

FOR PARENTS

by Parents

A Guide to Autism

Compiled by Jane Lee, Seo Young Lee, and Savannah Ray



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About Us

Autism Family Services of New Jersey (AFSNJ) is part of The Family Resource Network (FRN). FRN is one of the leading providers of community based services to people with disabilities living in NJ. For 45 years, FRN has been helping people with disabilities and their caregivers access the resources, benefits, and supports needed to live independent lives in the community.

Along with providing individuals with Autism and their families services like after school care, Saturday recreation, and various trainings, AFSNJ holds the largest yearly family gathering of children with Autism in NJ, at the Annual Beach Bash in Belmar.

For more information:

Phone: (877) 237-4477

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Savannah

Jane

Seo Young



About This Project

Dear Parent,

We are Savannah, Jane, and Seo Young and we created this book during the summer of 2015 while we were in Physician Assistant and Pharmacy programs at Rutgers University. This project began after we were accepted into the Community Oriented Primary Care (COPC) summer program through the Robert Wood Johnson Medical School, and joined The Family Resource Network. We met with members of Autism Family Services of NJ and the Epilepsy Foundation of NJ and came across the books called “For Kids By Kids” and “For Parents By Parents.” These epilepsy guidebooks were created a few years ago and have been a great resource for parents and kids newly diagnosed with epilepsy. We saw the tremendous need to make one for Autism as well, so we started interviewing parents of children with Autism, asking them about their personal experiences and advice for other parents.

“For Parents By Parents, a Guide to Autism” is a resource for parents of children with Autism to learn that they are not alone. It’s a compilation of stories, feelings, perspectives, and advice from real parents of children with Autism. We hope that you enjoy reading this book, learn more about Autism, and take comfort in the fact that there are many people out there impacted by Autism just like you!

Leslie

*Leslie is the mother of Brody and Seth.
Brody is 10 years old and Seth is 8 years old.*

First signs

Seth didn't talk. He was diagnosed at 2.
Brody wasn't diagnosed until he was older, like 5.
Brody had social interaction problems.

Initial reaction

I knew before the diagnosis because I'm a nurse,
but it was still heartbreaking. It still is every day.
I was devastated. There are no words to describe it.

Looking back, I wish I would have known...

I wish I had someone to sit us down and be like let's get
this for you and this for you, and this is what you need.

*"You take the **good** with
the **bad** and run with it."*

Finding information and resources

My husband and I went on the internet.
We moved to New Jersey right away. In
NJ, services are easier to get and are more
available, but you still have to pay for them.

How my life changed after diagnosis

I guess you see things in a different
perspective. Like you can't go out to a
dinner that costs \$80 when you have an
occupational therapy session that costs
\$80. Your priorities change I would say.
Like we can't afford a new car payment
because we have to pay \$320 a week for
Applied Behavior Analysis (ABA) therapy.

Daily challenges

Seth has trouble with communication
because he's almost non-verbal. Brody's
challenges are anxiety and adaptivity.
Like Brody wouldn't go to the movies this
weekend because he just doesn't want
to go to a movie. He just doesn't get
that his way isn't always the right way.
For our family, the financial strain
has been the biggest challenge.

My child's accomplishments

Seth actually can talk a little bit and
he's potty trained; that's his biggest
accomplishment to be quite honest.
Brody is placed in a normal class
because he's doing fine academically.
He's actually extremely smart.

*"I'm most proud
of the little
things day
to day."*

Proud moments

Brody is really empathetic toward other
children. He will never pick on..like he'll
be the first one at a playground to help
the kid on crutches do something.

For Seth, I'm most proud of the little things
day to day. Like he went to the bathroom
on the potty the other day and I was very
proud. People don't realize how great that
is. Like you have no idea. Unless you
have a kid like mine.

My advice to parents

You take the good with the bad and run
with it. Everyone is different and you have
to judge for yourself what you can handle
and what your kid can handle, and what
you're willing to change your life for.

Get a good ABA therapist, and let them
guide you. You have to have a good
rapport with them. You have to like them
and understand their ways of thinking and
the way they work. If you don't like the
way, then you have to say "What we can
do different?" The first time you meet your
therapist and she meets your child, you
have to see how she interacts with them.
She has to be knowledgeable too.



Kristina

Kristina is the mother of Nikolas. Nikolas is 11 years old and was diagnosed at around 29 months.

First signs

Lack of eye contact. He wasn't speaking. He was also lining up toys all the time. The big sign was pretty much the lack of communication.

Initial reaction

I was already aware. I had been a paraprofessional for years in classrooms for kids with Autism, and I knew what to look for. It wasn't too much of a shock. It was nerve-racking though. I didn't know what his future would hold, but I kind of took it and got him help as soon as possible.

Having dealt with kids with Autism before, I knew how bad it could be and feared how bad this was going to be.

Looking back, I wish I would have known ...

