Autism Stories

Tugging at My Heartstrings

by Ed S.

I am a single father of a beautiful 11-year-old girl named Marella with Autism/PDD-NOS. When my daughter was four, she started to develop delays, but her pediatrician at the time suggested we wait. He was sure that she would start to progress. Following that advice, and waiting, was one of the worst decisions I ever made.

Marella still did not speak at five, so she was diagnosed with PDD-NOS. That was when my wife, Marella‘s mother, left us. I was all alone, and felt like the whole world was coming down around me, but when I looked into my daughter‘s eyes I knew I had to do everything I could for her. She changed my life and my world, and she changed me.

Marella started out in an autistic program through the local school system, and she loved it. She met kids who accepted her differences and she developed strong friendships at her elementary school. I worked nights so I could be there for her during the daytime, and I swore that I would make her as happy as I could.

She began speaking little by little, and her behavior problems have all but disappeared. She is now 11 years old, and she is a very happy young lady. I remarried, and my wife loves my daughter like she was her own. Marella calls my wife her Barbie doll, because my wife has blonde hair and blue eyes. They play dress up, share stories, swim, and do all the girly rituals you can think of!

Just this year, we have reached another stumbling block. Marella is moving on to middle school, and she will lose all of the close friendships she has formed in elementary school. The middle school that has the autistic program is out of the area, so all of her old friends will not be going there. Marella has started to express her feelings a little bit more, and I know she is sad inside.

Recently, her eyes started to tear up, so I asked her what was wrong. Her answer was, –I am very sad, I am not happy at all.‖ When I asked her why she was sad, she replied, –Because I am not happy!‖ I asked her why she wasn‘t happy, and she said, –Because I am very sad!‖ A few minutes after that, she asked me what middle school each of her old friends were going to. As I named each one, I know she was waiting to hear me say the name of her new middle school, but I did not. It is heartbreaking to me.

Autism is a very powerful disability, but I know every child can overcome it. I would not have had it any other way. Marella has brought sunshine to many people‘s lives, and she is in every thought that I have, every second of every day.

You Do Have Support out There

by Paula R.

I first heard of autism from Clay Aiken, the runner-up from *American Idol*. He has formed a foundation for children with disabilities like autism. My son is going into first grade, and he reads at fifth and sixth grade level. When asked a yes or no question, he will respond with a –Maybe‖ or –Probably,‖ or when he‘s asked, –Which one do you choose?‖ His reply is –Random,‖ or, –You choose!‖

It‘s very hard for me to get my precious son to talk to me about his feelings or about his day. I now know about his condition, and help is on the way. He has trouble with his speech and language development. He speaks in a robotic tone. He has a –thing‖ about touching coins, money, etc. If he becomes in contact with any currency, he must wash his hands immediately! If my hands have touched any coins from checking out at the grocery store, he will not hold my hand. He will grab my wrist or my forearm as we walk out to our vehicle.

My son enjoys Thomas the Tank Engine, trains, and is a great storyteller. He makes up a new –Thomas story‖ every day. He recites it to himself, using movements of crashing with his hands. His ears are sensitive to very loud noises. I am going through a divorce, and I am a stay-at-home mom.

I have spent a lot of time with him, going to the library, and teaching him right from wrong. I try to do the best job that I know how; it helps when you have prayer and the Lord Jesus by your side. For anyone reading this, I hope that you will say a little prayer for us. With autism, even if it‘s just a small case of it, there are ways to get support, and I appreciate everyone‘s ideas and experience in treatment. I would like to say my son made a difference!

A is for Awe

by Mary S.

A is for autism. A is for Anna. My daughter Anna has high functioning autism. Or does she? That seems to be the problem with this diagnosis (a.k.a. PDD-NOS). She also has mild Cerebral Palsy (CP). I am not sure *how*, *why*, or even *if*. I‘m also not sure what the future holds. I do have now, and this is my now.

Anna was born October 2001. The tests they do at birth discovered she wasn‘t making the thyroid hormone. Two weeks after her birth, we began giving her Synthroid, and we were told as long as she took this pill every day, she would be fine. Each and every time she would get her shots, Anna would get very high fevers, vomit, and have diarrhea.

As a baby, she didn‘t like to be held by anyone else. I was blamed for that. She would stay interested in her mobile for hours, entertained by lights and sounds and nothing else. We thought she had a hearing problem. We spent a lot of money to learn that she didn‘t. We thought she would learn speech. We waited. She didn‘t. I voiced my concerns to her doctor, only to be told it was because I let her suck on a pacifier and that was why she wasn‘t talking (a pacifier that she refused, with tantrums, to give up). Oh, we could have taken it from her, but the puddle of a child that was left behind was too big to ignore. Anna used it as a security device, along with rubbing our faces constantly.

When she was turning three, I told her doctors that I felt her language had stalled out, and that I thought she needed to be evaluated. Alas, we did, and at three years of age, we were told what we already knew. Getting her into the special preschool program became a roller coaster ride I never, ever, want to ride again. They needed to do their own evaluations and testing. And once they were done, she qualified and started a program that just missed the mark. They didn‘t have the funding, the teachers, or the tools to do ABA or any other specific programs for autism. They had a mix of children, with mixed diagnoses from most severe to the least severe.

Autism or not? I battle with that question every single day. The school system fails these children. There is no program for the summer, to take over when the school year ends. This summer, I have had many ups and downs. Anna is almost four years old. Though her speech did come, her thoughts are so –out there‖ most of time. I am not able to have too many back and forth conversations with her. She is nowhere near potty training.

One night I had a few too many beers, and I had a hard time keeping my eyes and mind focused on things. I thought, –This is exactly, exactly what Anna does!‖ I had an epiphany, I suppose! I realized that her mind was clouded by some kind of force, but in her case, it was something I had no control over. Under that cloud– under that ugly, black, thick haze– exists a mind not belonging to autism, or PDD or any other diagnosis. That mind is hers, and I will spend my whole life in awe of it.

Taking Life As It Comes

by Jill B.

My oldest girl, Chelsey, was diagnosed with Asperger‘s at age two. I swore there was something wrong for a long time before that, but everyone always saw a happy active little girl. They never saw the child who would run in circles and scream like she was on fire! It was very hard, but finally others saw it too. When she was diagnosed, there was no real treatment and information, and my doctor told me, –Good luck, and try to hang in there.‖

That was almost 10 years ago. Chelsey is now a bouncy 12-year-old who thinks at about an 8-year-old level. She did make the honor roll at school, though, and she got Most Improved at baton twirling, so there is hope to find the path. It has been very hard to have people ask, –What did you do to her?‖ I learned to let it go, and to do what was best for her.

I keep Chelsey in assisted classes, as in mainstream classes, she gets lost. But she is so smart, and she can tell you everything there is to know about butterflies! She took up baton about three years ago; the repetition of it seems to make sense to her. She is lonely sometimes, not having the understanding of social graces, and that is hard to watch. She pulls herself away from groups, and it makes it hard for me.

She is blooming right now, so new worries are there– about boys, and what to say and do to help her find her way. There have already been so many worries over the past ten years; maybe there will be a way with these new concerns too. All I can say is, I believe she is here to show what she *can* do, not what she *cannot*. Asperger‘s is just something we live with. I also have a 9 year old who is bipolar, and they make each other crazy! But like all things, we take things as they come, and we share humor in everyday things. To folks new to this, hang in there. There really is a lot being done to help.

Still Waiting for Help

by Annemarie P.

My son Kevin has severe autism, and was diagnosed when he was two and a half. Kevin is 8 now, and he has two brothers and one sister; Kevin is my only child with autism. Kevin was a normal toddler until his checkup at 17 months old. He received his normal shots (including MMR and five others). Two days later, his fever was spiking to 106 and he was having severe stomach problems He was admitted into All Children‘s Hospital, and was eventually in a comatose state for a week.

Every test in the book was done on him, and there was no explanation for his illness. When Kevin came out of the ordeal, he was never the same; he had the tantrums, OCD symptoms, and absence of speech. About nine months later, he was diagnosed with autism. At first it was hard hearing this label, and we were in a state of denial. We signed up for all the programs and thought, –Great. We are going to get all the help we need, and he will come out of it.‖

We went to agency after agency to find help. They were all swamped, said that they would stay in touch with us, and that hopefully soon they could help. So we enrolled him in school, and just tried to live normally. At the same time, we had two babies and a son two years older than Kevin. It‘s somewhat easier to have a handicapped child when the siblings are young, but when they start to want their friends around, and they want to play sports and do the regular kid things, it gets a lot harder.

Going out and doing errands also gets harder, and sometimes seems almost impossible. A lot of people stare, and just about every time we do something, someone makes a nasty comment about Kevin or the –apparent lack of discipline‖ that he gets. After we get done with shopping or other things, we go to the car, and sometimes all we can do is cry about the words people use to describe Kevin.

My kids miss out on things because there are certain places that are impossible to take an autistic child. My husband and I can‘t go anywhere as a family, because one of us has to stay behind when Kevin can‘t handle being in those places. We are the only ones that can handle him, so a babysitter is out of the question. Family get-togethers turn into a discussion about Kevin‘s therapies, and how the meds and doctor appointments are going.

Kevin seems to be the center of attention in a room of 30 people, just because he has autism. It seems as though when people see us, they think we are a traveling sideshow or something! Kevin has been admitted into the mental hospital twice just to adjust his medications. The last time they admitted him, they had him in a straitjacket, helmet and ankle restraints. We live with the fear of having to take him back there every day.

Just recently Kevin was put on Zyprexa; it has caused him to gain 30 pounds, and he now is 108 pounds. Now people think that all we do is feed him, and along with his disability we are just terrible parents. There is a definite strain on our marriage; we are always dealing with these problems, and it seems we are drowning. Kevin has been on a waiting list for almost 6 years for respite and behavior services.

Giving Up is Not an Option

By Nadia R.

I have 6-year-old twins with autism/PDD. They where diagnosed at age 3. They used to bite, spit, and destroy anything, and their doctor was in denial about them having a disability. But I asked for more studies, because at age 2 they were still crawling and spoke no words. It was very hard, and there was lots of crying and sickness.

The doctor told me that if I gave them medications, it would make it easier for me. It was devastating to realize that my babies had a disability. I tried them with the medications, but Alex panicked, and Bobby was showing anger. That day, I made the decision to not give them meds. I said to myself, –They have enough dealing with their pain. I want them to be happy whenever they feel happy, and to be mad whenever they feel mad.‖ I realized that was the only way I would be able to help them.

Now they are 6 years old, they have become more verbal, and they are very smart. Last year, I lost my husband, and it‘s been really hard for the kids and me. But all I‘ve got to say is that I‘m not giving up on my babies! I love them, and they are the only things that my husband left me. They are truly precious to me.

Learning from Mistakes

by Carolyn S.

My son‘s name is Richard. I waited many years to have a baby boy. He was a very healthy 9.5-pound baby; he reached all the stepping-stones my girls had, and did them on time. But one morning, he was just gone. I kept telling the doctor he couldn‘t hear, because he had stopped speaking and didn‘t notice sounds. After being put off and ignored, I was finally sent to a doctor who specialized in autism.

I had lived so long wondering, *why does he do these things*? Richard would do things such as climbing counters, not sleeping, spinning, so finally when the doctor gave a diagnosis at age two (only 14 days till Richard‘s 3rd birthday), I felt almost relieved that they had a name for this: Autism. I remember just looking at the doctor, saying *okay*, and feeling relieved, devastated, angry, and left wondering what to do.

It seems I wasted a lot of time doing the wrong things, and for this, I would love to turn back the clock. We started out with occupational therapy; I had a great therapist. We also placed him in pre-kindergarten, which was a big joke, so I pulled him and home-schooled him with my therapist guiding me. She finally got such a load of kids that she even hired an assistant and gave her to me.

It was also a mistake that I became friends with the therapist, which made it really hard when I realized that she wasn‘t helping much. I finally had to turn from her, and we went to another therapist. That‘s when the tables started turning our way. Here was my son, who was now 4 and had no interest in anything but being active, and my new therapist was just sitting and watching. She finally said, –This is enough!‖ That same day we cleaned my laundry room, and we all sat in there on the floor. It was the first time I saw my little boy perform any sort of play! The therapy that was being given wasn‘t 100% occupational therapy, but was also mixed with ABA (Applied Behavior Analysis). I remember thinking, –This is perfect. My son is going to shine.‖

It‘s been almost a year now, and Richard can do so much more than he was ever able to before. Things I can remember crying myself to sleep about, because I never thought my son would be able to even match a number. Boy, did he prove me wrong. Thanks to the mix of ABA and o/t, he can match anything. Since pulling him out of the pre-kindergarten, about 7 months later I placed him in a –special day school for autism.‖ However, that was an even bigger joke, and he is now pulled from there also.

At this time, I‘m home schooling Richard, and I have a girl from a local college who comes out daily to work with him on ABA and o/t. Also, we are doing three days a week in a infrared steam room, which has brought him to become more verbal. All this, along with a lot of prayers, is what got us where we are today. I‘m still trying to piece it all together, days are still so tough, and I know the road isn‘t even close to being finished. I‘m also not really close to ending my sadness I feel for Richard. But I just keep pushing, in hopes that one day he will lead a –normal‖ life.

Listening, and Wishing

by Danielle E.

When my son, Logan, was between 12 and 18 months old, my sister in law, who is an occupational therapist, kept thinking something just wasn‘t right with him. I trusted her opinion, but thought that Logan was just a late talker. I discussed this with his pediatrician, and we agreed to contact the early intervention program. After that meeting with the EIP team when Logan was 20 months old, we got lucky enough to get an appointment with a developmental neurologist. That‘s when we heard the word *autism*.

It has been a roller coaster ride ever since. Luckily for us, we got a diagnosis early, so we were able to receive more therapies from the EIP therapists (eleven hours a week, as opposed to the four hours they had originally allocated us). Logan currently receives five hours of Developmental Integration therapy, along with five hours of Applied Behavior Analysis (which we had to fight for; the DI higher-ups thought ABA wasn‘t a good idea). I felt that there was no reason not to try all different therapies, since no one knows which one will work the best. Logan also gets one hour of occupational therapy, plus an additional hour at Tumble Jam, which is a special-needs gym and music class.

Logan drinks DariFree, and is on a gluten-free diet. His eye contact improved within one week of starting the gluten free diet. All along this journey so far, the one thing that always broke my heart to see was his big sister Claudia (six years old, and normally developed) wanting so much for her brother to acknowledge her. If he would even just brush up against her, she would be thrilled. She wanted so much for him to want her. I would always tell people I couldn‘t wait for them to interact. My cousin told me, –Be careful what you wish for.‖

Well, about two weeks after the gluten free diet started, he started to –play‖ with his sister! And we couldn‘t have been happier, until ... the fighting started. She would be watching TV, he would come over and put a tape in, and she would scream and take the tape out… and then he would grab her hair, and not let go until she moved, and so it went on. My cousin‘s words rang in my head, –Be careful what you wish for.‖

Truthfully, though, we‘re thrilled. We are also grateful for my husband‘s sister for not giving up, and for helping us to see what was most important for our son. I hope other people out there butt in where perhaps they are not welcome! These children‘s futures depend on the knowledge of people like these.

A Different Kind of Grieving

by Melanie B.

Michael was always a happy baby, and the only hard thing was his multitude of health problems. He had chronic ear infections, eczema, RSV, and pyloric stenosis surgery. Michael never babbled or pointed as a baby. He only learned about three words, and he walked at 18 months. My mother became concerned that he wasn't talking around the age of two, but my pediatrician wasn't concerned. He said that all boys have slower language development.

Michael was always walking in circles, and he was not responding to his name. We changed pediatricians, and our new doctor wanted us to call early childhood intervention. They did some testing and found severe developmental delays. They also hinted at autism. We waited five months to get his autism diagnosis at the developmental center.

Michael's dad was more shocked than I was; I was ready for it. Michael was enrolled in a special school for autism/PDD and began to make slow and limited progress. Now he is 4 years old, and doing great in a public school early childhood autism program. We have found that using sign language with Michael, combined with speaking a word, helps him understand his world better. We also really like using the Signing Time videos and music.

It has been a long, hard, road, but he learns new skills nearly every day. The grieving process was hard, and we felt people couldn't understand or help us with this type of grieving… grieving for the milestones and dreams you fear your child will never have. Michael is a challenge but we love him very much.

Mom on a Mission

by Wendy W.

I have a wonderful ten-year-old son. He is very gifted and bright. He is currently in a regular classroom achieving his goals. But it was not always this way. My son was first misdiagnosed at age 7 with ADD. Then he was put on five different drugs over the course of three years. I remember feeling *this is not right; there is more going on in his little body and mind*. Every day was a struggle; I felt so alone, and our family unit at home was in constant turmoil. Having good friends helped, but no one understands except other parents who have a child with autism or Asperger‘s.

His symptoms became worse, and school was becoming a nightmare in third grade. He was put on a new drug, and he ended up having a bipolar-like reaction to this drug and was hospitalized for a week. I thought I was in a bad dream … or a new horrible reality show called *Straight to Hell*. This was the turning point for me and our family.

After he was released, I researched Asperger‘s on the computer, and I felt as if I was reading my son‘s bio. I immediately took him to a neuropsychologist, who did diagnose him with Asperger‘s Syndrome and secondary anxiety disorder. I felt so happy knowing that we finally had the answers to some of his many weird behaviors, as well as his sensory and social issues.

We began with bio/neurofeedback, which seemed to work for a short time. Then we tried Risperdal. This only seemed to dull his personality, and caused him to be more rigid and serious. Finally I took him off of dairy, and he began to, as I call it, –come out of a fog.‖ He was starting to make friends, eye contact, and learn coping skills for his anger. I also had to change as a parent and become more educated, more calm, more kind, and treat him with respect and care. I was a yeller in the past, but after I changed to a calmer parent he changed into a calmer child.

