

**ALASKA STATE LEGISLATURE
SENATE EDUCATION STANDING COMMITTEE**

March 16, 2011
8:02 a.m.

MEMBERS PRESENT

Senator Kevin Meyer, Co-Chair
Senator Joe Thomas, Co-Chair
Senator Bettye Davis, Vice Chair
Senator Hollis French
Senator Gary Stevens

MEMBERS ABSENT

All members present

COMMITTEE CALENDAR

PRESENTATION: FETAL ALCOHOL SPECTRUM DISORDERS IN SCHOOL

- HEARD

PREVIOUS COMMITTEE ACTION

No previous action to record

WITNESS REGISTER

CINDY ANDERSON, Director
Special Education
Anchorage School District
Anchorage, Alaska

POSITION STATEMENT: Gave an introduction on the impacts Fetal Alcohol Spectrum Disorders (FASD) has on children and adults nationwide and in Alaska and answered questions regarding FASD in schools.

MARY ANDREWS, parent of child with FASD
Bethel, Alaska

POSITION STATEMENT: Shared her son's story and emphasized the importance of early intervention.

MONICA LEINBERGER, FASD Behavior Specialist
Lower Kuskokwim School District
Kuskokwim, Alaska

POSITION STATEMENT: Shared her perspective, as a teacher, in working with students who have FASD and the importance of early intervention.

MINDY CASON, Student
University of Alaska Anchorage (UAA)
Anchorage, Alaska

POSITION STATEMENT: Shared her experiences as a young adult with FASD.

JEANNE GERHARDT-CYRUS, parent of child with FASD
Kiana, Alaska

POSITION STATEMENT: Shared her daughter's story and emphasized the importance of early intervention.

DEB EVENSEN, Consultant
FASD Education Statewide
Anchorage, Alaska

POSITION STATEMENT: Answered questions from the committee regarding the impacts of FASD and the systematic changes that need to be put into place regarding prevention and education.

ACTION NARRATIVE

[8:02:58 AM](#)

CO-CHAIR KEVIN MEYER called the Senate Education Standing Committee meeting to order at 8:02 a.m. Present at the call to order were Senators French, Stevens, Co-Chair Thomas and Co-Chair Meyer. Senator Davis arrived shortly thereafter.

Presentation: Fetal Alcohol Spectrum Disorders in School

[8:03:25 AM](#)

CO-CHAIR MEYER announced the order of business would be to hear a presentation on fetal alcohol spectrum disorders (FASD) by the Alaska FASD Partnership.

[8:05:26 AM](#)

CINDY ANDERSON, Director, Special Education, Anchorage School District, said FASD includes a range of disabilities caused when a developing fetus is exposed to alcohol. It is preventable. FASD is a lifelong disability and can manifest in a variety of ways, including: learning disabilities, memory problems, poor judgment, impulsivity, attention deficit, physical issues, cognitive impairments, and severe emotional disturbance. She noted that Alaska has the highest per capita rate of FASD in the United States.

She said that she wanted to give a few parents the opportunity to share their stories with the committee.

CO-CHAIR MEYER noted that Commissioner Hanley has joined the committee for the day's hearing.

8:07:20 AM

MARY ANDREWS, parent of a child with FASD, said she is here today with her son, Terrell, who is diagnosed with a neurobehavioral disorder. She explained that she knew all along that he would have problems because of prenatal exposure to alcohol. She said that she is here today to share his story and ask for the committee's support in FASD.

She said that as an infant Terrell cried constantly. As a young child Terrell could not communicate well and would cry out of frustration. In school he was behind in many ways and by 4th and 5th grade he was no longer bringing homework home. She explained that during this time she began attending FASD meetings where she found support from other parents and received training. Terrell is doing much better through this support and medication. She explained that while Terrell does not communicate the way that she wishes he would through early intervention she has the gained the knowledge to help him in his every day challenges.

