Department of Developmental and Behavioral Pediatrics



Sharing HOPE

The stories of our patients and families

Cincinnati Children's
changing the outcome together

Funding for this booklet provided by:

Dr. Jack Rubinstein Foundation
Serving Persons with Developmental Disorders

We hope that as you enter into the Division of Developmental and Behavioral Pediatrics, your experience will reflect our values:

we value individuals with disabilities and their families, we believe all people should have the opportunities to fully participate in society, live healthy, safe, self-determined and productive lives, and we value the importance of interdisciplinary care as a foundational philosophy for care.

This booklet was written by generous families who have children who have received care through the Cincinnati Children's Hospital Medical Center Division of Developmental and Behavioral Pediatrics (DDBP). If your family is newly referred to our division, we hope these stories will help, as we know that it is easy to worry about what is ahead. If you are a family member of a child who has already been seen in our division, we hope these stories help you to see the many future possibilities, the resilience of children and families, as well as the natural ups, downs, disappointments, and joys. We hope that as you join the Division of Developmental and Behavioral Pediatrics, your experience will reflect our values:

- We value individuals with disabilities and their families.
- We believe all people should have the opportunities to fully participate in society and to live healthy, safe, self-determined and productive lives.
- We value collaboration between families, DDBP, and other Cincinnati Children's professionals, and community organization staff as the foundation of care.

In this booklet, you will get a glimpse of the experiences of families of children with developmental disabilities who have partnered with us in their care over the years. As a professional who has learned so much from so many children and families, I know that anyone who reads these stories will make a discovery or gain a new insight.

On behalf of the DDBP faculty and staff, I extend a huge and heartfelt THANK YOU to the many families who have contributed to this booklet, shared their children with us, and helped make us better professionals, better caregivers, and better people. It has been an honor and a pleasure to walk alongside you in this journey.



Tanya Froehlich, MD
Director, Division of Developmental & Behavioral Pediatrics





Patrick

age 9, autism spectrum disorder

I never saw it coming. He wasn't on the pediatrician's radar. He didn't fit the profile. "It's absolutely infantile autism" were the last words I expected to hear about my son. A flood of questions followed. Was it my diet? Was it my age? Was it his emergency C-section? Gestational diabetes? It was none of those. It is just who he is and I would not change him. You are going to get through this. It is going to be okay. It is okay to cry and to be nervous. But once you get through the acceptance, the sky is the limit. When my son was first diagnosed, I had no idea how to begin. I was scared and couldn't picture what the future looked like. Six years in now I can say without hesitation it is the most beautiful path I could have envisioned. Some of the stones are wobbly and disconnected, but the journey is full of curiosity and wonder. I learned how to appreciate things many take for granted. In my eyes, autism is a form of beauty in the brain. Everything is heightened. It is hard and at times overwhelming, but it is beautiful. My best advice is learn everything you can about autism to help your child. Attend therapy. Push the school. Seek out other parents. Attend a support group and befriend those parents. They are great respite. Always remember, your child is in there. They love you and need you. You can do it!!!!

—Amy, mom to Patrick

"It is okay to cry and to be nervous. But once you get through the acceptance, the sky is the limit."



Jacob

age 3, spina bifida

Jacob's spina bifida was found in utero. A day we will never forget. He was born via C-section and his back closure was that evening. His shunt was placed at five days. He stayed in the NICU for 21 days. Jacob began treatment for his clubbed feet immediately after the NICU and had surgery on each leg later that year. Jacob also started occupational, physical and speech therapies almost immediately and at 3 years old is still continuing those services. Jacob uses a wheelchair full time. His lesion is L2, but he has no feeling below the bellybutton. He has had seven surgeries thus far and has another one scheduled.

The most difficult thing about being Jacob's mom is knowing how hard to push him, verses adoring his perfection. Yes, our life is different than we expected when we decided to start a family, but it is amazing. We do three therapies weekly. We have surgery every so often. My mom, my husband and I share the appointments. My husband and I both work full time and my mom is able to take care of Jacob during the day which is a true blessing.

We are only three years into Jacob's journey, and he has taught us so much. He lights up so many people's faces and hearts it is unbelievable. I know he will continue to do so! Love your child for who they are and allow them to teach you things you never knew you didn't know.

—Jessica, mom to Jacob

"Love your child for who they are and allow them to teach you things you never knewyou didn't know."



Jada

age 17, hypotonia, intellectual disability, speech apraxia

Comfortable + Competent + Confident = Empowerment

These three “C-words” are my secret sauce for advocating effectively. The balance might not always be equal, but all three MUST be present. They overlap somewhat, but each has its own distinct purpose.

