

# Hiding in Plain Sight



*In Our Own Words:*

*Women with Asperger/Autism Profiles*

*Share their Life Stories*



Compiled by Nomi Kaim

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AANE

## Note to Readers:

The first 6 of these stories were presented at the AANE Spring Conference *Hiding in Plain Sight: Shining Light on Women with Asperger/Autism Profiles*, held on March 3, 2017.

The remaining 14 stories are being shared here for the first time.

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# I am Asperger's

*by Alyson Nichols*

I am a strong, independent woman—if you don't count the cat, or the hermit crab, or the 200 stuffed animals, 500 books, twelve American Girl dolls I never play with but need to have arranged just so (but not looking at me while I sleep), and thirty-some-odd texts to my mom and best friend daily. I am an adult—if you ignore the fact that I eat frosted flakes for dinner (which falls at two in the morning on a good day), get excited over animated movies, and look away from the screen when any sort of romantic displays of affection are shown. I am a girl, but most of the time I exist in men's flannel shirts and sweatshirts I pulled from the guy's department at stores because they give me more room. I am an English major, and although I can read a book in two hours that takes others days to get through, and get full marks on a paper I wrote in ten minutes, listening to the actual history of literature is incredibly boring to me.

I won't eat burnt food. I can't drink water. I don't wear socks—ever. I would be happy sleeping all day, just as I would be never sleeping again, if it meant I never had to leave my house. I like to socialize by means of an hour-long lunch here and there, and maybe a phone call, but otherwise, leave me alone. I would rather eat fruit cups and cereal than cook because cooking means dishes and time, and I like instant gratification. Sometimes, however, I don't eat at all, because it's too much work.

I am twenty-one. I was diagnosed with Asperger's at eighteen. The diagnosis has only been a factor in my life for three years, but my peculiarities have been here all along. I've grown and changed as the years have gone by, but the core of my being remains the same. Maybe now I have an explanation for my oddities—and an excuse, should someone ask me why the heck I don't wear socks in the middle of winter, or why I must sit in a room with the lights off sometimes—but I have always been this way.

In college, people don't know you have a disability unless you tell them. Teachers often give me strange looks when I take my shoes off and curl up in my chair to get comfortable for an hour-long class. Classmates give me envious looks when they learn I got an A on a paper I finished literally ten minutes before it was due, when they spent two weeks and three research sessions writing it. When I pull my phone out to show someone something and my cat is pictured on both my home screen and my lock screen, people are surprised to see I have a therapy cat, because apparently, I'm fine.

But I'm not fine. I'm functional, but I'm struggling. It feels like I was diagnosed too late for any intervention to help with the severe anxiety that prevents me from getting medical help when I'm sick; too late for any intervention that would make it easier to answer the phone when I don't know the number, or, in turn, to make a phone call for that interview I really want, or even just for a delivery pizza. Is there an online option? Yes, please. It feels like I was diagnosed too late to learn how not to overanalyze every situation; how not to get irritated by

every little thing people do, because people are flawed, and if you want to have friends you need to accept that. Too late for people to understand.

When I introduce myself, I won't outright say I have Asperger's, but I won't hide it. I'll let you know if I have a sensory problem, because I am an adult. I will wear shorts under my skirt, because I'm going to sit like a five-year-old and not give a damn. I will research the heck out of anything I need to know, and prove to you that I know it.

I am independent, but sometimes, even I have learned to ask for help. I am a girl, and I am Asperger's. It just took a long time for anyone to notice.

# Motherhood, Autism, and Me

*by Irene*

Yesterday was my sixtieth birthday. When I was 52, my cousin told me her grandson was diagnosed with Asperger's Syndrome. Within a day, I recognized that my father and my older son had Asperger's. Within three months, I self-diagnosed myself and my younger son as well. Two years ago, my older son was officially diagnosed with Autism Spectrum Disorder.

Discovering my autism led to years of reviewing my life experiences through a new lens. Hundreds of "ah-ha" moments. So much confusion about my past became clear. The gates of self-understanding and self-forgiveness were forever opened. Recognizing autism in my family was an epiphany. A welcome paradigm shift. After so many years of searching, I had finally found my tribe.

In a Women's Studies course in college, we examined our feelings about becoming mothers. Did I want to have children? I took this question very seriously. I didn't know the answer. I knew that I was not comfortable relating to children. I was confused about why that was so hard for me.

When my older sister became pregnant with her first child, I took it on as a project to learn about pregnancy and childbirth by visiting her often. She invited me to be present at the home-birth of her baby. I remember holding my newborn nephew and feeling a great sense of relief. I could do this. I could feel compassion and love for a baby. I loved to hold him and have him fall asleep in my arms.

When I was 28, I discovered I was pregnant with my first child. His father and I were not married. I wanted to start a family with this man, but he wasn't sure he wanted to commit to being my partner. He was embarrassed at social events when I would become what I now call "selectively mute." He questioned my ability to be a mother.

When I was three months pregnant, my partner committed to raising our children together. I wanted to get married, but he was opposed, having had two previous failed marriages. After he saw what I went through to give birth to our first child, he said he would marry me to show his appreciation.

I sought out alternative health choices and natural parenting. Having been at the home-birth of my sister's child, I knew that was a gift I wanted to give to my family.

I am forever grateful for my midwife. Without her I know I would not have succeeded at giving birth to my son naturally at home. I thought I was well prepared for birthing my baby. I thought I was ready to relax and trust my body. I didn't know I had deep hidden fears of childbirth. Days into my very long labor, my midwife told me if my baby wasn't born that day, she would have to take me to the hospital. A few hours later, I gave birth to my son, in our home.

I am also grateful to La Leche League, an organization of mothers helping mothers breastfeed. I credit them for providing a structure and philosophy that gave me the self-confidence to find my way in a neurotypical world. They taught me to trust my instincts and intuition. They taught me that a mother knows best what her baby needs. This is a lesson that has carried me through my thirty-one years of mothering.

For the next fifteen years, childbirth and babies were my special interests. I became a certified La Leche League Leader and attended numerous conferences around the US. For the first time in my adult life, I was comfortable in large groups of strangers. We all shared a conviction in natural parenting. I spent several years studying to be a midwife, but I hit a wall when it came to actually assisting at births. I feared instructing others and the great responsibility of birthing babies. I realize now the allure was the opportunity to surround myself with women who were the most warm and compassionate people I could find, and who included me in their circle. I mistakenly believed I had found my calling and my tribe. I was ashamed that I could not follow through. I wonder if it would have been any easier if I had known I was an Aspie.

I raised two autistic children without realizing their unusual characteristics had a name. How did their father and I miss this? How come teachers and doctors didn't recommend having our sons evaluated? In hindsight, I believe this was because I, too, am autistic. I related to their quirks. I was really tuned in. I was their translator. I gave them lots of breaks, lots of patience, and lots of love.

Unfortunately, my sons' father is not on the same page with me about raising children. Since I discovered autism, he has not been capable of recognizing and understanding it. He blames my parenting for our older son's disabilities. He believes in what I call the "hard love" method. I first learned this when he threatened to divorce me if I did not wean our son from breastfeeding. La Leche League had taught me that baby-led weaning promotes trust and independence. It was clear to me that this child needed all the love and security I could give him. When our son went off to college, his father proclaimed that he could no longer live at home. When our son wasn't able to support himself, I could not agree with not providing a home for him. This caused the breakdown of our marriage. My husband and I separated one year after learning that I am autistic. It took us four years to negotiate our divorce because I was trying to ensure financial security for our son, for whom I continue to provide housing.

My two sons and I have always been a team. Occasionally we have what we call Board Meetings. We discovered our autism together. In 2009, just weeks after learning about Asperger's, the three of us attended our first AANE conference together. It was a full day of Dr. Tony Attwood. I will never forget the feeling that he was describing us to our deepest core. I had felt misunderstood my whole life. I thank AANE for changing that. I know my sons are doing the best they can with what they were given, and I give them the best I can with what I was given. We are all beautiful people. I don't wish to be any different from who I am.

# Letting Go of Fitting In

*by "Eclectic Autistic"*

I have never fit in.