How much potential he really had. I wish I would have been able to know where on the spectrum he would be now. You always feel like you could've done more. I don't think I could have done more, but I always have that guilt that maybe if I had done this or that...

Finding information and resources

I just started looking up everything online, searching the internet, looking up different kinds of therapies and different things people have used. It's trial and error. Even if there is a new thing, it doesn't mean it's going to work. I tried a little bit of everything. I think ABA (Applied Behavior Analysis) works and early intervention is the key. The longer you wait, the harder it is.

How my child's life changed after diagnosis

I think our challenges were with communication. It was hard to understand what he wanted. We did a lot of sign language during the beginning of early intervention.

It's amazing to me that when he was diagnosed, I feared that he'd never be able to say 'Mommy, Hi Mommy, I love you Mommy,' and now he is completely verbal, does multiplication problems, reads out of a book, etc. I couldn't have asked for more.

Daily challenges

I would say the biggest challenge is making bowel movements. The other one is his weight. That's a big struggle because he doesn't know how to turn off that 'I'm hungry' message. He has no desire to exercise even though we try. We try to cut back on food with him but he sneaks it.

Basically his general health is a concern. Just because he doesn't understand why I want him to do this and that, or try new food. Trying new food is always a struggle.

Sleeping is also a struggle. Last night, at 2 o'clock in the morning, I was still begging him to go to sleep, trying to tickle him to sleep but he just would not go to bed.

My child's accomplishments

I would say being able to control himself in a meltdown and being able to communicate what his frustrations are and what makes him angry. He's able to express himself, using words instead of having a meltdown, and able to say why he's upset. Being able to communicate and express himself has helped him the most in the long run. He's gotten so far. He keeps proving me wrong.

Proud moments

He works very hard. He really is a sweet, amazing kid who's come so far and defied every expectation and every barrier. He's just broken through any limitation or barrier. It took longer but he's broken through them all. He is the sweetest kid and has the biggest heart.

My advice to parents

I think parents just have to be patient and try as much as they can. When one thing doesn't work, try something else. Just keep trying until you figure out what will reach your child.

I just want to say to never give up. You cry a lot but it's not the end of the world. Only you can make the end of their world by not doing anything. If you do nothing, nothing will happen and they won't get better. Doing nothing is the worst thing you can do. Doing nothing is not an option. Get started as soon as you can. You have to be proactive and **YOU** have to do it.



"Never give up."



"Doing nothing is not an option."



Lisa

Lisa is the mother of Michael. Michael is 12 years old.

First signs

Michael had lots of behaviors but being a first time parent, we didn't know if they were typical or atypical. He was nonverbal at that time and he had screaming fits, throwing himself on the floor, kicking and screaming.

Initial reaction

I wasn't surprised because of all the behaviors he had, but I was also kind of scared because I didn't know much about it and nobody in our family had a child with Autism.

Looking back, I wish I would have known....

How important it is to find a doctor that you feel comfortable with and can relate to. Someone you feel comfortable asking questions to and someone who treats you and your family with respect.

"Stick with what your gut tells you."



Finding information and resources

I had a connection at Children's Hospital of Philadelphia and they partnered us with an Occupational Therapist; she has been wonderful. They were a huge help and they also partnered us up with early intervention. We had a good support system. We chose to go to Defeat Autism Now (DAN) and that was huge for us.

We continued going to the same doctor for 2-3 years until I got my master's degree in Holistic Nutrition and I took it from there. It was clear to me that I didn't want to go the mainstream medical route because medicating just masks Autism; it doesn't always help it. Michael got 25 supplements a day. We did Methyl B-12 injections to help him speak. He also took DMG (dimethylglycine) combined with the Methyl B-12 injections and within weeks, he started to speak. It was amazing.

How my life changed after diagnosis

Michael had to go to so many therapies, at one point 10 therapies a week. With all of his services, I couldn't handle working full-time and I had to quit my job.

Daily challenges

It's basically learning to react to things calmly, and just his reaction to different circumstances. Once his brain has calmed down, he can react and talk to us and tell us what is wrong rather than just freaking out and screaming. It's just a challenge still dealing with those behaviors. And his hormones are changing as a teenager.

I have to plan everything. He will ask me "What are we doing over the weekend?" He needs to organize that in his head.

My child's accomplishments

School. Because they told us that he would never do well in academics. One evaluation that was completed at school indicated that he had below average intelligence. I knew that wasn't the truth. I knew that getting him the services he needed would help him grow. For him to make Honor Roll was great.

Proud moments

School. Honor Roll. Now he's like a typical kid. He's in the inclusion program and he's entering 7th grade. He's been making Honor Roll each marking period.

My advice to parents

Their brains function differently so you just have to figure out what works best for your child. Get as many services as you can. I would also tell them about the alternative route.

