

Senate Bill 2113

January 28, 2025

Chairman Lee, 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.

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. I welcome you to turn to page 5 for a brief minute.

During the last legislative session, this Legislature 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 some 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 once a year. His IQ is too high for higher levels of service and support. In jail, he doesn't get support for his disability.

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) He has other symptoms that are too numerous to mention. Our children with FASD deserve a level of basic care.

I am no therapist, clinician or doctor. 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.

In the last year, I have worked with more than 50 families across our state, from a family in the southwest to a single parent home in the northeast, from the far corner of the Bakken to near Wahpeton. All are begging for whatever support they can get. For understanding what they, through their child, are living with. Our kids aren't evil. They just need support. Most of the population prenatally exposed to alcohol will experience at least one of the following:

Interaction with the Justice System.
Homelessness
Substance Use Disorder
Domestic Violence

I guarantee that one person in this room has FASD. You can't tell by looking at me that I have the disorder. I was diagnosed last May at the age of 52. It doesn't change who I am, but it explains so much about my life. I am considered an outlier in FASD. Less than 15% of the population is estimated to be able to achieve my level of success. I have multiple college degrees, I have been married for over 30 years. My wife and I have five children and three grandchildren. The rest of the FASD community deserves the same opportunity, to live their best life outside of a prison. With the support necessary to do so.

In the link at the bottom of these pages is a YouTube URL to a video I was interviewed for called "Glimpses of FASD: Meet Carl". I welcome you all to watch the clip.

FASD needs a seat at the table.

As I close, I'd like to call your attention to an error in the language in the Engrossed Bill.

Page 32 line 25

f. One individual representing an organization advocating for individuals with fetal spectrum disorder;

Should read:

f. One individual representing an organization advocating for individuals with fetal alcohol spectrum disorder;

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