Building FASD State Systems Proceedings

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U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
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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 second "Building FASD State Systems" (BFSS) meeting in Kissimmee, Florida, May 5-6, 2004. The meeting was an update to the first-ever BFSS meeting, held in 2003. The BFSS meetings are designed to facilitate the creation and enhancement of comprehensive systems of care for FASD. The BFSS meeting is part of the FASD Center's response to its legislative mandate to provide technical assistance to communities developing systems of care.

Wednesday, May 5

Welcome and Introduction

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

Dr. Stone welcomed the attendees, who came from all 50 States, the District of Columbia, Puerto Rico, and several Federal agencies. She also thanked the members of the Planning Committee. For attendees new to BFSS, Dr. Stone provided a brief overview of FASD-related efforts being conducted by SAMHSA, the National Institute on Alcohol Abuse and Alcoholism (NIAAA), and the Centers for Disease Control and Prevention (CDC):

- SAMHSA's FASD Center for Excellence and Partnership to Prevent FASD
- CDC's Project CHOICES, Project BALANCE, and National Task Force on Fetal Alcohol Syndrome (FAS)/Fetal Alcohol Effect
- NIAAA's 100+ research projects and Interagency Coordinating on FAS

Dr. Stone reported that the first BFSS meeting received highly favorable evaluations. Since then, the number of FASD-related efforts has increased. Dr. Stone anticipates additional opportunities for networking and the development of State action plans during the upcoming year.

Ken DeCerchio, MSW Director, Substance Abuse Programs, Florida Office of Drug Control

Mr. DeCerchio welcomed attendees to Florida on behalf of Governor and Mrs. Jeb Bush and Jim McDonough, Director of the Florida Office of Drug Control. He recognized Florida's participants and thanked them for their efforts in the area of FASD prevention and treatment.

Mr. DeCerchio briefly described Florida's FASD-related activities. The Interagency Action Workgroup for FASD in Florida has made tremendous progress over the past 4 years and received a Davis Productivity Award for its services to children and families. Last year the workgroup sponsored a women's conference dedicated to FASD. He thanked the Family Resource Center of Washington State, SAMHSA, the FASD Center for Excellence, and others for their contributions to that conference's success.

In closing, Mr. DeCerchio noted that, despite significant gains, much work remains. He said that Florida looks forward to additional collaborative efforts.

Keynote Speaker

First Lady Hope Taft, Ohio

Mrs. Taft explained that her commitment to substance abuse prevention dates back to 1986, when she was asked to help address the problem of crack cocaine use in Ohio. Her involvement in that initiative opened her eyes to the devastating effect of substance abuse on children and families. She cofounded several anti-drug organizations, including
Ohio Parents for Drug Free Youth and Ohio Alcohol and Drug Policy Alliance. She serves as spokesperson for Ohio's Family and Children First Initiative and serves as co-chair of Leadership to Keep Children Alcohol Free.

Through her many activities, Mrs. Taft learned that substance abuse affects children in many ways, ranging from sudden infant death syndrome to FASD. FASD—which is entirely preventable—affects more children than spina bifida, Down syndrome, and muscular dystrophy combined. Mrs. Taft noted the high cost of services for children with FASD. Lifetime costs for one child are estimated at nearly $3 million. Most of that price tag is borne by taxpayers.

As a parent, Mrs. Taft recognized the tremendous need for support for parents and caregivers of children with FASD. Eighty percent of children with FASD have behavior problems, poor coordination, attention deficit disorder, or other problems that can follow them over their lifetime. Studies also show that children whose mothers drank during pregnancy are at increased risk of abusing alcohol themselves.

Mrs. Taft recognized that more strategies are needed to help affected children and adults, families, educators, and employers. In September 2004, Ohio will hold a town hall meeting to identify FASD-related needs. Goals include increasing the understanding of FASD, learning from effective practices used in other areas, and encouraging new State efforts. Mrs. Taft called for an additional focus on substance abuse prevention and increased emphasis on screening mothers at high risk of having children with FASD as well as children who may have FASD.

Mrs. Taft thanked the attendees for their efforts and for inviting her to participate. She closed by sharing the most important message to promote: For pregnant women, there is no safe amount of alcohol to consume and no safe time to drink.

SAMHSA FASD Center for Excellence: Accomplishments Since May 2003 and Future Directions

Callie Gass, Project Director, SAMHSA FASD Center for Excellence
Ms. Gass gave an overview of the FASD Center's accomplishments during the past year and resources that the Center makes available to States and communities. She noted that the Center's strategic plan calls for it to build comprehensive systems and advance the field. She acknowledged the FAS Family Resource Institute and NOFAS for their contributions in building a foundation for the Center's work and helping it to get started.

The Center's accomplishments include:

- Conducting the first-ever BFSS meeting in May 2003, which was attended by approximately 200 people from 49 States, the District of Columbia, and Puerto Rico.
- Working directly with Ohio, Mississippi, Texas, and the District of Columbia to develop State plans.
- Convening town hall meetings throughout the country for about 800 attendees and 500 testifiers. More than 100 agencies were involved in VIP panels.
- Conducting 58 trainings for approximately 3,200 people in 15 States, the District of Columbia, Canada, and Japan.
- Conducting a field trainer orientation for 30 participants in Reno, Nevada.
- Launching the FASD Web site in mid-February, which now features unique items such as Tip of the Day, Grab and Go (a source of downloadable informational materials), and a resource database with more than 3,000 FASD-specific items.
- Convening the first-ever Hope for Women in Recovery summit in September 2003, attended by more than 90 women from treatment centers and their counselors.

The Center's resources include:

- A viewing library in Rockville, Maryland, which gives visitors access to materials cataloged in the Resource Database, a work area, computer, and scanner.
- Presentations to interested groups, such as the Substance Abuse Librarians and Information Specialists.
- Journal articles, such as "The cost of fetal alcohol spectrum disorders," published by the American Journal of Medical Genetics.

The Center's next steps include:

- Curriculum development, including FASD 101 online, downloadable FASD 101 for trainers, and a certification curriculum for Certified Addiction Counselors

- Web site enhancements, including a Spanish adaptation
- Further publishing opportunities

Ms. Gass responded to several questions regarding Center activities and information presented by the Center. She noted that the Center would research the cost of raising a child without disabilities to compare to the costs of raising children with FASD. She also responded to an inquiry regarding feedback from the town hall meetings and noted that information from these events would be used in preparing a report to Congress in the Center's fifth year.

In response to an inquiry about efforts in Native American communities, Ms. Gass noted that the Center's targeted outreach and training efforts would be expanded and that an executive summary of a report on FASD in Indian Country is available on the Center's Web site. In addition, a new program administered by the Center will offer small, grantlike subcontracts to approximately 10 States, five judicial systems, and 20 community organizations. Attendees were advised to watch the Web site and their listserv for RFP announcements. The first RFPs were expected in about 60 days.

Evolving Consensus: An Update on Screening and Diagnosis of FASD

Moderator: Julie Gelo, Parent/Family Advocate/Trainer/Consultant, University of Washington FAS Diagnostic and Prevention Network, FASD Family and Community Support Network Member, SAMHSA FASD Center for Excellence Steering Committee Member

CDC/National Task Force on FAS/FAE Diagnostic Criteria

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

Dr. Floyd opened by saying that we are now prepared to address FAS in a united, synergistic way. In 2002, Congress directed CDC to develop guidelines for the diagnosis of FAS and other negative birth outcomes that result from prenatal alcohol exposure. These guidelines are to be included in medical and allied health curricula around the country and recognized by professional organizations on their accrediting board exams. CDC also was tasked with disseminating curricula, training providers, and coordinating efforts with the National Task Force on FAS/FAE and other federally funded programs.

