

## Testimony

## Study Resulting from SB 2268

January 17<sup>th</sup>, 2012

Chairman Representative Wieland and members of Interim Human Service Committee. My name is Brandy Kracke and I live in rural ND, Fredonia. I am married and we have a son, Jaidyn who will be three February 2<sup>nd</sup>, 2012. Jaidyn has autism.

We welcomed Jaidyn into this world on February 2<sup>nd</sup>, 2009. He was a very good baby, he ate well, and he slept well, and was reaching developmental milestones. We started noticing changes at around 5 months. It began with his sleeping; he would sleep for 15 minutes and then play for 45 minutes, and would repeat this throughout the day. He stopped responding to his name and would not look at anyone, including me, his mother. Slowly his speech went away and he became non-verbal. This was very heartbreaking. This would continue for 17 months.

In July of 2010, I contacted an organization named Family Voices of ND; they in turn recommended resources to include speech language services, and the infant development program in our region. We were also referred to the Great Plains Autism Service Treatment Clinic. I was told they would do a comprehensive, interdisciplinary diagnosis for my son to see if he had autism. We waited months for this to take place. In the meantime my son was receiving services through the early intervention program and Anne Carlsen. Finally in February, shortly after his second birthday the diagnosis was given. The GPAST clinic team said Jaidyn did not have autism but had developmental delays. Their recommendation was to put him in daycare and they would follow-up with me. Well, I have to say I did not feel that I was getting any help from them or family support from that clinic. I was handed a folder and told this will help and that was it. There was no follow-up either. I felt very lost again. I decided to search for a diagnosis on my own and went to a developmental clinic and got the same results. I then approached my pediatrician in Jamestown, whom did a referral to a pediatrician in Bismarck. He went over all of Jaidyns' medical files, listened and asked me questions about my son and then went through the criteria for autism and said in conclusion Jaidyn has autism. In some respects, I was relieved, at least now I could move on from that. This was a horrible experience to go through, I was fortunate to have the support of Family Voices and the infant development team members. I knew I could rely on them for support.

Jaidyn is still mostly nonverbal but is making gains at the Anne Carlsen Center, where he has speech 3 times per week. The hard part is driving 45 miles to Jamestown. He is also accessing food therapy at Anne Carlsen to help with his eating sensory issues.

My issues now lead me to the school. Jaidyn has qualified for special education and can go to Early Childhood Special Education. Living in rural ND, this is hard. He will receive minimal services in school. Speech, only 1 hr per week. I do not feel this is even adequate, especially for a child that does not talk. My biggest concern. The school also kept insisting that no more would be needed, and that it would be sufficient as that is what students with autism receive, 1 hr of special education, 1 hr of speech and just an OT consult, that's it. Jaidyn is not a statistic, I thought. He is Jaidyn, unique in his situation. I strongly hope that new policy will come into effect so that the children with disabilities, specifically autism receive the services that their child needs in school. Our children spend a large part of their early life in school.

To sum up, living with and taking care of a child with autism or any other disability is daunting and hard work. It is a 24-7 job that will never end as autism is across the life of my child. I worry about where Jaidyn will be in the future? I worry what will happen if I am not here for him? I need help from other organizations and programs for Jaidyn to have a good quality of life. Please take time to understand autism and what it means for a child to have autism and do the right thing.

Thank you for your time.

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January 17, 2012

Chairman Representative Wieland and Interim Human Service Committee:

My name is Mindy Iverson. I am a married, stay-at-home mother of two and have a degree in Elementary Education as well as Child Development. My son Jack is 4 ½ years old and was diagnosed with Autism in May of 2011. Here is our story.

