



# Building FASD State Systems Proceedings

Arlington, Virginia • May 18–20, 2003



U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES  
Substance Abuse and Mental Health Services Administration  
[www.samhsa.gov](http://www.samhsa.gov)



SAMHSA  
Fetal Alcohol Spectrum Disorders  
Center for Excellence

## Introduction

The Substance Abuse and Mental Health Services Administration (SAMHSA) Fetal Alcohol Spectrum Disorders (FASD) Center for Excellence convened the "Building FASD State Systems" meeting in Arlington, Virginia, May 18-20, 2003. This was the first meeting of its kind and was designed to facilitate the creation and enhancement of comprehensive systems of care for FASD. The meeting is part of the FASD Center's response to its legislative mandate to provide technical assistance to communities developing systems of care.

## Sunday, May 18

### Welcome

**Callie Gass**, Project Director, FASD Center for Excellence

Ms. Gass welcomed attendees, reviewed meeting logistics, and introduced Dr. Stone.

**Deborah Stone**, PhD, Project Officer, FASD Center for Excellence

Dr. Stone welcomed the attendees, who included two representatives from 49 States, the District of Columbia, and Puerto Rico. She also thanked the FASD Center for Excellence for organizing the meeting, the first of its kind.

Dr. Stone explained that SAMHSA had done limited work in the area of prenatal exposure to alcohol and other drugs prior to 2000, when it was given the opportunity to develop the FASD Center for Excellence. SAMHSA then invited many of those who were already active in the FASD field to collaborate with the new center. She thanked all the agencies that have made important contributions to the FASD Center and to FASD issues generally, especially the Centers for Disease Control and Prevention (CDC) and the National Institute on Alcohol Abuse and Alcoholism (NIAAA).

The legislative mandates of the FASD Center for Excellence include identifying comprehensive systems of care for FASD at the State level and providing technical assistance to States that lack a comprehensive system. Dr. Stone noted that the meeting attendees included FASD State coordinators and representatives working in diverse areas such as public health, maternal and child health, mental health, substance abuse, developmental disabilities, family support, governors' offices, and genetics. She encouraged attendees to network, foster communication and collaboration, and participate in future FASD Center efforts.

### Opening Speaker

**First Lady Mikey Hoeven**, North Dakota

Ms. Hoeven described her commitment to the health and future of the Nation's children, a commitment shared by her husband, Governor John Hoeven. The prevention and treatment of FASD is central to that commitment. Ms. Hoeven discussed her efforts to combat underage drinking in North Dakota, and she noted the connection





between underage drinking, unprotected sex, and FASD. She also stressed the importance of ongoing research into the relationship between prenatal alcohol exposure and birth defects, and she acknowledged the difficulty of obtaining proper diagnoses of FASD.

Illustrating the scope of the problem, Ms. Hoeven noted that more than 40,000 babies are born each year prenatally exposed to alcohol—more than spina bifida, Down syndrome, and muscular dystrophy combined. FASD is a lifelong problem, and raising children with prenatal alcohol exposure is extremely challenging. Many affected children grow up in multiple foster homes. Many also have problems related to school, alcohol and drugs, and the criminal justice system.

With support and services, children with FASD can lead productive lives, but needed resources are often unavailable. Lifetime care for a person with FASD can cost over a million dollars, while alcohol treatment costs only \$5,000 to \$20,000 per individual. Clearly, more resources are needed to prevent FASD.

In closing, Ms. Hoeven stressed the critical need to convey the message that there is no safe level of alcohol use during pregnancy. She also cited important areas on which State governments should focus, including prevention, treatment, case management, improved diagnosis, services for affected children, and outreach to physicians. Ms. Hoeven thanked the attendees for their commitment to preventing and treating FASD, and she thanked SAMHSA for inviting her to participate in the meeting.

After Ms. Hoeven's remarks, Ms. Gass thanked the speakers and led the attendees in a round of introductions before concluding for the evening.

### **Monday, May 19**

#### **The SAMHSA FASD Center for Excellence: Accomplishments, Future Directions, and Resources**

**Callie Gass**

Ms. Gass explained that the FASD Center for Excellence has six mandates from Congress:

1. Study innovative clinical interventions.
2. Identify exemplary community systems of care.
3. Provide technical assistance to communities.
4. Provide training on FASD.
5. Develop innovative prevention techniques.
6. Respond to recommendations by the National Task Force on FAS.



The Center conducts its activities in partnership with its steering committee, the Interagency Coordinating Committee on Fetal Alcohol Syndrome (ICCFAS), CDC's National Task Force on FAS/Fetal Alcohol Effects (FAE), and SAMHSA grantees (Alaska, the Four-State Consortium, and Community Initiated Prevention Intervention grantees). The Center's goals are to advance the field of FASD and to facilitate the development of comprehensive systems of care. The Center's vision is a nation without FASD; an integrated collaborative approach to FASD; exemplary community systems of care for those affected by prenatal alcohol exposure; and communities that share their experiences and lessons learned.

