

Building FASD State Systems

Summary of General and Affiliated Meetings

FASD: Reaching New Heights Together
Albuquerque, New Mexico • May 11-15, 2009

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U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
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Center for Substance Abuse Prevention
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SAMHSA
Fetal Alcohol Spectrum Disorders
Center for Excellence

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BUILDING FASD STATE SYSTEMS MEETING: BACKGROUND AND PLANNING

History

The Substance Abuse and Mental Health Services Administration (SAMHSA) Fetal Alcohol Spectrum Disorders (FASD) Center for Excellence convened its sixth Building FASD State Systems (BFSS) meeting May 12–14, 2009, in Albuquerque, New Mexico. The BFSS meetings support the Center’s legislative mandate to provide technical assistance (TA) to communities developing systems of care and are designed to support the Center’s goals of:

- Advancing the field of FASD;
- Facilitating the development of comprehensive systems of care for FASD prevention and treatment;
- Building infrastructures to ensure that FASD gets critical resources required for lasting change;
- Identifying components of a comprehensive system of care for individuals who have an FASD; and
- Incorporating evidence-based interventions and prevention practices.

The growth of the BFSS meetings reflects the development of the field of FASD.

Since the first meeting in 2003, the BFSS sessions have allowed health professionals and State officials from around the country to learn about effective FASD approaches, interventions, and new science through plenary and breakout sessions and through peer-sharing activities. Increasingly, BFSS is also providing an annual opportunity for the growing network of FASD-related organizations to share and coordinate their efforts to enhance the system of care available to those impacted by these disorders.

Attendees

A wide range of participants are invited to BFSS, with an emphasis on State and U.S. Territory government employees involved in issues related to FASD and policymaking. This year’s sessions feature representatives from 47 states (Nebraska, Rhode Island, and Tennessee were not represented), two U.S. Territories (Guam and the Virgin Islands), Washington, D.C., the Navajo Nation, and three Canadian provinces (British Columbia, Manitoba, and Ontario).

This year’s meeting included voices from across the entire spectrum of support and services to people with FASD, including representatives from primary care, the public and private sectors, criminal justice and social service workers, birth mothers and family members, advocates, counselors, educators, administrators, mental health and substance abuse treatment professionals, researchers, and scientists.

2009 BFSS Meeting Attendees at-a-Glance

207 participants from:

- 47 States and DC
- 2 U.S. Territories
- The Navajo Nation
- 3 Canadian Provinces

In addition, attendees included local, State, and juvenile court subcontractors working on FASD prevention and diagnosis and intervention programs, as well as members of the Center’s Expert Panel (EP), the National Association of FASD State Coordinators (NAFSC), the Birth Mothers Network (BMN), and the American Indian/Alaskan Native/Native Hawaiian

Expert Panel (NEP). Other agencies represented included the National Organization on Fetal Alcohol Syndrome (NOFAS), the Minnesota Organization on Fetal Alcohol Syndrome (MOFAS), the National Center for Infants, Toddlers, and Families, Prevention First, the Centers for Disease Control and Prevention (CDC), and the National Institutes of Health (NIH). The

framework of BFSS creates unique opportunities for collaboration among these organizations, which is in turn increasing opportunities to affect positive change in the FASD field.

Planning the Meeting

Each year since the first BFSS meeting in 2003, a BFSS Planning Committee has helped guide and direct the meeting agenda and activities. The Planning Committee consists of no more than 10 individuals from the field, with the Task Order Officer (TOO) and staff from the Center also participating with the committee. The Committee meets by teleconference as often as necessary—this year there were four meetings—to accomplish the needed tasks. In selecting Planning Committee members, Center staff looks for representation from:

- Diverse geographic locations;
- States at all levels of development;
- Various organizations;
- States that have received a local community and/or State subcontract;
- Non-funded states;
- A mix of cultures and ethnicities;
- The meeting’s host state; and
- Previous Planning Committee members.

For the 2009 meeting, Center staff submitted a list of proposed BFSS Planning Committee members to the TOO for approval. Once the Committee was approved, the BFSS program manager facilitated the work of the committee, scheduling teleconferences, developing the Planning Committee agendas, and forwarding input from the Expert Panel and information from previous meeting evaluations. The 2009 BFSS Planning Committee began working in November 2008. They developed the meeting theme and recommended plenary and breakout session topics and potential speakers. Many Planning Committee members also introduced speakers and served as session moderators and panelists at the meeting.

Albuquerque, New Mexico was chosen as the site for the 2009 BFSS meeting due to its central location, adequate meeting space and accommodation availability, competitive pricing, and because New Mexico has an FASD program and State Coordinator (Jerome Romero). As the theme for this year’s meeting, the Planning Committee chose *FASD: Reaching New Heights Together* to tie in the high-altitude location with the desire to both reflect on previous accomplishments and lay the groundwork for continued growth in the scope and availability of FASD services.

2009 BFSS Planning Committee

- Cynthia Beckett (Arizona)
- Susan Doctor (Nevada)
- Susan Green (Washington)
- Trisha Hinson (Mississippi)
- Sara Messelt (Minnesota)
- Melinda Norman (Ohio)
- Jerome Romero (New Mexico)
- C. Patricia Penn (Virgin Islands)
- Kathy Jo Stence (Pennsylvania)
- Enid Watson (Massachusetts)

MEETING OVERVIEW

Registration, First-Time Attendees' and FASD Overview Sessions, Poster and Exhibit Displays—Tuesday, May 12, 2009

BFSS participants were able to register for the general sessions beginning at 4:00 PM (MST) on Tuesday, May 12. Later that afternoon, interested participants attended the *BFSS First Time Attendees' Session* presented by Center Director, Callie B. Gass. Afterward, Dan Dubovsky, MSW, the Center's FASD Specialist presented a well-attended session titled *FASD Overview for Individuals New to the Field*. From 5:30 PM to 7:00 PM on May 12, the Center staged the annual Opening Poster and Exhibit Display Session, during which each of the 23 subcontracting groups and other non-subcontract participants shared posters and other materials about the FASD activities in their states. Attendees were able to network and browse the exhibits in order to learn about prevention and treatment programs and effective strategies being implemented throughout the country.

BFSS Meeting—Structure of the Sessions

The BFSS meeting began Wednesday, May 13 at 8:30 AM (MST). As in previous years, the meeting included general plenary sessions—attended by all participants—and breakout sessions, which allowed participants to select topics that suited their needs and interests. Five topic-oriented breakout sessions were conducted on Wednesday, followed by nine regional breakouts that allowed representatives from neighboring or close states to meet and discuss their activities and plans for the coming year. On Thursday, May 14, four topic-oriented breakout sessions were conducted. Brief descriptions of the plenary sessions are provided below. Listings of the breakout sessions offered on each of the two meeting days follow.

Day 1 Plenary Sessions—Wednesday, May 13, 2009

Welcome and Introduction

Patricia B. Getty, PhD, Task Order Officer, SAMHSA FASD Center for Excellence

Dr. Getty briefly welcomed participants and indicated how encouraged she is by the growth of the BFSS meetings and the expansion of the FASD field. She urged everyone to make new acquaintances and to actively network and share ideas, and stressed the importance of getting to know the key players in their states, including the local Single State Agency (SSA) and National Prevention Network (NPN) representatives.

SAMHSA FASD Center for Excellence: Accomplishments since May 2008

Callie B. Gass, Project Director, SAMHSA FASD Center for Excellence

The FASD Center for Excellence expanded its activities and reach significantly over the last year in order to meet the needs of states, communities, and those who access the Center's informational resources. Key developments since BFSS 2008 include:

- The continued growth of NAFSC, which now includes 19 states, the District of Columbia, and the Navajo Nation, and also the growth of the BMN to over 75 representatives nationwide;
- The launch of the American Indian/Alaskan Native/Native Hawaiian Expert Panel, which met for the first time on May 15 following BFSS activities and will guide the Center's efforts to address FASD among Native populations over the next four years;

The FASD Center for Excellence continues to expand its activities to reach new audiences and provide the information resources that the field needs.

- The Center’s ongoing training and technical assistance events, which have been delivered in six states to over 300 recipients just since the beginning of 2009;
- The full implementation of FASD-related interventions or screening, and diagnosis programs at 23 subcontract sites; and
- The expansion and increased usage of the Center’s Web site, including the launch of a state-specific research page and the Spanish version of the site.

