



Hope for Women in Recovery

Understanding and Addressing the Impact of Prenatal Alcohol Exposure

Baltimore, Maryland • September 8-9, 2003

DRAFT



U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
Substance Abuse and Mental Health Services Administration
www.samhsa.gov



SAMHSA
Fetal Alcohol Spectrum Disorders
Center for Excellence

Introduction

Nearly 40,000 babies are born each year with a range of birth defects known as fetal alcohol spectrum disorders (FASD). To address the problems related to FASD, Congress created the FASD Center for Excellence as part of the Children's Health Act of 2000. The Center is operated by the Substance Abuse and Mental Health Services Administration (SAMHSA). The Center has six legislative mandates, one of which is to develop innovative ways to prevent alcohol abuse among women in their childbearing years.

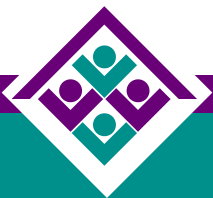
As part of its efforts to address the legislative mandate regarding prevention of alcohol abuse, the FASD Center convened the first-ever summit for women in recovery from alcohol abuse. The summit was designed to introduce women in recovery and their counselors to the issue of FASD. Treatment programs in and around Baltimore, Maryland, were invited to bring women from their programs to the Summit. Prior to the summit, the FASD Center and the National Organization on Fetal Alcohol Syndrome (NOFAS) provided a training for certified addictions counselors from the participating programs to prepare them for the summit.

The 2-day summit included three sessions. On the first day, experts talked about the science of FASD and parents and birth mothers shared their experiences raising children with FASD. That evening, a Town Hall meeting was convened for participants and other interested individuals to testify to Maryland officials about their experiences with FASD. The second day of the meeting was devoted to setting the foundation for a State plan in Maryland to address FASD.

Nearly 200 people attended the first day of the summit, including about 100 women from Maryland treatment centers, along with treatment center counselors, Maryland delegates, and staff from NOFAS, SAMHSA, and the FASD Center for Excellence.

Speakers included:

- Beverly Watts-Davis, Director of the Center for Substance Abuse Prevention (CSAP)
- Faye Calhoun, Deputy Director of the National Institute on Alcohol Abuse and Alcoholism (NIAAA) and Co-Chair of the FASD Center for Excellence Steering Committee
- Kathleen Mitchell, NOFAS national spokesperson and a birth mother of an adult with FAS
- Ed Riley, Co-Chair of the FASD Center for Excellence Steering Committee and Chair of the National Fetal Alcohol Syndrome/Fetal Alcohol Effect Task Force
- Julie Gelo, family advocate and parent of several children with FASD
- Diane Malbin, Marcy Ten Eyck, and Angelina Locklear-Taylor, birth mothers of children with FASD
- Paula Lockhart, a physician at the Kennedy Krieger Institute



More than 100 individuals participated on the second day, including Maryland delegates, NOFAS staff, SAMHSA staff, FASD Center staff, birth mothers, adoptive parents, physicians, and service providers.

Speakers included:

- Kathleen Mitchell
- Paula Lockhart
- Rick Harwood, Vice President, Lewin Group
- A panel of family members of individuals with FASD
- Deborah Cohen, Director of the Office for Prevention of Mental Retardation and Developmental Disabilities
- Thomas Davis, Director of the Drug and Alcohol Council in Maryland
- Tom Donaldson, Executive Director of NOFAS
- Kumar Barve, Majority Leader of the Maryland House of Delegates

This document includes proceedings of the 2-day meeting. A separate report on the Town Hall meeting and private testimony is being prepared.

Monday, September 8

Opening

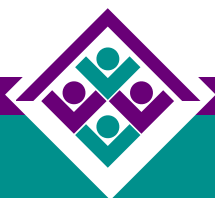
Kathleen Mitchell, National Organization on Fetal Alcohol Syndrome, welcomed participants. She then introduced Tom Davis, Director of the Maryland Drug and Alcohol Council and former Director of the Alcohol and Drug Abuse Administration for the State of Maryland. Mr. Davis presented a citation from Maryland Governor Robert Ehrlich. The citation noted that September is National Recovery Month and thanked SAMHSA and NOFAS for sponsoring the meeting. It also recognized NOFAS for its efforts to prevent and treat FASD. Governor Ehrlich and Lieutenant Governor Michael Steele signed the citation.

Deborah Stone, Government Project Officer for the FASD Center for Excellence, introduced CSAP Director Beverly Watts Davis, who joined CSAP in May 2003. CSAP works with Federal, State, and private partners. Ms. Watts Davis has extensive experience in substance abuse and community health and led prevention efforts in Texas.

Welcome

Beverly Watts Davis, Director, Center for Substance Abuse Prevention

Ms. Watts Davis commented that she was “in awe of the strength and power of the people in this room.” She thanked the governor for the citation and thanked NOFAS and the FASD Center for convening the summit. She specifically recognized Deborah Stone, Annie Acosta, and Ammie Bonsu of CSAP and FASD Center Steering Committee Cochairs Drs. Faye Calhoun and Ed Riley.



The FASD Center was created by the Children's Health Act of 2000. The Center works to prevent FASD by creating a prevention infrastructure in the States. One of the Center's activities has been convening Town Hall meetings to give people in the FASD community a voice. The meetings showed that women in recovery need more information about FASD.



The summit is the first of its kind. It is an excellent opportunity to network, share experiences, support each other, learn from the past, and connect with friends who share a common bond. It will also help the government learn how to create connected systems of prevention and treatment.

To illustrate several points, Ms. Watts Davis led the group in an exercise. She asked participants to form lines facing the wall. Then participants were instructed to pat the back of the person in front of them and to give that person a shoulder massage. Afterward, Ms. Watts Davis noted the lessons of the exercise:

- Participants had shown faith that they would be doing a good thing, because they followed the instructions without question.
- Participants crossed a divide to reach each other because some people had to move around to form lines.
- Participants connected and reciprocated and showed strength.

Summit Overview

Callie Gass, Project Director, FASD Center for Excellence

The goals of the summit are greater awareness of FASD. Through networking and sharing, participants will feel empowered to take action. They will be touched and touch others.

Ms. Gass invited participants to testify at the Town Hall meeting, which is a place for families to share experiences. There will be a report to Congress about the meetings. In addition, the meetings help guide CSAP and the Center for Substance Abuse Treatment. Finally, the FASD Center is forming a network of women in recovery. There is support for women whose children have FASD and hope for recovery for women and their children.

Alcohol and Women: What You Need To Know

Faye Calhoun, DPA, MS, National Institute on Alcohol Abuse and Alcoholism (NIAAA)

NIAAA is one of 27 institutes of the National Institutes of Health (NIH). NIH strives to improve the health of Americans through research. NIAAA focuses on alcohol-related issues. Its vision is to:



- Remove stigma
- Find mechanisms of individual response to alcohol and resulting risks and benefits of alcohol to health
- Develop effective prevention and treatment
- Improve access to quality care



The summit represents a partnership between NIAAA, SAMHSA officials, and women in recovery.

Dr. Calhoun discussed alcohol and health. Alcohol is all the same, whether it is beer, liquor, wine, or a cooler. The main ingredient is alcohol. Half of all women drink occasionally, and young women drink more than older women. The key is knowing when to stop, but the more you drink, the harder it is to stop. Alcoholism is a chronic, relapsing disease that consists of four symptoms: craving, loss of control, physical dependence, and tolerance.