To develop the FAS guidelines, CDC convened a workgroup that includes internal and external experts in the field, parents, and clinical researchers. The National Task Force served as a partner in this effort. For the past 2 years, the workgroup has strived to establish diagnostic criteria that:

- Enhance the ability of allied health professionals and communities to identify children with FASD or to direct them to a facility that can make a diagnosis

- Feature broad cut points to ensure that individuals potentially affected are properly diagnosed
- Work in harmony with existing criteria that are useful, correct, and appropriate

The guidelines address four components for diagnosing FAS:

1. Facial characteristics
2. Growth abnormality
3. Central nervous system (CNS) abnormality
4. Maternal alcohol exposure

Dr. Floyd reviewed thresholds established for each component. The workgroup found it most difficult to agree on the criteria for CNS abnormality, although they agreed that this abnormality could be met in three domains: structural, functional, and neurologic. Dr. Floyd reported that consensus on the CNS criteria was expected by May 13.

The guidelines also provide guidance to help allied health professionals determine when a child should be referred for assessment or monitoring. The determining factors include confirmation of alcohol exposure, parental concerns, presence of one or more facial features, growth abnormalities, evidence of a CNS deficit, or a combination of these factors.

Next steps include:

- Signoff on the guidelines by National Task Force
- CDC clearance of the report presenting the guidelines
- Completion of the report by the end of July 2004

4-Digit Code: Its Impact on Washington State's Screening, Diagnosis, and Surveillance of FAS

Susan Astley, PhD, Director, University of Washington, FAS Diagnostic and Prevention Network (FASDPN), Center on Human Development and Disability

Dr. Astley explained that to implement and assess FAS prevention efforts, a State must be able to accurately and efficiently screen, diagnosis, and intervene with high-risk populations. To achieve those objectives, Washington State has:

- Collected PRAMS data, which include questions on prenatal exposure
- Established the FASDPN
- Developed facial photographic software, available on the Internet
- Developed the 4-digit diagnostic code
- Established a foster care FAS screening program

The 4-digit diagnostic code assesses four indicators of FAS: growth deficiency, facial features, brain damage, and fetal alcohol exposure. Each indicator is ranked on a 4-point scale. The resulting 4-digit code ranges from 1111 to 4444, with 256 possible combinations. The code can be used to diagnose individuals of all ages and has proven very accurate.
Two pieces of evidence indicate that the State has experienced success in preventing FAS:

- PRAMS data show a significant decline in maternal drinking during pregnancy between 1993 and 1998.
- There was a significant reduction in the prevalence of FAS in each successive birth cohort examined between 1993 and 1998, as part of the foster care-screening program.

Diagnosis Within the Collaborative Initiative on Fetal Alcohol Spectrum Disorders

Ed Riley, PhD, Director, Center on Behavioral Teratology, San Diego State University; Co-Chair, FASD Center for Excellence Steering Committee

The Collaborative Initiative on Fetal Alcohol Spectrum Disorders (CIFASD) is a cross-cultural assessment of FASD that coordinates basic, behavioral, and clinical investigators in a multidisciplinary research project. The goals of the project are to develop effective interventions, strategies, and treatments for FASD.

To determine how to diagnose FASD reliably and identify children with FASD, CIFASD uses data from international studies and studies in the United States. Dr. Riley pointed out that international samples provide resources that otherwise would not be available. For example, data are available from countries with high prevalence rates, such as South Africa, and different drinking patterns.

Kenneth Jones, Luther Robinson, and Eugene Hoyme use a standardized assessment tool. A dysmorphology core physical examination form is used to collect data, which are entered into an Access database. The form and the data can be accessed online.

The consortium is trying to determine the best diagnostic methods, including the best way to screen nondysmorphic children prenatally exposed to alcohol. Two CIFASD collaborators, Elizabeth Moore and Richard Ward, wrote an article comparing data from children with FAS and those with partial FAS. The data were based on 21 measures. Although the scores of children with partial FAS were not as low of those with FAS, measurements from the two groups exhibited similar patterns. The researchers concluded that other characteristics of FAS might be as reliable as the standard three measures.

CIFASD also has engaged professionals to use three-dimensional photographs and computerized facial recognition software to determine the facial algorithm that indicates FAS. Dr. Riley reported that this technology is very good and is expected to improve. The consortium also is testing disparate groups to determine characteristics that can be attributed to alcohol exposure. Differences among the groups will be factors that are modifiable or caused by environment. Risk factors also are being assessed, with the hope that some can be modified.

Screening for Fetal Alcohol Syndrome in Community Settings

Larry Burd, PhD, Director, North Dakota FAS Center, University of North Dakota; FASD Center for Excellence Steering Committee Member

Dr. Burd presented reasons for screening for FAS:

- To determine prevalence
- To identify children early so that they can be linked to services
- To help with prevention
- To reduce mortality

Dr. Burd stressed that FAS screening is a science and that it is important to use tools that have been evaluated. However, a screening tool is not a diagnostic tool, and screening is not 100 percent accurate.

Screening separates the few who are at high risk from the many who are at low risk. Without screening, the cost of identifying FAS increases greatly. In addition to being less costly than diagnosis, screening should be reasonably accurate and linked to a diagnostic clinic so that those at high risk can be diagnosed and referred to appropriate services.

The North Dakota FAS Center (NDFASC) has successfully screened children in many settings, including the foster care system, specialty clinics, and the juvenile justice system. NDFASC has found schools to be one of the best systems for screening. It also has found it ineffective to screen children under the age of 2.

Some populations warrant careful screening, including:

- Children whose parents are in alcohol treatment
- Children with a mother in jail
- Children who are adopted or in the foster care system
- Children with behavior disorders
- Children enrolled in special education
- Children with birth defects

The goal (e.g., to determine prevalence or to identify cases) influences the choice of populations to screen.

When screening, it is important consider how positive assessments will be handled. It also is important to have a consent process in place. Parental permission to screen is very helpful when a parent must be approached regarding a positive screen.

Questions and Answers

An attendee asked if the tools discussed by panel members are effective for screening adults. Dr. Astley responded that the FASDPN has not attempted to screen adults. Caution should be used in interpreting an adult face until we know whether the FAS face changes with age. In addition, it is often difficult to get an accurate prenatal history for adults or obtain childhood photographs. Dr. Riley mentioned a study in Finland that might help identify facial characteristics that do not change with age. Dr. Burd added that in his experience adults do not fit into the growth parameter cutoffs used in childhood, and many do not have distinct facial features.

The same attendee asked about progress in testing meconium to confirm alcohol exposure in utero. Dr. Floyd responded that these studies are not definitive but show promise. Privacy issues complicate these studies. Dr. Burd added that results from a study testing the meconium plug and hair would be available in the next few years.

Another attendee asked about efforts to get universal recognition of the FAS diagnosis. Dr. Floyd replied that CDC had been charged with developing and disseminating the diagnostic criteria. She also reminded attendees that FASD is not a diagnosis, but gaining widespread recognition of FAS is an important step in getting FASD recognized.

Evolving Consensus: An Update on Screening and Diagnosis of FASD

Moderator: Karla Damus, RN, MSPH, PhD, Senior Research Associate, National March of Dimes; FASD Center for Excellence Steering Committee Member

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.

The System of Care Approach to Service Delivery for Children and Their Families

Lodi Lipien, MSPH, Assistant in Research, Department of Child and Family Studies, University of South Florida

Ms. Lipien began by defining FASD and explaining its prevalence. She reported that estimates of FASD prevalence are 10 per 1,000 live births, or about 40,000 infants per year. She reviewed signs of FASD and its long-term consequences (see box).