We then got an IEP (Individual Education Plan) at school; through this he got an aide, speech therapy, and occupational therapy, and he began to soar. He felt as if everyone now accepted him for him, and that people truly understood Asperger‘s. He‘s lucky to have a mom with ADD, because I can keep up with everything and everybody! I attend his school regularly to make sure the teachers and staff understand him, and that they are following my instructions and the IEP.

Someday all of my multi-tasking and running around like a madwoman will pay off. It already has shown to be working. My son‘s school now has 3 more Asperger kids this year, and they said because of our family, they now know what to do and how to treat these children. I am truly blessed with my child. He was sent to me to teach me how to be a better person. Because of him, I have changed my way of thinking and how I treat others.

He is now going into fifth grade and has friends, is a patrol officer, is in the band, and receives A 's and B 's on his report card. Two years ago we were in hell. Now, after becoming more positive and reading everything I can on Asperger's, I now have a support group for other parents, a local public access TV show, and a website. Life is good now, and my son was sent here to change the world one person at a time. He is my hero, and I'm glad God picked me to be his mom.

Sometimes, They Are the Teachers

by Justin S.

Justin was born a healthy 8 pounds, 14 ounces. He began to walk at 12 months, and began saying his first words: –Mama, dada, ball…‖ He was very bright. He could put together puzzles very early. At 19 months, Justin began having a lot of ear infections, and from that day on he never spoke another word. We were not worried, though, because our oldest son did not speak until he was 3 ½ years old. We took Justin to doctors, and they all said that he would speak at his own time.

He began to have other signs that something was wrong, because he would not play with toys. He threw everything out of the toy box, and loved to tear things off the walls. He ran around flapping his hands, and he loved to spin. We took him back to the doctor and he said not to worry. He had tubes placed in his ears for having so many earaches. We decided to have a hearing test done, and the technician that did the test asked me if I have heard of autism, because her daughter had it. I told the technician that Justin could not be autistic, because he is so loving.

I went home that night and read on the Internet everything I could about Autism. He had all the signs. I first began to cry, and then I started to help my son. He was diagnosed with autism at 3 ½ years old. He is now 6 years old and is nonverbal. He makes sounds and has a few signs. We started him a special school at 3 ½ years old. He now goes to a Special Ed class in the public school system.

Justin has come along way in three years. He now can sit at a table to eat. He follows directions and is learning how to use the toilet. He also sleeps through the night most of the time. (When he can‘t, Melatonin works great. It is a natural sleep aid.) We have tried medications and secretin, but repetition of skills seems to work the best. He is now on no medications except a mega vitamin.

My son who is nonverbal has taught me so much about patience and compassion for others. I am a registered nurse, and I am now a better nurse because of him. My son loves to be hugged and kissed. He may be in his own world at times, but he is an angel on earth. He does not know hatred, cruelty, or prejudice. If other kids laugh at him, he laughs also.

We pray that Justin will speak someday and lead a so-called –normal‖ life. I have to remind myself sometimes when I get down that Justin is happy, and has many people who love him, and that is what is important!

We Can All Learn More

by Leiontine M.

I have a young man who was diagnosed with Autism when he was 24 months old. This was a long process, because we thought John was deaf. It took nearly a year for them to do the tests to determine that he could hear, and then to diagnose him with autism. Social Security sent us to a specialist in 1994. This family therapist gave john a simple psychological test, (BAILY) and went on to tell me my son would never walk, talk, or be a productive member of society. He also asked me to sign papers committing my baby to a state institution. All he succeeded in doing was giving me the will to fight for my baby.

We left his office and went to UC Davis Medical Center, where we spent the day gathering every bit of information on autism that was available. Armed with information for the first time, we found Alta California Regional Center, who helped us locate a very good early intervention class. John had to be bused 45 minutes each way. He loved the motion of the bus, and over the next year he started to use signs to communicate. We used pictures and signing until John was five years old.

I had a baby girl in August of 1994, and as she started to reach her milestones, John did too. It has been like having a set of twins! As she crawled, John copied her. When she started talking, he made attempts at verbal language. When John turned 8 years old, he could use sentences and write short statements with the use of a computer. We then integrated him into an Equine therapy class, and everything seemed to fall together.

John will be 13 in September and can program a computer, has reduced self-abusive behavior, and is attending half a day of regular education and half a day of Virtual Academy. He will soon start a program with a computer tech from our local college to work on job-related skills in his field of interest. I also teach an Equine based therapy class to help other kids like John. I am going back to school to bet my MBA in Sociology so I can expand the classes to include a summer camp.

My goals are a direct result of having a very special boy in my life. I have another child with Asperger‘s, and he will graduate high school the same year I get my MBA. He is on track to be accepted to ISU ‘s engineering program. All I have ever wanted for my kids is to have them grow up to be productive members of society… to have decent jobs, and raise families of their own. I *will* see this dream realized. I still send progress reports to the doctor that started it all so many years ago. I hope he has learned something about autism since then.

A Young Mom Gets Wise

by Nicole W.

My daughter Sabrina was 18 months old when things changed. After her baby shots, five at a time, my daughter over a 3-month period lost her language, then things in her behavior were a nightmare. Eating stopped for days and days. The screaming came. I was stressed out so much, and no one understood me. People said it was due to my age; I was 22 at the time. I was also pregnant with my son during that time, and I was very sick during that pregnancy, so I missed seeing her a lot.

Finally, after my son was born in 2003, I was able to spend a lot of time with Sabrina. I started seeing strange behaviors, and I remembered my sister with disabilities when she was 6 years old. I hated Sabrina's doctor, who was no help in listening to me, so we changed to a new doctor. This new doctor was a god. He first got me to FDLRS for tests. They wanted to see if we could get Sabrina into the Special Ed. program in Pre-K for 3- to 5-year olds. They found that Sabrina was delayed in all areas. At 3 years old, she was only developed at around 18 months, and was an avoider too.

We got her into the program, but something told me to do more. So I went back to my pediatrician to get to see the All Children's Hospital development center for a diagnosis. I loved the people there! In the first visit, Sabrina was said to have PDD-NOS, and very severe receptive and expression language disorder and sensory decrease. From there, we got All Children's to do tests and start OT, PT and speech therapy. After 3 months, she was still in OT and speech, but then we had a problem.

I found out my insurance wouldn't cover us seeing these doctors, or even pay for taking Sabrina for tests. It's not covered for a child to get speech therapy unless an accident has happened! I cried, and tried to get help from the insurance company. I felt so lost and alone. I started screaming at everyone and everything, even the people on the phone day after day. My family didn't believe me, and my husband stopped talking to me and was distant. I had no friends; they had left after hearing about Sabrina. I was 24, so finding a Mom's group was hard.

Sabrina's therapy was more than what we made in a month's period… $1400 a month. I couldn't work because we couldn't do day care, and my husband's mom was sick at the time, so I worked very little. I have learning disabilities myself, and I couldn't sleep, but I wanted to get help. So I went back to FDLRS. Sabrina's teacher told me that because we are considered low-income, and her medical issues were so bad, we could get SSI and Medicaid. So I filed for those, but our families were fighting me, saying they would take her away. I did get the help for her, and therapy started; but family fights continued, with my husband lost in the middle.

Now, my daughter's life is so much better, because I learned to fight every living, breathing minute for her, and I have her back in every way. Sabrina now is in her 3rd year at FDLRS, and has OT and speech therapy in school. She also gets OT and speech outside of school to compare notes in all areas. She is has a beautiful smile, laugh, and memories that I will always love: learning new things, and doing things for herself without help.

Sabrina is now at a 2-½ year level in speech, and in all other areas, she is at 2. Her screaming has stopped, and she can tell us if she can't do something. We learned that Sabrina is an avoider, and hates people being in her face. We also learned that she is affected by weather and changes in pressure. She is a very unique case at All Children's too. They said they haven't seen anyone like her in 12 years. With that, Sabrina still has problems with many things, but they are less intense now.

Sabrina will now sit with other children, and she eats, talks, and tries to play with them. She's the boss in the classroom, keeping the younger ones going in class. She loves her little brother so much, and she's a beautiful child. I am happier, and my mother-in-law has even come around. The family is seeing the improvements; Sabrina can swim, jump, play, and even say her ABC's and knows their sounds. She loves The Wiggles, JoJo's Circus, The DoodleBops, horses, and other animals.

Now we are getting ready to meet with a doctor to get more tests done, and in October we are going to start music therapy, the first of its kind in the Tampa area. I am going to a Mom's group and meeting other moms, and my daughter has friends too, going to parties and learning more every day. I've learned to tell everyone about Sabrina and to not be upset by her autism, but to be proud of her and her life. Sabrina is a gift sent to me; she showed me life in a new meaning. I will always love her for that.

I now speak for public schools, and help out other moms online, mostly young moms in their teens and 20's with family problems. I read constantly, and I'm a fighter, so autism is my hobby now. I want to learn more, and to be with these kids and parents in any way I can. I have also been to workshops, and have my cards at a center for autism and related disabilities. My message is that life will be different, but you will see a new improved family in every way. You will be stronger then ever, and your child will be happy– and learning.

The Path to Acceptance

by Laura M.

Blaize came into the world at 9:00 a.m. on March 19, 1996, at 38 weeks by emergency C-section, as her heart had stopped while I was in labor. I had difficulty breastfeeding her, she was not gaining weight, and by three months she was put on formula. She had constant reflux. Later, I noticed two hernias developed, and at her six-week checkup the pediatrician discovered her heart defect (Ventricular Septal Defect, or VSD). She had an operation to remove the hernias. She was put on anti-heart failure medication, and at 11 months had an operation to repair the VSD and reflux, which was a success and she recovered.

But by the age of two, Blaize still had no speech and had no interest in potty training, and did not always respond when spoken to. I was convinced something was wrong. She had hearing tests, and we found that she was not deaf. I was told she was just a late talker, and not to be concerned until she was three. By then she still had no speech, had tantrums, was not potty trained, no longer smiled, and appeared aloof. After developmental tests, she was diagnosed as having PDD (Pervasive Development Disorder). She was enrolled at a school for autistic children during the year, where intensive intervention took place (speech therapy, occupational therapy, behavior therapy, etc.). She was behind her age for reaching developmental milestones and had developed chronic infections. She was later diagnosed with DiGeorge syndrome (a genetic condition).

Having a child with autism compels the parents to learn new skills, so that they can communicate and understand the child. I had to perceive her from an autism perspective and learn to understand –her‖ world, and at the same time teach her about –our‖ world. For me, it was difficult to accept that learning social skills was hard for her. I became very frustrated, and the task ahead overwhelmed me. I often felt resentful of her, including embarrassment at her lack of social skills.

It was only after I fully accepted Blaize unconditionally, including loving her despite her problems, then the process of healing started for me. I could see the funny side of her behaviors, and appreciate her weaknesses and strengths. I had to accept her for her unique character, and not for my expectations of her.

A year and a half ago, we immigrated to New Zealand (from South Africa) and struggled to place her in a good school. There were no special schools, as all –special needs‖ children have to attend mainstream schools. I was concerned about how the transition to mainstream education would affect her. Our application for a full-time teacher aide was turned down, as Blaize‘s needs were not severe enough.

Due to the fact that she did not qualify for a full time teacher aide, her IEP had to be specific, with goals addressing behavior changes conducive for learning, and for her to adapt to her environment. Instead of having constant prompts telling her what to do, classroom structure and learning aids became crucial. There was a time of trial and error where she did not have her needs met; the result was that she became disruptive in the classroom. Structure and predictability became absolutely mandatory at school for her success. She was given a visual timetable, and timer-clock and reward system, which made a huge difference to the classroom environment.

Blaize is 9 years old today. She has overcome many health obstacles, and is a talkative, loving and happy child. We have learned to accept her and her special character. Blaize has a great sense of humor, and loves relaying stories from TV, books and real life that she finds funny (which may not always be funny to others). I have used these experiences to teach her valuable lessons in life. Having her in my life has also taught me not to take life too seriously!

The process of acquiring knowledge through books, the Internet, and various other sources has benefited both my child and me. I have acquired wisdom and –revelations‖ that have added to my experiences when dealing with Blaize. I do realize that my learning will only be complete when I die. I do, however, now have the assurance that the future is no longer bleak.

A Grandmother's Special Love

by Deborah B.

My story is about my step grandson, whom I have guardianship of. His name is Nicholas, and he has autism. Nicholas was 6 weeks old when he came to live with me. He seemed okay, considering what he had been through; his parents were drug abusers. Nicholas learned everything at a normal rate, and was even talking some at age 14 months. But at 15 months, he just stopped. He wouldn't talk or look at anyone. I knew something was wrong. I later found out he had autism.

I started working with him right away. He now looks at me when I say his name. Nicholas goes to Special Ed preschool, and he loves to learn and do new things. Nicholas loves school. He is 4 years old, and he can say, –I go to school.‖ A year ago, he didn't say anything except faint sounds of words. He is also picking up on sign language.

A year ago, Nicholas wouldn't play with a ball; he would just watch it roll across the floor. Now, he tosses the ball, bounces the ball, and runs after it. I can't believe the difference. All it takes is love, patience, and understanding– with a lot of constant practice! Nicholas is a very loving child, and he can run really fast.

I don't know if this little story is of interest to anyone. I just know if you try hard enough, you can do anything. Having autism makes people a special kind of person, and everyone with autism is here to do something special. Some of the smartest people were thought to be autistic. Little Nicholas walks with his head held high, knowing he is special and very loved**.**

Looking to the Future

by Melissa B.

My 6-year-old son, Joshua, was diagnosed with PDD-NOS when he was three years old. I was pregnant with my third child when I started noticing that Joshua was not quite –on track‖ with other children his age. He is an absolute joy to have around, yet I felt like I was a failure because of his being behind.

My oldest, Danielle, is 8 years old and is in the 5th grade. She learns as quickly as you can give her the information. Because of this, I felt like I didn‘t have what it took to teach a child what they needed to know in life. Danielle, I felt, would have learned regardless of whether I had helped or not.

I pushed myself to learn everything I could about PDD, and tried to be the absolute best mother to Josh as possible. Little did I know that all the hard work would truly help me to become the greatest advocate for my son. He currently is in a general education classroom and is only pulled out for speech therapy. I am so proud of my son and his accomplishments!

When I think that a behavior is related to his PDD or to the medication he takes, I reevaluate, and I ask myself if it‘s really just a boy –being a boy.‖ A lot of the time, I realize that Josh is being more –normal‖ than I ever hoped for! Our story is not at an end because he is still progressing, but rather is just beginning. Josh has so much more to offer, and I can‘t wait to see his progression in the years to come.

A Perspective From Down the Road

by Cathyann B.

It‘s hard to believe that 23 years have passed since we adopted our precious son John. John was diagnosed with PDD shortly after we adopted him. He was behind developmentally. We were basically told to –wait and see‖ until a more decisive diagnosis could be made. When John was 4 years old, he was diagnosed with Asperger‘s Syndrome. Little was yet known about AS in the 80‘s, so we were given few suggestions by the doctors as to what we should or could do. So we, in essence, proceeded somewhat blindly to understand his needs and to meet them.

I remember feeling so frustrated and at a loss to soothe the John‘s constant uneasiness with himself and his surroundings. He was hypersensitive to just about everything– taste, touch, noise, etc. I remember wanting to blame someone, even myself, for the years that passed, that we could have been concentrating on specific treatments such as sensory integration, social cues, or scholastic interventions, for example.

John was already 5 months old when we adopted him. We had lost valuable time. I realize now that the first 2-3 months of life are the most rapid brain-cell-growth months of our entire lives. This is an important window of time to stimulate those cells to activity and response. I instinctively knew that John was far behind my other two children in responsiveness, and he seemed very aloof from the rest of us. We, as a family, spent countless deliberate hours talking, singing, stroking, playing music and making eye contact (which John seemed to avoid).

We sensed the urgency and necessity for human contact and challenge, as he seemed to be slipping into a world that didn‘t include us. We tried to move beyond objectivity to human touch and interaction. I wish I could say that there was a lot of help and support from the medical world that we accessed, but there was not. I was starved for help up until just a few years ago, as countless books, workshops and journals have appeared on the market. I am so encouraged, but I also know I would have been far more aggressive in my approach if I knew a few years ago what I know now.

Academically, I watched John struggle for years. My husband and I spoke at his school on AS and what we knew the staff could do to better understand and accommodate a child with Asperger‘s Syndrome. We suggested seating arrangements, a quiet place for un-timed tests, a mentor for stressful times, a seat–buddy‖ on field trips, etc. We were informed that the school (which was private) could not accommodate John‘s needs.

Looking ahead, I am very optimistic. John is a handsome and delightful young man. He has a sophisticated sense of humor, and is very precise in whatever he says or does. He has difficulty showing emotions, which is improving as we discuss social responsiveness and continue giving him cues. He struggles socially to find ways to enter into other people‘s conversations, or to simply address someone.

He does, however yearn for conversation, which is seen when someone taps into his interests. He has a variety of interests, from cooking and wrestling to transformers and history. Unfortunately, I must credit most of his knowledge in those areas to TV programs. John is also an avid reader, mostly fantasy books from which he says he vicariously feels a sense of power from the main characters. As a result of his reading, he has an amazing vocabulary.

Often, when there is a family dilemma, we turn to John to place the problem in its proper perspective, and we look to him for his usual succinct solution or resolution! John means the world to us, and he has brought our family to a level of concern for others, and enormous insight into ourselves– for which we will ever be indebted and grateful.