Keynote Address

Frances M. Harding, Director, Center for Substance Abuse Prevention (CSAP), Substance Abuse and Mental Health Services Administration (SAMHSA)

Ms. Harding opened by thanking the participants for their hard work and commitment. She then discussed CSAP’s overall vision for prevention, and where FASD prevention and education fit in the agency’s approach. Key points included:

- Mental health, treatment, education, and social service needs of mothers and children demand coordinated, blended strategies. CSAP’s overall vision is to:
 - › Integrate substance abuse prevention within a broader public health framework: One national prevention system which operates as a full and vibrant partner in the public health system.
 - › Build a skilled workforce.
 - › Strengthen leadership of State substance abuse agencies.
 - › Strengthen partnerships at the Federal, State, and local levels.
- Prevention’s role in addressing FASD is not confined to women at risk of alcohol-exposed pregnancies. It extends to reducing risks and enhancing protective factors for children and youth who have FASD. For example:
 - › Promoting FASD screening in various settings such as primary care and the criminal justice system and helping educators to tailor their methods in working with kids who have FASD-related learning challenges can prevent secondary disabilities including alcohol and substance abuse.
 - This view recognizes a full spectrum of risk levels and reflects a longstanding commitment to family-centered prevention approaches.
- State leadership entities such as those participating in BFSS are ideally positioned to:
 - › Serve as the bridge across which national policies and priorities take shape.
 - › Help strategies take root at the State and community level.
 - › Get out information about substance abuse prevention issues such as FASD.
 - › Promote collaboration among State agencies and systems.
 - › Foster connections among prevention, mental health, and treatment systems, especially in the context of a public health approach that embraces prevention at all levels of risk.
 - › Identify synergy between treatment and prevention and other complementary local actions.
 - › Foster collaboration among community programs.
 - › Track progress across a spectrum of priorities and targets.
 - › See how to best adapt to difficult and ever-shifting conditions.

Mountains of Success to Inspire Our Work: Sharing Personal Stories

Introduction: Mary DeJoseph, DO, Faculty Member, Department of Neuroscience, Physiology and Pharmacology, Philadelphia College of Osteopathic Medicine; SAMHSA FASD Center for Excellence Expert Panel Member; Birth Mothers Network Member

Speakers: Cheryl Kyser, Parent, Ohio; Sarah Kyser, Young Adult with an FASD, Ohio

Cheryl and Sarah Kyser shared their personal stories in dealing with FASD. Sarah is now 27 and was adopted at 11 months by Cheryl and William Kyser of Toledo, Ohio. Sarah was not diagnosed with a FASD until she was 16 (by the University of Washington team utilizing the 4-Digit Diagnostic Code), but the Kyser family noticed differences in Sarah at an early age. Her language development was delayed (worsened by hearing problems), and she exhibited many of the common struggles of a child with FASD, including low IQ, anger outbursts, poor short-term memory, and limited social skills. In addition, a noticeable gap developed between Sarah's real age and her 'emotional' age. She was placed in special education early in the 3rd grade, and was receiving private counseling by the age of 10, but bouts of depression and suicide attempts still followed, in addition to brief jail time due to anger issues.

Ms. Kyser indicated that an earlier diagnosis would have made a tremendous difference in how she and her husband approached Sarah's difficulties, as this would have eliminated much of the 'guesswork.' She considers it critical to maintain the structure of the individual's life and stressed the importance of accessing programs such as PACE that teach important independent living, social, communication, and job skills. She also indicated that most of the service eligibility Sarah has been able to access has not been a result of the diagnosis of a FASD but rather through diagnosed mental health issues. Nonetheless, Sarah's story is one of hope and success, as she is now living independently in a home she owns, she is working, and she and her boyfriend are planning for their future.

Invigorating the Field: A Working Lunch

Moderator: Melinda M. Ohlemiller, MA, Chief Executive Officer, Nurses for Newborns Foundation; SAMHSA FASD Center for Excellence Expert Panel Co-Chair

- CDC Programs and Initiatives for Individuals Affected by FASDs

Speaker: Jacquelyn Bertrand, PhD, Senior Scientist, FASD Prevention Program, Centers for Disease Control and Prevention

Dr. Bertrand provided an overview of the CDC's FASD activities, indicating that the mission of the CDC FASD Prevention Team is to *prevent* FASDs and other prenatal alcohol-related disorders, and to *ameliorate* these conditions in individuals already affected by them. As part of this mission, the CDC supports five FASD intervention research projects across the country. This research constitutes Phase I of the CDC's efforts. Phase II will be a science-to-practice initiative in collaboration with community programs, and Phase III will consist of materials development and dissemination to communicate findings.

The CDC's Five FASD Intervention Research Projects

- Friendship and Social Skills (UCLA)
- Math Knowledge and Skills (The Marcus Institute, Atlanta)
- Preschool Behavior (University of Oklahoma Health Sciences Center)
- Executive Functioning (Children's Research Triangle, Chicago)
- Clinically Significant Behavior Problems and Parent Needs (University of Washington)

➤ FASD Regional Training Centers (RTCs)

Speaker: Georgiana Wilton, PhD, Associate Scientist, Department of Family Medicine, University of Wisconsin; FASD RTC Co-Principal Investigator and Project Director, Great Lakes FASD Regional Training Center

Dr. Wilton discussed the CDC's five FASD Regional Training Centers (RTCs). The purpose of the RTC's is to: 1) Develop, implement, and evaluate educational curricula regarding FASD prevention, identification, and care for medical and allied health practitioners and students; and 2) incorporate the curricula into training programs at universities and colleges throughout their

regions, and into the credentialing requirements of professional boards.

The CDC's Five FASD Regional Training Centers

- SOUTHEASTERN: Alabama, Florida, Georgia, Kentucky, Louisiana, Mississippi, South Carolina, Tennessee
- ARCTIC: Alaska and neighboring Canadian provinces
- FRONTIER: Colorado, Idaho, Montana, Nevada, North Carolina, Utah, Wyoming
- MIDWESTERN: Arkansas, Illinois, Iowa, Kansas, Missouri, Nebraska, Oklahoma
- GREAT LAKES: Indiana, Michigan, North Carolina, Ohio, Wisconsin

The RTCs will provide training and skills development in seven key areas: 1) Foundation; 2) Screening and Brief Interventions; 3) Models of Addiction; 4) Biological Effects of Alcohol on the Fetus; 5) Screening, Diagnosis, and Assessment of FAS; 6) Treatment Across the Lifespan for Persons with FASDs; and 7) Ethical, Legal, and Policy Issues. Target audiences include medical and allied health providers and students. In Year One, specific disciplines will be targeted, including family practice, pediatrics, genetics, nursing, psychology, social work, and substance abuse treatment.

Day 2 Plenary Sessions—Thursday, May 14, 2009

Looking to the North to Learn From Our Neighbors: FASD Efforts in Canada

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

First Speaker: Dan Dubovsky

Mr. Dubovsky began by reviewing a presentation provided by Jan Andrews, A/Manager, FASD Program, Children and Youth, and Community Programs Directorate, First Nations Inuit Health Branch (FNIHB) of Canada. Ms Andrews was unable to attend, but her presentation provided an overview of overall health demographics in Canada, and discussed the nation's specific charge with relation to FASD. Canada's two-part goal in addressing FASD includes: 1) Prevention of future births affected by alcohol; and 2) interventions to improve quality of life for those already affected by FASD. This mandate is carried out primarily by two agencies: 1) the Public Health Agency of Canada (PHAC), which assists all people living in Canada not on reservations; and 2) the FNIHB, which assists the First Nations and Inuit Communities.

Ms. Andrews' presentation stressed that the Canadian approach to FASD is a collaborative effort between professional associations, universities, researchers, non-governmental organizations, provincial and territorial governments, the Federal government of Canada, and international partners. The country's long-term objectives in relation to FASD include: 1) Building the evidence base for decision-making; 2) supporting innovation and resource development at the regional and community levels; 3) strengthening partnerships between the Federal and provincial governments, territories, and the international community; and 4) anchoring FASD in broader programs in First Nations communities.

The FASD Life's Journey Program

Second Speaker: Brenda Bennett, Executive Director, FASD Life's Journey, Inc., Winnipeg, Manitoba

Ms. Bennett discussed the FASD Life's Journey Inc. Program, which targets youth with FASD transitioning to adulthood (15-18 years of age) and adults with FASD (18 and over). The program provides a variety of services including family support, client case management, transitional planning, psychiatric and occupational therapy, screening and referral for diagnostic services, and contraceptive counseling. Clients are generally high-risk, high-need cases referred from Children and Family Services or by outreach.