I must feel comfortable when making decisions as well as when seeking the guidance and wisdom of others. If I’m not completely comfortable I’ll have a nagging, unsettled feeling and this will result in my lack of full commitment to proceed forward. In being comfortable with a decision, I feel that I have made the best judgment possible based on what I currently know and understand about a situation.

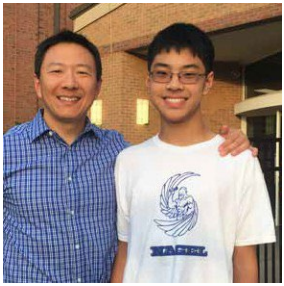
The next required “C-word” relates to competency and my knowledge base on a matter. Knowledge is very powerful, so I educate myself with the intent of acquiring a sense of competency. Sharing knowledge can be powerful and beneficial to others as well. I am a firm believer in the saying “the answer will reveal itself” and this often occurs when you delve into something at a deeper level.

For me, the three “C-words” continue to build on one another with confidence being a by-product of my sense of feeling comfortable and competent. Confidence will evolve over time and throughout one’s life experiences.

So, when faced with a situation or decision, I ask myself, “Do I feel comfortable, competent and confident?” If not, then what else is required? If I can answer “yes I do,” then watch out world!

—Elizabeth, mom to Jada

Comfortable + Competent + Confident = Empowerment



Nolan

age 15, autism spectrum disorder

I remember how much our son, Nolan, was fixated on watching things over and over again as a young child. I knew this was a common trait of kids with autism. As he got older, I learned how it specifically applied to our son. Nolan has a knack for discerning patterns in how things work. When he was around 10 years old, he figured out how to use all of the features of our digital piano, including the buttons used to record and play tracks. He used this to play songs and add his own accompaniment to it! He also learned how to time the pattern of arcade games so well that he could make a bouncy ball drop cleanly into a very narrow hole on a moving platform in order to win the jackpot prize. He could do this at least once if not twice on each visit. Understanding this has given me a much greater appreciation for how he thinks, and I now know that he isn't just doing these things because he is trapped in a different world. He is actually figuring out our world but in a way that is different from what I see.

—Alec, dad to Nolan

"He is actually figuring out our world but in a way that is different from what I see."



Marlee

age 5, autism spectrum disorder

We knew something was different about Marlee at 15 months. She hadn't hit her milestones and had stopped eating, saying words and playing with her sister. I went to the library and began researching. I knew right away that Marlee had autism. We got the diagnosis at 26 months. This day was a huge relief because we could get the help that she needed. At 17 months we started occupational therapy twice weekly and with early intervention got the support and direction we needed. We learned about the Play Project and immediately started to play/interact with her a little at a time until we were playing and interacting with her all day, every day and she liked it! She had come out of her shell! Marlee started music therapy because she loved nursery rhymes and began singing them. This led to her words and we were able to move forward to speech! Marlee is now 5! She's a kindergartner and has come from a nonverbal 3 yr old to a chatty little leader. She's very smart and very independent. She is in her 3rd year of dance class and is a daisy Girl Scout. We still use many of the techniques from the play project in our daily life.

She has friends and loves to play with them! She is loving, empathetic, and intelligent and to a lot of people who first meet her, just a shy girl! We still have daily struggles but we're moving forward and the future looks bright for her! It's heartbreaking to hear that something is wrong with your child but getting early help should be the priority. So much can change so fast with hard work. Marlee is worth it!!!

—Amy, mom to Marlee

"We still have daily struggles but we're moving forward and the future looks bright for her!"



Julian

age 13, autism spectrum disorder

I am the mother of a 13 year old son with autism spectrum disorder (ASD) and other disabilities. Although it is the hardest thing I have ever done, it is truly the most rewarding and that is not a cliché. Over time, I have watched him teach himself to read at the age of 18 months, outgrow certain repetitive behaviors and get into the number one high school in Ohio because of his intellectual capabilities. I never gave up on him. I always knew that there was something more to him than just his diagnosis. You may call it a mother's intuition. He is succeeding when I was told by professionals that he would not succeed and that his intelligence was just low average. It made me work even harder with him; I also put him into various therapies and social skills groups that helped propel him to this point. I would encourage everyone with a child with ASD to believe in their child's capabilities. They are more than worth it because they all have something to contribute to this world, something remarkable in their own right. You just have to discover what it is. Have patience; it will be revealed in time along with hard work. Oh, and lots and lots of prayer helps too.

—Shareese, mom to Julian

"I always knew that there was something more to him than just his diagnosis."



