

Town Hall Meeting on Fetal Alcohol Spectrum Disorders
Raleigh, North Carolina
July 20, 2005

VIP Panelists

- Linda Guzman, Arc of North Carolina
- Marcia Mandel, PhD, Raleigh Children's Services
- Peter Morris, MD, President, North Carolina Pediatric Society, Medical Director, Wake County Health Services
- Angela Mullin, Social Work Consultant, North Carolina Division of Public Health
- Peggy Seo Oba, Steering Committee member, SAMHSA FASD Center for Excellence
- Belinda Pettiford, North Carolina Division of Public Health
- Martin Pharr, PhD, Clinical Director, North Carolina Department of Juvenile Justice and Delinquency Prevention
- Starleen Scott Robbins, North Carolina Division of Mental Health, Developmental Disabilities, and Substance Abuse Services
- Susan Robinson, North Carolina Division of Mental Health, Developmental Disabilities, and Substance Abuse Services
- Kathleen Sulik, PhD, University of North Carolina School of Medicine
- Marceil Ten Eyck, MC, psychotherapist, Steering Committee member, SAMHSA FASD Center for Excellence

Moderator

Kathleen Tavenner Mitchell, National Organization on Fetal Alcohol Syndrome

Testimony

Mother with alcoholism and drug addiction. She has three children. It has been a struggle to find treatment. She started drinking at age 8 and later used drugs as well. Her father and stepfather were alcoholic. It was okay to drink and use drugs in her house. There was domestic violence, physical and sexual abuse. She told her school counselor but no one intervened. She left home at 15 and dealt drugs. She got pregnant at 24 and stopped drinking and using drugs. She married an abusive husband. Her addiction got worse and she started using crack. She wound up pregnant and in jail 2 years ago. Her daughter has developmental delays and is not in her custody. She has been clean for 9 months. She relapsed when her daughter was 3 months old. The Department of Social Services said she had to get help or lose her children. The judge said she had to get long-term treatment but none is available in North Carolina. She had to go to Rhode Island. She relapsed again. Her daughter was adopted and her son is with her ex-husband. She got pregnant again and got into treatment. Her daughter was born healthy.

Starleen Scott Robbins said that substance abuse programs are very poorly funded in North Carolina. The State is working to have specialized programs for pregnant women and women with children but there is not much long-term treatment for these women. She will take the message about the need back to her agency.

Belinda Pettiford with the Baby Love program said that we need more training on substance abuse. It is not always part of the culture. She will share information with others working in the program.

Single mother of a 4-year-old daughter with disabilities. She is recovering from alcoholism and addiction. She cannot figure out what is wrong with her daughter. She did not know about FAS until the women's summit. She is learning to be a mother. She needs to pay attention to her daughter's pain and other problems. Her daughter was born 3 months premature. No one told her about the effects of alcohol on a baby. She said that we need more long-term treatment. "I'm glad I had a chance. Other women should have a chance also."

Single woman, 8 months pregnant. She has been a resident at a treatment facility for 4 months. She was addicted to alcohol and crack for 14 years. She was living in a car with an abusive man. She went to Social Services and got a booklet with an 800 number (1-800-FORBABY). She called and got help and got into treatment. She needed support and got help from vocational rehab, a crisis pregnancy service, and a maternity outreach outworker. She said that long-term treatment is a blessing. "I hope the same for all the women in need. I hope you keep advocating for us because we need it."

Mother of two teenagers. She has exposed her baby to alcohol and drugs. She has been clean and sober for 3 months. She is at a treatment facility and is learning to be a better person through therapy. She said that we need services for men also. Her husband is also a recovering addict. There is not much for people without insurance. She noted that we need more services. There is an outpatient facility in her area across from "Crack Town." It is hard to stay clean in that situation.

Aunt of a niece with an FASD. The girl's mother was a crack addict and binge drinker. The aunt has three sons and a daughter. She noticed her niece was different. She was "clingy and clueless." She did not get that there was a family, and she exhausted her aunt. They got a nanny with trust money they had for her niece. Two of her sons have high functioning autism. She saw that her niece was different from them. It was like "autism with an attitude." She was very clingy at school or distant (no eye contact). Her aunt went online for information and realized her niece probably had FAS. The TEACH program helped her sons but could not help her niece. Doctors are not familiar with symptoms. They sent her to a therapeutic boarding school, where she is doing well academically. Her aunt asked where structure and supervision will come from when she leaves school. Her aunt is very concerned about her future.

