



"A gift of stories
from parents &
patients with
autism."



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by kids.com

Welcome!



If you are reading this, then you, like the contributors to this booklet, love someone with an Autism Spectrum Disorder (ASD). You are not alone. This booklet was created by the generosity of EmpoweredbyKids.com, the publisher of more than 23,000 Books of Hope for families affected by chronic health concerns. It is filled with stories of families at various stages of their journey with Autism. It can be daunting at times, but know that there is a community of families that, like snowflakes, are beautiful and unique, yet are all connected by this same common thread. Some days can be challenging, but many are filled with discovery and wonder.

This booklet is a labor of love from members or friends of the Autism Treatment Network Family Advisory Committee and individuals living with an autism spectrum disorder, who have generously offered to share their experiences. These are their stories of hope and inspiration. The ATN is a community of families and practitioners that are dedicated to improving the lives of individuals with ASD. Our network is creating an environment in which clinicians and researchers learn from each other, families are engaged as partners, and we are able to translate research findings to practice more quickly. Our goal is to improve healthcare for all children with ASD.

We have come a long way in my 30 years of working with children with ASD and their families. What was once a rare and relatively unknown disorder, currently impacts 1 in 68 individuals. Now, many people have friends and loved ones touched by autism. We have better awareness and understanding of the full spectrum that makes up an autism spectrum disorder.

We have improved diagnostic testing, more effective interventions, and increased funding for research and supports. We're not there yet. We still have much to do, but I am confident that we will continue to make huge strides in our understanding over the next few years.

I continue to be encouraged by the stories of former patients. I am thrilled when I hear of a first gesture, picture exchange, or spoken word to make a request, or a play date, job or college acceptance. The range of accomplishments may vary but the feeling of pride is the same. We celebrate the journey not always knowing where it will lead, but feel privileged to be a part. I know I have grown and have been changed for the better by the experience.

I hope that you will find inspiration from these stories and someday you will reach out to those who come behind you. Together we build a community of support.

Warmly,

Donna Murray, PhD CCC-SLP

Autism Treatment Network | Autism Speaks



About Autism Speaks



Autism Speaks is dedicated to promoting solutions, across the spectrum and throughout the lifespan, for the needs of individuals with autism and their families through advocacy and support; increasing understanding and acceptance of autism spectrum disorder; and advancing research into causes and better interventions for autism spectrum disorder and related conditions.



Autism Speaks enhances lives today and is accelerating a spectrum of solutions for tomorrow.

Autism Speaks was founded in February 2005 by Suzanne and Bob Wright, the grandparents of a child with autism. Since its inception, Autism Speaks has committed more than \$570 million to its mission, the majority in science and medical research. On the global front, Autism Speaks has established partnerships in more than 70 countries on five continents to foster international research, services and awareness. To learn more about Autism Speaks, please visit [AutismSpeaks.org](https://www.autismspeaks.org).



The Autism Treatment Network (ATN) and Autism Intervention Research Network on Physical Health (AIR-P) form an integrated network comprised of some of the leading children's hospitals and academic institutions in North America. Working together, the ATN/AIR-P combines the highest standards of clinical care with the latest findings and best practices in research to advance medical care for children and adolescents with autism. ATN is supported by Autism Speaks. The AIR-P is made possible through the Autism CARES Act of 2014,

funded by the Health Resources and Services Administration (HRSA).

Autism Speaks and the ATN/AIR-P have created free tool kits for managing autism-related issues for families and professionals. To access the tool kits: <https://www.autismspeaks.org/family-services/tool-kits>

Contact the Autism Response Team for information, tools, and resources: 1-888 AUTISM2 (288-4762) | En Español: 1-888-772-9050 familyservices@autismspeaks.org



Our Books of Hope are published with one thing in mind, to give families the strength to fight through the diagnosis of their child. When times are tough there is only one thing that helps – Hope.

Amy, Annie 14

When my daughter Annie was diagnosed with Autism at age 2, I was heartbroken and devastated. Being a young mother of three, with a baby son who was only 3 weeks old and another son who was 3 years, I could barely fathom the life ahead of me.



My mom is my best friend and her mom was her best friend and all I ever expected was that my daughter would be my best friend too. After her diagnosis, I had to grieve the "death of the daughter I wouldn't have." This was the most difficult thing for me. It took me years to wrap my head and heart around Annie's diagnosis. But one day it just clicked with me - I could have so easily been Annie! Autism could have happened to ME! It didn't run in our family, I had no known relationships or associations to it and it just happened. I had to stop blaming myself (the guilt was there, no matter how I tried to rationalize) and become her advocate and voice, because she DIDN'T have one.

Slowly over the past 12 years, my heart has begun to heal and mend. There will always be a scar, don't get me wrong. But I have learned that



the GIFTS that Annie and our journey together have given are absolutely remarkable. Recognizing these gifts and the small accomplishments are everything...and once you do, life changes in amazing ways. And guess what...Annie is my best friend and my HERO.

