduction in alcohol use and risky behavior in youth, could decrease the number of teenagers having babies with FASD and alter alcohol use habits in both the short-term and throughout life.
- In 2001 **CDC** funded Project BALANCE (Virginia Commonwealth University), a one-session adaptation of Project CHOICES targeting college-aged women. One objective of the project was to identify the prevalence of risky drinking and contraceptive behaviors using survey and focus groups. A second objective was to test the efficacy of an intervention for risky behavior using a randomized trial to compare a group receiving both assessment and one face-to-face session with a group receiving assessment only. The intervention focused both on drinking and unprotected sex, allowing a woman to modify either or both behaviors. Follow up occurred at 1 month and 4 months. The project has been completed and preliminary analyses indicate that women in the intervention group were significantly less likely to be at risk for alcohol-exposed pregnancy than women in the assessment only group (74.5 percent vs. 61.5 percent) 4 months post intervention. While both groups had large reductions in risk, women receiving the intervention showed less risk. Both groups decreased drinking amounts overall and increased effective contraception but no significant difference was found between the two groups on these variables at 4 months.
- One potential method of reducing fetal exposure to alcohol is to reduce maternal drinking through providing education to the staff of commercial establishments that serve alcohol. **NIAAA** is currently funding a study that targets women of childbearing age who are patrons of bars and evaluates the effectiveness of server training legislation by comparing States that have legislatively mandated such training (New Mexico) with those that have not (Oregon). The study has developed a program for server training that emphasizes the risks of FAS. Recently reported preliminary results demonstrate dramatic increases in refusals of orders for additional drinks for apparently pregnant women (actor pseudopatrons) at New Mexico sites with trained servers but not at Oregon study sites (Wheeler et al, 2004; Dresser, 2004).
- Under its Community Initiated Prevention Program **SAMHSA** awarded five 3-year grants in September 2001 to (1) University of Arizona College of Public Health, in collaboration with the Pascua Yaqui Tribe, which developed an approach to reducing alcohol use in women of childbearing age; (2) the Fetal Alcohol and Drug Unit, University of Washington School of Medicine, which implemented a modified version of its Parent-Child Assistance Program (PCAP) for rural Native American women; (3) Governor's Institute on Alcohol and Substance Abuse, North Carolina, which ran the Baby First Partnership; (4) the Bluegrass Prevention Center, Kentucky, which evaluated FASD prevention in rural communities; and (5) the American Indian Institute, University of Oklahoma, which evaluated the 7th Generation FAS/FAE Prevention Curriculum for American Indian youth in several school systems, faith-based organizations, and youth clubs. These projects have just recently been completed. Final results, evaluation, and presentation of relevant outcomes are being prepared.
- Following completion of the project "Improving Screening for Alcohol Use During Pregnancy Among Providers" **HRSA**'s Maternal and Child Health Bureau funded the project "Replicating 'Lessons Learned' in Alcohol Screening During Pregnancy Demonstration

Program." The replication grant was awarded to two sites, Massachusetts and Illinois, for FY2002-2005. This grant promotes the replication of strategies used in the original demonstration program that were found to motivate care providers to systematically screen women for alcohol use during pregnancy, provide information on associated risks, and consistently refer clients for interventions.

- To facilitate the translation of research to practice, the **SAMHSA** Materials Development Center for Excellence conducted a study on the effect of pregnancy on alcohol use in a combined sample based on 3 years of SAMHSA's National Survey of Drug Use and Health data (2000-2002). Unlike previous studies, the sophisticated analytic approach applied to the data took confounding variables into account (e.g., variables that affect both pregnancy and alcohol use such as age and marital status). Controlling for these variables, the study examined psychosocial variables that predict alcohol use among pregnant women. Study findings and their implications for future preventive interventions, including appropriate target audiences, were presented at the SAMHSA FASD Center for Excellence Steering Committee meeting held in Albuquerque, New Mexico in November 2004 and a written report is currently being prepared for submission to a peer-reviewed journal.
- In FY2003 **HRSA**'s Maternal and Child Health Bureau's Division of Healthy Start and Perinatal Services awarded three new community-based grants totaling $1.35 million over 3 years to develop an instrument that will screen simultaneously for multiple behavioral risk factors common for women during their childbearing years. The demonstration program, "Screening for Multiple Behavioral Risk Factors During the Preconception Through Postpartum Period" is designed to improve provider screening for domestic violence, alcohol use, and depression. Sites funded by the demonstration project were the Medical and Health Research Association of New York City, the Boston Public Health Commission, and Children's Research Triangle in Chicago, serving the city's south side.
- In FY2004, **OJJDP** awarded a grant to the Research Triangle Institute for a Girls Study Group. This project will run for at least 2 years. It will explore prevention and intervention strategies for violent and delinquent girls and will generate information on effective and promising strategies that are developmentally and culturally appropriate. Findings will be widely disseminated through a variety of mechanisms, including journal articles, online publications, OJJDP bulletins, listservs, teleconferences, conference presentations, and other media. The target audience for this information includes juvenile justice practitioners, researchers, and policy makers, as well as other professionals in agencies that serve delinquent and at-risk youth (e.g., child welfare, education, mental health, substance abuse). Local, State, and Federal legislators will also receive information from the results of this study on effective strategies for preventing violent and delinquent behavior among girls.
- In FY2004 the **IHS** Public Health Nursing Division awarded a grant to the Iowa Tribe of Oklahoma in Perkins, OK for their Maternal Child Health FAS Prevention Project to establish an innovative and culturally competent system of care. Public Health Nursing services will assist the Tribe to establish alcohol screening (FAS prevention) services that do not currently exist, provide prevention activities, and educate the community on the dangers of drinking while pregnant. This project is also expected to be funded in FY2005.
- In 2004 **CDC** funded St. Louis University (St. Louis, MO) and Nova Southeastern University (Ft. Lauderdale, FL) to develop interventions aimed at preventing FASD. These universities are developing, implementing, and evaluating community-level, self-guided change projects targeting women 18-44 years of age who are at risk for an alcohol-exposed pregnancy. The

goal is to demonstrate a 15 percent reduction in the proportion of women at risk for an alcohol-exposed pregnancy in community-based intervention sites compared to nonintervention community-based sites.

OBJECTIVE III and OBJECTIVE IV. Projects Combining Approaches to Reduce Drinking during Pregnancy and Intervening with Children and Families Affected by Prenatal Alcohol Exposure

- **SAMHSA** expanded its programs for FASD in 2001 in response to the Children's Health Act of 2000, Section 519D in which Congress mandated that awards shall be made for centers of excellence "to study techniques for the prevention of fetal alcohol syndrome and alcohol-related birth defects and adaptations of innovative clinical inventories and service delivery improvements for the provision of comprehensive services to individuals with fetal alcohol syndrome or alcohol-related birth defects and their families and for providing training on such conditions." A SAMHSA FASD Center for Excellence was established with a contract in the fall of 2001 to Northrop Grumman Health Solutions. The contract was expanded in 2004 so that the SAMHSA FASD Center for Excellence also serves as a project coordinating center to manage SAMHSA FASD subcontracts for State agencies, juvenile courts, and community groups to implement innovative FASD prevention and intervention strategies.
- **IHS** and the First Nations and Inuit Health Branch/Health Canada Ad Hoc Working Group on FASD developed a Memorandum of Understanding (MOU) to address concerns and share solutions regarding the disparity of FASD rates among indigenous peoples. The working group met October 26-28, 2004, to develop critical long-term goals and objectives to guide efforts of the working group through the remaining 3 years of the MOU. The purpose of this MOU is to "share knowledge through an agreed upon annual schedule of work which may include the exchange of information and personnel, the conducting of workshops, conferences, seminars, and meetings." These efforts focus on prevention and intervention. Dan Dubovsky, M.S.W., L.S.W., **SAMHSA** FASD Center for Excellence, has provided critical input as an advisor on this project.
- The Office of Fetal Alcohol Syndrome, State of Alaska Department of Health and Social Services, is nearing completion of Alaska's Statewide Fetal Alcohol Syndrome Five-Year Comprehensive Project funded in September 2000 by **SAMHSA**. The Office of FAS continues to work toward the development of a comprehensive, integrated statewide approach to prevent FASD, diagnose children as early as possible, improve lifelong outcomes for individuals with FASD through improved services, and evaluate program outcomes and document progress. Highlights of project accomplishments include a statewide public education and media campaign, FASD curriculum development for service providers, and funding of 40 community-based innovative FASD projects. These projects include prevention programs aimed at middle and high school-age youth, prenatal programs working with expectant parents, and training programs for school personnel working with children and youth with FASD. In the fall of 2005 the State will hold the last of its five statewide summits. At these summits regions present their plans and discuss how each regional plan will work in concert with other regions to develop a statewide FASD effort at the conclusion of Federal funding.
- Fetal and Infant Mortality Review (FIMR) is a community action process that continually assesses and improves service systems and resources for women, infants, and families through

confidential and anonymous review of individual cases. The National Fetal and Infant Mortality Review (NFIMR) is a resource center that provides information and advice about implementing the fetal and infant mortality review process and represents a partnership between the American College of Obstetricians and Gynecologists (ACOG) and **HRSA/MCHB**. **CDC** is involved with NFIMR as part of a larger cooperative agreement awarded to ACOG in 2003. The purpose of this project is to use the established FIMR process to expand the knowledge base about service systems, specifically addressing the personal knowledge, attitudes, and beliefs of women who have experienced infant morbidity and mortality that may be associated with fetal alcohol exposure. The project will identify service system improvements or enhanced health education (such as the effects of alcohol on the fetus) that may improve outcomes for future families. ACOG has subcontracted with the City of Detroit Health Department and the MedChi Foundation in Maryland to conduct activities under this cooperative agreement. This project will end in 2006.