The Center's current activities include:

- Releasing the 2002 Town Hall meeting report and convening the 2003 meetings
  - Six town hall meetings with 300 attendees and almost 200 testifiers
- Convening the Building FASD State Systems meeting
- Operating the Information Resource Center
  - Accessible by phone, mail, e-mail, and Internet ([www.fascenter.samhsa.gov](http://www.fascenter.samhsa.gov))
  - Publications, information, Web links, and customized literature searches
  - To date, 198 contacts received through the Web site and toll-free number
- Providing training and technical assistance (TA)
  - Training to over 2,000 providers, administrators, family members, government personnel, and community leaders
  - TA to family groups, provider organizations, corrections personnel, conference organizers, and agencies in Canada
- Supporting the replication of promising practices

The Center's future efforts include:

- Identifying, developing, and promoting best practices in FASD prevention and treatment
- Providing training and TA to increase competency in FASD diagnosis and intervention
- Assisting States and communities to develop comprehensive systems of care
- Fostering collaboration between family groups and providers to promote the delivery of quality services to those with FASD and their families
- Providing and evaluating trainings to professionals, families, women at risk, community members, and individuals with FASD
- Developing partners for universal FASD prevention
- Adapting state-of-the-art prevention practices to selective and indicated FASD prevention
- Responding to requests from the National Task Force
- Exploring opportunities for further collaboration with current and potential partners
- Identifying and responding to emerging issues



## FASD: Its Economic and Social Impact

**Moderator: Beverly Watts Davis, Director, CSAP, SAMHSA**

### The Science of FASD

**Edward Riley, PhD**, Professor, San Diego State University, and Cochair, FASD Center for Excellence Steering Committee

Dr. Riley thanked the Center and acknowledged his collaborators. He discussed early research on FAS that identified growth retardation, central nervous system anomalies, and distinct facial features as indicative of FAS. He then showed slides of children with FAS and FASD, emphasizing that those with FASD have normal facial features (nondysmorphic). Calling FAS "the tip of the iceberg," Dr. Riley noted that nondysmorphic individuals with FASD may be 4 to 10 times more common than individuals with FAS, although they typically are not diagnosed and lack access to services.

Magnetic resonance imaging has identified brain damage resulting from heavy prenatal exposure to alcohol, even in the absence of facial features characteristic of FAS. Studies indicate smaller overall brain size, as well as specific reductions in the cerebral vault, cerebellum, basal ganglia, and corpus callosum. Other brain abnormalities have been identified in subcortical structures, in the amount of gray and white matter, and in overall brain shape.

Prenatal alcohol exposure, at least in high doses, can cause permanent changes in the brain, resulting in obvious behavioral dysfunction even in the absence of distinct facial features. Individuals with FAS as well as those with histories of heavy exposure without FAS have significantly lower IQs than average. On assessments of areas such as language, fine motor skills, balance, and executive functioning, dysmorphic and nondysmorphic alcohol-exposed individuals are shown to be similarly affected.

FASD is an important issue for mental health providers. Over 90 percent of affected individuals have received mental health treatment. FAS also is the leading known cause of mental retardation. However, most individuals with FAS do not meet typical diagnostic criteria for retardation.

Attention problems are common among those with FAS, and these individuals, as well as nondysmorphic alcohol-exposed individuals, are often misdiagnosed as having attention deficit disorder. Secondary disabilities include conduct problems in school, criminal justice system involvement, alcohol or drug dependence, and dependent living. Protective factors for affected individuals are diagnosis of FAS before age 6, a stable home, and absence of violence.

FAS is a devastating disorder. Although it is entirely preventable, new cases continue to appear. Its consequences affect the individual, the family, and society at great personal and financial cost. Effective treatment and prevention strategies must be developed and made available.



## Economic Costs of FAS

Henrick Harwood, The Lewin Group



Mr. Harwood reviewed the economic costs of FAS, based on projections of estimates compiled in 1998 by the Lewin Group, a literature review conducted by Chuck Lupton of the FASD Center, and updated and extended versions of analyses published in 1986. The methodologies addressed cost-effectiveness, quality-adjusted life years, and willingness to pay (by the public). Mr. Harwood explained the assumptions, concepts, and components involved in different types of economic studies: cost of illness, cost-effectiveness, and cost-benefits.

In 1998, the direct economic cost of FAS was \$2.9 billion. The indirect cost was \$1.25 billion, and the total cost was \$4.15 billion. In 2003, the direct economic cost of FAS is expected to rise to \$3.9

billion. On an individual basis, lifetime direct costs average \$850,000 and may be as high as \$4.2 million; indirect costs in 2003 are expected to be more than \$2.5 million at birth.

New areas for economic study include the prevalence of alcohol-related birth defects, alcohol-related neurodevelopmental disorders, mental health problems (e.g., attention deficits, depression, autism), and criminal justice involvement. Little strong research exists on the cost-benefits of FAS interventions, and specific prevention efforts are difficult to evaluate rigorously.

The potential benefit of successful prevention can be examined. Using standard cost-effectiveness methods, a conservative estimate of potential savings from preventing one case of FAS is \$550,000 in quality of life value and \$300,000 in medical costs. Therefore, an intervention that costs less than \$850,000 per FAS case prevented would be considered cost-effective, presenting a compelling economic incentive for FAS prevention and treatment.

### **Priorities for FAS Prevention and Intervention: National Task Force on FAS/FAE**

**Louise Floyd, DSN, RN**, Team Leader, FAS Prevention Office, National Center on Birth Defects and Developmental Disabilities, CDC, FASD Center for Excellence Steering Committee Member

Dr. Floyd opened her discussion by providing background on the origins of the National Task Force on FAS/FAE. She stressed the need for evidence of the adverse results of prenatal exposure to alcohol, as well as effective prevention efforts.



Dr. Floyd then presented data on the prevalence of FAS in various States and areas of the United States, based on CDC-sponsored studies. The national estimate is about 1 case per 1000 births. About 1 in 8 women report alcohol use during pregnancy. Among nonpregnant women aged 18 to 44 years, 1 in 7 report drinking at high levels. Women who are at high risk for alcohol-exposed pregnancies include women in treatment, women discharged from treatment, and women who are incarcerated. About 2 percent of women in the general population are at risk.