I'm not entirely sure I fit in here, at a conference about women on the autism spectrum. I've never fully identified as a woman, and I found out only a year and a half ago that I'm on the autism spectrum. So trying to tell my story as an autistic woman almost feels revisionist, even when I'm telling the absolute truth.

I grew up not knowing why I didn't fit in. I was just too weird, my viewpoint and sense of humor incomprehensible. Academically, I was "too smart"; socially, I was mocked for my naiveté, teased for my way of speaking, bullied for my shyness. I was seen as a girl, but I didn't think like the other girls. As a teenager, martial arts classes gave me confidence, but I still felt out of place. In the classroom, I could hear the high-pitched whine of every piece of old equipment, every fidgeting student, every scrape of chairs on linoleum—but I was able to get past all that if I kept my head down and studied. I loved to learn, and I did well, graduating at the top of my class.

My love of science carried me to MIT to study physics, paid for by an Air Force ROTC scholarship. For a few short weeks I felt I belonged; here was a place where science was cool, people worked hard, and geeky jokes were appreciated. But it was hard, and it wasn't long before I felt overwhelmed and alienated again. It wasn't just the academics that were hard; it was also the social stress of living surrounded by other people, the extensive planning and prepping to keep executive functioning on track, the frequent sensory overload. Somehow I made it through, but I graduated feeling wrung out, bitter, and undeserving of my degree.

Thanks to the Air Force, I had a job for at least the next four years. I got to do some technical work and learn new skills—and at least in the military, expectations are usually made explicit, social interactions are fairly regimented, and you always know what you're expected to wear. Not being traditionally "feminine" is not unusual for a woman in the military, either. There is a lot of uncertainty, however, in knowing you have so little control over your own career, or even your own life: even in those (relatively) peaceful years, I could not say where I would be stationed next.

So I opted to leave when the four years were up. I moved back to the Boston area, got a job at a tech company, got married and bought a house. It was a lot of change over a short period of time, but I was making my own choices. I had friends. I earned my black belt and began teaching at and even helping to run the martial arts studio I attended. It was a busy four years leading up to my thirtieth birthday, during which—first slowly, then more rapidly—I began to hit a wall.

Some people call it autistic burnout: the point at which all the energy and effort you've put into keeping it together, managing executive functioning and sensory overload...just runs out.



I couldn't do it anymore. Full-time work, martial arts training and teaching, keeping the house clean, making time for my husband—I just couldn't do it.

Perhaps unsurprisingly, my first marriage fell apart around this time. My lack of specific gender had always been with me; among other things, it led to close friendships with men as well as women, and to the certain knowledge that I did not want children. These were things my husband knew about me from the start, but they ended up as deal breakers anyway. Looking back, I'm sure my burnout played a role, too, as well as my persistent inability to explain how I was feeling, or to understand his arguments when I found them irrational.

All this time, I still didn't know I was autistic. I just thought I was a failure, despite all I had accomplished. I held onto my tech job for another year or two, dropping down to part time and hating it more and more. During this time, however, I also grew close to a friend from the martial arts studio, and eventually we decided to move to a rural area and start over on our own terms.

That was twelve years ago. He and I are married now, and live in a beautiful house in the woods. We have struggled for money at times, but did so because we prioritized creativity and happiness over working long hours for other people. When I learned, at the age of 43, that I am autistic, I was overjoyed. Suddenly everything made sense. I started to see my life as a series of triumphs over struggle, rather than a lifelong failure to be “normal.”

I now work part-time for a software testing company that seeks to employ people on the spectrum. This leaves time for several creative pursuits and areas of independent study. I still struggle with anxiety and depression, but as I learn to be my authentic, autistic self, I find new ways to manage that. While I didn't know it for most of my life, autism has helped make me who I am. I wouldn't want to be anyone else.

# Embracing Asperger Syndrome in the Twilight Years

*by Verne Kaminski*

I was almost 74 years old, and I had never heard of Asperger Syndrome. I listened to a book by Michael Palmer, *The Second Opinion*, and as I listened to his description of the main character, I kept saying, "That's me, that's me!" I looked up Asperger's on the web and took an online test. This was a very happy revelation for me, as it really explained a lot about my life.

I am a woman who couldn't accept the traditional role set out for women, as most of my interests were not traditional. I grew up in the 1940s and '50's, in a family with a father who was ahead of his time, as he did not put his daughters into boxes. If he needed help, he would recruit the closest kid, be it girl or boy. I was 17 before I was told that I couldn't do something because I was a girl.

I loved doing things with my father, particularly fixing his cars, and in 1972, at age 34, I was fortunate to land a job with General Motors. It was the time of Equal Employment Opportunity, so this was to my advantage. I was right at home with all the geeks and car nuts. I was fortunate to have good bosses who worked with me and accepted my talents. I was the first woman in General Motors to receive the full Mechanics Certification.

Socially, I fit right in with this technical group of people. However, I was usually at odds with other groups.

I was married twice but determined this was not a life I wanted to lead, as I am too independent. Marriage in my time was different than today. A man's and woman's duties were defined and most didn't cross over these definitions. If I had had a husband who had treated me as an equal and respected my needs and desires, I think I could have had a successful marriage, but this did not happen for me. Women in my era were supposed to get married. A woman could be a secretary, a teacher, a nurse or a housewife. I didn't relate to any of those professions. I do not look down on professional homemakers. Raising the next generation is important. This just wasn't what I wanted from my life. At the early age of 11, I knew I did not want children.

After transferring to a different, less technical division of General Motors at age 46, I experienced some hostilities from co-workers and started going to counseling. I must have bored the first counselor, as he constantly fell asleep in our sessions. So, I stopped going and worked things out on my own. I continued off-and-on to seek professional help and probably had 3-4 more counselors. All they could comment on was that I was being too hard on myself, that I was an intelligent and loving person; none ever mentioned Asperger Syndrome.

After I retired, I continued to feel the hostilities of neurotypical people. I was told I was a know-it-all when I was only trying to be helpful. Many people would ask my advice. Instead of saying "you should" when I replied, I would answer by stating what I would do if it were my dilemma, as I felt this was a softer way to answer—but I guess it wasn't. I received lots of

mean comments and couldn't understand why all of a sudden people were treating me this way.

Then, at age 74, I listened to my “savoir book” and learned about Asperger Syndrome. This knowledge has helped me to understand better the turmoils I experienced in the past and to understand that others think differently than I do; they don't process information the same way. I now try to modify my behavior towards others, and if a person is too difficult to socialize with, I don't continue to develop the relationship. I have a select circle of friends who understand me and take me for who I am without trying to change me. I am a person who enjoys being alone and enjoys my own company. I am quite comfortable in my skin. I tell most people about my Asperger's; I feel it is nothing to be ashamed of. There is nothing wrong with me; I just think differently than most. I guess learning of my Asperger's made me more aware of how obnoxious I could be, when I was only trying to assist a person with something they were having difficulty with. I have learned to mind my own business now and let people struggle to their own solutions.

I have much sensitivity and itch a lot. I used to cry out of frustration; however, this is better now. I cut the tags out of all clothing that touches my skin. I also have problems with nylon threads and those annoying stretchy plastic things they put on shoulder seams to keep garments from losing shape. Noise levels bother me greatly; I don't turn on the radio or TV much at home for background sound. I dislike people touching me when they talk and find it annoying when they get in my face.

Knowing I had Asperger's when I was younger probably wouldn't have made much difference in my life, as the societal atmosphere was what I was fighting. I aggressively went after what I wanted and found it difficult to not do something because I was a girl. I felt that ability should be what made the difference.

I have somewhat entertained the thought of writing my life story. Maybe it would help a girl or young woman understand herself better and help her cope.

# Tasting the Autism Spectrum

*by Valerie MacIver*

I wonder if my message will capture the essence of what it is like for me to be autistic. My thoughts arrive in rapid, random order and end up tangled, drenched in a multitude of emotions. Intense emotions and deep thoughts. Which aspects of myself would be best to portray? My experience as an autistic person involves many ups and downs.

Every day I have different abilities. Some days I have less overall ability than other days. There are days when I can drive myself to Alewife, take the train into the city, and meet up with a friend at a new restaurant. However, there are also days when I panic over the thought of making a phone call to find out what time a store closes. Just because I can complete a task with ease at one point in time doesn't mean I can handle that same task at another time. So there continue to be ups and downs as I discover what works for me as a 22-year-old young woman with autism.

