

My name is Janna Robinson and I speak for my daughter Madalynn who was diagnosed with Autism Spectrum Disorder on July 15, 2010 at 25 months of age. I would like to share with you some entries from my online journal over the past year since her diagnosis.

July 17, 2010.



Madalynn, or as she is known Maddy, is the happiest child I have EVER known. I'm not just saying that because she is mine. I'm really not. And every therapist that comes to know her, agrees, NO QUESTION. She is happiness. She breathes in smiles.

So this girl. This precious smiley, happy, beautiful girl.
Has. Autism. Autism? Autism.

I don't know what Autism looks like. But I didn't think it was her. Yet, I was the one who made the call. I was the one who decided to stop trying to ignore the lack of eye contact and name recognition. To stop ignoring her rocking and groaning. To stop ignoring what was staring me in the face. She wasn't staring at me but it sure was.

Most people thought I was nuts too. "*she's so happy*" is the response I got. Yeah. I know. That's probably what prevented me from calling sooner. Who knows.



And I have been walking around like a living zombie. Wanting to crawl in a corner and cry for a few decades. Yet, there is this ticking time bomb going off in my brain. Here is the kicker.

Because it's not enough that your child now has a very multi-faceted disease. A very hard to define and incurable disease. No, then they sit you down and give you the great hope that because she is SO young that she can make huge strides before she turns 3. A pivotal time in her life. So we got very gung-ho about it. Let's do it. Whatever "it" is...therapy, medications, diet...you name it. Okay, great. But hang on a minute...we live in rural nowhere and there are no services for your child. None.

It's imperative for her development that she receive some very intensive therapy between NOW and three years old.

But there isn't any.

Just 6 hours of training, a book, some internet videos or DVDs...and off you go. Parent/teacher. Oh and before you are feeling TOO overwhelmed...let me just tell you that she needs at least 20-40 hours a WEEK of this therapy for it to be effective. The 40 hours are the most effective. Okay..see ya next week to discuss what you have decided.

I walked out of that meeting wondering what exactly I had to decide. *Doing NOTHING is not an option.* Waiting until she goes to preschool (*essentially doing nothing for a year and then passing her off to special education who already are underfunded and have their hands full*) is not an option.

The only option is to do this. Somehow. Do this. I have no idea how. I truly don't. I have 3 kids. All under 5. She has a twin who isn't speaking who needs some speech therapy. An older sister that is highly intelligent and doing great but she's 4...she still needs me too. 40 hours a week? I don't think I can do LAUNDRY 40 hours a week...let alone teach my kid. But I have to. HAVE TO. For her.

September 13, 2010

We had Maddy's ABA (Applied Behavior Analysis) workshop today and while I have loads to write about...I do not have the mental capacity to write anymore today.

I did want to quickly comment on how humbling it is to be in a room full of people devoted to helping your daughter. People who are freely VOLUNTEERING to work one on one with your child. To help her. To love her. To see her thrive. To help us help her. To help Maddy shine.

I don't know if any of you have ever been in that kind of situation. The kind of situation where you find yourself unable to truly do all that is asked of you so you must reach out for help. And to need people volunteering their time as there is no way you can pay all your medical bills, let alone pay people to do therapy for your child. To ask for help and then see it unfold.

It's very humbling. It makes me want to cry. I have never felt so loved in my life. Ever.

To look around a room of 15 or so people and see them truly devoted to helping Maddy. Helping YOUR child...to see them smile when she smiles. To see them relish in the light that Maddy is. They know she is going to throw tantrums and be difficult. To sacrifice that time they have with their own families to help yours.

Time is a sacred thing. Everyone wants more of it. Yet time is of the essence for Maddy. And to see these people gearing up for battle. Them vs. Autism. Bolding going into a land of unknown to bring your daughter back....it's speechless. it's breathtaking. it's love.

October 23, 2010

Today. Maddy. Reached. To. Hold. My. Hand.

She said "hold hand" and gently slipped her hand into mine as I stood talking to Ashley about their session. So quiet. So innocent. Like she had always been doing such a thing as that. Not knowing that her Mama had been waiting 2 years and nearly 5 months for her to do it. Hoping. Praying. Maybe someday.

Today was that day. She held my hand for a few short moments before she realized that we weren't ready to leave yet. My stomach did flips and I wanted to swing her around the room and tell her how awesome she truly is....but I held back, fearing that kind of outburst might prevent her from doing it again. It seemed to her, quite a natural thing to do.

Maybe she will never know just how unnatural that had become in such a short amount of time.

Starting ABA, we planned for the worst. Typically kids with Autism lash out at any kind of intrusion into their world and ABA is quiet an intrusion. A very physical and emotionally demanding experience on "their world" - and sure, Maddy did protest but not the extent I had prepared myself for and nearing the end of week 5 and calendar wise - a month into this - she hardly ever protests now. School has become fun.

We see so many wonderful things emerging from Maddy now. We have alot of work to do....don't get me wrong...ALOT. But she really is coming out....inch by inch.

July 21, 2011

On the 8th of this month...we received the official letter from that Maddy's diagnosis was Autistic Disorder Remission. The observed behavior and tested scores proved that she was Non-Autistic. But it wasn't just those words that freed us. It wasn't just that we got to see the words REMISSION in all caps. It was the fact that a year ago, this child was suffering from moderate autism. Her overall age level was well below average at the 7th percentile.

7th. This isn't like height/weight...this is her cognitional living. 7th percent of her peers. It still makes me want to throw up.

Today she is at 63rd. She is average....slightly above average. 63! In one year.

Dr. Adams Larsen writes "The profile observed today is consistent with that of a typical functioning 3 year old." She goes on to state, "the support and advocacy that Maddy has within her family and community is outstanding, and her progress is directly related to their time and dedication."

Today:



Maddy attends preschool with her peers. She has 45 minutes of speech therapy a week. She is a bouncy, happy, 3 year old. She is also one of the very few, if not the only, child in North Dakota to be in Autistic Disorder Remission.

I am here to confirm that Applied Behavior Analysis works. It is the #1 recommended treatment for children with autism according to the American Academy of Pediatrics. We are also proof that it can be done. But we need more help. I didn't realize that while Maddy needed at least 30 hours a

week of ABA, I would put in at least 70 hours a week being the team leader, putting together her curriculum, her daily data sheets, driving her to therapy, doing sessions with her, and so forth. I had 8 volunteers helping me and an entire community providing meals for my family, watching my other kids, providing financial relief and materials, something that if it were not for volunteers, would have cost us between \$30,000 to \$40,000 if not more.

We are very fortunate to have Maddy back. To have a wonderful volunteer network. Our connections with Anne Carlsen Center and the Center for Autism and Related Disorders. I am here to tell our story, to lay the foundation for other families going through the exact same things that we went through. To tell them they are not alone. To tell the state that we need to do something. We support Anne Carsen Center in their efforts to bring hope and more Maddy stories across this wonderful state of North Dakota.

For more information on Autism: <http://www.centerforautism.com>

For a more detailed account of our story: <http://maddysvoice.blogspot.com>