Women develop alcohol problems faster than men. A higher percentage of women than men die from complications such as high blood pressure and liver damage. The alcohol-related death rate for women is 50 to 100 percent higher than for men. Women are also more at risk of accidents and are more likely to have difficulty fulfilling their responsibilities. Due to differences in metabolism, women also get drunk faster from the same amount of alcohol as men, regardless of body size.

Alcohol damages the structure and function of the brain and can lead to heart disease. It also affects the thyroid and kidney function, damages bones, and can cause head, neck, and digestive cancers. In addition, alcohol can cause stillbirth and may be related to sudden infant death syndrome (SIDS). Alcohol also interacts with many medications, such as those for depression, diabetes, and pain. Persons taking these types of medication should not drink.

Risk factors for alcohol problems include having an alcoholic husband. Women with alcoholic husbands are also more likely to have depression and may self-medicate with alcohol. In addition, alcoholism runs in families and stems from a combination of genetics and the environment.

Children of alcoholics are four times more likely to have alcohol problems. They also may have school problems, or mental health problems, or experience embarrassment, shame, and stigma. However, not all children of alcoholics develop problems. Prevention with high-risk children can reduce risk. The National Association of Children of Alcoholics can offer support.

Alcohol problems in women are not treated at a rate that reflects occurrence. However, some successes have been reported. A project funded by NIAAA, Project Match, showed sustained drinking reductions and treatment gains for 3 years. The program combined cognitive-behavioral approaches, 12 step principles, and



motivational components. Combining these elements with Alcoholics Anonymous (AA) produced better results.

The chronic nature of alcoholism needs to be addressed. Treatment reduces health care costs and costs to society. In addition, related issues, such as mental health, need to be addressed. Forty percent of adolescent girls in treatment have posttraumatic stress disorder.

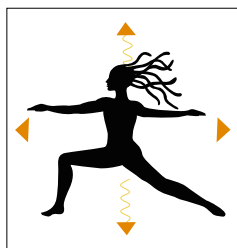
A major issue NIAAA is addressing is FASD. NIAAA sponsors the Interagency Coordinating Committee on Fetal Alcohol Syndrome (ICCFAS). ICCFAS has representatives from all the major government departments that deal with FASD, such as Education and Justice. ICCFAS encourages schools and the justice system to take action and works with health care providers as well. One project involves health care providers in the District of Columbia screening women for alcohol use and raising awareness of FASD.

It is important to reduce stigma. Talking about alcohol use with friends and family can help. "Be your sister's keeper." Dr. Calhoun suggested steps such as supporting Recovery Month and Alcohol Screening Day in April, taking a loved one to the doctor, and supporting NIAAA and SAMHSA in their efforts. She closed by recommending pamphlets from NIAAA and sharing NIAAA's Web site, www.niaaa.nih.gov.

Alcohol and Pregnancy: What I Wish I Had Known

Kathleen Mitchell, MHS, LCADC, National Organization on Fetal Alcohol Syndrome

Ms. Mitchell introduced her daughter, Karli Schrider, the artist who created the NOFAS logo, which has been trademarked. NOFAS is a nonprofit organization devoted to educating treatment centers, medical schools, educators, and anyone who will listen about alcohol use during pregnancy. It is important to understand the connection between preconception health and FASD. Women who drink can prevent FASD by preventing pregnancy.



The summit logo is the warrior mom. This symbolizes moving from victim to warrior. The logo illustrates the warrior stance in yoga, which is centered and focused. The logo also incorporates the circle to symbolize the circle of life and directional signs to symbolize balance and harmony. Birth mothers are fighting across the country and will stop at nothing to help their children with FASD. They are moving toward empowerment and reducing the sense of isolation.

Ms. Mitchell is the birth mother of an adult with FAS and one of seven children of an alcoholic father. All the children were affected by the father's drinking, but not all developed alcoholism. It is impossible to raise children in an alcoholic or addicted household and not affect the children. This is one of the toughest issues to face for parents in early recovery. Alcoholism is a physical disease, not a copout. Years of research from NIH have shown the evidence of this.



Ms. Mitchell shared her experiences while in active addiction. She had an unplanned pregnancy at 15, got married, and dropped out of school. She drank wine periodically during her pregnancy, believing that wine was “good for the baby’s blood.” When her son was 9 months old, she got pregnant with Karli. About 5 years later, she had another baby. She drank through all three pregnancies, and her life became more and more unmanageable.

She got pregnant with a fourth child, who died at birth. That baby’s death just fueled the “victim” mentality; “poor me; pour me a drink.” When she got pregnant again, she saw it as a message. This was to be her miracle baby. Tragically, her infant daughter died suddenly at 3 months.

The intervention for recovery occurred when Ms. Mitchell’s father got into treatment and understood that the only way to help her was to take custody of her children. He took her three children and told her she could not see them until she got treatment. About 18 months later, she went to Mountain Manor. She later relapsed and went to Second Genesis. She said, “You are blessed to get treatment. A lot of women don’t.”

Ms. Mitchell passed the GED test and certified addictions counselor test and eventually received a master’s degree. Today she is a licensed clinician. She did not find out that her daughter Karli had FAS until Karli was 16. Karli had a history of slow development, chronic ear infections, and memory and coordination problems and was misdiagnosed for years. Finally at age 16, she was correctly diagnosed with FAS.

Ms. Mitchell closed her remarks and received a standing ovation.

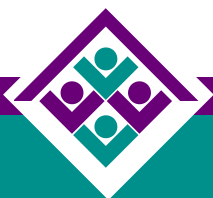


FAS, Not Just Another Pretty Face: Alcohol and the Developing Fetus

Ed Riley, PhD, San Diego University, and Chair, the National FAS/FAE Task Force

Dr. Riley opened with definitions of key terms. Teratology is the study of birth defects. Teratogens, such as alcohol, cause birth defects. A behavioral teratogen affects behavior even when obvious physical problems are not present. Alcohol is a classic behavioral teratogen.

The effects of alcohol on the fetus have been known for thousands of years. There are references in the Bible and the writings of Aristotle. In 18th century England, when the gin tax was lifted, infant mortality increased. When the tax was reinstated, the problem decreased. In the 20th century, alcohol was believed to be safe. In fact, alcohol drips were used as a treatment for premature labor.



The situation changed in 1973 when Jones, et al., published an article identifying FAS. In 1981, the Surgeon General warned about the dangers of alcohol use during pregnancy. Later prevention efforts included warnings on alcohol bottles, comic books, educational materials for doctors, and public education campaigns.

Alcohol use among women has declined since 1995, but frequent drinking and binge drinking levels are still high. In addition, one in seven women of childbearing age engages in risk drinking. This behavior is of concern because half of all pregnancies are unplanned.

In the United States, FAS occurs in 0.3 to 2.2 per 1,000 births. Some countries have higher rates. In South Africa, the rate is over 50 per 1,000 births in some areas. FAS is only one end of a spectrum of disorders resulting from prenatal alcohol exposure. Full FAS includes specific facial features (small eye openings, flat philtrum, and thin upper lip), growth retardation, and central nervous system damage. Anywhere from 10 to 40 percent of children of alcoholics have FAS. In the United States, the rate of effects from prenatal alcohol exposure is believed to be about four times the rate of FAS. These children show evidence of having been exposed to alcohol prenatally but do not have all of the anomalies required for a diagnosis of FAS.