Signs of FASD

- Cognitive deficits
- Multiple organ dysfunction
- Growth retardation
- CNS damage, which can result in lower IQ
- Head and facial abnormalities
- Behavior and mental health problems, such as attention disorders, depression, suicide threats or attempts, and panic attacks

Long-Term Consequences of FASD

- Problems at school
- Alcohol and drug problems
- Trouble with the law
- Confinement

Ms. Lipien noted that individuals with FASD often are not identified as having an organically based mental health or cognitive disorder. This prevents them from qualifying for services and interventions that could improve their long-term outcomes. Although interventions for children with FAS have not been fully developed, services recommended as beneficial include:

- Medications
- Behavior therapy
- Educational placement in proper settings
- Speech and language services
- Occupational therapy
- Direct advocacy
- Parent education and support
- Social services
- Vocational services

The systems of care approach, originally designed for treating children with serious emotional disturbance, is an effective way to provide services to children with FASD. With this approach, various systems work together in a coordinated network. Traditional systems have been criticized for their lack of organization, communication, accountability, and individual adaptation. A system of care:

- Focuses on the needs of the child and the family
- Treats families as full partners
- Involves collaboration and communication among agencies
- Promotes culturally responsive support and services
- Promotes ongoing evaluation and accountability

Over the past decade, various systems of care demonstration projects have increased:

- Funding
- Development of individualized and culturally competent services
- Family involvement in treatment
- Agency focus on practice-level changes and workforce development
- Stakeholders' recognition of the complexity and difficulty of implementing a system of care approach

Future needs include improving service provision and practice, bringing increased attention to developing theories of change, and implementing evaluation and quality control procedures. The desired outcome is to support the development of children who live with their families, participate in family, school, and community activities, and ultimately become adults with a high quality of life.

Are There Legal Barriers at the Federal Level?

Rutledge Hutson, JD, MPH, Deputy Director, Child Welfare and Mental Health Division, Children's Defense Fund

The Children's Defense Fund focuses on giving all children a safe, healthy start in life. It is particularly concerned about vulnerable children who face physical, mental, emotional, and economic challenges. The goal is to engage these children in systems of care that provide needed services, involve the family in the planning process, use family strengths, and create a sense of partnership.

Many challenges arise when creating and implementing a comprehensive system of care. These include legal challenges, information system challenges, concerns raised by performance indicators, and a range of managerial and administrative issues. Ms. Hutson focused on legal concerns, which include:

- Ways funds can be used
- Ways funds can be combined
- Eligibility for services and supports
- Cost allocation

Attendees were referred to a paper provided in the meeting notebook titled Providing Comprehensive Integrated Social Services to Vulnerable Children and Families: Are There Legal Barriers at the Federal Level to Moving Forward? Ms. Hutson noted that this paper presents an analysis of funding streams. Some funding streams are very restrictive but most are flexible.

Concerning the issue of eligibility, some programs have prescriptive requirements, some have broad parameters, and others are flexible. For example, some programs allow the State to set requirements. In terms of funding allocations, more problems arise from a practical standpoint than a legal one.

Confidentiality is a legal consideration. Ms. Hutson focused on Federal regulations. She pointed out that although there are exceptions (e.g., information on child abuse) and provisions for court-ordered permission, some information must be kept confidential. She stressed that the key is obtaining consent. Ms. Hutson said that families are usually receptive to signing a consent form if they are approached as partners.

Ms. Hutson summarized by saying that few legal barriers exist at the Federal level but many other challenges exist, which can be addressed. She closed with this example. El Paso County, Colorado, a very conservative area, adopted as its mission eliminating poverty and family violence. It became obvious that families facing those challenges have trouble navigating the system, so the agencies involved convened joint teams. Working from this standpoint helped them make the philosophical shift needed to overcome legal barriers, set aside "turf" issues, set up the comprehensive set of services needed to help families, and achieve their common goal.

New Jersey's Statewide Screening and Diagnostic Program

Susan Adubato, PhD, Coordinator, Northern New Jersey FAS Diagnostic Center, University of Medicine and Dentistry of New Jersey/New Jersey Medical School Department of Pediatrics

Dr. Adubato presented a historic overview of activities in New Jersey, beginning in 1983 with the establishment of the Governor's Council on the Prevention of Mental Retardation and Developmental Disabilities through the formation of a statewide FAS Task Force in 1998. The mission of the Task Force is to prevent FAS and promote effective, lifelong interventions for individuals and families affected by FASD.

In 2001, the New Jersey Task Force submitted a report on the status of prevention, diagnosis, and treatment of FAS to Acting Governor Donald DiFrancesco. After receiving this report, the Governor appropriated $450,000 to initiate FAS diagnostic centers in the State.

The Task Force report determined that New Jersey needed comprehensive FASD prevention, diagnosis, and services integrated into existing systems. The made recommendations in six areas:

- Prevention and outreach
- Community education
- Professional education

- Risk reduction
- Diagnosis and treatment
- Surveillance and evaluation

Dr. Adubato highlighted achievements in each area, including:

- FASD education is included in New Jersey core curriculum standards.
- Foster parent organizations and individual foster parents participate in the FAS Task Force.
- The New Jersey Medical school is a CDC-funded regional FAS training center.
- Perinatal addictions certification developed in 2003 will be implemented in the summer of 2004.
- All six Maternal and Child Health Consortia in the State have at least one perinatal addictions specialist.
- New Jersey has "real time" reporting of all cases diagnosed at the diagnostic centers.
- The New Jersey Medical School designed and implemented an FASD surveillance system to improve data collection.

Dr. Adubato summarized by noting considerable progress in prevention and outreach. Treatment services are "a work in progress." Concerns include increasing the number of hours that the FAS diagnostic centers operate and increasing research efforts.

Developing State Goals and Objectives

State teams met to discuss goals and objectives for developing a State system. Afterward, each State was asked to choose one 5-year goal to put on newsprint and post in the meeting room. States were also told that they would use the forms they completed in the regional working groups that would meet in the afternoon.

Legislative Challenges

Developmental Disabilities

Moderator: Kathy Mitchell, MHS, LCADC, Program Director, National Organization on Fetal Alcohol Syndrome (NOFAS)

Representative Linda Lopez, State Representative, Minority Whip, Arizona House of Representatives

Rep. Lopez noted that the Arizona Legislature has 90 members, most of whom are extremely conservative. Working with them can be a challenge. Fortunately, Governor Janet Napolitano supports children, families, and education and called a special legislative session on reforming child protective services. Substance abuse was examined as a form of child abuse or neglect. The goal was not to punish parents but to ensure that children could receive services. Rep. Lopez noted that 17 States now include some form of substance abuse in their definition of child abuse.

Unfortunately, Arizona has not had many activities related to FASD. A primary issue is lack of funding. Between 1997 and 2002, trainers were sent to the Indian reservation to talk about the dangers of alcohol use during pregnancy, but the State does not have specific FASD programs.

Rep. Lopez said this must change. She said that after she attended the town hall meeting in Tucson in 2003, she returned to her office and talked to staff about the need to act on FASD. They began to brainstorm on ways to pay for initiatives. They knew that a tobacco tax increase was being used to support certain health programs and began to talk about increasing the alcohol tax. Stakeholders are now being assembled to discuss the broad impact of FASD and the amount of funding needed for a comprehensive plan to address FASD.

The alcohol tax will be placed on the ballot in 2006. Meanwhile, advocates must educate legislators and other interested parties. It also is critical to develop a good strategic plan since there is a strong alcohol lobby in Arizona. If the bill does not pass, it will be 7 to 10 years before it can be placed on the ballot again.

Representative Ken Svedjan, State Representative, North Dakota House of Representatives

Rep. Svedjan shared that before Dr. Burd got him involved with the North Dakota FAS Task Force, he knew nothing about FAS. He had no experience with FAS among family or acquaintances. He could not even remember a client with FAS from when he worked in the mental health field.