Ms. Bennett stressed that Life's Journey develops individualized, strengths-based plans that are designed to meet the individual's needs and utilize networks that include those the youth has identified as significant in their life. While Life's Journey does not rely solely on evidence-based models, the program does assess functionality through the use of functional assessment tools and evaluates its program outcomes. The overall goal of Life's Journey is to improve lifelong outcomes through the provision of appropriate and accommodating service delivery.

Whitecrow Village FASD Society

Third Speaker: Kee Warner, Executive Director, Whitecrow Village FASD Society, Nanaimo, British Columbia

Ms. Warner described the Whitecrow Village FASD Society, a unique community funded through a grant from the Victoria Foundation. Begun in 1994, Whitecrow now has 15 members, five of whom are full-time staff. Of these 15, 13 have some form of FASD.

The design of Whitecrow is a summer camp in which participants are able to learn social skills, engage in fun and educational activities, and participate in group decision-making (there is no administrative hierarchy; the entire group makes decisions in a speaking circle). In its third year, Whitecrow began to involve family members in activities, and later providers were brought in. The program is now operated from a facility jointly owned by participants and is funded in four primary areas; employment skills, independent living skills, education, and substance abuse treatment. Staff provide workshops around the country to discuss the program's results, and Whitecrow is currently developing a second video overview for educators.

Fetal Alcohol Spectrum Disorder: Current Science and Research Trend

Feng C. Zhou, PhD, Professor of Anatomy, Cell Biology, Neuroscience, & Psychology at Indiana University School of Medicine's Stark Neuroscience Research Institute; President, FASD Study Group

Dr. Zhou reviewed some of the recent developments in the science and research of FASD. He discussed several promising studies being conducted with animals to examine the impact of prenatal alcohol exposure on the development of neural tubes, gray matter, the corpus callosum, and the cortex, as well as verbal and visual functions.

Dr. Zhou then outlined advances in telemedicine that may in the near future allow for easier and more accurate diagnosis of FASD through facial features, even across ethnicities. In addition, he provided an overview of fatty acid ethyl esters (FAEEs) as a biomarker for alcohol-exposed pregnancies, traceable through testing of such features as meconium (a matrix unique to the developing fetus that is commonly used in neonatal drug screening) and hair testing (as FAEEs have prolonged stability in the hair matrix).

Among the potential advances in treatment, Dr. Zhou highlighted nutritional supplementations such as choline and folic acid, as these have been shown in animal studies to reduce alcohol-

related defects. He also stressed the importance of continued research into neural stem cells, as these are now believed to contribute to overall health and wellness (prenatal alcohol exposure reduces neural stem cell development).

Day 1 Breakout Sessions

On Day 1, participants were given the opportunity to choose one of five breakout sessions. The offered sessions were:

National Association of FASD State Coordinators Moving On Up: A Showcase of State Efforts

Moderator/Speaker: Jerome Romero, National Association of FASD State Coordinators (NAFSC) Chair; BFSS Planning Committee Member; SAMHSA FASD Center for Excellence Expert Panel Member

Speakers:

- Felisha Dickey, MSW, MPA, Human Services Program Consultant II, Florida Department of Health; NAFSC Member
- Trisha Hinson, MEd, CMHT, FASD Project Director/State FASD Coordinator, Mississippi Department of Mental Health; NAFSC Member; State Treatment Subcontractor
- Kathy Jo Stence, CAC, Program Analyst, Pennsylvania Department of Health, Bureau of Drug and Alcohol Programs; NAFSC Member; BFSS Planning Committee Member

FASD State Coordinators from Florida, New Mexico, Mississippi, and Pennsylvania, who also participate in the Center's NAFSC group, shared information on various topics, including the benefits of having a State Coordinator, how their states established the State Coordinator position, the systems of care they have created in their states, successful strategies they have employed, and the challenges they have faced.

For additional information on developing a State Coordinator position, contact Jerome Romero, Chair of NAFSC, at aggie@unm.edu.

Reaching High to Build Engaging Partnerships to Prevent FASD

Moderator: Susan Doctor, PhD, MEd, FASD Specialist, University of Nevada, Reno; BFSS Planning Committee Member

Speakers: Dr. Patricia Getty and Callie B. Gass

Dr. Getty and Ms. Gass discussed SAMHSA's Partnership to Prevent FASD, which was developed as part of a broad prevention mandate under the Children's Health Act of 2000 and launched in 2001 within CSAP. The Partnership is based on the conviction that prevention works best at the community level, via a network of partners who understand local needs. Thus far, the Partnership has been successfully implemented in four pilot communities in Louisiana, New Mexico, New York, and South Carolina, and their experiences and lessons-learned have been translated into a manualized, community-based approach titled *Partnership to Prevent FASD Public Education Program Manual*, available for free from the SAMHSA's National Clearinghouse for Alcohol and Drug Information (NCADI).

The manual outlines a four-stage program that includes: 1) Partnership mobilization and program planning; 2) provider involvement; 3) materials dissemination; and 4) program evaluation. The core principles of this approach include: 1) Preventing the problem before it begins by eliminating alcohol use during pregnancy; 2) mobilizing communities to implement a local FASD prevention program using their partner networks and existing resources; and 3) using multiple information sources and multiple settings to communicate core messages. The target audience for this particular approach is adult women age 21 and older and their support network.

A Sneak Peek at Implementation of Evidenced-Based Programs Provided by FASD Coordinating Center Subcontractors

Moderator: Melinda Norman, OCPS II, Prevention Regional Coordinator, Ohio Department of Alcohol and Drug Addiction Services; BFSS Planning Committee Member

Speakers:

- Shelly Bania, CPC-R, FASD ACHIEVE Project Director, Community Assessment Referral Education-CARE, Michigan (Diagnosis and Intervention)

Community Assessment, Referral and Education (CARE), a community-based agency, is one of eight diagnostic and intervention subcontractors funded by the FASD Center for Excellence to screen children for FASD, refer for an FASD diagnostic evaluation all children who screen positive for FASD, and provide interventions for those children. The target population is children aged 0-7. Diagnostic evaluations are provided by Children's Hospital of Detroit, University of Michigan, and Children's Trauma Assessment Center, Kalamazoo. CARE provides in-kind support for a Professional Liaison and Screener, and has provided FASD prevention services for its clients and the community for many years.

Two lessons learned are: 1) Case management services must begin when the child screens positive to support the family in completing the diagnostic evaluation process, rather than after a positive diagnosis has been received; and 2) the referral for diagnostic evaluation process is lengthy.

- Janet Burt, MA, MFT, CAS, Clinical Supervisor, Southern California Alcohol and Drug Programs, Inc. (Parent-Child Assistance Program)

Southern California Alcohol and Drug Programs, Inc. is one of two subcontractors funded by the FASD Center for Excellence to implement the Parent-Child Assistance Program (P-CAP). The P-CAP model includes intensive, long-term paraprofessional advocacy with high-risk mothers who abuse alcohol and other drugs. The goals are to prevent alcohol and drug exposure for future children of the mothers in the program; increase use of contraception; and if pregnant, to abstain from alcohol use during pregnancy.

Challenges have included getting clients to use birth control; working with women who have emotional and psychological trauma that has resulted in low self-esteem. Two lessons learned are: (1) confirmation of the need to individualize services to meet the special and unique needs of each client; and (2) client advocacy is an on-going and important part of the services.

- Tracey Waller, MBA, RD/LD, IBCLC, WIC Director, Public Health-Dayton and Montgomery Counties, Ohio (Screening and Brief Intervention)

Public Health-Dayton and Montgomery Counties, Ohio is one of seven subcontractors funded by the FASD Center for Excellence to provide Screening and Brief Intervention services. In the case of this subcontractor, services are to women who participate in the federally-funded Special Supplemental Nutrition Program for Women, Infants and Children (WIC). The goals are to screen all women enrolling in WIC, provide Brief Intervention to all women who screen positive, follow women receiving Brief Intervention during her pregnancy, develop a process for a referral to treatment services, and incorporate maternal alcohol history in an infant's pediatric file.

The tools used by this program are the TWEAK and Brief Intervention. Challenges have included assessing the accuracy of self-reporting, low literacy rates of women who receive WIC, language barriers to utilization of services, and participants who bring their own mother to their appointments (which may affect their ability to be candid about their alcohol use). Two lessons learned include: 1) Counseling technique and skills are very important; and 2) there is very little resistance to completing the screen form.