Kenta 10

Hope



Once I was in a dark tunnel, feeling isolated.
One day I saw the light.
I managed to hold it.
It gave me a way to communicate with others.
It was an amazing feeling I had never felt.
I was saved by the people who believed in me.
I am not alone any more.
I live with hopes and dreams.



Angeletta, Londyn 8

Singled out. In the span of one year my marriage was failing and my daughter was diagnosed with autism. I became a special needs mom and a single mom, all at once! What a major adjustment!! We'd never experienced autism in my family, and I found myself reaching out to any support available. The initial problem was I felt singled out in support groups as well. My daughter was usually the only girl and the only minority. I found my stories were never relatable...so I thought. It finally occurred to me that in our autism world there is uniqueness, but also, we have a common bond. We are all traveling this journey of autism. Along this journey, we will come across the same forks in the road, bumps, sharp curves and turns, but we'll get through it, together! I encourage new families that I meet along the way to see this journey as a road trip. Who would be the person or people you'd take with you for the ultimate road trip? Invite this person on this autism road trip with you. They will choose to get it when you make unfavorable decisions that work best for your child. They are available as a sounding board, a crying shoulder, or will supply the rocks when throwing them is needed. Most importantly, they will stand with you when you're calming down a meltdown that refuses to be calmed down. I found my road trip crew and I'm no longer singled out!

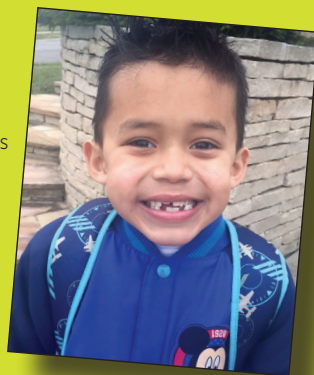


Charles, Charlie 7

What were some of your initial fears after your child's diagnosis? How has that changed?

I went through and touched every stage of the Kubler-Ross model (grief stages) of denial, anger, bargaining, depression and acceptance. Because our son was diagnosed early (before the age of two), it was not as readily apparent that he had a developmental disability. This is perhaps what extended the denial phase longer than normal. His differences were not as visible as they became later on. Frustration more than anger came into play and the bargaining phase was me attempting to perhaps falsely believe that this was a phase. Often times I would research ways to "teach" him out of his condition. Depression then kicked in when I realized I had little control of how he would turn out.

Given the timeframe since our son was diagnosed (over four years ago), I have spent most of my time in the acceptance phase. This is perhaps what has changed my interactions with our son. He is a handsome, intelligent, unique and wonderful little guy. I have learned that I need to help and guide him, but at the same time let him be himself. He continues to grow, develop, and impress me in ways I never thought possible. I love him as I always have, but have even more compassion for him given the struggles he has to face every day.



Charlene

I vividly remember the day and the room we were in with our 39 month old son as we received our diagnosis of severe autism. I remember holding him in my lap and trying to hide my tears, my fears, my grief. I remember waking every morning and hoping it was a bad dream. Then I would hear the unmistakable sound of our son waking in his room, getting out of bed, ready to start his day full of energy. And I would think - no, this is real.



I don't remember when this stopped being my first thought each day, but it did. I do remember, though, when he was 3 and handed me a PECS (Picture Exchange Communication System) picture and pairing it with a word for the first time; when he was 4 and spoke his first full sentence; the kindergarten Christmas concert, as he stood on stage ringing jingle bells with his classmates; at age 7, his first full haircut without squirming and screaming; when he led us through Disneyland to his favorite attractions at age 9; his first flight on an airplane at age 11; age 13, when he asked when it would be his turn to drive. LOL

On that life changing day, years ago, I didn't see the possibility of making wonderful memories.

All the meltdowns, the effort, even the tears - worth each memory, too many to list. Similar to everyone else, yet I appreciate them much more. It's possible, just start.



Crissy, Andrew 13

I WOULDN'T HAVE IT ANY OTHER WAY

I used to worry, "What will become of Andrew if something happens to me?"

The truth is: I don't know what would've become of me without Andrew. I've learned more from my son than he'll ever learn from me. He has taught me the meaning of unconditional love. He loves me the way I am. He sees the best in humanity, yet uses discernment when necessary.

Andrew is the first to share what he has, and the last to ask for anything. He's the bravest person I know. His spirit is undefeatable. He never lets anything get him down, and never complains.

Life isn't easy for Andrew. He faces many challenges. But to him, it's just the way life is. Andrew has made me an optimist. He inspires me to look for the best in every situation, seeing challenges as an opportunity for growth.