Soraya

age 4, developmental delay, hypotonia, and g-tube dependent

There is so much that I have learned about myself and my child that has surprised me since our realization that she has global developmental delays. I learned that whatever dreams that I thought were lost, there were new ones being created. She has surpassed the expectations that I had when she was initially diagnosed. She CAN do so much more despite all the fears I had of what she wouldn't be able to do. I have met and created friendships with so many amazing people that I would have never met without being on this journey. I have learned that no matter what set-backs there are along this path that you can't give up, as your efforts do make a difference. Your little one will surprise you. I learned what it meant to truly love unconditionally. I see clearer and I love deeper.

—Tasha, mom to Soraya

"I learned that whatever dreams that I thought were lost, there were new ones being created."



Amelia

age 7, autism spectrum disorder

Ten Important Things Amelia Needs Me to Know

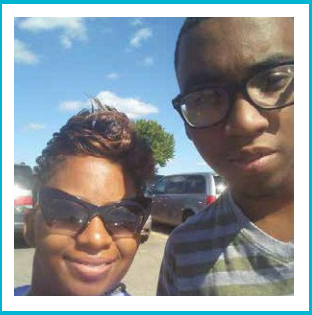
Amelia was diagnosed with autism just a couple weeks short of her third birthday. In the three-and-a-half years since then, I have learned a lot from her. Here are the top ten things she has taught me.

1) She does some things very well.
2) Even if she's not looking at me, she's paying attention.
3) She's glad we never even considered raising her and her "non-ASD" siblings in separate homes. She deserves to be included—at home, at school, anywhere.
4) She's not the same every day.
5) She will let me do it for her if I don't wait for her to do it herself.
6) She needs to move around. She learns by exploring her environment.
7) Just because she likes music doesn't mean she likes every song.
8) Just because she's not talking to me doesn't mean she doesn't want me to talk to her. She listens more than she speaks.
9) Sometimes, she needs to do things that she doesn't want to do. I shouldn't let her get out of that.
10) Let her tell me that she loves me in her own way.

Most of all, Amelia needs me to remember that all of these aren't because she's a great kid with autism, but just because she's a great kid.

—Michael, dad to Amelia

"She needs to move around. She learns by exploring her environment."



Jeffery

age 14, autism spectrum disorder

In 2006, our son Jeffery Chapman III, was diagnosed with autism spectrum disorder. He was only three years old. Jeffery was nonverbal at the time but after intense speech and occupational therapy, Jeffery's vocabulary has increased. Being young parents to a child with ASD was not easy. Now at 14, Jeffery is in the 8th grade and he spends his time in school between his autism class and regular classes. Hs favorite class is drama. He was able to participate as Santa in the school Christmas play. Jeffery loves puzzles, playing basketball with his dad and his peers, and he loves playing with his siblings. With the support of family, teachers and intervention specialists we are his advocates to help him succeed not only in school, but in life. Our advice to parents—if you ever feel alone, you are not. Always remember the earlier you begin intervention, the better.

—Catherine, mom to Jeffery

"Our advice to parents—if you ever feel alone, you are not."



Nora

age 5, Down syndrome

Nora was honored to be included in the annual video for NYC Buddy Walk, celebrating the lives of individuals with Down syndrome. The video is shown on Times Square before the walk kicks off. I love how the video shows so many individuals doing totally regular, everyday things. It's inclusion at its best, and it gives everyone who watches it a great reminder that Down syndrome is no big deal. When the diagnosis was new to me, I was most worried that Nora wouldn't be included or accepted and that the life of our family would be drastically different. Now 5.5 years later, it is different in so many wonderful ways, but Nora is just herself: a kindergartner among peers, a sister who fights back, a daughter who loves snuggles, and a ballerina learning new dances.

—Emily, mom to Nora

"When the diagnosis was new to me, I was most worried that Nora wouldn't be included or accepted and that the life of our family would be drastically different."



Giovanni

age 8, fragile x/ autism spectrum disorder

I get by with a little help from my friends…

When our son was diagnosed at 18 months with Fragile X Syndrome the overwhelming fear of EVERYTHING to come was paralyzing. It was in those early days that I realized this journey was going to be impassible without friends.

Girlfriends — you need a gaggle of girlfriends who will make you laugh and have fun and forget your worries, momentarily.

Disability Community Friends — will help you navigate the terrain of dizzying acronyms.

Seasoned Friends (families with adult children who have a disability) — they have lived through it and survived and you will too, they will be your cheerleaders when your path seems too difficult to pass.

In The Trenches Friend — you need one girlfriend that you can talk with for hours about everything. I have talked with my best friend in this category for no less than 50 hours about poop!

Sibling Friend — your child's sibling/s will be the longest relationship your child will have. Never forget they are going through this journey right beside you and they crave respite too.

Most importantly, Spouse/Partner Friend — your partner knows what it is like to live in your house day in and day out with all of the idiosyncrasies of YOUR child. Be kind to each other, respect each other and DATE each other, even if it is a trip to Kroger without the children.