FASD refers to a continuum that includes FAS and other fetal alcohol effects, such as alcohol-related neurodevelopmental disorder (ARND). Prenatal alcohol exposure can result in behavior problems even without obvious physical effects. The diagnosis of FAS is dependent on particular facial features. The face develops during certain critical periods early in pregnancy and many of the features common in FAS result from alcohol exposure at that time. However, the brain develops throughout the whole pregnancy. Prenatal alcohol exposure, at least at high doses, can cause permanent changes in the brain, which can affect the individual's behavior. Behavioral difficulties in persons with FASD can include hyperactivity, attention deficits, and learning problems.



Studies show that children with FAS have smaller brains than control children. The cerebellum appears to be particularly affected, which may relate to balance and attention problems in these children. In some persons, the corpus callosum may be missing and is also smaller than one would predict. The corpus callosum is the major connection between the two hemispheres of the brain; thus, the left and right sides of the brain may not communicate effectively. This might affect the ability to deal with complex stimuli and situations, where integration between the two hemispheres is required.



Persons with FAS may also have smaller frontal lobes and basal ganglia. The fact that these areas are smaller may relate to difficulties in executive functions, including problem solving and memory. Knowing which brain areas are most affected by prenatal alcohol exposure may help inform treatment.

FAS is the leading known cause of mental retardation in the western world, but most people with FAS are not retarded. The average IQ is in the low 70s and the average IQ of persons without full-blown FAS but with known prenatal exposure to heavy alcohol is in the low 80s. Individuals with FASD have speech and language problems, balance problems, and slower motor skills. They may have difficulty getting organized, staying focused, following rules, forming concepts, and making decisions.

Individuals with FASD can develop many behavior problems as they get older. More than 90 percent have received mental health treatment. Sixty percent have experienced school disruption. Many also experience trouble with the law, including incarceration, as well as substance abuse problems. Factors that may protect persons with FASD from negative outcomes include a diagnosis before the age of 6, a stable home, and a lack of violence. In addition, an FAS diagnosis is a protective factor because persons with FAS are more likely to receive services.

Individuals with FASD can have a pattern of strengths and weaknesses. We hope to identify a behavioral profile that can help in the diagnosis of FASD, especially in those cases where obvious physical characteristics are not present. Doing so may assist in providing for early intervention, which is known to have beneficial effects on subsequent outcomes. Effective and available treatment is essential, as is prevention, because FASD is entirely preventable.



If the Eyes Have No Tears, the Soul Has No Rainbow

Julie Gelo and Kathleen Mitchell, MHS, LCADC, NOFAS

Ms. Mitchell opened by saying that maternal alcohol use is the leading known cause of preventable mental retardation and can cause lifelong disabilities. In the United States, 3,890,000 babies are born each year. About 1 percent, or 38,900, of these babies have FASD. About 8,000 have full FAS. In contrast, 3,890 have Down syndrome and 1,244 have spina bifida.

Individuals with FAS may have symptoms similar to those of other disorders, such as attention deficit hyperactivity disorder (ADHD), but differences are evident. Children with ADHD have trouble focusing and sustaining attention but do not have memory deficits. Children with FAS can focus but have trouble shifting attention and also have memory deficits.



Most people with FASD are misdiagnosed. The disorders are not genetic but are caused by maternal drinking. In describing maternal drinking, it is important to understand the levels of drinking. A binge is four drinks at one time, such as one Long Island iced tea that contains four shots of liquor. Pregnant women who drink five or more drinks at one time during the first trimester are eight times more likely to have an infant die of SIDS.

Proper diagnosis is important in obtaining appropriate services. It also helps to look at the strengths of persons with FASD. Many are friendly, helpful, likeable, pure of heart, and good with younger children. It is important to change from linear thinking to circular thinking. Instead of looking at milestones that may not be met, it is better to ask, "What is right about my child? What are the lessons?"

Primary prevention of FASD includes reproductive health planning. If women who drink do not become pregnant, then FASD will not occur.

Ms. Gelo described persons with FASD as falling along a spectrum developmentally. Difficulties during infancy may include:

- Sleep disorders
- Feeding difficulties
- Health concerns
- Over- or underresponsiveness to stimuli
- Developmental delays

Infants need routines to function well. Ms. Gelo described her son Brandon as an example. He had feeding problems and needed a feeding tube. He also did not walk until 24 months and needed a walker.

Among toddlers, infancy issues may remain. Toddlers also may have motor and speech delays. They may be impulsive, distractible, and hyperactive, and some experience sensory defensiveness.

School-agers have trouble staying on task. They also have social communication problems, boundary issues, and poor peer interaction. Many have academic issues and handwriting difficulties and need classroom modifications. Because services are often tied to IQ, some children do not receive the assistance they need.

During puberty, youth with FASD may become defiant. They do not understand cause and effect and are easily influenced by peers. They may have hygiene problems and trouble making and keeping friends. Many children with FASD may function at half their chronological age cognitively, socially, and emotionally. Issues arise related to driving, sexuality, mental health, substance abuse, and future planning in terms of jobs and independent living.

Issues for adults with FASD include:

- Birth control
- Pregnancy
- Substance abuse



- Mental health
- Parenting children with alcohol exposure
- Parenting children who are higher functioning than they are

It is important to shift thinking from noncompliant to noncompetent. The idea is to change from “won’t” to “can’t.” For example, a person with FASD is not a thief. He does not understand ownership. A child who will not stop playing to do chores is not willful or disobedient. He has trouble with transitions and impulse control.

Ms. Gelo announced a meeting of birth families called “Creating a Circle of Hope: Birth Families Unite,” to be held as part of “Truth or Consequences of FAS” at the Atlantic City Convention Center in New Jersey on October 27 and 28.

Birth Mother Panel

Before the panel presentations, Mountain Manor presented Kathleen Mitchell with an award of appreciation.

Diane Malbin

Ms. Malbin’s daughter taught her the “heart of fetal alcohol,” unconditional love, and trying and trying and trying. Her energy borne of grief and shame turned to energy to “not sit down and shut up.”

Marcy Ten Eyck and Sidney Guimont (Marcy’s daughter, 28, with FAS)

Ms. Ten Eyck has been sober for 23 years. After 2 years of sobriety, she went for certified addictions counseling training and learned about FAS. She had Sidney diagnosed. Her teacher in middle school adapted to her learning style and Sidney teaches people how to help her. Marcy said that women need to work through the guilt to avoid relapse. “Warrior moms” can be confused and lonely.



Angelina Locklear-Taylor

Ms. Locklear-Taylor drank while pregnant. Her doctor said that it was o.k. to drink. When her son got to school, the faculty spotted problems but did not know what was wrong. He was a slow learner but his grades were o.k. By middle school, he was way behind and hated going. He was truant in hopes of being suspended.

Ms. Locklear-Taylor became sober in 1988. Her son got into a wilderness program and later was working. But one night he shot and killed his father. He is now on death row and his case is on appeal. Ms. Locklear-Taylor said to “remember that we have a disease.”



Julie Gelo

Ms. Gelo went to Al-Anon and thought that her problems were related to her husband's drinking and her father's drinking. She finally realized that she had a problem and got into treatment and AA. She took her foster children for diagnosis and recognized the signs and symptoms of FASD in her birth daughter. She took her for diagnosis as well. Diagnosis is important. Young adults coming to the clinic where Ms. Gelo works are relieved to know what is wrong and to get help.