- Paulette Romashko, LCSW, Project Director, ARC Smart Start , ARC Community Services, Inc., Wisconsin (Project CHOICES)

ARC Community Services, Inc., a licensed substance abuse treatment agency specializing in providing AODA services for women, is one of six subcontractors funded by the FASD Center for Excellence to implement the CHOICES program. ARC's Smart Start FASD Intervention project integrated the CHOICES/FASD prevention protocol into ARC's nine gender-sensitive Madison, Wisconsin AODA treatment programs serving the needs of women and their children in Dane County.

Project goals include abstinence from drinking alcohol during childbearing years (18-44) and effective use of birth control methods if sexually active and actively drinking. Challenges in their work have included high mobility of clients which affected service delivery and failure to anticipate the high number of women who could not get pregnant. An important lesson learned was that integration of a highly successful "birth control shopping" program into ARC services increased the number of women who were using contraceptive methods; however, this meant that they were no longer eligible for services.

A Conference for Us: Exploring New Vistas in Camp Settings

Moderator: Sara Messelt, Executive Director, Minnesota Organization on Fetal Alcohol Syndrome; BFSS Planning Committee Member

Speakers:

- Julie Gelo, Trainer/Consultant/Advocate/Executive Director, National Organization on Fetal Alcohol Syndrome Washington State; SAMHSA FASD Center for Excellence Expert Panel Member

Ms. Gelo discussed the outcomes of a five-day overnight camp that is designed specifically for children with FASD and their families. Grant money was received for the first year; subsequent years have seen a collaborative effort from NOFAS, the Washington State Department of Health, SAMHSA, and donations. (There will not be a camp for 2009 due to lack of funds.)

In this camp model, children are assigned to volunteers and counselors based on their age and level of development. Parents attend training during the day on such issues as sensory processing disorder seminars, positive behavior support, and home and classroom modification. A support group is also provided for fathers. In the evening, family activities are planned. Participants include a total of 18-24 campers with an FASD; there are 125-150 participants altogether including family members. All types of family arrangements are welcomed, including birth families, foster families, adoptive families, and relatives. Training is provided to counselors and volunteers prior to camp.

The objectives of the camp are to: 1) Increase protective factors for children with FASD by providing access to services and support systems; 2) focus on the prevention of the secondary disabilities of FASD; 3) increase family protective factors to develop and enhance their network; 4) increase family protective factors with opportunity for respite, education and network; 5) increase opportunities for supervised camp; 6) decrease incidence of FASD; and 7) support the family and remember how to have fun. Positive parent feedback has included decreased stress, increased competence, resiliency, hope and healing, increased parenting attitude and techniques, improved child's social skills, and increased support system with other families.

- Barbara Wybrecht, RN, FASD Clinical Nurse Specialist, Spectrum Health

Ms. Wybrecht described a different camp model, one that is essentially a conference by and for people with an FAS/ARND. Over 50 percent of the planning committee were prenatally exposed to alcohol. Sponsors and supporters include the ARC of Michigan, the Speckhard-Knight Charitable Foundation, the Kellogg Foundation, the CDC, and the FASD Center for Excellence.

The goals of this camp/conference are to: 1) Decrease the sense of isolation that these individuals feel; 2) increase their self-advocacy skills; 3) increase understanding of the brain differences caused by prenatal alcohol exposure; and 4) decrease the risk of developing secondary disabilities. The three-day event is structured around plenaries and workshops, and all participants have a buddy at the conference. Training is provided to all volunteers and counselors. The camp/conference Model has been replicated twice in Minnesota.

Utilizing Mentoring and Modeling to Improve Services for Youth Through a Medicaid Waiver

Speakers:

- L. Diane Casto, MPA, Manager, Prevention and Early Intervention Services, Division of Behavioral Health, State of Alaska; SAMHSA FASD Center for Excellence Expert Panel Member
- Barbara Knapp, Project Director, RPTC/FASD Waiver, State of Alaska, Department of Health and Social Services
- Dan Dubovsky, MSW, FASD Specialist, SAMHSA FASD Center for Excellence
- Cheri Scott, FASD Family Support Project Manager, Stone Soup Group

These speakers outlined the SED Medicaid Waiver Demonstration Project in Alaska, and the important role of the mentor in this effort. The State had eight years of preparation for the Medicaid Waiver including FAS Summits, Diagnostic Team and the development of two curriculum, FASD 101 and 201. The State's application for SED Medicaid Waiver Demonstration Project was approved, and the program has now been operable for two years.

The mentoring portion of this project is critical. As the speakers described it, the TIM (Treatment and Intervention Mentor) is not a case manager or a therapist, or a sitter, or a disciplinarian, or spy for the family. Instead, the mentor forms a positive relationship with the individual and family which takes time, and acts a role model, coach, and cheerleader. In addition, the mentor models behavior by demonstrating appropriate methods for addressing problems and issues (as opposed to telling someone what to do).

Although the Demonstration Project has seen challenges in its first two years, a family member shared her story of how difficult it was to send her son out of state for appropriate services and how often those services failed. The Demonstration Project offers the opportunity for Alaska to keep such youth in state and at home, allowing them to stay connected to their communities, their activities, and a known environment.

Regional Breakout Sessions and State/Territory Goals Update

At the Regional Breakout Sessions and State/Territory Goals Update, State and Territory representatives participated in an assigned regional group with other State and Territory representatives, where they discussed accomplishments and ongoing work, examined the possibilities of cross-state collaborations, and considered how the Center can be most helpful in achieving identified goals. In addition, each State/Territory completed goal-related forms for use by the State/Territory and the Center in assisting with work over the next year. The completed forms help the State/Territory identify those who need to be involved to best achieve goals and possible strategies for overcoming barriers. They will also assist the Center in keeping track of

issues for each State/Territory, being more targeted in following up during the year, and helping to identify intervention points to support states and Territories with their goals.

Day 2 Breakout Sessions

On Day 2, participants were given the opportunity to choose one of four breakout sessions. The offered sessions were:

The Journey from Adolescence to Adulthood and Beyond

Moderator: Elizabeth Dahms, MS, RNC, Public Health Consultant/Nurse, New Jersey Department of Health and Senior Services; NAFSC Member

Speaker: Brenda Bennett

This was an expansion of the presentation on Life's Journey Program, Inc. in Winnipeg, Manitoba (discussed above on page 8).

Rising to the Challenge: Increasing Identification of Children (birth-3) with an FASD

Moderator: Cindy Beckett, PhD, RNC-OB, LCCE, Director Pediatrics/Perinatal Services and Evidence-Based Practice, Flagstaff Medical Center; Arizona Task Force for the Prevention of Prenatal Exposure to Alcohol and Other Drugs; Co-Chair; BFSS Planning Committee Member

Speakers:

- Enid Watson, MDiv, Director, Screening and Early Identification Programs; Massachusetts FASD State Coordinator, Institute for Health and Recovery; NAFSC Member; BFSS Planning Committee Member
- Norma Finkelstein, PhD, Executive Director, Institute for Health and Recovery, Cambridge, Massachusetts; FASD Center for Excellence Expert Panel Member

Ms. Watson and Dr. Finkelstein provided an overview of the Institute for Health and Recovery (IHR), a statewide service, research, policy, and program development agency in Massachusetts. Their mission is to develop a comprehensive continuum of care for individuals, youth, and families affected by alcohol, tobacco, and other drug use, mental health problems, and violence/trauma, based on the principals of: 1) Establishing collaborative models of service delivery; 2) integrating gender-specific, trauma-informed and relational/cultural models of prevention intervention, and treatment; 3) fostering family-centered, strength-based approaches; and 4) advancing multicultural competency within the service delivery system.

The IHR has initiated the Fetal Alcohol Screening for Today (FAST) Project to prevent FASD through prenatal alcohol screening, identify and treat children with an FASD in early intervention settings, and provide FASD health education to two substance abuse treatment programs for pregnant women. To assist in meeting these goals, a special subcommittee has designed the Project FAST FASD Screening Tool. Contributors included a clinical geneticist with expertise in FASD, a pediatrician, a pediatric psychiatrist, and a developmental psychologist with expertise in FASD.

The Sky's the Limit for Connecting with Tribes and Native American Groups to Strengthen State Systems

Moderator: Candace Shelton, MS, Senior Native American Specialist, SAMHSA FASD Center for Excellence

Speakers:

- Danielle Glenn-Rivera, CDS, Planner, Los Angeles County Alcohol and Drug Program Administration; AI/AN/NH Expert Panel Member
- Pat Moran, LADC, CADC III, ICADC, Program Manager, White Earth Substance Abuse Program; AI/AN/NH Expert Panel Member
- Violet Mitchell-Enos, MSW, Executive Director, Department of Health and Human Services, Salt River Pima-Maricopa Indian Community; AI/AN/NH Expert Panel Member

Three speakers provided overviews of the prevention projects, strategies for addressing public health issues, including FASD, and systems of care currently in use in their communities. Each of the speakers agreed that providing FASD services is essential to sustaining the lives in and cultures of the American Indian, Alaska Native, and Native Hawaiian communities. It was noted that there are over 550 different Tribes, with different languages, creation stories, ceremonies, and ways of looking at the world, and stressed that in making connections with Tribal and other Native groups that these differences be honored.