A Long, Rocky Journey

by Marjorie Kidman

My son Mark was born in the summer of 1984, perfectly healthy and weighing a big, strapping 8 ½ pounds. I trusted in the system, and allowed him to be vaccinated at birth, six weeks, and at other regular intervals until he was about six years old. At about the time of his six-week shots, I remember him crying in excruciating pain but I couldn‘t determine where he was hurting.

My 12-year-old son noticed there was something wrong with his eyes, but I dismissed it as his being too young to focus. Other neighbors thought he was blind, which disturbed me because I knew he wasn‘t. He didn‘t walk until he was 22 months old, and had continual ear infections, which we finally cured with lots of Vitamin C and acidophilus. (This method worked much better than the doctor‘s antibiotics, which he had been loaded up with since birth.)

Upon examining his ears, a (substitute) doctor wanted to put shunts in his ears. I said, –No, there will be no shunts in his ears,‖ and explained to him that I had heard shunts always caused some kind of brain damage. I guess I must have made him mad at me, because he shortly thereafter reported me to social services. A couple of years later I ran into that doctor‘s son (purely coincidentally) and told him, –Be sure and tell your father that my son is cured of his ear problems without any shunts, and that he is doing just fine!‖

At that time, I didn‘t know about his autism, as hardly anybody even knew the condition existed. I had never even seen or heard of it before. I enrolled Mark in –special needs‖ kindergarten, 1st grade, 2nd grade, and 3rd grade, and was greatly disturbed to learn the teacher was probably hurting the children when they didn‘t behave by pulling their arms up together behind their backs. This was reported by one autistic child, who could talk and report what was happening at school.

In a subsequent meeting with this teacher, she stated to me, –I hope you don‘t have any illusions about Mark being normal when he‘s 18 years old, because he‘ll be lucky if he can count to 10 and mail a package somewhere.‖ This infuriated me, and I wrote letters to the local school district and to the Denver Regional School District, complaining about her poor teaching methods. I stated that I was very concerned that her type of education and discipline would indeed bring about her limited vision that she saw for my Mark and others like him.

Around that time, I clipped out a newspaper article stating that approximately 300 autistic children in a neighboring city were being institutionalized. (I still have that article.) From working in a mental institution in my younger years, I knew what institutions do to people, and the horrors of placing anybody there. So I wrote more letters to the school district, and I told them how unhappy I still was with the education my son was getting; how the law guarantees he receive a proper and adequate education, and that in my opinion, he was merely being babysat– and that I suspected his teacher was not even doing a good job of that.

I had been teaching Mark to read, write, spell, and do math at home, and I could tell he had a very good brain and remarkable memorization skills, if the teacher cared to take a look (which she didn‘t). The final realization that something had to change drastically if my son had any chance at all to grow up normally was when we were at McDonald‘s having a hamburger, and Mark stood out like a –sore thumb‖ while playing on their fun house equipment with its tunnels and slides. The other kids made comments about him, the parents made comments about him, and I could just imagine how Dumbo‘s mother must have felt. He kept saying, –Leave me alone!‖ and it broke my heart for him.

It was then I realized that because he had been kept separate from –normal‖ kids for four years, and had been in schools where there were no proper role models or appropriate stimulation, he hadn‘t learned how to fit in with normal kids. He had only been with other children with special needs who didn‘t know how to act normal either! For many, it was wall-to-wall autism all the time, and I decided it was time to get him out of that kind of schooling. So when the school district, shortly thereafter, sent me a letter stating they had decided to provide some –special needs schooling‖ for children such as Mark in the normal school classroom, and asked if I would be interested in mainstreaming my Mark into the 4th grade, I said, –Would I ever!‖

That first day, Mark was scared to death, and I had to carry him into the classroom. I asked the children if they would help him, because he really needed some help, and they said, –Yes!‖ We had many meetings thereafter with the principal, the teaching staff, and the school psychologist regarding Mark‘s behavior and progress. They even gave him a test on which he scored two grade levels ahead of his class in math, reading, and spelling.

Still, of course, his teacher from his previous school stated emphatically that she was against his being mainstreamed, and thought it was a big mistake. I don‘t think she ever knew of his remarkable abilities in spite of his autism. Thank God that was the last of her in Mark‘s life. There is a saying that, –One of life‘s greatest joys is achieving what others say you can‘t,‖ and I have always pictured good achievements in the future for my Mark.

It wasn‘t smooth sailing after that, though, by any means. Mark acted out in many inappropriate and exasperating ways, and perhaps some of it may have been justified because sometimes he couldn‘t do a thing without someone always correcting or trying to help him, and that would get old for anybody. The school psychologist requested to videotape Mark during some of these episodes, but I declined because I didn‘t want emphasis put on his negatives, or make him an oddity and the subject of debate in the mental health circles. I don‘t think the psychologist liked my refusal, because shortly thereafter he sent a social service person to my home.

That fall, I took Mark trick or treating, and he said in very plain words to startled door openers, –My name is Mark, and I‘m going to be on TV!‖ And sure enough, there he was a few months later on Channel 5. They were televising about his being mainstreamed into the normal classroom setting, and how they were going to mainstream other children with special needs also.

Shortly thereafter, his school held an assembly demonstrating how smart the –Rainman‖ Kim Smith was (with some help from Kim‘s father). I was a little started to hear Kim say how he thought my Mark was –Rainman #2.‖ One of Mark‘s remarkable feats at that time was the ability to identify every dinosaur bone on our computer and to tell which dinosaur that bone belonged to. He also could spell some 500 words, sometimes as many as 20 at a time, correctly and in their order– without even looking down at the page. Additionally, Mark had memorized the name, address, and phone numbers of everyone in his class, just by reading it on the wall in the school office. He thereafter found all the places they lived, by figuring it out in the phone book street diagrams. As we drove around, he could spot a school and tell me what school that was (because he had looked up their school addresses in the phone book).

Sadly, by the 6th grade, the other kids caught up and passed Mark in many ways, and it frustrated him greatly. He couldn‘t play baseball or football, and he would become exasperated and would go out and grab a player by the clothes and try to pull them off the field. He couldn‘t conceive abstract concepts in his head and deduce them down to a concrete hypothesis. It had to be black and white, and he had to be able to see it with his eyes. Increased pollution in the skies (from MagCorp, a major polluter at that time) bothered him greatly, and sometimes I had to get him out of town just to get him well.

The school thought he had some terminal disease, and made things very difficult for me as a single mother trying to earn a living and cope with everything. During one of our meetings, they even brought in *another* social services representative to investigate me. The school principal and I went the rounds many a time, especially when they left Mark at school while they bused the rest of the students to the City and County Building to celebrate Salt Lake‘s being selected to host the upcoming 2000 Winter Olympics. The principal‘s excuse was, –It‘s just too difficult to keep track of Mark in a crowd.‖ I explained that his actions were extremely cruel to exclude Mark because of his –special needs,‖ and why didn‘t he call me to talk about it, and possibly I could have even taken time off from work and have gone with them.

I sent letters to the school district and to the state‘s –Children with Special Needs Center‖ expressing my frustration and to get some help, because I felt that Mark and I were getting ganged up on. I also sent carbon copies of these letters to the school, and requested that my complaints be made a permanent part of Mark‘s school file so they would get the message. (Isn‘t there a saying that offense is the best defense?) By the time the next school year came around, or shortly thereafter, that same principal and the school psychologist had left to find other jobs.

By the 7th, 8th, and 9th grades, Mark fell really behind, and could not understand what they were talking about in the classrooms most of the time. He couldn‘t read or understand a book without pictures, or even tell you what it said. I helped him all I could with his homework and school projects, but it wasn‘t enough. I remember having quite a time getting him to write straight across a page as I dictated to him what to say. His left brain and right brain seemed to get mixed up, and he would run the letters on top of each other.

In a meeting with his Junior High principal, the principal commented to me about whatever was Mark going to do when he grew up, because he couldn‘t even tie his shoes or buckle his belt. I stated that he could wear Velcro-strapped shoes and wear elastic waistband pants. But Mark was becoming sickly and white faced, and many times would only eat cereal and milk and maybe a dried piece of bread; so I had to take care of that by emphatically insisting he learn to eat everything on his plate whether he liked it or not. Once in a restaurant, when he was being overbearing and refused to eat, he asked me in an angry voice, –What did you do to me?‖ And so I explained to him that I believed that when he was a baby, the vaccination shots he received caused him to have some damage in certain parts of his brain, and that I had been too trusting and was very sorry. He seemed to understand and accept my explanation.

I think it was about the 8th grade when Mark had a fight with a pushy and overbearing teacher‘s aide, and he accidentally hit her in the nose during the scuffle. In her report she stated she –never touched him,‖ but I remembered in his workbook she stated she sometimes had to hold him down, so that refuted that. So there were more meetings, and I had to again call in two doctors from the Children‘s Center to try and remedy the situation. They were wonderful, and they gave some great suggestions about not worrying so much about Mark‘s grade performance (as I could help him with that), and instead try to place emphasis on his socialization skills by busing him (during school hours) to outings such as movies, restaurants, shopping, etc., along with his other classmates who also had special needs.

That seemed to work like a charm, and Mark was able to fit in and to grow and develop socially, along with his classmates, and to have an outlet for some good times they all desperately needed. During his junior and senior years, it helped to have a really great teacher who understood Mark and could communicate and understand him really well. He helped Mark a lot.

And so, Mark graduated– well, –kind of‖ graduated, because if he had received a diploma, he wouldn‘t have been eligible to receive an additional four more years of specialized schooling (what a stupid ruling). So because of the –no diploma‖ ruling and fact that we couldn‘t afford the horrendous costs of a graduation gown and a yearbook, we just stayed home. I don‘t think Mark even knew. When my now-grown son Troy heard of this, he became exasperated and said he would have paid for all of this. I stated to him that in past years, Mark had torn up all his yearbooks in frustration, and that he would have felt left out (again) because he would have noticed he didn‘t get a diploma like the normal kids.

It‘s a sad state of affairs in our schools when money dictates who are the haves and the have-nots, and when stupid rulings hurt the ones they‘re supposed to help. There was all kinds of money for those teaching about how to treat or deal with autism, but there was very little allocated to those who were autistic and who really could have used the help.

But thankfully, we got by it all pretty much unscathed. Financially, I couldn‘t afford a babysitter (at age 18) for Mark, and I couldn‘t leave him by himself while I worked (even though I sometimes did), so our only other alternative was to move. I had been allowing him to go for walks, and we had the police and other neighbors came knocking on my door because he had been –acting weird‖ and wouldn‘t answer their questions. They sometimes thought he was lost, to which I replied, –Well, he‘s managed to find his way back home so far.‖

So we moved away from the city, away from pollution, and away from crowded subdivisions, and we now live on a 10-acre ranchette in a double-wide that I own outright. It was tough for a couple of years, but now I‘m retired and it is getting easier. Mark has grown in stature (is now 6‘1‖) and has developed in his abilities in many ways, and has even learned to wash dishes pretty well, too! He still needs constant help, supervision, and repetitive instruction (he is reading this as I type), but he‘s a great companion and I feel I‘m very lucky to have him. He can reach things for me and fetch things I need, and is able to lift heavy objects. He often takes walks with our neighbor‘s dogs.

He‘s healthy and becoming very strong. He‘s a gentle soul, and is very kind and loving. He‘s my constant companion, whether we are taking a trip into town for supplies, making repairs, or just stopping to have dinner somewhere. And yes, due to the remoteness of where we live, I decided to not continue his special-needs schooling, and I feel that I made the right decision. Time will tell, but others tell me that it is remarkable to see the overall improvement he has made since we moved out here.

I hope our story can be of some help to people that are struggling to cope with helping their child to deal with his/her autism. It is not easy, but I do believe it is easier today with the increased knowledge and understanding of what autism is about. I even have a 13-year old granddaughter who, during her school day, volunteers and goes in and helps autistic and special-needs children with their schoolwork. I am so proud of her!

A Small Gift

by Rose M.

I'm the mother of two beautiful sons. Jimmy is 18, and Mikey is 6 ½ years old. At age two, Mikey started early intervention for speech delay and sensory integration. I knew two years ago that something was still not right, so we had him evaluated again. That's when he was diagnosed with autism/PDD. I cried for weeks.

But as time went by, I grew stronger. I had to, for Mikey's sake. Mikey has taught me to look at life through his eyes. We constantly play, and I'm forever reading to him; Dad does too. We have learned to take life one day at a time, and he can learn through play. Mikey has taught the neighborhood kids to be accepting of others, and Mikey has taught us all patience and, most of all, love.

I would not trade Mikey for all the money in the world. My husband and I feel God gave us Mikey for a reason; because He knew that we have the patience, love, and the heart and understanding to raise a special needs child. Early intervention is where to start. And always remember, love and patience goes a long way.

First Words… At Last

by JoAnn K.

I feel that I have to share my story with all parents of autistic children who have moments of helplessness. I am the mother of a 14-year-old nonverbal, severely autistic son–nonverbal, that is, until yesterday!

Yesterday, my son started speaking out of the blue. I credit it to the Baby Einstein - Baby Wordsworth video. My daughter is a nanny for a family who swears by these videos, and as she was watching them on a daily basis, she decided to purchase Baby Einstein - Baby Wordsworth for her autistic brother who loves watching videos. He continued to watch it every waking moment for two days straight. Up until yesterday my son was completely nonverbal, and communication has been challenging, to say the least.

Last night he came out of his room and said the word –eat‖ as clear as day, and also did the sign for it! I almost dropped dead! Over the past two days, I have continued to reinforce simple words with him; along with the signs, he is currently able to say nine words with meaning and clarity. So, for any of you who have felt hope is all lost, and that your autistic child will never be able to develop speech with meaning, keep this story in mind from a parent of a 14 year old autistic child who just spoke his first words! My son is currently watching the Baby Babble Speech-Enhancing video, and Bee Smart Baby, Vocabulary Builder 1.

Letting Go of the Fantasy

by Stacy G.

Brock is almost two years old. He has big brown eyes, soft brown hair that spikes straight up all on its own, and the start of his daddy‘s unibrow! Yikes! He also has yet to be officially diagnosed. We noticed after he was a year old, when –the freak-outs‖ began. We joked that we were entering the Terrible Twos early. Anything could set him off. He would shake his head side to side like someone trying to get water out of their ear. We affectionately referred to it as his –Rain Man‖ dance.

At Brock‘s 15-month checkup, I mentioned this in passing to our pediatrician. (As luck would have it, she was privy to a private performance during this visit.) When she said, –I think you are looking in the right direction,‖ referring to our –Rain Man‖ comment, I could not believe what I was hearing. Not us. Not my kid. This happens to other people. People with more patience than me– that was for sure.

No! No! No! I‘ve already done my penance! I‘ve paid my dues, and then some! A nasty divorce after a horrible marriage… my beautiful boy from that marriage suffering from severe ADHD (and taking everyone around him along for the suffering; I had a front row seat). I had endured the whole single, struggling mom thing. Working too much, making too little, always questioning my abilities as a capable, competent mother, and all the while, carrying that trunk of guilt around with me.

Brock was supposed to be my reward. I had met his dad, and knew by the second date he was the one. It sounds cliché and corny, but that‘s how it happened. We have a good marriage, and I‘d marry him all over again. But this blended family thing is not something I would recommend. He had two kids from his first marriage. They don‘t like to visit often, but at least they still come. So we both knew, when we found out we were expecting, this was the gift from God to make up for all of our trials and tribulations. We were so excited!

Then four weeks along, I miscarried. I was devastated, but not deterred. I became pregnant again just four weeks later. Brock gave us a rough couple of weeks. He was very fussy, and he did not like to be held very much. We could never rock him to sleep; we had to just lie him down or put him in his swing and let him calm himself down. Not the dream baby I was wanting, but I knew once he was a bit older things would be great.

My husband and I would lie in bed and talk about Brock‘s future. He would be happier and better adjusted than our other kids, because he didn‘t have to go through the trauma of divorce and the every-other-weekend-swap. He‘d be big and excel at wrestling and football like his daddy. He‘d be ornery; that was a given. He‘d hate to see his brothers and sister go to the other parent‘s home, but would soon come to appreciate the one-on-one time he would have with just us. The three of us would go to the zoo and the park, and maybe on some mini-vacations. And we relished the thought that we did not have to share this child with anyone else. He wasn‘t going to have to adjust to two sets of parents, two homes, two different sets of rules. He was all ours! Yes, sir, this boy was going to be awesome! Not perfect, of course. But close, by our standards.

Fast-forward two years. We have had our area education agency coming to our home several times a month to work with Brock. We will go to our child health specialty clinic in a few weeks for another evaluation. Our first visit with them left us with renewed hope. The evaluator thought Brock, though delayed in language, was far too sociable to be considered autistic.

Whew! What a relief! Well, of course he’s not autistic! What’s that? You want to see him again around his second birthday for another evaluation? You bet! Wait till you see how far he’s come by then! He’ll be caught up and then some! My husband and I even joked that at our second appointment Brock would be driving the evaluator crazy with his incessant chatter! That she would look at us and say, –Now, why is it you‘re here again?‖

I have a sneaking suspicion it won‘t be like that. The older Brock gets, the more noticeable the gap is between where he is and where he should be. I‘m so used to him and his behaviors that I don‘t think anything is wrong, until I see him around children his age. There‘s a six-year age difference between Brock and my oldest boy, and I don‘t easily remember his developmental milestones at age two. I do remember I could have some kind of verbal communication with Kevin, though. Sometimes Brock seems as if he is a very tall one-year-old. I almost wish he weren‘t so tall for his age, and that we could pass him off as a baby.

I don‘t know what the future holds for Brock or us as his parents. If he will continue to slowly (oh so slowly) progress with intervention, and eventually be able to blend into the crowd as just another ordinary kid. Or, will we continue to work with him and employ outside resources, for him only to have him sustain his existence as he is? Will he be able to function as a contributing member of our society, to find a job he loves, to find love in a woman, to know the joys of parenthood, or will he live with us and our aid in his daily living? Or will he find more comfort in a residential home with other individuals like himself? Will he ever feel the immense love his dad and I have for him?