Gather them, cherish them, and open your heart to your FRIENDS!

—Laurie, mom to Giovanni

"I get by with a little help from my friends..."



Kendall

age 7, Angelman syndrome

It gets easier, and your dreams for your child are not over. You may not believe this now—I bet you're thinking, like I did, that you'll never be able to handle this; that your hopes and dreams have crumbled before your eyes.

Then I remembered that my job as a mom is to help my children be the best they can be. I have the same expectations for my daughter diagnosed with Angelman Syndrome as I have for her typically developing sister.

Here is some of the best advice I received when we first started our journey:

1. Don't change your vision for your child. Is it college? A career? Being a contributing member of the community (or all of the above like us)? Focus on these dreams and find what services and assistance can you can provide. Until our daughter tells us or shows us differently, we will do everything we can to help her achieve her dreams.
2. Presume competence. Always. Just because your child may not be able to verbalize or show you what they know, does not mean they don't or cannot "get it." They are so smart—always believe this.
3. Do NOT give in to "assisted helplessness." Have high expectations for what your child can and will do—in all areas. Never let yourself or your child off the hook because of their diagnosis. We want our daughter to learn to live independently. It may take extra time, but it is worth the effort.

—Marcia, mom to Kendall

"My job as a mom is to help my children be the best they can be."



Noah

age 7, autism spectrum disorder

He Is Not Sick

Noah was diagnosed with autism spectrum disorder shortly after he turned six. After about a year of evaluations, we received the diagnosis and a part of me was happy to finally have validation and professional confirmation of what I always knew to be true. Then came the sympathy. I understand that people want to be comforting and that they don't always know what to say but I hated when people would tell me, "I can only imagine what it is like to have a sick child." I would get upset and try to stay calm while I accepted their condolences but then told them that Noah was not sick and autism is not a disease. I would point out to them that there was nothing "wrong" with Noah and I would firmly tell people that we did not need to fix Noah; we needed to fix how we responded and interacted with Noah. This idea gives me the strength that I need when Noah has a meltdown in public and I see the looks that others are giving us or when Noah is the only child asking where the parents are while his class watches "The Polar Express." Autism is not an illness; it is a difference that requires a change in how we interact with the individual. The most inspirational thing that I have ever read and that I keep in my mind about Noah is that he's not sick but he's Always Unique, Totally Interesting, and Sometimes Mysterious.

—Melissa, mom to Noah

"The most inspirational thing that I have ever read and that I keep in my mind about Noah is that he's not sick but he's Always Unique, Totally Interesting, and Sometimes Mysterious."



Sylvia

age 3, Down syndrome

August 5, 2013, I gave birth to a beautiful baby girl with almond shaped eyes. The doctors and nurses didn't notice, but I did. After days of waiting and watching we were given a diagnosis over the phone. A diagnosis we were expecting, but silently praying would be negative for Down syndrome. We cried, called our family, sent a letter on Facebook and grieved the loss of what was "supposed" to be.

Fast forward a few weeks...a few months...a year...

My baby is the most amazing baby on earth! She makes our family complete. She smiles so big, and gives hugs that melt your heart. She has taught me to celebrate the smallest achievements and not to sweat the small stuff (too much). She has changed the way I teach and the way I love—all for the better.

When I go back to that day, I have regrets, but I reacted in a human way, and it was a natural response to what lay before me.

One thing I don't regret is my Sylvie. Without her, I would not be me! I look forward to this journey with her and have high aspirations for what she will do and become in this precious life she has been given.

To anyone going through what we have this year...have your feelings...they are normal...hold your baby and love her...she needs you and loves you like any other baby...she will be amazing and so will you...just look at us!

—Sarah, mom to Sylvia

"To anyone going through what we have this year...have your feelings...they are normal..."



Joey

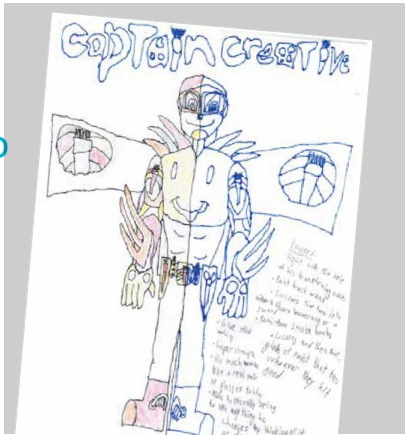
age 19, autism spectrum disorder and bipolar disorder

My son Joey is my hero. Ever since he was in preschool, teachers told us he was different, or that he was “quirky.” He was lost in the pretend world of superheroes and fairy tales. One day when he was in kindergarten he climbed on the roof of his school because he wanted to fly like Peter Pan. Loud noises and change were very hard for him. Throughout our search for help they told us that there were many things that he had: ADHD, RAD (reactive attachment disorder), OCD (obsessive compulsive disorder), Tourette syndrome to name a few. We went from clinic to clinic, doctor to doctor, and school to school. We were discouraged to say the least. But we never gave up. We wanted to find some help for our dear loving son Joey. We finally found a doctor to understand and treat our son. He had autism and bipolar disorder. We found a school to help him thrive. I want to share a poem that Joey wrote about himself called “Welcome to my World.” To me this poem shows what a beautiful, loving and giving person he is, and why he is my hero. Please remember to never give up. Keep trying because there is always hope. With God, family, friends, and professionals there is hope!