- As part of the "State Agencies and Community Organizations Planning and Implementing the FASD Initiative" the **SAMHSA** FASD Center for Excellence is funding and providing technical support to 20 selected community-based organizations and 10 States to develop initiatives designed to reduce the number of cases of FASD and to improve functioning and quality of life for persons with FASD. Among the initiatives funded under this program are 13 community-based projects and six State projects that address FASD prevention and treatment. The projects began in late 2004 and early 2005. The first phase of the projects is a planning year, followed by 4 option years to implement the plans.
- **AHRQ** funded an information dissemination conference, "Best Practices in FAS Prevention and Intervention," August 18 – 19, 2004 in Muskegon, Michigan, sponsored by the Arc/Muskegon. Because alcohol-related birth defects are 100 percent preventable, professionals need to be educated on the most effective methods for disseminating prevention and intervention information. Conference objectives included acknowledging the need for a consistent message about abstaining from alcohol during pregnancy, identifying effective methods to screen for alcohol use with pregnant women, and identifying effective intervention models and components of beneficial therapies for individuals with FAS/ARND. The audience included healthcare providers and support persons, who help women maintain abstinence from alcohol during pregnancy. Videotapes of the conference session are available for other groups. The proceedings can be reviewed on the Michigan FAS Workgroup Web site - www.michigan.gov/fas .
- The **SAMHSA** FASD Center for Excellence convened the first-ever Building FASD State Systems (BFSS) meeting in 2003. Representatives from 49 states, the District of Columbia, and Puerto Rico attended. The meeting addressed various topics related to developing comprehensive systems of care for FASD prevention and treatment and facilitated the creation of the National Association of FASD State Coordinators (NAFSC), which now has 15 members. The Center continues to support NAFSC. The meeting was highly successful and was repeated in 2004 with representatives from all 50 states, DC, Puerto Rico, and the United Kingdom. The third BFSS meeting was held in San Antonio, TX, June 21-24, 2005. In addition to small group discussions on elements of a comprehensive system of care, at the San Antonio meeting there was a group panel that discussed some of the difficulties in screening and diagnosing various FASD. Several ICCFAS committee members from other Federal organizations have given presentations and moderated discussion panels at these meetings. As part of this BFSS effort, the SAMHSA FASD Center for Excellence has

developed a model of a comprehensive system of care and gathered information from States on which elements of the model are in place.

- **IHS** and Health Canada Ad Hoc Working Group on FASD held a meeting on April 27 and 28, 2005 in Seattle, WA in conjunction with the International Child Health Conference - First Nations and Inuit Health Indian Health Service and Research Conference. The purpose of the Working Group on FASD Meeting was to conduct a final review of the IHS draft document, "joint FASD preferred and best practices scan" and the dissemination strategy; discuss the creation of a joint Web site for sharing knowledge on FASD and current MOU activities, (currently, FASD MOU Working group activities are posted on the IHS DBH Web site); and clarify and reach consensus regarding the topic for the "one joint project in FASD."
- In September 2003 the **SAMHSA** FASD Center for Excellence coordinated with the National Organization on Fetal Alcohol Syndrome (NOFAS), **NIAAA**, and various Maryland treatment centers to plan "Hope for Women in Recovery: Understanding and Addressing the Impact of Prenatal Alcohol Exposure." This first meeting was designed to increase knowledge and awareness about FASD among treatment center staff and clients and included town hall meeting for women in treatment to share their stories. About 200 women in recovery and treatment counselors participated. ICCFAS chair Faye Calhoun, NIAAA, addressed the meeting. A second day focused on Maryland agencies and policymakers to set the stage for State FASD efforts. The conference also included a workshop on counseling clients with FASD. A second meeting was held in Phoenix in June 2004 for a primarily Native American audience and drew 300 attendees from across the state of Arizona. On the first day instruction was given about the effects of prenatal alcohol exposure and the needs of children with FASD. On Day 2 State policymakers, tribal leaders, and IHS officials met together to learn about FASD and its impact in Arizona. A third "Hope for Women in Recovery" meeting was convened July 18-21, 2005 in Raleigh, NC. About 150 people attended the instruction and discussion sessions of the first day. Participants included women from surrounding treatment centers, treatment center counselors, and staff from NOFAS. State policymakers and government officials attended the second day to listen and provide feedback.
- To address the needs of American Indian/Alaska Native communities related to FASD prevention and treatment, the **SAMHSA** FASD Center for Excellence assembled a Native American/Alaska Native Stakeholders Group and convened its first meeting in March 2005. Recommendations from the group led to the development of the FASD Center's American Indian/Alaska Native Initiative. Plans through this initiative include Building FASD State Systems-type regional meetings, training institutes, and women's summits.

OBJECTIVE IV. Intervening with Children and Families Affected by Prenatal Alcohol Exposure

- The **SAMHSA** FASD Center for Excellence collaborated on two family summer conferences in Michigan and Washington in 2002 and 2003. The programs included training for parents and recreational and educational activities for youth. Training presenters in Michigan included **ICCFAS** chair Faye Calhoun, **NIAAA,** and ICCFAS member Karen Stern, **OJJDP**. The Michigan program also included a town hall meeting where family members, individuals with FASD, professionals, and other interested parties could testify about service needs to a VIP panel. Evaluations indicate that the family summer conference can be an effective short-term

intervention that promotes social skills among youth and provides information and respite for parents and caregivers.

- In 2001 **CDC** funded five universities for 4 years to develop interventions aimed at improving the developmental outcomes of individuals with FASD, reducing secondary conditions (such as difficulties in school, trouble with the law, substance abuse problems, and mental health problems), and improving the lives of families affected by prenatal alcohol exposure. For each site, children received comprehensive multidisciplinary assessments that guided referrals for standard care and services as indicated (e.g., speech therapy, special education). Treatment groups also received interventions focused on one of the core vulnerabilities associated with FASD: math skills, social communication, peer relations, foster care stability, compliance, or challenging behaviors. Interim analyses for all five sites have shown significant positive results for affected children and their families. Final analyses and submission of articles to scientific journals and conference presentations are anticipated in late 2005.
- **ED**/Office of Special Education Programs (**OSEP**) funded two personnel preparation projects (1999-2002) at the University of Alaska with FASD-related content for master's level teachers and related service personnel to serve infants and toddlers with autism, FASD, and severe disabilities and their families in rural Alaska; and recruitment and education of Alaska Native people to provide effective early childhood services by building leadership for policy and practice in early childhood systems. Coursework included study in autism, FASD, and speech and language delays. This content is now infused into teacher preparation syllabi at the University of Alaska indicating the sustainability of these efforts.
- Because of developmental delays and deficits in abstract thinking, children with FASD can miss the connection between cause and effect, which often results in risky behaviors and dangerous encounters with their environment. **NIAAA** has funded a project through the Small Business Innovation Research (SBIR) program to develop a computerized virtual reality Safety Skills Training Program to help children better understand and practice correct safety actions. In Phase I of the project, a home fire safety module was developed and evaluated with promising results. The full ongoing program will include multiple safety modules, an integrated safety game, and support tools to allow a child to practice correct safety actions in controlled virtual worlds on a home PC and to help the child generalize these actions to the real world (Padgett et al, 2004).
- **OJJDP**'s "Safe Start" initiative seeks to reduce the impact of family and community violence (including abuse and neglect) on young children from birth to age 6. Goals of the program include increasing access to quality prevention programs and improving identification, referral, and intervention for children and families in need of services. An initial set of program sites is in their last year of funding, and a solicitation for new sites was released in FY2004. There are 11 original sites, including 2 sites that serve exclusively tribal populations. Awards for 14 new sites are scheduled to be made early in 2005. Two **NIAAA** publications, "Prevention of Fetal Alcohol Exposure and Treatment of At-Risk Drinking "and "Identification and Care of Fetal Alcohol-Exposed Children" were distributed to all of the initial Safe Start sites and will be provided to the new sites as well. Since this project was designed to effect systems change, both process and outcome evaluations are included in the design of the project. Results of evaluations at both a local and national (cross-site) level will be reported after the end of the program funding period.
- **NIAAA** continues to support preclinical studies that evaluate potential therapies, including pharmacological agents or nutritional supplements, for preventing FASD or treating deficits in

children affected with FASD. In one project, administering choline in the diet of postnatal rats that had been exposed to alcohol during the brain growth spurt enhanced performance on a learning and memory task; however, alcohol-induced motor deficits were not affected by choline supplementation (Thomas et al, 2004a, 2004b). These findings highlight the fact that alcohol effects are multifaceted and a single drug or supplement is not likely to be effective for the range of FASD deficits. New drug discovery efforts probably should focus on the most problematic behavior deficits.

- **NICHD** spearheads 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. Here, investigators consider pharmacological approaches in children carefully, especially for those with organic brain deficits (such as children with FAS) that may cause unusual and idiosyncratic reactions to neuroactive compounds. The investigators also evaluate the response of children exposed to prenatal alcohol to certain stimulants that have proven particularly useful for treating children with attention deficits and hyperactivity disorders.
- In early FY2005 the **SAMHSA** FASD Center for Excellence announced a new program "Local Juvenile Courts Planning and Implementing Fetal Alcohol Spectrum Disorders Initiative." The design of this initiative came from close collaboration between the Center and ICCFAS member Karen Stern, **OJJDP**. The purpose of this new program is to mobilize and build capacity of local juvenile courts to develop and implement policies and procedures to screen, diagnose, and treat juveniles with FASD. Under this new program, five sites have been awarded year 1 planning funds, and will potentially be eligible for an additional 4 years of implementation funding.
- Alcohol-exposed animals exhibit stress responses to handling that are exaggerated compared to animals not exposed prenatally to alcohol. An **NIAAA-**funded research project is pursuing, in animal models, the potential for environmental enrichment to compensate for such behavior deficits resulting from prenatal alcohol exposure. The study assesses behavioral, anatomical and biochemical response to raising alcohol-exposed and control animals in environments that differ broadly in social, sensory and experiential factors.
- Indian Children's Program (ICP) is a congressional/**IHS** initiative composed of a consortium of university-based centers of excellence in developmental disabilities (at University of New Mexico and Northern Arizona University). The ICP focuses on early detection of developmental disabilities (including FAS) and intervention based on the assessed needs of the child and family. The ICP is a grant with 90 percent of its program services provided in the home and community setting (in 116 communities, 3 reservations and 2 States that make-up the delivery area).
- **NIAAA** is supporting an individual investigator-initiated research study that is helping to evaluate a social skills training program for children affected with FAS and ARND and their families. The project includes study of the relationship between neurocognitive and social skills integrity. Preliminary results indicate that some of the executive function deficits seen in children with FAS and ARND are related to their poorer social functioning and that this neurocognitive status should be kept in mind when implementing social skills training (Shonfeld et al, 2004).
- In late 2002, **NIAAA** issued an RFA titled "Collaborative Initiative on Fetal Alcohol Spectrum Disorders (CIFASD)" soliciting new grant applications for research designed to evaluate and

develop effective interventions and treatment approaches for FASD. Under this initiative NIAAA has funded a consortium to conduct interdisciplinary, collaborative research on FASD. The purpose of the consortium is to facilitate highly integrated multidisciplinary research involving basic, behavioral, and clinical investigators and projects that will result in the application of new ideas and technology to the study of alcohol-related fetal injury. Major goals are to provide opportunities for collaboration between scientists in the alcohol field and prominent investigators from other research areas; to integrate existing resources within the alcohol research community; and to create new resources that are crucial to the success of the research questions to be addressed. A long-term goal of the initiative is to evaluate and develop effective interventions and treatment approaches for FASD. NIAAA currently funds thirteen 3-year research grants under this program.