One particularly dark time for me was when I failed ninth grade twice upon re-entering the public school system. It was quite the challenge to give ninth grade a third try, but at least this time I was headed to a new school with more appropriate supports for my needs.

Although my placement at the new program was not perfect, it was a much better fit. For the first time in my life, I was around people who accepted me for who I am. They understood my challenges even more than I did, especially at the beginning. The staff scaffolded my exposure to new experiences within the school setting as well as in the surrounding community. They encouraged me to step outside my comfort zone to meet a greater variety of people. I appreciated being in a program that allowed me to progress at the rate that was right for me. I needed to feel safe but not trapped as I expanded my social horizons.

One of the reasons the program was not perfect was that I was the only girl. I wished there had been other girls to talk to about my problems and interests as a girl, including crushes, fashion, and cute animals. I wanted to have a friend I could invite to hang out after school and go to girly stores at the mall. I wanted to be around other girls so I could learn the social expectations for “how to be a girl.”

In my last year at the program, I was selected for a fellowship at the nonprofit organization Massachusetts Advocates for Children. My year at MAC was one of the best experiences of my life, because my (female!!) boss was passionate about making the fellowship individualized. The staff at MAC saw my potential and helped bring out my strengths while also encouraging me to work on my challenges. They provided me with strategies and support for the difficulties I faced as a young woman on the autism spectrum. I am grateful for the opportunities I had to collaborate with professionals and clients. That year, I took classes at a community college, earned my driver's license, and learned to take the bus to the train to MAC.

After completing my fellowship, I enrolled as a full-time student at Lasell College. For my first semester, I lived on campus in a single dorm room, as this had sounded less daunting than trying to handle a roommate. However, toward the end of the semester, I decided living away from home was too much of a transition.

So for the spring semester, I am a commuter student. Being social, as well as working on academics, caring for myself physically, and keeping my emotional health in check, are all within reach now—as long as I live in my familiar home. I am proud that I have made the Dean's List, with a GPA of over 3.5.

I used to wonder how I would ever catch up with the other students in my classes at high school, and then at college. While I had the academic skills to be successful, I was painfully aware of the stark differences in emotional maturity and social awareness between me and my classmates. I think if I had had more exposure to other girls similar to myself, I would have been better prepared to handle living on campus at Lasell. I was in a rush to measure up to my peers. I thought if I could “just be neurotypical enough,” then life would get easier and more meaningful.

Is that the case? In other words, would I be happier I could just get rid of my autism? I don't know. I have never been neurotypical. All I know is that right now, I am happy. Happy to have the opportunity to give people a taste of who I am as a female on the autism spectrum.

# Wait, I'm Confused: Or, How I Experience Social Relationships

*by Kelsey Oates*

When I was little, I could do anything. I could head down the street to have mac 'n cheese with Adam, I could call up Eric and Craig to build snow forts, and I could get along at any recess or gym class by running, tagging, and throwing just as well as the rest of them.

Life was good, and life was social. Sure, sometimes people would call me weird, but I didn't really have the self-awareness enough to care. For better or worse, criticisms and insults would roll off me and I would go about my merry, dorky way. All I had to do was pick up the phone and ask if a friend wanted to play, and I would be all set.

But then one day in fifth or sixth grade, I asked a friend if she wanted to play, something I had done many times before, and she laughed. Not out of cruelty, just out of awkward surprise at my seemingly obvious faux pas. Apparently, playing had been replaced by "hanging out," a freeform concept that I still don't quite get. It didn't involve running around, it didn't involve pretending, it didn't even involve eating, it just involved ... hanging.

Things got hard in seventh grade, but as the years went on and my mental health went up and down, I always had homework to do, practice to go to, and even though I had problems with a lot of my classmates and teachers, I also got along pretty well with some really cool people and had some amazing teachers. I finally started seeing a psychiatrist my senior year, and I was ready and excited to start college and begin the rest of my life.

Spoiler alert: Things did not turn out so great. I got my degree, but that was about all I left college with. I've made two attempts at a master's degree, both lasting under two months. I've had several jobs, none of which I was able to hold beyond six months. One winter I lived down the Cape and worked in a group home and was so lonely and anxious I gained 35 pounds, so that was fun.

I got diagnosed at 24 and didn't start to really figure things out until a couple of years ago, when I got more involved at AANE. I got to meet other young women who had stories similar to mine. I was able to find great resources and hear from fantastic people who seemed to know exactly what was going on in my head, some of whom are here today. And I've spent a lot of time just trying to understand how my brain works in relation to the neurotypical brain and how best to articulate and adapt to these differences.

As much as I've learned and as happy as I am, there's still one thing that I just cannot figure out, and that is how to create and, more importantly, how to maintain social relationships.

It's not that I'm not social or that I don't like people. Getting along with people, at least on the surface, is not a challenge for me. I feel like I have a pretty solid conversational fluency and I

do just fine in basic interactions. But going from acquaintance to friend still poses a challenge. My parents have to like me. But venture into the world of social relationships, and reciprocity is neither guaranteed nor owed.

Part of why I have trouble forming social relationships stems from the fact that I don't have a regular work environment, and thus do not get to see people with the mundane frequency that inspires true closeness. I've gotten to do this with the groups at AANE, which is great, but it's also shown me how much time it takes for me to establish such relationships.

Part of it, though—and this is something I've realized only more recently—is that I seem to experience and process events in time differently and more intensely than others. I had heard of the social hangover, but I hadn't realized just how physically I feel social interactions and how lasting their effects.

Imagine a memory foam mattress and a hard spring mattress. Press down with the same amount of pressure and the impression in the memory foam will be much deeper and will take much longer to reset than the impression on the hard spring mattress. For me, everything is just more intense, more focused, more exhilarating, more overwhelming, and therefore more physically and mentally exhausting than it is for many of my peers. It can take me weeks to reset from a simple social event, and by the time I'm ready to emerge from my social cocoon, everyone else will have moved on. Maybe I can start a friendship, but building social capital without the structure of an ongoing group is beyond me right now.

I don't really have a conclusion to this story, but I promise you I'm working on one.

I've spent a lot of time trying to figure things out and I've gotten some really great advice and encouragement that I think will help me in this pursuit. I've gotten back into tennis, I'm taking an online class that, if I like it, might lead to an on-campus class. I've also gotten more involved in AANE, which has given me great joy and a newfound purpose.

Maybe I'll have some new friendships to talk about next year, or maybe I won't. Either way, I'll just have to end this story with hope and a “To be continued...”

# My Life

by Amy Frechette

I was 28 years old when I first diagnosed with Pervasive Developmental Disorder, Not-Otherwise-Specified. This was the result of a long process to learn more about my learning style and needs. The process began after I finished my Associate's Degree with a Major in Criminal Justice in 1997. After graduation, I wanted to continue my schooling to obtain a bachelor's degree (something I am still working on!), so I transferred to a 4-year school and stayed 3 semesters. I was academically severed from the school, as my GPA was 1.86.

So, I moved back home and began to try to piece my life back together again. I started working full-time while living at home and bought a new car. My time within the employment field did not last very long; I decided to quit once my relationship with my boss and the job itself became strained. During my unemployment time, I decided to go to the local community mental health center to get some services. One of the services I got was medication, something very new to me; then counseling, followed by some intensive neuropsychological testing.

My doctor gave me a diagnosis but did not tell me what the next steps might be for an adult recently diagnosed as on the spectrum. The doctor was not very clear himself in what exactly PDD-NOS means to someone, how it will affect the rest of her life and whatnot. I still was not satisfied with my new diagnosis and had many questions, and I did not know who could help answer them. I turned to the Internet and found some good websites, such as the Autism Society of America, and later learned of a chapter here in my home state. I connected with mothers of children on the spectrum at first, through message boards. Again, all this was pre-Facebook, so the way we connected was email, message boards and phone calls. I learned as much as I could and am still learning about the spectrum even now.

I did not feel my PDD-NOS diagnosis was appropriate, so then I decided to get a second opinion in Boston. Two years later, I was diagnosed with Asperger's Syndrome, and I felt this was a more fitting diagnosis for me than the first one. This was the mid-2000s and more was becoming known about Asperger's Syndrome than previously. The folks in Boston were spot on, but they, too, did not offer much information about next steps.

