

March 20, 2013

As I sit here watching my now 3 year old daughter, I see how far we have come in this journey called Autism. I also see how far we still need to go. You see our daughter, Raylin, was diagnosed with Autism Spectrum Disorder at 21 months. Since then, our lives have been a roller coaster, to say the least. We had little knowledge where to go and what to do.

The day of diagnosis at KU Center for Child Health & Development, we were told that she will likely require many therapies. She was, & still is, considered non-verbal and has some physical challenges. I remember distinctively being told that we needed to get her into Speech, PT, OT, and ABA therapies as soon as possible. Feeling lost, we didn't even have a starting point, except for the Autism Spectrum Disorders Family Resources Booklet they gave us at KU Med. This was somewhat helpful, but living in rural Kansas made, and still makes, this a challenge for us and other families.

After we got home, I decided I had better see what our insurance would cover. My husband is considered self-employed and has NO benefits. I am a school teacher for USD #413 and we have Blue Cross Blue Shield of KS insurance. I know in the past, they have always covered our family well. To my surprise, it didn't seem to cover as much as we need for our daughter, that was now considered to have a disability. I was relieved to find out that PT and OT was unlimited as long as the doctor recommended it. At the time of 21 months, she was not crawling or walking! So I knew that was the first thing we needed to accomplish. We later stopped because we could not afford to do PT, OT, and speech therapies.

Next on our Autism "to do list" was speech. At 12 months, she had a few words and could point to things when she was asked. Then around 14 months, she was a different child. Speech had left, along with pointing, and the typical Autism characteristics began. I contacted insurance to ask about speech therapy & to my surprise, it was NOT unlimited. You may have 90 days of speech therapy in a calendar year. That equals out to about 7 months and that is going 3 days per week, for 30 minute sessions. I questioned the lady from BCBS and she said it is because some children with Autism may never speak, so they limit it. I believe that is an unfair assumption that MY child may not speak. They seemed to be putting all the kids with Autism in the same category. Statistics say that they have a higher risk of NOT talking if they do not speak by age 5. She wasn't even 2 yet! So, we did a couple of times per week, so we didn't run out of insurance covered speech times. Right now, she goes 1-2 times per month. Our cost before insurance kicks in is about \$500 per month. Since she has begun speech therapy, she is more confident and tries to talk. She is also learning alternative ways to communicate, but has not given up trying to speak. She's in there and these therapies are helping. It has been recommended, by Temple Grandin & other professionals, to have her in a minimum of 15 hours per week in speech and language therapy. As you can tell, we are far off because of cost.

ABA therapy has yet to formally take place with Raylin. Our insurance does not cover it. I have looked into centers that are in the city and they told me that our insurance does not cover them. One of the doctors at KU Med told us that ABA therapy is going to be key to her learning. I can only imagine how much further she would be if she had the opportunities that KS state employees have. If she had these therapies before she was in elementary school, maybe she wouldn't have to have an IEP or Para support in the classroom. Carrying an IEP and having to have a Paraprofessional costs more money to the state than this bill will. I would love for her to get the services from the KS Waiver, but it is unrealistic at this time, due to the LONG waiting list. This waiver should service children BEFORE they reach school age, unless diagnosis is late. We could reduce the need for services in Public Education, therefore reducing the cost to the State of KS for the need for services. I think that is a win win situation.

If we stay at the rate of learning that our personal pocketbook can afford, what we are doing now is all we will be able to do for our Raylin. We have had to stop OT and PT, which she still needs on a weekly basis outside of preschool.

The cost to us for therapies and therapies we need for her have put us over the edge, financially. I possess a Master's Degree in Education & my husband has an Associate's Degree. We work hard and do not take assistance from the State of Kansas. We want to be able to pay for these services for our child, while raising our other 2 daughters. Currently, we cannot do it. Our house is for sale and so are our vehicles. We are racking up debit in the meantime, due to circumstances we cannot control. People should not have to sell off all their assets so we can help our children. We need this Insurance bill. Other Kansans need this bill. We love our kids and our state. We just ask that you give us the support we need to have our children be the next generation of productive citizens in our country. Autism is not a hopeless diagnosis. Our kids just need extra care and consideration. Thank you very much for your time.

Sincerely,

Nikki S. Jacobs

Mother of an Autistic Daughter

Elementary School Teacher

President of Autism Hope for Families