The statistics had a significant effect on him. He learned that FAS affects people from every walk of life, that it is the leading known cause of mental retardation, and that the cost of providing services to an individual with FAS over a lifetime is staggering. He was particularly troubled to learn that FAS is totally preventable.

With the help of Dr. Burd and colleagues, Rep. Svedjan developed legislation that called for funding for FAS prevention and assessment. At the time, the total State budget was $4.8 billion; he asked for $750,000. He felt it was a small amount to ask since caring for people with FASD was costing the State an estimated $3 million per year. This essentially gave the State startup funds, publicized the issue, and opened the door for pursuing Federal funding.

Because this small sum was being pursued for a totally preventable problem with high economic and human costs, he did not anticipate how hard it would be to pass the legislation. Rep. Svedjan described the struggle and surprises that ensued along the way. Support was gained and lost, as several motions

to reconsider were required and the legislation was sent back to committees for review. Eventually, it passed the Senate 44 to 40.

Rep. Svedjan said that he learned a lot from this experience. "First," he said, "never give up hope. Second, assume nothing." He also gave the following tips:

- Try to identify a legislative champion.
- Know your statistics.
- Build your case, but keep it simple.
- Build coalitions.
- Rally your supporters. Get them to the hearing. If they can't attend, get their testimony in writing.
- Talk to members of the Ways and Means (Appropriations) Committee. Ideally, reach the legislator. If not, get access to his or her staff.
- When you approach legislators, remember that they tend to deal with the here and now. But don't be afraid to build a case for prevention. Push the cost-savings issue.

In closing, Rep. Svedjan noted that we are entering a different era with more emphasis on prevention. For that reason, he urged attendees to go for it, succeed, and then celebrate.

Questions and Comments

Rep. Lopez added that she recommends communicating with legislators one-on-one, if possible. She said to avoid using e-mail because legislators receive so many messages. Rep. Svedjan agreed and said to also be careful about how correspondence is packaged. Letters should not be difficult to open or include too many inserts.

An attendee noted that he had been told not to submit bills that involve money. He asked for advice on how to get funds for needed services. Rep. Lopez said in that in Arizona, referendums for a tax increase are being used, so the people make the choice. Rep. Svedjan said North Dakota has not had increased sales or income taxes but has still been able to fund a growth in services. He encouraged attendees to submit bills even during tight economic times, noting that in many States, all bills must be heard. However, he stressed the importance of effectively making a case, preferably by showing the cost advantages.

Building a State System: Reports from Last Year's Participants

Four States were invited to talk about what they learned at the 2003 BFSS meeting and how they have used that information to move forward with building a State system.

Moderator: Diane Casto, Manager, Prevention and Early Intervention Services, State of Alaska, Division of Behavioral Health, FASD Center for Excellence Steering Committee Member

Texas: Carolyn Smith, LMSW-ACP, Executive Director, Texas Office for Prevention of Developmental Disabilities, BFSS Planning Committee Member

The Texas Office for Prevention of Developmental Disabilities has a combined budget of $225,000 and two full-time employees to address FASD and spinal cord injuries. Ms. Smith said that when she joined the office, she made hundreds of telephone calls to get information about these conditions and to find out what was being done at the national level.

Since Texas did not have a strategic plan, Ms. Smith determined that system components should include:

- Substance abuse treatment
- Awareness of FASD for women at risk and the general public
- Professional education (screening, diagnosis, assessment, and intervention services)
- Data
- Contributions to the knowledge base

Promoting awareness among the general public is the first component being addressed. A slide presentation was developed and 11 presentations were given in Central Texas. Four professional teams traveled to the University of Washington for diagnostic training; a fifth team will go in September. Twenty-five intervention and prevention networks are being trained to provide services to families affected by FASD. Texas also has an FAS consortium that meets quarterly. Obstacles include a lack of human and financial resources, a lack of consensus, a large population, and a high birth rate. However, Ms. Smith said she felt energized and up to the challenge.

Ohio: David Shore, MD, Chief of the Family and Community Health Division, Ohio Department of Health

Dr. Shore reported that Ohio benefited from the energy and ideas that Carolyn Givens brought back from the 2003 BFSS meeting. As a result of attending that meeting, she recognized the importance of talking about FASD within her agency and with Ohio's first lady. Consequently, a multiagency workgroup was convened to develop State goals and objectives. The workgroup hopes to hold a regional meeting similar to this one. A town hall meeting is planned for September 2004.

Ohio received a CSAP State incentive grant to develop a prevention framework and to produce and disseminate information on evidence-based practices that work in the field. A Children's Cabinet was formed that meets monthly and produces a monthly report on FAS efforts in the State. Efforts are being made to get a State policy change so that resources can be obtained for children with severe behavior disorders and their families. State objectives include promoting early detection and intervention and developing community-based resources.

Other activities include:

- Targeted training of case workers and foster and adoptive parents
- A survey of training received by medical students
- Investigation of funding for clinicians to provide FASD education to other professionals
- Update of the "Care and Comfort Guide" to make it more relevant to current issues, including FASD
- Ongoing data collection and dissemination of information
- Examination of methods to identify women at high risk of having children with FASD
- Synthesis of information and strategies from other sources, such as CDC, SAMHSA, and current research studies

Mississippi: Brenda Scafidi, EdD, Director, Division of Children and Youth Services, Mississippi Department of Mental Health, FASD State Coordinator

Dr. Scafidi reported that progress in Mississippi began when the State hosted a town hall meeting in 2003. Mississippi was selected as the site for this meeting because it had the Nation's highest rate of teenage pregnancy.

Dr. Scafidi explained the linkages between the State Department of Mental Health, Division of Alcohol and Drugs, Department of Mental Retardation, and Developmental Disabilities Council. She also summarized State FASD activities, including:

- Trainings by Dan Dubovsky of the FASD Center for Excellence
- Development of a State Task Force on FASD
- Efforts to coordinate with other task forces around the State that address children's needs
- A symposium to facilitate collaboration and involve legislators
- Assessment of approaches and identification of specialized approaches
- Two-day work session attended by experts such as Faye Calhoun of NIAAA and Dan Dubovsky

Dr. Scafidi reported that she had developed a guide that explains how to determine goals and objectives, identify resources, develop a workplan and timetable, and define accountability. A handout on principles explored in the guide and other materials describing Mississippi's FASD programs were made available to attendees.

South Dakota: Gib Sudbeck, Division Director, Division of Alcohol and Drug Abuse

Mr. Sudbeck gave an overview of the evolution of services in South Dakota and a history of State legislation that protects children from prenatal alcohol exposure. He also summarized North Dakota's activities and accomplishments over the past year:

- More than 100 individuals provided testimony at an FASD town hall meeting in Rapid City.
- The Center for Disabilities, University of South Dakota School of Medicine and Health Sciences (USDSMHS), opened an FASD Clinic.

- With funding from the March of Dimes, USDSMHS developed public service announcements on FAS prevention.
- In October 2003, the University of North Dakota, along with the Departments of Health in North and South Dakota and USDSMHS, received funding from CDC for the Dakotas FAS Prevention Project.
- The Center for Disabilities/USDSMHS became an affiliate chapter of NOFAS.
- Through a contract with the Aberdeen Area Indian Health Service (IHS), the Center for Disabilities/USDSMHS began providing maternal screening at IHS sites throughout South Dakota.

Ongoing and future activities include:

- Educational resources through the Fetal Alcohol Syndrome Handbook and the FASD Institute newsletter and Web site
- The Center for Disabilities/USDSMHS annual FASD symposium
- Inservice and preservice activities regarding FASD prevention and identification

Working Group Sessions

Earlier in the day, attendees met by State to develop 5-year goals and objectives for developing a State system to address FASD within their State and to identify possible barriers and strategies for success. During this session, attendees met in regional working groups to compare their findings, identify common goals and objectives, share strategies, and look for opportunities to network and work collaboratively. Each working group was asked to designate a reporter to present findings to the full group.