Last thoughts

Parents, go with your gut. Stick with what your gut tells you. Keep pushing until you get the answers that you need. Find the right doctors that match well with your family.

A+

Honor Roll Student

Melanie

Melanie is the mother of Logan. Logan is 16 years old.

First signs

I would say the biggest thing was lack of communication. He would babble one word but then he sort of plateaued. We saw a lot of repetitive behaviors in Logan. At a very young age, he would line up all of his toy cars. He would take his trains and line them up. He would go up to his baby sister and take the bottle out of her mouth and line that up behind the cars and trains. Everything was lined up. We also saw the usual lack of eye contact.

Initial reaction

I think I was expecting it. We had suspected that a diagnosis was coming, so I think we tried to mentally prepare for what that was going to feel like for us. I think even as prepared as we were, when you hear the doctor say those words for the first time, you have that moment of loss as a parent.

I remember walking out of the doctor's office and thinking to myself 'this is the same little boy who I'm putting in the car seat to take home as I put in there to take with me to the appointment.' Nothing's changed. They can put a label on it but it's not changing my son. It wasn't changing who he was 10 minutes before he got the diagnosis.

Looking back, I wish I would have known...

I really wish that I knew there were other families out there experiencing the same challenges that we were experiencing. I wish there was someone there to really let us know that there was hope and support out there. They didn't give us a bright outlook for my son's future. There was no making sure families had any support whatsoever. The services were so different then than they are now. You didn't even know another family with a child diagnosed with Autism back then like we do now.

How my child's life changed after diagnosis

We realized as a family that it takes both parents being involved in this process. At first, I needed to be in charge of everything dealing with Logan's services, treatment plans, schooling, and therapies, but over time I realized that I had to let up some of that control to allow my husband to participate as much as I was. This was not only my son, it was **our** son.

If you ask me how my life's changed, it went from a sole focus on services for Logan to making sure that I'm spending an equal amount of time with my daughter and my husband. I had to be conscious of making sure we had time as a family as a whole and also as a couple; to make sure we didn't lose the relationship and support we were able to give each other in order for us to be the most effective parents that we could be for both of our kids.

How my life changed after diagnosis

It really made me realize I had to have a new focus in life. A lot of the things that we had once focused on as being important weren't really all that important anymore.

My child's accomplishments

Logan wants to work. Logan in school has SLE (Structured Learning Environment) and it allows him an opportunity to job sample at different locations. Logan is super proud of himself when he has the opportunity to show the skills that he has gained in those environments. I think he feels like he's part of a group outside of school. He's part of his community, and giving back to his community in a really great way, while gaining the skills he needs to be more productive as an adult. That's been a great opportunity for him. We really advocated for him to have an opportunity to job sample in a place that was really specific to his skills and his interests, and that made a world of difference for him.

Proud moments

I'm proud that he's starting to know what his dreams are. He's letting us know that he wants to work, which used to not be considered a possibility for him. He's letting us know that he wants to live on his own one day, maybe not when he's 18 or 21, but that's one of his goals. I'm proud that he's able to share his goals so we can work on the skills he needs to be as independent as he can be, and give him more options in his future.

I think he has some incredible skills, we just have to look at those skills and see where we can transfer them to.

How I would explain Autism...

I would definitely stress that no two people with Autism are alike. Just like no two people without Autism are exactly alike. And that the symptoms of Autism are different for different people.

My advice to parents

It's not a one size fits all diagnosis and it's not a one size fits all treatment plan. For someone with Autism you have to base their supports around that individual. I think quite often that's missed. People with Autism know what they want. They may not be able to express it in the same way, but the people who are working with them the most should help that person identify what their interests are. We had some really good people surrounding Logan to support him in that area. With that, he's able to have these experiences he wants to have, and that allows him to be more successful.

You have to educate yourselves. You have to take every chance you can to gain additional information on the services that your child may need and may have to access in their future. Become as educated as you possibly can so you can effectively navigate the different systems that you're going to come in contact with throughout your child moving from childhood into adult life. Really look for the support of other families that are around you. It's not something you have to do alone. Don't be afraid to ask for help when it's needed.

Expect great things. Set the bar for expectations high and really encourage your child to keep reaching, and encourage the people working with your child to keep reaching. Follow their lead while following your heart. Identify and embrace the interests that your child has and let your child be themselves.

Last thoughts

I keep going back to expect great things. I wish that message was given back when Logan was diagnosed and it wasn't. We still have high hopes and dreams. We dream big for Logan. It's just that our dreams look a little bit different than they did when he was born.

"Expect great things."

"It's not a one size fits all diagnosis and it's not a one size fits all treatment plan."

Fran

Fran is the father of Colton. Colton is 17 years old.



First signs

He didn't make a sound from the time he came to us. Colton was adopted. We were his foster family and that's how he came into our life. We took him to a couple of doctors and that's when they told us about Fetal Alcohol Syndrome because of his facial features. We didn't know about Autism until later on.