—Jenny, mom to Joey

“We went from clinic to clinic, doctor to doctor, and school to school. We were discouraged to say the least. But we never gave up.”

—poem and drawing by Joey, 19



Welcome to my world

Welcome to my world,
the world of me.
My last name is Burger,
my first name Joey.
I'll show you the ropes that
hold my mind steady
The ropes that work hard to
make me, ME

First on the list, I love being
friendly and kind.
I always love sharing
what's first on my mind.
I love to laugh,
and I love to smile
And that is one part of my
personality style

Next on the list
is what I detest.
I detest my little sister when
she acts like a pest.
Video games are my
least favorite.
I dislike the actions of the
class clowns at my school
who chat in class
for the heck of it.

The actions of criminals,
bullies, and murderers
are at the top of my hating list
And that is all that I dislike.
There is none else
that I've missed.

I try to love more than I hate
I try to be good and great
I try every day
To use nice words
in whatever I say
And that's what I call
my best trait

My interests are crafting
and drawing,
Legos and iPading and
photography and authoring,
Organizing messes and
making up jokes.
I guess you could call me
a jack of all trades and I
wouldn't be provoked.

I have bipolar disorder
and autism,
And yet, thankfully,
I'm not set apart
from anyone else.
I'm not a schism.
I have stuttering problems
and yet I'm understood.
My disabilities don't keep me
from being myself,
and that is good.

I have to take pills
at every night and day.
They support my mood
so that I'm not left in dismay.
I have shots to help with growth,
before my growth plates close.
My meds are there
to back me up,
and keep me well
from head to toes.

My family and my friends
are always there for me,
whenever I need them most.
My mom and dad and God
have always been
the best life hosts.

Guiding me through life
every night and day,
I love them most in
every way.

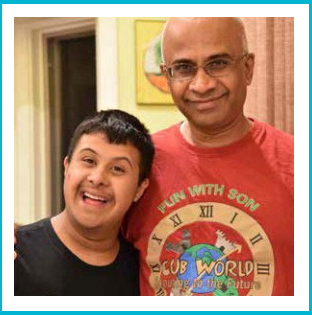
With everyone else:
the rest of my family, friends,
and neighbors,
I love them too.
I consider them my reward from
life labor.

I'm very creative and smart
in whatever I do.
It's one of the things
that sets me apart
from people like you
I make pipe cleaner hats and
poems that rhyme,
I am a hard worker and try
to be right on time,
For class.

My favorite sensory
solutions are taking walks,
Feeling soft things,
bending rubix cube sticks and
having talks.

Though there is still much
more to me than all this,
I'd say it's enough
for this poem to list.

One more thing:
I am girl crazy, crazy for girls.
And that's all for now
in my world.



Vineet

age 17, Down syndrome

When our younger son, Vineet, was born he was diagnosed with Down syndrome. He also had a significant heart complication that required fairly complex neonatal care and surgery. The emotional and logistical impact on my wife and I was quite overwhelming. Despite the challenges, I felt that we were well placed to take care of Vineet. I told myself that God had specially sent Vineet to our family because we were capable of providing him the best care and upbringing. Time would tell how wrong I was.

Vineet is now 16 and has indeed grown up to be a fine young man. In Cincinnati, he could get the best medical and educational support. His heart is perfectly normal after a wonderful surgical correction. He is a very popular rising junior at High School, enjoys track and Taekwondo and loves to dance to the latest pop music. Like any typical teenager, he enjoys interacting on social media with friends and family.

I am very proud but not surprised by Vineet's growth. The surprising part has been how he has helped me grow. Vineet has taught me the power of overcoming challenges with boundless positive attitude and what it really means to have unconditional love for others. He has repeatedly shown us that there are no boundaries around what a child can accomplish … that when challenged and stretched they can surprise us. Vineet has taught me that his needs may be special but his drive and desires are typical.

—VS, dad to Vineet

"He has repeatedly shown us that there are no boundaries around what a child can accomplish. "



Nathan

age 15, autism spectrum disorder

Count it all Joy

I remember the day my son was diagnosed with autism. Fears raced through my mind. I wondered how it would be when he got older and wasn't able to communicate. Would he know that he was loved? Would he be made fun of at school? What would happen to him when he grew up? How would he take care of himself?