I do my best to be the person Andrew can count on to help him achieve his dreams. While my hopes and dreams for him change and evolve, I hold close to my heart the knowledge that he is destined for great things. In my darkest hour I never lost hope. I know we face many challenges and opportunities for growth ahead, but if Andrew can do it with a positive attitude, I have no excuse. If I'd known all that I know now about what life would be like raising a child like Andrew, I still wouldn't have had it any other way.



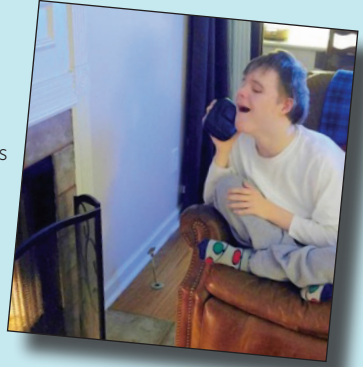
Dawn, Andrew 18

My son, Andrew, was born 18 years ago with Down syndrome, and later, also diagnosed with autism. He does have struggles, but I am so proud of him for doing his best to deal with them daily. Our unconditional love and prayers will always be with him!

It is a blessing to try to look at life through Andrew's eyes. This helps me think of the little, special things around us that are easy to forget in this busy world. There are reasons behind many of his behaviors and helping him to feel more peaceful and comfortable inside (by sometimes being a detective) is one of my goals.

Autism can sometimes be like a roller coaster ride, but then, Andrew will give us one of his sweet hugs and that ride slows way down! Sometime ago, my dad gave me a bit of advice, "Don't fight things so much, just let go a bit and relax with Andrew." When I can do this, he feels that from me and it helps him calm down too.

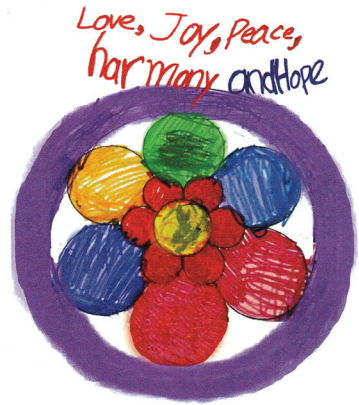
I smile whenever I think of all the times my daughter is playing the piano and Andrew is swaying and moving to the music! I am so thankful he is with us, doing the things he enjoys and feeling the peace and comfort of home! My hope for you is that when riding this roller coaster of love, you will ride it with all your heart and know that everything will be okay.




Kameena, Keena 13

When my daughter Keena was diagnosed almost 10 years ago, I had no clue what an autism spectrum disorder was. In fact, I was still very young, had just become a single mother, and was in a really dark place. At that very moment though, my only thought was how to be the light my daughter needed to improve the quality of her life. All I wanted was for the tantrums and embarrassing moments in public to stop! This encouraged me to be strong and find out how I could help my child. Then again, during that time, I guess you could say I was only strong because I had to be. But, it was when I began to reach out and make calls, that I received the best advice I could've ever gotten from other parents, an amazing doctor and one awesome clinic nurse care manager who told me, "on those tough days, find your breath and say... it's ok, it's just for today." What this means is, go slow when you need to and take time to love yourself because you've got this! Those words really helped me to realize that the stars only shine at night and what is now dark will, once again, be light. So for yourself and for your family, you must continue to... Shine On!

P.S. To your child and all the kids with autism my daughter Keena would like to tell you to "Love who you are and don't stop trying!"





Kimberly, Blake 14

As a young child, my son Blake was diagnosed with ASD. First came the wave of worry and angst. I was afraid of the obstacles we would both face in our future together and of questions that couldn't be answered. Would Blake be alright? Would he be able to function "normally" like other boys his age? The millions of questions that showered over me like rain wouldn't end. Then, though, came the burning determination. My son, though living with ASD, is just like any other child his age—just as all children with ASD are fundamentally like children who do not have ASD. As Blake has grown, we've always challenged each other and we've never used his diagnosis as an excuse to take the easiest path. We speak to each other with patience and empathy, working on skills he needs to hone and skills I need to learn in order to give him the mother that he deserves. Admittedly, every day is a tug-of-war, but it is well worth the fight. Every day, more importantly, is a miracle with a new milestone reached, no matter how little it may seem. Children with ASD are strong and it's a beautiful experience to see my son reach the peak of each mountain placed in front of him. There's no obstacle he, or any other child with ASD, cannot conquer and there's no limit to their love. Keep Fighting, Stay Strong, and Have Hope.



Love, Kimberly his devoted mom

Liza, Mark 18

Someone once asked me what the saddest day of my life was. My mind instantly flashed back to the day I pulled up our driveway; our two toddlers playing under the watchful eye of my husband to whom I was about to share sad news. I had just returned from the doctor's office: Mark at four years old was diagnosed with autism. The news hit us like a ton of bricks. We wept uncontrollably at the driveway because we both knew what that meant. A door was shut and the diagnosis felt like a life sentence. Autism wasn't part of our plan. There is no way of adequately explaining the emotional devastation parents experience when told that their child or loved one has autism. All we know is that the journey for each family is and will be different. So once we decided that the grieving had to stop, we were able to move on. And that we did. Our family accepted and embraced the autism journey. This became the NEW plan.