May 6, 2004

Reports from Working Groups

States were asked to take the forms they had completed during brief State meetings to working group sessions convened by region. The forms captured:

- Each State's 5-year goal for building a State system to address FASD
- Key tasks involved in accomplishing that goal
- Major barriers to achieving that goal
- Strategies for overcoming those barriers

During the regional working groups, the States identified common goals, barriers, and opportunities or strategies for overcoming those barriers. Each group was asked to appoint a reporter who would share the group's outcomes with the other attendees.

Northeast Region I

Connecticut
Delaware
Maryland
Massachusetts New Jersey
Reporter: Connie Carol, Massachusetts

Common Goals

- Develop a State plan that includes prevention, surveillance, diagnosis, and services.
- Include on a task force individuals with FASD and family members.

Barriers

- Funding at all levels
- Fragmentation within and between systems
- Politics within organizations and governments
- Limited communication among programs
- Border issues (working with families who live in one State but receive services in another)

Strategies

- Increase education.
- Learn from other States.
- Participate in trainings (with New Jersey).
- Develop a regional network and hold regular meetings or conference calls.

Northeast Region II and Washington State

Maine
New Hampshire
New York
Pennsylvania
Rhode Island
Vermont
Washington State

Reporter: Julie Gelo

Common Goals

- Increase acknowledgment and awareness of FASD.
- Increase communication and education.
- Build an FASD task force.
- Establish legislative advocacy.

Barriers

- Funding
- Difficulty pulling together stakeholders
- Difficulty getting messages to providers
- Geographic issues (e.g., distance some people must travel for resources and treatment)

Strategies

- Address stigma of addiction and FASD.
- Collect State data to use in seeking funding.
- Let people self-select; involve people who want to be involved.
- Increase public and professional education.
- Work regionally with other States.
- Partner with stakeholders to get messages to providers.
- Work cooperatively and collaboratively with communities, parents, and others.

Southeast Region

Alabama
Florida
Georgia
Kentucky
Mississippi
North Carolina

Reporter: Kathryn Shea, Florida

Common Goals

This group found that they were in very different stages of long- and short-term planning. Some were gathering data; others were involved in developing a comprehensive State system. All agreed on the importance of:

- Assessing resources
- Calculating level of risk
- Determining needs

Barriers

- Funding
- Lack of a State FASD coordinator who can move efforts forward
- Lack of direction at State level for task force

Strategies

- Use parent groups and bring parents to the table.
- Piggyback on existing efforts, such as the folic acid campaign.
- Place posters in OB-GYN and other physician offices.
- Examine available resources and look for internal partnering opportunities.

Southeast Region II

Puerto Rico
South Carolina
Tennessee
Virginia
Washington, DC

Reporter: Dusty Williams, Tennessee

Common Goals

- Conduct basic research that can be taken to State legislators for grant purposes.
- Educate professionals.
- Conduct awareness programs.
- Work with other groups, such as Healthy Start.
- Get on national agendas and work with the Association of State and Territorial Health Officials.
- Identify a champion in the legislature.
- Target significant others.

Barriers

- Lack of communication within and between agencies
- Competing interests
- Conflicts of interest (e.g., some States have a strong alcohol lobby)
- Lack of funding
- Lack of knowledge about addiction
- Lack of data (affects ability to get planning grants)
- Lack of advocacy

Strategies

- Replicate successes.
- Partner with professional organizations, such as the American College of Obstetricians and Gynecologists.
- Provide information to medical and nursing programs.
- Use listservs to disseminate information.
- Focus on primary and secondary prevention.
- Emphasize early prevention in Head Start, daycare, and schools.

Central Region I

Illinois
Indiana
Iowa
Michigan
Ohio
Reporter: Cindy Schroder, Iowa

Common Goals

- Work with current data and determine research base.
- Share ideas and strategies.
- Increase training.
- Improve communication within and across States and regions.
- Work with a wide variety of service providers.

Barriers

- Funding
- Lack of other resources, such as staff
- Clinician reluctance to screen (tied to stigma)
- Lack of knowledge and training across all professions, including educators
- Difficulty finding champions
- Competing priorities

Strategies

- Identify and support champions.
- Advocate for additional legislative funding.
- Explore creative ways to obtain more funding.

Central Region II

Minnesota
North Dakota
South Dakota
West Virginia
Wisconsin

Reporter: Georgiana Wilton, Wisconsin

Common Goals

- Develop or enhance diagnostic assessment and screening services to ensure identification and referral.
- Reduce drinking during pregnancy.
- Develop a multidisciplinary system to address diagnosis and screening and reduced alcohol use during pregnancy.

Barriers

- Lack of funding
- Inflexible funding allocations
- Lack of buy-in from stakeholders
- Strong alcohol lobby
- Stereotypes (misconceptions about who is at risk)
- Lack of statewide data

Strategies

- Formalize support and get buy-in from the top.
- Use skills learned at the BFSS conference to approach legislators.
- Increase efforts toward general public awareness and targeted public awareness.
- Share information through the FASD Center for Excellence.
- Develop nonthreatening messages that provide consistent, accurate information.

Western Region I

Alaska
Arizona
California
Hawaii
Idaho
United Kingdom

Reporter: Linda Lopez, Arizona

Common Goals

This group discovered that it had diverse needs and issues. There were wide variations in terms of their programs and the resources available, which resulted in wide variations in their goals. Alaska's goal is to maintain what it has accomplished with a budget of $2.5 million a year. Idaho is trying to determine how to initiate efforts.

Barriers

- Geographic barriers that affect travel and communication
- Funding
- Awareness
- Reluctance of tribal leaders to address FASD because they do not want it identified as a Native American issue

Strategies

- Use the Internet.
- Use education and information to overcome misconceptions about prevalence.

Western Region II

Montana
Nevada
Oregon
Utah
Wyoming
Reporter: Barry Lovgren, Nevada

Common Goals

- Develop a holistic approach.
- Build a constituency and unite stakeholders.
- Access consistent, reliable, and clinical useful diagnostic criteria that can applied in an interdisciplinary manner.
- Increase capacity of community-based services.

Barriers

- Lack of funding
- Lack of knowledge about FASD due to lack of information dissemination
- Stigma associated with FASD, toward individuals with FASD and birth mothers
  - Fragmented service delivery systems
  - Lack of community-based approaches
  - Institutional resistance
  - Lack of a case management continuum

Strategies

- Educate the general public and delivery systems.
- Promote intergenerational healing to overcome stigma of addiction.
- Develop nonjudgmental cooperative relationship among all who address FASD, including addressing spirituality issues.

Southwest Region I

Arkansas
Colorado
Kansas
Louisiana

Reporter: Pamela Gillen, Colorado

Common Goals

- Gain support around prevention.
- Provide appropriate interventions.
- Address gaps in diagnostic and intervention services.
- Develop and sustain a comprehensive plan for prevention.
- Develop a comprehensive system of care.

Barriers

- Lack of an integrated system of care
- Geographic barriers
- Lack of funding for services, including substance abuse treatment

Strategies

- Continue to educate legislators and encourage them to fund projects.

Southwest Region II

Missouri
Nebraska
New Mexico
Oklahoma
Texas

Reporter: Jerome Romero, New Mexico

Common Goals

- Identify stakeholders.
- Identify funding sources.

Barriers

- Inadequate funding
- Lack of passion among legislators and among those whose agenda includes FASD

Strategies

- Identify legislative champions.
- Appoint a statewide coordinator.
- Develop strong coalitions.