FASD Strategies for Families Through the Lifespan

Diane Malbin, MSW, and Marcy Ten Eyck, MC, LMHC, MAC, CDP

Ms. Ten Eyck said that the family is a system. FASD is like a stick in the engine that keeps the system from running. Everything revolves around FASD. She recommended the book *Adult Children of Alcoholics* by Janet Woititz, which talks about family roles. The roles are:

- Chief helper
- Mascot (makes people laugh, gets attention)
- Scapegoat
- Hero
- Lost child

Each role serves a purpose for the person, but no one gets any nurturing. In addition, problems can arise if people seek attention outside the family.

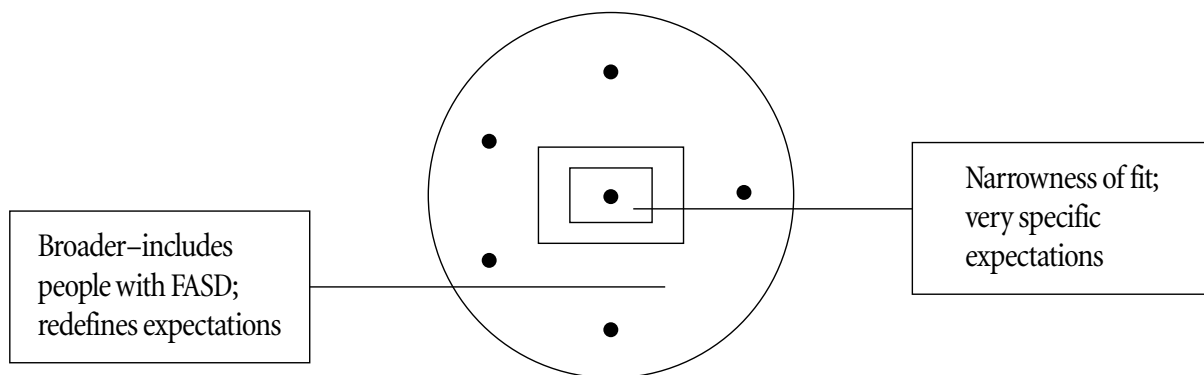
In dealing with FASD, there is a cycle of grief, similar to the one Kubler-Ross described in the stages of death and dying. The person who has a family member with FASD goes through shock, denial, bargaining, anger, deep sadness, and acceptance. Acceptance involves accepting that someone we love has a disability, that it is a brain injury, and that he or she is not a bad person. Many people get stuck in anger.

Ms. Malbin emphasized that it is important to get our needs met—the need to matter, to be heard, to be important. Relationships help in getting our needs met. Information leads to knowledge and understanding, which promote acceptance, which helps in establishing relationships.

It is important to look at where a child is developmentally. She talked about a boy named Fred, who was 7 years old but functioned as a capable 3-year-old. His teachers' goal was to get him to act his age appropriately. This goal was inappropriate because Fred could not act his age. He had auditory processing problems and processed information slower. Fred was a "10-second kid in a 1-second world."



It is important to meet the needs of people with a physical disability that manifests behaviorally. Punishing the child for the disability is inappropriate. The individuals' needs should be addressed on a case-by-case basis. Modifying the situation to fit the child's needs creates "goodness of fit." Ms. Malbin illustrated this concept with a diagram.



Diagnosis and Treatment: How Do I Begin?

Paula Lockhart, MD, Kennedy Krieger Institute

Dr. Lockhart started out looking at prenatal drug use and saw the effects of alcohol, so she moved into the field of FASD. If a child is alcohol exposed and has problem behaviors or academic trouble, the first step is to obtain an informed mental health evaluation. The person conducting the evaluation needs to know about FASD. This individual can provide useful suggestions on how to help the child, which can lead to appropriate treatment that may slow or reverse the progression of the child's difficulty.

It is best to get an evaluation as soon as possible. An evaluation can bring relief and decrease the emotional fallout from an undiagnosed disability. The types of complaints leading to an FASD diagnosis include:

- Inattention
- Memory problems
- Immature social skills
- Living skills that are not age appropriate (e.g., tying shoes, getting ready for school, brushing teeth, taking a bath)



- Fearfulness
- Nervousness
- Hyperactivity
- Impulsivity
- Tearfulness
- Pessimism
- Low self-esteem

The first step in determining the type of evaluation needed is a pediatric visit for advice and a physical. It is important to discuss suspicions. If the physician cannot help, NOFAS can provide help and resources.

An informed child psychiatrist, developmental pediatrician, licensed clinical social worker, or clinical psychologist can perform a mental health evaluation. A multidisciplinary evaluation includes an occupational therapist, developmental pediatrician, psychiatrist, and dysmorphologist. The mental health evaluation includes:

- Present and past history of problems
- Medical, developmental, and family history
- Mental status exam
- Recommendations

Information needed includes birth history, developmental milestones, and alcohol exposure (amount, duration, and timing).

Treatment may include:

- Environmental restructuring
- Medications
- Talk or play therapy
- Social skills therapy
- Positive behavioral support
- In-home support
- Mentoring

Environmental restructuring may include decreasing stimulation and creating a child-friendly setting. Medications may involve trial and error because they have not been tested on individuals with FASD.

We still have a long way to go in the psychiatric field. Parents are the best advocates for children with FASD. They can share FASD information and Web sites with practitioners.



Preparation for Testimonies: An Overview

Julie Gelo and Marcy Ten Eyck, MC, LMHC, MAC, CDP

Ms. Gelo and Ms. Ten Eyck shared some tips for testifying at the Town Hall meeting. These tips apply to testifying at any type of open forum:

- There is no right or wrong thing to say or way to feel. The key is to talk about how you feel and how you see the situation now. Your story may change from one day to the next. You may feel frightened, tearful, angry, or proud. You can turn grief and anger into constructive energy.
- You are the expert in the care of your child with special needs. Family stories are important to both parents and professionals. They help parents know they are not alone and they provide insight for professionals and providers. The information can help service providers create new and effective programs.
- Share your story when you feel comfortable. You can provide written testimony if you prefer.
- Issues to address can include medication, finances, emotions, education, dependency, fears, dreams, and impact on marriages. Share positive and negative experiences.
- Open with name, partner, where you live, and number of children.
- Relax. Take a few deep breaths and look for a friendly or familiar face, project (use the microphone), and speak calmly and slowly. It helps to write your story down when you have only a specified time to talk.
- Make eye contact, look at friendly faces, and look around so that everyone feels included.
- Humor is o.k. but not sarcasm or teasing. Also, it is o.k. to say “I don’t know” or “I don’t want to answer that.” If you cry, take some deep breaths and take a moment to compose yourself. You might want to use a squishy ball to relax.
- You are not alone. You are the expert. Strength and power come from accepting, sharing, and change.

Tuesday, September 9

Welcome

Deborah Stone, PhD, Project Officer, Substance Abuse and Mental Health Services Administration, Center for Substance Abuse Prevention

Callie Gass, FASD Center for Excellence

Dr. Stone noted that it was FAS Awareness Day. To commemorate the occasion, St. Paul’s Church had a bell ringing. Bells symbolize the purity and innocence of children. They also are used as a warning.

Ms. Gass gave an overview of the FASD Center. She noted that the Center worked with NOFAS on the summit, which was an incredible experience and created a wonderful partnership.



The FASD Center was mandated by Congress in the Children's Health Act of 2000. The mandates are:

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

So far, no exemplary community systems of care have been identified. The women's summit and the birth mother network are part of the efforts to develop innovative prevention techniques.