Federal legislation was passed in 1990 creating the National Task Force on FAS/FAE. Dr. Edward Riley chairs the Task Force, which has the following mandates:

- To advise Federal, State, and local programs and research concerning FAS and FAE
- To coordinate its efforts with ICCFAS
- To report on the current and planned activities of the participating agencies

The Task Force's mission is to prevent FAS and alcohol-related neurodevelopmental disorders and to promote effective lifelong interventions for those affected. Dr. Floyd outlined the Task Force's specific goals and a series of 15 recommendations. The next steps toward implementing its recommendations are:

- Identifying which Federal agencies will be working on specific recommendations
- Encouraging close collaboration among Federal, State, and nongovernmental agencies with regard to implementation of the recommendations
- Continuing to seek relevant information from the scientific community and the public to inform future recommendations



### **Systems of Care Discussion**

**Moderator: Faye Calhoun, DPA, MS**, Associate Director, NIAAA, and Cochair, FASD Center For Excellence Steering Committee

### **History of the ICCFAS**

#### **Faye Calhoun**

In 1995, Congress mandated that Federal agencies collaborate to address FAS, and NIAAA was asked to take the lead in establishing ICCFAS. ICCFAS includes representatives from the Department of Education, Department of Health and Human Services, and Department of Justice. NIAAA, CDC, and SAMHSA all participate in ICCFAS.

Dr. Calhoun cited the importance of the committee members' overlapping FASD-related missions in forging an effective partnership: research, special education, prevention, professional training, human development,



pediatrics, reproductive health/obstetrics, patient outcome research, practice guidelines, juvenile justice, health care services, information dissemination, alcohol treatment, and demonstration projects.

ICCFAS's goals are to exchange information and foster collaborative projects and to improve communication among research, service-provider, and other professional groups supported by the member organizations. Its objectives are to:

- Improve diagnosis.
- Improve the ability to screen for and prevent drinking during pregnancy.
- Improve the quality of intervention/alcohol treatment for women.
- Educate communities and health care professionals.
- Improve health care, education, and correctional interventions for affected children.
- Foster basic research to identify mechanisms of alcohol teratogenesis, leading to improved interventions and treatments.



## CDC

### Louise Floyd

Dr. Floyd described CDC's focus on surveillance, prevention, and intervention. She noted that CDC has about 30 cooperative agreements related to FASD in over 20 States. She encouraged attendees to track relevant Behavioral Risk Factor Surveillance System data in their States.

Dr. Floyd then reported on a CDC study (Project CHOICES, Changing High-Risk Alcohol Use and Increasing Contraception Effectiveness Study) that provided women aged 18-44 with motivational counseling and a visit to a family planning provider.

The study showed that after 6 months, two-thirds of the women were no longer at risk for an alcohol-affected pregnancy. Women drinking at lower levels did not tend to change their drinking behavior but did increase their use of contraception. Women drinking at medium and high levels recognized the problem more than those at lower levels. They decreased their risk by both decreasing alcohol use and using effective contraception. The study highlighted the added value of contraception for those who do not change their drinking behavior.

CDC is working to increase education and awareness of FASD through 3-year grant programs in four States. Its curricula and programs ultimately will reach more than 30 States. The agency also has released a number of targeted media campaigns in high-risk populations targeting pregnant and nonpregnant women aged 18-44. CDC plans to fund clinical studies to identify successful interventions for children with FAS. In addition, the



agency is working to develop diagnostic guidelines and to disseminate them through regional training centers. Dr. Floyd encouraged attendees to visit CDC's Web site ([www.cdc.gov](http://www.cdc.gov)) for additional information on its activities and funding opportunities.

### **Juvenile Justice**

**Karen Stern, PhD**, Program Manager, Office of Juvenile Justice and Delinquency Prevention (OJJDP), FASD Center for Excellence Steering Committee Member

Dr. Stern reported that youth with FASD are at high risk for entering the juvenile justice and criminal justice systems and that the system probably has high numbers of people with FASD. An integrated continuum of services is far more effective in reducing risk than fragmented competing services. The most exciting work in this area is taking place at the State level with Federal support.

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*“Youth with FASD are at high risk for entering the juvenile justice system.”*

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OJJDP was created in 1974 to provide national coordination, resources, and leadership on juvenile justice. Most of its appropriations from Congress go to individual States. Dr. Stern encouraged the attendees to identify their OJJDP State representative by calling (202) 307-5921 or visiting the OJJDP Web site at [www.ojjdp.ncjrs.org](http://www.ojjdp.ncjrs.org). She also encouraged them to contact their representative regarding available grants in their State. She provided a handout with details.

Helpful contacts at the State level include State advisory groups, which:

- Advise the governor and legislature on juvenile justice issues
- Develop and monitor each State's 3-year juvenile justice plan
- Award grants to accomplish the plan's objectives

Each State also has a juvenile justice specialist who typically is well informed about State-level resources and juvenile court policies and procedures.

### **Maternal and Child Health**

**Ellen Hutchins, ScD, MSW**, Chief, Perinatal and Women's Health Branch, Maternal and Child Health Bureau, Health Resources and Services Administration, FASD Center for Excellence Steering Committee Member

Through the HRSA Perinatal and Women's Health Branch, each State has a director of maternal and child health and a director of children with special health needs. Together, they administer Title V maternal and child health block grant funds. In the last 10 years, the program's focus on preventive women's health has been expanded.



The Title V block grant serves all women and children, regardless of insurance status, through Federal and State partnerships. Last year, the funding helped to serve 62 percent of all women who delivered babies and 90 percent of all newborns. States vary in how they use the block grant funds (e.g., administer clinics, contract for services, conduct policy or research activities). Dr. Hutchins provided contact information for the State directors and encouraged attendees to collaborate with them.