Although I'll never forget that fateful day, autism is now part of the fabric of our lives. Mark, now 18, has made strides towards independent living. For all the challenges along the way, we've changed to see the best in others. Lessons in patience, creativity, empathy, and acceptance have also made us better parents and a kinder family. We've been given these special gifts through Mark because he is special.

Look around and breathe. There is help and hope.



Lora, Blake 13

It wasn't supposed to happen to me. A speech-language pathologist who worked with children with autism was not supposed to have a child with autism. I could handle anything else. Well, it appears I can handle autism, too. I wish someone had told me then that it was okay if I didn't "cure" him. I wish I would have known how strong I would become and how much joy he would give me. Maybe I would have worried less or shed fewer tears. Because of Blake, I became a better SLP and person. I started a support group, helped develop the Thompson Center, and helped create programs in our school district. These things have helped many children. I have found a bigger purpose through my son. Through Special Olympics and other organizations, Blake has won medals for swimming, basketball, and baseball. Like any other teenager, he loves to ride his bike and play on his iPad. Although there are ups and downs, you find your path. It may not be what you planned but it will be yours...and it will be wonderful. Blake is more than a diagnosis. He is beautiful, not broken. Blake is different, not less. He has a lot to offer the world, just like your child. Today my support system is strong. It takes time to build that system though. Don't be discouraged. One day you wake up and although there are still fears, you feel at peace with where your journey has taken you.



Janet, Andrew 20

"It might have been easier, but it wouldn't have been better," words I have thought of many times throughout my son's life.

I was reminded of these words the first time I was asked by a newly diagnosed family, "What was one thing you did for your son that you felt would contribute to his success as an adult?"

After much thought, I realized for us, getting him to partake in as many experiences as he could outside in the world was our answer.

Throughout his life, we tried to expose him to travel, sleepaway camp, and college. We searched for places that we felt would allow him to safely access enriching experiences. He was hesitant with each new opportunity. However, he learned through his involvement that although there were some rules or activities he didn't like, there was always a fun take-away or an amusing moment to be a part of.

Sometimes he needed more support in those settings, sometimes he was able to manage with less support, but throughout we all realized he was achieving much success, and being involved was becoming important to him. We were constantly impressed by his passions, strength, and motivation. He soon began seeking these opportunities on his own.

Yes, some days it would have been easier for us not to make the choices we did regarding our son's activities, but all those experiences helped a little boy progress into a wonderful young man and who would have wanted to miss that?!



Maria, Max 13, Kasey 9

“Your child has autism.”

These are the words we have all heard in some way and in some form. My journey with autism began long before I became a mother to two active, precarious, unique and talented sons; two sons with a diagnosis of autism spectrum disorder (ASD).

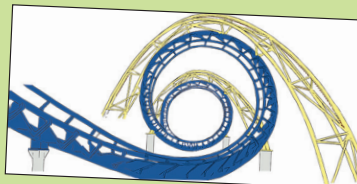
I was a high-school teacher for students with exceptionalities and had been working with students with autism for almost 10 years. I loved my students - loved helping and providing them and their families with the tools needed to become successful, productive young adults. However, nothing could have prepared me for the day it was my turn to hear the same words my families had heard; it was now MY child, MY children with autism. Max, age 13 was diagnosed with autism in 2006 and Kasey, age 9 followed with a diagnosis in 2009.

How one reacts to the news of a diagnosis is different and unique for every parent and family. There may be feelings of guilt, confusion, anger, sadness and even fear. If I could reach through the pages of this story while holding your hand, I would say; please don't worry, it will get better; I promise. There are people and resources available to help. The journey of an autism diagnosis may not be easy, simple or straightforward, but it will get better and you are not alone. Those that have heard the same words as you do now stand alongside you – with you. Always.



Nolan 14

Hi, my name is Nolan and I'm 14 years old. I'm in 8th grade and my favorite subject is math. I like to go to Kings Island and travel to new places. When I was little, my mom used to take me and my brother to the Children's Museum. I remember I used to take off to the elevator as soon as we got past the main entrance. My mom couldn't find me sometimes and would get really worried. It never bothered me to not stay with an adult. Now that I'm older and I remember then, I used to be scared of how tall the ceilings were at the Museum. Being there made me feel like I was going to float away like a balloon. I hated that feeling but I didn't know how to tell it to my mom. So that was why I used to run into the elevator immediately because being inside it made me feel safe. The space was smaller and quieter: I also liked pressing all those buttons and the motion of going up and down was relaxing. Today, I still enjoy riding elevators of all kinds. My parents have even taken me to hotels that have really cool elevators. I also love roller coasters and zip lining - the higher, the faster, the better! I love the speed and the feeling of flying when the coaster drops or when I'm zipping through the trees. Many things in my life are less scary now.