FASD and Co-Occurring Disorders

Introduction: Pam Gillen, NDRN, Fetal Alcohol Syndrome and Prenatal Substance Abuse Prevention Outreach Project Director, University of Colorado Health Sciences Center; FASD Center For Excellence Steering Committee Member

Dan Dubovsky, MSW, FASD Specialist, FASD Center for Excellence

Mr. Dubovsky began by stating that it is important to integrate people from all systems into the concept of being aware of FASD and addressing it. He also noted that in his experience, the passion of many people involved in addressing FASD evolved from their efforts and desire to help loved ones. He said that his son, Bill, was his inspiration for working in the field and his most important mentor.

Mr. Dubovsky explained that people with FASD often have other disorders. Conditions that co-occur with FASD include:

- Attention deficit disorder (ADD) and attention deficit/hyperactivity disorder (ADHD)
- Substance abuse
- Schizophrenia
- Bipolar disorder
- Major depressive disorder
- Anxiety
- Separation anxiety disorder
- Reactive attachment disorder
- Posttraumatic stress disorder

Many individuals are misdiagnosed with disorders that are actually FASD. It is extremely important to recognize a co-occurring FASD when treating a person who has been diagnosed with a mental health or substance use disorder, because:

- Optimal outcomes in the treatment of co-occurring disorders occur when all are accurately diagnosed and treated simultaneously.
- Secondary disabilities (e.g., academic failure) may occur when primary conditions are not diagnosed and treated.
- Cognitive impairments in FASD, such as literal thinking, problems with follow-through, and difficulty following multiple directions, can interfere with the success of typical treatment approaches.

Because FASD is not a diagnosis, sometimes another diagnosis is used so that a person can obtain services. Another provider may then treat the designated diagnosis, rather than the FASD.

People with mental illness frequently have a co-occurring substance use disorder, and many self-medicate with alcohol and drugs. Some mental illnesses, such as major depression, bipolar disorder, ADHD, and schizophrenia, and some substance use disorders have genetic components that lead to vulnerabilities in offspring. When working with people who have mental illnesses and substance use disorders, it is important to remember that they might be at increased risk of giving birth to a child with an FASD or genetic vulnerabilities.

To correctly identify and treat all conditions that may affect an individual, a thorough diagnostic workup is needed. Mr. Dubovsky also recommended that parents ask providers whether a behavior problem could have an underlying medical cause that could be treated. For example, undiagnosed seizure disorders sometimes look like aggressive, antisocial behavior.

Failure to recognize and treat FASD can have serious results. Persons who do not receive needed services and support may experience unemployment, psychiatric hospitalization, loss of family, homelessness, incarceration, or death due to accidents, suicide, murder, or untreated physical illness. Accurate diagnosis and appropriate treatment can decrease anger and frustration, prevent people from feeling that they are bad or lazy, help them focus on their strengths, and help them to succeed.

Mr. Dubovsky closed by reminding attendees to use person-first language, such as "a person who has FAS," rather than "an FAS person." He also recounted a story that illustrates how many people in the field feel about their efforts. In the story, a man walking along a beach is tossing starfishes that had washed ashore back into the sea. When told that there are too many for one person to make a difference, he tosses another in, saying, "It made a difference to that one."

Personal Stories From Families and Individuals With FASD

Moderator: Mercedes Alejandro, The Arc of Greater Houston, FASD Center for Excellence Steering Committee Member

Betty Dotts, Parent

Ms. Dotts and her husband adopted their son John as an infant. Although he seemed to take on developmental tasks slowly, his pediatrician told the family that he would "catch up." But John continued to lag behind his peers, and he developed physical problems.

When he was 5, the Dotts took John to a university for assessment. He was diagnosed as learning disabled and placed in a special school. He did reasonably well, but by 6th grade, he wanted to go to public school. The family worked with his teachers to help them understand John's limitations, but he lacked the interest and ability to succeed. Sadly, he did not understand why he was having problems at school and kept asking his parents what he was doing wrong.

In adolescence, John developed behavior problems, such as lying. Efforts such as special tutoring failed to help, so the Dotts took him to another doctor and pointed out physical characteristics. That doctor also said that he was "o.k."

Ms. Dotts shared that dealing with John's problems as he matured caused great tension in the family. He ignored rules and began using cigarettes, alcohol, and drugs. The family continued to seek a diagnosis. A psychiatrist said that John was narcissistic; a neurologist diagnosed ADD.

When Betty Dotts read The Broken Cord, she recognized that her son had FAS. However, she could not find anyone to provide a diagnosis, because his IQ is in the normal range. The lack of a diagnosis has prevented John from receiving needing services.

John is now 44 years old. He lives in an apartment above his family's garage. Although he can use a computer, loves animals, and has a great sense of humor, John needs much direction with everyday tasks. The Dotts' greatest concern is what will happen to John when they die.

Ruth Ortega, Grandparent

Ms. Ortega is a Native American grandmother who has taken care of her grandson, John, since he was an infant. John will be 18 in July. In

addition to having FAS, John survived a terrible car accident that killed his sister and brother. As a result, John must wear diapers and his language skills are very poor. John attends school, but a lack of transportation on the reservation for individuals with disabilities makes it difficult.

Ms. Ortega hopes that by speaking out, she can educate people in her tribe about FASD and highlight the needs of individuals with FASD and their families. She stressed that these needs continue over a lifetime. She closed by saying that she likes to think of people with FAS as "special," rather than "disabled."

Rob Wybrecht, Individual With an FASD

Mr. Wybrecht, who was diagnosed with an FASD at birth, described the challenges he has faced and shared ways he has addressed those challenges. In school, Rob experienced problems with math and writing. He also found it difficult to listen and to remember things he was told. "If you tell me," he said, "I may forget. But if you show me, I will get involved." Mr. Wybrecht was greatly helped by one teacher who wrote key information on the board using different colored chalk for different subjects.

As he grew up, Mr. Wybrecht showed talent in the culinary arts and found an employer who wanted to help him succeed. This man took specialty salads off the menu so that Rob needed to prepare only two kinds. When this boss left, his replacement was not willing to make these accommodations, so Mr. Wybrecht was fired.

Because he had successfully held a job, Mr. Wybrecht could not get services for persons who cannot work. He is now a church custodian. He worked with his vocational rehabilitation counselor to develop a checklist and a map of the church that he uses to keep track of his tasks.

Mr. Wybrecht wants people to know that even though he is easily distracted, has trouble remembering verbal instructions, and struggles with multistep tasks, he is reliable, dependable, and punctual. He wants more teachers and employers to learn how to work with people with FASD. He also hopes that more people with FASD will receive an early diagnosis.

Erica Gitis-Miles, University Student with an FASD

Ms. Gitis-Miles' birth mother had alcoholism and killed her first child. Ms. Gitis-Miles was adopted when she was 7 years old. She always had problems in school. Her grades were under par, she

would forget her homework, and she often had conflicts with teachers and peers. From age 7 to age 14, her adoptive parents did not know why she was having these problems. Through reading, her mother recognized her daughter's problem and sought a diagnosis. Luckily, they were able to confirm that her birth mother drank during pregnancy.

Ms. Gitis-Miles said that she was grateful to have a diagnosis. Throughout her life, she had suffered from depression and behaviors, such as lying and arguing, that affected her relationships with others. Knowing the underlying cause was a relief, although she called coping with an FASD "a full-time job."

In 1999, she started college, and she has now completed 2 years. She explained that she has a normal IQ but tests poorly. She does o.k. on essay tests and verbal tests but cannot do multiple-choice tests. Therefore, she needs professors who are willing to work with her so that she can demonstrate her knowledge.

Ms. Gitis-Miles stressed that it is important for people with FASD to have rules and structure. Other people have trouble understanding this need. She said that she learned to explain why she appears so rigid, and she said that she is happy she has friends who accept her as she is.