On August 20, 2007, a 6 pound 5 ounce healthy baby boy was born. Jack was an easy baby. He slept through the night at 5 ½ weeks only waking up once a night the first five weeks, would eat and go right back to sleep. He was happy, alert and hit all the mile markers on time. At 18 months, we noticed a change in our little boy. He started throwing tantrums. We joked that he was so advanced he entered terrible two's early. His tantrums started with head banging. If you told him no or he thought you were going to tell him "no" he would throw his head into whatever was closest. The doctors assured me he wouldn't hurt himself and told me to ignore the behavior. This was hard to ignore when your child tries to hit his head onto a concrete driveway. We would later find out that with sensory dysfunction Jack's body doesn't register feeling as it is happening. He doesn't get dizzy by spinning in a circle until he is ready to throw up, nor does his head immediately hurt if he hits it. Yet, doctors are still convinced he won't do it if it was hurting him. His tantrums also consisted of hitting me in the face. This occurred mostly during transitions. I noted it when we tried to take a parent/child gymnastics class and a parent/child music class. It is very hard as a parent to have everyone in the room look at you like you are bad parent because your child runs around screaming and when you try to calm him down he starts hitting you. I went through a period of time where I felt like a bad parent, because it seemed that was how everyone was looking at me. Shopping was a nightmare, my husband and I would go to a store and hope to get through it without a meltdown. We referred to it as being like a ticking time bomb; you never know when it would go off.

In June 2010 I took Jack to a free speech screening at Medcenter One. I had been concerned about his speech for a while and despite everyone telling me I had too high of expectations for my son I wanted to get a screening for peace of mind. During the screening, Jack threw one of his "typical" meltdowns. The person screening him asked if he does this often. I replied, "yes, terrible two's". She then wanted to know if I had time to take him to an Occupational Therapist Screening. After the screening, we needed to have our doctor refer us to St. Alexius Medical Center and have him screened by their Occupational Therapy Department. (St. A's is our primary network). Jack was diagnosed with Sensory Dysfunction and began Occupational Therapy. My husband and I went to the Internet and found out everything we could about Sensory Dysfunction and how we could better help our son.

Still unhappy about his speech, I kept pushing for Jack to begin Speech Therapy. By August 2010, Jack was going to OT and Speech at St. Alexius Medical Center. At first he loved it. He

did well there. But as time went on we saw less and less progress. In Speech Therapy my three year old was expected to sit at a table and identify a picture with the appropriate word. Not what I felt was an age appropriate approach, but I trusted that they knew what they were doing. During Speech sessions, I would pick him up from under a desk, run out in the hall and bring him back in. If he said 5 words in a 30 minute session, we were lucky. At OT I did not go in the room. I had frustration here too, when we asked about potty training, we were told that is not her job. Food aversions were not really worked on. My understanding was that OT was to help them with life skills. They did some swinging, worked on fine motor skills and heavy lifting activities. Towards the end of our time at St. A's I would have to go in with Jack to OT until he was distracted in the swing and sneak out so he could finish his session. Then the phone call came, Jack's OT and Speech Therapists were both on the line. They had finally ran into each other and visited about Jack's progress at therapy or lack thereof. I find it important to mention they share a receptionist and their rooms are on the same floor, in the same wing, very near each other. I did not want to hear what they had to say. My worst fear was that my son has Autism and they called to tell me they thought Jack needed to be seen by a Psychologist. They felt it was more than Sensory Dysfunction and the Psychologist could make that diagnosis.

Next stop was a Psychologist at St. Alexius Medical Center. We saw her three times. She confirmed my fear. My son has Autism. My new job was to be his advocate. I knew I needed to find a new place for Jack to receive therapy. My wish is that there would be a place he could play with other kids and get therapy. Jack loves playing with children. At that time he would ask daily to play with kids. I am a stay-at-home mom. He attended drop-in daycare when I had appointments and did very well. I tried to put him in part-time daycare so he could play with other children but our area has limited daycare opportunities. In my searching, I found Red Door Pediatric Therapy and BECEP. With BECEP, we met with a team consisting of a Speech Therapist, Occupational Therapist, Special Education Teacher, and Psychologist. In this meeting they agreed to observe Jack to figure out how we could move forward to best help our son. The Special Education teacher suggested they observe Jack in her room instead of coming to our home. We were in awe. We just disclosed how our son has tantrums, head bangs, hits, screams and this woman wants him in her room. It was 30 wonderful days for Jack. He participated, showed progress and received Speech and OT services. Being so close to the end of the school year, they did not have enough documentation for Jack to attend BECEP's summer program. I was back at square one. What would I do all summer? He was doing so well with schedule and routine. He did attend Red Door for therapy.