Mike, Cooper 7

The official diagnoses came at around 30 months. What we feared for months was coming true.

"Your son is on the spectrum in the mild to moderate range," said the doctor. My son's life flashed before my eyes before she even finished speaking. Would he ever talk, have friends, play sports, have a girlfriend, learn to hunt and fish, drive a car; get married? Would he ever be "normal?" All the things I dreamed about for my son long before he ever came along. The things I thought were important.

It didn't take long to realize what I thought was important or "normal" were insignificant, to say the least. It made me mad! I was angry at autism for taking my dreams for my son away. He's MY SON!!

We all worked very hard to give Cooper the tools he needed to progress. Coop worked the hardest. He endured countless hours of speech and occupational therapy, both public and private.

One night, as I was tucking Cooper in for bed, I said, as I always do, "I love you, Coop." What he said changed my life forever; "I love you too, Dad!" In that moment, I realized my dreams for him are his dreams now. My dream had come true! He said I love you Dad. Never in my life have I ever felt so lucky.

Coop is now in second grade with no IEP. Still struggling with the social part, but getting better every day! I love you son!



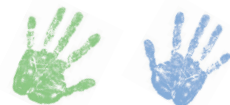
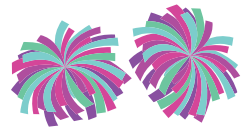
Regina, Granddaughter, Londyn 8

I'm thankful for many things in life - family, friends, the love of God, my children and wonderful grandchildren. As grandparents, we're all proud of our grandchildren and believe our grands are the best of God's creation. Well, my three grandchildren are the best!

I remember the day, however; when we knew that Londyn behaved differently. As a parent or grandparent you know when something is wrong. This is when our journey began. There were months of therapy and doctor visits before anyone could tell us anything concrete. It was either a speech delay or developmental delays only to later find out that neither was correct.

When we first heard the news of Londyn's diagnosis of autism, there were many uncertainties, many questions and much fear. That's why I'm thankful for family and the support it brings. I'm thankful that Londyn's parents were diligent in finding the help she needed and for the support they received. Because of that support I can attend Londyn's dance recitals, cheerleading competitions and listen to her voice of song.

Autism is not a curse. Life did not deal us a bad hand but rather a blessing from God. Our children are blessed and so it is with my granddaughter Londyn. I smile as I write this because I see her beautiful face; I hear her knock-knock jokes and her outbursts of laughter. Londyn fills my soul with joy, not because of a diagnosis but because she is my grandchild and I love her unconditionally.



Tara, Rye 12

Dear Friend, Today is going to be hard; you will make it, no matter the outcome. There are a few things I would like you to remember today, tomorrow, and every day moving forward.

1. You are right to be here today. I know there is a part of you that wants to run screaming from the building. Don't. Waiting or doing nothing isn't going to help anybody, including you.

2. A medical diagnosis indicating a disability is not the end of the world as you know it. There may be days ahead that feel like it, but I promise you it is not.

3. Parenting is hard for everyone. Receiving a diagnosis today might not make your journey any easier, but it is parenting just the same.

4. One of the most important things to remember today is that you are leaving today with exactly the same child you came into the building with, no matter what the doctor tells you.

5. Take a deep breath and remember all of the amazing gifts and talents that are waiting to come to life within your child. Today is the first step of learning to uncover all of your child's abilities and your own.

Sincerely,

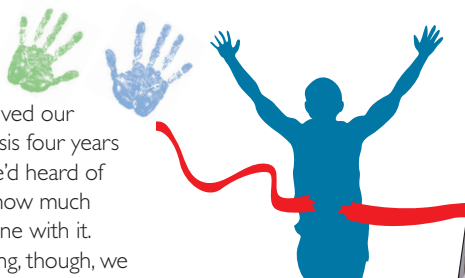
A friend who understands and is pulling for you



Teresa, Tyler 6

When we received our son's autism diagnosis four years ago, we felt lost. We'd heard of autism but didn't know much about it — or anyone with it. After some searching, though, we met a mom whose son also had autism; the help she gave us was an unbelievable gift. From there, our new community grew. We entered a whole new world, not the one we had dreamed of for our son. We were determined to make his life better so we started therapy — speech, ABA, and occupational therapy; placed him in a developmental preschool; and registered him for sign language classes. He has improved so much. He was nonverbal when we received the diagnosis, but now he's saying more words and also has an augmentative and alternative communication (AAC) device to help him communicate. I never thought I would hear him say "I love you," but he does now and it melts my heart. This year, he started kindergarten; in a regular classroom with a paraprofessional to help... he made the principal's honor roll this quarter and continues to amaze us every day!! We've learned so much since our son was diagnosed. For my part, I've learned to be more patient and not to worry what others think. There's a saying in the autism community, "when you have met one child with autism, you have met one child with autism." So, don't compare your child to others; autism affects everyone differently.