Initial reaction

We didn't know what Autism was. We had no idea what we were in for and that's probably a good thing because it was extremely difficult. We weren't devastated because we had no clue what was coming down the line. We were just like we'll have to do what we have to do. Whatever that is.

Looking back, I wish I would have known...

I'm glad I knew absolutely nothing about it because if I had known what was coming, I might have shied away. Everyday was a new day and everyday was a learning experience.

Finding information and resources

We started to research everything we could research. My wife went on the offensive with doctors, programs, and medications...trying to find the answer. It was a process of learning and elimination.

How my child's life changed after diagnosis

He was 4 weeks old when we got him. Never spoke, never. Now he's 6 feet tall and 220 pounds. He's in school. Hey, he just won 4 medals in swimming at the Special Olympics. We got him involved in sports a couple of years ago. He swims and plays football. There are a lot of challenger leagues around. I think since we got him in sports he became a lot more social and accepting of other people, more kind and caring.

He had seizure disorder for a long time. We think we have that under control with medication but his seizures were different. He would stay in this catatonic state for like 15-20 minutes.

How my life changed after diagnosis

I'm a firm believer that everything happens just the way it's supposed to in your life. Even the stuff that doesn't feel so good or stuff that's troubling to you, it's all there to teach you something. If you have your eyes open and you are receptive, you will learn a lot. He made a man out of me. He taught me patience and tolerance to the extreme, and what's important. I'm grateful. He taught me a lot.

But we were in trouble a couple of times. And the kids were mad at us. My two daughters were like "You spend all your time with him, what about us?" They were right. It is 24/7 job.

I just retired from my professional job to help transition him into trying to be an adult. I'm not going to be here forever so whoever he's with, I don't want him to be a burden. I'm working him into a job where he's going to make a paycheck.

I'm also a teacher now. I teach Autism awareness to police, firemen, and EMS guys who run into these kids all the time and don't know what to do with them. I'm involved with Project Lifesaver with the Monmouth County Sheriff Office. We track kids who are lost. If you told me I was going to be involved in Autism, I'd have told you that you're crazy, but I'm all about it now. I live and breathe it.

Daily challenges

Controlling his behavior sometimes. I think his biggest challenge is coming now after we sheltered him incredibly for 17 years. Now we're switching gears here and trying to move him out a little bit and let him be more responsible on his own. It's really scary because he doesn't have a lot of common sense. He's working at a place where he could get hurt. His challenge is being aware of his surroundings and being able to be productive. We don't want him to just be the kid that's hired because he has Autism. He's not that kid. We are trying to teach him how to work so that he can be productive and feel good about himself.

My child's accomplishments

He knows there's something wrong with him. He tries really hard to deal with it and to dispel some of the myths about him. He's come a long way.

He couldn't focus for the longest time. When they're fidgety and running around the room, you can't teach them anything. When we finally got the right medications, he was able to focus, then we were able to keep him going to school. He reads now at about the 3rd or 4th grade level. I don't think he's ever going to be a mathematician or an author but I think he will be able to carry his own weight in this world.

Proud moments

I think I'm incredibly proud of the way he handles his struggle. There's an internal struggle with these kids who can't say what they want to say, who can't do what they want to do, and who can't express themselves really the way they want to. I think the way he handles himself almost all the time makes me proud. And he's a kind person.

When I teach cops, he comes with me and allows himself to be seen. A lot of these kids can't deal with stuff like that. They don't like crowds, they prefer to be by themselves. He's worked his way through a lot of that.

How I would explain Autism...

There's a whole medical side of Autism that I don't really care too much about. They compare you to other kids, and I was never really into that. All I can tell you is that it's baffling and difficult, and you better hang on and get some help because you won't make it by yourself.

My advice to parents

Get some help, immediately. Call someone you know. You have to be mentally and physically fit to deal with this stuff. You need someone you can talk to and there's a lot of places to get that support. People are embarrassed or reluctant to talk to people or to admit it, but it's not about you. It's about your child.