The Perinatal and Women's Health Branch recognizes the impact of substance use, depression, and domestic violence on women and children, as well as the need to assess risk for all three related problems. Its demonstration projects place a strong emphasis on pilot research and dissemination and provide the impetus for funding additional research. Areas in which the branch is active include:

- State and local training
- Technical assistance
- Screening
- Development of a State resources directory
- An initiative to motivate prenatal providers to screen for alcohol use in pregnancy
- A domestic violence initiative to improve local linkages among providers, shelters, the legal system, and law enforcement
- Early risk/preconception screening and education

Additional information is available at [www.mchb.hrsa.gov](http://www.mchb.hrsa.gov).

### **Mental Health and Substance Abuse**

**Paul Brounstein, PhD**, Director, Division of Knowledge Application and System Improvement, CSAP, SAMHSA

Dr. Brounstein discussed recent changes at SAMHSA, particularly the effort led by SAMHSA administrator Charles Curie to have the agency speak with a single voice. Congress has mandated that SAMHSA become involved with FASD, which is germane to six of SAMHSA's 11 priority areas: prevention, children and families, strengthening the mental health system, strengthening the treatment system, co-occurring disorders, and the juvenile justice system. Each priority area has a set of goals and objectives that address effectiveness, capacity development, and accountability.

Dr. Brounstein emphasized the need to stop the intergenerational transfer of FASD, and he attributed the problem to a behavioral deficit that can be changed. He also stressed the importance of integrating FASD with other issues, such as co-occurring disorders.





## Developmental Disabilities

**Steve Eidelman, Executive Director**, Arc of the United States

Mr. Eidelman described inherent challenges in the fragmented developmental disabilities system:

- Most of the funding for developmental disabilities comes from Medicaid, but most of the authority comes from the Administration on Developmental Disabilities.
- Each State's approach to developmental disabilities is structured differently.
- Department of Education funding for developmental disabilities is split according to the age of the individuals served. Individuals past the age of 21 are not covered at all.
- Most people with developmental disabilities are adults, not children.
- Poor collaboration exists between alcohol and drug agencies and developmental disabilities agencies.

Most of developmental disabilities services are provided by private nonprofit organizations, such as Arc, which has chapters in 44 States. Mr. Eidelman encouraged attendees to contact Arc for a copy of a resource guide for families of a child with developmental disabilities. The guide lists every relevant Federal program available.

### Remarks

**Beverly Watts Davis**, Director, Center for Substance Abuse Prevention

Ms. Davis applauded the attendees' leadership on FASD issues and expressed CSAP's commitment to providing the consistent support needed to build an infrastructure that advances their work. She asked attendees to note on their meeting evaluation forms the two most important things CSAP can do to sustain their efforts.

### Insurance and Other Financial Benefits

**Moderator: Ellen Hutchins**

#### Medicaid, Children's Health Insurance Programs (SCHIP), and Early and Periodic Screening, Diagnosis, and Treatment (EPSDT)

**Jane Perkins, JD, MPH**, National Health Law Program

Ms. Perkins discussed Medicaid eligibility requirements. Candidates must fit into a certain category (children, pregnant women, adult caretakers, disabled, elderly). They also must have limited income and resources, have approved immigration status, and be residents of the State in which they apply.

The mandatory Medicaid benefit package includes inpatient and outpatient hospital services; physician services; nursing facility services for those over age 21; laboratory and X-ray services; home health services for individuals entitled to nursing facility services; pregnancy-related services; and Early and Periodic Screening, Diagnosis, and Treatment (EPSDT). The optional benefit package includes medical/remedial care furnished by





licensed practitioners, home health services for persons not entitled to nursing facility services, prescription drugs, rehabilitative services, and case management.

For adults, the scope of benefits depends on whether the services fit Medicaid criteria, are medically necessary, and meet utilization controls. Services also should not be experimental, and there should be no less costly, equally effective alternative.

EPSDT is a mandatory benefit program for youth under age 21. The program entails aggressive outreach and information about EPSDT, a broad treatment package, and the provision of four types of screens: medical, vision, hearing, and dental. Screenings must be done periodically according to accepted guidelines. When problems are detected, Medicaid must arrange for corrective treatment as needed, directly or through referrals.

Alcohol and drug treatment may be covered through Medicaid as inpatient/outpatient hospital services, clinic services, rehabilitative services, EPSDT, or home health care, or through home- and community-based care waivers. Additional information is available at [www.healthlaw.org](http://www.healthlaw.org)

### **Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI)**

**Lewis Gelobter, JD, LLM, Legal Services of Northern Virginia**

Unlike Medicaid or CHIP benefits, SSI/SSDI benefits are cash benefits paid to qualifying claimants. In many States, Medicaid and SSI eligibility are actually linked. SSI is a means-tested program. Drug and alcohol use as a "material factor contributing to a disability" typically is a disqualifying factor, unless it can be shown that the disability would remain if drug and alcohol use ceased.

Children under 18 can be eligible for SSI benefits if they meet certain conditions. They must have marked impairments and meet a three-step sequential analysis to determine the combined effect of a child's impairments in determining disability:

- Is the child engaged in substantial gainful activity (e.g., school, work)? Does the individual incur special expenses, work in a specific program, or require certain accommodations without which he or she would be unable to work?
- Does the child have a severe impairment?
- Does the impairment or combination of impairments meet the criteria of specific impairments?

The Social Security Administration has identified functional criteria in six domains, which it uses to consider how well a child performs specified activities compared to others of the same age without impairments. A



range of factors is used to assess impairment; children must show a "marked" level of impairment in two domains or "extreme" limitation in one. The "interactive and cumulative," combined effect of all impairments must be considered. A diagnosis of FASD would not automatically qualify an individual for SSI eligibility; associated impairments must be demonstrated. However, the Social Security Administration could work with those in the FASD field to incorporate FASD factors.