- Several of the 15 nationwide **NICHD-**funded Mental Retardation and Developmental Disability Research Centers provide direct access and services at their testing core facilities not only to NICHD researchers but also to investigators supported by other organizations, including those with alcohol-related projects.
- Dr. Susan Ryan, the director of the **ED** personnel training project at the University of Alaska, is doing a Fulbright fellowship (2004-2005) funded by the ED's Office of Post Secondary Education at the National Institute on the Study of Learning Difficulties at Trinity University in Ireland. The goals of Dr. Ryan's fellowship projects include identifying the factors that contribute to successful educational outcomes in general education classrooms, describing educational practices that foster the inclusion of students with autism and FASD, and identifying policies and practices that support families in Ireland with children affected by FASD and autism.
- Head Start programs in AI/AN communities include a mental health curriculum and mental health screening and consultation. **IHS** and tribal behavioral health staff provide classroom observation for Head Start programs to identify children with emotional or behavioral problems for early intervention.
- As an extension of the collaborative Maternal Lifestyle Study, a 3-year contract was awarded by **NICHD** and NIDA for the development of a neurobehavioral assessment tool for use in infants, the "Neonatal Intensive Care Unit Network Neurobehavioral Scale" (NNNS) (Lester and Tronick, 2004). The prospective longitudinal multisite study was designed to assess of effects of prenatal cocaine exposure but can be used as a neonatal assessment tool for other at-risk babies and normal babies. Several normative scales have been developed for full-term and premature babies. Recently published results indicate that prenatal alcohol exposure had a significant effect on orientation and cry measures from offspring of polydrug-using mothers (Lester et al, 2004). The NNNS may be a useful adjunct with other tools to assist in early assessment of potential FASD.
- In 2004 and 2005 the **IHS** provided N.W. Portland Area Indian Health Board funding to assist in planning a conference to address FASD and research related to FASD within AI/AN communities. The goal of the Northwest Portland Health Board's Northwest Tribal FAS Project is to reduce the level of FAS through the development of effective programs and multidisciplinary collaborative partnerships. The current project seeks to identify and track women of childbearing age who were potentially prenatally exposed to alcohol. The project includes eight sites and conferences to share information with the community.

- Among the thirteen 3-year projects funded in September 2003 under the **NIAAA** Collaborative Initiative on Fetal Alcohol Spectrum Disorders (CIFASD) is a project in South Africa that will determine the degree to which certain linguistic and literacy training programs and other cognitive and behavioral interventions improve academic performance and behavior of children with prenatal alcohol exposure. Researchers will also evaluate the degree to which interventions focused on improving communication between children affected by FASD and family members may improve academic skills and behavior of the children. If the interventions prove to be effective, they may lead to improved educational outcomes and overall quality of life for children affected by FASD around the world.

OBJECTIVE V. Increasing Research on Etiology and Pathogenesis

- In FY2003, **NICHD** and **NIAAA** funded four cooperative agreements to create a network for the development of community-linked studies to investigate the role of prenatal alcohol exposure in the risk for sudden infant death syndrome (SIDS) and adverse pregnancy outcomes such as stillbirth and fetal alcohol syndrome and their relationship. Two Comprehensive Clinical Sites, a Developmental Biology and Pathology Center, and a Data Coordinating and Analysis Center compose the network. The comprehensive clinical sites will work with Northern Plains Indian communities and populations in the Western Cape of South Africa. The investigators will work collaboratively with NICHD and NIAAA over a 3-year period to plan and pilot multidisciplinary investigations using common protocols within communities at high risk for prenatal maternal alcohol consumption. The long-term goals of this initiative are to decrease fetal and infant mortality and improve child health in these communities. In the first year the network has made great strides in developing a study design that will combine prospective and retrospective data collection. It incorporates the use of methodologies in epidemiology, physiology, pathology, and the neurosciences to decipher the complex relationship between alcohol use and abuse during pregnancy and their effect on the developing fetus and infant.
- In FY2004 **NIAAA** funded 57 research grants for studies to elucidate the etiology and pathogenesis of FASD. These include projects that focus on elucidating the mechanisms of craniofacial dysmorphology, abnormal brain growth and tissue differentiation, other abnormal system development, general growth retardation, cerebrovasular effects, structure-function relationships, behavioral consequences, alterations in stress response systems, relevant genetic variation in sensitivity and metabolism, and dietary factors. For example, alcohol has been shown by numerous investigators to induce excessive cell death (apoptosis) through the generation of reactive free radicals in developing tissues (see review in Cohen-Kerem and Koran, 2003; and Marino et al, 2004). Researchers are identifying the specific molecular pathways affected by alcohol that regulate apoptosis. This will facilitate the design of specific inhibitors to prevent alcohol-induced cell death.
- **NICHD** has funded studies of the determinants of birth weight, low birth weight, and preterm delivery. In addition, NICHD sponsors research efforts within the Neonatal Intensive Care Unit 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 investigates the development and family outcomes associated with prenatal exposure to polysubstance abuse among 1400 mother/infant pairs. In another network, the Maternal

Fetal Medicine Units will continue to research ways to improve the management of pregnancy and prevent specific obstetric problems, including those that may be relevant to alcohol exposure.

- **NIAAA** continues to support research efforts that use innovative imaging technologies to understand the nature of brain damage resulting from prenatal exposure to alcohol. In addition to magnetic resonance imaging (MRI) which has been in routine clinical use for a number of years and allows for previously unattainable clarity and precision in images of brain structure, functional MRI (fMRI) and magnetic resonance spectroscopy (MRS) allow for images of brain functioning as reflected in activation and neurotransmitter levels and disposition. It is hoped that understanding of the changes in brain function, as well as structure, will allow specific remedial procedures in the future, e.g., specific exercises (mental or physical) that will strengthen ability in damaged areas.
- On August 2, 2002, **NICHD** released a Program Announcement (PA) titled "Tools for Genetic Studies in Zebrafish." This PA was developed collaboratively by **NICHD**, **NIAAA** and several other NIH institutes and solicited applications for research to exploit the power of rapid discovery of gene changes in zebrafish. The mutations identified can be used to characterize genes, pathways, and phenotypes of interest in development and aging, organ formation, behavior, and disease processes. FAS research should benefit from studies under this program that may identify genes or biomarkers for susceptibility to alcohol teratogenesis and general alcohol sensitivity.
- **NICHD** supports a study of acute brain injury, mechanisms, and consequences. Alcohol was found to trigger apoptosis (programmed cell death) by the blockade of NMDA glutamate neurotransmitter receptors and excessive activation of $GABA_A$ neurotransmitter receptors. The subsequent reduction in brain mass due to apoptosis may explain some of the neurobehavioral disturbances associated with FAS.
- **NIAAA** is encouraging the development of new animal models of FASD to enhance progress in understanding the pathogenesis of alcohol. Recent research has established that teratogenic effects of alcohol can be detected in zebrafish embryos at physiologically relevant doses. Craniofacial defects include loss of neural crest cells (also seen in rodent and chick models), the progenitors of facial bone and connective tissue, correlated reduction in distance between the eyes, and abnormal development of the craniofacial skeleton. These findings suggest that the zebrafish can be used as a model system for aspects of FAS that can be correlated to genetic manipulations (Ahlgren et al, 2002). Other studies have demonstrated that alcohol impairs plasticity of the visual system and reduces orientation selectively in the visual system in the ferret (Medina et al, 2003, 2005). Because the mechanism of visual plasticity involves the NMDA neurotransmitter receptor system, which is important in many models of learning and long-term memory, and the ferret visual system is very similar to the human system, the findings from mechanistic studies may be translated more readily to human FASD than from other models.
- An **NICHD-**funded animal study examined the mechanism by which fetal alcohol exposure decreased glutathione (a major antioxidant in the lung) in the epithelial lining fluid and impaired alveolar macrophage function. NICHD also supports a study of risk factors and vulnerabilities of the developing brain that examines the impact of alcohol and iron homeostasis on brain lipids and respiratory enzyme function.

- Following the discovery by **NICHD** intramural scientists that NAP and SAL, two active brain peptides (proteins) known to protect nerve cells against a variety of toxins, also prevent alcohol-induced fetal death and reduced growth in mice, **NIAAA**-supported researchers have been collaborating with NICHD scientists to further understand the protective mechanism of NAP and SAL. Together they have shown that NAP and SAL protect nerve cells from alcohol disruption of the cell adhesion process mediated by L1, a protein necessary for normal nerve development. They also demonstrated that NAP and SAL can protect mouse embryos in culture from excessive cell death resulting from alcohol exposure (Wilkemeyer et al, 2002, 2004).
- **NICHD** supports a laboratory study investigating the role of disruptions in retinoic acid signaling that has been suggested as the basis of alcohol-induced disease in developing fetuses. The transcriptional activator retinoic acid is essential for the normal development of the central nervous system and disruptions in retinoic acid signaling may help explain cerebellar malformations found in alcohol-induced congenital disease. Another NICHD-funded study of the teratogenic effect of alcohol during pregnancy examines the mechanism by which alcohol alters retinoid metabolism and retinoic acid receptor function leading to abnormal testicular cell proliferation.
- Early alcohol exposure was shown to produce a long-term disruption in circadian rhythmicity in rats in an **NIAAA-**supported study. Early alcohol exposure affects the superchiasmatic nucleus of the hypothalamus. This structure is the master generator of a diurnal rhythm for a wide range of physiological functions. The consequence of this disruption is that many physiological functions are no longer optimized. It is anticipated that dysfunction similar to that observed with jet lag and shift work result (Farnell et al 2004, Allen et al 2004).
- Besides the known teratogenic (causing development malformation) effect of alcohol exposure during pregnancy, alcohol exposure is also associated with fetal growth restriction and low birth weight. One of the critical functions of the placenta is to mediate adequate nutrient and gas exchange between the mother and fetus for optimal fetal growth. These processes depend on maintenance of an adequate blood flow and network of blood vessels within the placenta. An **NICHD-**sponsored project tests the hypothesis that alcohol exposure creates oxidative stress that in turn affects placental blood flow and angiogenesis (development of new blood vessels). Published results to date indicate that alcohol exposure appears to induce oxidative stress and results in a decrease of nitric oxide, an important vasodilator. Thus, decreased nitric oxide availability could adversely affect placental blood flow regulation, which could account for the growth restriction seen in alcohol-exposed fetuses.
- Current observations from an ongoing **NIAAA-**funded research grant show a gender difference in stress responsiveness associated with prenatal alcohol exposure. In prepubertal rats exposed to alcohol prenatally, both genders exhibited elevated first stress hormone (ACTH) responses. However, male rats showed a blunted response further down the stress hormone response cascade (at the corticosterone secretion step) while females showed the expected exaggerated response (Halpert et al, 2004). Preliminary data from other studies on these gender differences in stress response implicate alcohol-induced changes in testosterone regulation in male rats prenatally exposed to alcohol (Lan et al, 2004).
- Bacterial vaginal infections, also called bacterial vaginosis (BV), are associated with an increased incidence of adverse outcomes in late pregnancy, such as premature birth and low infant birth weight. The association of BV with early pregnancy loss is unclear. **NICHD**

sponsors an ongoing study of the prevalence and predictors of bacterial vaginosis and a number of the risk factors, including alcohol, tobacco and cocaine use, as they relate to early pregnancy loss. This study is still in the data collection phase.

