



January 2007

Fetal Alcohol Spectrum Disorder: Several State Initiatives

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“Fetal alcohol spectrum disorders” (FASD) is an umbrella term used to describe a variety of conditions resulting from prenatal exposure to alcohol including Fetal Alcohol Syndrome (FAS), Partial Fetal Alcohol Syndrome, Alcohol-Related Neurodevelopmental Disorder and Alcohol-Related Birth Defects. FASD is more common than Down Syndrome, Muscular Dystrophy and spina bifida combined. According to the Centers for Disease Control and Prevention (CDC), there are anywhere from .2 to 1.5 cases of FAS per 1,000 live births depending on the region of the United States and FASD occurs as many as three times as often as FAS.¹ The National Organization on Fetal Alcohol Syndrome (NOFAS) estimates that more than 40,000 infants are affected each year by FASD.² NOFAS also notes that in 2003, FAS—the most severe and least common condition under the FASD umbrella—cost \$5.4 billion in direct and indirect expenditures. In 2002, CDC estimated that the average lifetime cost for one individual with FAS was \$2 million—and much higher for individuals with severe problems such as profound mental retardation.

The purpose of this document is to describe the characteristics of FASD; identify several federal-level FASD initiatives that emphasize education; and describe four state-level FASD initiatives that involve state education agencies (SEAs). An appendix at the end of the document provides a list of educational resources for students with FASD. Project Forum at the National Association of State Directors of Special Education (NASDSE) produced this document as part of its collaborative agreement with the U.S. Department of Education’s Office of Special Education Programs (OSEP).

Characteristics of FASD

According to NOFAS, characteristics of children with FASD may include:

- specific facial characteristics;

¹ For more information, see CDC’s website at www.cdc.gov/ncbddd/fas/faqs.htm.

² For more information see NOFAS’s website at www.nofas.org.

- growth deficits;
- mental retardation;
- heart, lung and kidney defects;
- hyperactivity and behavior problems;
- attention and memory problems;
- poor coordination or motor skill delays;
- difficulty with judgment and reasoning; and
- learning disabilities.

CDC also notes that children with FASD are at greater risk for psychiatric problems, criminal behavior, unemployment and incomplete education. Significantly, although FASD is a permanent condition, it is entirely preventable if a woman does not drink alcohol while pregnant.

Federal-level FASD Initiatives

Several current federal-level initiatives address issues specifically related to FASD. The following section describes these initiatives, emphasizing how they pertain to FASD and education issues:

- *Interagency Coordinating Committee on Fetal Alcohol Syndrome (ICCFAS)*—Created in 1996, this committee meets semi-annually to foster interagency collaboration by coordinating federal activities related to FASD. It is chaired by the National Institute on Alcohol Abuse and Alcoholism and members include the following agencies: Department of Education, Office of Special Education and Rehabilitative Services; Centers for Disease Control (CDC); Department of Justice, Office of Juvenile Justice and Delinquency Prevention; Substance Abuse and Mental Health Services Administration (SAMHSA); the Department of Health and Human Services; Health Resources and Services Administration, Maternal and Child Health Bureau; Indian Health Service; National Institutes of Health; and National Institute of Child Health and Human Development.³ ICCFAS has an Education Committee chaired by OSEP that works to ensure that students with FASD receive appropriate educational services and supports. The committee plans to convene an Education and FASD Symposium in July 2007.
- *OSEP FASD Workgroup*—As a result of involvement with ICCFAS, OSEP formed an internal FASD workgroup in 2005. Members met with OSEP grantees and other stakeholders to determine how resource materials on FASD are accessed and used, which special education eligibility labels used for students with FASD, and whether an FASD education network or community of practice would be beneficial.
- *CDC FAS Prevention Team*—Since 1991, CDC has worked with partners to monitor exposures and outcomes; conduct epidemiologic studies and public health research to identify maternal risk factors associated with giving birth to a child with FASD; and

³ For more information on ICCFAS, see its website at www.niaaa.nih.gov/AboutNIAAA/Interagency/.