### Guest Speaker

**Terry Lierman**, Health Ventures

Mr. Lierman discussed the urgent need to prevent prenatal alcohol exposure, the number one known cause of mental retardation in the United States. He recognized the work of the attendees and the organizations represented at the meeting and the importance of their continued collaboration. Reflecting on the poverty he saw during a recent visit to Nicaragua, he compared the tremendous lost potential of poor children to the lost potential of children with FASD.

Mr. Lierman described his work with the National Organization on Fetal Alcohol Syndrome (NOFAS), which seeks to increase public awareness and educate the public, physicians, and young people about FASD. He also cited data that illustrate the breadth of the organization's work. For example, in 2002, NOFAS responded to 21,000 information requests, held 208 workshops and seminars, and reached thousands of high-risk women. Mr. Lierman encouraged participants to take advantage of the resources that NOFAS offers and to share their needs with NOFAS.

Raising the issue of FASD with legislators at every opportunity is crucial, particularly in the face of so many competing needs. Mr. Lierman urged attendees to be passionate about FASD, to demand the resources needed to address it, and to build constituencies in their States.

### FASD: Impact on the Family

**Moderator: Dan Dubovsky, MSW**, FAS Specialist, FASD Center for Excellence

**Teresa Kellerman**, Executive Director, FAS Community Resource Center

Ms. Kellerman discussed her experiences as the single parent of John, a child with FAS who is now 25 years old. John was diagnosed with FAS at birth. He had a strong startle reflex, sensory integration disorder, slow weight gain, and sleep problems.



Due to sensory overload, outings and large family gatherings were impossible. John's behavior was blamed on poor parenting and abuse. He has impaired judgment and requires constant supervision. Ms. Kellerman could not use babysitters, and other children did not want to play with him. John also had to have heart surgery at an early age.

John has worked for 5 years at a plant nursery. He also has a mentor who does recreational activities with him 4 hours per week, providing Ms. Kellerman with her only respite. He had no friends until 2 years ago, when he met Sheena, a young woman with FAS to whom he is now engaged. John has escaped secondary problems such as addiction, criminal involvement, and depression. He is ready to live away from home, ideally with Sheena, in a group home or in independent living with services. However, due to the State's economic constraints, there are no such options.

Ms. Kellerman has been unable to work due to John's needs; her time is devoted to caring for him and volunteering with the FAS Community Resource Center. She discussed typical problems faced by families affected by FAS, such as limited access to services, inability to get a diagnosis of FAS due to the birth mother's denial of alcohol use during pregnancy, failure of the system to reveal FAS status, and failure to recognize FAS before tragic consequences occur. The families dream of normal lives for their children, and they fear for their children's well-being after they are gone.



**Jocie DeVries**, Executive Director, FAS Family Resource Institute

Ms. DeVries screened a video clip of herself speaking about the impact that FASD has had on her family. As an FASD educator working to help others identify, understand, and develop appropriate care for affected individuals, Ms. DeVries is the adopted mother of two siblings with FASD. A few years ago when her children were still teenagers, she learned that her son, who had a normal to high IQ, had FAS. Her daughter had several co-occurring disorders and was also diagnosed with FAE.

Although the road has not been easy for her daughter, she is happily married and is employed full time. The son is more severely impaired. Even though he has a normal IQ, he was found eligible for SSI and lives with a group of other young men. He has a deep need for a structured environment, which those in his household provide. At times he is volatile, easily confused, and extremely vulnerable to peer pressure but he has a sunny disposition and is well liked by his peers.

Ms. DeVries recommended several strategies for helping children with FASD: firm structure, "boisterous fun," and feasible vocational training. She also called for funding from the alcohol industry to address FASD and for recognition of FASD-related disabilities regardless of IQ. After concluding her remarks, Ms. DeVries was presented with a proclamation signed by Governor George Pataki recognizing her work on FAS. It also was noted that Ms. DeVries received an award from *Woman's Day* magazine.





**Kathy Mitchell, MHS, LCADC, Program Director, NOFAS, and Karli Schrider**

Ms. Mitchell introduced herself as an advocate for FASD issues and the birth mother of Karli Schrider, an adult child with FAS. Ms. Mitchell spent 17 years in active addiction and had five children prenatally exposed to alcohol. For years, medical professionals had failed to diagnose Karli's FAS.

Ms. Mitchell was erroneously told that Karli had ear infections, was slow but would catch up, and had cerebral palsy. One of Ms. Mitchell's children died at birth, and another died at 3 months. Ms. Mitchell has been sober for 19 years. While she was drinking, she was in denial about her illness, and her children suffered due to lack of intervention. Karli's brother and sister show no effects from prenatal alcohol exposure. Karli described how her life is different from theirs, noting that they drive, live independently, are married, and have checks and credit cards.

However, she also described her own contacts with a former president and U.S. senators. Karli goes to a community center daily, where she receives services and has a job.

Ms. Mitchell said that her family has been affected tremendously by FAS but comes together as a team to ensure that Karli has a safe, loving, and happy environment. She stressed that the stories of FASD-affected families make a difference and are effective advocacy tools.

### **Bringing It All Together: FASD State Systems**

**Moderator: Annie Acosta, MSW, Alternate Project Officer, FASD Center For Excellence**



#### **Alaska's Comprehensive FAS Project**

**Diane Casto, Program Manager, Office of FAS, FASD Center for Excellence Steering Committee Member**

Alaska established an Office of FAS in 1998. The Office initially focused on identifying statewide needs related to FAS and conducting planning efforts. In October 2000, Alaska's Comprehensive FAS Project was awarded funding from CSAP for 5 years (\$5.8 million per year, for a total of \$29 million). The project's goals are prevention, diagnosis, improved lifelong outcomes for individuals with FASD through improved services, and documentation and evaluation of processes and outcomes.