Strengthening Advocacy by Turning Educators into Collaborators

Moderator: Kathy Jo Stence, Program Analyst, Pennsylvania Department of Health; NAFSC Member

Speakers:

- Barbara Morse, PhD, Director, Fetal Alcohol Education Program, Concord, Massachusetts
- Kathryn Dole, MS, OTR/L, District Program Facilitator, Minneapolis Public

Ms. Morse discussed the role of schools in addressing FASD. She stressed that a school's primary role is to educate, but that they are also required to coordinate services, deliver designated services, collaborate with the medical system, and identify children who are undiagnosed. To implement a plan to collaborate with a school, she stressed that some of the sources of support include the school itself, parents, the PTA, high school service projects, and local Council on Aging volunteers.

One such collaborative effort is the Minneapolis Public Schools Project, an interagency initiative between the Minneapolis Public Schools (MPS), the University of Minnesota FASD Clinic, and the Minnesota Organization on Fetal Alcohol Syndrome (MOFAS). The goals of this partnership are to: 1) Improve educational outcomes for students with FASD; support families seeking resources for their children; 2) educate Minnesota Public School staff about the individual needs of students; 3) determine appropriate eligibility for special education services; 4) develop educational and behavioral strategies to support students with FASD; and 5) identify data elements needed for research to verify student improvement. Program components include a task group from all agencies that meets each month, and funding from MOFAS which allows the school district to hire an FASD Liaison. The program focus is on training and education of school staff, research and data collection, and work with students, family, and staff.

ASSOCIATED MEETINGS

Feeding into the comprehensive national system supported by the FASD Center for Excellence is the work accomplished by:

- The National Association of FASD State Coordinators;
- The Birth Mothers Network;
- The Expert Panel;
- The FASD Subcontractors; and
- The American Indian/Alaskan Native/Native Hawaiian Expert Panel.

Each of these groups held meetings in Albuquerque during the week of May 11–15, 2009. Below are brief synopses of the charges of the groups, and the work accomplished at their meetings.

National Association of FASD State Coordinators—Monday, May 11, 2009

Representatives from 19 states, the District of Columbia, and the Navajo Nation attended the NAFSC meeting on Monday, May 11, 2009. NAFSC was established in 2003, starting out with seven members. There are currently 21 Coordinators in the Center’s NAFSC group, including Washington, D.C. and the Navajo Nation. Their half-day agenda included:

- Brief updates on activities from each State.
- A presentation on the mission of the National Prevention Network (NPN) and the critical role it can play in helping the members of NAFSC raise awareness about FASD.
- Report-outs from the subcommittees, including:
 - › Policy & Legislation: This subcommittee has developed a report on these issues and will send out a draft. Their report addresses the disconnect between legislation and treatment-related policy, as well as between local and systemic policymaking.
 - › Warning Labels: The subcommittee sent letters to 18 different pharmaceutical companies that develop pregnancy test kits, providing new recommended verbiage to strengthen package warnings related to alcohol and pregnancy.
- Establishment of several new subcommittees, including:
 - › Airlines (subtask of Warning Labels subcommittee): Tasked with creating a letter that can be sent to all major airlines to advise them about appropriate alcohol/pregnancy warnings for their customers. (The FAA may be a good resource for identifying what airlines are currently doing—or are required to do—in this regard.)
 - › NAFSC Orientation: Tasked with creating an information resource that can be shared with new or prospective member states to instruct them on how to set up a State Coordinator office and what it does.
 - › Primary Care: Tasked with formulating an effective method for approaching primary care providers and organizations (e.g., obgyn’s, ACOG, AAP, family practitioners, etc.) and making them more aware and active relative to FASD.

The Birth Mothers Network—Monday, May 11, 2009

The BMN was established to support and serve families with alcohol-exposed children and women at risk for alcohol-exposed pregnancies. The group met Monday, May 11, 2009; seventeen members attended.

Kathleen T. Mitchell, MHS, LCADC, Vice President and National Spokesperson, National Organization on Fetal Alcohol Syndrome (NOFAS), led the discussions. She indicated that

NOFAS is receiving more and more requests for information on the BMN. She also announced that NOFAS has recently completed a school-based FASD education and prevention curriculum for grades K-12. The curriculum provides age-appropriate information about the consequences of alcohol on human development and also encourages youth to be tolerant of individuals regardless of individual capabilities or disabilities. It was developed in conjunction with the CDC. Other general discussions included:

- Brief updates from State BMN Coordinators;
- Addressing stigma, both for the parent and the child;
- Providing supports to birth mothers;
- Effective methods for sharing information with affected children;
- How BMN members can collaborate with state systems; and
- Providing support and orientation for newcomers to the BMN.

The Expert Panel—Tuesday, May 12, 2009

The Center's Expert Panel convened for the second face-to-face meeting of its term. A quorum was present at the meeting, with 12 voting members and three ex-officio members in attendance. Their 1-day agenda included:

- A reading of highlights from the Expert Panel protocols and a review of the Panel's charge;
- A presentation on the Center's newly activated American Indian/Alaska Native/Native Hawaiian Initiative (the Expert Panel will act as liaisons with Native communities and provide the Center with important guidance to enhance efforts in Indian Country);
- An update on FASD-related activities and research at NIAA;
- An update of the activities of the FASD Prevention Team at CDC;
- An overview of the activities of the Indian Health Service;
- A presentation on the Center's research for a concept paper on issues related to alcoholic beverage warning labels and signs;
- An update on the round of subcontracts that began February 1, 2008;
- An overview of the Women's Services Network (WSN) and the NPN and how they are collaborating, as well as the importance of each State knowing and collaborating with their NPN representative;
- A discussion on how the group can best respond to inaccurate press or other media; and
- The possibility of establishing a national network for individuals with an FASD.

The FASD Subcontractors—Tuesday, May 12, 2009

The Coordinating Center of the FASD Center for Excellence oversees 23 subcontracts that are implementing prevention and diagnosis and intervention programs. The programs include states, tribal courts, juvenile dependency and delinquency courts, and local providers. The subcontractors convened on May 12, 2009 as part of their subcontracts' annual meeting requirements. The meeting consisted of a plenary session and breakout sessions for each of the subcontract program categories funded.

The plenary consisted of an update on subcontract activities and accomplishments during the past year, which was the first year of implementation for the programs. Jill Hensley, Program Manager of the Coordinating Center for the Center, presented the overall update on key activities

in this first year, aggregate data on numbers of participants served as of March 2009, and key findings from implementation to date. She also emphasized the learning community that is being shaped by the programs as they generate important findings to enrich one another and the field. The plenary closed with introductions of each of the subcontract teams and a brief highlight of lesson learned.

Four breakout sessions were conducted following the plenary for each of the subcontract categories: Project CHOICES; Screening and Brief Intervention (SBI); Parent-Child Assistance Program (P-CAP); and Diagnosis and Intervention. The three prevention program (CHOICES, SBI, and P-CAP) sessions were each led by the program's respective content experts, who provided booster training on the prevention models that are being implemented. The diagnosis and intervention session focused on training on developing customized service plans based on diagnostic reports and recommendations.

The American Indian/Alaskan Native/Native Hawaiian Expert Panel—Friday, May 15, 2009

The American Indian/Alaskan Native/Native Hawaiian Expert Panel (Native Panel) met for the first time on Friday, May 15, 2009. Fourteen members attended the meeting. Over the next four years, this panel will be tasked with:

- Conducting environmental scan of current efforts to address FASD in Native American communities;
- Planning and implementing Native Leaders Regional Meetings to bring together Native leaders and elders to discuss the issue of FASD;
- Convening semi-annual meetings of the American Indian/Alaska Native/Native Hawaiian Expert Panel to provide expert guidance on the initiative;
- Providing support for the implementation of Tribal FASD Task Force in select Tribes and communities;
- Providing training and technical assistance to tribal entities and communities; and
- Expanding and updating the Native American Resource Kit.