Yet, I still kept plugging away in life, trying to find the light at the end of the tunnel, so to speak. I was taking medication to help with my ADD and depression, and also was receiving SSDI benefits so I could get more routine medical care. Being diagnosed as an adult is very hard, as one has missed the window of time for Early Supports and Services, ESS. ESS is critical for young children with developmental challenges and, as years of research have



**Amy, with dog Judah**



taught us, the earlier the intervention, the better the outcome later in life. When one gets diagnosed after early childhood, I think it's harder to obtain services for the individual. It's not ideal, but people are still being diagnosed at many different ages in life. The revision of the DSM-5 helped to clarify what the spectrum is, and now there is only one diagnosis versus 5 from the DSM-IV-TR. As I tell my students, people with autism are on a continuum, and everyone's experiences are very different from the next person's. As well as the differences between males and females on the spectrum, which is going to be (already is) an upcoming research topic of interest.

## Just Trying to Get an Education

*by Anastasia*

From the beginning, my interests were animals, art, music and religion. I remember crawling around on a red carpet at church, reaching up to play the keys of our upright piano and drawing on the walls of my room. Instead of a doll, I lugged my cat Mittens around. I spent my early years in the backyard closely studying the plants, birds, bugs, rocks and gazing at distant mountains. Our dog tried her best to keep me from wandering off on some whim. My family valued learning so we had books: nature and science books, atlases, art books, encyclopedias & a beautiful set of The Harvard Classics. Even as a baby I was fascinated by the pictures in books, pondering them for hours. Later, I realized that by studying images, and particularly art, I could find answers to questions about life and people and the confusing world around me. Here were truths the grownups weren't always willing to divulge. I remember my older sister walking me safely to and from kindergarten. My formal education had begun.

The next summer we moved, driving all the way from Seattle to DC. We stopped to camp at Yellowstone and other memorable places. It was 1953. There I started first grade but stubbornly resisted the whole idea of learning to read, saying I was afraid to read—too big a responsibility! I have always been like that. Many things I fought or feared have been things that I later loved or which changed my life for the better. We'd been staying with my grandmother, an artist, during our house search, but finally we found a home of our own out in the country in Western Maryland. I still remember the long bumpy bus ride to our K-12 school. The teachers were extremely strict and kids who broke rules got whacked. I tried not to space out. That year the focus was reading and I still have my treasured Second Grade Reader—Singing Wheels—about a pioneer family. Once I got the hang of it, I started reading everything I could get my hands on. By age 8 I read at a high school level. My sister proudly showed off my skills to her friends as I read aloud from her textbooks. Every week we left the local library loaded down with books of every kind.

What a joy it was to roam free in the forests and fields. I was pretty good at finding my way home and the dog always came too, so I was allowed to wander to my heart's content. I walked to nearby farms, their old barns filled with hay, chickens, cows and other livestock. I played in thawing creeks, collecting tadpoles and frogs and caring for foundling birds and rodents. We had flowers and a garden and I got to have pets: cats and dogs, goats and rabbits, a whole menagerie. When asked about my future plans, I'd always say I was going to be a veterinarian. I did well in scientific subjects but there were curriculum requirements and sadly, my scholastic struggles began early. I remember being stymied even by third grade arithmetic, especially the memorization requirements. To use my grand-dad's phrase: I had a head of solid ivory. There were respites though, since little kids get to draw and paint in school, I really liked Art. We had music too.

I was not athletic or competitive and because I had no idea how to play with the other kids, recess was a struggle. (Later on, sports, and especially the personal indignities of Phys. Ed were an even worse nightmare.) So usually I headed to the far side of the five acre playground, where cows and horses grazed by a little creek, to get as far away as I could from the pressure to fit in and from trying learn the un-learnable. On rainy days I would haunt the tiny one-room library and I truly think I read every book in it. My favorite was *Les Misérables* by Victor Hugo. I can still see it in my mind's eye, a very thick book with a green and black binding. To be honest though I preferred my own company. The other kids had such childish interests. I was lonely sometimes, but those feelings seemed like a cosmic state of affairs, which had no remedy and was never going to end so I might as well get used to it. I did try to fit in—I joined the children's choir at our church and persuaded my Mom to start a Girl Scout Troop, but I found myself most at home with the kids who were bullied or had been cordoned off as misfits—the really poor kids, minority kids, others who were struggling like me. Looking back I can see that many of the teachers participated in those divisive and hurt full activities—clearly we did have less value to them. Sometimes I spoke up and challenged this marginalizing. I think I was trying to be an advocate for the underdogs, even while I was one.

By the 7th grade, with its paradigm shift of rotating classrooms, subjects and teachers, ritualized teaching and textbooks, inscrutable and endless homework assignments, I was swamped. And worst of all—we had started algebra. Algebra was not just hard—it was impossible. I could not understand it and it could not be explained to me. It was as if part of my brain was blind! I tried to communicate my difficulties but all I heard was “You are just not trying hard enough.” So of course I blamed myself. As my difficulties deepened I got more frantic and more depressed. I remember hoping for the world to end or even for nuclear war (which was already on everyone's mind)—anything to save me from the next test. On top of all that, about a month and a half into the school year, my Dad died. In a way he was the closest person to me. I was his helper for home repairs, but we also had quiet times together, looking at sunsets or the night stars and talking about deep things. I was devastated and inconsolable. I guess I “withdrew” as they say, but somehow I muddled through next few years, often in the shadow and comparison to my brilliant older sister who'd won two scholarships and was the first girl ever to go to college from those parts. When everyone else matured and started dating, I was totally left behind. At a loss to understand this change of focus, the near obsession with this new topic. Sex was way too intense and scary for me. There was one boy I liked, we'd played together sometimes over the years. He was very handsome and quiet. A musician. Now we seemed to be swimming in opposite directions. Looking back, I think he was probably on the spectrum too.

Teachers were starting to ask what we'd chosen for our careers. I was still pretty sure—a Vet! Over the years I'd been caring for animals—practicing my skills. I even talked to our local vet sometimes. I knew this meant college. But already there were doubts—not about my career choice but about the trajectory I'd need to travel to get there. On my sister's visits home from college I'd noticed that she never seemed to talk about her classes and future plans but instead about friends, dates and parties. I was starting to wonder if college was even about

learning. For some reason I thought college was a serious thing, that all the confusing social stuff would finally get shoved aside so one could study. It now appeared I was wrong. Social stuff was clearly the main attraction at college. Was I going to even fit in at vet school!

For many reasons, but mainly loneliness, Mom moved us back to DC, midyear of 1962. I was 15. I had planned to run away that day. But plans thwarted, we landed in a house in the suburbs. Mom got a job, and it was assumed that we kids would just naturally adjust to our new life. I was crushed and frantic—there were no fields and forests. Even the animals were missing. My dog got hit by a truck the week before we moved and my cat, disoriented by an indoor life, had “accidents” so she ended up at cat sanctuary. Eventually I found MY sanctuary spot—the National Cathedral. With its pillars and high vaulted ceiling it was a little like a forest and it was very beautiful and peaceful. The school was something else again. The campus was gigantic and there were thousands of students. I was literally and utterly lost. Luckily I'd signed up for a choir class where a wonderful teacher reached out to me and took me under her wing, corralling the smartest, most popular boy in the class to be my mentor.