8:10:06 AM

MONICA LEINBERGER, FASD Behavior Specialist, Lower Kuskokwim School District, said her district is fortunate because many districts in Alaska are not able to have a special education teacher focused on this population of individuals. Prenatal exposure to alcohol affects every individual differently and it is life-long. This means that, within the classroom, it is important to change the classroom so that they can succeed. She explained that in the classroom students like Terrell can't multitask, they have to do one task at a time. She emphasized that as a special education teacher she wants children with FASD to be able to point out what is upsetting them. It is important to change the environment around these students in order to help them succeed.

8:14:17 AM

MINDY CASON, Student, University of Alaska Anchorage (UAA), said her story begins in elementary school when she was diagnosed with learning disabilities. She noted that she knew that something more was going on. She explained that, as a child, she

was seen as defiant and with a lack of drive. As a teenager she opted not to receive special education services because it was difficult for her to be taken out of regular classes and be singled out by her peers. She struggled with the high school qualifying exam and had to take the SATs eight times before receiving the minimum scores to attend college. While taking a break from school she worked in prevention and intervention with Volunteers of America. During a training class on FASD, she said that "every bullet point spoke to me." She explained that her mother had substance abuse issues but it was not until she was 21-years-old that she realized she had FASD. She explained that within those 21 years she damaged relationships, made poor decisions and did not follow directions because she did not understand the directions. She returned to school in 2009 and will graduate on May 1, 2011 with a bachelor's degree. She has decided to apply for a master's degree at the school of psychology at UAA. She stressed the importance of early intervention for children with FASD. She explained that if she had received more screening when she was screened for learning disabilities as a young child, she could have received more support and been taught the coping skills that she had to teach herself. These skills took her many years to acquire.

CO-CHAIR MEYER asked what group she was last in Juneau with.

MS. CASEN replied with the Youth Summit.

[8:19:06 AM](#)

JEANNE GERHARDT-CYRUS, parent of a child with FASD, said she and her husband are parents to multiple children with prenatal exposure to alcohol. She said that there is a difference between supported success and independent failure for both students and teachers. She explained that for her daughter Ivory, her experience in primary school was of building frustration, diminished communication and a decreased ability to cope. She explained that upon her daughter's removal from school she was taken away from the social aspects of life. She said when they have supportive success it is completely different. She said that FASD needs to be addressed in special education classifications, like autism. She added that now her daughter has increased communication and accommodations, with individuals who are trained to aid in these accommodations. She stressed that teachers need to be trained in FASD and that they need to be supportive. She noted that it is not just about educational success, it is about lifelong success. Early intervention would have been helpful for all of her children.

She read a statement from her daughter: "Hello my name is Ivory Dominica Gerhardt-Cyrus. I never had a challenge before, but my teachers are very nice to me."

8:24:26 AM

MS. ANDERSON agreed that the types of services provided to students, provides success. She explained that the Anchorage School District (ASD) hired a consultant, Deb Evensen, who provides training and support to ASD staff on FASD. Ms. Evensen does "talking head training" along with demonstration teaching and mentorships which allows teachers to practice the skills that they have learned. Next year they will continue giving as much support as possible. These "talking head" trainings are also filmed so that other teachers can access the trainings and help support their students. She noted that ASD has also assured that within their curriculum for high school students that there is an emphasis on teaching the effects of alcohol consumption during pregnancy. She said the hope is that students will make better decisions as they move into adulthood and parenthood. ASD also has a STEP [Student Educator and Parents] Center library section on FASD, which parents, students, teachers, and community members can check out. She stressed that there is a need to continue that level of support and build capacity within ASD. She noted that the district has also been training individual schools for inclusive practices. With the right supports in academics and behaviors, all children can be successful in a general classroom.

She stressed that the skills gained by teachers to support children with FASD support all students. The ability to differentiate instruction and provide accommodations to build success is critical to increasing test scores, meeting AYP [Adequate Yearly Progress], and teaching skills to students for success in life.

