



My name is Tiffany Moen and I am from Mayville. My husband Corey and I have two children, one who has a diagnosis of Autism Spectrum Disorder, his name is Andrew and he is 4 years old. My husband and I farm and have enjoyed doing so for the past 11 years. Up until this past February I worked outside the home but do to Andrew's needs I resigned to allow myself more time to focus on getting the treatment he needs.

It has been a frustrating journey thus far; from the pediatrician not picking up on red flags that there were true indications there were developmental issues to getting the proper services to cope with those issues. We do not have many if any autism friendly physicians in the area. They do not understand autism, how to treat it or how to work with a child on the spectrum when they come in for an office visit. Luckily we have found a wonderful support group called TACA (Talk About Curing Autism) that has introduced us to many new providers such as an Audiologist to test for CAPD, a Defeat Autism Now doctor, and an OT that specializes in Sensory Integration. It's because of these people we have made the strides we have with our son.

Andrew received his diagnosis of ASD at the age of 2 from the Mayo Clinic in Rochester, MN. We spent 4 days at the clinic visiting with a pediatric neurologist, psychiatrist, genetics, and a speech language pathologist. To be told that your child has autism is difficult to hear, but to be told your child has autism and live in North Dakota was horrific. There are so few services for autism in our state. When I read about what other States provide for families affected by autism it makes we want to pack up and leave.

The very first recommendation given by the doctors at Mayo was to find an ABA (Applied Behavioral Analysis) program. When the social worker was researching as to who could provide this service for us, only one person in the entire state showed up. We contacted her as soon as we returned and got a program started which entailed myself and my husband getting trained to do ABA with Andrew as well as hiring staff to help with the ABA. We are fortunate enough to have these expenses covered by our insurance provider, but not all families are that fortunate because most insurance providers do not cover these types of therapies. ABA is not well received by many people, including our Education Department, but I will attest that it works and have seen wonderful results with my son.

Andrew received services from Southeast Kids Infant and Development until the age of 3. We feel that this program was of little help for us. 1 visit per week didn't do justice for the services Andrew needed. They provided bits of information for us but in the grand scheme of things we didn't feel they provided us with a wealth of knowledge or service. At the age 3 Andrew began attending a special needs preschool at in Mayville. This preschool room is part of the GST (Griggs-Steel-Traill) multidistrict which is a resource for kids with special needs. Preschool has been beneficial for our son but having said that it's not all spectacular as to how they have been to work with or the type of facility they maintain. If you

ever have a chance to drop in, unannounced, on their facility in Portland, do so so that you can see what type of environment the kids are learning in, I think you would be appalled. Our teachers are not well educated on working with kids with autism and they are not open to the idea of outside people to provide feedback as to different ways to work with these kids. We need our educators to be more open minded and willing to get up to speed on working with kids on the spectrum. There shouldn't be such a struggle with our schools to get our kids what they need in order for them to receive an education.

Self-directed supports through the Human Service Center in Fargo have been very beneficial for us. Our case manager has been great to work with and has been very proactive in helping get the services our son needs.

North Dakota MA is rather difficult to work with. We do not have doctors in the state whom are specialized in treating autism, and yes they do exist. So therefore when requesting to leave the state to see a doctor that is specialized, it would be beneficial if MA could approve those requests rather than deny them. The small amount that MA is willing to pay for services is unacceptable in my opinion. Our SLP has purposely waited to submit claims to insurance until our deductible has been fulfilled just so that she doesn't have to take such a hit from the small payment she would receive from MA. By waiting until the deductible has been met, by other providers, means she will be paid better for her services. This in turn has caused our out-of-pocket expenses to increase because we do see a doctor in another state that is specialized in autism, and those expenses go towards our deductible but until it's satisfied, we pay for it out of our own pocket.

If the state of North Dakota would mandate insurance companies to cover services for autism it would be opening the doors of opportunity for so many families that are affected by autism. If autism services were covered by the insurance providers that in turn would hopefully lead to drawing more and better services to our State.

If you've seen 1 child with autism, you've seen 1 child with autism. No 2 children with autism are the same and therefore they cannot be treated the same. These children can and do learn, they just do not learn they exact same way typical children do. They need to be provided the proper tools/services to do so. Therefore I ask that the state of North Dakota make necessary changes that will allow these tools/services to be provided to our kids so that they can benefit from all that can be offered.