- Many **NIAAA-**funded studies have shown that adult rats exposed to alcohol prenatally exhibit exaggerated responses to a variety of stressors. However, the relevant pathways involving activation of specific genes for such alcohol-induced changes in the stress response system have not been elucidated. At the present time, genetic determinants and analyses of gene activation are more readily studied in mice than in rats. Development of a new mouse model for prenatal alcohol exposure that circumvents the use of confounding pharmacological intervention (Kang et al, 2004) moves us closer toward clarification of the gene pathways and neuronal plasticity involved in fetal alcohol-induced hyperactivation of the stress response system.

OBJECTIVE VI. Improving Educational Outreach, Training, and Information Disseminations

- In 2001 **CDC** funded four nonprofit organizations for 3 years to develop, implement, and evaluate educational curricula for parents and families, school staff, and law enforcement personnel regarding FASD and how to secure access to appropriate services for children with these conditions and their families. Funded sites were the National Indian Justice Center (Santa Rosa, CA); The Arc of the United States (Silver Spring, MD); Double ARC (Toledo, OH); and the Education Development Center, Inc. (Newton, MA). Results of curricula evaluations presented in 2004 for each project showed statistically significant increases among training participants in knowledge of FASD and in confidence in being able to better cope with the conditions (including how to access services, etc.). The final curricula and related materials are available from the funded sites; see sharable resource table in Part II, Section B, Item 7.
- **OJJDP** collaborated in the development of the Minnesota Organization on Fetal Alcohol Syndrome's (MOFAS) Resource Guide, *Tools for Success: Working with Youth with Fetal Alcohol Syndrome and Effects in the Juvenile Justice System*. NIAAA funded development of the guide with OJJDP staff providing advice on the content and preparation. Interested individuals can order the guide from the MOFAS Web site: www.mofas.org. A training curriculum based on this resource guide is being developed by MOFAS and the **SAMHSA** FASD Center for Excellence with OJJDP staff providing advice on the curriculum's content and format.
- **IHS** contracted FASD-related activities and services with the University of Washington (1998-2004) to provide consultations to American Indian and Alaska Native (AI/AN) clients with FASD and their families, as well as technical support and training for service providers in issues related to FASD. Approximately 64 health providers have been trained at the University of Washington since 1998, when the training program for IHS was initiated. IHS will continue to fund the University of Washington for FASD activities and services in 2005.
- Intervention studies with high-risk women from diverse populations are needed to determine the most effective approaches in special populations. In 2001 **CDC** funded San Diego State University (San Diego, CA) and the University of Texas School of Public Health (San Antonio, TX) to design, implement, and evaluate epidemiological and intervention studies aimed at reducing the risk of alcohol-exposed pregnancies in Hispanic/Latina women of

childbearing age. San Diego State University has conducted an educational feedback intervention in nonpregnant Latina women who report various levels of current alcohol use in an effort to influence intention to reduce alcohol consumption or avoid alcohol in a future pregnancy. The University of Texas has developed a FASD prevention curriculum based on a community action model to be used with Latina/os in colleges and community-based groups. They also tested an intervention designed to increase knowledge of FASD and associated risks, increase healthy attitudes toward alcohol consumption and associated sexual behavior, and reduce risky behaviors related to alcohol-exposed pregnancies. Final analyses of data are forthcoming in 2005 and submission of articles to scientific journals and conference presentations will follow.

- Since its inception in 2001, the **SAMHSA** FASD Center for Excellence staff and field trainers have conducted nearly 200 training sessions, for almost 10,000 participants on 22 FASD-related topics in 36 states, the District of Columbia, Canada, Japan, and the United Kingdom. The various target audiences include alcohol policy personnel, alcohol research personnel, American Indian school personnel and service providers, case managers, Certified Addictions Counselors, community members, consumers, families, government officials, health care professionals, individuals with FASD, juvenile probation officers, mental health professionals, public defenders, public health professionals, school personnel, service providers, social workers, State FASD coordinators, and substance abuse treatment and prevention providers. Venues have included professional conferences, FASD summits, Native American training sessions, health, social service, and criminal justice agencies, family summer camp programs, an international symposium on FAS, school districts, and a residential treatment center. The Center has also posted FASD-The Basics, a downloadable slide show for self-study or use in presentations, to its Web site, http://www.fascenter.samhsa.gov .
- The **SAMHSA** FASD Center for Excellence has developed training programs covering a broad spectrum of medical and social issues. Topics include children, adolescents and adults with FASD; FASD in families; impact of FASD on everyday life; anger management for people with FASD; FASD case management; ethics and boundaries related to working with people with FASD; FASD as a co-occurring disorder; FASD in education, FASD in the criminal justice system; identifying women at risk of having children with FASD; loss and grieving in individuals and families affected by prenatal alcohol exposure; motivational interviewing as a FASD prevention strategy; psychopharmacology in FASD treatment; and therapeutic alliances in FASD treatment.
- To increase the research-based knowledge of social workers in all areas of practice, including direct work with alcohol patients, **NIAAA** has developed a teaching curriculum, "A Social Work Curriculum for the Prevention and Treatment of Alcohol Use Disorders." The curriculum can be used by faculty in schools of Social work to teach students about alcohol problems. To provide a solid foundation base for the student, the curriculum begins with the epidemiology of alcohol problems in the United States. It follows with a group of modules that include topics such as etiology, prevention, screening, diagnosis and assessment to topics such as women and alcohol, pregnancy and birth defects. One module is dedicated to FAS. Eleven additional modules cover the prevalence of alcohol use and abuse among special populations, including cultural or gender-specific considerations for intervention and treatment. The curriculum contents were formulated in 2001 by research experts in alcohol. Most modules were written by social workers from 2001-2004. NIAAA is currently supporting curriculum dissemination to schools of social work within the U.S., training of

social work educators in using the materials, and evaluation of the impact on their teaching after receiving training. The curriculum can be viewed and downloaded to CD-ROM via the NIAAA Web site: http://www.niaaa.nih.gov/ .

- Additional mandates accompanying the directive that **CDC** develop uniform guidelines for FAS included developing curricula and providing training for medical and allied health students and practitioners regarding these guidelines. In addition, CDC was to incorporate FAS content into curricula for medical and allied health students and practitioners and into the credentialing requirements of professional boards. To achieve this mandate, in 2002 CDC established four Regional Centers for the Education and Training of Medical and Allied Health Students and Professionals on FAS and Other Prenatal Alcohol-Related Disorders. These regional training centers (RTCs) are Meharry Medical College (Nashville, TN) and Morehouse School of Medicine (Atlanta, GA) - Southeastern; University of Medicine and Dentistry of New Jersey (Newark, NJ) - Northeastern; St. Louis University (St. Louis, MO) - Midwestern; and University of California, Los Angeles (Los Angeles, CA) - Western. The grantees have developed educational and training materials and have conducted a variety of educational events for medical and allied health students and professionals in all regions. In 2005, in their third and final year of the project, the RTCs will continue the evaluation of educational events and materials.
- To reach women in substance abuse treatment programs, the **SAMHSA** Materials Development Center for Excellence developed an hour-long video about FASD, as told by women who drank alcohol during pregnancy and now live with the lifelong effects on their children. The video, "Recovering Hope: Mothers Speak Out About Fetal Alcohol Spectrum Disorders," is supported by two companion print pieces. The first is a video discussion guide that prepares addictions counselors to show the video to women in treatment and the second summarizes key information and resources and is meant for distribution to women after they have seen the video. The need for the video and its companion materials was determined through in-depth interviews with mothers of children with FASD and substance abuse treatment counselors. These materials are available through SAMHSA's National Clearinghouse for Drug and Alcohol Information (NCADI) at www.health.org or http://ncadi.samhsa.gov , the SAMHSA FASD Center Web site, http://www.fascenter.samhsa.gov/about/index.cfm , or by telephone request to 1-866-STOPFAS (786-7327) between 9:00 a.m. and 6:00 p.m. EST.
- The objective of **NIAAA**'s science education programs is to translate research into practice in an engaging, inquiry-based science classroom format. Ultimately, prevention would be a desired outcome, but one of the primary objectives is an increase in knowledge about the science of alcohol. One curriculum module developed with this philosophy in mind maintains an FASD focus. "Better Safe than Sorry - Preventing a Tragedy" was developed by researchers at the University of North Carolina, Chapel Hill, teachers, and educational consultants. This curriculum specifically focuses on FAS and FASD highlighting behavior and dysmorphology, the correlated areas of focus in the brain, and social impact. The materials and lessons are adaptable for grades 5-12, can be taught in 1-4 class periods, are aligned with the National Science Education Standards, and are based on current research relevant to a life-science curriculum. Kits include teacher instructions, data tables and background, a video with lab instruction and information on FASD, a CD-ROM with all hardcopy materials and a post-assessment game, color transparencies, and brochures. A hands-on lab experiment allows students to view the impact of alcohol on a developing organism (brine shrimp) and compare

this with actual laboratory animals (mice) and with humans. Training and presentations on this program are available upon request. Complete hardcopy materials, videos and PowerPoint slides are available at http://www.niaaa.nih.gov/publications/Science/curriculum.html.