I'd managed to get pretty good grades in the country school so they put me in the higher level classes, which was a big mistake. The classes were so advanced they seemed like college level to me. Most of the time I had no idea what they were even talking about. I promptly nose-dived from A's and B's to C's and D's and worse. I repeated classes in summer school with mixed success. I think the summer school trigonometry professor gave me a D just so he wouldn't have to try to explain it to me next summer. At that time, schools divided kids up the into two groups: the ones who were going to college and the ones who weren't. Soon I had been moved all the way down to the slowest track, which wasn't really a track at all. It was like study hall all day. Occasionally there were workbooks but no one was really taught anything, and the students with anything going on—basically the juvenile delinquents—took off. I wouldn't even have known where to go. Occasionally we got to sit outside under the trees or go to the library, so I managed to keep busy. By then, of course, it had dawned on me—it wasn't a matter of whether I was going to fit in socially at college. I was not going to college. I was not going to be a vet. A shattering realization. A frightening prospect. What was I was going to do instead? They had school counselors but they were all focused on the Ivy League bound students, the Science Fair and Honor Society kids. They had no time for study hall losers—who clearly were not trying! I remember meeting with a counselor and making a pitch for real art classes—which they had at this school, but was told those are for the wealthy kids—you can't make a living at that. Maybe you could be a nurse or a secretary, or work in a shop. No one bothered to tell my mom about this downgrading of my career goals and options. I have no idea where the report cards ended up. There must have been some denial in there somewhere. I remember that despite my protestations that there was no point, my Mom, my sister and I went to visit a famous college I couldn't possibly have gotten into, because “that's what people do at your age.” Mom kept saying not to worry—there would be time to pick a school later, “maybe the state college.”

The annoying thing about all this was that my younger brother was having all the same kind of difficulties I had had with math. But being younger he was at a different school. And his school did talk to my mom about his troubles. Granted, they initially said that he was just not very smart—a low average achiever. But she was not buying that and she got them to find him a tutor, and with extra help he did pass his courses and eventually was able to graduate with a real diploma, getting into the school of his choice where he became what he wanted to become. Now has several more degrees in the field he chose. He became a geophysicist. He's been very successful in his career, and has had a comfortable and fulfilling life. Was it because he was a boy—that he got extra help? I think that was part of it.

I certainly wasn't aware that I had a learning disability, though I definitely knew something was wrong. I thought there was something wrong with me mentally—that I was crazy! I know I was afraid to mention my thoughts or feelings or concerns to anyone—something told me it might even be dangerous to do so. (And who knows what kind of diagnosis I might have been given.) So I kept it all inside. I was already a person of few words and I had become good at changing the subject when I didn't know what to say. Underneath, though, I was very depressed, anxious and totally frazzled. You wouldn't think that needing help with algebra would alter the entire trajectory of one's life. But everything snowballed. I couldn't keep up with homework even in subjects I was good at. While sometimes I could get the right answers by drawing pictures or by using my intuition, I soon learned that alternative methods were not only not allowed, you could be accused of cheating if you didn't do it the right way or couldn't “show your work.” Often I couldn't understand test questions because to me they had more than one meaning. I really was trying my hardest—until I no longer had anything to do. There were no tests in study hall.

Not having a future is a very scary thing. I was failing and I knew it. Time was running out and I was very worried. What was I going to do when school ended and I had nowhere to go. How was I going to live? I had a good family, people cared about me. But I knew I was expected to do something, to be something, to make a living and have some kind of life. And no one was taking this problem seriously. Clearly it was up to me to figure out some different kind of life since what was being expected of me was impossible.

Luckily I was not totally alone. That boy who'd showed me around the first days of school, had gone a step further—he'd become my friend! He introduced me to his gang: all the other brilliant creative bohemian types who'd soon be heading off to Ivy League schools and beyond. And miracle of miracles—they liked me! I was a little different but so were each of them. So for the first time in my life I kind of fitted in. At last I had peers and real friends. They thought it odd that I wasn't in any of their classes, but no one else seemed to notice the unique place I'd ended up. So while I spent my days in teacher-less rooms with disinterested or departed students, after school I was with the in-crowd of smart, sophisticated, nice kids. Talking about life and doing interesting things. Being with them made me somebody. Prior to that I had not been sure I really even existed. Of course, they were also into dating and sex and all that, but they accepted me as the wallflower I was. Being in the choir was a positive

experience too. We were pretty good. We often sang at the National Cathedral and twice for the President. As graduation loomed, my friends were more and more involved with making plans: college or travel abroad. I knew that soon they would all leave. I was sad about that. But at least until then I would have a life. I was figuring out that I could make choices and forge a path of my own.

Finally the end of high school arrived and since most of my grades were bad I was told I was not going to graduate. I knew my mother would be beside herself since she really thought I was exaggerating about not doing ok. I shared this news with the Choir teacher. She was shocked. We talked. Then she got mad. She charged off “to see some people.” And somehow she convinced the principal or whoever that despite my poor showing I was not stupid and that I deserved a diploma. So they gave me one! It didn't mean very much and was useless for college purposes because I still had all the terrible grades, but at least I got to wear a shiny blue cap and gown. I sat in the rows with my friends and got my picture taken with my family on the big day.

School days end very suddenly. You think it will be a slow parting but everyone's anxious to get started on their new lives right away. Soon they'd all left for summer jobs and vacations, then on to school. Their life journeys were heading away from mine never to return. Once again I was left behind. Ultimately I decided to get a job at the nearby telephone company. My family was disappointed and a bit horrified. They finally came to terms with the fact that my life wasn't going to work out the way they imagined. It wasn't a difficult job being very ritualized and scheduled. I was fine with it. I thought it a noble life purpose. Connecting people together—getting the fire department to the fire. Important things like that. I fully expected that this is what I would do for the rest of my life. And after a year or so I moved out and got a room near a college that a friend was attending, getting my meals at the cafeteria. Going to work and spending my free days at the library or the Cathedral. I came home every few weeks. Then suddenly in 1968 I woke up. I had started to notice that something was going on in the world. Next thing I knew I was protesting a war, literally on the front steps of the Pentagon. Next stop—a visit to my sister in New York City. Center of the World.

I had finally broken out of my shell but like most hatchlings I was quite vulnerable and at the mercy of predators. I was way too trusting and it was really not safe for me out there. I finally did find a safe place to land. I spent the next 20 years on a secluded organic farm in a sheltered community where I could do the things I was good at—like caring for animals and making art without having to worry about making a living. I got to read and learn about things I was interested in. I tried various kinds of jobs while someone else paid the bills. Finally in 1986 I was strong enough to set off on my own and try managing my own affairs again. I've had quite a journey since then and both good and difficult times and it's still a bit touch-and-go. But I am a survivor. And you'll all be glad to know, in 2009 I finally did get to college—Art School. Currently I'm working as an artist, animal caregiver and Autism Rights Activist.

## Gnothi Seauton (Know Thyself)

*by Anonymous*

I was diagnosed only about 6 months ago, when I was 36, and now I am 37. Since the diagnosis is so new, I do not really feel qualified to discuss in depth everything that it means at this point, simply because I have not figured it all out yet. I realized when I was younger that people do not seem to like me when I am my true self, so I needed to put on a facade in order to garner acceptance. I first had this awakening sometime in middle school, where I was bullied horrifically. I was a shy and quiet child, and identified as gifted, so I had always assumed that it was because I was a nerd. I have never been officially diagnosed with other mental health issues, but I have always set my life up in such a way that it was comfortable to me. I now realize that I may have been hindering myself in an effort to avoid taking too many uncomfortable risks, and decided recently to go back to school for a graduate degree.

I have been lucky in life in that I always had one or two friends who completely accepted me for who I am, and even tended to encourage me. For instance, when my son was a toddler, and I decided to sew all of his clothing; I had a friend who wanted me to use my skills to make clothing for her daughter too (rather than scoff that I was weird). I met my now-husband when I was in my teens, and we share so many characteristics that I never felt painfully abnormal. When we were younger we would wonder what was wrong with others, rather than consider that we were the ones with differences.

Ironically, I discovered my diagnosis through my son. A few years ago, a therapist told us that he thought our son “sort of” had Asperger's, and that information might be helpful, even though the groups available to people with ASD might not be a proper fit. We tried him in a group for children with ASD, and indeed it was not a good fit. However, over time I realized that I share the traits that my son has that made the therapist think Asperger's. So I contacted AANE to find a therapist who specializes in adult ASD, and that psychologist said that she did think I have Asperger's.

I think that having the diagnosis is extremely helpful to me on a personal level, because for the first time in my life, everything that happened to me in the past made sense. Also, I am learning to leverage my strengths and work around my weaknesses now that I am back in school. Apparently I have been offending people all of my life, often oblivious that I was doing so! I finally understand why certain things that seem so easy to others are so difficult for me, and why I am able to hyperfocus my way through other tasks and come out on top. I am not “out” with my diagnosis, except to family and two friends. I think I come off as eccentric, and I have a feeling that some at school may suspect that I have Asperger's, because I am probably not as “passable” as I like to pretend I am. I am not sure. I wish that staring at people in the eyeballs was not the norm, or at least that it was not considered so important.