8:27:57 AM

DEB EVENSEN, FASD Education Consultant, said for the last two years she has been involved as a consultant with ASD. She explained that there are two important things that are needed in order to increase the capacity to deal with FASD. First, everyone needs to understand FASD. She noted that most students with FASD are not in special education at this time. Second, the education system needs to understand FASD. She stressed that it is important to tweak the system from the inside so that students can be helped in each grade level to become successful in their adult life. She said that if there is any way for the legislature to help get a FASD expert in each district this

would change the education system in the state. Alaska has the ability to take the next step forward and teach the system how to work with individuals with this disability. She noted that individuals with FASD are out of sync chronologically with their peers. She said that throughout Alaska they are losing many of these students by middle school.

8:32:35 AM

MS. ANDERSON concluded that those with FASD have a higher likelihood of depression, substance abuse, perpetuating problems, serving time in jail, becoming homeless, or suicide. She noted that early diagnosis allows families, schools, and communities to work together and address prevention, intervention, and ongoing support.

CO-CHAIR THOMAS asked if it is generally accepted that the earlier a child's diagnosis the better the outcome.

MS. ANDERSON replied yes. She said that being able to diagnose early and understand what the disability is is extremely important. Currently, in order to diagnose a student there are 14 different categories of special education identification, FASD is not one of them. She explained that trying to find the right services for these students can be very difficult. Having the correct diagnosis early on is extremely helpful in teaching them the skills that will allow them to be successful.

CO-CHAIR THOMAS noted that she is discussing children who are already in school. He asked if it is possible to make this diagnosis right after birth.

MS. ANDERSON answered that there are assessments that can be done early on. She explained that one of the best ways to identify FASD is for a family to disclose that a child has been exposed to alcohol prenatally. ASD does provide preschool services for ages 3-5 where students can be provided additional support and services. She noted that often what happens is students with FASD are not identified right away, do not receive services in preschool, and step into kindergarten without any previous help.

CO-CHAIR THOMAS said 16.2 percent of urine samples obtained from pregnant women in labor in Alaska tested positive for drugs or alcohol. He asked if there is an issue with this information being passed along or the parents counseled at that point.

MR. ANDERSON replied that this information would not be disclosed to anyone outside of the hospital's medical staff unless a parent agreed.

[8:36:57 AM](#)

MS. EVENSEN answered that right now there are parents that may not have or want to get the medical diagnosis for FASD. She explained that many parents do not want to deal with this because they do not believe it will make a difference and will shame them. She said that, as an educational system, they are handicapped when they don't know what the problem is. She stressed that when the system is ready to accept this issue, parents will bring them this information.

CO-CHAIR THOMAS commented that this is after the situation has already occurred. He asked what the system can do to prevent the situation.

MS. EVENSEN replied that the individuals who are the most at-risk of having children with FASD are typically people with unidentified FASD. She explained that helping people who already have FASD is the best step towards prevention.

[8:39:23 AM](#)

MS. GERHARDT-CYRUS said "without intervention we have no prevention." She explained that individuals who are not completing their education are more likely to become parents at a younger age and use substances to cope with the chronic frustration. She added that once things are going well for a child with FASD it is important that these supports are not taken away. FASD is a lifelong disability.

MS. EVENSEN noted that adult life is the most difficult for individuals with this disability.

CO-CHAIR MEYER said he understands it must be difficult for adults with FASD. He added that for children with FASD it must be even more difficult, because kids are so hard on each other. He asked how schools deal with children being pulled out of the classroom and labeled as different.

[8:42:11 AM](#)

MS. LEINBERGER said that there are unobtrusive ways for children to receive these services, which can also help their peers as well. She explained that it depends on each child and where their deficits are. For example, if a child is far below reading than their same-age peers then they may get some pull-out

services specifically for reading. She stressed that it is important to mold the environment around the child rather than segregating them even further by pulling them out of the classroom all the time.