implement and evaluate FASD prevention and intervention programs. In 2001, the CDC funded four grants for educating families and professionals about FASD.⁴

- *National Task Force on Fetal Alcohol Syndrome and Fetal Alcohol Effect*—Congressionally mandated in 1998 by the Public Health Service Act, this task force meets twice per year to coordinate efforts among governmental agencies, institutions of higher education (IHEs) and community groups that conduct or support FASD research, programs and surveillance. The task force reports biennially to relevant committees of Congress regarding the current and planned activities of participating agencies. The task force commented on IDEA 2004 proposed regulations regarding inclusion of FAS in student eligibility criteria.⁵
- *FASD Center for Excellence*—Administered by SAMHSA’s Center for Substance Abuse Prevention, the Center for Excellence was established under the Children’s Health Act of 2000. The Center provides technical assistance to communities developing FASD systems of care and sponsors public awareness and prevention activities. The Center has also conducted 17 town hall meetings across the nation to gather information regarding concerns of FASD-affected families and communities as well as three “women in recovery” summits that focus on FASD prevention.⁶

State-level FASD Initiatives

Information Gathering

In April 2006, Project Forum surveyed SEAs to find out which were involved in any state-level FASD initiatives. Of the 28 SEAs that responded to the survey, four indicated that they were involved in such an initiative: *Alaska, Florida, Maryland and North Dakota*.⁷ In collaboration with OSEP, Project Forum developed an interview protocol for use with these states. Feedback was also solicited from several members of ICCFAS. Interviews were conducted during September 2006.

Findings

The following section describes individual state initiatives with a particular focus on the role played by the SEA:

⁴ For more information on the CDC FAS Prevention Team, see its website at www.cdc.gov/ncbddd/fas/cdcaactivities.htm.

⁵ For more information on the National Task Force on FAS, see its website at www.cdc.gov/ncbddd/fas/taskforce.htm. For information on recommendations generated by the National Task Force, see www.cdc.gov/mmwr/preview/mmwrhtml/rr5114a2.htm.

⁶ For more information on the FASD Center for Excellence, see its website at www.fascenter.samhsa.gov/index.cfm?&print=y.

⁷ Although several additional SEAs reported state-level FASD initiatives, they did not indicate that the SEA was involved in these initiatives.

Alaska

According to a survey conducted by CDC, Alaska has the highest known FASD prevalence rate in the nation, with a prevalence of 1.5 per 1000 live births and a rate more than three times that frequency (5.6 in 1000 births) among Alaska Natives. In 1998, the Office of Fetal Alcohol Syndrome was established using seed money from the Alaska Department of Health and Social Services (DHSS). In 2000, the office was awarded a five-year, \$29 million grant from the Substance Abuse and Mental Health Services Administration (SAMHSA) to initiate a statewide program addressing FASD prevention and systems improvement.⁸ Of this, \$500,000 was dedicated to educational services through the Department of Education and Early Development (DEED) and helped to pay for the following:

- The SEA created a full-time FAS education specialist in 2001. This position was a general education position and enabled the SEA to provide FASD training at the local education agency (LEA)-level throughout the state.
- One of the catalysts for DEED's involvement in the statewide FASD program was the passage of a law mandating that all new teachers and administrators receive drug and alcohol-related disabilities training within 45 days of hire.⁹ In response to this, funds from SAMHSA and the Alaska Department of Special Education were used to develop an e-learning module on FASD specifically tailored for teachers that is available at no cost via the Internet. Over the past three years, more than 1,750 educators have enrolled in the e-learning module.
- The FAS education specialist collaborated with Rural Cap, a non-profit organization targeting rural populations, particularly Alaska Natives. Together, an Early Decisions curriculum was developed with a focus on FASD awareness and prevention for middle- and high-school aged students.
- The SEA awarded several three-year \$90,000 innovative grants to LEAs implementing interventions and accommodations recommended for FASD. Preliminary evaluations of these programs indicated that they were each quite effective. Together, these programs served approximately 100 students with FASD per year.
- In collaboration with DHSS, DEED helped coordinate an annual FAS summit that includes more than 600 participants each year. The Department of Special Education offered \$50,000 in scholarship support to educators throughout the state and approximately 100 full scholarships were offered for each summit.
- The FAS education specialist also worked with DHSS to develop two FAS curricula—one focusing on the basics of FASD and one describing interventions.