From Janice Kern, Grafton North Dakota



I am the mother to four boys, one affected by autism. His name is Charlie and he just turned 10 years old. We love our great state of North Dakota. I have lived here my entire life, growing up in Bottineau county in Westhope as Janice Boettcher. I met my husband while working on the Fort Totten Reservation as a dental hygienist and he as as dentist. We now own Kern Family Dentistry in Grafton for the past 14 years. North Dakota is a great place to live. However, had I known that I would have a child with autism and had I known that there are few services available for autism in our state, I might have chosen to live somewhere else.

My family is one of the fortunate ones. I am healthy, educated and have the financial ability to get my family what they need. Even with these good fortunes, I cannot get what my son needs in our state of North Dakota. I can't imagine the children whose families have unhealthy parents, single parents, uneducated parents and financial concerns.

Insurance providers need to cover the cost of ABA or behavioral therapy for children with Autism. We can do years of speech, years of OT, years of PT and years of school. But without using strategies specific to kids with autism, this is like giving a wheelchair to a diabetic. We cannot continue to simply offer services to families because it's "what we've got". Ask any OT providing services to a child with autism. How much of their session is spent trying to get the child to sit down? Stop throwing things? It's because they lack specific knowledge regarding treating kids with autism. We also can no longer expect our schools to pick up where our insurance companies are lacking.

Fortunately, we were able to provide ABA for our son out-of-pocket. And because of ABA, we have a child who speaks and can learn and follow along with his peers in a classroom. ABA taught him *how* to learn and imitate. Typical children can learn by observing and imitating other people. Children with autism cannot do that. ABA made it possible for Charlie to reap the benefits of OT, PT, Speech and special education.

Our diagnosis experience is similar to many in North Dakota. Our diagnosis came about from Right Track and Infant Development. Charlie was 2 years old when he was diagnosed. That was 8 years ago. And we are forever grateful for this early screening resulting in a correct diagnosis. I feel confident with our state's ability to refer families for a diagnosis through Right Track and Inf Development. It is the point immediately following the diagnosis and everything after which leaves me with less confidence.

In 8 years, I have not met an autism-friendly doctor in North Dakota. They have been able to treat a short-term illness or rule out other disorders but not provide treatment to lessen the severity of Charlie's symptoms of autism. One doctor provided a phone number to "someone who seems to be helping kids with autism". We called and it was a provider of ABA. We got lucky. That is one of few helpful things that came from a ND physician - a phone number 8 years ago.

Services that have helped our family - Right Track, Self-Directed Supports through the Human Service Center

Services that have helped our family somewhat - Infant Development - They need to be better at referring and directing families to other providers and support groups. Once a week, hour-long home visits will not ensure a bright future for our kids.

North Dakota Medicaid - If BC/BS would cover ABA therapy and more treatments for autism, this would help drive Medicaid to be the secondary provider. Medicaid helps families who are fortunate enough to get it. But with autism, not many families can get it. I am one of the fortunate ones. It doesn't cover some of the best treatments we have been able to get for our son but it has been a tremendous help.

Many people have been good providers and have helped our family along the way. Audiologists have helped with CAPD (a common diagnosis among children with autism but which we had to find ourselves). Optometrists have helped with vision screenings as well as vision therapy (again nobody referred us, we found them through other parents). ENTs have helped with tonsillitis and tonsillectomy. Family Voices of ND helps many families directly and indirectly (such as their involvement with legislation). Several educators have had a dramatic impact on Charlie's education. But several also have had a detrimental impact.

We have been to the ER for anaphylactic reactions and a broken bone. Charlie was treated poorly by staff and was repeatedly called "an autistic". Even though the entire time he was asking questions such as "what are you doing with that?" He was not combative at all, not disruptive in any sense. The nurse still considered restraining him. I informed her that restraints actually cause more injuries and she reconsidered.

The fact is, our children can learn and can improve. I have a 10 year old kid to prove it. The state of North Dakota should all it can do give kids like Charlie the services needed to learn and benefit from all that can be offered to them.