Partners include the Steering Committee, NOFAS, the FAS Family Resource Institute, and anyone working on FASD. The Center's goals are to advance the field and develop systems of care. The vision is a nation without FASD and an integrated collaborative approach to preventing and treating FASD.

Activities include Town Hall meetings, an Information Resource Center, training, and replications of promising practices. The FASD Center has held 13 Town Hall meetings and the testimony has been similar. Over and over we hear that many systems are involved:

- Education
- Mental health
- Social services
- Developmental disabilities
- Substance abuse treatment
- Justice
- Vocational rehabilitation
- Health
- Entitlement (e.g., Social Security)

These systems need to have a better understanding of FASD.

Other needs identified at the Town Hall meetings include developmental disability eligibility regardless of IQ, appropriate services (e.g., diagnosis, education, housing, job support), respite care, and financial support. In addition, coordinated and collaborative prevention and treatment systems are needed, as well as consensus in terminology and national standards of care.

The FASD Center operates an Information Resource Center, which is accessible by phone, e-mail, and the Web. It provides information in English and Spanish. Services include publications and customized literature searches. Training and technical assistance can also be requested.



FASD Center staff have identified services in the United States and Canada. Staff found 411 programs: 87 universal, 37 selective, 33 indicated for women with alcohol and drug problems, and 254 indicated for persons with FASD. Half the programs are in Canada.

Ms. Gass urged participants to use the FASD Center and its recommendations.

FASD Overview

Kathleen Mitchell, MHS, LCADC, NOFAS

Ms. Mitchell opened by saying that we need to educate providers to recognize risk, distribute information, and encourage contraception. She noted that 120 women in recovery attended day 1 of the summit. Summit goals are to educate women in treatment and the professionals who treat them, to empower women, and to bring together policymakers to build momentum and develop a plan in Maryland to address FASD. The summit and the Town Hall meeting will be documented.

Maternal alcohol use is the leading known cause of preventable mental retardation and a leading cause of birth defects. However, most people with FASD do not have mental retardation. They do have problems with memory, sequencing, and other aspects of learning. Misdiagnosis can be a problem and can last for years as multiple professionals misdiagnose.

FASD includes FAS, ARND, and alcohol-related birth defects (ARBD). FAS includes facial features, brain and central nervous system damage, and growth retardation. ARND includes central nervous system and brain damage without the characteristic facial features or growth retardation. ARND is often misdiagnosed. ARBD includes physical defects such as cleft lip, scoliosis, and organ damage.

FAS is the tip of the iceberg. In the United States each year, more than 4 million babies are born. Nearly 40,000 have FASD, of whom 8,000 have FAS. In contrast, about 4,000 have Down syndrome and 1,200 have spina bifida.

Over the years, it has become more permissible for young women to drink. Drinking by college women has increased. One study showed a 400 percent increase in frequent drinking (7 drinks/week) and binge drinking (5 drinks in one episode) by pregnant women between 1991 and 1995.

Alcohol is a teratogenic drug that can cause functional deficits, malformation, growth deficiency, and death. For example, out of 120 women in recovery at the summit, 4 reported SIDS in one of their children. Alcohol affects certain parts of the brain and has a dose-response effect. The frequency, amount, and timing of consumption affect the fetus. Effects can include disorders such as microcephaly, muscle tone problems, learning disabilities, and hyperactivity. Still, persons with FASD have many strengths. They can be friendly, helpful, likable, and pure of heart. They want to be liked and are usually good with younger children and older adults.





Ms. Mitchell talked about her daughter Karli (shown in the photo with her cousin Brooke). Karli was a healthy baby. She developed ear infections, but the doctor said that she was fine. Her school said that Karli was manipulative because she would learn something one day and forget it the next. She was diagnosed with cerebral palsy at age 9. When she was 16, she was diagnosed with FAS.

It is important to diagnose FASD to eliminate or reduce misdiagnosis and get appropriate medical care and therapy. It also helps in creating systems to address the needs of persons with FASD. In addition, it can help break the cycle within a family by providing parenting skills education and counseling.

Global prevention efforts can help prevent FASD as well as secondary disabilities, such as substance abuse. Other suggestions include advocacy for families, screening of mothers and children, and treatment. The State of Maryland can help disseminate information, such as brochures and posters, and conduct workshops.

Costs of FASD in Maryland

Rick Harwood, Vice President, The Lewin Group

Deborah Stone introduced Rick Harwood. She began by sharing new statistics that 12 to 17 percent of pregnant women drink and binge drinking among young women has increased 500 percent in the past few years. She also noted that the FAS facial features occur in the third week of pregnancy, before many women know that they are pregnant. Dr. Stone thanked SAMHSA's partners: the Centers for Disease Control and Prevention (CDC), the Health Resources and Services Administration, NIAAA, NOFAS, and Conwal.

Mr. Harwood talked about research on costs of FASD. Currently, costs focus on FAS, but researchers are attempting to update the figures. FAS cost the United States \$5.4 billion in 2003. In Maryland, the cost was about \$102 million. Maryland may have up to 760 alcohol-affected births each year.

Lifetime health costs are about \$860,000, which means investing \$300,000 today to have enough money available over time. The costs can be as high as \$4.2 million. FAS prevention may be cost-effective at up to \$850,000 per child. FAS occurs in as many as 2 births/1,000. In Maryland, the figure is 150 births total. FASD may occur in four times as many births, or 600 births in Maryland. Currently, about 50,000 people in Maryland have FASD but more information is needed.

Cost-of-illness studies identify the types of problems caused by FASD and the resources needed to address them, such as special education and housing. The costs are not just determined by economics. Epidemiologists are also involved to help determine incidence and prevalence, which affect cost estimates.





Costs are usually divided into two categories: direct and indirect. Direct costs include health care, social services, and criminal justice (e.g., trial, incarceration). Indirect costs include lost productivity from morbidity and mortality and disability. Services include neonatal intensive care, audiology, special education, and residential care. Additional costs may include mental health, criminal justice, and vocational rehabilitation.

Nationally, direct costs for FASD in 2003 amounted to \$3.9 billion. Indirect costs amounted to \$1.5 billion. In Maryland, direct costs in 2003 were \$74 million. Indirect costs were \$28 million.

New areas of study include prevalence of FASD and cost-effectiveness of preventive interventions. Very little strong research has been conducted on effectiveness. It is difficult to rigorously evaluate particular prevention efforts. However, it has been determined that FAS reduces quality of life years by 17 percent or 11 years. Preventing one case of FAS would save \$550,000 in the value of quality of life years and \$300,000 in medical costs.

Diagnosing and Treating FASD

Paula Lockhart, MD, Kennedy Krieger Institute

FASD occurs in about 1 percent of all births. Persons with FASD have a high incidence of mental health problems and behavior problems. Protective factors include:

- Early diagnosis
- Stable environment
- IQ below 70 (due to ability to qualify for services)
- Full FAS facial features (due to ease of diagnosis and ability to qualify for services)

Mental health professionals need to appreciate the value of prenatal alcohol exposure information in evaluating clients.

Professionals who can perform mental health evaluations include:

- Developmental pediatricians
- Pediatric neurologists
- Psychiatrists
- Licensed clinical social workers
- Clinical psychologists
- Certified professional counselors
- Clinical nurse specialists



Not all children with FASD have mental health problems, but an evaluation can document challenges, show how the individual is functioning, and identify educational issues. A psychiatric evaluation is recommended when emotional and behavioral issues interfere with functioning, behavior is dangerous or bizarre, or the child is persistently sad, moody, or withdrawn. Mental health risk factors include genetic predisposition, extreme deprivation, and exposure to violence.

