

Chair Weisz, members of the committee, my name is Carl Young. I am the Executive Director of FASD-North Dakota. FASD is an acronym for Fetal Alcohol Spectrum Disorder. I am also a lobbyist here in North Dakota, and my ID number is 136. I am here today in my capacity as Executive Director and as a parent of a child with FASD.

My son was born substance exposed. His chart refers to his early days as "Day of Life 1, Day of Life 2..." He spent his first weeks in neonatal intensive care here in Bismarck. Outside of the womb, he has never known his birth mom. He came to us when he was 18 months old, though in truth we knew him much earlier because my wife did daycare for his foster mom. The adoption was finalized at the age of two. We knew early on that something wasn't quite right for him. He could stay awake for 72 hours at a time. In fact, he was on adult doses of his mental health medication by the age of five, and we had to frequently rotate his meds because his body would metabolize them so quickly. Some years we would travel more than 15000 miles around North Dakota trying to find appropriate support for him.

He first tried to kill me when he was eight. Thus began the roller coaster ride that is getting residential care in North Dakota. We would spend the next ten years trying to get him appropriate care. Each time he was discharged from a facility the time home would be decreased before we had to find another placement for him. He thrived in the structure. A level of structure that we were unable to provide for him in our home.

We have been threatened by facilities with charges of abandonment because we questioned their practices. Questioned their "cure". Yes, we heard that word several times. "We cured him."

When he was 15, a careful review of all of his birth records and a lot of testing was completed at the FASD Center in Grand Forks. It was then that we learned about the FASD.

We applied for developmental disability services only to be denied those services because his IQ was too high.

At age 17, he made one last attempt on my life. Over the course of his life, he tried to take mine six times. It is not in us to make excuses for the things that he does. In fact, we have gone to considerable lengths to hold him accountable. To teach him to hold himself accountable. He knows that there is something not wired properly in his head. He knows he needs help.

Currently, my son is a convicted felon. He is serving the balance of a sentence in the Case County jail for stealing a car. He struggles to hold jobs, in fact struggles to even get jobs. He is frequently homeless and unmedicated for those mental health conditions that he has that are to an extent controllable by medicine.

There are a lot of reasons why he isn't being supported currently. According to him, most providers that he has tried are not able to staff him.

In the 1980's a lawsuit was brought against the state that resulted in the transfer of residents to home and community based settings from institutions in which they had been placed. Over time, society has begun to use prison and jail as an alternative.

All my son wants to do, is live in the community. To have the supports that he needs.

My wife and I created FASD- North Dakota in 2018. It was founded as Family Services Network. Our goal was to help families not have to struggle to get the support they need for their children. Initially we would get a call or referral every couple of months. Now, I get calls and referrals 3 to 5 times a week.

It is not our goal, nor is it the practice of any organization serving this population to shame the birth mom. Often, mom might not know that she is pregnant when she is drinking during that first trimester. There is no safe amount of alcohol that can be consumed during pregnancy.

Conservative estimates are that 1 in 20 children may have an FASD. In our Tribal communities, that number is closer to 1 in 17. SB2335 is the start to helping these families that are affected by FASD. It is our hope that you will support SB2335 in its current form.

This legislation will have minimal impact on my son. It is our hope that future children will have better luck accessing care. That their families won't feel the pain, the anxiety of not being able to support their child.

Source:

Mitchell, Ann M. PhD, RN, AHN-BC, FIAAN, FAAN; Porter, Rebecca R. MS, LPC; Pierce-Bulger, Marilyn MN, FNP-BC, CNM; McKnight-Eily, Lela R. PhD, MEd. Addressing Alcohol Use in Pregnancy. *AJN, American Journal of Nursing* 120(7):p 22-24, July 2020. | DOI: 10.1097/01.NAJ.0000688188.28322.9c