Health Canada Update on FASD: Key Initiatives and Partnership Introduction

Introduction: Annie Acosta, MSW, Alternate Project Officer, FASD Center for Excellence

Nadine Huggins, Manager, First Nations and Inuit Health Branch—FAS/E, Health Canada

Ms. Huggins began by saying that Health Canada recognizes FASD as a complex, multifaceted public health, social, and economic issue that affects Canadians from all walks of life. In Canada, it is estimated that 9 out of every 1,000 children, or about 3,000 children per year, are born with FASD. Prevalence varies by community according to risk factors and drinking patterns.

The Canadian government looks to Health Canada to take a leadership role in activities related to FASD. Health Canada has the only dedicated funding from the Federal Government to address FASD; however, other departments are working on this issue. The first budget allocations were made in 1999 to build capacity and raise awareness of FASD. Additional funding has been granted through various programs in the ensuing year.

The First Nations and Inuit Health Branch (FNIHB), which deals with First Nationals on Reserve and the Inuit North of Sixty, currently receives $16.7 million per year for FASD. The Population and Public

Health Branch (PPHB), which deals with the entire population, receives about $4.3 million per year, and efforts are under way to raise that amount.

Many public agency departments in Canada understand that FASD affects their programming and activities, and these departments work in partnership with Health Canada. The Minister of State for Children and Youth serves as a champion for FASD in Canada. Areas of focus vary by department, but all departments work together to develop a plan that respects the needs of each.
Partnerships are required at the Federal level in Canada. One entity cannot execute unilateral action. Partners include:

- Provinces and territories
- National aboriginal organizations
- National Advisory Committee on FASD
- Intergovernmental FASD coalitions
- Community and national organizations
- Health and allied professionals and organizations

The vision statement and goals of the two other programming areas (PPHB and FNIHB) complement each other. Because trust between First Nations communities and the Federal Government is an issue, input at the community level was sought on the FNIHB vision and goals.

Generally, PPHB focuses on:

- Coordination and collaboration
- Screening, diagnosis, data gathering, and reporting
- Professional awareness, education, and training
- Public awareness and education
- Capacity building

FNIHB focuses on:

- Programming for populations at risk
- Early identification and diagnosis
- FASD-related education and training
- Support for parents and families of children with FASD

Because the available funding is insufficient for a universal program, it has been divided into two funds—the capacity building fund and the program pilot fund. A large percentage of the capacity building fund will be used for asset mapping, which will identify and build on strengths. This effort

will be done by and for the community. Program pilot funds will focus on mentorship and multidisciplinary teams.

Future plans will focus on:

- Reinforcing a lifespan approach to FASD
- Establishing partnerships
- ntegrating services and collaborating
- Collecting data
- Continuing to support efforts to build the evidence base, increase capacity, and strengthen public and professional awareness, knowledge, and skills.

NOFAS Affiliates: Building a Community Coalition

Introduction: Marceil Ten Eyck, LMHC, CCDCH, Psychotherapist/Counselor, FASD Center for Excellence Steering Committee Member

Adam Litle, Director, Government Affairs, NOFAS

Mr. Litle began by asking, "Why NOFAS?" He answered by explaining that NOFAS is a recognized leader in the broad national effort to address and prevent FASD, with more than 13 years of experience in the field. This fast-growing organization works with many private and public organizations. The concept is that there is strength in numbers. In the past, the FASD field has not spoken in one unified voice. To get more funding, numbers are needed, so NOFAS has created a strong network of family, agency, and advocacy contacts to raise public awareness and support families affected by FASD.

Mr. Litle explained what is meant by a coalition. He explained that one important reason for building coalitions is to spread responsibilities and avoid burnout. He said that the way to build coalitions is to reach out to the masses and to systems. It also is important to reach the media, because the media informs policymakers about their constituencies' interests.

He defined "advocacy," saying that it is essentially education. It is only lobbying when directed to legislators for policy purposes. He also announced that NOFAS contracted with CDC to develop a step-by-step advocacy guide that will be available on the NOFAS Web site in September. Mr. Litle also explained how FASD differs from other issues that compete for health funding and why it is so important for the FASD community to become more vocal and more visible.

An overview of NOFAS activities included efforts to:

- Have FASD included in the Individuals With Disabilities Education Act.
- Have FASD included in the Diagnostic and Statistical Manual of Mental Disorders.
- Have alcohol included in the Prematurity Act started by the March of Dimes.
- Identify a cosponsor for the Prevention and Comprehensive Treatment Act sponsored by Senator Tom Daschle.

Attendees also were advised that a new FASD Caucus in Congress would be formally introduced via a press conference in early June. The Caucus currently has 17 members, but more are needed.

Before closing, Mr. Litle noted that NOFAS is trying to identify additional affiliates. He spoke about the benefits of becoming a NOFAS affiliate, as well as the benefits that the affiliates bring to NOFAS. He stressed the value of collaborative funding endeavors and shared infrastructure and resources. He said that a "field day" is planned for June 23 and that attendees would receive information via e-mail.

Promising Practices for FASD Prevention and Intervention

Moderator: Deidra Roach, MD, Medical Office, National Institute on Alcohol Abuse and Alcoholism, National Institutes of Health; BFSS Planning Committee Member

Effective Intervention With High-Risk Mothers Who Abuse Alcohol and Drugs: The Parent-Child Assistance Program Model

Therese Grant, PhD, Director, Washington State Parent-Child Assistance Program

The Parent-Child Assistance Program (PCAP) works with mothers who do not have FASD but are at high risk of having children with FASD. The program's goal is to prevent future births of alcohol- and drug-exposed children. P-CAP helps women to stop using alcohol before or during pregnancy or to use family planning to avoid pregnancy.

Most of the women enrolled in the P-CAP program have had multiple treatment program failures. Many come from homes where substance abuse is an issue, and they often began abusing substances themselves at a young age. Most are polysubstance users. In Washington State, alcohol and cocaine is the most popular combination of drugs. Almost all P-CAP participants use alcohol. Most also have been physically or sexually abused, and half have a mental health diagnosis.

The program enrolls women anytime during their pregnancy. Most often this is near term, since that is when they come to the attention of the system. Although the program would prefer to reach them earlier, it is important to enroll them whenever possible.

The 3-year home visitation intervention is designed to help mothers at high risk develop a long-term, positive relationship with an advocate. Choosing appropriate advocates is important. These clients are suspicious of persons who have not "been there" and respond well to those who have. Therefore, persons selected as advocates have experienced the same types of adverse life experiences as the mothers but seldom to the same degree. The advocates also must be sober and able to serve as positive role models. Currently, the program has 25 advocates.

The advocates work with clients and their families as well as community service providers to create an integrated network of services. Advocates use motivational interviewing to acknowledge and assess each woman's situation. The program is based on harm reduction, so any positive steps are viewed as progress. Program staff realize that total abstinence with no relapses may not be achieved. They also recognize that women are in various stages of readiness to change. The advocates work with clients to establish a plan to reduce their risk and provide support.

P-CAP program outcomes for 1991 through 1995 demonstrate improved FASD prevention results. The number of clients who completed the program increased from 50 percent in the early years to 75 percent. The length of abstinence also has increased. Most clients are abstinent at exit; many are still abstinent 6 months and 1 year after completing the program. Use of birth control also has increased significantly. Between 25 and 30 percent of clients have another baby during the 3-year program; however, abstinence rates throughout pregnancy increase over time.

Dr. Grant explained that P-CAP staff work with legislation, provide outcome data, conduct cost-effectiveness studies, and arrange for successful clients to talk with legislators. The result has been sustained and growing funding for the program. Staff also volunteer for State task forces that address issues relevant to the program.

The State has helped tremendously by increasing the number of gender-specific inpatient residential beds from 55 in 1991 to 149 in 2004. The Fetal Alcohol Syndrome Diagnostic and Prevention Network also refers clients to the program.