- In 2003 **CDC** established a cooperative agreement with the National Organization on Fetal Alcohol Syndrome (NOFAS) to develop and disseminate new FASD prevention and education resources, thus enhancing the quantity and quality of available resources for parents and family members, educators, students, professionals, and the public at-large. Activities of this project include developing a school-based FASD curriculum for teachers to implement with students in kindergarten through grade 12; developing and implementing culturally appropriate FASD prevention activities and materials for the Cherokee Nation in Oklahoma; developing an FASD public awareness training guide for use by local and national community-based organizations, FASD parent support groups, students, and others sponsoring FASD prevention activities; and expanding the NOFAS Clearinghouse on Alcohol & Pregnancy. NOFAS is currently completing these activities and the resulting materials will be available in 2005.
- **NIAAA** sponsored the development of a curriculum, "A Toolbox for Educators (K-5)," (R. Schwatrz-Bloom and C. Zieff, 2004) to provide educators and support professionals with tools to help children with FASD address problem behaviors and experience greater success in school. The "Toolbox" provides a brief tutorial on FASD, behavioral and learning profiles, and strategies for effective teaching. In late 2005 this curriculum is expected to be available on the NIAAA Web site, http://www.niaaa.nih.gov .
- **IHS** and the Association of American Indian Physicians collaborated with the CJ Foundation for SIDS in the development of an American Indian and Alaska Native SIDS Risk Reduction Resource Kit, with CDROM, videos, and print material designed for use by health and medical service providers, and community trainers. Funding was provided by the DHHS, Office of Minority Health; The Robert Wood Johnson Foundation; and the CJ Foundation. Available at https://www.cjsids.com/resource_kit/resource_form.htm
- Dissemination of information and training on effective intervention strategies to educators, social workers, legal and criminal justice workers, and medical providers can increase the availability of appropriate services and support to people living with FASD. In 2004 Black Hills State University (Spearfish, SD) received funding through **CDC** to develop and adapt, implement, and evaluate materials about FASD to educate professionals working in school systems, social service agencies, court systems, and public health service agencies in South Dakota, including some of the State's American Indian populations.
- **SAMHSA** launched the Fetal Alcohol Spectrum Disorders (FASD) Materials Development Center for Excellence (SAMHSA FASDMDCFE) in April 2004, subsuming work previously funded under a July 2001 task order for Fetal Alcohol Syndrome and Alcohol-Related Birth Defects Material and Message Development. In the past year, this Center, which focuses on message and materials development, has produced more than a dozen new documents on FASD issues for the public. Materials developed by the Center are disseminated through the National Clearinghouse for Alcohol and Drug Information at www.health.org or http://ncadi.samhsa.gov and through the SAMHSA FASD Center for Excellence Web site at http://www.fascenter.samhsa.gov and by telephone request to 1-866-STOPFAS (786-7327) between 9:00 a.m. and 6:00 p.m. EST. In addition, this Center has disseminated information on FASD through conference presentations at the American Public Health Association,

National Prevention Network, Society for Community Research and Action, and the Society for Prevention Research.

- As indicated in the prevention section, each April a National Alcohol Screening Day (NASD) is conducted by **NIAAA**, the **SAMHSA**, and Screening for Mental Health, Inc. to raise public awareness about alcohol's effects on general health. Each site that registers for NASD is sent a kit of materials (English and Spanish versions are available) to be used in their events. Included in these kits have been both general informational materials about the dangers of alcohol misuse and materials developed by NIAAA for women and some specific FASD-related materials (such as "Drinking and Your Pregnancy," NIAAA and NOFAS, 2001; and "Alcohol – A Women's Health Issue," NIAAA, 2003). Kits sent to primary care sites have usually included the monograph "Identification of At-Risk Drinking and Intervention with Women of Childbearing Age: A Guide for Primary-Care Providers," NIAAA and NIH Office of Research on Minority Health, 1999, and the brochure "Personal Steps to a Healthy Choice: A Woman's Guide, 2000." The number of these educational materials distributed has increased dramatically in the past 4 years due to the increase in numbers of attendees at primary care sites hosting NASD from 1,173 attendees in 2001 to more than 25,000 in 2004.
- **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 FASD 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 FASD. Five hundred copies of The FAS State By State Resource Directory were printed in 2000 and most of these were distributed to States (public health, departments of education, etc.), to national organizations (early intervention, child welfare, teacher organizations, etc.) and at conferences. Some were sent to the National Maternal and Child Health Clearinghouse. In addition, the Directory was placed online by the Four-State Consortium (based in Minnesota) that is funded through SAMHSA. This Directory is available from HRSA http://www.ask.hrsa.gov/detail.cfm?id=mchm053 and online at the FAS Law Center at the University of Washington Web site (select legal issues), http://depts.washington.edu/fadu/ and the National Organization on Fetal Alcohol Syndrome Web site, www.nofas.org .
- From March 2002 through June 2004, the **SAMHSA** FASD Center for Excellence convened 15 town hall meetings nationwide, including one for Native Americans. The Center coordinated the meetings with assistance from the National Organization on Fetal Alcohol Syndrome (NOFAS), the FAS Family Resource Institute, and the Alaska Office of FAS. More than 800 people attended, 500 people testified, and over 100 agencies were represented on VIP panels. VIP panelists included several ICCFAS committee members from other Federal agencies. Major issues raised include the need for respite care, education of professionals about FASD, better support in schools for students with FASD, and difficulty dealing with many service systems. The Center also provided technical assistance to Ohio in convening its town hall meeting in September 2004.
- **NIAAA** provided copies of FASD-related information materials available from the Institute at an information booth at the First **CDC** Conference on Birth Defects, Developmental Disabilities, and Disability and Health, Atlanta, Georgia, September 17-19, 2002.
- The **SAMHSA** Materials Development Center for Excellence designed, implemented, and assessed the "Partnership to Prevent FASD," a community-based public education program.

The Center designed the program in collaboration with lead organizations in four community pilot sites selected for their geographic, cultural, and socioeconomic diversity: Doña Ana County, New Mexico (Ben Archer Health Center, Lead Organization); East Baton Rouge Parish, Louisiana (Capital Area Human Services District, Lead Organization); Erie County, New York (Erie County Council for the Prevention of Alcohol and Substance Abuse, Lead Organization); and Sumter County, South Carolina (the Prevention Center, a division of the Sumter Commission on Alcohol and Drug Abuse, Lead Organization).The Partnership targets preconceptional and pregnant women to encourage them to abstain from alcohol use during pregnancy. The program also enlists the support of women's family members, friends, and social service and health care providers to help them in their efforts. To support the pilot sites, the SAMHSA Materials Development Center for Excellence conducted formative research and, based on the findings, created materials including a poster, four informational rack cards, four print public service announcements, and four "how-to" booklets (materials are available in English and Spanish). Local dissemination strategies were subsequently developed using a mix of mass, group, and interpersonal channels. The Center is currently summarizing the Partnership program and its pilot in a combination CD-ROM and print program manual featuring tools for implementation (including all the materials), case studies, and lessons learned so that other communities can replicate it.

- In 2004, **CDC** began a cooperative agreement with the American College of Obstetricians and Gynecologists to develop user-friendly educational materials for providers regarding screening for alcohol use during pregnancy and brief interventions for women at risk for an alcohol-exposed pregnancy. Materials will be developed, tested, and made available in late 2005 or early 2006.
- During summer 2004 **NIAAA** completed its "Play it Smart. Alcohol and Pregnancy Don't Mix" campaign, a 2-year multimedia public awareness campaign targeting African-American in Washington, DC. The research-based campaign, containing culturally appropriate messages about the consequences of drinking during pregnancy, focused on women ages 21-29 and their friends and family. NIAAA conducted the campaign through the National Organization on Fetal Alcohol Syndrome (NOFAS), with additional funding from the National Center on Minority Health and Health Disparities (NCMHD) of NIH. Literature searches and focus group testing provided information about the attitudes and beliefs of the target audience, as well as feedback on the draft materials. This formative research revealed information about the intended audience that helped guide the message development for the campaign. The campaign included a combination of print and broadcast materials including radio and television public service announcements, mass transit displays, information booths, magnets, posters, and bookmarks. It also included community events with local government agencies, hospitals, and churches, as well as innovative Metrorail dioramas and cinema advertising in targeted theaters. The campaign was designed to serve as a prototype for possible replication in other cities. More than 100,000 products and displays featuring the campaign tagline, themes, and messages were disseminated among the intended audiences.
- **OJJDP,** together with the Office of Special Education and Rehabilitative Services (**OSERS**) of the Department of Education (**ED**), provided funding for the National Center on Education, Disabilities and Juvenile Justice (EDJJ). Located at the University of Maryland, EDJJ is designed to provide assistance to both parents and professionals in understanding and meeting the needs of youth with disabilities in or at risk of entering the juvenile justice system. Information is provided on how parents of incarcerated children can ensure that their child

receives the special education and related services to which he or she is entitled. For example, the EDJJ Web site, www.edjj.org, contains the fact sheet, "What Parents Need to Know about Children with Disabilities and the Delinquency System." (Garfinkel, L, EDJJ, College Park, MD, 2001) The Office of Special Education Programs (**OSEP**) in **ED** currently provides financial support for EDJJ.

- The **SAMHSA** FASD Materials Development Center for Excellence drafted a booklet that targets elementary school teachers, staff, and administrators to improve their understanding of how FASD can be addressed in the classroom, to help them develop a positive approach to FASD, and to improve their ability to teach children with FASD. Families and caregivers can also use this booklet to improve communication with schools. The booklet, "Reach to Teach: Educating Children with Fetal Alcohol Spectrum Disorders," is based on a series of key informant interviews and was developed in consultation with Barbara Morse, Ph.D., Fetal Alcohol Education Program, Boston University School of Medicine, an expert on FASD. Revisions based on peer review are currently under way.
- **NIAAA** was invited to participate in the District of Columbia Eighteenth Annual Maternal and Child Health Citywide Coordinating Conference, Ensuring the Health of Families in the Nation's Capital: A Plan of Action. The February 24, 2004 conference was held at the Convention Center in the District of Columbia and was open to the public. The goals of the conference were sharing information about the availability of health care services for District families, educating the District community on how individuals could help improve and become involved in some of the District health programs, sharing current research and research methods related to maternal and child health initiatives, and providing a networking opportunity for public and private entities, nonprofit organizations, advocacy groups, families and professionals. NIAAA's Dr. Megan Adamson facilitated a workshop on "Fetal Alcohol Spectrum Disorders: Identification, Linkages and Advocacy Services for Children and Their Families". The audience included teachers, health care workers, mothers, family members, and caregivers.
- The **SAMHSA** FASD Center for Excellence operates an Information Resource Center (IRC), which includes a toll-free telephone line, viewing library, and Web site. Since the IRC's launch in February 2003, the information specialist has responded to approximately 800 calls and e-mails from prevention providers, service providers, parents of persons with FASD, educators, government staff, State officials, FASD State coordinators, support groups, students, and researchers. The viewing library is located in Rockville, MD, and houses more than 3,000 items, including journal articles, books, CDs, videos, and other materials. It is open to the public by appointment. The Web site averages about 2,600 unique visitors per month and 6,500 visits (average length - 18:40 minutes).
- As part of the **IHS** and Canada Memorandum of Understanding activities, the IHS Division of Maternal and Child Health is currently updating "Promising Fetal Alcohol Spectrum Disorder Practices and Resources for American Indians and Alaska Natives in North America," a central information repository (a comprehensive directory) of existing American Indian/Alaska Native (AI/AN) FASD promising and best practices. The Working Group plans to disseminate the binational FASD resource directory among indigenous populations through various media (e.g., CD-ROM, database, and Internet) once it is completed.
- The **SAMHSA** FASD Center for Excellence developed a web-enabled searchable database of FASD literature, publications, and other materials for providers, families, individuals with FASD, and the scientific community. This database represents one of the first attempts to

electronically index FASD materials. The database has approximately 5,000 records and is updated monthly. Materials cataloged in the database are housed in the viewing library, except for items that can only be found online.