Resident at a treatment facility. She has been at the facility for 11 months. She is a survivor of domestic violence and has five children. She had a baby in 2003 who was

born with alcohol and drugs in her system and was taken from her. She would like to see more programs like the one she is in.

Father of four adopted children with FAS, three without FAS, and four grown children. He and his family moved to a more remote area so that the children were not exposed to much. He and his wife adopted two children from Russia in 1996. In 1997 they adopted two children from Texas who had been abused and had a mother who drank. They are 10 and 11 and still in diapers. In 2000, he and his wife adopted three children from Russia, two with FAS. The State could have done more to help them adopt domestically. The State is not adoption friendly. They also have to prepay medications and get reimbursed. He would like to change that so that the bills can be run through insurance.

FASD professional in North Carolina. We need interagency collaboration. The Office of Prevention needs to include treatment. Families with adopted children with FAS are being pushed to adopt more. We need to think about the stress on families. She conducts educational activities at conferences and continuing education for providers but cannot advertise. Doctors still say it is okay to drink when pregnant or they do not ask about alcohol use because “You don’t look like the type.” Doctors also say why diagnose when there is no cure or they suggest it is just used as an excuse or to get a lighter sentence for crimes. We need more support from the State to educate providers. It is not on the radar. About 1 in 100 live births have an FASD but she only got \$60,000 in funding for her project.

Dr. Morris offered to talk to her about ways to educate physicians beyond lectures. She also said parents need to push doctors to get information and that a parent group is needed. A group is forming in North Carolina.

Birth mother from Alaska. She has five children. Her middle son, 15, was diagnosed with an FASD a couple months ago. She has been sober for 14 years. Her son had speech delays and hearing problems and was diagnosed with attention deficit/hyperactivity disorder in fourth grade. She suspected an FASD and self-referred to a diagnostic clinic. She talked to three women at the women’s summit who realized their children probably had an FASD. She has learned about FASD on her own. She said that we need to get information to treatment centers and domestic violence shelters. Challenges include learning about Section 504 plans for services for people with disabilities. We need to educate systems about FASD. Alaska has the highest rate of FAS in the United States but only one substance abuse treatment facility for women with children.

Pregnant mother of three. She is in recovery from alcoholism and drug addiction. She is 32 weeks pregnant and is in treatment. She went to jail, got out, relapsed, went to the hospital for help, later relapsed, found out she was pregnant, relapsed again, and went to jail. She finally found a yearlong treatment program for pregnant women. She said that we need more treatment for pregnant women so that babies are not born addicted to drugs and alcohol.

Nurse at a community hospital. She noted that even brief intervention can be effective with pregnant women. Her hospital does this with inpatients but not outpatients. Early intervention can help with prevention. She said that we can come up with an action plan similar to what has been done with tobacco use. She has started educating providers on FASD. Not many doctors attend but the training has been well attended by nurses. They need a parent to speak at the sessions. They are incorporating alcohol and drug and domestic violence questions at all visits and are making information on FASD available. The social worker refers women to treatment when possible. It is important to keep the Baby Love program and Smart Start and to start including FASD information in prenatal classes. She suggested funding materials development and making information available in schools, houses of worship, and ladies' rooms and in public service announcements. She also said that the Arc should be represented on the Infant Mortality Commission.

Peggy Seo Oba suggested putting information in pharmacies and allied health offices (e.g., dentists, ophthalmologists).

Adoptive mother of a child with an FASD. She noted that we need to get more information on FASD out and educate everyone involved in the child's life. We need education on FASD in schools. Her son has had a number of misdiagnoses. He is 19 and in a vocational technology course. It is a 3-month course but is taking 6 to 8 months. He functions at the ninth grade level, seventh in some areas.

Kathleen Sulik said that the Centers for Disease Control and Prevention is funding NOFAS to develop a K-12 curriculum. North Carolina has developed a curriculum for middle schools. It is hard to fit it into the program. We need to get questions on FASD onto the exams required for graduation. They are trying to get FASD information into science classes and end-of-course exams.