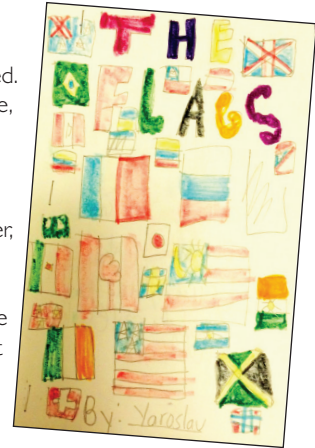
Remember: this is a marathon, not a sprint.



Oksana, son 9

People, who can read and write, take these skills for granted. However, in our culture in North America, it's likely that people, who don't have those skills, will be kept from educational and employment opportunities.

When my son was first diagnosed with autism, he was non-verbal and couldn't read or write. His kindergarten teacher, although well-meaning, decided not to send a weekly book with reading and comprehension assignments home. She thought he wouldn't benefit from getting the book. During one of the school meetings early into the school year, I insisted that we get the book like everyone else. I told the teacher, "I'll read to him at home. He enjoys story time before bed." I had a question on my mind, "How can you know his limits when he doesn't even know his own?" (Kunc, 1987)



In two years my son started printing, reading and, eventually, talking. His decoding skills were much better than his comprehension and speech. By the end of Grade 2, he became comfortable with reading aloud in class. On one occasion he even helped another student, who was struggling with reading in class. By Grade 3, my son started writing and illustrating his own mini-books. Currently, he's in Grade 4. He likes reading books, doing online research and wants to become an architect one day.

Don't give up on your child! Keep raising the bar to see your child's true potential!

Reference: Kunc, N. (1987). Presentation - Play for Play's Sake. Toronto, ON: Roeher Institute.



Andrew, 20

The thing that surprised me the most as a person with an autism spectrum disorder was to learn that we are fixated on our unique interests and we obsess about them.

For me, I was fixated on certain topics such as elevators when I was young and airports and aviation later on, and then photography and Smart Boards now. My strategy is to use my interests to help me find a career; try to make connections, and find friends that love these same topics as much as I do. Using my strategy for the things I am interested in gives me great opportunities to become successful in my field of studies and enjoy satisfying friendships as I get older.

Often, we are intelligent and very smart on the autism spectrum and we do extraordinary things like inventions by focusing in on what we do in the moment.

I believe it's important for everyone to see individuals for who they are and what they can do, instead of focusing in on a label. People are not defined by their label or their disabilities. Instead, people should be viewed with consideration for all factors such as intelligence, having great skills, and interests like myself.

If people with disabilities were viewed this way, there would be more opportunities in society for awareness about autism and appreciation for a diversity of interests.



Luz, Mia 10

When Mia was younger, she was a perfectly normal toddler with no signs of autism. As a professional who has worked with children with disabilities, I began to notice something was different. I attended a conference about autism and realized that Mia had 8 out of 10 symptoms mentioned.

There is no way to prepare for a diagnosis of autism; however, I was glad to know why Mia was acting so differently so that I could begin to take action. After she was diagnosed, I immediately put her in therapy. I have pushed for my daughter to have services in and out of school. Mia's teachers, therapists, administrators, and advocates work together to ensure that everything is in a good place for her development. A wonderful example of her development can be found in her participation in the yearly class plays. The first year, she didn't participate. The second year, she stayed on the stage with her assistant behind her. The next year, she sang and danced a little with her assistant off stage. During her third grade performance, she was on the front row singing and dancing. Her final year, she had her own speaking part!

Mia's development is truly something to celebrate. There is hope. Hope lies in the professionals and teams that work together for the success of each child. We nourished her emotionally, physically, and academically. She is still growing, but she has the ability to go wherever she wants to go.



William, Yanni 13

When Yanni was born we knew something wasn't right. We had him evaluated and found out he had autism. I had no idea what that meant.

We got in-home services to help with speech and coordination when he was about two. When he started school, the school helped us out greatly. But then we moved and things weren't so great. We found we had to press hard to get Yanni the services he needed. It also helped that we were in a support group.

The struggles and joy Yanni brings to our family are great. I have watched Yanni grow and become independent. We spend lots of time together. We explore the Zoo and Cincinnati Nature Center. We especially enjoy seeing snakes and other reptiles (Yanni more than me!).

Yanni is now 13. Through the years I have come to understand him as a person and not just as a child with autism. He is smart and enjoys new things but I realize there is only so much he can handle at one time. It is better to do one or two things rather than a bunch of things all at once.

I have a wonderful time with Yanni. I was overjoyed recently when he said "I love you Dad" and asked for a hug! I believe with love and support Yanni will become the best he can be. As a dad I am so proud of him and I feel blessed to have him in my life.