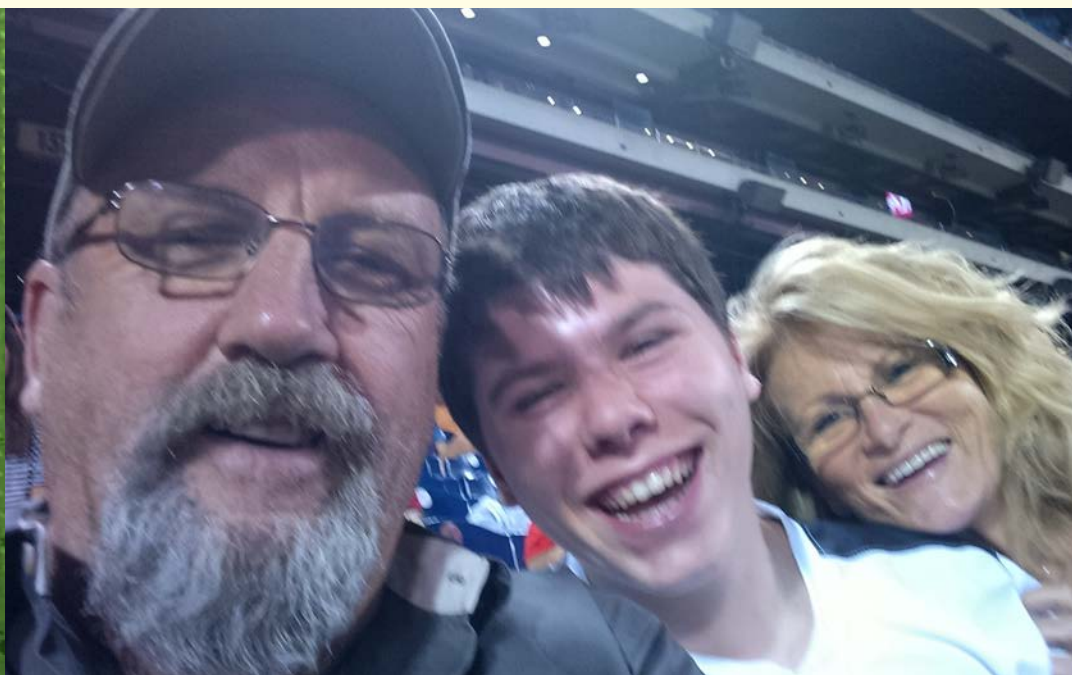
It's not fair to the child that all this stuff is going through their head and they can't deal with it. You're the adult, you're the parent. You have to go the extra mile to do whatever it is you need to do to help that child. Because you're not going to be around forever and nobody's going to love 'em like you love 'em. Nobody.

Last thoughts

We have to provide services. The biggest thing is what are we going to do with these kids when they age out.

Also if you met one kid with Autism, you met one kid with Autism. They are all different in some shape or form. There are a lot of similarities and characteristics and behaviors, but if you met one, you just met one.

"Colton made a man out of me."



"Everyday was a new day and everyday was a learning experience."

Lauren

Lauren is the mother of Stephanie. Stephanie is 23 and was diagnosed with high functioning Autism when she was 7 years old. Stephanie has multiple medical conditions, including a seizure disorder.

First signs

Stephanie wasn't reaching the normal developmental milestones so when she was 13 months old I contacted early intervention and said **HELLO**, I'm a first time mom but I know this child is delayed. However, it wasn't until she got into the structured school environment that we really figured out what was going on. She was diagnosed with Autism at 7 and the seizure disorder came much later. She didn't have her first seizure until she was 19.

Initial reaction

I kind of knew. I had been researching, just in terms of trying to figure out what was going on with her, and it sounded like some form of Autism.

The diagnosis of a seizure disorder actually scared me more. When we got the seizure disorder diagnosis we were extremely proactive and got baby monitors to listen to her at night and those kinds of things. It's more life and death.

Finding information and resources

We knew another child who had Autism and the mother of that child was one of the first people I called when we got the diagnosis. Having someone who's been there and knows the system is very helpful. I went to support groups, and even started a support group of my own. Any information was helpful because when you start hearing the same things from different sources, you can start weeding out what might not be as scientifically proven. It was helpful to know what will work with your child.

What we tried

Honestly if you name it, we've probably done it. We had excellent advice from a doctor who said 'as long as it's non-invasive you can try it because it can't hurt her.'

Initially most parents start looking for a cure, but honestly it doesn't exist right now. It may in the future, but I think what happens is that different things help with different areas of concern. It's kind of like pieces of the puzzle.

Stephanie was initially nonverbal and we used sign language until she was about 6 years old. We found that very helpful.

How my child's life changed after diagnosis

I did see that some people saw her differently. Family members and friends would talk to her like she was a much younger child. She can understand much more than she can communicate. She's always been that way. People tend to underestimate her.

How my life changed after diagnosis

We didn't know about DDD (Division of Developmental Disabilities) initially so we didn't get any help until she was about 8, and we didn't know about respite care until she was like 12. There was a big gap where we were on our own.

I've always worked full time and I've had to work from home the last 3 years. It's hard when Stephanie's home and I'm stuck trying to work, and not being able to attend meetings and so forth.

Daily challenges

I would say communication. She's verbally inappropriate now; she may curse or even bark. There are occasions where she will still act out when she gets overwhelmed. She has developed multiple life-threatening conditions, and her Autism blocks her from being able to do some of the self care for her medical complications. Also, sometimes if she's not feeling well, she may start behaving differently too.

My child's accomplishments

She's had several. She's very creative, and has gone to the county level in some art reflection programs. She gave a speech to the whole church at her communion.