CO-CHAIR MEYER noted that this takes a very talented teacher. He asked Ms. Cason for confirmation that she did not know she was impacted by FAS [fetal alcohol syndrome] until she was 21 years old.

MS. CASON replied yes.

CO-CHAIR MEYER asked whether knowing this in junior high or elementary school would have been beneficial.

MS. CASON replied that it would have been beneficial because she knew that there was something else going on outside of learning disabilities. She explained, for instance, that she had all the steps to learn how to read, but her brain could not process those steps. She continued that as an adult this has been difficult as well. When it comes to basic job skills she has to ask a lot of questions in order to understand the job. Because of this she has been fired from a number of jobs. She noted that if she discloses that she has a disability she often will not receive a phone call regarding that job. She said "it's kind of a catch-22 for me." She noted in regards to relationships as an adult, her disability is noticeable. It is not something that goes away. She explained that she struggles with communication and understanding the boundaries of other individuals.

[8:46:30 AM](#)

CO-CHAIR MEYER asked how individuals are diagnosed for FASD.

MS. EVENSEN answered that it is a medical diagnosis by a doctor who has been trained specifically for this. It is a very specific diagnosis that is precise and scientifically sound. She said that "we know how to diagnose it and know what they need. We just don't know how to do it as a system."

CO-CHAIR MEYER asked if these doctors are available in Alaska.

MS. GERHARDT-CYRUS replied that there are diagnostic teams in Alaska. She noted that North Slope, Northwest Arctic, and Bering Straits do not have diagnostic teams available. The Alaska FASD Partnership is currently looking into this. She clarified that FAS is a medical diagnosis and the other diagnoses come under

the umbrella of FASD. FAS include the lowest amount of people that are impacted.

MS. EVENSEN noted that all of these diagnoses involve the brain and are permanent.

MS. GERHARDT-CYRUS added that school success is not always about academic functioning. She explained that the majority of individuals with prenatal exposure to alcohol do not experience mental retardation or cognitive impairment. However, it is often through processing and behavioral issues that brings children to light in the classroom. Once this is recognized teachers and aides can provide the right support and teach children the necessary skills for the classroom, the workforce, and relationships.

[8:50:19 AM](#)

SENATOR STEVENS asked what the legislature can do to help prevent FASD and educate children before they become parents.

MS. ANDERSON replied that included in the document packet is some priorities for the Alaska FASD Partnership. This includes assisting families who have FASD, maintaining the family unit, early intervention, testing, and assessments.

MS. LEINBERGER answered that alcohol is such a huge problem in the state of Alaska. She said that starting with intervention with the birth mothers in order to prevent future children who are prenatally exposed to alcohol is an important start. She stressed that it is important to continue giving support and education to mothers who can then advocate for their children. She continued that it is important to support teachers. She recommended that when a teacher renews their teaching license a mandatory class on FASD be included. Finally, it is important to have a teacher in every district who is available year-round and can provide training on FASD.

MS. EVENSEN added that through her experiences working in Canada with adults living with FASD she realized that she wanted to return to Alaska and help schools recognize FASD. She stressed that the system needs to recognize FASD in adults and support these individuals as well.

[8:57:05 AM](#)

MS. ANDREWS said "we don't know what they go through and how they feel." She explained that her step son did not finish high school and could not hold a job. Through the poor choices that

he made his life ended at a very young age. She stressed that early intervention can really help.

CO-CHAIR MEYER said he appreciates the testifiers for educating the committee on FASD. He recognized how challenging it is for the teachers, the schools systems, and the students. He asked about the Slingerland program taught at the Baxter Elementary School in Anchorage and if this tool helps children learn how to read.

MS. ANDERSON replied yes. She added that ASD's special education program has purchased "The Language Program," which is one of the top reading programs across the nation. She said there are multiple options for teaching and they are looking at research-based curriculum that will allow all students to be successful.

[9:01:26 AM](#)

There being no further business to come before the committee, Co-Chair Meyer adjourned the meeting at 9:01 a.m.