

Jan 27, 2025

Chairman Dever, Members of the Committee, my name is Carl Young. I am the Executive Director of the Family Services Network here in North Dakota. In my work within the Fetal Alcohol Spectrum Disorder (FASD) space I work with people from every region of the state. I provide parent to parent support, Individualized Education Plan advocacy, and training for social workers and educators.

Through my work I frequently find it necessary to refer clients to the FAS Center at UND.

I speak to you today asking your committee to fund the FAS Center at UND, which was established by North Dakota law in 1993. The North Dakota Legislature established the FAS Center via the passage of House Bill 1313. Dr. Larry Burd is the Center's director. Through his efforts, many people have been able to get a proper diagnosis. However he is only able to see clients 2 days a week, with a third day dedicated to paperwork and follow-up with clients. The Center currently has a wait list of 2 months. Dr. Burd is no longer accepting new clients. He is retiring from his work. Your funding for the FAS Center will entail hiring someone to replace him in his role there. While I don't know what he is paid, I can't imagine that a replacement will be found for the same money he is being paid.

Through my work, which is not funded through the Center, I have been able to assist more than 50 families in the last year. I follow a multi-step process when referring clients to the Center. First, I have them schedule an appointment. Then I have them complete a pre-assessment that is offered through the University of California San Diego. It takes approximately 3 weeks to get the results of the pre-assessment. Pre-assessment helps give families hope.

Almost all the families I work with are either in a foster/adopt or a kinship care situation. Where foster care is the situation, those families are travelling on the state costs to get care for the kids. Without the FAS Center at UND, these families would need to either travel to Minneapolis with the hopes of getting an appointment with Dr. Jeff Wozniak at the University of Minnesota or they would need to travel to Sioux Falls and the University of South Dakota. There are other options, however they don't accept ND Medicaid, and it gets expensive taking kids to other states to get a diagnosis. When the kids are in care, that expense falls to the State of North Dakota.

How do I know about FASD? My son was diagnosed at the Center 8 years ago. We adopted him through foster care here in North Dakota. Before that diagnosis, he had been diagnosed with a significant number of mental health disorders and autism. The Centers for Disease Control and a large number of academic research papers show that the prevalence rate is at least 1 in 20 children. According to the National Center for Education Statistics in our school system, the average classroom size ranges from 19.3 in the self-contained classrooms to 20.4 students in departmentalized classrooms like we would see in middle school or high school levels. This would indicate that FASD affects at least one child in every classroom. Most of these children are undiagnosed. They are typically seen as extreme behaviors, not symptoms of

a disorder.

What is the cost of care for a child with FASD? I would ask that you review the information in the charts in my supplemental handout which is available to each of you in the packet of files I gave you. I'll reference those numbers now.

The FAS Center at UND provides a significant service to our state. Last biennium the appropriation through the Legislature was \$350,458. For whatever reason, this session the Department cut the funding from the budget. I am not here to question that logic. I am here to ask that you reinstate an appropriation for the Center. In my view, \$350,458 is not enough, I'd like to see a higher number.

Currently in our state, other than the work I do, which doesn't include the Center, and is not funded by the Center, Dr. Burd is the only practitioner that I have been able to connect with who is working with this population. He doesn't provide support, the center only does diagnosis. While I am certain that there are people who are listening to this testimony, who would say they work with the population, I am not aware of who they are. I can't make referrals if I don't know there are professionals.

Right now, the FAS Center is the answer for so many kids.

I conclude with a few facts. During the last legislative session, this body saw fit to place Fetal Alcohol Spectrum Disorder in the state code as a developmental disability. We must ensure this population is served. We don't have special health care clinics like the Autism Pediatric Specialty Clinic.

A bit about my son for those of you who have never heard his story. He was born substance exposed right here in Bismarck. He is 23, and yes, I have his permission to talk about his case. By age 3, we began to see some significant behavioral challenges. By age 5 he was on adult doses of most of his psychotropic medications. At age 7 he first encountered the criminal justice system. At age 8, he had his first Psychiatric Residential Treatment Facility stay. He would have more. He was eventually diagnosed with Autism, where he was able to get some services, but not the correct services for his needs. At age 17, he left home. Since then, he has spent every Christmas and birthday in a detention facility. He has periods where he is free in society.

He does not have services or support. He does have a Developmental Disability case manager who checks in with him. In jail, he doesn't get support for his disability. His IQ is too high.

What areas of his life are affected: (this is typical in some way for most of those affected by prenatal alcohol exposure) my son has issues with Executive Function, Adaptive Life Skills, Understanding Cause and Effect, as well as Dysmaturity (while he is 23, developmental maturity is at approximately age 12). On January 28, he was released from the custody of the Cass County Sheriff. We have no idea where he is, as he hasn't been in contact with us. My understanding is that he is currently homeless and living somewhere in the Fargo area.

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He has other symptoms that are too numerous to mention.

The children of our state with FASD deserve a level of basic care that includes diagnosis. If you take away the diagnostic clinic by not funding it, you end that basic level of care in our state. There is no one else. I am no therapist, clinician or doctor. My understanding is that the funding request for the FAS Center has been placed in Public Health.

I am a parent with the lived experience of raising a child with the disorder. A disorder that is severely misunderstood, misdiagnosed, or under diagnosed across the state.

Our children deserve a diagnosis as early as possible, they shouldn't have to travel with their families to another state to get that diagnosis.

It is my view that failure to fully fund the FAS Center would be a violation of state law. I say this because the Center was established in North Dakota law.

I thank you for your time and will stand for any questions.