The biggest thing is that she graduated. Despite 15 hospitalizations, some of which were up to 4 months long, she kept up with her studies and graduated on time. She is attending a program at Mercer County College in the fall. They have a nurse going with her, and we were the first family in the state to be approved for the medical support piece. I'm hoping this will open the door for other families with kids that may not meet the traditional criteria for round the clock nursing but may need extra help to go to work or school or a day program.

She was homebound for the past 3 years so she's finally able to go back into the world again.

Proud moments

The fact that she is so positive no matter what is happening. She has a great sense of humor. Even if she gets overwhelmed because of her Autism, when major things happen she can think "Eh, minor set back." Despite everything, she's a happy person. She listens to her music everyday and dances, sings and makes jokes. And she did all this in the hospital too, no matter what was happening. I'm most proud of the fact that she's much more brave than I think I would be in those circumstances.

How I would explain Autism...

I tell people that she is developmentally like a younger child. For example, if you're gentle and firm with her, she will behave better for you. But I don't want them underestimating her intelligence.

My advice to parents

Get as much information as you can. Gathering information is the most important thing because then you don't feel so helpless and hopeless when you know what you're dealing with.

Look for support services early on because there are wait lists.

You have decisions to make. One of the most important things someone once told me is that you may not have all the choices you had before, and you may not even like some of the choices you have, but you still have the ability to choose.

The most important thing to remember is that children change over time, so the person you have now may not be the person you have in the future. Also remember that there's a large range of abilities within the same diagnosis.

I think the piece of self advocacy needs to start not just at transition age, but when they're really young. For example, with a child who doesn't want to get a shot, you can say "Yes you have to get a shot but you pick which arm." That child could be 2 or 3 years old and already starting to self advocate. I think that's huge, and is really going to help them down the line.

Last thoughts

Honestly I see parents completely devastated by a diagnosis of Autism, and they really shouldn't be. It just means that things are different. It's sad, but it's not the end. In the grand scheme of things, I understand the diagnosis is devastating, but it's not life threatening. It's just life changing.

"In the grand scheme of things, I understand the diagnosis is devastating, but it's not life threatening. It's just life changing."



Bobbie

*Bobbie is the mother of Alanna and Austin.
Alanna is 24 years old and Austin is 23 years old.*

First signs

I think the most obvious was that neither one of them started to talk on time. For Alanna, she had a lot of strange behaviors, like lining things up and having to do things over and over again. She also used to touch something that was really hot and although she would say “Ouch,” she would just touch it again.

Austin was a little bit different. He had more of the classic repetitive behaviors like hand clapping. He didn’t talk early enough but he had beautiful eye contact which actually kept him from being diagnosed for awhile. He really didn’t care about being involved with anything or being social. He would stay in one area for a very long period of time and he would just watch everybody else.

Initial reaction

My initial reaction was actually one of relief. I know that’s a really weird thing to say, but we had been searching for about a year and a half to find out what was wrong and why Alanna wasn’t talking to us. So when they told us that it was Autism, there was a little

bit of relief because then we at least felt like we had some idea of where we could start looking for help.

For Austin, we kind of knew what the diagnosis would be by the time we got there.

Looking back, I wish I would have known...

I wish I knew more about the differences between what’s good teaching and what’s not. So that I wouldn’t have wasted my children’s time with some of the teachings that were not effective. I wish I would’ve done more with them at a young age when it came to education.

I wish there was a way to tell like if the child has these symptoms, this is the better intervention but if you have those symptoms, then this might be better. You kind of just have to try. Even with the two children in one household, the same thing didn’t work for both of them. Although Alanna did better verbally than Austin did, Austin was better about change and transition. The same methodology for the same instruction didn’t work in the same way for each of them.

How my life changed after diagnosis

Well, I became a Special Education teacher. I continued from that and became a board certified Behavioral Analyst. I opened a business to help other families with children with Autism and I became an educational advocate.

I would say my children have probably helped me more than I’ve ever helped them. Alanna and Austin have been the reason that I have pretty much done anything. I have them to thank because I don’t know who I would’ve been if I didn’t have them. I had no real desire to be so heavily involved in anything prior to that. They are the reason I’m doing this.

Daily challenges

For both of them it’s communication. Both of them really lack communication. For Alanna, it’s understanding. For example, Alanna doesn’t understand the difference between ‘no’ and ‘know.’ She can’t see the difference between these. She can’t differentiate when people are talking to her versus people talking to others in the community. That has become a big challenge for her now that she’s out in the community more.

For Austin, it’s always been kind of the same thing. He doesn’t want to try new things and that takes a lot of encouragement. Unless my husband and I are initiating with him, he won’t do it. He really doesn’t like to be around people. Employment is usually a place where there are a lot of people and that’s just not going to be something he can do.