Ms. Casto provided details on Alaska's approach, which centers on:

- Community and system awareness and education
- Global, targeted, and specific prevention
- Community-based diagnostic teams
- Innovative community-based grants
- Parent leadership
- Systems change
- FAS surveillance
- Multidisciplinary partnerships

Ms. Casto stressed the importance of sustainability, community-based approaches, data, and integration of FAS strategies into existing programs. Key project activities include:

- A community-based innovative project
- A statewide survey
- A public education/media campaign
- A curriculum development and training certification program
- An annual FAS summit
- A partnership with the State Department of Education and Early Development

### **Minnesota State Model of an ICCFAS**

**Susan Carlson, JD**, President, Minnesota Organization on FAS (MOFAS), and FASD Center for Excellence Steering Committee Member

Ms. Carlson explained the concept of an interagency coordinating committee on FAS, which allows agencies to communicate, cooperate, coordinate, and collaborate. She said that all States need an ICCFAS to foster integration of FASD prevention and intervention programs into existing State systems and to increase awareness. FASD is not just a health issue. It crosses many disciplines, such as education, criminal justice, and mental health.

In her earlier work with juvenile courts and as first lady, Ms. Carlson learned about FASD-related brain damage and its effects. In 1997, she established the Governor's Task Force on Fetal Alcohol. The task force studied current research and held nine public hearings, resulting in several key findings, over 100 recommendations, and funding of \$6.75 million per year for FASD prevention and intervention services. Most important, the task force's work served as a blueprint for action.

One key task force finding—that poor coordination hampers prevention, diagnosis, and services—led to a recommendation for a State office to coordinate all FAS activities, with public and private funding. In response, the Minnesota Fetal Alcohol Coordinating Board was established in 1998. Although the board lost its funding



after only a year, it represents a good model for a State ICCFAS. It developed a vision, mission, and strategic plan and initiated a Web site, newsletter, and statewide training conference. Its top priority was to review FASD-related programs of State agencies.

In closing, Ms. Carlson summarized her advice for creating an ICCFAS:

- Have someone who "gets FASD" in power to start the process.
- Develop a plan/blueprint for action.
- Define membership and duties.
- Determine how much power the ICCFAS will have (e.g., will it have power to recommend policy changes?).
- Develop a plan to sustain funding.



### **Four-State FAS Consortium**

Judy Struck, MA, Executive Director, Center for Disabilities, University of South Dakota School of Medicine, FASD Center for Excellence Steering Committee Member

Ms. Struck described the Four-State FAS Consortium, which includes North Dakota, South Dakota, Minnesota, and Montana. The Consortium was established through a congressional earmark in 2000 and receives funding through CSAP under a cooperative agreement. It is the only multistate FAS effort of its kind. It serves a significant population of American Indian tribes and reservations, includes State/tribal representation, and is endorsed by the Indian Health Service. The participating States are very rural, with sparse populations spread across large geographic areas.

The purpose of the Four-State FAS Consortium is to build capacity and reduce risk factors for prenatal alcohol exposure. Its intended outcomes are to develop cooperative efforts among the four States, work together for common causes, collect and share common data elements, and test common intervention strategies. Its primary objectives are:

- Develop and evaluate the formation and operations of a four-State consortium on FAS/FAE.
- Develop an information system that systematizes data collection to help determine high-risk populations and areas.
- Implement and test a science-based prevention/intervention model and intensive case management model.

Ms. Struck detailed the Consortium's key elements and strategies, which include commitment from participants at all levels, planning, structure and procedures, common terminology and data elements/instruments, and consistent communication across the Consortium and with the CSAP project officer. She also discussed specific issues that the Consortium is working to address.



The Consortium appears to be a cost-effective method of implementing strategies across State lines. Plans call for sharing results and data, continuing to expand a database system, and providing training to increase recognition and referral for FASD. Ms. Struck encouraged attendees to visit the Consortium Web site, [www.usd.edu/fourstatefasconsortium.org](http://www.usd.edu/fourstatefasconsortium.org).

## **Bringing It All Together: State Systems on Their Way**

**Moderator: Edward Riley**

### **National Approach to FAS in Canada**

**Jocelyn Cook, PhD, MBA**, Senior Program Consultant, FAS/FAE Team, Division of Childhood and Adolescence, Health Canada

Dr. Cook reviewed Canada's investment to date in addressing FASD. The FAS/FAE National Advisory Committee, formed by the health minister, works closely with other segments of the health department and the government, including those that serve native populations in Canada. Key activities include community capacity building, public and professional awareness and education, surveillance and epidemiology, and coordination and collaboration.

The FAS/FAE National Advisory Committee provides advice and recommendations for program and policy development. In addition, regional offices in Canada conduct projects in their respective areas and collaborate with each other. The committee's vision is "to develop a broad-based collaborative effort to prevent FASD and improve the quality of life of people and families affected across Canada." A forum is planned to develop a national plan of action.

Dr. Cook listed lessons learned from the Canadian experience:

- Seek advice from experts in the community, researchers, and all relevant stakeholders.
- Foster communication and coordination among all levels.
- Agree on guiding principles for working together.
- Develop common goals and objectives.
- Be sure that roles and responsibilities of regional and national staff are clearly outlined.
- Work together to develop policies and programs.

### **KIDS NOW, Kentucky's Substance Abuse and Pregnancy Initiative**

**Elisa Klein, MSW, MPH**, Division of Substance Abuse, and Patti Deitsch, MS, Program Coordinator, Institute on Women and Substance Abuse

Ms. Klein and Ms. Deitsch discussed Kentucky's KIDS NOW initiative (Kentucky Invests in Developing Success), which seeks to reduce the incidence and effects of perinatal substance abuse. Activities include educating women and service providers, partnering with providers to identify and intervene with



substance-abusing women, and eliminating barriers to treatment. They discussed the program's key components, such as Medicaid benefits, outreach, and networking, as well as funding barriers. The program is in its third fiscal year.