I then found out about the Autism Waiver. So I began the application process, which I was warned could take a while. It was May 2011. Awhile, was ok with me. I figured in two months I would have him qualified and I could get intervention in the home to help me help my son. Months passed and we still had not heard anything. Jack turned 4 on August 20<sup>th</sup>. One can only be on the waiver until age 5. I made it through the summer. I started to question if I should continue with the waiver. Then I made phone calls to our case manager and got excuses about the delays due to the flood along with St. A's not sending records. I find it important to mention that I waited at Best Buy for three hours to get the video of Jack's day to day activities done immediately for the committee to review only to find out our case manager dropped the ball on providing our records to St. A's. This is when I learned an important lesson: I need to baby-sit every person even if they assure me they are taking care of it. In October the team assigned to us

finally came out to observe my son. This was 5 months after I turned in my paperwork. The team that came to observe reassured us they would get their paperwork in within a week, two at the most. They observed Jack, asked him questions, and thought we were doing great things for him. Three weeks passed and we still were not approved for the waiver. I started making calls weekly to our case manager. As Thanksgiving approached, I called our case manager's supervisor, our team's supervisor and still got no where. Everyone reassured me they felt bad for me and were still waiting on the OT's report from the Team that came to observe. I then called Family Voices, I had their brochure and just needed to know what I could do to light a fire under these people. When I explained everything to them, they gave me a name of one more person at Minot State University I could call, and luckily that person is someone I personally know. One more phone call and then the report finally was in the Monday morning after Thanksgiving. We officially were on the waiver Dec. 2011. Keep in mind this is 7 months after I turned in my paperwork. This is unacceptable. In ND we do not have many resources and the ones we have take entirely too long.

Red Door has been a great fit for Jack. Our OT made a potty training video, works on food aversions, and fine motor skills. His speech skills continue to blossom. They use a similar approach to what he is used to at school. BECEP is where Jack will go for the rest of the year and next year before beginning Kindergarten in the Fall of 2013. I am thankful for the teacher he has there and happy she will be by my side to get him ready for Kindergarten. Now that we are on the waiver, Jack has new equipment in our home to go with the equipment I had previously purchased. All of them help him in different ways. We are working on bringing intervention into the home to give us new ideas on certain issues.

Early intervention is the key to helping children with Autism. I have now lost 1 year of intervention on the therapy we got at St. A's, and another 7 months waiting for intervention from the Autism Waiver. We need more resources, as well as doctors that can guide parents. Ideally, you should be able to go to a doctor and then be provided resources for medical treatment, homeopathic treatment, therapy services, and resources to use in the home and day-to-day life. It should not take two years for a person to find services for their child. I am still not done with my search, next I need to find a nutritionist. Other states have centers for Children with Autism, even Fargo has something similar. It is something that needs to be looked at for Bismarck. I am thankful that I do live in Bismarck because I can't imagine those who live in small, rural communities in ND. The financial commitment is not something our family planned for. Having a child with Autism adds many expenses out of pocket for special diet, therapies and other added medical expenses. We are fortunate to live in Bismarck where the resources are available and we do not have the added travel/lodging expense.

As an individual with an education background I feel it is important to add, teachers need more training when it comes to Autism. With the statistics that are out there, teachers are going to have children with autism in their classroom. They need to be provided with tools on the best ways help these children succeed. I have always advocated that every child learns differently. We cannot expect all children to read a chapter and take a test, there are many kinds of learning and as a teacher you need to present material so all children are set up for success. Now as a mother of a child with Autism I will push even more for teachers to strive to find ways to reach

all students. When I enter the workforce this is how I intend to teach and I hope there are resources for me to do so.

Jack is a cute little boy. He has a smile that charms you and eyes that sparkle. He loves to joke with people and get a laugh. Animals, monster trucks and riding bike make him happy. He has always been aware of emotion in others and is now becoming aware of his own feelings. We credit Red Door Pediatric Therapy and his BECEP classroom experience with the gains we have seen in Jack. My goal for Jack is no pull-out services when he enters Kindergarten. I will try to find every opportunity necessary to make that possible for him.

Thank you for listening to our story. We look forward to seeing and using the improvements implemented. I would be happy to visit with anyone personally to answer questions or provide more insight.

Sincerely,

A handwritten signature in cursive script that reads "Mindy M. Iverson".

Mindy M. Iverson