Maybe that‘s the worst part of this whole thing. The not knowing. Not knowing what is wrong with your child. Not knowing how to help him. Not knowing what the future holds for him. Not knowing what caused this. Not knowing how to prevent it from happening again. And not knowing why God chose us as the parents of this wonderful little boy. There are many days I am angry at God for all of this. Why us? Why him? Why autism? The days I have it out with Him about these –whys‖ are usually the days I need Him most.

So after I push Him away and yell and scream and cry, and tell Him if this is what He has planned for my life, He can just keep it because I never signed up for this, I ask Him to forgive me. I ask Him to protect Brock, to watch over him, to give him a good life, to help me give Brock a good life regardless of where or how he spends it, to help me to let go of my wants and wishes and to be more open to another way of life, to help maintain my marriage despite these stresses, to maybe someday be a guiding light for someone who will wear the very shoes I‘m wearing now, and I thank Him. I thank Him for Brock. Every day we have with Brock, I thank God for it.

Finding the Child Inside

by Maronica

I am a 30-year-old mother of twin boys. One of my boys was diagnosed with PDD-NOS. I started to notice something was wrong when he wasn‘t talking at age 2 and a half. He was always behind his twin brother, but he still did things on a normal schedule within the limits. He was pretty much a normal, happy child. I have him on video at around 12-14 months, and he would turn towards me when I called his name to look at the camera. At the age of 19-20 months, I have him on video, and he was just sitting there staring into space.

I took him to his pediatrician to find out why he wasn‘t talking, and why he didn‘t understand what I said to him. Because of the delay, the doctor referred us to First Steps, which provide services from birth to age 3 to children that are delayed. He started speech, occupational, and physical therapy, as well as having a developmental interventionist coming to our house to work with him. He hated all of his therapies because he didn‘t want to sit still, and he refused to do anything they wanted him to do. At the age of 3 he was enrolled into a Head Start program so he could continue therapies. None of these seemed to help either, because he would not cooperate.

After several attempts to be potty trained, he would go to the potty sometimes, and others he would not go. I think, as of right now, that is still our major problem. He is still in Pull-ups at age 7, and he also enjoys playing in his feces and smearing it everywhere before I can get him cleaned. He is now in 2nd grade, in a special education room full time, and he is making quite a few improvements. He is talking more and understanding a lot more. He is making better eye contact, and actually loves affection now. He is still aggressive sometimes and very active. The aggression usually comes when he is being reprimanded, or when we try to get him to do something he doesn‘t want to do.

In the last five years, I have watched my son go from staring in space to actually enjoying seeing me at the end of the school day, and giving me a hug. Yes, I have to chase him when he runs from me and won‘t come back, and I have to clean feces off of the walls and him. But those hugs, and the way he looks at me, tell me that he realizes that even though I have to take the bad with the good, that I still love him and he loves me.

My advice to all parents with children with autism spectrum disorders is this: even though they refuse to do the things expected of them in therapies and school, find something they like to do, and go with that. Talk to them, and keep them involved in our world, even if you look silly doing it. My child loves little plastic animals, and I have actually got him making all the animal sounds when I ask him what each one says.

Small Victories

by Krystal P.

My story involves two of my four beautiful children, Junior and Fabian, both with autism. It is a hard life to handle two children with ASD and two other children who still need the attention of both parents. On a daily basis I worry and wonder, *How is their day going to be? Are they going to have a good day, and smile and play, or are they going to have a bad day, and cry and get hurt?*

Junior, who has improved in his speech skills, has not been able to control his emotions and behaviors. Whenever he is frustrated, he throws himself against the wall and sometimes does damage. One instance was a day I will never forget. This day showed me how resilient children are, even when they are as special as our autistic angels. He was so upset he threw himself backwards, his head hit the windowsill, and he cracked his head open (thankfully, there was no bone break). He was crying from the initial shock, whereas I was crying because he was bleeding so much.

Needless to say, we were transported to the hospital via ambulance and forced to wait in the waiting room. Meanwhile, he was still bleeding, and all I had was gauze to hold the bleeding down. Once he was seen by triage, he was bandaged, and again we were told to wait in the waiting room. Throughout this ordeal, I was a nervous wreck, crying and upset, I was by myself with him, and receiving no attention. Somehow he noticed my emotion, and he started singing a song he learned in therapy that day, and began to dance a little bit with it.

I‘ll never forget it; the song was *Row, row, row your boat*. Even though he can‘t speak clearly, I understood him, and he placed the biggest smile on my face– and he immediately smiled too. We kept singing together the entire time we were there. After about three or more hours of not seeing a doctor, my husband finally arrived, and we went to another ER and received the help we needed. But Junior, a two-year-old, was the one who took care of me, when it should have been the other way around.

My other son, Fabian, is completely nonverbal. The only sounds we hear do not contain any meaning or significance, and are mostly to satisfy sensory needs of his mouth. His physical therapist had begun teaching him some of the basic sign language words so he can express himself; mind you, he is only twenty months old. I had no idea of it until I sat in on a session with her. She had told me to work with him on a sensory diet that involved tickling, because he really enjoyed it. I asked her how I would know that he wanted to continue the tickling. She told me that she had begun teaching him the sign for –more,‖ and she taught me and to reinforce it when I was giving him input.

A few days after, I was tickling him on his bed, and all of a sudden he looked at me, grasped my hands and signed –more.‖ I immediately looked at him and he smiled. I was able to understand him! And he knew it, too! Now I know when he wants more of anything. His little hands grab hold of mine, and we sign –more‖ together.

On these occasions, I have fallen in love with my children all over again. They are not any better or worse than my other two children without ASD; they are just as special and unique, and they fill my heart with just as much love and joy as the others do. All four of them are my miracles of Heaven!

Respect the Differences

by Carissa S.

I am the mother to three special needs boys. One of my boys, Justin, has Autism Spectrum Disorder (ASD). Cody is my youngest, and I will be having him evaluated soon, but he is suspected to have High Functioning Asperger's Syndrome. Autism has changed my outlook for Justin, Cody and myself. I now know the reasons why they do some of the things they do, and why I couldn't understand why they did them.

Most of the time, I would continually tell Justin and Cody to stop doing something, and Justin would tell me he couldn't help it, but Cody doesn't understand at all. Justin is just like any other boy, except that he is socially and emotionally challenged. A lot of the time he likes to be by himself, even with his brothers around him. He gets very upset if his area of play is disturbed. Cody is much different. He plays by himself the majority of the time, and will occasionally get upset if anyone attempts to interact with him. Cody has an expressive/receptive language disorder.

Justin also has ADHD, ODD, OCD and has trouble with Social Anxiety issues. He also doesn't make friends easily, but is always looking for a friend. He likes to ride his bike and play with cars. He has two little brothers that he plays with every day, and also has four cousins that are all girls. He doesn't get to see them anymore, and that makes him sad.

Justin likes cars *a lot*, and when he plays with them, he lines them up or puts them in a circle and drives one at a time around that circle. Cody has learned to do this, too. Justin carries his cars and whatever other little things everywhere. He has over 100 cars that include Matchbox and Hot Wheels. He also loves NASCAR and has a few of those too. Cody is stuck on Buzz Lightyear, Elmo, and Clifford right now. Cody likes to play with doors, mostly cabinets and cupboards.

I am not as hard on Justin and Cody when it comes to discipline. I used to be, because I thought Justin was doing things on purpose to annoy me, and that he was arrogant. I now know that his impulsivity causes him to do some things, and that he doesn't do them on purpose. He does get his time-outs for certain things, but mostly for normal boy stuff.

Justin did things on time, except for talking. He was forced to be potty-trained by the time he was 3 ½, because at the time we didn't know anything about autism, or delays, or anything of that sort. We potty-trained Cody on his time. He is potty-trained for daytime, but still has to wear a Pull-up at night. We think the Hypotonia that affects his muscles may be interfering with telling him to get up to go to the bathroom in the middle of the night. For this, we have stopped all drinking after 7 pm. What's amazing is that Cody potty trained himself with going #2 (bowel movements).

Justin has a specific diet of his own choosing because of a disorder called Food/Texture Aversion. This has to do with Sensory Integration Disorder as well. He only likes certain foods, and he will get upset if he is offered new foods to try. He just wants to eat what he likes, and nothing more. Cody is not so picky about food, but is underweight because of feeding issues. We don't know why, but Cody only likes to drink and hardly eat. We hope to find out what is causing him to have food aversion issues.

Justin and Cody are very thoughtful and loving boys. They are smart and do well in school. Justin used to dislike going to school during first and second grades. Towards the end of the school year for second grade, we moved, and he went to a new school. I am so glad we made the move, and he was finally placed in an EH (emotionally handicapped) classroom. Did that ever make a big difference! He was finally enjoying school, and was upset if he missed the bus, had to stay home sick, or had to be pulled out early for a doctor appointment. He was finally doing his homework, because his teacher did not mind him doing his homework on the computer. He hates to write, literally! Third grade was another challenge. Justin had a female teacher, and his grades fluctuated. This year, he is in the fourth grade and being mainstreamed.

Cody is attending his first year of Head Start. He attended 2 ½ years of the Early Head Start program in Fort Myers, Florida. He loves school and anticipates it every day! He is riding the bus for the first time, and he loves that too. He is such a big boy! Justin sometimes has trouble sharing and getting along with his brothers or his cousins. This is where his time-outs come in. If he doesn't get his own way, he will call names or scream demands at everyone. Sometimes, he makes demands from me too. Cody has learned these behaviors from Justin, so I get a double dose of it.

If someone even thinks about teasing Justin about his habits because they don't know about the kind of child he is, he will find a place to crawl under and hide until it's time to go home. He's a very emotional child. I can see a lot of myself in Justin, and can remember some of the things I had to deal with growing up. Cody doesn't like to be pushed, because he gets scared easily. I usually let him feel his way around before fully introducing things to him. Sometimes he will do it on his own, and finds he enjoys them, and sometimes, he will just hide behind me and be shy.

Justin and Cody might have autistic tendencies, but that doesn't make them any different from any other children. They run, play, smile, laugh, jump, hop, cry, cough, and sneeze just like you and me, and they are still human and deserve the same respect. If you see a child that doesn't fully listen to their parent, please, don't automatically think that this child is spoiled or has a bad parent ... it may mean that the child has autism or an Autism Spectrum Disorder.

919 Steps

by Shannon W.

In September 2000, my miracle baby arrived. It had taken us five years and fertility drugs to become pregnant with Shane. It was such a long road, but all that was forgotten when they handed me the six-pound bundle. The first thing I remember is how very deep blue his eyes were. What a precious gift.

Shane started developing normally. He had slight delays, I thought, though his pediatrician assured me boys are just sometimes slower to develop. He didn‘t sit up until almost 8 months, and did not walk until 15 months. He was so intelligent, though. The family thought he was a genius; I, of course, being a first-time proud mom, agreed. I remember standing in the driveway of my mother-in-law‘s house holding my 18-month-old son and him saying D-O-D-G-E over and over again. What we thought was babbling turned out to be him spelling off the letters on my brother-in-law‘s truck!

After that, we really started seeing things that were unusual. He would line up all of his Cheerios before eating them, one by one, in the order he had lined them up in. God forbid if he dropped one, or we moved them around. He did the same with his toys. What toys he played with, I should say. Shane had, and still does have, an obsession with electrical cords and outlets, surge protectors and small appliances; if given the choice, to this day Shane would choose a trip to Lowe‘s over a trip to Toys R Us!

Shane would also repeat back what we said to him. If I said, –Do you want juice?‖ he would say –Do you want juice?‖ He called himself –you,‖ and had pronoun reversal forever, it seemed. He would script Toy Story over and over again. He had an extraordinary vocabulary. He told the preschool teacher after he had just turned three that he did not enjoy water because it was –translucent.‖ His rote memorization was extraordinary. At one point, I was convinced he was reading, but I now know that he just memorized the books we read after the first time. At age two, Shane was putting together United States map puzzles, quickly without any help.

Only after I put him in preschool at three did I start to see that all of his little quirks could possibly cause me a very serious problem. See, Shane had not been around other children that much, so we were unaware of how socially inept he was. He had been kept secure in our home, surrounded by loving parents, older cousins, and grandparents; he seemed fine socially to us. Preschool was horrible. Shane had tantrums for hours, he would scratch himself until he was bloody, he would pounce on other children, and he would stare at the ceiling fans for what seemed like hours.

I had the teacher start documenting things, because by now autism was a suspicion for his teacher and me. However, he was so verbal, so bright and affectionate, and he had a marvelous sense of humor. But something was wrong with my little boy. He could count to the highest number imaginable, but he couldn‘t ask a peer to play blocks– and he really had no desire to do so. After collecting enough data, I convinced my husband (who is still somewhat in denial) that something had to be done.

We had him evaluated by three different mental health specialists. The first diagnosis was PDD-NOS, but I knew it was something more specific. I had been doing a lot of research on Asperger‘s, and it fit him perfectly. The second two doctors agreed with me, and he was officially diagnosed about two years ago. Every day has its challenges with Shane, who is now five and doing very well in a regular kindergarten classroom. He has staff support (TSS & BSC), and the teachers are all very aware of his quirks. He gets Speech, OT, Sensory Integration Therapy, and PT. We also keep him in a lot of social situations (karate, dance, hockey), but nothing too stressful.

His story reminds me of our vacation last year in Nags Head, North Carolina. We were walking to a restaurant along the beach from out hotel. Shane was very quiet as we were walking (but by now, I had a two-year-old and was pregnant with #3, so the silence was nice). When we got to the restaurant, he looked up at his dad and me and said, –919 steps.‖ He had counted his steps from the hotel to the restaurant.

Part of me wanted to cry for the little boy whose mind asked him to count the steps in the sand, instead of enjoying the beach air and the feeling of the ocean spray and the sand on his bare feet. And yet another part of me realized by the smile in his eyes, and the sense of five-year-old wonder on his face, that he was getting that, he was feeling what we were feeling. Maybe in his own way, but isn‘t that what matters?

He was happy, we were happy as a family. And we wouldn‘t change a beautiful precious hair on his head, because we have come to love and appreciate Shane for who he is and what he gives to us each day. We see the obstacles he will face, especially socially, as he gets older. But we tell ourselves, and my advice to you is, to love them now for what they offer, don‘t mourn any longer than you have to for what you dreamed they could be because what they are– who he is– is enough.

And I thought, yes 919 steps. And 920, and 921 … we would keep taking the steps together, and give him the most wonderful life possible. Even if it takes 919 *million* steps.

Spread the Word

by Leanna P.

My story is for my daughter. She was 2 ½ when she was diagnosed with PDD-NOS. We had already had a hard time, as she already had cancer. So this was a double whammy for us. Alexis was 9 months old when we found her cancer. So we really didn‘t have a starting point for her developmentally. She had a brain tumor, so she was not talking to begin with.

I had no idea about autism until our physical therapist asked us to go to a child development doctor. While I was there, she was asking me all the standard questions, like, –Does she respond to her name?‖ I said no to nearly all of the questions, so after an hour the doctor told me that Alexis had autism. I was thinking, *no way, this is just stuff from her tumor*. But the more that she told me, the more it made sense.

A lot of my relatives had a hard time at first with it. They kept saying, –Has she not been through enough?‖ But I made a promise to Alexis that I would always do what was best for her. I started to get all of the books, and I visited all of the web sites. I called people in my hometown. I just wanted all the information I could get my hands on. Information is power.

Alexis is now 5 ½ years old, and she has made a lot of progress. Much of that is thanks to ABA therapy. Sometimes, people still ask me if Alexis –still has autism,‖ and I tell them that this is something that does not have a cure, not yet. The more that we get the word out, the more people there are out there with an understanding. Alexis still has a way to go, but I will be there every step of the way.

The Silver Lining

by Carla E.

My son Jacob was diagnosed with PDD-NOS last year, when he was 9 years old. It was very difficult to get a diagnosis for him, since he wasn‘t a –textbook‖ case. He has some varying characteristics. He is nonverbal, but he tries really hard to communicate (he can use profanity with surprising clarity!) He also shows much interest (I call it –getting stuck‖) with objects that turn, such as clocks and wheels. He also has arm, hand, and leg –flapping‖ when he gets excited, and lack of eye contact, especially when he is in trouble! He also has lots of other distinctive characteristics.

Thankfully, Jacob is as healthy as a horse, with the exception of chronic constipation. I have found some Gummy Bears with fiber that work really well, since he won‘t eat or drink anything that resembles vitamins or medicine. Now that he is 10, I see how much progress that he has made, and I am really enjoying him. I guess since I have gone through so many cycles of grief, guilt, anger, and resentment, that now is the time for enjoyment.

Since Jacob turned 5, he has been unable to get any private speech, OT, or PT (I guess you‘re supposed to outgrow everything by then), since our private insurance will not cover these expenses. He *finally* got to the top of the waiting list for Medicaid, based on his disability *after 5 years*, so he should be able to get some services once the paperwork is completed. I often wonder how much progress he would have made during the past 5 years if he has access to therapy.

The hardships are many, especially getting him to be independent in his living skills, but I don‘t think I would change him for the world. At least I‘m pretty sure he won‘t suffer from teenage depression, and he definitely won‘t pierce his own lip like my 12-year old daughter did! God Bless all that read this, and know that there is always a light at the end of the tunnel.

Don't Be Afraid

by Gina W.

Daniel was first diagnosed with possible autism when he was 17 months old. He is now 2 years, 5 months old. A lot has transpired in that short time. I have two older sons, and did not, in a million years, ever think that I would ever be blessed with this child that has changed my life.