The half-day agenda for this inaugural session included:

- Introductions;
- SAMHSA Vision for this initiative;
- Overview of the FASD Center for Excellence and the history of its work with Native populations;
- Overview of CSAP's Native American Center for Excellence;
- The roles, responsibilities, and structure of the Native Expert Panel;
- Identification of Expert Panel Chair(s); and
- Introduction of the Native Resource Kit.

OUTCOMES

Each BFSS meeting has been evaluated by participants to obtain feedback on their satisfaction with the agenda, the speakers, and the site, and to elicit recommendations for the next meeting. In addition to formal evaluation findings, positive trends (or outcomes) emerge each year during and after the meetings. Noted trends this year include:

- **Increased interest in participation**—Attendance at this year’s BFSS event increased by 24 percent over 2008, to 207 participants, including greater representation from birth moms, individuals with an FASD, and Native communities.
- **The growth of FASD-related groups and organizations**—The NAFSC and the BMN both increased in size since last year’s meeting, and 2009 saw the inaugural gathering of the American Indian/Alaskan Native/Native Hawaiian Expert Panel. The number and diversity of groups and organizations who can address the need for greater FASD infrastructure and support is clearly growing.
- **Increased collaboration among individuals, programs, and groups**—An ‘unofficial’ theme of this year’s activities was for each participant to actively network with other participants. Not only did members of the NAFSC, the BMN, and the Expert Panels present at each other’s meetings and share ideas, but the general attendees also sought out potential partners and collaborators and looked to become familiar with important State officials, such as their SSA’s and NPN representatives.

MEETING EVALUATION

Introduction

The evaluation component for the 2009 BFSS meeting focused on determining the attendees' overall level of experience of certain attributes of the meeting, such as quality and clarity, information sharing, networking opportunities, and applying lessons learned to work situations. In addition, attendees were asked to provide feedback on the usefulness of each of the sessions.

Methods

An evaluation form was designed to elicit feedback from meeting attendees (Appendix A). Evaluation forms were provided to all attendees and filled out and turned in to Center staff at the end of the meeting. Completed evaluation forms were checked for data accuracy, followed by data entry and analysis. Responses were compiled as a frequency for the close-ended questions and a content analysis was performed for the open-ended responses.

Evaluation Questionnaire

The questionnaire was designed to include both close-ended and open-ended questions. The first question was designed to get respondents' ratings on general aspects of the meeting. The second question was regarding the usefulness of the general and breakout sessions.

Attendees were asked to respond to open-ended questions on the following topics:

- The most useful part of the meeting;
- Plans to use what they learned at the meeting in their work; and
- Topics or speakers for future BFSS meetings.

Evaluation Results

A total of 142 respondents submitted completed evaluation forms. Quantitative and qualitative results are presented below. One session, Drinking Among Women of Child Bearing Age and Policies to Address the Issue was canceled and the ratings are not presented. The quantitative results for the Regional Breakout Session are not presented because the numeric response categories were missing from the evaluation form.

Quantitative Results

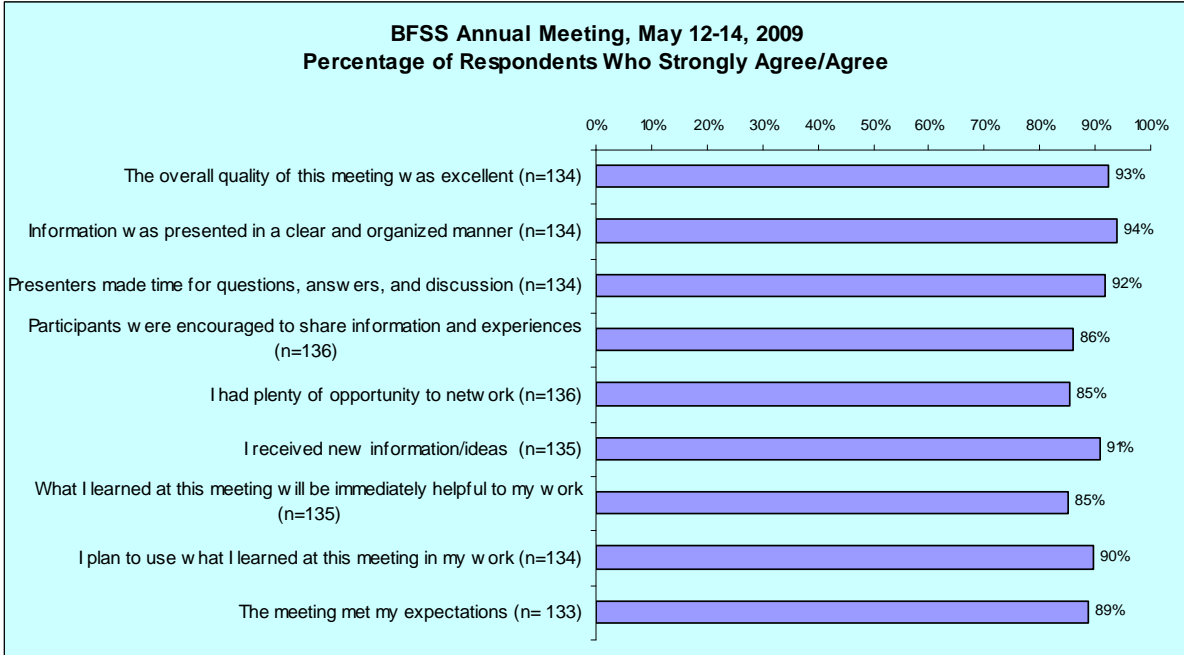
Respondents' ratings of the meeting overall, and of the sessions held during this event, are presented in Tables 1 and 2 below. The percentages of respondents shown in these tables are based on the actual numbers of those who answered a particular question, as shown in the last column of Table 1 and Table 2.

Table 1—General Assessment of the Meeting

Item	Strongly Disagree	Disagree	No Opinion	Agree	Strongly Agree	Total
The overall quality of this meeting was excellent.	0 (0%)	6 (4%)	4 (3%)	64 (48%)	60 (45%)	134 (100%)
Information was presented in a clear and organized manner.	0 (0%)	4 (3%)	4 (3%)	64 (48%)	62 (46%)	134 (100%)
Presenters made time for questions, answers, and discussion.	0 (0%)	7 (5%)	4 (3%)	57 (43%)	66 (49%)	134 (100%)

Participants were encouraged to share information and experiences.	0 (0%)	10 (7%)	9 (7%)	58 (43%)	59 (43%)	136 (100%)
I had plenty of opportunity to network.	0 (0%)	16 (12%)	4 (3%)	51 (37%)	65 (48%)	136 (100%)
I received new information/ideas.	0 (0%)	6 (4%)	7 (5%)	51 (38%)	71 (53%)	135 (100%)
What I learned at this meeting will be immediately helpful to my work.	0 (0%)	9 (7%)	11 (8%)	61 (45%)	54 (40%)	135 (100%)
I plan to use what I learned at this meeting in my work.	0 (0%)	4 (3%)	10 (7%)	55 (41%)	65 (49%)	134 (100%)
The meeting met my expectations.	0 (0%)	6 (4%)	9 (7%)	62 (47%)	56 (42%)	133 (100%)

Figure 1—General Assessment of the Meeting



As shown in Figure 1, respondents gave the meeting a highly favorable assessment, with the vast majority (93 percent) rating it as excellent in quality and indicating that they planned to use what they learned in their work (90 percent). Almost all respondents also felt that the information presented was clear and well organized (94 percent), and most agreed that presenters made time for questions, answers, and discussion (92 percent).

