

Mr, Ms.) Chairman, and Committee Members,

Thank you for the opportunity to testify on behalf of families affected by autism. My son Alexander received his diagnosis in August of 2010 at the Great Plains Clinic that was held at the Anne Carlson Center. When our daycare first mentioned that he might be autistic it took me over a month to find information on how to get him a diagnosis. We checked into Early Intervention and I called South Central Human Service Center and Social Services and no one really knew where to tell me to go. My friend who works at the HSC finally dug deep and found the Great Plains clinic and gave me contact info for them. When I finally contacted the clinic we had to fill out paperwork, answer questionnaires, take videos and submit them before he was even accepted into the clinic. Once he was accepted into the clinic he was seen by a team which included a speech therapist, Occupational Therapist, Physical therapist, Dr. Myra Quanrud and numerous others. It was so nice to have the clinic be right here in town so it wasn't so traumatic on our son. It was also nice to have a team of therapists and doctors to do the diagnosis as they provided different outlooks on different areas.

We were there at the clinic for over 3 hours. After it was over, I sat beside my husband in front of all those people while my son slept in my arms and heard those dreaded words.. Your son is Autistic. I felt my whole world crumble as I tried to wrap my mind around what this all meant for our son and his future.

They gave us pamphlets and binders and then sent us home. For a week we struggled and cried until I finally found a pamphlet in the binder for Family Voices. Then we had someone from Family Voices contact us, Which.. Was a life saver! Other than that we weren't told much about supports or services that were available. Family Voices help guide us thru what was available and where we needed to go to get help. Mindy Blackmore our Early Interventionist through the Infant Development Program was also helping us thru the process.

Outside of the Early Intervention Program Staff and Family Voices staff, we felt like we were an island unto ourselves. We needed more info on process, navigating systems and supports. We only received that information from these 2 organizations. Our greatest support was from families who had walked this path before us. They helped us to ask questions that we were seeking, supporting us every step of the way.

One of the first books that I had read about autism had a statement in it that said " When finding out the diagnosis you will go thru the grieving process, but you need to step back and dive into therapies and programs like your life and your child's life depends on it" So that was the approach I took. I dove in head first and just kept calling and calling whoever I could to find out what to do and where to go. I went with the Anne Carlson Center because to be perfectly honest with you, I have no clue what else is out there for help for my child. There was very little guidance, 90% of the services and supports for my child have been because of my own advocating for my child.

Right now Alexander is verbal and is able to put at least 3-5 word sentences together which is a HUGE accomplishment. He still has issues with repetitive behaviors and has low tone in his body and issues with changes in his everyday routine. Alexander still will not play with other children, but has begun some parallel play. He is attending Gussner Pre-School and is receiving therapies thru the school as well as the Anne Carlson Center. Now the concern is whether he needs physical therapy or not.

I know that I should have concerns for his future.. And I do, but my main focus right now is getting him the help he needs and trying to make his life as normal as possible. Basically we are living our lives by a calendar a month ahead of time. Alexander was the first child on the ASD waiver, and now my biggest concern is what is going to happen to him when he is off the Waiver. I am one of the lucky ones who have private health insurance for my son, but I also have a \$2000 deductible and if he does not get approved for a waived service after he turns 5 we can go about one more year with therapies before we would be out of money. What happens if he regresses? What happens when he gets mainstreamed in the school system? We will lose our in-home supports and his Medicaid and will have to stop most of his therapies. The Waiver has been a godsend for us, we have been able to go to our other children's functions and to have been able to actually have time away as parents for "date nights" and sometimes.. Just peace and quiet..

But it is still a concern about what happens when he is off the waiver. It scares me to go back to the eligibility board and have a bunch of people who have never met my son or lived in our lives decide on what my child's future is going to be. We need more time as he needs these supports to strive to be the best he can as they have proven to benefit him immensely.

My experience in this all is by just being a parent of a child with Autism. If you have technical assistance groups that are full of individuals that have only seen autism thru text books and on a screen they will never be able to grasp the full concept of what is needed or not needed with a child with autism. They need to have on hands experience in situations and 1 or 2 hours a week isn't enough. When you have decisions that you are making regarding programs for families they need to have a voice. When you have a waiver like this that has such a huge potential to impact families lives and do so much good on a grand scale you need to have the voices of families that are ACTUALLY living thru this experience. I just can't stress enough how important that is.

You have a generation of families with younger and younger parents with children being diagnosed with autism and these parents are looking for guidance. Right now there is early intervention and Family Voices after that it appears there is nothing. You have to hope that you have good health insurance or have a lot of money. It's my guess that of all the families on the waiver that there are less than 10 that have health insurance. I'm very lucky.

One of the main services I see that this waiver needs is Behavioral therapy that could also include ABA therapy. Your waiver right now is based more for physical disabilities than Autism. You also need to have some sort of guidance for families, the more information available the better. If the parents get the diagnosis from an autism clinic then they shouldn't have to go thru another diagnosis to get on the waiver, it is painful enough the first time and then to learn you have to go thru it again makes it like you are re-living it all over again and it is emotionally draining.

Most of these families don't have time. This is a critical age where so many gains can be made with the right intervention. Take the waiver and make it from 3 - 9 or even 10 and eliminate the birth to 3 that will save money. ~~If you~~ ^{Learn from them} take the time to work more with parent groups and educate DD program managers and work with to help be more educated.

I'm scared on what the future will hold for my son, but I know that I will give 110% to fight for the help and support for him that he needs and deserves.



Toby Cherney, Mother to Alexander Cherney 3 yrs old.