- **IHS** personnel, tribal members and advocates participated in nationally directed FASD Town Hall Meetings (sponsored by **SAMHSA**) in 2003 and 2004. IHS Community Health Representatives, in their triennial national meeting, have been briefed by the National Native Americans Together (http://www.idahocdhd.org/text/projects/famtogether/index.htm) (funded by **ED**) on children with special education needs, State parent information and support systems, and Native American family specific advocacy agencies.
- Two **NIAAA** staff members (Margaret Mattson and Diana Urbanas together with University of Washington Professor Andrea Kovalesky) developed and taught a lecture series "Taking An Alcohol Problem Abroad," in two rural, high poverty towns in Lithuania (Akmene and Majeikai) with high mortality, morbidity, and social problems from alcoholism. The program was conducted under the auspices of the American Professional Partnership for Lithuanian Education. A major feature of the series was educational information on ARND presented to teachers, social workers, and law officials from these towns. The teaching team discovered that knowledge of the consequences of drinking during pregnancy was very limited and identification and remediation of children with alcohol-related impairments nonexistent. The class attendees received the new information and discussed it in relation to the children they serve. Several local and regional newspapers interviewed the teaching team and published articles to bring these issues to the attention of the general public. As a result of these outreach efforts, a Lithuanian pharmaceutical company is considering translating NIAAA educational brochures into Lithuanian to make this information broadly available in the country. In addition, NIAAA materials provided through this program resulted in a chapter on FAS in a newly published text on pediatric neurological developmental disorders, which is largely unrecognized and undiagnosed by the Lithuanian medical community.
- **OSEP** facilitated a working session on FASD for personnel from the OSEP-funded Parent Training and Information Centers at the 8th Annual Alliance Meeting in Washington, DC, in February 2005. Session participants enthusiastically agreed that there was a great need to create an FASD Education Network.
- The **SAMHSA** FASD Center for Excellence develops and disseminates various products through the National Clearinghouse for Alcohol and Drug Information www.health.org or http://ncadi.samhsa.gov, and the FASD Center Web site, www.samhsa.gov or www.fascenter.samhsa.gov. Products include a fact sheet series, "What You Need To Know," which includes topics such as the FASD Center, the language of FASD, diagnosis, independent living, and tips for teachers. The Center also produced a video, "Recovering Hope," to educate women in recovery about FASD. Additional products include rack cards, posters, reports, and a quarterly online newsletter to which NIAAA and CDC have contributed.
- Mr. Jason Lazarow, **NIAAA** Education Specialist, has made more than a dozen presentations of an NIAAA science curriculum that specifically focuses on FAS and FASD, highlighting the behavioral and morphological characteristics, the correlated areas of focus in the brain, and the social impact. These presentations have been largely at various professional conferences for teachers but also for advocacy officials and at several other meetings: ICCFAS (May 2003, Bethesda MD); Teratology Society Annual Meeting (to British Columbia teachers), Vancouver, BC, Canada, June 2004; and the FASD Research to Practice Conference, Chapel Hill, NC,

September 2004. Reference:
http://www.niaaa.nih.gov/publications/Science/curriculum.html

(i.) Relevant Web sites

ICCFAS home page: http://www.niaaa.nih.gov/AboutNIAAA/Interagency/

CDC home page: http://www.cdc.gov
CDC FAS home page: http://www.cdc.gov/ncbddd/fas/default.htm
Department of Education home page: http://www.ed.gov
Office of Special Education and Rehabilitative Services home page:
http://www.ed.gov/about/offices/list/osers/osep/programs.html
HRSA home page: http://www.hrsa.gov
Maternal and Child Health Bureau home page: http://mchb.hrsa.gov
IHS Behavioral Health home page: http://www.ihs.gov/MedicalPrograms/Behavioral/
IHS Child Health home page: http://www.ihs.gov/MedicalPrograms/MCH/CH.asp
NIAAA home page: http://www.niaaa.nih.gov
NICHD home page: http://www.nichd.nih.gov
OJJDP home page: www.ojjdp.ncjrs.org www.ojp.usdoj.gov/ojjdp
SAMHSA home page: www.samhsa.gov
SAMHSA FASD Center for Excellence: www.fascenter.samhsa.gov
http://fascenter.samhsa.gov
National Clearinghouse for Alcohol and Drug Information: www.health.org
http://ncadi.samhsa.gov

(ii.) Sponsored workshops, symposia and conferences

Events for Health Care Providers, Biomedical Researchers, Science Faculty, and Education and Justice Professionals

"Fetal Alcohol Syndrome: An International Perspective," a workshop at the 10th International Society for Biomedical Research on Alcoholism Congress sponsored by **NIAAA** in Yokohama, Japan, July 2000.

"Development and Teratology," a session at the "Genes and Gene Delivery for Diseases of Alcoholism," conference sponsored by **NIAAA** and **NICHD**, in Chapel Hill, North Carolina, May 7-10, 2001.

"Detection of Prenatal Fetal Alcohol Exposure," a satellite workshop at the Research Society on Alcoholism annual meeting sponsored by **NIAAA** and Office of Rare Diseases, NIH in Montreal, Quebec, Canada, June 22, 2001.

"Prenatal Alcohol Exposure and Risk for Adverse Pregnancy Outcomes and SIDS," a workshop sponsored by **NIAAA**, **NICHD**, and the NIH Office of Rare Diseases in Bethesda, Maryland, August 6-7, 2001.

"Prenatal Alcohol Exposure: Advancing Knowledge Through International Collaborations," a workshop sponsored by **NIAAA** and Conselleria de Bienstar Social, Generalitat Valenciana in Valencia, Spain, September 2001.

"Experimental Therapeutics for Fetal Alcohol Syndrome," a satellite workshop at the Research Society on Alcoholism annual meeting sponsored by **NIAAA**, San Francisco, California, June 27, 2002.

"Identification of Risk During Infancy Associated with Parental Alcohol Problems" symposium organized by NIAAA (Isabel Ellis) at the 8th World Congress on Infant Mental Health, Amsterdam, The Netherlands, July 15-19, 2002.

"Indian Children's Programs/Cross Cultural Lessons Learned about FASD," a workshop sponsored by the **IHS** at the first IHS/SAMHSA conference, June 25-27, 2003.

"Adolescent Brain Development: Vulnerabilities/Opportunities" **NICHD**, NIMH, NIDA funding to the National Academy of Sciences, a conference held in New York City, Sept. 18-20, 2003.

"Neurotrophins: Neuronal Development, Neuronal Function and Survival, and Structural Plasticity," a symposium session at the **NIAAA-** and **NICHD-**sponsored International Behavioral and Neural Genetics Society (IBANGS) Meeting, New Orleans, Louisiana, November 5-7, 2003.

The **IHS** sponsored three FASD-focused workshops: "Indian Children's Programs/Cross Cultural Lessons Learned about FASD" presented by P.W. Kodituwakkyu and C. McClain ; "FASD Center for Excellence," presented by D. Dubovsky and C. Shelton; "Working with Individuals who are 'Difficult to Treat:' Who Are They & What Can We Do to Improve Outcomes?" presented by D. Dubovsky at the second **IHS/SAMHSA** and The National Behavioral Health Conference, Expanding Partnerships to Meet Substance Abuse Prevention & Treatment Challenges in American Indian & Alaska Native Communities, June 8-10, 2004, in San Diego, CA.

"Teaching Children with FAS," a workshop for science and special education teachers from the Vancouver school district, sponsored and conducted by **NIAAA** and the University of California, San Diego, was a part of the Annual Society of Teratology Meeting in Vancouver, British Columbia, June 26-30, 2004.

" Fetal Alcohol Spectrum Disorders (FASD) Training for Health Professionals at the Cherokee Nation," sponsored by the Jack Brown Treatment Center (funded by **IHS**), The National Organization on Fetal Alcohol Syndrome, and the Oklahoma Department of Mental Health and Substance Abuse Services in Tahlequah, Oklahoma on July 13, 2004.

"Community-based Prevention of Fetal Alcohol Exposure Targeting Women at Risk," a symposium at the Research Society on Alcoholism annual meeting co-organized by **NIAAA**, Vancouver, British Columbia, Canada, June 29, 2004.

"Second Annual Conference of the Partners of the National Center for Birth Defects and Developmental Disabilities (NCBDDD)," **CDC**, held in Washington DC, July 25-26, 2004.

"Fetal Alcohol Spectrum Disorders: An International Perspective," a symposium at the Twelfth World Congress on Biomedical Alcohol Research, Heidelberg, Germany, September 30, 2004 was chaired by Dr. Kenneth Warren. This **NIAAA** sponsored symposium included presentations on opthalmological research in Sweden, brain imaging studies in Finland, neurobehavioral and intervention studies South Africa, and a USA directed study comparing neurocognitive deficits in children affected with FAS in Moscow, Russia, and San Diego.

"Identifying and Working with Individuals with Fetal Alcohol Spectrum Disorders (FASD)," a workshop chaired by Candace Shelton and Dan Dubovsky of the SAMHSA FASD Center for Excellence sponsored by **IHS** and **SAMHSA** was held at the Third Annual IHS/SAMHSA Behavioral Health Conference on Alcohol, Substance Abuse and Mental Health: "Weaving Visions for a Healthy Future," June 28-30, 2005, San Diego, CA.

Events for Community Leaders, Policy Makers, Advocacy Groups, and the Public

"Needs of Native Americans Related to FASD," **SAMHSA** FASD Center for Excellence sponsored listening sessions, one for adults and one for youth, at the annual UNITY National Leadership Conference, June 2002.