Before Daniel came into my life, I did not have any type of perseverance or patience. I have had no other choice but to change. It's hard, but it's a good thing. I know this is not all about me at all, but the many ups and downs over the course of the last two and half years have brought me to a place where I am so thankful; because not only is Daniel changing and learning, but so am I.

When I was first informed of the autism, I did not know how to react. I think that for about a year, I was in denial– to the point where I wasn't reaching out for help or any type of therapy for him. I watched him closely, and I just didn't want to believe it. To me, if it *was* autism, it was just a very mild form of it. Finally, I was able to start dealing with it when one day I heard a man on the radio talking about people with compulsive disorders.

One of the big issues for me was always that people just don't know what this is like, until they go through it. When I am in Wal-Mart and I see a kid throwing a tantrum, I‗m not so quick to judge that parent anymore, because I just don't know that situation. One night, my sister and I went to a restaurant, and her husband sat at the bar area with his friends while we sat at another section of the restaurant. Well, Daniel was not happy that night, and I could not calm him down. My brother-in-law's waitress was at his table and said, –I'm sure you all want to hear that.‖ She didn't know he was my brother-in-law. He told us about it, and I felt like giving her a piece of my mind. People just do not have a clue what they are talking about.

But back to the guy on the radio, he had said, –Don't be afraid to get help.‖ My main thing was that well-meaning people in my church would always tell me, –Don't believe those doctors; believe God.‖ The thing is, I do believe God. And as many times as I have said that I don't understand this at all– and I have left Daniel in God's hands time and time again– I know that this is no mistake, and it is all going to work together for the best.

Every day is a challenge. This week I have had a problem with Daniel biting everyone, and he has been very cranky. I could keep going on and on, but all I can say is that I will never be the same because of this, and I refuse to give up helping him to be the best he can be. We have both come a long way.

A Sister's Wish

by Christine A.

I'm a twin, and at a few months old, my parents discovered something odd about my twin brother. They discovered he had autism, and so he couldn't go to the same school as I did. The problem was that my brother was so attached to me, and he was upset by the fact that we couldn't be together at school.

We are both 17 now. I love my brother as though he was my best friend, and I get upset when my brother is upset or if someone's picking on him. I look out for him a lot. Because of this, I always get people asking me if I have the same disability, even though I'm not autistic. My wish for my brother is that people will grow to understand autism more.

Looking Back

by Patrice K.

My son will be 4 years old on January 24th, so looking back, there were little signs here and there. If I had only gone with my gut feelings, I may have saved myself from a lot of anger, frustration, and not wanting to talk to my husband because he wasn‘t going through what I was. The one person I have to give thanks to would be my baby sister, Lacey, who was 18 years old at the time.

Knowing LeDuc was very much a handful, people would say –Oh, don‘t worry, he‘s just a boy.‖ By the time my son was a little over two years old, he was getting mad, not talking, and hitting and punching his sister Tayler for no reason. He was always climbing up on the sink, nightstands, and bookshelves to get what he wanted, and he was so S-M-A-R-T! I was totally tired!

Lacey works with kids that have disabilities; it‘s definitely her calling. One day she was with me hanging out, and I had asked her to take LeDuc out to the car because he was getting into everything at the store. About five minutes later, I got to the car, and she told me how LeDuc wouldn‘t let her put him in his car seat, and that he was having a major fit. When she had finally gotten him into his seat, he started to bite himself. My reaction was, –Yeah, and … ? He‘s done that before.‖

–Sissy...‖ she said, –That‘s a sign of autism. There‘s a little boy I look after, and he is autistic, and that‘s one of the things he does. This little boy now has calluses up and down both arms. Please, could you get LeDuc looked at?‖ I wasn‘t hurt by what she said, but did think it would be something to look into.

I started talking to whoever I met ... and then I was making small talk, with my tax lady of all people, and it turns out she has a family member that has 3 –A‖ kid‘s that range from mild to major. So she gave me the number to O.C. Regional Center. I called, not knowing if I really had a case for them, and then was told to call L.A. Regional Center, since I was in their area.

They came to do an in-home study of my son, and found he had delayed speech and would do well with speech therapy and occupational therapy as well. I also had his hearing checked, because I could sit right next to him and yell into his ears and he wouldn‘t seem to hear me. Also, to get him to put on long pants, long-sleeved shirts, or jackets was like pulling teeth without pain killers for him.

So the past two years have been a major learning lesson for me and my family. When I went to get him looked at by a psychologist to see what category he might fall under, the doctor told me within 15 minutes of trying to test him, –he may have ADHD, and by the time he gets to kindergarten there are medications you can put him on.‖ I was thinking, *okay, ADHD, meds, if need be we’ll go naturally*. But the bomb dropped when we had him tested to get ready for the school district. They spent 2 ½ hours with LeDuc, and then asked me, –Why are they saying he has ADHD? We are seeing a lot of signs of autism.‖

More than 90 days later, I got the report from the doctor, and his findings showed that my son had PDD. So any services he had got cut before he turned 3 years old that January 24. LeDuc turned 3 years old, and the very next day he started school in a normal school, but they had just opened their doors to Pre-K little ones with autism. Within five months of him being there, he finally said –Mama‖ and –Daddy.‖ Talk about your heart jumping for joy!

LeDuc is almost 4 years old now, and he‘s my blue-eyed, blond-haired surfer boy. He talks a lot now, and I can deal better with him, but thanks to his teacher, her staff, and the daycare that lets him be himself ... I am almost doing okay! But looking back on everything, never would I ask for a different kid. It‘s just the outside world I‘d like to slap sometimes, when people look at me funny while I‘m trying to help my child with a meltdown.

Something Missing in the System

by Sarah S.

My son is twelve years old, and was diagnosed with autism when he was three. Timothy didn't talk, act, or respond like my other children did, or like other children I have known. He didn't talk or want to be cuddled as a baby, and when this continued at three we started seeking help. We were told he had autism, and were given ideas on where to send him for help and so forth, but not all states are set up to deal with this disorder.

We were one of the lucky ones, though; at age five, he was also diagnosed with ADHD and started on Ritalin. After his first dose, everything changed. Now, you have to picture in your mind five years of silence from your child, only grunts when he wanted something. And thirty minutes after taking his first dose of the drug Ritalin that is prescribed for ADHD, your son starts talking to you in complete sentences– a little fast, so you have to slow him down to get him to repeat what he just said.

It was a miracle; all I could do was cry. He was opened up to a whole new world. He started picking up everything in the house and studying it, smelling it, like he never saw it before. This was a miracle, but still a long way from where we wanted him to be. He started school and couldn't get past the third grade, the schools all wanted to label him as being *retarded*. I would argue and say, no, *autistic*, and they were like, *what's the difference*?

They were not able to teach him math or to read; they would put him in a room and let him color or watch TV. This was the special education that our taxes got to pay for! I finally had enough, and took him out of public school and started home schooling him using the Switched on School House. By using that and going at his pace one on one, repeatedly, he began to learn.

He is now twelve, and is reading on a kindergarten to first grade level, but he is reading. He is learning math, adding and subtracting three numbers on top and bottom, and doing fractions. He's learning all the subjects; he is on a first grade reading level, but is at third grade level in math, science and history, and Bible. We are very pleased with this accomplishment for him. He is a very fun-loving child, is well behaved, and wants to learn.

There is so much that I believe these children can do, but I know the resources to help them are not everywhere. The public schools need to wake up and provide better services; not all parents are able to home school, due to work schedules and other situations. I believe these children are not getting enough help publicly, and that is a shame. Public schools would rather spend their money on sports and bigger gyms to help those that get them attention, not the children that need help and struggle just to learn how to read. Those children are put in a room and ignored.

I will continue home schooling my son. I would like for him to be involved in sports and so forth on his level, but there is nothing here that offers that. We have an Opportunity

Inc., that helps with that disorder, but here is the kicker: It is only from birth to age 5, then they pawn you off on the public schools. Then they offer programs for when people are eighteen and over. The most important time, to me, is this in between time! It‘s such a shame that not all public school systems aren‘t offering these kids what they need.

The Land Of Autism

by Marlowe K.

It was the day after Riley‘s second birthday. We had been referred to a Pediatric Developmental Delay specialist, because he had become so difficult to manage. He was throwing extreme tantrums to the point of injuring himself, and was not communicating with us other than hand-pulling us to objects he wanted, then screaming. The specialist seemed to have a way with Riley. He was calm, happy, and not aggressive at all. In fact, the doctor actually held him, and got eye contact out of him that day!

The diagnosis was PDD, or atypical autism, as he put it. Riley exhibited some, but not all, of the criteria for autism, and he would like to see him again in 3 months. Needless to say, that days and the months that followed were filled with confusion, denial, anger, and resentment. Somehow, through all the fog we learned about therapy options and speech pathology.

A month after the diagnosis, Riley began his ABA therapy, and I began taking some classes through the speech center. Now only three months later, he has much better eye contact, has began to use words (and no longer drop them, as before), and his tantrums have subsided. We are very optimistic about his future. Don‘t get me wrong; it isn‘t all sunshine and roses! We still can‘t take him out for dinner, and he still plays alone most of the time. He still flaps his little hands when he gets excited, and he runs around in circles on his tippy-toes.

Riley still has a lot to learn about our neurotypical society. I call this just learning –how to act.‖ And we have so much more to learn about the Land of Autism. The most important thing we have learned so far is that we are blessed to have him in our lives, and we are honored to be his parents! We have learned to respect his autism, and to find humor in our journey together.

Just the Beginning

by Mitchelle G.

I am a 21-year-old wife and mother of two. Our daughter, who is now 2 years old, has PDD. In other words, she has autism, but they haven't yet given her an exact diagnosis of it yet. We never actually noticed anything until she was about 10 months old; since we were first time parents, we didn't realize that our daughter had not been reaching her developmental milestones.

We took her to the doctor for her 10-month checkup. He lifted her and tried to get her to place her feet down on the ground, but she refused. She started crying when he tried to get her to put pressure on her legs. The doctor also said she should be sitting up, rolling over, crawling, and eating solid foods– none of which she was doing. We had started her on solids at 4 months, and that lasted about 2 weeks; she started to gag from it and started crying uncontrollably, so I stopped giving them too her. I still offered, but it was a constant battle. She also used jump in her Johnny Jump Up at the age of 6 months, but then one day she started screaming when I placed her in it. Developmentally, she had gone completely backwards.

So we were referred to every type of doctor you could think of. Her MRI's were normal, her heart was fine (although she had a slight murmur, but nothing that was of concern). Eventually we went to Mayo Clinic in Rochester, Minnesota, where they repeated all of these tests, and all were once again normal. They left me with many unanswered questions, as well as a sense of helplessness.

My daughter does receive therapy three times a week. She is now sitting up on her own, and her way of getting around is scooting on her butt, which is very cute! She can pull herself to standing now, and she jumps in her crib. She still hates taking steps with us, though, and she still does not eat solid foods or talk. She is very distant from us, and it is very hard too see her like this, although I am proud of the accomplishments she has made.

But I still don't feel like I'm doing everything I can. I am working while my husband attends school. We're trying to support this family off of a part-time income, which is almost impossible. Tonight I'm writing, afraid for my daughter's life. She is only in the 3rd percentile for her weight, and she has acid reflux. She gets really sick about once a month, so much that she can't keep anything down (not even the Prevacid they prescribed for her acid reflux). We usually have too take her into the ER and get fluids through an IV. This happens once a month.

It is so aggravating. I keep asking *why...why, why, why*? I don't understand how her fragile body can handle all of this. She is so thin; I can't stand holding her without crying. I don't know if they are going to resort to a feeding tube or not, but I am quite surprised that the doctors haven't requested it yet. She is not gaining weight at all; in fact, she's losing, then gaining, but never going over 20 pounds.

We go to the doctor in the city on Thursday. This is our first time going to this doctor, so I am hoping and praying for a breakthrough– maybe some other form of treatment other than what our therapists are giving her. We know that we still have a very, very long journey ahead of us, and all I can do is stay strong for my daughter, and for my family. I hope those parents out there who are experiencing similar problems can learn from my story.

Follow Your Feelings

by Denise M.

My son‘s name is Richard, but we all call him Richie. He just turned two last week, and this week I just learned that he has PDD-NOS. I don‘t know much about it yet, but I am learning that this is a serious condition.

I first noticed that there was something different about Richie when he was one year old. He didn‘t like to be hugged, and he wasn‘t playing with toys or trying to just say even one word. I started asking my pediatrician if this was normal, and he stated that it wasn‘t. So I got Richie started in a program called CDS (Child Development Services), and they did all kinds of testing with him.

At first, I thought that it was just him, just his personality, and that he would grow out of it. In my mind, one day he would just wake up and start talking and playing with other children– but he never did. Then I found out that if I keep waiting, it will just be worse if there is something wrong with him.

My message to parents is that if you think that something –just isn‘t right,‖ don‘t just go on a feeling– seek professional help. Don‘t ignore the signs that may be right in front of you or imagine that you don‘t see them. Richie is now two years old, and he still doesn‘t talk or play with other children; but someday, because I found the right help, he will be a happy, healthy, normal child and adult.

Trusting Your Instincts

by Kelli V.

My son Damon, who is 3 years old, was diagnosed with autism about 7 months ago. He had a very high fever of 104.7 when he was 13 months old, and he doctors were very slow to take care of him. I believe this is what caused his autism. I soon realized something was wrong when he stopped talking and socializing. His motor skills also dropped dramatically. My mother told me I was delusional, and that there was nothing wrong with him; I knew better.

I had Damon seen by his primary care doctor, who thought it might have something to do with his hearing. We were sent to an audiologist at that time, only to find out his hearing was fine. From there, they referred us to the San Diego Regional Center. They concluded that he was autistic.

They enrolled him in a program where teachers came into our home five days a week and worked with him. Soon his –spinning‖ habit stopped. He has since developed an anger problem, and still has a communication problem, but I am happy to report that his diagnosis has changed from autistic to PDD.

For my son‘s sake, I am happy that I went with my instinct instead of my mothers –wisdom,‖ and had him treated at such an early age. If you catch it early, some of the problems can possibly be reversed. The moral of my story is to go with your gut instinct, and know that there *is* hope for a change to occur!

Counting My Blessings

by Alma L.

Yes, I am a mother of a 13-year-old son with autism. I have learned so much in life because of Stephen. You see, my son is considered severely autistic. He is non-verbal, and chronologically about 18 months. He is, unfortunately, also built like a football player. As you can imagine, we stay home a lot. Stephen doesn‘t do very well outside the home. As a matter of fact, his doctor recently did his checkup in the van outside in the parking lot!

I have so many –hardship‖ stories when it comes to my son… too many to count. Let me just give you one example. Two years ago, I hired a babysitter for Stephen; she said she knew –everything‖ about autism. My son climbed out of his second story window, and broke his foot in a few places, then still managed to walk over to our neighbor‘s house. The babysitter had no idea he had climbed out. His foot needed surgery and three screws in place. He was in a body cast for well over a month to keep him from ripping the screws out.

That was a rough time. But as I look back, I think, *man how did I do that? I made it through that?* I used to cry and feel sorry for myself because my son has autism, and the fact that he was so severe. I used to cry and whine to God about everything. But what good does that do you or your child? I stopped feeling sorry for myself, and started to count my blessings.

Sure, I get disappointed. But you get through it the best way you can. Ask questions, read, and get involved. I have to take things one day at a time. Sometimes I take things *five minutes* at a time. Whatever it takes to keep me from –rocking the boat.‖ I can‘t see my future or know what is going to happen. If I think about that, I can get easily stressed.

For example, I hate it when people ask me, –What are you going to do when Stephen gets bigger?‖ Hello! People need to be compassionate and understanding. You will know soon enough who your family and friends are by the way they act around your disabled child. I have faith that we can be all right if we just accept things. No blaming ourselves. We need to love ourselves too, you know. If I can do it, anyone can.

The Importance of a Positive Outlook

by Mariella C.

We have a 5-year-old boy and a 3-year-old boy, both diagnosed with high functioning autism/PDD. We began early intervention on both of them from the time that they were 2. They are both in the Pre-K program at regular schools for children with disabilities, and we had to fight at the IEP Meetings for their school placements and therapies. Also, at home we work with them actively.

The first neurologist told us, –Forget the school systems, because they have a no tolerance policy, and your son would never make it. The second neurologist told us, –Do not expect your children to have conversations with you.‖ Finally, after many months had passed, my husband and I took both boys to see a very well known, top-of-his-game neurologist at the famous Dan Marino Center. He told us, –Yes, your children are PDD, but they are such high functioning, sweet, lovable, boys who have progressed immensely with early intervention,‖ and he is not very worried about their future.

He strongly recommended we place our boys in a structured activity, such as swimming or karate. He told us to continue with their treatments, and to integrate them into every outing possible to expose them to various people, noises, and situations for socialization purposes. He also told us to simply treat them as typical children. He very strongly believes that our boys will grow to be typical children with a few quirks here and there. And truth be told, we all have quirks of some sort!

This neurologist was like a fresh of breath air to us, full of promise and optimism, and we believe him deep down to the core of our souls. I, too, believe with continuation of therapy, constant love, understanding, and consistency by parents and caregivers, that all of you who are also dealing with autism in your families can help overcome many obstacles. Think positive, and don‘t focus on the things that seem wrong and what your kids *can’t* do, but focus on what your autistic child *can* do and go with it.

Make him or her be the best they can be, no matter at what level the child has been diagnosed. Give them the therapy and treatment they need for those areas that require intervention. I refuse to believe that these intelligent children cannot dream or aspire to be what they want to be! The problem lies with those professionals who generalize and know not what they say. There is no way to predict the future of your child, yet you can alter their today.

You're Not Crazy!

by Candice D.