Peggy, Granddaughter Annie 14

Hello Friend

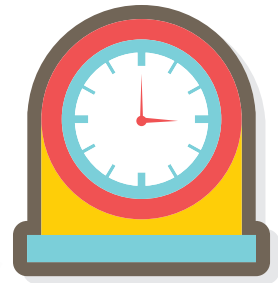
We have not met yet. Our friendship begins with the life circumstance we share - a family member diagnosed with autism. My granddaughter Annie was diagnosed with autism at two. Annie is now 14 years old.

My name is Peggy, known as "Gram" to four grandchildren and to the therapists, teachers, and doctors who have come into our lives with guidance and direction.

As a mother, it was heart wrenching to watch my daughter go through the pain and shock that occurred with Annie's diagnosis. As Annie's Grandmother, my fairytale vision of life with my granddaughter flew out the window.

Wanting to ease the burden of my daughter's pain, it didn't take long for the "mother instinct" in me to kick into action. The one thing I know for sure: I can, I do, and I will assist my children when they are in need. Grandmas, grandpas, brothers, sisters, aunts, uncles, cousins, friends: Be Available. Offer your help. Leave your expectations at home. Start with mundane work - the tasks we all dislike and avoid but are necessary to life. Be generous with your time. Be active in your family member's therapy sessions. The more time you spend, the more knowledge you gain.

Never underestimate what your loved one is capable of achieving. Be patient. Be creative. Keep at it. It works! Our Miss Annie has quite the sense of humor and loves a giggle with the girls.



The three Girls: Mom, Annie and Gram



Maari 15, Brother Salah 16

What is it like to have a brother with Autism?

My brother, Salah, is a year older than me and is living with autism. Each day with him is a new experience. It has never been easy to understand what he goes through, but I try my best. When I get frustrated with him, I always think about what is going on in his head. But that tends to frustrate me even more. I do not know what is going on in his head, and he cannot tell me. Because of this I find myself treating him as if he were a baby rather than a 16 year old. I know that my brother is intelligent and I constantly wonder how many times he gets annoyed by the way I treat him. However, one aspect of my brother that is irresistible is his compassion, and love for others. He is the first person to pull me into a hug when I come home, if I am stressed, or even just because. His goofy smile lights up my day. Dancing, singing, playing games with him are the reason that all the not-so-good situations do not feel so bad anymore. That is how it is, living with someone who has Autism. You need to make a lot of assumptions, and whether right or wrong, you love each other anyways.

Jezreel
Shyne 12

"Due to our findings, it appears that your child, Shyne Jezi Griffin, is on the autism spectrum."

Words spoken to me in plain English, but words that sounded as if they were spoken in a foreign language. I had no idea what autism was. It was as if he'd been diagnosed with a terminal illness.

I was only 20 when I received my child's autism diagnosis. It was a year and a half after I began to see visible signs. But this is not a story with a terrifying ending. This story is about a journey to the road of Recovery and Victory that has no ending, as new chapters are being written every day!

Early intervention is the key to newly diagnosed families that offers a wide-range of resources, support, and training that will enable you to work and play with your child more effectively. It also provides the child with instruction that will build strength to teach new skills, improve behaviors, and remediate areas of weakness. This can and will, save your child's life.

During the course of our actions, my child and I faced many negative experiences. But if you allow negative experiences to become a call to positive action, miraculous things can happen. Having your child diagnosed can be extremely scary, but I'm here to tell you that even when the odds appear to be against you, when all looks impossible, you can, no you **MUST** make a way!

You can beat the odds.

Kim, Justin 12

Twelve years ago my seventeen-month-old son and I sat in a badly lit examination room as his pediatrician gave him what I thought would be a routine exam to help with his reflux. Twenty minutes later, after regaling me with a list of developmental delays he hadn't mentioned at our last visit mere weeks before, our pediatrician handed me several articles with "autism" in the title, told us to see a developmental pediatrician, and rushed out the door, leaving me shaking and devastated. I skimmed those articles before I dressed my boy, and was hit with all the things he would supposedly never do. I read about milestones I'd always taken for granted, such as his ability to speak. It took ten years, but my son finally conquered his apraxia enough to utter his first words. I know these days kids are being diagnosed as young as Justin was, and even younger. My advice is never let anyone, no matter what kind of practitioner they are, tell you what your child will or won't do. No doctor or therapist can see into the future. It's too early to know your child's progress; too early to know how he will benefit from all the therapy, teaching, and love he will receive. It's way too early to know the trajectory of your child's life. Work hard with your child, push harder even on days when it seems impossible to summon the energy to do so. And no matter what, keep hope alive.