My child’s accomplishments

Alanna’s biggest accomplishment is that she has a job. She works. She files and makes binders for the company. The reason she has the job is because everyone loves Alanna. She’s very outgoing that way, and enjoys being out with people. She’s such a good worker. She gets the job done. She doesn’t do much talking or socializing on coffee break things...apparently, she is just too good of a worker. It’s really cute actually.

As far as Austin, he’s always going to be a challenge and I will say for Austin, his biggest accomplishment is coming out of Kennedy Krieger 12 years ago and still being the kid he is now. It was tough time. It was an institutional setting. More recently, he got very ill. He was on life support and had some really challenging issues. If anybody told me that he were to handle that, I would’ve told them that they’re crazy. He has not only handled it, but he handled it beautifully. He was quite a champ through the whole thing.

Proud moments

The way that they touch the lives of other people. I don’t know what it is about my children, and probably many children with Autism, how they actually have a big impact on people that they meet. I was working one day and somebody came in for an interview. She saw me and said “You are Mrs. Gallagher.” She goes “I’m a BCBA because of Austin Gallagher.” I was just like ‘Wow.’ Just the way they touch people and make them want to do something. Their impact on others is probably far more reaching than they would ever know.

My advice to parents

I would tell them that their world is going to change but that doesn’t mean it’s going to get worse. Their world is probably going to revolve entirely around Autism. They might lose some friends, but they will gain new friends. They will start to eat, breath, and live Autism, and I know that sounds daunting, but it’s not the worst thing that could happen and they have to do what they can. They have to find what works for their child and go down that avenue, but they also have to be accepting of other people’s choices within the Autism community. Sometimes this Autism thing is pretty awesome and sometimes it sucks.

I don’t think it’s any different than a lot of other things. It’s just a matter of how you deal with it and the best thing you can do is to get involved. Get involved with support groups and agencies, and try to connect with others in order to build those relationships.

I would tell them that they need to educate themselves as best as they possibly can and read a lot. Not just relying on the internet because that’s really been a challenge for a lot of families now. They need to actually see it and experience it.

Last thoughts

My biggest challenge is still the education system for our children and that it doesn’t always offer what our children need. And many families are too willing sometimes to accept whatever is given to them. I want them to research what their children are actually entitled to versus somebody just saying this is what they can have. A lot of people will say to me “Oh, my school has an ABA program,” and I’ll have been to that school and I’m like, “Well, they might be calling it ABA, but it’s not.” Families need to educate themselves on what it should look like.

One thing I would love to tell other families is not to be embarrassed by this label, because sometimes families choose not to get the diagnosis because they don’t want their child to be labeled. I really want them to know that I don’t know of any situation where that has actually been of help.

*“Parents need to educate themselves
as much as they possibly can.”*

*“I would say my children have probably helped
me more than I’ve ever helped them.”*

Sharice

Sharice is the mother of Tinajah. Tinajah is 24 years old and was diagnosed with Autism when she was 3.

First signs

Tinajah listened to music and commercials, the same thing over and over and over again. She made no eye contact. We weren't really sure if she understood. Once we started practicing her alphabet and she intoned it exactly the way that we said it, I knew for sure that something was going on.

The doctor told me that she was progressing normally, that I was too worried, I was a new mom, and I should relax. The doctor suspected there was a hearing issue because of her many ear infections so she suggested putting tubes in...things like that. But I started accepting the fact that it was something else.

Initial reaction

I think I accepted it before I actually got the diagnosis.

Looking back, I wish I would have known...

There was nothing that I wish I would have known when she was first diagnosed. Once I had my mind wrapped around what I thought was wrong I started doing research. I didn't leave any stone unturned. I immediately immersed myself in all things related to Autism, related to developmental delay, and of course I was not a doctor, but I knew that I would have all the tools necessary to take care of my daughter.

Finding information and resources

A lot of library time. I spent a lot of time in the library doing a lot of research.

Once I got the diagnosis, I realized that I had work to do, because I wouldn't live forever and I wanted to make sure that when I was gone, she would still be fine. I started putting together a plan to ensure that. I looked at all the different things that people do who are typically developing and saw that as an end picture, and worked backwards from it.

How my child's life changed after diagnosis

It didn't change. It's been her entire life so there really was no time for change. When I got the final diagnosis when she was 3, I had already started on my course so there was no change. That's the path that we were already on. It just became more definite.

I wasn't concerned very much with what she wasn't able to do. I didn't really focus on what she couldn't do. If there was something she couldn't do, I adapted it so that she could. We made the accommodations early in her life the best way we could so she could do whatever she wanted to do. And then that became required. I didn't really make a lot of excuses for her.

I know for a fact that I'm more involved in her life than a parent would be for a typically developing 24-year old. I know that she would have been out on her own and have been able to go to college, different things like that. But when I look at her and see how she feels about her life, I don't see her having missed out on anything.

How my life changed after diagnosis

I realized okay, I really have to do this. I had a reality check. I was married at the time but I still felt like I was going to be doing this on my own.