Other components of the SAMHSA grant included 36 community-based grants to local non-profit organizations throughout the state with a focus on FASD prevention, a public education/media campaign and 14 community-based FASD diagnostic teams. In order to administer the grant, a FAS steering committee made up of various stakeholders met semi-

⁸ For more information on Alaska's Comprehensive FAS Project, see its website at www.hss.state.ak.us/fas/.

⁹ See Alaska Statute 14.20.680.

annually. Monitoring the outcomes of grant-supported projects is a priority activity, with approximately 11% of grant funds devoted to evaluation activities.

Florida

Florida's FASD Interagency Action Group was founded in 2000 and meets between two and four times per year. The lead agency for the Interagency Action Group is the Infant, Maternal and Reproductive Health Unit of Florida's Department of Health and the group is made-up of approximately 25 stakeholders including representatives of the Florida Department of Education, Bureau of Exceptional Education and Student Services; Department of Health and Human Services; medical establishment; juvenile justice; and parents of children with FASD. Funding for the Interagency Action Group comes primarily for the Department of Health and one of the main objectives of the group is to secure ongoing funding.

In an effort to train education personnel to better identify and serve students with FASD, the SEA developed and funded a FASD teacher training guide in 2004 and disseminated it to teachers and school psychologists throughout the state. The training guide is available free of charge and has been disseminated to approximately 2,000 individuals. It is available on the websites of both the Department of Education and the Department of Health. Although the SEA does not fund a full-time position dedicated to FASD, responsibilities for staffing the Interagency Action Group and handling other issues related to FASD have been assigned to a staff person from the Bureau of Exceptional Education and Student Services.

Other components of the initiative include the following varied strategies: In 2003, the Interagency Action Group sponsored a FASD conference attended by several hundred individuals. Town hall meetings were held throughout the state in 2005 to better identify key issues. As a follow-up to these meetings, the Interagency Action Group developed a strategic plan and various action steps. Priority areas include prevention of FASD, diagnosis of FASD, intervention for children with FASD, and life support/extended services for adults with FASD. Prevention efforts have so far targeted a wide range of populations, including teachers, health care professionals, teenagers and pregnant women. The Florida Center for Child and Family Development's FASD clinic, established in 2005, provides diagnostic assessments, professional FASD trainings, case management and advocacy services for children and families.

Maryland

In 2003, the Maryland state legislature passed a measure titled "Public Health—Fetal Alcohol Syndrome Prevention—Public Awareness Campaign" that established a state-wide FASD public awareness campaign.¹⁰ A FASD work group was convened in 2004 under leadership of the Maryland Department of Health and Mental Hygiene (DHMH), Center for Maternal and Child Health and the Governor's Office for Crime Control and Prevention. DHMH later assumed sole responsibility and members include the Department of Education, Division of Special Education

¹⁰ See Maryland House Bill 1274. Also, for additional information on Maryland's FASD initiative, see the Report on State Approaches to FASD and the DHMH FASD Progress Report.

and Early Intervention Services; the FAS clinic at the Kennedy Krieger Institute; NOFAS; and parents of children with FASD. During its first year, the work group reviewed medical literature and developed a mission and goals.¹¹ Public awareness efforts have included a variety of presentations and publications by coalition members. In 2005, FASD was identified as a priority in the Maryland Title V-Maternal and Child Health Block Grant Five-Year Needs Assessment. Recommendations generated by the work group were presented to the House Special Committee on Alcohol and Substance Abuse and included:

- establishing a Maryland State FASD Coalition staffed by DHMH;
- establishing a FASD coordinator within DHMH;
- developing a long-range plan for increasing FASD awareness;
- securing funding for a five-year public awareness campaign; and
- developing a comprehensive action plan for preventing FASD and improving systems of care for individuals affected by FASD.