Adoptive mother of a child with FAS (she is from Kansas and wrote a letter read by Peggy Combs). Her daughter was diagnosed at age 6. Her daughter's speech teacher suggested a visit to an FAS clinic. She recognizes the difficulty of pregnant women staying sober. There is a culture of drinking in the United States. Some doctors tell women it is okay to drink in the last trimester. Challenges with FAS include needing structure; hitting, kicking, and pinching to deal with frustration; and being picky about food and clothes. It used to take 2 or 3 hours to get her to bed but medications help. Shopping can be overwhelming. She said that she does not sell her daughter short because of FAS. She is more capable than most people realize. She told birth mothers to forgive themselves. She also said that if you are an educator, remind women not to drink when they are pregnant or thinking of having a baby.

Outreach director for a local organization. She teaches about FASD. She has given training at schools, emergency medical services, and the Housing Authority. She encourages interagency collaboration. She mentioned her cousin who fell through the cracks. He is 27 now. He had problems in school and trouble with the law and was on the streets. She learned about FASD and the family intervened with the District

Attorney. They got him into drug court and put in extra support. They are trying to get housing. It is harder to get a diagnosis since the facial features are harder to measure. His mother drank and his other signs are “textbook.”

Case manager at a treatment center. She advocates for clients. She noted the need for aftercare, such as supportive housing. The lack of safe, affordable housing is a crisis for women in recovery. There is not enough public housing or Section 8. The housing is not always safe. We need money for housing programs and transitional programs. Many mothers relapse due to a lack of support.

Staff member of East Coast Solutions. She sees what is lacking and plans to do something about it.

New mother in recovery. She held her baby and said that her healthy, happy baby is the product of substance abuse treatment in North Carolina. She thanked Marcia Mandel for helping get Hope Meadow started. She reinforced the need for housing and aftercare. Women often relapse after treatment, which can be prevented. FASD needs to be addressed by physicians. She is a middle class white woman and was never asked about alcohol or drug use. She does not want to exploit her child, but she said this is what you need to think about when you go to policymakers.

Mother in recovery with an adult child with FAS. She is 17 years sober today. She started drinking at 14. She became pregnant at 21 and drank when she was pregnant. Her doctor never told her not to drink. He told her it was okay to drink some. Her son was monitored for oxygen loss but they said he would be okay. He was held back in first grade and did not do well in middle school. He skipped school a lot. She remarried when he was a teen. He got along with his stepfather but they were drinking and her son shot his stepfather and killed him. He turned himself in and was in jail for 2 years. They were never warned that the prosecution was going for the death penalty. He is now on death row and they are trying to get his sentence overturned based on mental retardation. They have documented his mental retardation. She noted that he was never offered a plea bargain.

Concluding Comments by Panelists

Ms. Mullin said that she would take the comments back to her agency. Ms. Pettiford will look for opportunities for provider training and community training and efforts to give consistent messages. Ms. Robbins said that was an extremely powerful day and she was honored to be part of it. She commented on the need for more resources and noted that communities can advocate for services. She encouraged participants to be a voice in their community.

Dr. Sulik said that it was an honor to hear everyone and she learned a lot. She is continuing to work on curricula for youth. Ms. Ten Eyck thanked everyone and said that she was honored to be part of the proceedings. Ms. Mandel noted the need for more

education on FASD and integration of services. Ms. Oba was honored to hear the stories and asked parents and family members to keep this issue alive.

Ms. Robinson thanked participants for their voice, heart, and soul. She will take their comments seriously and will act on what we have and can integrate. She spoke of the need for continuity among prevention, early intervention, treatment, and recovery programs to develop best practices. She will look at how to sustain and integrate services so that we have goodness of fit. She will share comments with Social Services and schools about postadoption services and curricula.

Dr. Pharr is greatly concerned about youth in the juvenile justice system with an FASD who go on to the adult system. He said that we need treatment, support, and identification of FASD. Dr. Morris said that he hopes we will show perseverance and commitment to addressing this issue.

Ms. Mitchell thanked everyone on behalf of the SAMHSA FASD Center and NOFAS.