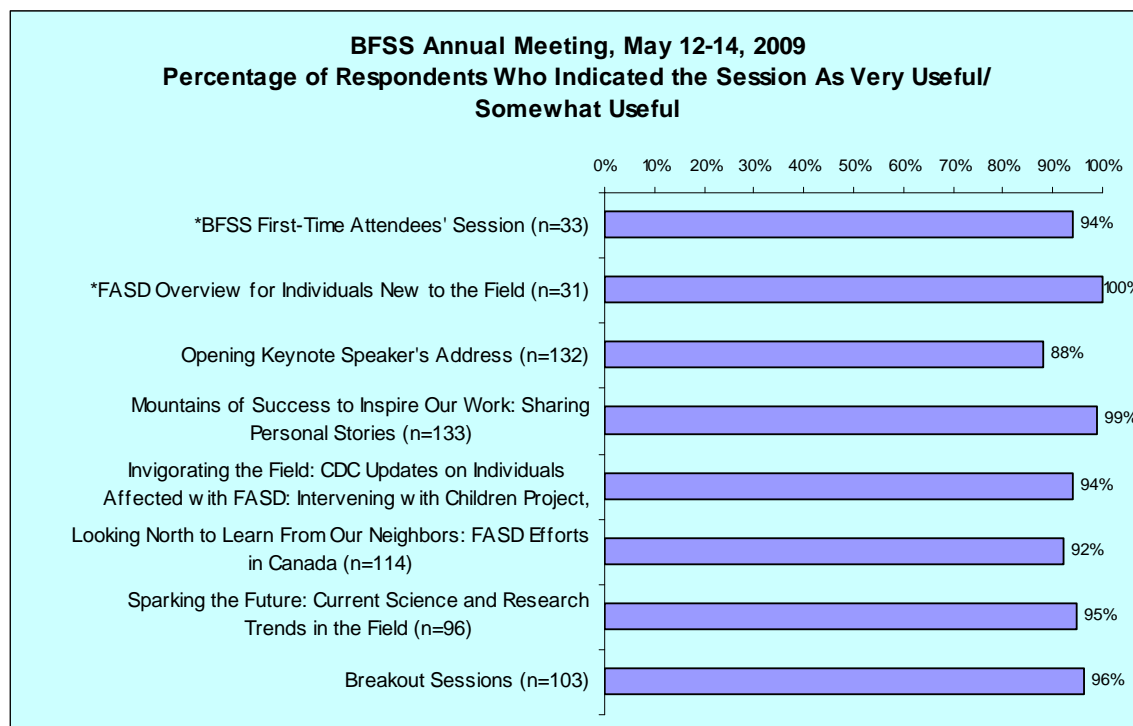
The 2009 BFSS evaluation form included an additional rating option for participants in the general assessment of the meeting section. The option “No Opinion” was added between agree and disagree. This may have caused some variation in the scores. When comparing this meeting to the 2008 BFSS meeting in Colorado Springs, CO, there were slightly lower scores.

Table 2—Assessment of the Sessions

Please circle the number that matches your answer.	Not at All Useful	Not Very Useful	Somewhat Useful	Very Useful	Total
*BFSS First-Time Attendees' Session	0 (0%)	2 (6%)	13 (39%)	18 (55%)	33 (100%)
*FASD Overview for Individuals New to the Field	0 (0%)	0 (0%)	10 (32%)	21 (68%)	31 (100%)
Opening Keynote Speaker's Address	0 (0%)	16 (12%)	52 (39%)	64 (49%)	132 (100%)
Mountains of Success to Inspire Our Work: Sharing Personal Stories	0 (0%)	2 (1%)	29 (22%)	102 (77%)	133 (100%)
Invigorating the Field: CDC Updates on Individuals Affected with FASD: Intervening with Children Project, Funding Opportunities, and Regional Training Centers (RTC)	3 (2%)	5 (4%)	61 (47%)	61 (47%)	130 (100%)
Looking North to Learn From Our Neighbors: FASD Efforts in Canada	0 (0%)	9 (8%)	41 (36%)	64 (56%)	114 (100%)
Sparkling the Future: Current Science and Research Trends in the Field	1 (1%)	4 (4%)	25 (26%)	66 (69%)	96 (100%)
Breakout Sessions	0 (0%)	4 (4%)	30 (29%)	69 (67%)	103 (100%)

*Sessions were only required for BFSS first timers.

Figure 2—Assessment of the Sessions



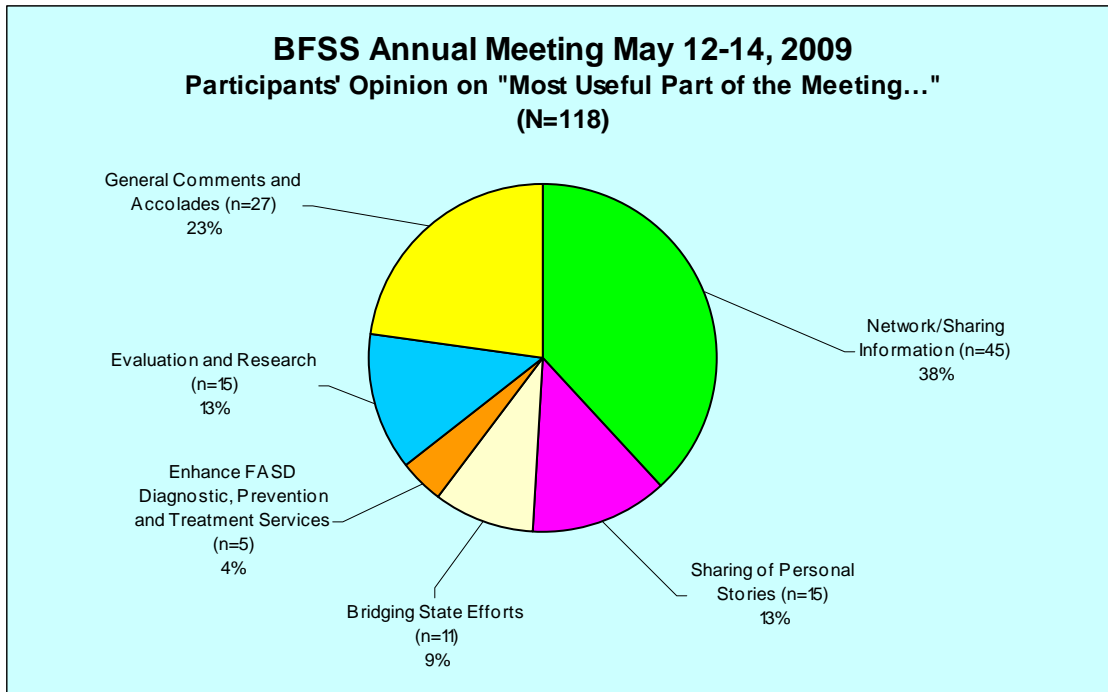
*BFSS First Time Attendees' and FASD Overview for Individuals New to the Field was for the BFSS first timers.

As illustrated in Figure 2, the sessions that were rated as “very useful/somewhat useful” by the highest percentages of respondents were *FASD Overview for Individuals New to the Field* (100 percent), *Mountains of Success to Inspire Our Work: Sharing Personal Stories* (99 percent), and the “Breakout Sessions” (96 percent).

Qualitative Results

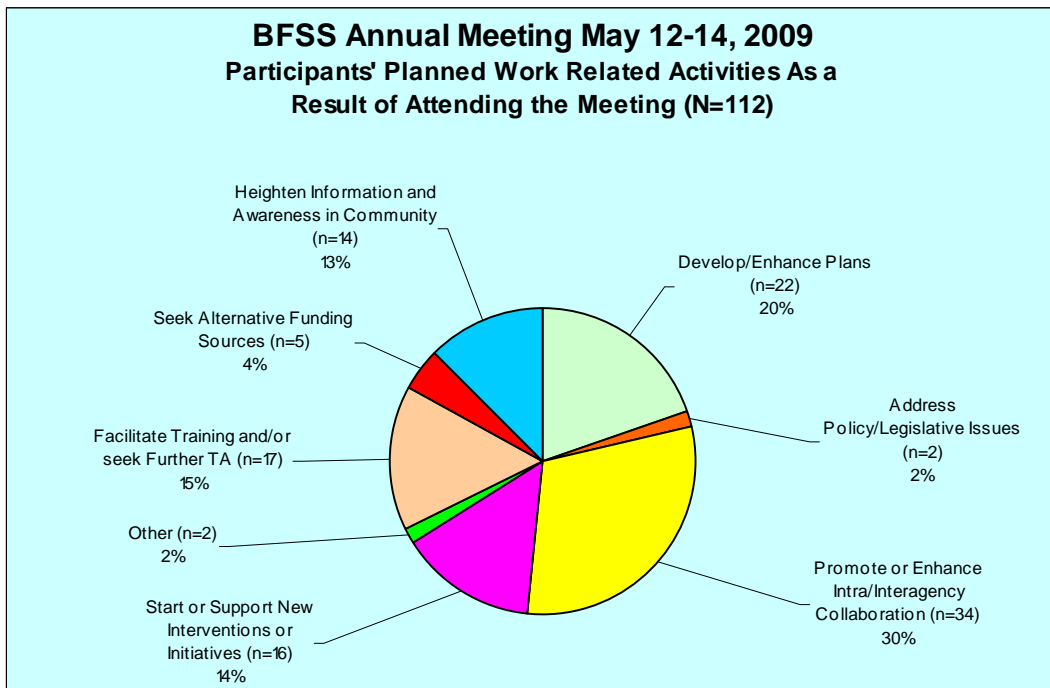
Respondents provided written comments about this meeting to three open-ended questions. For each of the open-ended questions, responses were grouped under specific topic areas. The total number of responses within each topic area for each of the questions is represented in the pie charts below.