I began grieving the loss of events such as a Bar Mitzvah, typical school activities, family vacations and outings. But, grieving is normal. Every parent goes through this process at different times as their child grows. We have found that many parents experienced the same struggles we experienced.

Since my son was diagnosed he has become verbal. As he is getting older I'm finding that he didn't view himself as having limits. He learned to read Hebrew and had a Bar Mitzvah. He competed in the Scripps School Spelling Bee where he won his school bee two years in a row and even qualified for the WCPO Regional Bee.

My son still has a severe disability and all of us will face challenges as he grows. But, if I could go back, I would tell myself to enjoy each moment with my child and not to dwell on what could happen. I spent too much time when my son was younger worrying about his future. My children have brought me so much joy in life. Each day takes care ofitself.

—Lisa, mom to Nathan

"But if I could go back, I would tell myself to enjoy every moment with my child and not dwell on what could happen."



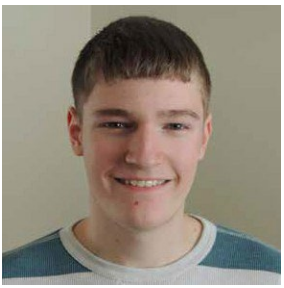
Cassie

age 28, mild cerebral palsy and developmentally delayed

My advice is to get your child involved in as many things as you can; learn what they like and enjoy doing. Participating in activities such as Special Olympics provides parents with a community of like-minded people from whom they can learn a lot. I can't tell you how much information we exchange about things like getting benefits, how to work with the different systems and agencies and what's out there for our kids to do. And, the love and moral support is so important. Family and friends who do not have children with special needs, while being well- intentioned, cannot completely understand what it's like, so having friends that do understand is important. I have made many lifelong friends through my daughter's activities. I don't know what I would do without them. And, these associations don't just benefit parents: my daughter, Cassie, loves her friends and they have a great time together. We have a local group, the Friendship Club, and we get together once a month for activities. It's all quite informal, but Cassie looks forward to our outings with the group. There are times when it feels like all we do is run, but it's so worth it because Cassie has a full life and for that I'm grateful. I was told once by a family member that she doesn't need to do everything. My response was, if she were "normal" she could do all this herself. So I make sure she can.

—Connie, mom to Cassie

"My advice is to get your child in as many things as you can; learn what they like and enjoy doing."



Tyler

age 16, autism spectrum disorder

When my son was diagnosed with autism in 2005, I feared the worst for his future. Everything was a challenge, from simple things like getting dressed and eating, to more complex things like communicating and interacting with others. I feared I would never learn to reach him, be able to handle the outbursts and meltdowns, or help him have a happy life. I was barely able to protect him from the big, bad world he was withdrawing from. Since my husband traveled, I faced these fears alone, often times drowning in feelings of helplessness and hopelessness. The phone call that would change our lives came the following year. We would be able to participate in behavior modification therapy at Cincinnati Children's Hospital Division of Developmental and Behavioral Pediatrics. After almost a year of therapy, our psychologist taught me how to change my behavior so that my son's would too. He taught me ways to communicate with my son and how to promote reciprocal conversation and good behavior. He also provided me with support and encouragement. I will never forget the first time my son touched my face and said "happy" or looked at me and said "love you" instead of using sign language. It may have begun with small, painful steps, but in the last 10 years my son has improved with giant leaps. Today we remain forever grateful to that psychologist who was the first to show us that success was possible and the future hopeful!

—Anne, mom to Tyler

"He taught me ways to communicate with my son and how to promote reciprocal conversation and good behavior."



Ryleigh

age 7, autism spectrum disorder

Our daughter Ryleigh was diagnosed with Autism Spectrum Disorder at the age of two. As a mother this was one of the hardest days of my life. I felt as though all my hopes and dreams were slipping away. My head was filled with fears. I wondered if she would ever be able to live a normal life. I could literally see my dreams of sleepovers and dance recitals vanish and I was terrified of what the future held for her. Most importantly, I was scared I would never be able to communicate with her. I remember thinking that I would give anything just for her to look at me and say, “I love you, Mommy.” At the time of her diagnosis she was mostly non-verbal and had meltdowns several times a day. I spent hours on the phone just trying to figure out what options were available for her.

Ryleigh is now seven years old. She is a thriving, sweet, kind, hilarious, bubbly little girl. She loves to make people laugh and can tell some pretty hilarious knock-knock jokes. She participates in gymnastics, baseball, soccer, swimming and Girl Scouts. Ryleigh is a fighter. She can do anything she wants to do in life. Though she continues to have challenges, she has persevered. She is my hero. I think back to those early days but today I couldn’t be more proud to be her mom than when she looks at me and says, “I love you, Mommy.”