Program staff wondered if loss of custody increased the birth rate among these women. Preliminary data indicated that when the target child lived with the mother, there was a 60 percent reduction in the risk of a subsequent birth. Since the State cannot return a child to an unsafe situation, P-CAP is working closely with child welfare to change policies so that more women can keep their children.

FASD: A Toolbox for Educators (K–5)

Rochelle Schwartz-Bloom, PhD, Professor of Pharmacology, Duke University Medical Center

FASD can be a hidden disability, and teachers are often baffled by the behavior of students with these disorders. The Toolbox for Educators was developed with educational consultant Chandra Zieff. The toolbox provides educators and support professionals with tools to help children with FASD address problem behaviors and experience greater success in school. The program, designed for elementary school educators, is currently under review by NIAAA, the project sponsor. It will be publicly available soon.

The toolbox provides a behavioral and learning profile, identifies effective teaching strategies, and includes two case studies. Specific chapters address:

- Scientific information, such as the physical, neurologic, and behavioral characteristics of FASD
- Classroom environment, including how environment affects children with FASD and environments that promote learning
- Learning issues, such as difficulties with math, writing, executive function, and information processing, and strategies to address these issues
- Behavior issues, such as being overly friendly, stubborn, hyperactive, moody, and easily confused under pressure, and strategies to help with these issues
- Case studies of a first grader and a fourth grader that illustrate the importance of getting a history of the students' problems, describe information needed by the Student Study Team, and discuss how to develop an individualized education plan
- Support staff, which provides strategies for other educational professionals who may become involved with students with FASD, such as speech and occupational therapists

Preliminary results from a workshop on the toolbox indicate that it is very useful for teachers and other support staff.

Questions and Answers

An attendee asked if the toolbox can be used with children who have not been diagnosed or have normal IQs. Dr. Schwartz-Bloom responded that the curriculum is helpful for all students who have the identified learning and behavior issues. When asked to comment on the fact that some behavioral approaches will work for some children but not others, Dr. Schwartz-Bloom noted that it is important to know the child well since the approaches in the toolbox can be presented in different ways. When asked if the techniques work in older children, Dr. Schwartz-Bloom responded that many of the approaches work through adolescence.

Motivational Behavioral Interventions To Reduce the Risk of Alcohol-Exposed Pregnancies

Mary Velasquez, PhD, Associate Professor, The University of Texas Medical School at Houston

CDC supported Project CHOICES to conduct epidemiologic surveys in three sites (Florida, Texas, and Virginia) of women ages 18 to 44 considered at high risk of having babies with FASD. These women were recruited at jails, in primary care settings, at health maintenance organizations, and through the media. "At risk" was defined as:

- Being fertile
- Having unprotected sex in the last 90 days
- Having 8 or more drinks per week, or 5 or more drinks on more than one occasion, during the last 6 months

Almost 2,700 women responded to the survey recruitment, and 333 women were found to be at risk for alcohol-exposed pregnancies. This number is 12.5 percent of the total surveyed, or a rate 6 times higher than that found in the general population. Half of these women were unemployed, and about 70 percent had incomes below $20,000. About 71 percent drank, 31 percent were binge drinkers, and 25 percent were frequent drinkers. Correlates for risk included:

- Prior or current use of drugs
- History of substance abuse treatment
- History of smoking
- Homelessness at any time
- History of mental illness
- White race
- Age over 30
- Early onset of drinking
- Lower education level

A Project CHOICES Feasibility Study, which followed the surveys, had two goals: reducing drinking, increasing use of birth control, or both. The intervention consisted of four sessions with an individual counselor who had a master's or doctorate degree, a visit to an obstetrician/gynecologist, and two followup contacts. Around 2,400 women were screened, 230 were found eligible, and 190 enrolled.

The women in the study were asked to keep careful records of when they drank, when they had sex, and when they used birth control. The project wanted to see if the women could improve contraception and avoid drinking. The women knew the project was designed as a study and not as treatment.

Motivational interviewing was the chosen approach, since it is designed to explore and resolve ambivalence about changing behaviors. The interviewing was done in a respectful and empathic way. The project anticipated that many women would be in early stages of readiness for change and would need motivation. It was beneficial for the women to know that the counselors were listening to them and understood what was important to them.

The interviewing was client-centered and emphasized personal choice. The counselors stressed that they were not trying to force change. Skilled motivational interviewing can selectively reflect "change talk," getting the women to talk about the reasons they want to change. The project found that education alone does not work. A woman needs to believe that she can make changes.

During the second session, women were provided with personalized feedback on their risk behavior. Most were surprised to learn their level of risk. Readiness for change also was discussed. All of the women attended the first two counseling sessions and about 60 percent attended the fourth one.

The project had a 75 percent followup rate. At 6 months, 68 percent of the women were not at risk and 32 percent were at risk. Specifically, 18 percent reduced drinking, 34 percent used contraceptives effectively, and 48 percent did both.

The study showed enough promise to move on to a randomized control trial (an efficacy study) with collaboration by the same sites. Recruitment for the trial has been completed and the intervention is almost complete. The project would like to add a social component (social worker) to future interventions.

Positive Behavioral Support: A New Way of Looking at FASD-Related Challenging Behaviors

Pam Shackelford, MA, Program Manager, Institute for Positive Behavioral Support

The rate of FASD in Alaska is 1.4 per 1,000 live births in the general population and 4.8 per 1,000 among Native populations. Stone Soup Group sustains the health and well-being of a wide range of Alaskan children by supporting families. Ms. Shackleford reported that this group heard a great deal about the challenging behaviors of children

with FASD. They were concerned about the loss of opportunities for children who could not overcome these behaviors.

Staff of Stone Soup learned that the best practice intervention for children with developmental disabilities was a protocol called positive behavioral support (PBS). They attended a PBS training in Oregon and became a State PBS affiliate of the University of South Florida's Rehabilitation, Research, and Training Program.

Ms. Shackleford explained that Stone Soup started out using a very academic training model and then translated information into practical strategies and processes of observation and intervention. They also discovered that a model that works well in cities and larger communities does not work in small villages. Therefore, they adapted their model to account for challenges and services of Alaskan villages.

PBS works well with a broad range of children. It is not diagnostically driven and works well with children with FASD. Interventions are based on functional assessments. The goal is not to eliminate problem behaviors but to increase self-esteem. The approach uses a team of collaborators (anyone who touches the life of the child) to support change.

At the heart of PBS is a functional behavioral assessment where one looks for the reasons for a child's behavior, triggers of problem behaviors, and results as viewed by the child. The objective is to develop a hypothesis of what is happening and understand what it is. There is a significant difference between traditional behavior management, which tries to eliminate challenging behaviors, and PBS, which looks to improve quality of life and develop a person-centered plan based on the idea behavior is a form of communication.

PBS has been empirically and socially validated. In a 1999 study, when the success criterion was to overcome 100 percent of the challenging behaviors, the success rate was 27 percent. When the goal was decreased to 90 percent of the behaviors, the success rate increased to 55 percent. When the goal was set at 80 percent, the success rate increased to 68 percent.

Stone Soup's own preliminary data show clear differences between pre- and posttests for frequency of challenging behavior, reduction of challenging behaviors, and identification and avoidance of events that trigger such behaviors. PBS builds plans that are consistent for home, school, and other settings. Success comes from avoiding triggers and improving focus. Stone Soup is planning two additional studies to corroborate the preliminary data. They will continue to develop and disseminate the PBS training.

Ms. Shackleford noted that what has been accomplished in Alaska shows promise for replication in other areas, particularly given the State's challenges, which include inclement weather and geographic isolation.

Conclusion

Callie Gass

Ms. Gass acknowledged and thanked the staff members who supported the development and implementation of the meeting. She also thanked presenters and attendees and reminded everyone to complete and submit the conference evaluation form. Ms. Gass wished everyone a safe trip home and adjourned the meeting.