I would love it if more women would be open with their diagnoses. If more women start coming forward, I think that more of us will recognize the similarities in ourselves, and seek

the correct diagnosis. I am worried about what disclosure will mean to my future career prospects, but I am also tired of posturing as someone that I am not in order to be accepted. I feel like I am blazing my own trail out here, because like my son, I do not quite fit into the ASD groups. Still, I would highly recommend seeking diagnosis if there are suspicions, because becoming more self-aware is invaluable.



# Living in a Human Puzzle

*by Anonymous*

I was nineteen years old when I was diagnosed with Asperger's Syndrome. At the time, I was in treatment at a place called Alpine Academy, in rural Utah, for depression. It was a residential treatment center where I finished my last year of high school after dropping out of my public high school in my hometown. I'd been nervous to get diagnosed, but I was happy that I was finally getting an answer. I got diagnosed at the University of Utah Autism Clinic, with a joint Autism-Nonverbal Learning Disability diagnosis. Being diagnosed at nineteen was a burden in some ways, because I had to suddenly realize my identity and take on all of these burdens associated with the Autism community, instead of having had all of my life to get acquainted with it. But in some ways it was a gift, because I could see my life in a whole new way through these lenses.

Being a female with Asperger's has affected me vocationally in many ways, most commonly getting me into tight spots with my employers when they didn't understand me or my motivations. I used to have a job as a clerical aide in a preparational setting in a hospital, and I got into lots of tight situations as someone who learns differently from others. I also worked in a retail store selling guitars, and I was essentially asked to leave because they didn't understand that I couldn't move up the ranks and didn't know how to deal with people in a professional way. I had disclosed my AS at work before, at the guitar center, but my managers weren't really empathetic towards it, despite the rumor that the manager himself had an Autism spectrum disorder. I am working at a grocery store now, and I haven't disclosed because I am afraid I am going to get skepticism or treated differently.

I have suffered from depression, anxiety, and low self-worth for most of my life; I went into treatment, as said earlier, for manic depression and suicide attempts. I was self-harming and very depressed, essentially convinced that I was worthless. I'd had low self-esteem my whole life, which wasn't helped by the fact that I'd had very few friends—with the exception of my unusual bonds in the Utah center—and I'd been ignored and bullied a lot as I grew up. I was this alone kid who thought differently and spoke differently, and no one understood that, so I assumed I was worthless. I wasn't the only weird one in my school; I was just the only one they didn't understand. So the depression reached a head in my junior year of high school, after going up and down on a roller-coaster my whole life. I am still depressed and struggle with mental health issues, but I am learning ways to manage it. I was able to receive effective mental health treatments, despite the fact that my ASD made it hard for most therapists to relate to me. Most of my therapists, from the time I was eight onward, were horrible, until I found a therapist who was good for me a year ago. He is based in New Jersey, where I used to live until I moved to Massachusetts last summer, but we still Skype. I have received incorrect psychiatric diagnoses by a few professionals unfamiliar with ASD—one of them said that I was “just a spoiled brat with ADHD—NLD shmen-el-d.” Another one said, “There might be a cure

for Autism—maybe there's a pill that can help you make friends!” The professionals I worked with in the past were not understanding, but I got a better therapist after years of looking.

My relationship with my mother is typical in some ways, but it is knotted up by the fact that I have Autism. My mom is a neurotypical, and we don't get along well sometimes. I can be very rigid, and my mother doesn't like that—we get into fights about the stupidest of things, but we don't understand each other as clearly as we should and that complicates things. My diagnosis of ASD has changed our relationship a little bit, because my mother now understands that I have certain differences that will never go away and she needs to accommodate them. We are both stubborn, and we are both unwavering in our beliefs—we need to work with each other and understand each other in order to be able to live successfully in the same house.

Being a female with ASD has influenced my romantic relationships somewhat; most of the people I've had romantic experiences with in the past have had Asperger's syndrome. My ex-girlfriend had Asperger's syndrome, although she was probably undiagnosed with it and had no idea that she had it, and my ex-boyfriend had Asperger's syndrome. My recent partners, especially my ex-boyfriend, had not had a helpful dynamic with me over the course of our relationship, because he was always telling me he wanted to marry me and doggedly pressuring me into doing things with him in the future that I didn't want to do. That being said, I obviously broke up with him and told him I didn't want to marry him, but he still bothers me to this day and asks me inappropriate questions. My ex-girlfriend and I had an interesting dynamic, because we were both interested in a lot of the same things—i.e., Star Wars, the Lord of the Rings, Harry Potter—but she didn't talk that much. She just wasn't that vocal a person, and it stymied me that she would not talk about things that were relevant to us unless I brought them up. We were sexually active somewhat ... we had our first kiss under the roof at a pizza parlor that I took her to in New Jersey. The most helpful thing I found when having relationships with people with Asperger's syndrome was to be very specific. They needed to be specific about everything, to know what was going on and what I meant when I said something that had double meaning. I feel that there is not so much a connection between my ASD and my sexuality, although the media and Asperger's specialists have said there can sometimes be a connection ... I am just a person with Asperger's (an Aspie), who is bisexual.

I am queer in many ways, from the way that I am androgynous to the way that I don't like talking to people who do not have particular mannerisms in common with me. I feel more comfortable with people who are quirky also, who aren't afraid of being different. A lot of people I've met have had very interesting stories, a lot of them with Autism but a lot of them not. Being an Autistic person is especially hard given that I have social anxiety and feel like people are out to get me. I have had spotty experiences with making friends, a lot of which have been disappointing and made me feel very different. I have had fickle friends in the past, who have shown interest in me one day and then none the next. I have had experiences with being manipulated, but I've learned the only way for people to respect you is to respect yourself.

# The Aspie Who Came In From the Cold

*by Cheryl Abel*

People tell me that they never truly understood Asperger's until they heard the story about the day I realized I was different. In Summer 2011, on the day that changed my life, I was looking for a job. I received an email from a sweet, cheerful woman, Elizabeth, whom I used to work with. She now worked at the Sheriff's office, and she invited me to meet her coworkers and apply for a clerical job opening.

The next day, I showed up wearing a beautiful navy blue suit, armed with copies of my resume. Elizabeth hugged me, then introduced me to her coworker, Kelly. Kelly asked me how I knew Elizabeth, so I told her how we used to work together and how great Elizabeth was. Kelly said *oh she's not that great*. And I countered *yes, she is*. Kelly responded *in fact, Elizabeth is kind of a slacker*. I told Kelly that she must be misreading Elizabeth. After we went back and forth a few times, I realized Kelly was kidding and looked impatient. I quickly added *yeah, Elizabeth really isn't that great*. Everyone looked relieved. Then Kelly said something about what she was working on. I kept talking about Elizabeth until I realized Kelly had turned away. I missed the signal that she was done talking.

Then I met Elizabeth's boss. We also talked about how great Elizabeth was. Again I kept talking but realized too late that she had already signaled that she wanted to end the conversation. Everyone looked annoyed.

Afterward, Elizabeth and I sat down to eat our sandwiches. Again I was slow in interpreting her signals, constantly trying to catch up. By the end of the lunch, I felt exhausted. A dense fog had settled in my brain.

I drove home and thought about how I've never held down a job for long, despite being bright, skilled, conscientious, resourceful, and eager to help. At work, someone would inexplicably become irritated with me. After that, they'd watch me, looking for more evidence to support their dissatisfaction with me. Others would notice and also adjust their perception of me. Sometimes it got so bad at work that people would go out of their way to openly ridicule and harass me. Even clueless me couldn't help but sense the growing number of hostile coworkers, but I could never figure out what happened, much less what to do. I could almost hear my gentle grouchy Dad yelling, "Don't you have any common sense?"