Taylor, Brother Jax 18

Growing up with a brother on the autism spectrum had its difficulties, but as a child only four years older, it seemed more difficult for me. He didn't have to do chores, he didn't have to eat what was for dinner if he didn't like it, he was able to spend more time on the computer; he didn't have homework. The list goes on and on as to what made me not like my brother and how many times I got the response of, "he's just different," from my parents.

As I grew older, I realized how lucky I was. My brother is great with remembering dates, has a great sense of humor, excels in math, creates his own stop-frame movies mashing different shows, movies, and characters together; and seems to be more independent than me at times. I've realized that his autism doesn't slow him down. It doesn't stop him from doing what he loves and being who he is. Just because he does things differently or may not be able to match your conversation topic perfectly, he is still an amazing brother, friend, and son to so many people. Getting to see the world through his perspective has been one of the most amazing things. Take the time to get to know their quirks, reasonings, and weirdness - you'll be surprised at what you can learn.



Kimberly, John 13

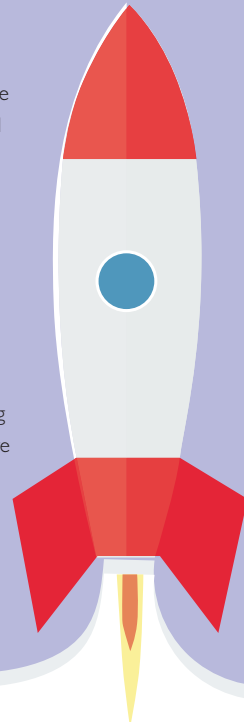
Our son was typically developing, and then he fell behind in reaching his developmental milestones. As first time parents, we sought answers. When we received a diagnosis of ASD, shock, fear, and anger kicked in. Then, we shifted into "time to go to work" mode to give him what he needed to move forward. Our goals were for him to be happy, healthy, independent, and a productive member of society. We have experienced many emotions from anxiety to hope, and from frustration to joy.

Our son has worked hard and deserves credit for the progress he has made. He is not defined by his diagnosis. As with any child, we try to draw on his strengths, and tweak any deficits. He has received therapy and support services and we continue to provide him with resources to help manage his ASD. He has participated in Cub Scouts, soccer, baseball, and other sports. He has been recognized as the most improved on a team, a title he is proud of. He has given back to his community through charity work. He is a unique individual with a great soul and spirit. He loves to laugh, tell jokes, and have fun. He enjoys music, sports, games, history, politics, friends, and family. We believe that he will set realistic goals for himself, accomplish those goals, manage his life, and be a contributing member of society. It's all about the journey! Be optimistic! Don't give in or give up!

Forge ahead! It's all worth it!

Love,

A Devoted Mom



Susan, Liam 12

Phoenix 12

If there's one thing I wish I'd been told when my first son was diagnosed with ASD so many years ago it would simply be "Don't forget to grieve." I received all manner of advice from all kinds of people; everything from trying unusual treatments to cure him, to reading him more books, to people who told me my life as I knew it was over. But nobody reminded me to grieve.

Grief isn't a bad thing; it's the human way of processing what we've lost, creating a plan to move forward after that loss, and finally embracing a new reality. As your child was diagnosed, you did lose something... you lost your vision of your ideal future, and you deserve to grieve that loss.

The amazing thing about grief is that it's temporary.... It evolves differently for everyone but it always evolves. Grief breeds acceptance and determination. Those feelings open doors to a new life that you didn't know you'd love until you live it. With determination you discover that you and your child can change the world. Suddenly you're an advocate and just getting through the days and loving your child wholly and completely will change how the world sees you, your family and children with ASD.

Embrace your feelings, allow yourself to feel them deeply and take your time. When my second son was also diagnosed with ASD, the first thing I did was remind myself to grieve. My next step will be to change the world.

Rosanna, Stephany 6

My girl's name is Stephany, but we call her "Teffy". Shortly before her second birthday, a relative who had recently visited us urged me to check on Teffy's development. Following an appointment with an audiologist, and then a speech and language pathologist, I accidentally stumbled across a likely diagnosis: AUTISM

The days that followed were the saddest and toughest of my life. I stayed awake at night realizing our lives would never be the same. I wondered what would be, and worse, what might never be. I grasped for hope and strategized as to how I could make this horrible uninvited change disappear from my mind and from my life. When I couldn't find answers, I made an appointment to see a psychologist. As we talked, she reassured me that my new feelings and my reaction to this sudden news, was perfectly normal. As I admitted that my feelings for my daughter had already changed, I will never forget what she said to me next: "Your daughter is still the same wonderful little girl she was before you became aware of autism – she is just not the girl you thought she was." And there it was. I began to understand that I would need some time to adjust, and that somehow, everything was going to be ok. Our lives are now very different from the one I imagined. But we also have renewed hope, and we know that an autism diagnosis is just the beginning, not the end.





Remember when
you need a lift:
this is a marathon,
not a sprint.

Teresa