I have a daughter named Hope who was born in September of 2002. At first she was a normal baby, and it seemed like nothing was wrong. How wrong we were; when she was 5 months old, I figured out that something was wrong. Hope wasn't sitting up, rolling over, or doing anything that a 5-month-old is supposed to be doing. All she would do is scream! She didn't want to touch anything or be around anyone except me, her father, or her big sister.

My family said that I was just overprotective, or that she was a lazy baby. So I decided to bring her to the doctor, against my family's advice. When I brought her to the doctor, I was told that she was at least 4 months behind. I was referred to a pediatric neurologist who put Hope in therapy right away. After Hope had been in therapy for a year with some mild progress, I demanded a diagnosis, and that is when I got the shock of my life.

Hope was diagnosed with autism (autistic spectrum disorder); it was hard to face the fact that she had autism. As a parent, you never think that your child will have something wrong. You don't think that it is possible. At a year and a half, she was still waking up at night, and the mood swings were sometimes unbearable. People used to say, –She looks so normal,‖ and that would bug me all the time. It was like I constantly had to prove that she was autistic!

She is three now, and she can walk and talk a little; this is a big improvement from where we started out. I am writing to let everyone know about Hope and her story, and to also let the moms in the world know that if they think something is wrong with their child have it checked out. Don't let others convince you that you are crazy, or that your child is spoiled, because much of the time that is not the case. With early intervention, an autistic child can improve; my little Hope is proof of that.

The Moment It All Changes

by Tanya S.

I remember walking with my husband, Scott, and our two-year-old son, Jackson, through a seemingly endless maze of hallways. There were bright fluorescent lights and huge metal double doors at every turn. We found the elevator, and quickly rose to the third floor. The doors opened, and the sign in front of us read, *Developmental Pediatrics*.

We were at the best hospital in our state. We sat, nervously waiting for them to call our name, full of anticipation for what was to come. When it was our turn, a nurse led us to a small, rectangular sized room filled with toys. There were tiny tables and child-sized chairs, and giant, colorful therapy balls on racks on the wall. There were red and yellow mats in the corner by the door, the kind that you would see in a gymnastics class. On the wall there was a huge chalkboard to draw on, and next to that, a small two-way mirror.

The carpet was dark blue and was covered with juice stains. I stared at the stains on the carpet, thinking of the other little boys and their parents. The ones who came before us, and the ones who were yet to come. I seemed to be soaking in every detail of this small, rectangular shaped room. I didn‘t want to forget. I think I was trying to hold on to the –before,‖ because I was terrified of what I would do –after.‖

When the doctor was finished with her final evaluation, we were left to ourselves while she and her colleagues compiled the results. We already knew what she would say. After all, we‘ve had this child for two years. We knew he was different.

We sat in our child-sized chairs, watching Jackson wander aimlessly around the room, clutching his favorite thing in the whole world, his blanket. We watched as he bumped his chin on the soft quilted brown and green teddy bears, over and over and over again… the way he does all day, every day. We watched as he ran over to lick the chalkboard, then bend over to stand on his head. We watched as we always do, while Jackson does these unusual, quirky things that comfort him in a way that nobody seems to understand.

The doctor came back in the room and sat down in another one of the tiny chairs, directly across from us. The words she was about to say would change our world forever. We brace for it, and then it hits. –Your son does fall on the spectrum,‖ she said. I know what the –spectrum‖ is from reading everything I could get my hands on. The autism spectrum. –Jackson scores in the moderate/severe range. I‘m sorry.‖

I knew it was coming, but hearing the words ... there was a lump in my throat, and a strangeness in my chest. I was feeling my heart break. The –before‖ was over, and this was the –after.‖

In the days and weeks that passed, I grieved the loss of the perfect child I thought was taken from me. The hopes and dreams I had for him, for who he might become. These feelings were soon replaced with the realization that it really didn‘t matter if he was

President of the United States, if he worked in an ice cream shop, or if he was never able to hold a job at all. What mattered was Jackson, the purest gift I had ever been given. In accepting autism, I could accept the totality of my son. What came with that was a sense of immeasurable peace, a never-ending determination, and a love like no other. Jackson's journey had begun.

Just Work Towards Happiness

by Nydia C.

My son, Keith, was diagnosed with autism at the age of 6. Although I was scared and did not have any really good information about it, I felt better just holding him. He has been the light of our family's life. Keith makes us remember that nothing is that bad. He is loving, funny, and is the happiest person we know.

He is now almost 15 and is doing so well; no one could have predicted that he would be doing this well. Just remember that this is your child, and you know what your child is capable of. Do not let others put limitations on that. This is still your child, and they need you more than anything.

My son told me one day that even though people think he is strange, he does not care, and that he likes the way he is! He makes us laugh, and I know that he will always be a success. The best thing I did for him is to have expectations for him within his limitations, but he still gets punished and corrected just like any other kid. In this way, you are preparing them for the world early.

Life will not be easy, but if you are truthful and firm, they will be more prepared for it. Keith has taught us more about life than anything or anyone else could have, the good and the bad.

The Struggle for a Diagnosis

by Lynn B.

As a baby, Jacob didn‘t want to be with anyone but me, his mom. He was breastfed, and I attributed it to that. He also would not take a bottle. When we would leave him with his grandma, he would scream the whole time. When we would ride in the car, all he did was scream. He was also very attached to his pacifier. We tried to take it away when he was two, but when his sister was born he would snatch hers away; so we gave in and let him have his own.

Jacob met his developmental milestones up until he was 18 months old. He would only say a few words, and did not talk in short sentences till he was 3 years old. Jacob started having chronic ear infections when he was around a year old. He was on long-term antibiotics at one point. Jacob had no interest in potty training. He was almost 4 years old by the time he was potty trained during the day. He has a quirky thing he has done since a baby, and he still does it to this day: he rubs your elbow.

Jacob never played with toys as an infant or toddler. When he was in preschool, he could not write his name. The teachers were concerned about his fine motor skills. We thought they were crazy, because he could use a screwdriver to take all the screws out of the door hinges! It took him a lot longer to learn to write his name than other kids. He was in first grade before you could figure out that his scrawl said –Jacob.‖

Jacob was very hyperactive, and had no fears. We took him in to be evaluated, and he was diagnosed ADHD and ODD. In the psychiatrist‘s office, he had a meltdown. She showed me how to restrain him, and it made him even worse. He has been on numerous medications, many of which made him 100 times worse. Ritalin, Adderall, Concerta, Clonidine, Risperdal (which worked for awhile), and now he‘s on Tenex and Strattera. We don‘t believe any of these medications are helping him.

I was tired of all the different meds, so I didn‘t give him anymore till he started having problems in preschool. He then was put on Risperdal. He was on this up till he was almost 9. He continued to have problems, but the school system never would do anything to help, even though we called the AEA. In kindergarten, he finally got an IEP because he wasn‘t on the same level as the rest of the class. Since then, school has been a struggle for Jacob.

In June 2004, Jacob killed the family guinea pig with no remorse. I called his psychiatrist and made an appointment. In the meantime, my therapist had stated that it sounded like Asperger‘s. I researched that, among other diagnoses I found, and printed it all out and took it with me to the appointment. His doctor blew me off, saying that it was just ADHD and ODD. He suggested play therapy.

So we went back to play therapy, and I didn‘t even mention what I thought about the Asperger‘s until the therapist brought it up. She informed us that we had to go through the AEA to get anywhere. That didn't work either. The AEA wouldn't do anything. So we hit the brick wall! With each year that goes by, Jacob gets further behind, and he acts out more. He is now in 3rd grade. He has been in five fights this year, and the principal is about to suspend him.

This is what got the ball rolling! Being so tired of the brick wall we kept running into, I gave it one more try! His dad was finally admitting that something was wrong and that we needed to get something done. Jacob was no longer making progress on his IEP goals, and the school didn't know what to do for him. I called his psychiatrist and couldn't get a referral from them so I tried his pediatrician again. He called back and said sending him somewhere where they knew about autism would be the best choice.

I finally got a referral to the University of Iowa Hospital's Children's Autism Clinic on this April 3rd. It will be such a relief to finally have someone listen to us. Hopefully we can find an answer and some advice on how to help Jacob succeed! This is only a little bit of what we have been through with Jacob. He lives with his dad, because he can't function with his siblings. We are fearful of his violent outbursts and what will happen when he gets older. He is the most lovable child when the situation is perfect for him. Every parent wants their child to succeed. Every day is a struggle for him, and it is so sad to watch him try so hard but not make any progress!

Taking It Day By Day

by Brandy T.

My son Luke was born January 4th, 2002, and was happy and healthy. A week after his birth, my daughter, 21 months old, was diagnosed with cancer. Luke spent his first few months of life in a hospital bed next to his sister, who was close to dying. Thanks to God, our daughter is now almost 4 years recovered from her cancer.

When Luke was 18 months old, we started to notice he was a bit –hyper.‖ Everyone said, –He‘s just a boy; they are more active.‖ He also had speech problems and soon developed insomnia. By his second birthday, he hadn‘t slept through the night in 4 months. He started in a –special ed‖ class at a school for special needs when he was only 2 ½. He was working with a speech pathologist, a behaviorist, and an OT. I asked all these professionals around us if he could be ADD or have some other disorder. My husband is in the Army, and for some odd reason, military doctors and the people we were working with would not test him or anything until he was 4.

So Luke became more difficult. His insomnia got really bad, he became aggressive with me, and his dad got deployed to Iraq. In the next year, Luke became uncontrollable; I suffered many injuries at his hand, including black eyes, split lips, and a broken piece of cartilage in my face as a result of him hitting me with a cup. Still, no one would help. So we moved on, and his dad came home to a different boy than he left. All this time, I was still telling doctors something was wrong, but no one would listen.

In January of 2006, Luke turned 4. At a routine doctor visit, the nurses yelled at me, –Can‘t you control him?‖ I finally broke down and said in tears, –No, and I‘ve been trying to tell you for two years that there‘s a problem.‖

So now it‘s almost March, and Luke has a full time therapist he sees each week, a psychologist, and is still in pre-K for his second year. He was diagnosed with autism and ADHD. We have known for a while that he also has a sensory disorder and what they call global development delays. The specialist that finally saw him and diagnosed him was amazed that he wasn‘t diagnosed sooner, because it was –so obvious that he‘s autistic.‖ The doctor gave me the diagnosis, a prescription for antidepressants for sleep, and sent me on my way with no resources or information of any kind. Not one little piece of advice as to where to look for help.

Dad‘s deployed again; he just left January 18th and I have no friends or family. And somewhere along the line (oh, around 18 months ago) when Luke took a two-minute nap, we found a way to have a third baby. So I have a 6-year-old daughter, Luke who is 4, and a 9-month-old son. My baby is normal so far ... knock on wood.

My everyday is filled to the brim and running over with difficulties. Luke has to be watched every second of the day. He has already broken four bones and had one head laceration. He is extremely hyper, and is always into something. It‘s hard enough to have a child with any one of Luke's problems, and you can't believe how hard it his for him and I when he's having three major problems at once. We just go minute-by-minute, day-by-day, and keep hoping for the best.

Clues From Television

by Deirdre N.

Sierra was born May 25, 2003, a healthy little girl. When we went to all her doctors‘ appointments, she was always where she supposed to be on the charts. About a month after Sierra‘s first birthday, my husband and I noticed that Sierra stopped saying –Daddy‖ and –Mommy.‖ Every time the vacuum was turned on, she screamed. We also noticed her hand going in her ears. Sierra had a favorite toy; on it was a red light, and she would sit under the covers with the toy for hours if we let her.

I took her to the doctor, and I asked about a hearing test. A couple of days before the hearing test, on a Sunday night, my husband and I were watching *Extreme Home Makeover*, the show where they help families redo their homes. That Sunday, it happened to be an episode where the parents were deaf, and they had two children that were boys. One of the boys was a typical 15-year-old boy, and the other boy had autism and was blind.

On the show, they were telling some things about autism. They showed how he loved to swing. I looked at my husband and said, –Honey, Sierra loves to swing; she will sit in the swing for hours.‖ My husband replied, –When we go to our friend Anne‘s, she will stay in the swing for awhile and wants her sister to push, and if she stops, Sierra screams.‖

The big thing, though, was when the host, Ty Pennington, sat in the seat in the middle of the room, and about six people yelled at him to show how all the sound goes in an autistic child‘s ears at the same time. My husband said, –Babe, Sierra is always running from the light in the living room, Sierra always screams when we turn on vacuum, and she puts her hands in her ears.‖

Soon came the day for her hearing test. Sierra would not sit in the room, no matter what. She did not look any of the people administering the test. She was having a panic attack. Then someone told me about *Babies Can’t Wait.* We scheduled a meeting to talk about what Sierra was doing, and we scheduled the ADOS test with Dr. Yeargin, who also works for the CDC in Atlanta, Georgia. It took about six months to get in with Dr. Yeargin. On February 10, 2005, we got Sierra‘s diagnosis. She was diagnosed with –being on the autism spectrum.‖

Close Enough to “Mommy”

by Sylvie M.

I met my husband on the Internet, and while we were chatting he would always ask me if I would give him a baby. Of course, I thought he was crazy. We met for the first time in 2001. I have three kids of my own from a previous marriage, and he had five from his previous marriage. I had already gotten my tubes tied, so what I did was crazy! I went to my doctor and had it reversed, but because I had my tubes tied for over 10 years, I only had a 30 percent chance of getting pregnant. One month later, though, I did. Nine months went by, everything went well, and here came a beautiful baby boy named Gage Samuel. He was a miracle baby; I guess that God gave him to us for a reason.

Gage was a happy baby; his eye contact was great, he loved the water, and he really loved food! He had all his vaccines, and on the 12-month vaccine, which was the MMR shot, everything changed. The very next day, my husband looked at our son and saw that the baby‘s eyes were glassy-looking. As weeks passed, I also noticed that my baby‘s eye contact changed and that he was not responding to sound. So I took him to his pediatrician, and she said he was fine. I was still convinced that there was something wrong, so I had his hearing checked, and they told me that he could hear.

I was getting very upset that there was no one out there to help me. Before my son had the MMR shot, he was saying –Daddy,‖ –Mommy,‖ –baby,‖ and –bottle,‖ and now he had lost his speech. Today, Gage Samuel is 2 and a half, and all he can say is –Daddy‖ along with one other word. No, it is not –Mommy,‖ which was so heartbreaking for me. Actually, there is a little story about Gage‘s –other‖ word.

Gage has a routine; every morning Gage will have a Tim Horton chocolate glazed doughnut. He‘s been having the same doughnut for the past six months, but someone told me to put my son on a gluten free diet, so I stopped buying the doughnuts. Well, I saw that Gage was getting very upset. I decided one morning to give in and get him his doughnut, and when I got home, he saw that I was holding the Tim Horton bag, and he lost his mind with excitement. When I handed him the doughnut, he looked up at me and said –Hi Honey.‖ I broke down and started to cry. Gage does hear my husband call me –Honey,‖ or we always say –Hi, Honey‖ when we see each other, so I guess Gage wanted to say the same thing.

I thank God every day for giving me such a great husband. He is so patient with our son, and there is so much love for Gage; remember, Gage has 8 brothers and sisters. All I can say to the parents out there is to love your child no matter what, and remember God has plans for these children. We thank God for the joy that He gave us, and for our Bubblebee, who Daddy and –Honey‖ love so much!

The Slow, Steady Miracle

by Lori M.

In 1992, my son started his rocky life in the NICU after developing an infection shortly after birth. At 3 years of age, we became quite concerned about his lack of speech and his inability to link two words together. He was also extremely afraid of loud noises, keeping us from happily attending parties, fireworks, shopping malls, playgrounds, etc. He also disliked climbing, going down a slide, riding in a car, or anything that didn‘t have his feet firmly planted on the ground. He didn‘t color, draw, or put together puzzles.

Along with his lack of speech and sensory issues, Zach had small and large motor skill problems. He couldn‘t button, zip, or pick up small objects with two fingers. He couldn‘t jump with two feet together, skip, or do a jumping jack. By the time he started kindergarten, we started speech therapy along with occupational therapy for all of his sensory and motor skill issues. We had him in soccer, baseball, and anything else that would help him both physically and socially.

When Zach was in the fourth grade, we tried a modulated sound therapy that worked a miracle for Zach and the rest of our family. For the first time, Zach was able to ride comfortably in the van without holding his ears and crying, and he could finally attend parties and shopping malls. But we still noticed that after attending a big event, he would lose speech skills, attention, and the ability to interact for a couple of days.

By the fifth grade, Zach needed severe school intervention that forced us to obtain a diagnosis and medication. Later that year, he was diagnosed with Asperger‘s Syndrome, and he received a full IEP. Zach struggled in middle school, with mediocre to very low grades. Zach would talk and sing to himself in the hallways, creating peer problems. We continued with the speech therapy, with more emphasis on social skills. We also went to a psychologist who taught social skills to autistic kids in a group setting.

Zach progressed beautifully! When Zach started seventh grade, he developed a personality! This sounds so sad, but it was as if he emerged from his own world and into ours for the very first time. Zach was funny, caring, and for the first time excited about life! I still cry when I think of this. This was the year I got my son back. His teachers were very excited about this transition. Through eighth grade, Zach struggled to catch up with his peers both academically and socially. Sadly, the other kids still viewed him as –odd‖ because of his past behaviors.

By the time Zach entered high school, you would have never known that he had any problems. A few quirky behaviors still existed, but only around the family. But the biggest improvement was with his grades! Zach is now in the tenth grade, with a 3.5 GPA with hardly any intervention and no medication. He attends standard classes, he is learning to drive, he golfs, loves sports, and is looking forward to not only attending college but also living on campus. I once thought that autism was a life sentence for Zach. But these are happy days, and I feel as if we truly beat autism!

Writing My Life

by Marc L.