My childhood was no better; I was ridiculed at school. In sixth grade, a thoughtful girl, Rhonda, once asked me, dismayed, "Why are you so goofy?!!" I read countless psychology and self-help books, searching for the right formula for how to interact with people. I used to tell family or the occasional friend about my difficulties, and they'd tell me that I brought it on myself or I had a persecution complex. So I learned to keep my mouth shut. And I kept reading books, trying to figure out what I was doing wrong. Deep down I was terrified that I'd never be able to fix it or even figure it out, that I was doomed to being an outcast, never

understood, never loved. As more and more years passed, I eventually let go of the wistful hope that people would be nicer once they got to know the real me.

After I got home from visiting Elizabeth, I made coffee for the brain fog and sat, while I continued to look over memories of past job failures. This time, however, a new piece of information was emerging: I was missing social cues. And people usually got angry or irritated when I missed.

As I added the same missing piece to each bad memory, the memory finally made sense. Then another puzzling memory would immediately take its place, begging for attention, for resolution, as if it knew that I might finally complete the puzzle. I started to see a bigger picture and felt relief from finally understanding how, over the past fifty plus years, people misunderstood and disliked me. But I also felt an overwhelming grief as I tallied all the losses. Why had I never done this mental math?

Well, I already knew the answer. I remembered the night, over 30 years ago, when I stopped doing the math of adding up my failures.

At the time, I was in my 20s. Because of my poor people skills, I would get only temp jobs at the worst dysfunctional corporate environments, jobs that no one else wanted. On that day, my latest supervisor had, speaking in incomprehensible code, seemed to condemn me for something I couldn't figure out, and two of my co-workers had ridiculed me in the elevator. I had no clue what was going on, or even what to ask.

That night long ago, like every night, I lay awake tensely sifting through the day's poisonous failures, my daily futile search to understand what happened, cringing, feeling the years of shame and failure eating away at my life force, my life spiraling downward. The way people treated me was getting worse and I had no idea why; I felt very alone and scared. I wondered, how was I to keep heart and the will to keep going?

I'd start a new job thinking, *This time, someone will finally notice how much I give.* But eventually they'd forget all those times I'd eagerly volunteer my help without hesitation, gladly share my skills and knowledge, and kill myself to get things done; it was as if they'd never seen how I treat everyone with kindness, pitch in with my best ideas, volunteer for the most unpleasant menial tasks, even my clumsy attempts to be friendly. By that time, my self-esteem and hopes for a new beginning would be destroyed by the constant and unrelenting misunderstanding and scorn from others, my psyche would be scrambled and *very* confused, and deep depression and shame would disable my ability to do a good job; by then, they'd be justified in firing me.

So that very night, as I lay there wondering, I thought of an ingenious solution: If I ignored all the abusive words, acts, and attitudes from other people, I could keep moving. Even better, I could pretend that my shame and failures did not exist. I must never look back. If shame or failure dared to creep into my mind, I'd quickly shove them out, close my mind, and refuse to listen. They were banished! Just like that.

From then on, it was a Sisyphean task to shut up those evil twins, Shame and Failure. Although they kept grabbing at me, night and day, I never allowed myself the slightest peek, knowing that my spirit wouldn't survive. If there were ever an Olympic contest for shutting things out, I would have won, hands down, absolutely no contest.

To help drown out jeers and accusations from the “twins,” I began to live for tomorrow, looking only at future possibilities where I could also squeeze out bits of (borrowed) hope and happiness. If someone was rude to me, I'd focus on kinder people or things to come. If I lost a job, I'd just get another one. I wore out my welcome at a minimum of ten temp agencies and three cities.

From that night onward, for the next 30 plus years, I was always running—constantly one step ahead, frantically trying to stay out of reach from the poisonous clutch of fear and shame.

So now, there I was, sitting and drinking coffee, looking over the past wreck of my life, my failed experiment in tunnel vision, wondering *What the hell am I going to do?*

I couldn't simply tell everyone up front, “Hello. Pleased to meet you. By the way, I miss cues so, if I piss you off, I apologize in advance.”

That wasn't going to cut the mustard.

I didn't yet know about autism. Doctors didn't start looking for autism until the mid-90s, focusing mostly on children; by then, I was over 30 years old. Most of my generation was only dimly aware of autism.

I was thrilled that I'd finally figured out most of what was missing; it was only a matter of time before I'd have, in my hand, THE formula for how to interact with people. My search was almost over. It buoyed the hope that someday my life might get better. I was tired of running away. But how could I fix my life? I felt like the solution, and a wonderful new life, were just beyond reach, if I could only figure out what to do with the new puzzle piece. What else was I missing?

To find the solution, I needed to figure out exactly what the hell was going on. I looked more closely at the problem.

I remembered back to when I was 19 years old, working as a clerk for the federal government. Even back then, I was under siege every day, a typical day filled with confusing moments. In a rare beautiful moment (before I messed it up), Paula, a kind older woman, told me about how her job was being posted for application, although she wanted to keep it. I immediately told her I'd apply for it, because I knew I was expected to be competitive. She gave me a strange look. I was already accustomed to strange inexplicable looks by then, so I just mentally tossed it into the ever-growing pile of “inexplicable stuff I'll never figure out.” A week or two later, however, I realized that I had betrayed Paula's gesture of friendliness: she shared with me something about her life, and I threw it back in her face. I wanted to apologize, but by then, I

could see in her face that familiar look of estrangement and wariness that I had come to expect from everyone. Besides, what could I say? Who's going to believe I didn't intend it? Can you spell f-u-t-i-l-i-t-y?

I reviewed the incident even more closely: I, the moron, said something thoughtless although I knew better. Also, I noticed her strange look, which gave me a signal. However, I didn't interpret her signal until *much later afterward*, when it was far too late to prevent it. Bingo! There was a delay in my central processing unit—my fracking brain was slow!

At that moment, I realized there would never be a solution to this problem. My wonderful new life came to a grinding halt. Worse, though, now I also realized how I would continue to miss literally millions of moments to connect with others. Relating to other people was always going to be difficult and perilous. My SAT scores were among the top 5% in the U.S.; my people skills, the lowest 5%.

Again, I looked out over all the devastation and waste spanning all the years of my life. Well, at least the shame was gone; it could no longer grind me down and tell me *It's your fault* for all those times I had said and done the wrong things and made bad decisions. The shame had lost its power, and for the first time in my life, my spirit felt lighter, freed from the Sisyphean task of smothering the cries from so many bad experiences. I simply wasn't going to swallow all that blame and shame any more. Plus, I knew what to look out for, so I could take steps to reduce the damages.

The job at the Sheriff's department never materialized, but that was okay because I had a new job—to repair my life. For the first time in years, I felt hope for my future. In order to get help, I besieged my HMO with countless requests. Finally, in 2013, I was diagnosed with Asperger's, ADD, and PTSD.

These days, I'm training myself to recognize more of your cues when I trigger your irritation or anxiety. And to say things to ease your social fears. I still struggle daily to speak up so you don't interpret my silence or ill-chosen words as uncaring or even harmful. I also struggle to filter out what I *shouldn't* say.

Best of all, now I wake up in the morning without dreading yet another onslaught of sneers, snubs, slights, dislikes, and insults. I'm slowly beginning to trust that people won't inevitably turn on me. Also, I no longer call myself a moron; instead, I console myself and say, hey, maybe you missed it this time, but you're getting better at responding to cues.

I met with Elizabeth again a few years after my diagnosis. She's still a cheerful, unfailingly kind angel with an uncanny ability to discern between superficial versus essence.

Unfortunately, my diagnosis came too late for my 27-year marriage. I had thought that, aside from the occasional tiff, we got along beautifully. So my husband's departure was a complete surprise. How did I miss all the clues? Was it because I had become a master at tuning out the lifelong parade of negative feedback and setbacks?

Before my husband left, he told me his friends didn't like me. He also cited a lack of intimacy, which I understand now. I never shared with him the details of my daily living hell, because I never wanted him to see me through the eyes of others.

I hope that the next time you meet someone like me, you will overcome your fear and suspicions long enough to look beyond my silence and my clumsy words.

*Cheryl can be reached by email at [elastogirl1@gmail.com](mailto:elastogirl1@gmail.com).*

# Aspie Enough

*by Kathryn Brewer*

My name is Kathryn Brewer. I am a Change Management Consultant living and working in Boston. I work with organizations leading technology projects and with individuals coaching them on specific goals.