Figure 3—Most Useful Part of the Meeting



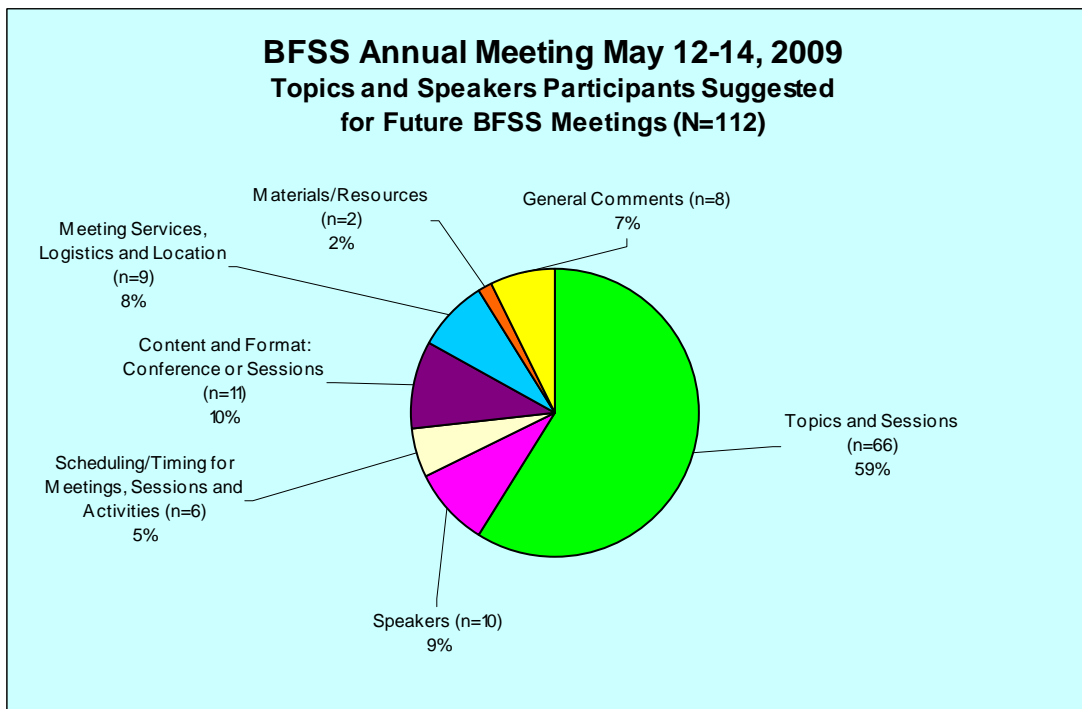
As presented in Figure 3, the majority (38 percent) of the responses indicate that participants found networking and information sharing to be the most useful. Twenty-three percent of the responses were general comments and accolades.

Figure 4—Respondents’ Planned Work-Related Activities as a Result of Attending the Meeting



Among the 112 responses received to this question, the most frequently reported priorities were to promote or enhance collaborations between/within agencies to form partnerships (30 percent).

Figure 5—Suggested Topics or Speakers for Future BFSS Meetings



Of the 112 responses for suggestions for topics or speakers for future BFSS meetings, the majority (59 percent), provided suggestions on new ideas for topics and sessions.

Evaluation Conclusions

Evaluation results presented above indicate that this meeting was a success. Significant findings from the quantitative and qualitative data presented in Tables 1 and 2 and responses to the open-ended questions are as follows:

- Overall, 93 percent of the respondents rated the quality of this meeting as excellent, and 94 percent also agreed that the information presented was clear and well organized.
- The vast majority of respondents (92 percent) agreed that presenters made time for questions, answers, and discussion, and that they intended to use this information when they got back to work (90 percent).
- The FASD Overview for Individuals New to the Field was viewed as the most useful (100 percent). Mountains of Success to Inspire Our Work: Sharing Personal Stories (99 percent), and the “Breakout Sessions” (96 percent), were also viewed as highly useful.
- The Regional breakout session was well attended with 113 participants indicating that they attended the session.
- Thirty-eight percent of the responses indicated that networking was the most useful part of the meeting.
- The most frequently reported work-related plans, were to promote or enhance collaborations between/within agencies to form partnerships (30 percent).

The majority of the responses (59 percent), on topics/speakers for future meetings, were new ideas for topics and sessions.

NEXT STEPS

The next steps following the 2009 BFSS meeting include:

- Following up with states who have expressed an interest in establishing a State Coordinator position;
- Following up with states who have not submitted their FASD plans;
- Checking in with states throughout the year to see how they are progressing with their FASD plans;
- Pulling together lessons learned from the planning process and meeting evaluations to refine and improve next year's process;
- Holding a staff debriefing session on lessons learned from the 2009 BFSS meeting to ensure that next year's meeting flows just as smoothly;
- Updating the Center's Web site with information from the meeting including the meeting summary, presentations, speaker biographies, photographs, and participant lists; and
- Incorporating participant feedback in upcoming planning sessions for new products, product revisions, and potential new initiatives.

CLOSING

All indications are that 2009 BFSS meeting was yet another success story, more than meeting the Center's goals of advancing the field of FASD and facilitating the development of comprehensive systems of care for FASD prevention and treatment. As with previous meetings, it also provided a broad range of people in the field with useful tools, new contacts, and information that can be used to face their local challenges.

Perhaps most importantly, this year's meeting showed the incredible growth of the FASD field over the last five to six years, as well as its collaborative spirit. The Center for Excellence exists to facilitate the development of a framework to support individuals with FASD, and we are seeing that framework grow at a tremendous rate. The field is truly 'taking the ball and running with it.' This suggests that the Center is meeting its goals, yes, but also—and much more significantly—it suggests that the resources and support that individuals with FASD have so long lacked are starting to take shape and find their way to them. We can have no greater goal than that.

APPENDIX A—EVALUATION FORM

SAMHSA Fetal Alcohol Spectrum Disorders Center for Excellence



**Building FASD State Systems Meeting
Albuquerque, New Mexico
May 12-14, 2009
Evaluation Form**

Date Completed: _____

Title/Position: _____

1. Have you attended a BFSS meeting in the past? _____

2. To what extent do you agree with the following general statements about this meeting?

Please circle the number that matches your answer.	Strongly Agree	Agree	No Opinion	Disagree	Strongly Disagree
The overall quality of this meeting was excellent.	5	4	3	2	1
Information was presented in a clear and organized manner.	5	4	3	2	1
Presenters made time for questions, answers, and discussion.	5	4	3	2	1
Participants were encouraged to share information and experiences.	5	4	3	2	1
I had plenty of opportunity to network.	5	4	3	2	1
I received new information/ideas.	5	4	3	2	1
What I learned at this meeting will be immediately helpful to my work.	5	4	3	2	1
I plan to use what I learned at this meeting in my work.	5	4	3	2	1
The meeting met my expectations.	5	4	3	2	1

3. How useful were the following sessions?

Please circle the number that matches your answer.	Very Useful	Somewhat Useful	Not Very Useful	Not At All Useful	Attended Session (Circle Yes or No)
BFSS First-Time Attendees' Session	4	3	2	1	Yes No
FASD Overview for Individuals New to the Field	4	3	2	1	Yes No
SAMHSA FASD Center for Excellence: Accomplishments since May 2008	4	3	2	1	Yes No
Opening Keynote Speaker	4	3	2	1	Yes No
Mountains of Success to Inspire Our Work: Sharing Personal Stories	4	3	2	1	Yes No
Invigorating the Field: CDC Updates on Individuals Affected with FASD: Intervening with Children Project, Funding Opportunities, and Regional Training Centers (RTCs)	4	3	2	1	Yes No

Breakout Sessions	4	3	2	1	Yes No
Regional Breakout Sessions					Yes No
Looking North to Learn From Our Neighbors: FASD Efforts in Canada	4	3	2	1	Yes No
Drinking Among Women of Child Bearing Age and Policies to Address the Issue	4	3	2	1	Yes No
Sparking the Future: Current Science and Research Trends in the Field	4	3	2	1	Yes No

3. What was the most useful part of this meeting for you? Please explain.

4. What are one or two things you plan to do in your work, based on what you learned at this meeting?

5. What topics or speakers would you suggest for future BFSS meetings?

Thank you for your feedback. Please drop in the evaluation box.