Unrealistic expectations and being called slow can cause mental health problems in persons with FASD. Therefore, it is important to integrate behavioral and cognitive issues in an evaluation. Because mental health problems in FASD are multifactorial, it is best to conduct a case-specific multidisciplinary evaluation. Serious behavioral, emotional, and cognitive problems can exist anywhere on the spectrum of FASD. Cognitive disabilities, behavior problems, social skills deficits, speech/language disabilities, and alcohol exposure can range from mild to severe.

The purpose of a mental health evaluation, diagnosis, and treatment is to diagnose and treat Diagnostic and Statistical Manual (DSM) diagnoses. Although the DSM is inadequate in the area of FASD, one can diagnose the severity of FASD effects and psychosocial disabilities. It is important to get as thorough a prenatal alcohol history as possible. The primary historian for the child and family is important. This person needs to be knowledgeable and reliable. The person may be affected by burnout, crisis, or grief and loss and these issues need to be considered in gathering information.

Common misdiagnoses occur. The child may have the condition that is diagnosed, such as ADHD, psychosis, or autism, but FASD is missed. A child may also have a co-occurring disorder. A thorough mental health evaluation involves determining the presenting complaint, developmental and academic history, and medical and psychosocial history. This evaluation can help in identifying FASD. Other helpful consultations include developmental pediatricians or neurologists, speech and language specialists, educational specialists, and occupational therapists.

In terms of treatment, psychotropic medications, such as antidepressants, can help but may not be useful when FASD has not been identified. Other interventions are important as well, such as restructuring the environment. In addition, it is essential to uncover and reinforce strengths, as this builds self-esteem.

FASD: Effects on the Family

Panel of Families Living With FASD

Vince Bianco is the adoptive parent of five children ages 7 to 32. The younger three have FASD. They experienced a range of prenatal alcohol and drug exposure. His 17-year-old son is the most severely affected and is borderline intellectually. Mr. Bianco has had to educate health and social service workers, juvenile corrections staff, and Easter Seals. He feels as if he and his wife are experts but do not have all the answers.





Betty Simmons lives in Baltimore. She has six adoptive daughters with FASD. One daughter is in a detention center after an assault at a treatment center. The judge did not charge her but no residential treatment center will take her. Ms. Simmons needs income support to help her other children remain at home. She said that services are not working.

Mary Bianco is married to Vince Bianco. One of her sons was diagnosed at 4 months with FAS. He was very difficult from infancy on. She had to teach him sign language, and his learning and cognitive disabilities were so bad that she home schooled him. At 13, he got involved with a manipulative child and did not know right from wrong. He was convicted of a felony. The State conducted a 45-minute evaluation, found him antisocial, and recommended incarceration. A private evaluation was conducted for 1 1/2 days.

The State finally said that Ms. Bianco's son could stay home but had to attend treatment. However, the treatment did not fit him cognitively. He functioned at the 5-year-old level, but the youths were 13 to 17. Thus, after 25 years in one place, the family moved to Maryland to get better services. Ms. Bianco said that the justice system needs to be revamped because "these children don't know what they're doing and cannot be held responsible."

Jennifer Goudy has two adopted children from Russia with FASD. They initially tested normal for emotional and intellectual functioning but problems arose. The family has provided no support. She is constantly meeting with therapists and educators to convince them of the children's learning disabilities. It is hard to find doctors who understand FASD. There is a very small group of people in the medical community who really understand the implications of FASD. That needs to be expanded.

Her younger son is on psychotropic medications and it is helping. Her children have the same diagnosis but handle it differently. One child is suicidal and one is homicidal, so "I'm stuck in the middle." She is going through a divorce, and her husband will not pay for interventions because he does not believe in them. The judge said that she would have to sell her house, but moving would devastate her children. Support is needed from the justice and education systems to help these children. In addition, there are not enough medical professionals who understand what happens to families. "I have lost friends, I have lost family members, my entire life has changed. The stress is unbelievable."

Lydia Klene has one biologic child and two adopted from Russia. She immediately knew that something was wrong with her daughter. She was hyperactive and did not learn like other children. Two doctors diagnosed her at Children's Hospital. She could not tolerate medications, so Ms. Klene said, "I felt like a prisoner in my home."





Her daughter is now on Concerta and it is helping a lot with her learning. Ms. Klene said that teachers do not know about FAS. There are programs for autism and Down syndrome but nothing for FAS. We need to educate medical students and teachers. She also said that she cannot afford private testing but is not doing any State-provided educational testing for fear of not qualifying for services.

Joan Carter is the birth mother of a 39-year-old woman with FAS who has been seeing specialists since she was an infant. When her daughter was 19, Ms. Carter saw a *Family Circle*

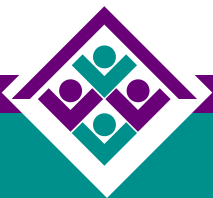
article and suspected FAS. She said that a lot of children are not diagnosed because doctors are not comfortable telling mothers that their children are damaged and it is their fault. She said that we need more education in medical schools on how to communicate about FAS and prevent FAS. She suggested warning signs, education starting in 6th grade, and programs for siblings who are hurt by FAS. Her daughter has had one-on-one teaching and programs focusing on her strengths. She is now in a program for people with mental illness. She has bipolar disorder and alcohol problems. She is learning to communicate through mime but needs long-term services.

Dave Duncan has a 33-year-old son adopted from Alaska at 2 months. He took his son to doctors and specialists. When his wife read *The Broken Cord*, "the light went on." His son has an average IQ, so he does not qualify for services. He has had trouble with the law but he had an understanding lawyer who convinced the judge that he needed treatment. He still lives at home. He is working but has problems managing money and planning. The biggest concern is his future. He needs support when his parents are no longer available.

Lisa Leandre has three girls, including an 11-year-old niece who came to live with her and her husband at age 3. She was diagnosed with fetal alcohol effects 2 year ago. Their niece has poor motor coordination and attention deficits. They had problems with the pediatrician and changed to Children's Hospital. When they moved to Michigan, they found a family support group. Ms. Leandre is a teacher and found that teachers did not understand how the children learned. She spent time educating teachers about classroom strategies. Parents need to advocate for their children and pediatricians and counselors need to listen to parents.

Emma Royal has five adopted children, including two with FAS. She feels very blessed and would do it again. She wants her son to have dignity and independence. She said, "Before I leave this earth, I would like to know that he's safe and that he's happy." She wants to have her son placed outside her home with her involved and his agreement. She does not want to sever her family.

Julie Graziani has a 14-year-old son. He has been going to Dr. Lockhart for 7 years. They are trying medications. Ms. Graziani said that we need a way to test children with FASD. They need special accommodations. "They don't fit in a box." Familiarity and stability are also very important. She is going



through a divorce and is focusing on her son. They live in a neighborhood where he has thrived, but she is scared about the future.

Nancy Rhodes is a foster and adoptive mother of four children and has two grown biologic children. She has experienced misdiagnosis. She said we need education, understanding, and support. We need more doctors who are understanding like Dr. Lockhart.