My 12-year-old son, William, was diagnosed with Asperger‘s 9 years ago. It‘s taken me a long time to appreciate that while he faces great challenges, he has a remarkable personality and talents to compensate.

I just spent the past six years (and 63,000 words) burrowing into his world to better understand William and kids like him. I recently self-published a novel, *Eddie and Me on the Scrap Heap*, available on Amazon.com. It‘s about a 9-year-old boy with autism who plays guitar like –a ring in a bell‖ who transforms the lives of a junkyard pirate, a reggae singer, a modern day witch, and other dysfunctional characters.

It takes place largely in a junkyard, a metaphor for Eddie‘s life. Everyone tries to fix Eddie because they think he‘s broken, but he ends up fixing them. In the process he accepts himself, and by the time I wrote the epilogue, I had accepted my own son. He had fixed me. The book is funny and life affirming but packs a serious message: my son and others with special needs shouldn‘t be defined by their disabilities. They often have remarkable personalities and talents to compensate.

A Message From an Autistic Adult

by Michael C.

I was diagnosed at age 11 with PDD-NOS. I always knew I was different than the children at school. I had problems paying attention, playing group sports, with hand-eye coordination, and controlling bodily functions. My mother took me to specialists to –get help.‖ I was in an institution, but it did not help me.

What helped me to get overcome my problems were Christian people who were willing to befriend me and encourage to do right! Yes, they did rebuke me when I did wrong, but they did it in love. The specialists I went to as a child (except for one person) were only doing their jobs, not caring about me personally. The first friend I had in life was a girl who liked to sing and acted silly! I appreciated her. As a teenager, I had more girls like her befriend me and encourage me.

Unfortunately, my dad did not have an active part in my life, so I had other adult men who were –sub-dads‖ to me. For the most part those men were preachers! It took time on their part to get me to attend Sunday school (instead of sitting in the car), to get me to sing in church (I just sat there and did not open my mouth), to get me to preach (I was quiet and did not really have a speaking voice), to help the coaches at the Christian school by videotaping ball games (I had never touched a video camera before), and to actually study and try to get good grades (I failed 3rd, 4th, and 5th grades).

When I graduated from the Christian school, I was on the Honor Society and had the most Academic competition awards! They encouraged me to go to a Christian college. I am the only boy they sent who graduated; the other nine quit. I made Who‘s Who Among Students in American Colleges and Universities. I also got a Master‘s degree in the seminary with the highest grade point average.

Today, I am the college postmaster. Yes, I am not able to drive, but they appreciate having me anyway. I decided to let Jesus Christ have His way in my life. There have been struggles along way, but He helped me to overcome them. When dealing with ASD people, remember that we know if you care! You can try to –help‖ all you want, but we will not listen to you if you don‘t care about us.

Too Cute to Ignore

by Jenni

I have a 3-year-old daughter with autism. She can use three- to five-word phrases to tell us her needs and wants, and that is it. There are some days, like last night, she just couldn‘t tell us, so she did everything to show us.

We arrived home from visiting my daughter‘s grandparents, who live two hours away. She indicated to us, by crying when removed her from the car, how unpleased she was that we were home and not at grandma and grandpa‘s home. That evening, wearing only a diaper because she had just had a bath, she brought me her white tennis shoes and said, –Shoes on?‖ I put the shoes on. She said, –Okay. Lets go bye-bye.‖ I told her, –We can‘t go bye-bye.‖ (I don‘t say –No,‖ because she gets overly upset over the word. We think it is because she thinks –No‖ means –No forever.‖)

She gave a little whine and walked off to the bedroom. Half an hour later, she returned with a shirt and skirt. I helped her get dressed, and she ran to the door to try to open it, telling me, –Go bye-bye?‖ I just ignored her in order to avoid a meltdown. Then she went back into the bedroom again, grabbed her Dora backpack, and filled it with all of her favorite Dora figurines that *no one* is allowed to touch. These are her most cherished possessions. She ran to the door to –go bye-bye‖ carrying her most cherished possessions, as if she is going for a long trip (like we did this past weekend). I finally told her that we were not going back to her grandparents. She got upset and went to the back of the room.

About 20 or 30 minutes later, she came back butt naked, wearing only her white tennis shoes (because she doesn‘t know how to take them off yet) and handed me her bathing suit. I put a Pull-Up on her (but called it a swimmer) and her bathing suit. She indicated she wanted me to remove her shoes, so I did. She looked at me in the sweetest face and said, –Want to go swimming?‖ She then ran to the door.

I walked to the bedroom to see where her clothes were. Next to the dirty clothes hamper were her clothes, diaper, and backpack. She must have seen the bathing suit and thought: *I want to go swimming right now*. And that was exactly what she did, undressing on the spot.

The greatest thing is that my daughter almost used a complete sentence to get her point across, and I could actually see her thought process in trying to communicate what she wanted. All of this occurred at 8 or 9 in the evening. It is moments like these that make me so proud of her and how far she has come from being practically non-verbal and non-responsive (most of the time) 8 months ago. She has come such a long way in such a short time...I am so grateful.

He’s a Keeper

by Kathy

T.J. has really never been –right.‖ Having a twin sister makes you notice differences rather quickly. After 15 months of complaining, his pediatrician finally sent us for evaluation from Early Intervention. He was first diagnosed with behavior problems and sensory integration. He started therapy for speech (he only said about 8 words at 2 years old), OT, DT, and he saw a psychologist.

The psychologist didn‘t want to come out and say autism, but just hinted around. We finally had enough of her games, and we switched to a different psychologist and got a diagnosis of moderate to severe autism with severe sensory integration. Even though I knew it in my heart that he was autistic, the diagnosis devastated me.

T.J. has made great progress in Early Intervention after adjusting his therapist around a few times. He now has a vocabulary of over 100 words. He is starting to say sentences that people other than my oldest daughter and I can understand. He is now 3 and will be starting preschool this month. He has gone from being lost and isolated to actually initiating play with his sisters and therapist. After starting him on Tegretol last month, he has made huge leaps and progress. Before the meds, he could not stay focused for longer than a few moments. Now I can actually read him a bedtime story, and he can listen– as long as it is a short one.

I really don‘t know where we would be if not for Early Intervention. How can I properly thank someone for –finding‖ my little boy? He is changing daily, and never ceases to amaze me. Every day is a challenge, but I really don‘t think I would change it for the world. T.J. has forced us to look at things differently and to thank God every day for His blessings. He has made me a better person. I wouldn‘t trade him for the world; he will always be my little man. Quirks or not, he is a keeper!

Moments of Clarity

by Corina

My son Ian, 16 was just diagnosed with high-functioning autism three weeks ago. He was diagnosed PDD-NOS as a preschooler. We were told that when they got his speech –working‖ after two years of special ed, and he wasn‘t drooling or crying every time they went outside, that he was now –fine‖ and ready to mainstream. All this occurred right as we moved to a new city and switched to home schooling; we never really realized what PDD-NOS meant until now.

It breaks my heart to realize what we could have, would have, or should have been doing had we known. A few years ago, I ran across an article about a new field of research known as –Asperger‘s.‖ My heart leapt; it sounded like our special little –geek‖ of a cherub, except for the delayed speech. This led to further research and a personal diagnosis of HFA, agreed upon by our pediatrician. She didn‘t think it was necessary to pursue an official diagnosis, since Ian was then doing fine in school. (We had been instinctively adapting to his strengths and weaknesses.)

Then came the day when our math genius announced that he –hated math‖ and was –bad‖ at it. What was he talking about? In third grade he passed a test at an eighth grade level, because I answered a seemingly harmless question about how to do a math problem he‘d seen at the end (eighth grade section) of the test. He extrapolated that information to help him pass all the other sections! But now he was –bad‖ at it? First he appeared to struggle, then stall, and he has regressed for the last year back down to the fourth grade level. The diagnosing psychologist explained that Ian has a lot of trouble holding multiple pieces of data (i.e. numbers) in his head, manipulating them and then outputting. Aha! That explained so much.

So that devastating day, we drove the six hours home from the UW Autism Center, trying to sound as happy and positive as Ian was (he was thrilled to have an explanation for others). In actuality, we were crying inside about the finality of the diagnosis we had –known‖ for two years. Then Ian announced, –Hey, there‘s another pattern on my watch!‖ –What kind of pattern?‖ I asked. –It says, –616,‖ and that‘s a pattern,‖ he replied matter-of-factly. Skeptically I asked, –So it‘s a pattern because of the sixes on either side of the 1?‖ –Yes,‖ he said. –Well, what if it was a 2 or 3 in the middle?‖ –Then those would be patterns too,‖ he stated. –Why?‖ I asked. He said, –Because they all go into 6.‖

My husband‘s face lit up as he drove through the rain. –Ian! Those are all common denominators!‖ –What would the numbers in the middle be if they were 8‘s on either side?‖ I countered. –Um, 1,2 and 4.‖ –Ian!‖ I cried, ‖Those are common denominators too!‖ –Wow!‖ Ian exclaimed… –So that‘s how that works…‖ My tears lifted for the moment, just knowing that we might finally get beyond being –bad at math.‖

Not My Imagination

by Jennifer

Ethan started preschool when he was three. His teacher was new, and she seemed really in over her head. She started reporting that he was hiding under tables and kicking out at the other children. He ran away a lot, and she had to put up a baby gate to keep him in the room.

Also, on the day of his orientation, he immediately went to the dinosaurs and lined them up in one nice long row. Which wasn‘t troubling to me, since he had been lining stuff up since he was one. He didn‘t play with the other children, and when I got blank coloring sheets, I asked her if he colored. She said ‗No, he just lines the markers up.‖ It was very hard to understand him, and he didn‘t always respond to his name really well. Still, I didn‘t think anything about it. I thought he was just a little quirky.

I realized something was wrong in January of last year. He started gymnastics at our local recreation department. He refused to get anywhere near any of the other children. He stayed in the corner and wanted me in there with him. He screamed and threw himself down onto the floor when I tried to get him to join the other children. He threw his shoes across the room. But when I would try to take him out of the room, he would cling to the doorpost and scream some more. Finally, after 30 minutes (the class is only 45 minutes) he calmed down enough to jump on the trampoline. I just stood outside the door and cried, because I knew something just was not right.

So I went to the pediatrician, who listened and brought up Asperger‘s, and then told us to wait until he is four to go to the Marcus Institute for an evaluation. While we were waiting, since this was in February and the appointment I made was for November, the speech therapist recommended that we have his hearing checked, since he was failing some of the low noises. We did that, and his hearing was fine.

Then Ethan started chewing on things. He would chew his shirt, and he would chew sores onto his hands. He also started scratching. He would scratch himself until he bled. One morning I changed his shirt, and his underarms were bleeding. So I decided not to wait on the Marcus Institute. I made an appointment at Emory, who could see us 5 months earlier. In the meantime, we saw a psychiatrist who said that he could evaluate and diagnose for autism. (Oh, and by the way, our insurance doesn‘t cover mental health, and **no one** takes it). So we spent 300 dollars to hear that he doesn‘t feel he is proficient enough in his research to diagnose Asperger‘s.

So to sum things up, we took Ethan to Emory and they diagnosed him. He is going to pre-K this year and is doing wonderful. When I first started to think there was something wrong, I was told by family and friends that I was overreacting; that I was making it into something it wasn‘t. I would say *the scratching is really bothering me*, and someone would respond *well, I scratch too sometimes*. Yeah, do you scratch until it bleeds? Now, I‘m worried about my one year old, but I find that I keep my worries to myself.

Achieving Beyond Expectations

by BethAnn

Cole was a normal baby up until age 5 months. Then the severe asthma set in, and he spent practically 6 months in the hospital. By the time he was 11 months old, he had been in the hospital 27 times, including 3 procedures and surgeries. He got on a new medication for toddlers, and his asthma and reflux seemed to stop.

By the time he was 2, we all noticed his behavioral problems. He would bang his head on the floor and walls. He had tantrums constantly, and he had no idea who we all were. His sister didn‘t even exist to him, and he had absolutely no auditory processing. We all thought he was deaf, so I took him to a specialist. The ENT said the asthma caused a lot of fluid to build up in his ears, and he needed tubes. This was supposed to increase his vocabulary, which currently consisted of about 5 words (mostly relating to Blue‘s Clues).

The tubes were put in 5 days after his 2nd birthday. The doctor said we would see amazing changes in his ability to speak and understand spoken words. Well, that didn‘t happen at all. We were supposed to wait 3-6 months to witness a change, but I didn‘t buy that; so I made an appointment with the local Children‘s Therapy Unit. The SLP that we saw was amazing and didn‘t beat around the bush at all. We were told that he had major developmental problems and needed to have a PT evaluation done next to determine his balance and equilibrium problems as well.

Cole could walk, but he fell every three steps, and he couldn‘t negotiate between hard surfaces and carpet. He never caught himself when he fell, and he couldn‘t go up and down stairs. He was a very late walker (16 months to maneuver without furniture totally), but the doctors said it was from the hospitalization and all the weight he had gained from the steroid treatments for his asthma. He was about 20 pounds at 2 months old, and 34 pounds at 8 months old. His weight is normal now; he weighs 34 pounds at age 3.

So with our weekly Preschool Language Group information in hand, we went to the PT for an evaluation. She diagnosed him with developmental physical delay, scheduled him for weekly appointments, and sent us to an OT for Sensory Integration testing. Naturally, he had that too! So yet another weekly appointment was scheduled. We were then referred to the local Birth to Three service; they evaluated Cole and determined that he qualified to have all of the above paid for by them, as well as sending another therapist to our home to teach Cole how to play. At this point, he couldn‘t even ride in a car without screaming around the corners, and he had no friends at all.

That Christmas the –elves‖ built my children a playroom which happened to include a platform swing, ball pit, slide, climbing toys and 3 other swings that could be changed out one for another. A girlfriend of mine made me sensory paddles that hung from the wall, and all but the platform swing and pit were purchased from IKEA (awesome place). By age 34 months, he had learned to speak, and finally said –Mom‖ and –Love you.‖ He stopped screaming in the car, and could now tolerate swinging!

But at age 35 months he was diagnosed with ASD and Hypotonia. His to date diagnoses are: Asthma, ASD, Sensory Integration Disorder, Developmental Language Disorder, Hypotonia, Auditory Processing Disorder, Sleep Disorder, Reflux, and they will be ruling out Muscular Dystrophy as soon as he is old enough for the testing. He currently attends a developmental preschool four days a week where they provide PT, OT and SLP services. He also still sees his OT and SLP at the Children‘s Therapy Unit where we got started. The good news is that they have recently ruled out seizure disorder.

Cole is doing very, very well in his school, and the neurologist says that he has made more progress than any ASD child he has seen. He has the ability to speak and be understood 100%. His articulation has issues, but he speaks in full sentences. Before he was diagnosed, he wouldn‘t respond to *any* verbal cues; now he can understand anything a normal 2-3 year old can. He has excellent cognitive skills, including the ability to recognize shapes and colors, as well as numbers and letters in and out of sequence. He LOVES Spider-man. He can access the Internet and find his Nickjr.com website *by himself*, and is currently playing a VSmile game for ages 6-8; he is three and a half.

He has finally made friends. He comes off the bus and gets excited to tell me about his teachers and kids in his class. He recognizes people, and remembers them from other places. In October, my mother-in-law flew in from Florida to help us out while my husband and I had surgery. Today, he wanted to see her; he told me to fly her on the ‗hariplane‘ to see Cole-man. He still isn‘t potty trained, and I would love some insight on how to do that one. We have Spider-man Underoos and Pull Ups. But he just stands in front of the toilet and yells –GO PEE PEE, c‘mon.... dooooo it!‖ He has his idiosyncrasies, but he is my –amazing Cole-man,‖ and I can‘t believe what he has overcome so far.

Piecing Together the Puzzle

by Melissa

We are parents of three sons: Andrew, 13, Austin, 10, and Skylar, 3. Our story of autism starts on August 28, 2001. That is the day one of our loving sons, Austin, came into our home. We are foster parents; the social worker called and said they had a sibling group of 4. One was severely mentally retarded, she said, and she didn't know if we would take him. She was not very trained at all; she believed that he should be in an institution or something like that. After going though all of the legalities of parental rights being terminated, his brothers and sisters were moving to their maternal aunt's home. The state finally picked us as Austin's forever family.

We have struggled with the school system since he came into our home. I am a firm believer that a child will only do what you allow them to do, and that is how it is with Austin. If you want to do it for him, he will let you. The school would use a wheelchair to get him from the special education building to the primary school. After much complaining and telling them that he didn't need it, they stopped it.

Austin is nonverbal, but that doesn't mean that he doesn't understand you; they often mistake that. After much of my own research, I have a different diagnosis then the doctor. I know because I spend more time with him than any one. I believe that he is more autistic than MR. It frustrates me that people see that label and think that he should be treated with special hands, and not equal to other children like he is treated in our home.

There was a lady once that worked with Austin for a couple of months, and she didn't know he could laugh! When I found that out, I didn't think she needed to work with him anymore. I have tried to have different tests done on him, but the only thing they will do is an evaluation. I want chemical tests done; they said that they did genetic testing on him at some point, but I have never seen it.

He does a lot of self-stimming, like banging his head, hand flapping, slapping his ears, chewing, and he loves to play with string. He will sit and rip up socks just for the string. He also loves hair, and anything with stringy material. He also loves to rip up paper. He likes little containers, like Play-dough cups. He doesn't like his hair being brushed or cut, and he also hates hats. He loves baths, though!

He loves musical toys, anything with noise, except loud ones. He loves music of any kind; it usually calms him down. He loves to go places, and hates being home all the time. He also loves to play with pool balls! When we go to the coffee shop, he will run to the pool table and try to roll the balls down the table. Austin is very loving, and he doesn't hate anyone; too bad more people aren't like that. All the kids in our home, or that have come in contact with him, protect him. They look out for him, and treat him as an equal.