—Mia, mom to Ryleigh

“Though she continues to have challenges, she has perservered. She is my hero.”



Aaron

age 23, autism spectrum disorder

An author once wrote that “humor is despair refusing to take itself seriously.” Fortunately, humor seems to be a common trait among parents of children on the spectrum. Raising a child with autism is much like raising any child. They hold the key to our greatest joy, as well as to our greatest despair. During rough times, I try to remember that I hold the key to my interpretation of them.

All my children were born with a sense of humor, but my son with autism has refined it to an art, sometimes unintentionally. Once when he was little and very upset, I suggested he write a list of everything that made him angry. He titled it, “Things that Piss Me Off.” While many items on that list are not suitable for publication, there are those that still make us all laugh today, like “when teachers make you use a #2 pencil,” “mom’s nagging,” and “Miley Cyrus.” It’s easier to laugh at things in the past, especially the more remote they are, but not so easy to laugh in the moment. I’ve promised myself to always do the former, even if I can’t do the latter. The one thing I can never laugh at, however, is my son’s suffering. I admit that I live vicariously through my children. Helping my son keep his sense of humor helps me keep mine, so we can laugh together, making his path a little lighter.

—Sheryl, mom to Aaron

“Helping my son keep his sense of humor helps me keep mine, so we can laugh together, making his path a little lighter.”



Kenzie

age 18, autism spectrum disorder

Hi, I am Kenzie Dreyer, and this is who I am. Throughout my life, from a toddler to a young adult, I have had an autism spectrum disorder (ASD). That is when your brain works differently than others, you get excited or stressed over some things easily, and it can be tough to get through it. However, I know for one thing it is not always tough because I never let it stop me from doing the things that I have an affinity for. This is how it all started.

Although I do not remember a whole lot, I have been told this took place in 2001, the worst year ever for my family. Two months after 9/11, my parents noticed some unusual behaviors about me, like screaming and throwing fits. They took me to see Dr. Glaser, our family doctor. When he told the news to my parents, they were shocked! I mean, it was the first time they learned about it. I don't blame them. Anyway, as years went on, they started to learn more and more each day, like how I arrange my markers in a certain order, how I communicate with other people, how I do well in school, and even how I react to tests or exams.

So, that is my family's life, but there are a few secrets you should know about me. First of all, I am a visual learner. That means I learn better from seeing things, whether it is on television or in picture books. That is why I still have so many kid videos in my play room: "Little Bear," "Blue's Clues," Sesame Street," "Barney," "Mary-Kate and Ashley," "Hannah Montana," "The Big Comfy Couch," "Rugrats," "Dora the Explorer," "Bear in the Big Blue House," "Alvin and the Chipmunks," "SpongeBob SquarePants," "Arthur," "Peanuts," and "Winnie the Pooh." Whew! It is a lot, I know, but I watch those shows because they bring back so many memories.

Second of all, I love going to see my autism specialist, Dr. Manning. She is the sweetest woman in the whole world, in my opinion. She always makes me feel better when I need to talk to her about something, good or bad. We talk about my stress levels, my medication, my life, my friends and family, and I even show off some special talents in front of her. The first time I went there, I was around

three-and-a-half. I have been told that I felt uncomfortable there because I did not know what was going on at the time. As years went on, I got used to it. At the age of 15, however, I asked her why I go to these visits. Then, the truth came out. The bombshell exploded. She told me I have autism. I did not know what to say except cry. This whole time I thought I was living a normal life. The truth is I was living a normal life. It is just that I have a condition.

Finally, I will talk about my future. I am 17 years old, going on 18, and Dr. Manning has talked me into seeing Dr. Pittinger, a psychologist, at the DDBP (Division of Developmental and Behavioral Pediatrics). I learned that even though it is four hours long, it is still going to be a lot of fun. There will be an interview, puzzles to solve, and the suspense for the results. My mom and dad will help me with the interview. Then, an hour later, Dr. Pittinger will take me into a room and ask me to take some trusted personality tests and solve some puzzles and maps at my level. While I am doing that, my parents will watch me through a computer screen. Then, we wait a month later for the results, but my parents find out first. No fair! Anyway, besides the psychologist, she also told me someone is making a book called A Book of Hope, a book about autism, and I am one of their helpers. You see, this whole story is in the book right now and you are looking at it. Isn't that cool? (I hope you are not jealous.) Also, The Simons Foundation is doing research on autism and Dr. Manning has asked me to be a part of it, and I had to say "Yes!" and "Definitely!" All we do is sign up for free online and wait until we get tested. The researchers take a spit sample and take it to the lab for research. Hopefully, our results will show up soon enough.