"Building FASD State Systems" First Meeting, a Conference convened by the **SAMHSA** FASD Center for Excellence, Arlington, VA, May 18-20, 2003.

"The Partnership to Prevent Fetal Alcohol Spectrum Disorders: Uniting communities in a national concern." Symposium chaired by Dr. Rebecca M. Buchanan, **SAMHSA**, FASDMDCFE, at the Ninth Biennial Conference of the Society of Community Research and Action, Las Vegas, NM, June 2003.

"Innovative Strategies in Tribal Communities," a conference convened by the **IHS**, **SAMHSA** and the National Behavioral Health Conference in San Diego, CA, June 25-27, 2003.

"Building FASD State Systems" Second Meeting, a Conference convened by the **SAMHSA** FASD Center for Excellence, Kissimmee, FL, May 5-6, 2004.

"Expanding Partnerships to Meet Substance Abuse Prevention & Treatment Challenges in American Indian & Alaska Native Communities," a conference convened by the **IHS**, **SAMHSA** and the National Behavioral Health Conference in San Diego, CA, June 8-10, 2004.

"Working Session on FASD for OSEP Parent Training and Information Centers," a meeting session sponsored by **OSEP**, **ED,** at the 8th Annual Alliance Meeting in Washington, DC in February, 2005.

(iii.) Publications by ICCFAS members or other staff from ICCFAS member agencies

Publications for Health Care Providers, Biomedical Researchers, Science Faculty, and Education and Justice Professionals

Bertrand J, Floyd RL, Weber MK, O'Connor M, Riley EP, Johnson KA, Cohen DE, NTFFAS/E. Fetal Alcohol Syndrome: Guidelines for Referral and Diagnosis. Atlanta, GA: Centers for Disease Control and Prevention; 2004. Available at: http://www.cdc.gov/ncbddd/fas/documents/FAS_guidelines_accessible.pdf. Accessed August 4, 2005.

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The following SAMHSA documents are available through the SAMHSA Resource Center http://www.fascenter.samhsa.gov/resource/index.cfm and NCADI quick order: http://store.health.org/catalog/SC_Itemlist.aspx

SAMHSA. "Alcohol Can Harm the Way Your Baby Learns and Behaves." Informational rack card. Inventory no. AV245, 2004.
SAMHSA. "Alcohol Can Harm the Way Your Baby Learns and Behaves." Print public service announcement in Spanish. Inventory no. AV246, 2004.
SAMHSA. "Be the Best Mom You Can Be." Brochure for women to accompany "Recovering Hope: Mothers Speak Out About FASD" video for women in substance abuse treatment. Inventory no. PH408, 2004.
SAMHSA. "Como ayudar a un miembro de su familia o amiga a ser una futura madre que no toma: Consejos para hombres." Booklet for family and friends in Spanish. Inventory no. PHD1086S, 2004.
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SAMHSA. "El alcohol puede dañar la habilidad de su bebé para aprender y para comportarse." Informational rack card in Spanish. Inventory no. AV245S, 2004.
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SAMHSA. "Have a healthy baby. Be an alcohol-free mother-to-be." Poster. Inventory no. AV250, 2004.
SAMHSA. "How to have a healthy baby: Be an alcohol-free mother-to-be." Booklet for preconceptional and pregnant women. Inventory no. PHD1088, 2004.
SAMHSA. "How to help your family member or friend be an alcohol-free mother-to-be: Tips for Men." Booklet for family and friends. Inventory no. PHD1086, 2004.
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SAMHSA. "¿Le ofrecería alcohol a su bebé? ¡Por supuesto que no!" Informational rack card in Spanish. Inventory no. AV243S, 2004
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SAMHSA. "Recovering Hope – Mothers speak out about Fetal Alcohol Spectrum Disorders." Videotape for women in substance abuse treatment. Inventory no. CR69, 2004.
SAMHSA. "Tenga un bebé saludable. Si esta embarazada, ¡no toma!" Poster in Spanish. Inventory no. AV250S, 2004.
SAMHSA. "What You Need to Know: SAMHSA Fetal Alcohol Spectrum Disorders Center for Excellence." Fact sheet. Inventory no. RP01023, 2004.
SAMHSA. "What You Need to Know: The Language of Fetal Alcohol Spectrum Disorders." Fact sheet. Inventory no. RP01024, 2004.
SAMHSA. "What You Need to Know: Fetal Alcohol Spectrum Disorders: Tips for Elementary School Teachers." Fact sheet. Inventory no. RP01025, 2004.
SAMHSA. "When You're Pregnant, Your Baby Drinks What You Drink." Informational rack card. Inventory no. AV244, 2004.

SAMHSA. "When You're Pregnant, Your Baby Drinks What You Drink." Print public service announcement. Inventory no. AV248, 2004.
SAMHSA. "Would We Give Our Baby Alcohol? No Way." Informational rack card. Inventory no. AV243, 2004.
SAMHSA. "Would We Give Our Baby Alcohol? No Way." Print public service announcement. Inventory no. AV247, 2004

(iv.) FASD-Related Presentations by ICCFAS Members or Staff from Their Agencies

Presentations for Health Care Providers, Biomedical Researchers, Science Faculty, Education and Justice Professionals

Bertrand J, CDC, presented "Framework for diagnosis and intervention for children with Fetal Alcohol Syndrome and their families" at the American Public Health Association Annual Conference, San Francisco, CA, November 17, 2003.
Bertrand J, CDC, gave two presentations, "Public Health Methods: FAS" and "Overview of Project CHOICES for preventing alcohol-exposed pregnancies in high-risk settings," at St. Petersburg State University St. Petersburg, Russia, June 2004.
Bertrand J, CDC, presented "Interventions for children with Fetal Alcohol Syndrome and their families" at the Second Annual Conference of the Partners of the National Center for Birth Defects and Developmental Disabilities (NCBDDD), CDC, held in Washington DC, July 25-26, 2004.
Buchanan R, SAMHSA, made a poster presentation "Preventing the emergence of program fidelity/adaptation imbalances" at the annual meeting of the Society for Prevention Research, Quebec City, Canada, May 2004.
Calhoun F, Deputy Director of NIAAA, was an organizer, session chair, and presenter for the "South-Africa-U.S. Consultation on Fetal Alcohol Syndrome Research" in Cape Town, South Africa (S.A.), November 7-8, 2002.
Chezem L, NIAAA, presented "What Problems Does FASD Create for the Justice System in the USA?," at the Fetal Alcohol Spectrum Disorders - Research to Practice Conference, Chapel Hill, NC, September 11, 2004. A live presentation of this is available as a CME course online at http://www.clinicaltools.com .
Dufour M, former Deputy Director of NIAAA and Chairperson of the ICCFAS, was the luncheon speaker at the April 27, 2001 conference titled "The National Fetal Alcohol Syndrome Conference." This conference, held in Atlanta, Georgia, was hosted by the Fetal Alcohol Syndrome Task Force of Georgia, Atlanta Alliance on Developmental Disabilities, CDC, Emory School of Medicine, and the March of Dimes.
Floyd LR and Baio J, CDC, had a poster presentation "Preventing alcohol-exposed pregnancy: Epidemiological and clinical basis of Project CHOICES." Presented at the 2001 Annual Meeting of the American Public Health Association, Atlanta, GA, October 2001.
Floyd L, CDC, presented "Impact of baseline drinking on participant response to a motivational intervention to reduce alcohol-exposed pregnancies" at the American Public Health Association Annual Conference, San Francisco, CA, November 17, 2003.
Helfert S, SAMHSA, presented "SAMHSA FASD Center for Excellence Database: Linking Science to Service through Web Technology," at the Substance Abuse Librarians and Information Specialists Conference, San Francisco, April 2004.

Howard J, NIAAA, gave a short lecture on "FAS-Focused Prevention Research" at Grand Rounds for OB-GYN and Family Medicine residents at the Washington Hospital Center in Washington, DC., December 10, 2002.

Hutchins E, MCHB, HRSA, presented the keynote address "Improving Alcohol Screening During Pregnancy: Lessons Learned" at the Massachusetts State Alcohol Summit, Marlboro, Massachusetts May 1, 2001.

Hutchins E, MCHB, HRSA, presented "Integrating Psychosocial Screening and Referral into Prenatal Care" at the American Public Health Association Annual Meeting, Atlanta, Georgia, October 22, 2001.

Hutchins E, MCHB, HRSA, presented "Best Practices on Alcohol Screening During Pregnancy" at the American Public Health Association Annual Meeting, Philadelphia, Pennsylvania, November 12, 2002.

Hutchins E, MCHB, HRSA, chaired the preconference workshop "Alcohol Use in the Prenatal Period" at the National Perinatal Association Conference, Savannah, Georgia, December 5, 2002.

IHS and Health Canada Working Group on FASD presented "Lessons from International Collaboration between Canada and the United States on FASD in Indigenous Communities" at the International Meeting on Inuit and Native American Child Health 17th Annual IHS Research Conference, Seattle, Washington, April 29, 2005.

Li TK, Director of NIAAA, presented "Genetic Polymorphisms: Impact on the Risk of FAS and FASD," at the Teratology Society Annual Meeting, Vancouver, British Columbia, Canada, June 28, 2004.

Mattson M, NIAAA, presented, "In Utero Exposure to Toxic Effects of Alcohol: Social and Emotional Adjustment of Children with FAS," at the Fifth International Baltic Psychology Conference. University of Tartou, Estonia, August 22, 2002.

Miscally M, Buchanan RM, Crosse S, Ensley G, and Miller G, SAMHSA, gave the presentation "Empowering significant others to prevent fetal alcohol syndrome" at the 131st Annual Meeting and Exposition of the American Public Health Association, San Francisco, CA, November 2003.

Morrow D, ED, OSEP, presented, "Services provided through the Individuals With Disabilities Act (IDEA)" at the meeting of the National Task Force on FAS/FAE in Atlanta, Georgia, December 8, 2003.

Parra Dang E, CDC, presented "Disparities in healthcare-seeking behavior and access to care among women at risk for an alcohol-exposed pregnancy" at the American Public Health Association Annual Conference, San Francisco, CA, November 17, 2003.

Scott M, NIAAA, participated in a CDC-sponsored Partners Planning Meeting of the Roundtable of the National Center of Birth Defects and Developmental Disabilities, a coalition of government and private sector agencies whose focus includes enhancing the prevention mission, and in activities of the Roundtable held in association with CDC's First Conference on Birth Defects, Developmental Disabilities, and Disability and Health on September 17-19, 2002, Atlanta, GA.

Sharpe T, CDC, presented "Risk of alcohol-exposed pregnancies among poly-drug users in community based settings" at the American Public Health Association Annual Conference, San Francisco, CA, November 17, 2003.