The first two recommendations have been implemented. The new FASD coalition is currently working to implement the remaining recommendations. The primary contribution by the SEA to these efforts has been the assignment of a representative from the Division of Special Education and Early Intervention Services who actively participates in work group and FASD coalition meetings.

North Dakota

The state's FASD task force was established in the mid-1990s and is administered by the Department of Human Services, Division of Mental Health and Substance Abuse. Other members of the task force include representatives from the Office of Special Education, Department of Public Instruction; Department of Health; medical professionals; American Indian groups; and families of children with FASD. Meetings were held on a quarterly basis, although the interviewee noted that in response to recent changes in leadership within the Department of Human Services, most FASD task force activities are "on hold" at this time.

In addition to participating in the FASD task force, the SEA's Office of Special Education contributed to the state's FASD initiative by preparing extensive training materials and hosting a state-wide conference for school psychologists and other educational personnel on the educational impact and appropriate educational services for children identified with FASD. The SEA strongly encouraged representatives from each LEA to attend.

Other components of the initiative included a public awareness campaign and efforts to establish long-term funding, via legislation, for the North Dakota FAS Center located at the University of North Dakota.¹²

¹¹ For more information on the Maryland FASD Coalition's mission and goals, see its website at www.fha.state.md.us/mch/fasd/html/md_fasd.html.

¹² For more information on the North Dakota FAS Center, see its website at: www.med.und.nodak.edu/depts/peds/fas/.

Concluding Remarks

The breadth and scope of the four states' FASD initiatives vary considerably. For example, *Alaska's* initiative has been in existence for more than a decade and received generous federal funding. *Maryland's*, on the other hand, is much newer and operates on a very small budget. The degree of SEA involvement also varies. While none of the SEAs interviewed were the lead agencies for the FASD initiative, some play more active roles than others. Furthermore, three of the SEAs interviewed assign a representative from the division of special education to handle FASD-related issues, with *Alaska* being the only state that assigns someone from general education. Significantly, all interviewees noted that interagency collaboration—essential for addressing a problem like FASD—is an ongoing challenge because different agencies approach the problem from varying perspectives and with different sets of priorities.

Acknowledgements

Project Forum gratefully acknowledges the extensive contributions of Anne Smith of OSEP, as well as the contributions of Carole Brown and Hugh Reid (members of the ICCFAS Education Workgroup), in helping develop the interview protocol, reviewing an earlier version of this document and identifying additional educational resources pertaining to FASD. Project Forum also wishes to thank the following individuals for participating in interviews and reviewing an earlier version of this document: Art Arnold, Director of Special Education, and Todd Brocius, Education Specialist, Alaska Department of Education and Early Development; Lee Clark, Program Specialist for Students with Emotional Disabilities, Bureau of Exceptional Education and Student Services, Florida Department of Education; Marjorie Shulbank, Special Initiatives and Parent Support Specialist, Division of Special Education and Early Intervention Services, Maryland State Department of Education; and Bob Rutten, Director of Special Education, North Dakota Department of Public Instruction.

This report was supported by the U.S. Department of Education (Cooperative Agreement No. H326F050001). However, the opinions expressed herein do not necessarily reflect the position of the U.S. Department of Education and no official endorsement by the Department should be inferred.

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Appendix A: FASD Education Resources

- Alberta Government Education Learning Resources Center. (2002). *Kindergarten to grade 9 health and life skills guide to implementation*. Edmonton, Alberta: Author.
- Alberta Government Education Learning Resources Center. (2004). *Teaching Students with Fetal Alcohol Spectrum Disorder: Grades 1-12 — A resource for teachers of health and life skills, and career and life management*. Retrieved on December 22, 2006 from http://www.education.gov.ab.ca/k_12/curriculum/bySubject/healthpls/fas.pdf
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