Coming Up Roses: Cultivating a Continuum of Services for FAS Prevention, Diagnosis, and Service in the Garden State

Deborah Cohen, PhD, Director, Office for Prevention of Mental Retardation and Developmental Disabilities, Department of Human Services, State of New Jersey

Dr. Cohen talked about the Governor's Council on Prevention of Mental Retardation and Developmental Disabilities. In the early 1980s, the President's Commission on Prevention of Mental Retardation had a conference. New Jersey received funding and set up the Governor's Council in 1983. The State also organized the first FAS task force. In 1985, they published a seminal report on New Jersey prevention programs and recommended a permanent Governor's Council and Office for Prevention.



In 1987, a law was enacted in New Jersey creating the Governor's Council and Office for Prevention. In 1989, the Department of Health established an FAS risk reduction program and provided support for prevention staff in clinics and inner-city hospitals. They would refer women for treatment, but there were not enough treatment slots. This is still a problem.

In 1991, CDC sponsored a national FAS conference and featured the New Jersey program. A year later, New Jersey held a conference to educate judges and other justice system professionals about FAS. In 1994, the Governor's Council on

Prevention set aside funds to support FAS prevention and education programs. The following year, the Governor's Council held a conference to educate physicians about FAS and possible legal and malpractice issues. Unfortunately, only 10 physicians attended.

In the mid-1990s, prevention efforts in New Jersey increased. In 1995, the State enacted point-of-sale warning sign legislation. The signs have helped educate bartenders about liability issues related to serving alcohol to pregnant women. In 1997, the Arc of New Jersey organized its first two Pregnant Pause events in two counties. Events are now held in all 21 counties through the collaborative sponsorship of community agencies. Pregnant Pause events include baby showers with nonalcoholic drink contests.



In 1998, New Jersey sponsored “Truth and Consequences of FAS” with Ann Streissguth as the keynote speaker. After the conference, the State revived the New Jersey FAS Task Force. It is now a standing committee of the Governor’s Council on Prevention of Mental Retardation and Developmental Disabilities. In 2001, the Task Force submitted a report on the status of prevention, diagnosis, and treatment. The Task Force recommended a comprehensive system to address FASD.

New Jersey’s efforts related to FASD now include:

- **Prevention and Outreach.** New Jersey core curriculum standards include FASD education in grades 8, 10, and 12. Presentations are given annually at the teachers’ conference and all school nurses receive information about FASD.
- **Community Education.** FASD staff are focusing on protective services because they are often the first people to encounter the children. The Office for Prevention is working with the Division of Youth and Family Services (DYFS) to implement training. Foster parent organizations and foster families participate on the Task Force. The State is working to put together a certification program for DYFS case workers and supervisors related to drug and alcohol effects on families.
- **Professional Education.** The New Jersey Medical School is a CDC-funded Regional FAS Training Center. The centers are working on standardized curricula for medical schools and other allied health professionals, including nurses. The Regional FAS Training Center plans to require FAS as part of continuing education. A perinatal addictions certification program began in summer 2003.
- **Risk Reduction.** A system is in place in the maternal and child health system. Regional perinatal centers have added perinatal addictions specialists.
- **Diagnosis and Treatment.** There are now six diagnostic centers. About 1,400 children have been referred and screened. Of those, 89 were diagnosed with FAS and 14 with ARND. In addition, more than 70 presentations have been given to 1,500 people.
- **Surveillance and Evaluation.** Diagnostic centers report all cases.
- **Treatment Services.** This is a work in progress. There are special child health services staff. Juvenile and criminal justice workers need to be trained. The biggest barrier to treatment is eligibility criteria.

Dr. Cohen announced the “Truth and Consequences of FAS” conference in Atlantic City in October.

FASD in Maryland: Where We Are and Where We Are Going

Thomas Davis, Governor’s Office, Director, Drug and Alcohol Council (moderator)

Mr. Davis praised the meeting and the value of firsthand stories at the Town Hall meeting. “We do not want anything we have learned to be lost.” He also said that Maryland will take the responsibility to follow the lead of other States, such as New Jersey and Minnesota.



The purpose of the panel is to look at what Maryland is doing. The five panelists are:

- Pauline Menes, a delegate from Prince George's County and one of the founders of the Women's Caucus. She is chairperson of the House Special Committee on Alcohol and Drug Abuse.
- Raymond Miller, chief of treatment services for the Maryland Alcohol and Drug Abuse Administration. He also serves on the new governor's task force on the needs of persons with co-occurring mental health and substance abuse disorders.
- Dr. Diana Cheng, director of women's health at the Department of Health and Mental Hygiene.
- Dr. Marisela Gomez, medical director for health services at the Department of Juvenile Services.
- Rosemary Murphey, deputy director of health choice and acute care administration in the Office of Health Services in the Department of Health and Mental Hygiene.

Mr. Davis discussed issues facing Maryland related to FASD, such as:

- Lack of diagnosis
- Lack of awareness in the medical profession and in the education system
- Fragmentation in delivery of care, which affects referral, treatment, and payment for treatment
- Lack of education and treatment resources
- Need for family case management to connect families with resources
- Challenges for the justice system in dealing with FASD
- Need for sibling services
- Need for long-range services for people with FASD

There are successful outcomes for the women and families who have children with FASD and it is through treatment. Also, persons with FASD have strengths. We need to stop focusing on what they cannot do and start focusing on what they can do.

Delegate Menes said that she is typical of her colleagues, who know very little, if anything, about FASD. There are many things Maryland could be doing but is not doing. She is not aware of any legislative endeavors addressing FASD. Ms. Menes plans to be more active in the legislature around FASD issues.

Ms. Menes plans to bring information to the Women's Caucus. One-third of the Maryland House and Senate are women, who will be interested in hearing about FASD, so there will be allies in supporting anything that comes along in this area. Very few of them have any background in FASD.

The Special Committee on Drug and Alcohol Abuse has been very interested in drinking and driving but not in the problems related to pregnant women drinking and the results of that drinking. Delegate Menes will work to educate the committee members on the effects of prenatal alcohol exposure. She is also looking to New Jersey as a model for the State of Maryland to replicate.



Mr. Miller talked about the Alcohol and Drug Abuse Administration (ADAA) within the Department of Health and Mental Health Hygiene. It is the single State agency for alcohol and drug prevention and treatment. There are 374 certified treatment programs in Maryland and prevention programs in all 24 political jurisdictions in Maryland.

Of the 374 treatment programs, 156 are funded by the ADAA. The others are privately funded and run the gamut from nonprofit to for-profit. Maryland has approximately 44 medication-assisted treatment programs; half are funded by the State. There are also 23 certified women's programs; some will take women with children. Six or seven are residential programs for women with children.

All the prevention programs and most of the drug treatment programs have varying degrees of FASD education. But the State is nowhere near where it needs to be. As a clinician, Mr. Miller would talk about FAS and the role of the father. He would encourage fathers to stop drinking alcohol before the mother got pregnant. However, he did not know where to refer people. He now knows of many resources and learned a great deal at the conference.



Mr. Miller talked about an adolescent who came in for an evaluation. Mr. Miller suspected FAS. The young man had been through the legal system, had been institutionalized on and off, and had been in outpatient and residential alcohol and drug treatment programs. But no one raised the possibility of FAS. The young man could not get consistent treatment, relapsed several times, and ended up in the juvenile justice system. Mr. Miller believes the outcome might have been different if he had the information then that he has now. He will take information back to the administration and Peter Luongo, ADAA director, as well as the Maryland Addiction Directors Council.