Well, that is my autism story. I hope you liked it, especially to all of the other people who have disorders, whom I know and not know. Hopefully, this story has inspired you to be the wonderful person that you are now and will continue to be in the future. Again, I am Kenzie Dreyer, and this is who I am. I love you all. Thank you.



Lily

age 4, spina bifida

We received our daughter's diagnosis of Spina Bifida when I was 20 weeks pregnant. She wasn't even here yet, but I desperately wanted to know how to plan for her—What help would she need? Did I need to quit my job? Should we downsize our house to make sure we could afford her care? Could I handle her medical care? I read, researched and combed through test results looking for answers, but answers weren't there. I've learned that clarity is most likely to come through experience, patience and relationships. My advice:

1. Get to know people who have experience with your child's diagnosis (other families, nurses, local associations). Build a network. Ask questions. Learn via their experience.
2. Let your child show you what they are capable of, and encourage them to try new things. They may need to do things differently. It may take a lot of time and patience… but wow is it exciting when they finally "get" something new!
3. Celebrate every effort and "inch stone." Because things are often harder for our kids, it's important to build resilience within them. Celebrate acts of trying (not just being successful), and "catch" your kids doing little, but great things ("Nice job using your left hand! I know that's really hard for you.").
4. Be an active participant in your child's care. While medical professionals are skilled in their craft, YOU are the expert on your child. Don't be afraid to speak up and ask questions.

—Amy, mom to Lily

"Let your child show you what they are capable of, and encourage them to try new things."



Lexie

age 14, autism spectrum disorder

Autistic Girl

My life has problems like autism quite a bit.
It always pops up like an annoying zit.
People treat me like a baby most times.
Is that I practically pace all the time?
I see normal poeple, the thing I want to be.
But alas, normal people talk is foreign language to me.
People think that I'm a 2nd class person a lot.
People think that I am worthless, but I'm not.
My eyes sweat everyday from day and nigh.
I'm so tired I want to die.
People think I am sad to be.
BUT, I'm not you see! I'm a sweet girl with all my heart.
I was and am from the start!
I will let everyone know in the world.
That I'm me, the autistic girl!

—poem by Lexie



Jeremy

age 8, autism spectrum disorder

SO, WE HAVE AUTISM Mom can you comb my leg!

My great-grandson, 7 year old Jeremy, has been diagnosed with autism spectrum disorder and together, our entire family, must learn all the best ways to deal and assist him with his multiple challenges.

Before a diagnosis we knew that we were seeing something that involved a totally different set of daily experiences. We had come a long way and learned a lot by seeking information, and of course trial and error.

Most of society, unfortunately is not engaged enough to recognize this disorder, and do not have your back. Instead they see all the negative aspects, and the smart, loving, beautiful child that is our Jeremy, is often looked at aghast.

As a result, we must be extremely diligent to assure ourselves that Jeremy is afforded every resource available, as needed, and that these resources are implemented properly. We have learned not to assume that other people responsible for our child's care and education have the proper training and understanding of his needs.

Jeremy requires people in his life who are caring, dedicated, and willing to go the extra mile with him. I give thanks and praise for those people because together we can help him to achieve goals and have a bright future.

I feel that one very good resource is discussions we have with other families having autism. I always come away with hope, encouragement, and inspiration.

—Jill, Great-grandmother and guardian to Jeremy

"I feel that one very good resource is discussions we have with other families having autism."



Jaia

age 5, Down syndrome

I love Down syndrome. I get to have Jaia. She is the best sister I could ever have. I love to teach Jaia new things. It's kind of hard sometimes because she doesn't want to listen, but usually it's very good. If I had a friend who had a new brother or sister with Down syndrome, I would tell them that it's not a problem. They learn a little bit slower than others, but it's not a big deal. Jaia will be the smartest person ever and still have Down syndrome. What I love best about Jaia is that she never gives up. And her hugs and kisses. I love her.

—Jaxson, age 8, brother to Jaia

I was surprised and scared when I found out my sister had Down syndrome. I thought she wouldn't understand things and I wouldn't be able to communicate with her. Jaia might take longer to do things but she's not that different than any other 5 year old. She's just like the rest of us. If I had a friend who had a new brother or sister with a disability, I would tell them to treat them the same as they would treat any other sibling. What I love most about Jaia is that she is very sweet and loving. If I'm ever sad she will come and give me a hug and say, "It's ok". She's the best. I love her.

—Jarren, age 15, brother to Jaia

"She's the best sister I could ever have."

“Please remember to never give up.
Keep trying because there is always hope.”

—Jenny, mom to Joey

“Please remember to never give up.
Keep trying because there is always hope.”

—Jenny, mom to Joey

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