Sidhu J and Floyd LR, CDC, "Regional trends in alcohol exposure prevalence rates among pregnant women in the United States, 1995-1999. " Presented at the Annual Meeting of the Research Society on Alcoholism, Montreal, Canada, June 22-28, 2001.

Sidhu J and Floyd LR, CDC, had a poster presentation "Alcohol consumption among childbearing-age women, United States, Behavioral Risk Factor Surveillance System, 1991-1999. " Presented at the 19th Annual BRFSS Conference, Atlanta, GA, March 11-14, 2002.

Sidhu J and Floyd LR, CDC, had a poster presentation "Trends in alcohol consumption among Hispanic pregnant and non-pregnant women in the United States, 1995-2000" at the Annual Meeting of the Research Society on Alcoholism, San Francisco, CA, June 2002.

Smith A, OSEP, ED, and Gass C, SAMSHA FASD Center for Excellence, presented "FASD Information Exchange, Networking, and Partnership: Constructing an Action Agenda for Young Children "at the OSEP National Early Childhood Conference, Washington DC, February 2005.

Warren K, NIAAA, presented "Have We Made Progress in Preventing Fetal Alcohol Syndrome? Insights and Lessons Learned from a 20-Year History" at the Second Annual Conference of the Partners of the National Center for Birth Defects and Developmental Disabilities (NCBDDD), CDC, held in Washington DC, July 25-26, 2004.

Weber MK, CDC, presented "Knowledge, attitudes, beliefs, and health message recognition about the dangers of drinking during pregnancy among women in community-based settings" at the American Public Health Association Annual Conference, San Francisco, CA, November 17, 2003.

Presentations for Community Leaders, Policy Makers, Advocacy Groups, and the Public

Bertrand J, CDC, presented "Information for Parents and Teachers Affected by FAS: CDC Intervention Research Projects" at the Assistive Technology Access Partnership Conference, Washington, D.C., December 2002.

Bertrand J, CDC, presented "Fetal Alcohol Syndrome" at the workshop of the CDC Science Ambassador Program, Atlanta, GA, June 2003.

Buchanan RM, SAMHSA, presented "Anticipating the program fidelity/adaptation balancing act" at the Ninth Biennial Conference of the Society of Community Research and Action, Las Vegas, NM, June 2003.

Buchanan RM, SAMHSA, presented "Creating resources to deal with program fidelity/adaptation through interdisciplinary collaboration: Integrating community psychology and social marketing" at the Ninth Biennial Conference of the Society of Community Research and Action, Las Vegas, NM, June 2003.

Calhoun F, Deputy Director of NIAAA, presented "What Is the Federal Government Doing to Help Me?" at the Living and Learning With Fetal Alcohol Syndrome conference sponsored by the Michigan FAS Network, Newaygo, Michigan, August 15-17, 2002.

Calhoun F, Deputy Director of NIAAA, presented "History of the ICCFAS" at the first annual meeting of Building FASD State Systems convened by the SAMHSA FASD Center for Excellence, Arlington, VA, May 18-18, 2003.

Calhoun F, Deputy Director NIAAA, presented "Alcohol and Women: What You Need To Know." Hope for Women in Recovery: Understanding and Addressing the Impact of Prenatal Alcohol Exposure, a workshop held in Baltimore, MD, September 2003.

Crosse SB, SAMHSA, presented "The Partnership approach to uniting communities in a national concern" at the Ninth Biennial Conference of the Society of Community Research and Action, Las Vegas, NM, June 2003.

Dubovsky D, SAMHSA, gave the keynote address, "Understanding the Diagnosis: Promoting Positive Growth" at the Atlantic Canadian Conference on Fetal Alcohol Syndrome/Effects, 2002.

Dubovsky D, SAMHSA, presented the poster "An Approach To Improving the Quality of Life for Mothers and Babies: The CSAP FAS Center for Excellence," and participated in the roundtable, "Altering Strategies for Optimal Success With Mothers and Babies: The Importance of Identifying Prenatal Alcohol Exposure in the Mothers" at Connections 2002: National Healthy Mothers, Healthy Babies Coalition Biennial Conference, Florida, 2002.

Dubovsky D, SAMHSA, presented "FAS Work in the U.S.: Potential for Collaboration" at the conference: Developing Strategies and Proposals for Fetal Alcohol Syndrome Research in Canada, 2002.

Dubovsky D, SAMHSA, presented "Co-Occurring Mental Health Disorders and Fetal Alcohol Spectrum Disorders: Addressing the Issues to Improve Treatment Outcomes," at the Mental Health Section, American Public Health Association annual meeting, San Francisco, California, November 2003.

Ensley G and Miscally M, SAMHSA, participated in the panel "Using research to design a community-based model: The Partnership to Prevent Fetal Alcohol Syndrome" at the 16th annual National Prevention Network prevention research conference, Albuquerque, NM, August 2003.

Floyd L, CDC, presented "Priorities for FAS Prevention and Intervention: National Task Force on FAS/FAE" at the first annual meeting of Building FASD State Systems convened by the SAMHSA FASD Center for Excellence, Arlington, VA, May 18-18, 2003.

Floyd L, CDC, presented "CDC/National Task Force on FAS/FAE Diagnostic Criteria," at the Second Meeting of Building FASD State Systems, a conference convened by the SAMHSA FASD Center for Excellence, Kissimmee, FL, May 5-6, 2004.

Hutchins E, MCHB, HRSA, presented "Prenatal Alcohol Use" at the Secretary's Advisory Committee on Infant Mortality, Crystal City, Virginia, November 21, 2002.

Hutchins E, MCHB, HRSA, presented "Federal Substance Abuse Initiatives and Funding Opportunities" at the Center for Substance Abuse Prevention State Partners Meeting, Arlington, Virginia, September 8, 2003

McClain C, Morse J and Ortiz D, gave presentations at an IHS sponsored FASD workshop: "Innovative strategies in Tribal Communities" at the first IHS/SAMHSA conference which was held June 25-27, 2003 in San Diego.

Miller G, SAMHSA, presented "Incorporating diversity in materials development" at the Ninth Biennial Conference of the Society of Community Research and Action, Las Vegas, NM, June 2003.

Miscally M and Zamora A, SAMHSA, presented "Tailoring program implementation: Partnerships with community groups" at the Ninth Biennial Conference of the Society of Community Research and Action, Las Vegas, NM, June 2003.

Parra Dang E, CDC, presented "Preventing fetal alcohol syndrome: Educational efforts and targeted interventions" at the Learning Disabilities Association of America 41st Annual International Conference, Atlanta, GA, March 19, 2004.

Stern K, OJJDP, in cooperation with Rob Wybrecht, a young man with FASD, presented the workshop, "What to do if you are stopped by the police" at the Living and Learning With Fetal Alcohol Syndrome conference sponsored by the Michigan FAS Network, including The Arc Michigan, the W. K. Kellogg Foundation, the CDC, SAMHSA, and others, Newaygo, Michigan, August 15-17, 2002.

Stern K, OJJDP, presented "Juvenile Justice" at the first annual meeting of Building FASD State Systems convened by the SAMHSA FASD Center for Excellence, Arlington, VA, May 18-19, 2003.

Stern K, OJJDP, presented the priorities of the Juvenile Justice Working Group subcommittee of the ICCFAS at a Town Hall Meeting organized by the FAS Family Resource Institute in Washington, DC, June 2003.

Warren K, NIAAA, and grantees Drs. Sandra Jacobson and Claire Coles were the three featured guests on a one hour broadcast of *The Diane Rehm Show* discussing alcohol, pregnancy, and fetal alcohol syndrome. National Public Radio distributes *The Diane Rehm Show* across the nation. The show aired live in Washington on WAMU-FM on November 10, 2003.

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Appendix C. Other Recommendations on FASD

National Task Force on FAS/FAE Recommendations

In September 2002 the National Task Force on FAS/FAE published (Weber et al, 2002) the following recommendations (some of which are relevant to ICCFAS activities):

1. Develop a clinical case definition for diagnosing FAS, including a neurocognitive phenotype, and begin work on establishing a clinical case definition for ARND.
2. Develop a uniform surveillance case definition for FAS and begin formative work on a uniform surveillance case definition for ARND.
3. Develop a white paper to review and summarize relevant epidemiologic research addressing the scope of the problem, prevalence, risk factors, impediments to diagnosis, and number of women at risk for an alcohol-exposed pregnancy.
4. Develop a white paper to review the evidence for effective prevention and treatment strategies for women at risk for or engaging in prenatal alcohol use. The report should describe women at risk, identify barriers to implementing effective strategies, and proscribe against implementation of untested models or models that are not evidence-based.
5. Develop a health services research agenda focusing on families of persons with FAS and ARND that address such concerns as why certain families do well and stay together, the impact of FAS/ARND on families relative to other birth defects, and how the legal system deals with FAS/ARND.
6. Develop a science research agenda, including translational research that brings basic research findings to the clinical domain (e.g., neuroimaging), and address concerns of maternal and fetal susceptibility to FAS/ARND.
7. Complete a profile of State, tribal, and private entities with existing services for persons with FAS/ARND and women at risk for an alcohol-exposed pregnancy; the profile should include eligibility criteria and ongoing educational efforts for professionals regarding FAS/ARND.
8. Develop an agenda that will lead to a national standard of care for persons with FAS and ARND during their lifespan, including best practices and plans for dissemination of standards to relevant health-care professionals.
9. Endorse a national coordinated media campaign and request that ICCFAS recommend how to coordinate this effort among all federal agencies.
10. Endorse the U.S. Surgeon General's Advisory statement regarding drinking during pregnancy, and urge that the statement be reissued as part of the coordinated national media campaign.
11. Contact the Office of National Drug Control Policy to recommend inclusion of information regarding FAS and ARND in their resource materials.
12. Develop a checklist of essential State services needed to prevent FAS and ARND, to treat persons with FAS and ARND and their families, and to better identify women at risk for having an alcohol-exposed pregnancy.
13. Develop and disseminate a plan for system-wide education regarding prenatal alcohol-related disabilities to be offered to professionals in health services, judicial services, education, child

welfare, vocational rehabilitation, juvenile justice, maternal child health clinics, and disabilities services and prevention.

14. Develop and disseminate a kindergarten--grade 12 curriculum to address FAS, ARND, and prenatal alcohol use.
15. Investigate incorporating information related to prevention and treatment of FAS and ARND into the credentialing requirements for teachers, juvenile justice workers, lawmakers, and health-care professionals (e.g., include FAS-related questions on State board exams).