Dr. Cheng is an obstetrician and gynecologist. She learned about FASD while working on the West Coast. When she came to Maryland, she asked how many babies were born with FAS and she was told of one baby. In light of that statistic, she said that Maryland needs more screening and diagnosis.

Dr. Cheng worked in maternal and child health and helped develop a pre-conception health campaign. The goal was to have women plan their pregnancies and stop drinking before they got pregnant. However, half of all pregnancies are unplanned and the number is probably higher in the alcohol-using population.

Dr. Cheng moved into women's health, focusing on screening women of childbearing age for alcohol use and promoting family planning among women with alcohol problems. She recently obtained a Federal grant and is



using it to screen alcohol use in women who come to the family planning clinic and refer them for assistance. They are also looking at gender differences related to alcohol use, such as metabolism, tolerance, and treatment preferences.

In closing, Dr. Cheng noted the lack of knowledge about FASD among medical professionals. Teaching priorities do not deal with alcohol issues. The most recent edition of an OB/GYN textbook was 1,600 pages long but only included 1 1/2 pages on FAS. In addition, physicians are not comfortable addressing issues such as substance abuse and mental health. We need more training in behavioral and psychosocial issues and outreach to the medical community to address FASD.

Dr. Gomez did not learn much about FASD until her public health and preventive medicine training. Public health professionals understand prenatal alcohol exposure better than medical professionals. She is now the medical director for the Department of Juvenile Justice. She described symptoms of FASD, including impulse control problems, anxiety, learning disabilities, susceptibility to environmental factors such as a family with alcohol problems, and substance use. These symptoms overlap with the risk factors for juvenile justice involvement.

In one study, almost 36 percent of youth in the juvenile justice system had FASD. Another study compared youth in juvenile justice custody and youth in the custody of the mental health system. Youth in the juvenile justice system had impulse control problems and conduct disorder often associated with FASD.

Dr. Gomez said that the Department of Juvenile Justice has adopted a public health approach. They screen youth for diagnoses that are risk factors for delinquency so that they can be diverted from juvenile justice to the appropriate system. We need to view youth not as failures but as having unaddressed needs. It is also important to identify substance abuse problems so that youth can get treatment and drug and alcohol education. They may become pregnant later so this helps prevent FASD.

The Department has also met with the Brain Injury Association of Maryland, which is interested in screening the juvenile justice population for non-mental health outcomes. Dr. Gomez plans to follow up with them on this issue. She also urged people to look to the Department of Juvenile Justice for data on FASD incidence and prevalence.

Ms. Murphey works with the Medicaid program in the Department of Health and Mental Hygiene. They work in partnership with the maternal and child health programs, which allows the Medicaid program to address the needs of pregnant women and children more effectively. The Medicaid program has expanded to cover pregnant women at up to 250 percent of the poverty level, or up to \$30,000 for a family of three. Medicaid covers one-third of all births in Maryland.



Since 1989, the State has encouraged the use of a risk assessment tool with pregnant women to identify alcohol use and has paid providers to use the tool. Since then, there has been an increase in screening, but self-reporting of alcohol use is small. In addition, Medicaid is paying for health education about alcohol and drug use during pregnancy. They provide a free handout with referral information to providers, as well as a free booklet, "If You Are Pregnant," which has information on alcohol and drugs.

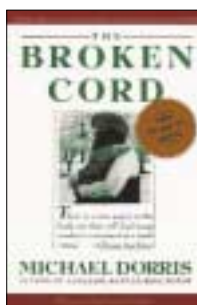
In addition, the Medicaid program's managed care organizations have prenatal case management programs, and Ms. Murphey plans to discuss FASD with the special needs coordinators. The Medicaid program also obtained a waiver to provide family planning-only services to postpartum women at risk. Also, treatment programs have been expanded for pregnant women and day treatment programs are required to allow women to bring their children. Women can also self-refer to substance abuse treatment.

Finally, 27 percent of children in Maryland receive Medicaid services. Early, Periodic Screening, Diagnosis, and Treatment requires screening, including developmental screening from birth. The program encourages mental health screening at 3 and substance abuse screening at 12. Medicaid also is required to cover treatment services to correct or ameliorate physical and mental illnesses. For example, school systems can be reimbursed for services such as occupational therapy. Coordination is an issue, but local health departments are a good resource.

NOFAS Overview

Tom Donaldson, Executive Director, NOFAS

No one was aware of the issue of FASD in the 1950s and 1960s. Then, in 1973, a paper was published about FAS and gave the problem a name. In 1981, the Surgeon General issued a warning to pregnant women not to drink. The Surgeon General also encouraged providers to screen pregnant women for alcohol use and to discuss prenatal alcohol exposure. In 1988, the government warning on alcohol labels was required. The warning is not effective by itself and has not been completely evaluated, but it raises awareness.



By the late 1980s, efforts by individual agencies, such as SAMHSA and NIAAA, were taking place, but there was no coordinated effort or national organization. In 1989, Michael Dorris published *The Broken Cord*, a book about his experiences raising a child with FAS. The book later was turned into a successful television movie. Around then, the founder of NOFAS, Patti Munter, became aware of FAS and wanted to find more information. When she could not find anything, she decided to start an organization that could provide information.

Ms. Munter met Michael Dorris in 1990 and he was very encouraging. She also met with Senator Tom Daschle, who was concerned about his constituents in South Dakota. Ms. Munter founded NOFAS in 1990 and incorporated the organization in South Dakota. She later moved NOFAS to Washington. Primarily, it served as a clearinghouse.



In the mid-1990s, NOFAS expanded its activities and developed the first curriculum on FAS for medical students. The curriculum was piloted at the University of New Mexico and continues today at Georgetown University and Northwestern University. NOFAS also decided to work with youth to educate them about the risks of alcohol and drug use. The organization continued to grow and in the late 1990s changed its logo to use a design by Karli Schrider, who has FAS.

NOFAS has a responsibility as a national organization to perform, to deliver. That is the most important theme in the work that the staff does. The bottom line is raising public awareness of FAS. Additional goals include educating medical professionals, developing culturally appropriate awareness and prevention messages, providing resources, and partnering and collaborating to coordinate activities.



Keynote Presentation

Kumar P. Barve, Majority Leader, Maryland House of Delegates

Mr. Barve apologized for missing Monday's session. He had to work that day. He also said that it was his birthday, so in a way he was celebrating the 45th anniversary of his mother not drinking when she was pregnant. Mr. Barve also acknowledged his colleague, Delegate Menes, and her efforts.

Delegate Barve talked about the importance of getting votes in the House and Senate for legislation. To get votes, it is important to be on the right side of the issue and to have advocates for the issue. He talked about the defeat of legislation to require warning signs in restaurants about FASD. Restaurants had lobbyists available who could advocate on their behalf.

Grassroots support is essential. There are 47 districts in Maryland with constituents who can have an influence. Parents, caregivers, and service providers can be identified in each district who can visit legislators and make them aware of FASD. Mr. Barve said, "Nothing speaks as loudly as a constituent who has a problem they want you to solve."

FASD is not a partisan issue. There is no reason for someone to presume that because a particular party is in charge we cannot begin to craft solutions. The challenge is to go beyond giving money and to give time and energy. This is a problem for which we can find legislative solutions to educate people about FASD. It takes person-to-person contact and a lot of legwork to put together a force for change, but "this is one that we're going to be able to put in the win column."

Closing

Dr. Stone and Ms. Mitchell thanked the participants and staff.