KIDS NOW activities have included collaborating with the public health department and providing onsite services at local health departments. Additional activities relate to screening, prevention, case management, priority admission to treatment, incentives for pregnant women, gender-sensitive treatment, marketing to providers, and networking.

The Kentucky initiative sheds light on a number of lessons learned, including the importance of flexible funding, prevention and treatment collaboration, full-time dedicated staff, and variation when necessary. In addition, addressing stigma and fear, forging relationships in the community and with women and families, and raising community awareness are essential.



### Working With Policymakers

**Tom Donaldson**, Executive Director, NOFAS

Mr. Donaldson stressed that the attendees can make a difference through advocacy. He urged them to build and lead a constituency to address FASD.

Advocacy must be a daily activity, and it is a particular challenge to raise awareness of FASD. However, individuals with FASD and their families are heroes with compelling stories to tell, and they can be effective partners in advocacy.

It is vital for advocates to be credible; to know both the facts and the misperceptions surrounding FASD; to know what tactics are most effective with their audiences; and to be persistent, moving forward with passion and enthusiasm. Critical strategies include media outreach and policymaker education. Mr. Donaldson stressed that policymakers want to serve their constituents and therefore need to know how FASD affects them. He called on attendees to identify people in their communities who could benefit most from FASD advocacy efforts, give them a voice, and work with them to raise awareness about FASD.

### Tuesday, May 20

#### Bringing It All Together: FASD State Coordinators

**Moderator: Judy Struck**

**Jane Stueve, RN**, FAS State Coordinator, Kansas

Ms. Stueve provided an overview of the demographics of Kansas and the geographical service area she serves. Recent results of the Kansas Behavioral Risk Factor Surveillance System (BRFSS) show a high prevalence of frequent drinking and binge drinking among women.



When Ms. Stueve was hired as the FAS State coordinator, only 16 of 126 hospitals in the State were reporting on FAS. She identified and began maximizing two existing State laws, one that requires hospitals to report cases of FAS and another that makes grant funds available for pilot programs to address FAS.

Coordination of FAS services in Kansas involves the following:

- Bureau for Children, Youth, and Families, which includes the FAS Program, Birth Defects Registry, and newborn screening program
- Bureau of Epidemiology and Disease Prevention
- Office of Local and Rural Health, which includes Kansas County Health Profiles
- Bureau of Health Promotion, which administers the BRFSS

Ms. Stueve described the lessons she has learned during her tenure as FAS State coordinator, emphasizing the importance of identification, knowledge and training, data, and collaboration.

**Pam Gillen, RN, ND, CACIII**, Project Coordinator, FAS Prevention, Colorado Area Health Education Center, University of Colorado Health Sciences Center, and FASD Center for Excellence Steering Committee Member

Ms. Gillen provided information on the origins of Colorado's efforts to address FAS through a statewide prevention project, which is housed in the Area Health Education Center (AHEC). The center's mission is to serve the health needs of the State, especially rural, minority, and underserved populations, through educational outreach.

There are five regional AHECs across the State. The prevention project is a collaborative effort involving numerous community sectors and health, education, social service, law enforcement, and community groups. The project uses the AHEC system to provide program services to all areas of the State.

The project's goal is to reduce the use of alcohol, tobacco, and other drugs by pregnant women, using information dissemination and community-based and environmental strategies:

- Information dissemination involves the development and dissemination of materials and curricula on FAS and substance use, as well as public service announcements, speaking engagements, and a hotline.
- The community-based strategy focuses on community needs assessment, training, community development, multiagency meetings, coalitions, parent support groups, and technical assistance.
- Environmental strategies involve providing technical assistance to help communities advocate and develop services for individuals, as well as targeting prevention efforts at State legislators to foster policy changes.



## Breakout Groups

Five breakout groups were held, and each session was repeated once to allow attendees to participate in two sessions each. Representatives from the breakout groups then summarized the discussions for the full group. Highlights from the discussions follow.

### Challenges With Statewide Prevention Efforts

**Pam Gillen**

This discussion centered on five particular challenges encountered in statewide prevention efforts:

- Budgets (rigid divisions between prevention and treatment budgets; need more flexibility; sustainability)
- "Performance partnerships" (challenges regarding data collection and reporting)
- Limited travel dollars (use of technology, such as video conferencing)
- Local continuity (need for matching funds for Federal programs, which many States cannot generate; some States unable to accept Federal funds)
- Community readiness (access to planning grants)

Other issues discussed included:

- Individual interventions vs. environmental/policy issues (e.g., mandatory reporting, birth defects registries)
- Commitment to prevention (e.g., true prevalence data, marketing of cost-effectiveness of prevention to third-party payers)
- Physicians and other health professionals (professional accountability, consistent abstinence messages)
- Coordination with related fields that have had success
- Parent support groups/parent networks (comfortable environment, day care, transportation, food, social events, and other incentives)

### Training as a Critical Component of Developing a Statewide FASD System

**Jane Stueve and Dan Dubovsky**

Participants in this breakout session conducted a SCOT analysis, exploring common strengths, challenges/barriers, opportunities, and threats involved in developing a statewide FASD system, with an emphasis on training.