Daily challenges

She still struggles to communicate. She's doing fantastic in her attempts to communicate more effectively now. As she gets older, I see that she's engaging more, but there are still obvious delays with that.

Also her perception, her ability to perceive. She takes her time with things so she's not understanding that there's a time limit. Her time management and her perception of time limits are challenges.

My child's accomplishments

She lives a glamorous life. She's a confident social butterfly. She travels. She travels alone and with us as a family. The things that she wants, for the most part, she gets. She is capable of a semblance of independent living, of course with some guidance and guidelines placed on her, and probably with me helicoptering over her somewhere nearby but I'm doing that anyway.

Proud moments

Her resilience. She is so resilient. She is also very kind and very loving. People say that those with Autism aren't loving or warm or affectionate, but she is all of those things. Now don't get me wrong, she will retreat to her space when she's had enough. But her effort to be a part of family gatherings and to be with people is what makes me most proud of her because that was something that according to the textbooks could never be.

How I would explain Autism...

I would say that someone with Autism is simply a differently abled person, a person who is differently abled to communicate. Typically, hypersensitive and apathetic at the same time. That's what your kid would be.

When explaining it, I've asked people to imagine being in a room and being able to hear every single thing that's going on in that room and the 3 houses around it. Imagine how your mind would process that, and then you can sort of understand what a person with Autism is experiencing. Most people say I wouldn't be able to take it. And then I explain, exactly but the person with Autism has no choice. That's how I describe what Autism is. Being able to focus on everything and absolutely nothing at the same time.

My advice to parents

I would tell them that they have just been blessed with the task of creating the best of all possible worlds for their little person. And it doesn't mean that they will get it right every single time and they don't have to expect to.

Allow others to assist you, whether or not it's the way you would want to do it, just allow them to. Be gracious recipients of all of the blessings. Be gracious recipients of all of the true help, nurture, and support for your little person, because ultimately that is what they need.

We want the world to understand our little people, our grown people, as a part of this world. Make all of the necessary accommodations but none of the excuses.

We are required as parents of people with special needs to do a good job. We can't just leave them to the TV or in a room by themselves for hours a day. We have to interact with our children. Take that on and realize it, but take time for yourself too.

Last thoughts

I would tell parents of people with Autism not to be totally devastated should you get another child that has a disability. After you have one, you don't have to stop. If you have enough room in your heart, if you have another space, then go ahead and make the other baby. Don't be afraid. Tinajah's brother has epilepsy so its a different set of challenges, but like I said we make the most of all possible worlds. Live your life. Live your life with your children. Understand that life doesn't stop, but actually it is enriched.

"She's a confident social butterfly."

"Life doesn't stop. It's actually enriched."



"We have to try to give them the opportunity to have the best of all possible worlds."



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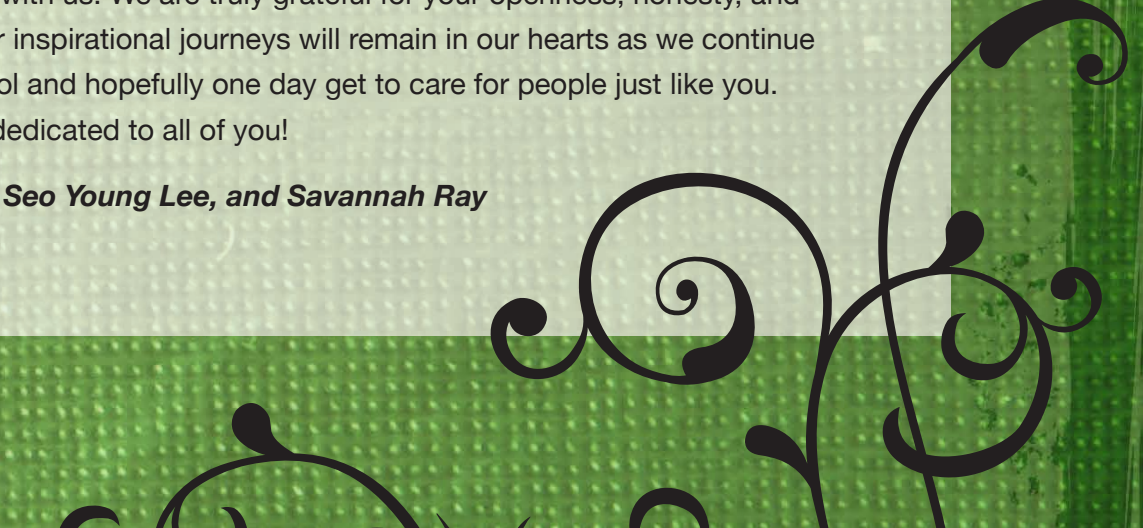
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— **Jane Lee, Seo Young Lee, and Savannah Ray**





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