Unfortunately, we have not found an effective way to get Austin to communicate. He does use a couple of signs for eat and drink. He shows gestures by getting his coat if he wants to go somewhere, or giving us a cup if he wants a drink. We have tried the PEC cards and he just doesn‘t –get‖ them. He receives ST and OT, but they have not found any way that gets him to connect the dots, either. With autism, that is part of the puzzle: getting all the pieces to fit so they understand it. Their way of getting the information is completely different then ours.

The Autism “Life Change”

by Mandi

My son Toby is always busy. He has bright eyes, blonde hair, and is cute as a button. He looks at books and color on walls. He enjoys cartoons. He loves the toy of the hour. He prefers to be left alone to play. My son would live in the water 24 hours a day. He could swim before he could crawl. He, like other children his age, has a blanket he carries everywhere. He can be shy at times; once he gets to know an adult, he may play with you, or may not. He is a strong judge of character and picks and chooses his –safe‖ friends. Toby loves to be held and tickled. He likes kisses and to snuggle. He is really as close to perfect as one child may get.

My son Toby does not enjoy playing with other children. He has a temper. He often will hurt others if he is angry or frustrated. His siblings have learned to defend themselves from birth. Toby does not talk, nor does he immediately communicate his needs. Toby does not eat what the rest of the family eats. He is on a rigid schedule, which, if broken, will make him angry the remainder of the day. Toby is actually a full-time job for a PCA, my husband and myself.

My son Toby is autistic. He is three years old. He attends therapy three times a week. He has made many improvements, but nothing major. Do you know how people never forget their wedding day or the day their children where born? I will never ever forget the day I brought Toby to the doctor. I thought my questions where the normal –nuts parent‖ questions. When the doctor started to ask me questions, my heart started to sink more with every question. In the back of my head I was thinking, *do other 2-year-olds play with other kids, talk, listen, follow directions*? Then the word came up like a swear word, *Autistic*. I drove home with a number for an agency that specializes in special needs kids and diagnosis. I lay in bed that night and cried myself to sleep.

Someone told me early on that this newfound family issue would make or break mine and my husband‘s 8-year relationship, and man, they were right. Telling him was the easy part. Making the man listen was the hard part. He denied everything the specialists and doctors said, and still does. I, on the other hand, do believe what they say. This made it extremely hard.

Then came the blame game. I guess it‘s human nature to have to blame something, or someone. I blamed myself. I had another child immediately after him, and one before. He must have not gotten enough attention. I read books from 15 years ago that confirmed my thoughts, and then the make or break part came in. My husband, the biggest support of my life, blamed me. I really thought I did this horrible thing to my son. I finally called my doctor, after two weeks of this horrible head game I played with myself, and got the information that I needed to realize this isn‘t anyone‘s fault. Furthermore, my husband did admit that he was just frustrated. It isn‘t something a person can do to a child; it‘s just a thing that no smart-as-hell specialist from Harvard can figure out.

In the beginning of our life change (this is what I call the early days of Toby‘s diagnosis), life was so hard. We both worked full time, and raising two other children was hell; ADD therapy three times a week, and then school once a week even in the summer. Busy, busy, busy. I was so tired. My husband worked out of town, and there was only me to do everything. Then came the bills for therapy and doctors; we ended up in financial ruin. Finally, I was discussing these issues with a therapist, and she asked why we had not applied for a Personal Care Attendant (PCA). I was shocked to learn that he may be able to get help. I was so nervous at the place to get a PCA, I spilled my coffee. I should not have been. After three days and a lot of running around, Toby had a PCA come to take him to his appointments, medical assistance to pay the bills, and even a SSI check to pay for his needs. I wish someone had told us before.

My relationship with my son became closer and closer, and it is wonderful. I still took him to every appointment for a year, and loved every minute. Mine and Toby‘s relationship is like no other. A relationship of no words. One that does not include the quick smile to say –I love you‖. Our relationship isn‘t strengthened by the usual child things like a new toy or a special outing. It is solely built on touch, tons of love, and the tons of time we spend together. In the beginning, I would pray for the day my son could say, –I love you, Mom‖; now I am happy with his long hugs and quick eye contact to say –I love you.‖

I believe that I have finally come to terms with Toby‘s diagnosis, and so has my husband. He still questions everything the therapists recommend, and I still do whatever they say. We still are constantly coming up with new ideas for Toby. Trial and error is the key to any life, and there is no difference in ours. Our lives really revolve around Toby in its entirety. At times, I wonder if my other children get enough attention, but between my PCA, my brother, and us, I think they do. Toby has finally started to play with my oldest son Tommy once in a great while, and every time he does my I get butterflies in my stomach. Toby says a word every now and again, and whenever he does we all jump. My 5-year-old son will even come running from another room, –Mom, Toby said a word, Mom listen, Mom, come on.‖

Don‘t get me wrong– our life is no breeze. We had to make a million sacrifices to better accommodate for Toby. We usually rarely leave Toby with a babysitter unless he is asleep. So normally we just take turns going out. Toby will get up and wonder around in the middle of the night if he sleeps alone, so he sleeps with my husband, and I sleep in the other room. Toby does not like to spend a lot of time in crowded places, so I go with the other kids and my husband will take Toby. Toby isn‘t ready for the toilet, and may not be for awhile, so I will wait another 6 months and then attempt to potty train my 4-year-old. Toby does not eat like us, so I have to make him his own meals. Toby does not just go to bed; we usually have to lay with him for a long time and then sneak out of the room. The hardest part of all is that Toby can be very aggressive. He pinches, bites, punches, and pulls hair to others and himself.

Although we have new lives, I would not change one minute for anything in the world. I have grown alongside Toby. Being a young mother of 24 to start out with, I have had to grow up and put my life on the back burner. I am grateful that I have such wonderful, supportive family and friends. I will never forget the early days, and I will never forget my friends and family that listened for hours to me. I know now that our lives are just beginning to change, and will be changed forever, and today I am okay with that. Tomorrow it may piss me off, but today I am grateful. I pray to God every morning to help me be patient and keep me sane, and thus far I am (just barely) making it. My dad is my biggest mentor, and he always uses the line *God will only give us what we can handle*, and although I have questioned that a million times, I have made it through every time.

I hope and pray that other parents like me don‘t feel as alone as I did in the beginning. I hope that someday there will be a support center for parents to know the options out there. I hope that someday there will be a support group for every family, but until then I can only share my story and hope that someone out there can learn something from it. Good Luck to all the new families of autistic children, and remember that you are not alone.

The Fight For Support

by Heather S.

I'm a single mom of two boys. My 10-year-old has high-functioning autism, and my 8-year-old is gifted. My 10-year-old actually developed normally until about the age of 2 ½, and then it was like he stopped developing. The only exception to that was his extreme sensitivity to sound from very early on, which I didn't realize until much later was the result of the autism. He was a light sleeper as a baby, and couldn't stand being in the church nursery with a dozen other 18-36 month old children.

Anyway, as time went on I believed that he was simply a kinesthetic learner -- always wanting to touch and handle things. So for kindergarten, I enrolled him in a charter school that catered to different learning styles. Then the education nightmare began. He wasn't learning well, had speech difficulties and a lack of age-appropriate social skills, and behavior problems. The school's special-ed person was supposed to evaluate him for a few things, but never got around to it. After a second child study meeting 2 ½ months later, she said again that she would get to it. It still never happened. Then, in January, my son got expelled for a certain behavior under their no tolerance policy. What's worse... the school's director had a doctorate in psychology!

At this point, I was wondering if there really was something –wrong‖ with my son, so I searched more thoroughly for a good school setting for him. I got him into a class that a friend of mine taught, and she got the ball rolling. I authorized the school to evaluate him, but it took some tooth-pulling to find out what their suspicions were– Asperger's. Amazingly, at the same time my son's therapist (he was seeing someone for the loss of his dad and other mis-diagnoses) thought the same thing. Now we're making progress, I thought; two people are on the same wavelength!

So I secured an appointment with a child psychiatrist, miraculously one week before the scheduled child study meeting. I never thought I'd say this, but what a blessing! I was able to get a diagnosis before the meeting, and it turned into an IEP. Phew, I thought, there's finally a reason for my son's behaviors and lack of learned skills, other than the presumed poor parenting.

So my son was put into a self-contained classroom, where I thought he'd do well. Wrong! He was getting over his separation anxiety, but the school insisted that he go on meds (I didn't know of other options then), and his teacher wouldn't listen to me regarding his toileting issues. He wasn't even progressing in the general curriculum, which is required by IDEA. And when I asked his teacher about teaching him to read (he wanted to SO badly), she said that she wanted him to write better before she'd pursue that. If I only knew then what I know now! Finally, the end of his second grade year approached, and I was grateful that he'd be changing schools (per the program design). I found out that they planned to keep him at the same school because of a lack of restroom facilities at the other school. *No you don't*, I thought.

I‘m so glad I fought for him to move on. It came in a roundabout way because of the toileting, but he enjoys school, is doing better with toileting (since starting Positive Behavior Support), is READING, has better handwriting, is spelling, and is progressing in general. His speech therapist works on changing the number –free‖ to –three‖ and social skills. And he‘s doing better with coordination with his OT.

And the best part is that with the Positive Behavior Support, I have the hope of turning his behavior around and getting him off the meds that are causing who-knows-what long-term health problems! Of course, there‘s still a long row to hoe. But I was honestly relieved that his problems have a solution, and that his potential has greater chance of being realized as a result, with the right support and programs.

For Those Feeling Hopeless

by Hellina

This is just one of many stories out there. All children with autism are so unique.
Our sweet little boy was born on Halloween night 2000. I was so excited to be a new mommy and experience all the joys of having a child.

The excitement soon turned to worry around the time he turned 5 months old. I first thought that he might be deaf, because he wasn‘t responding to my voice. I would sneak up behind him and clap, and he would turn, so I knew he could hear. As he got older (6-8 months), I noticed other odd behaviors, such as twirling his hands and feet when excited. He also would sit in front of the TV for long periods of time. This is the only thing I could do to keep him calm. He would just sit and flap the day away watching –Do the Alphabet.‖ He could sit there and flap his hands and watch TV for hours if I let him. When I turned the TV off, he would scream, cry and tantrum.

When his first birthday rolled around, he cried the entire time at the party. I would constantly make excuses to family and friends for his behavior - he needs a nap, he is not feeling well, etc. At this point, I knew something was really wrong, and I was fresh out of excuses. I never thought that raising a child would be so challenging! The other moms didn‘t seem to be having so much trouble. I felt like a failure.

I then decided that maybe I need to get him out of the house, and have him socialize more with other children. He was now around 13-14 months at the time. I decided to sign him up for a Mommy and Me at the local library. Big mistake! The kids all played with the toys and each other, my son would run aimlessly around and crash into the other kids. He was completely uninterested in the other children. The other moms gave me dirty looks and ignored us. I left feeling very sad.

At 14 months of age my son didn‘t point, didn‘t respond to his name, didn‘t have any words, had little to no eye contact, didn‘t imitate, didn‘t play with his toys. He would stare at sand running through his hands for long periods of time, would lick doors and other objects, and would do other odd things such as flapping his hands and hanging over the stroller to stare at the wheels turning while I pushed him around the mall. When I decided to stop to look at something, all hell broke loose. He also would have horrible tantrums.

Something was definitely wrong! On the other hand, at 14 months he also amazingly knew the entire alphabet and could point to each letter; he knew every color, many numbers, every shape, etc. I thought that maybe he was some sort of genius. Little did I know that a lot of autistic children have these scattered skills.

At this point, I decided to bring up my concerns *once again* to our pediatrician, who kept assuring me all was well. She would talk a mile a minute, puncture him with a bunch of shots, and tell me at each visit that it was all perfectly normal. –Each child develops at his/her own rate.‖ I left feeling like she never heard a single word that came out of my mouth.

Later on in the week, I shared these same concerns with my sister, and she said that he sounded very similar to a child of a friend at work. The little girl was autistic. I looked up in a medical book –infantile autism.‖ My son had every sign. I knew at that point he was autistic. I had horrible visions of me taking care of a child that would never love me, never speak, and just scream and flap. I couldn‘t believe this was happening to us. I cried like never before.

During this very sad time, I started researching autism on the Internet. I found out that the best chance of him ever being anywhere close to normal would be to get help *very* early on. The next morning, I immediately called early intervention. The evaluators came in and put him through a battery of tests. They gave me speech and special education services a few times per week. The psychologist said –possible PDD.‖ He said the best thing I could do for him was to play, talk and interact with him all the time. Even when he ignored me, just keep at it.

At that point, I tuned off the TV and I became Elmo. I made silly faces, silly sounds, what ever it took to get him to look at me. This was not an easy task. It is very difficult to spend time with a child that wants nothing to do with you. I did this all day every day for weeks on end. Eventually, it actually started to work. He started to respond to me and his name 80% of the time.

A lot has happened since those dark days. I have faced family and doctors all looking at me like I was nuts because I voiced my concerns. Even my own husband had a hard time accepting that our son had a disability. I have even heard relatives say (not directly to me) horrible things, such as we didn‘t love our son because they never see us playing with him. Can you imagine? If they only knew what I had to go through to finally get my son to say –Mommy‖ for the first time, or to hug me, or for him to say that he loves me. The first time I heard the word –Mommy‖ he was 3 years old. It was one of the most exciting days of my life.

It was a long road to finally getting a diagnosis for him. He didn‘t receive one until he was 4. The first developmental pediatrician said that he was –too social‖ to be autistic. I kept bringing him to different doctors, until finally one was over an hour late for our appointment. He was acting so autistic at this point there was no way this one would be fooled. I finally got the diagnoses that I was looking for – PDD-NOS.

Today, my son talks, hugs me, plays with other children, reads, and is one of the brightest 5 year olds I know. He attends kindergarten in a special education classroom (12-1-2). He gets pulled out for speech and OT a few times per week, and has an autism consultant that comes into the classroom 2 times per week. He has been doing so well. We are so proud of him. Don‘t get me wrong; he still shows some signs of autism, but most people would probably never be able to pick him out in a crowd of his typical peers. He is learning how to hide some of the telltale signs (flapping, looking at his fingers). He will now say to himself, –no stimmy stuff at the party, only at home.‘

I have taken the time out to write this because I wanted to give everyone hope. I felt so hopeless 4 years ago. The hardest part is accepting that your child has a disability. If you can make some sort of peace with this, you can finally move on. We moved on and accept him for who he is – our smart, silly, & –stimmy‖ Christopher.

From the Inside of Autism

by Athena I.

This is my autism story....

I was late in walking and talking in complete sentences. I read an early report recently, and the attending doctor had listed me as being echolalic on that report… I might have been three at the time.

I was more interested in exploring the vast world around me than talking to people. I wanted to watch the ants crawl in the grass instead of walking to school! My parents (usually my father, he brought me to school most often) had to escort me to school at times.

I attended a special education school for 8 years. I didn‘t really get into the swing of school until the 5th grade, though by the middle of 4th grade, I was starting to –get with it‖ more. When I first started, I won free trips to the principal‘s office quite a lot, because I could not sit still in my seat! Sometimes a teacher, thinking I was completely unaware of what was going on in class, would ask me a question, and more often than not I could answer it correctly. This is what my parents told me.

Towards the end of 8th grade, I got tired of that school… the silly conference system… being at the highest level in my class didn‘t afford me any special chance to go first. My only problem with that was that we were not allowed to move on to any other subject during a specific time. For example, one could not work on reading during math time. This caused me much frustration, because it meant that I would have to sit twiddling my thumbs, waiting for my name to be called for a teacher conference.

I tried to move into a private school for high school; all of my interviews were disastrous. I didn‘t know how to behave while visiting a school. I wasn‘t really unruly, but I couldn‘t keep my hands away from things… like the spigot for the Bunsen burner! Fortunately, no one got hurt, so I repeated the 8th grade at a public middle school. That‘s the year I really, really got into academia and loved it.

I‘ll have to finish this story sometime later on… for the moment my attention has wandered elsewhere.

Just a Great Little Person

by John

My daughter Amanda was born 7 years ago. She was 2 pounds 12 ounces, and 6 weeks early. She suffered a number of GI problems the first year and a half, before she was correctly diagnosed by– of all people– a psychologist. After the medication started on that malfunction, she grew rather quickly. She is PDD with extreme delays in speech and motor skills. She did not walk until she was 3 and a half years old. Fortunately, she does everything on a major holiday.

She learned to roll over at Thanksgiving, sit up on New Year‘s, walk on the 4th of July, and say –Daddy‖ on New Year‘s.

Because of so many physical problems and her preemie status her first few years, we didn‘t get an accurate diagnosis until last year. Up until that time, we were just trying to keep her alive and get through the day. I think many of you can relate.

The hardest part with the whole situation has been dealing with other people. Family and friends were not very supportive, because– as we all know– they just don‘t understand. But the past year or so, many have seen the light about what a special child she truly is.

She is our only child, and the love of our lives. She has changed my wife and I; I believe she has made us better people. After hundreds of meltdowns, I can handle one without raising my voice, and I have lost that sad feeling. It is part of the way she is, and she is getting better emotionally. At least now her meltdowns have a reason, even if some of them are pretty odd.

I wouldn‘t go through the past 7 years again for anything, but I wouldn‘t have run from it even if I could have. This little girl and my dear wife needed me, and still do.

The best way to describe Amanda‘s personality is that she is a people person. She interacts extremely well with people she knows. She is the darling of my office, and spent countless hours here over summer vacation. Now that she is back in school, people keep asking for her. She has a sense of humor, and she loves to tease. She is a great mimic, and has a cell phone fixation. She loves horses, and is terrified of dogs. She is very loving and physically tough.

All and all, she is a great little person.