#### *Strengths*

- General
  - Internet as a resource
  - Passion, stamina, and experience



- Common goal
- National (Federal) recognition (e.g., CDC, FASD Center for Excellence, NIAAA)
- Access to economic/cost-benefit analyses
- Positive attitude
- FASD covered at meetings and conferences
- Ongoing research
- Local
  - State organization dedicated to FASD
  - Buy-in from "powers that be"
  - Legislative recognition
  - Parents' investment and experience
  - Direct providers available within the State
  - Available curricula
  - Knowledgeable trainers

### ***Challenges/Barriers***

- Funding
- Overburdened systems
- Need to identify potential partners
- Need to change accepted norms
- Attitude of "been there, done that"
- Lack of coordination on Federal, State, and local levels
- Alcohol industry advertising
- Lack of sharing of lessons learned (need to stop reinventing the wheel)
- No behavioral screens for children, adolescents, and adults
- Lack of a champion for the cause
- Lack of connections to support networks

### ***Opportunities***

- Connecting with powerful individuals
- Training everyone in every system of care
- Accessing grants/foundation funding
- Developing a birth mothers' network
- Mentoring other States
- Networking with other States
- Accessing Title II monies
- Tapping into existing places where people congregate



### ***Threats***

- Possible loss of services due to changes to Individuals With Disabilities Education Act
- Problems with short-term grants/lack of sustainability
- Turf issues (within and between departments, programs, and systems)
- Possibility of FASD losing priority status
- Shifting politics

## **Bridging the Information Gap**

**Teresa Kellerman**

This breakout session identified where information gaps exist as well as information sources, key issues, barriers, and solutions.

### ***Information Gaps***

- FASD individuals and families
- The system—educators, professionals, and service providers
- Policy—legislators, leaders, and government agency directors

### ***Information Sources***

- Arc
- March of Dimes
- NOFAS (see [www.nofas.org](http://www.nofas.org) for a national directory of resources)
- Internet ([www.fasstar.com](http://www.fasstar.com))

### ***Key Issues***

- Lack of knowledge of FASD
- Lack of knowledge of services available
- Difficulty changing the system
- Resistance within the system
- Only about 16 percent of children with FASD qualifying for developmental disabilities services; about half of States using IQ-based criteria, half using function-based criteria

### ***Barriers***

- Denial (about alcohol, alcoholism, FASD)
- Lack of quality information, training, and funding
- Lack of curricula
- Eligibility problems
- Chronic frustration due to unrealistic expectations (children with FASD)
- Clinical depression and suicidal ideation (adults with FASD)



- High rate of alcohol abuse among adults with FASD (as well as behavior problems and high-risk behaviors); prevention needed
- Lack of information among children about their disability early enough for them to have some understanding and accept restrictions
- Lack of recognition that alcohol is a drug
- Power of alcohol industry lobby over lawmakers

### ***Solutions***

- SAMHSA FASD Center for Excellence, FAS Community Resource Center, Association of University Centers on Disabilities, Center for Science in the Public Interest, and Partners in Policymaking are good resources for advocacy training/education.
- Educate parents, providers, and policymakers.
- Recognize that respite care helps people learn about caring for children with FASD.
- Make sure that employees are well educated about FASD and dedicated; have high hiring standards.
- Recognize that intervention is a key component of prevention.

### **Core Components of an FASD State System**

**Diane Casto**

Participants in this breakout session discussed core components of an FASD State system, while recognizing that States have different environments, needs, and structures.

### ***Challenges***

- Funding
- Lack of data
- Buy-in from providers
- Community ownership of issue
- Crossing disciplines

### ***Strategies***

- Find a "valley forger"—a strong, committed FASD advocate.
- Educate multiple audiences.
- Integrate FASD programming throughout State systems.
- Be creative and flexible.
- Focus on community-level efforts.
- Build capacity.
- Plunge forward.



### ***Solutions***

- Work with four-digit code/focus on function.
- Get buy-in early.
- Use student interns.
- Seek alternative funding (e.g., alcohol trust funds).
- Advocate for unfunded mandates if necessary (get funding later).

### **Creative Funding Efforts**

**Jerome Romero**, FAS State Coordinator, New Mexico

Participants in this breakout session identified a number of creative funding efforts and strategies, with an emphasis on collaboration:

- Recruit local dairies to put FAS messages on milk cartons.
- Partner with local radio stations and disc jockeys to air public service announcements.
- Collaborate with the Partnership for a Drug-Free America (ask about "alliance coordinators").
- Distribute posters to facilities that receive set-aside money.
- Pool education funds.
- Collaborate with the March of Dimes.
- Hold a party for pregnant mothers with prizes, bartenders mixing nonalcoholic drinks, and media representatives.
- Use billboards and public transit to carry messages.
- Think creatively.



## Closing Remarks

**Annie Acosta**, Center for Substance Abuse Prevention

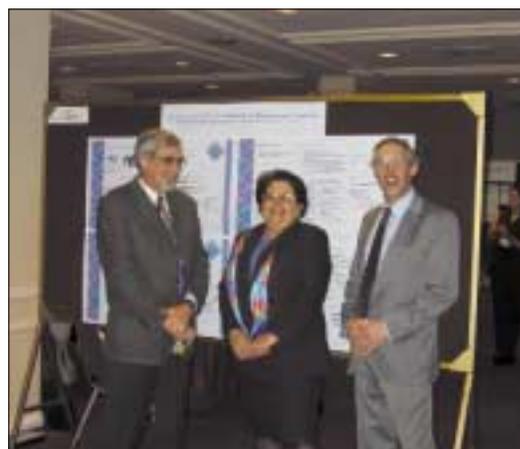
Ms. Acosta thanked Ms. Gass and the FASD Center for Excellence team for planning a successful and energizing meeting. Ms. Gass then summarized the Center's next steps:

- Preparing the conference proceedings
- Posting the conference materials on the Center's Web site
- Building a listserv
- recommendations to build into the Center's plans
- Developing an FASD curriculum for certified alcohol counselors

Ms. Gass thanked the attendees for their enthusiastic participation in the meeting and for their continued dedication to addressing FASD across the country.



**Exhibit of an FASD Prevention Program**



**Ed Riley, Callie Gass, and Chuck Lupton at the SAMHSA FASD Center for Excellence Display**