I find the natural unfolding of my career interesting, as I fell into technology leadership quite by accident. See, I was the person whom everyone else thought was so organized because I always asked, wrote down or knew who was doing what and when. As a woman with an Autism Spectrum profile, I've never *felt* organized a day in my life, regardless of all the positive feedback that I have received that says otherwise.

It wasn't until my son was diagnosed with Asperger's Syndrome that my life started to make some sense. Before that, my life seemed very akin to the Lemony Snicket books named "*A Series of Unfortunate Events*."

My track record with relationships was terrible. I never got along with my parents and was glad to leave home at 17. While it was easy for me to make friends, no one ever kept up a long-term relationship with me, nor I with them. My first husband and college sweetheart left me two months after we were married. My second husband and father of my two children, left four days after my daughter's 2nd birthday which just also happened to be the Friday before Father's Day. With so many people willing to part ways, it was easy for my parents and others to assign the blame to me.

Thus, my son started kindergarten without his father and with me as a bad mother. He continued to get into a lot of trouble so I moved us to another area with good schools thinking that this would help. It didn't. All the unsolicited parenting advice I received reinforced my belief that I was a bad parent. All this negativity merged into a tsunami that quickly and savagely destroyed what little confidence I had in my ability to be a single parent.

I went back to our family doctor to see if she could help us figure out how to deal with these continuing issues only for her to say that his symptoms were common for children who have autism. She went on, as if she hasn't just dropped a bomb in my lap, to explain that she has suspected that my son had Asperger's Syndrome since he was three and a half. She had chosen not to mention it before now because she didn't want to overwhelm me due to all the other issues our family was facing because of my ex-husband. I stared at her in shock as my son was seven.

While I was reading up on Asperger's to better understand and support my son, memories from my own childhood kept replaying in my mind as I learned more about the behaviors of children on the autism spectrum. I spent about three weeks crying for myself in regards to my own childhood and adult traumas. A lifetime of being bullied and taken advantage of made so much more sense as I learned that it was common for Asperger's people to be treated this way by otherwise decent people.



As soon as I could pull myself together, I pursued testing and received my own Asperger's diagnosis at age thirty-five. Armed with this new information, I was able to reframe many of my past experiences into a more neutral light.

Meanwhile, I was left on my own with two difficult yet wonderful kids. While my son had his issues, my daughter was by far a greater handful. The frustrating thing was that it was so much more difficult to get help for her. I had to practically do a mix of begging and threatening to get our new primary care doctor to refer her for testing.

Even once she received her Asperger's diagnosis it was still much harder to get others to accept and help her, even among autism professionals. One went so far as to say that the science showed that girls just didn't have autism except in extreme outlier situations. I told them based on my experience their science was wrong.

At this point, I hated my life. I was always angry at having to give up my wants and needs again and again. One day, I had a meltdown in my living room and heard myself say out loud that I hated my kids.

Immediately, I knew I had gone too far. I loved my kids. I was just tired of my kids being the ones that were doing everything “wrong” and overwhelmed because I was the one expected to “fix” the situation. Couldn't anyone see that I was in over my head with my own issues much less able to handle theirs? It was as if I didn't even exist.

I couldn't find anyone to help me. I disclosed to a parent employee of the Autism Society only to hear her say “Surely you don't have Asperger's—you just confused it with having traits.” I also reached out to a TEACCH support professional and was told my issues probably stemmed from just being stressed out from being a single parent of two kids.

The straw that broke my resolve to get help, was when my holistic doctor said that my test results looked the way he'd expect from someone on the autism spectrum but his interaction with me didn't meet the same expectation. Out of shame, I never went back to any of these institutions for help again.

Hurt, embarrassed and confused, I found myself at a local autism conference. Liane Holliday Willey was the keynote speaker. I was moved to tears at the similarities between her experience and my own as she spoke. I got over my own shyness to thank her for sharing her experience. Luckily the timing of her talk was perfect as it helped me to validate my own knowing when no one else around me would.

Shortly thereafter, I had a very difficult time at work due to not being able to navigate the political climate. I had also had a falling out with another parent of a special needs kid due her not being able to deal with my Aspieness. Pushed to the edge by the school always sending the problems home instead of handling them, I decided to move us to Boston where we could just start over.

At age forty-four, nine years after my initial diagnosis, I have finally found acceptance and support in the AANE community. I have gotten off the black and white see-saw of whether I am an Aspie or not and decided I am *Aspie enough*. Because of that decision, I am now

learning to manage my Aspie needs. Finally, I feel as if the missing pieces of my life are coming together.

I still have issues that I struggle with daily. I regret that I am just now learning how to regulate myself emotionally and sensory-wise. With sadness, I wonder what could have been possible for me and my kids if I had known how to address these issues for myself sooner. On the flip side, I have been a great resource for my kids, providing them a roadmap created from my own personal experience.

As a woman, I am proud to have found my voice within the Asperger's community. Ironically, my neurodiversity allows me to successfully navigate transformational change. I enjoy sharing my Aspie gifts as a change agent by valuing and believing in people ... especially myself. It is my hope that you will join me in doing the same.

# Oops, My Asperger's is Showing!

*by Kimberly Gerry-Tucker*

There are certain things “never to be spoken of,” like Voldemort's name in the Harry Potter series.

But who gets to make the rules in real life as to what is okay to speak of? As to what is allowed to be frowned upon?

I will preface this purge by saying I'm a person who feels hobbled some of the time by the diagnoses of Asperger's and Selective Mutism. Don't get me wrong, I fully embrace my whimsy, my attentiveness to details and beauty, my insights, my immersion in fascinating topics, my uniqueness, too ...

However, if you are “neurologically typical” (NT),

Imagine FEELING deeply, but there being some people who don't think you're affected or that you notice, or that you are real, or that you feel at all—because they don't see it.

I'm telling you: There is such a thing as feeling in a way that is delayed, by minutes or even weeks or more, depending on how weak or strong the processing is. This means the emotion isn't SHOWING in the “appropriate” time frame. But it is appropriate, entirely appropriate, for some folks like myself. Just accept that not everyone is like you. And that there is nothing truly so odd about it. If you care to put it in perspective. I do this every day, after all: accept not everyone is like me.

Diversity is the factor—it is why human beings came about in the first place!

Imagine, too, a marionette with the strings cut. I am not saying I am puppet-like; I am thinking of connections, of the strings used, of the hands that operate the connection to give the limbs the movement. You can will the marionette to appear to be moving, but if the strings are cut, what to do? Put in more effort; that's what. And move those limbs yourself.

A connection can be a bullet train from here to there, or the Pony Express. It can also be a weak wifi signal, a crossed wire, or, like I said, trying to operate a marionette by manually putting every limb (or thought or feeling or emotion) through the motions because the strings are clipped. A laborious way to make that marionette appear fluid, right? Well, it gets the job done, even if it may appear to some people as “rigid” or “stilted.”

Getting the gist of how tiresome life stuff and adulting can get? Oh, it's mentally draining. Downtime, to simply be, is crucial. Meltdowns are inevitable. But I get along fine. I really do.

Certain things seem secretive, even taboo—like “scripts,” for example, and how they ENABLE a person like myself and so many others to get along in the world. I mean, a magician doesn't like to give up trade secrets.

“Scripts” include what others may call “mimicking,” “parroting,” “being overly formal and/or polite,” or “borrowing learned catchphrases and/or behaviors.” And yet all of this is, to me, a very real, an ingenious, an EXCELLENT survival tactic—indeed, not only a survival instinct and coping strategy, but, when decoded, a brilliant response to feeling hobbled. A self-preservation mechanism.

We all share the world and are getting by by going with the flow, blending with the scenery, flying with the flock—which at times feels necessary.

Whether one is NT or, like me, has Asperger's and/or Selective Mutism, everyone should recognize the personhood in every person. It's not so important that you point out that you see what you perceive to be flaws. One comment or hurtful word can unravel a person like me.

Example: “You just don't know how to give a proper hug, do you?”

Well, I could say that hugs often leave my skin in a state, like big indents in my skin that won't pop back out.

Oh no, my Asperger's is showing!

Well, what's wrong with that?????

I'm as real as anyone else, even if not everyone can truly hear or see me, and sometimes it's okay to say Voldemort's name aloud. It has less power that way. At least I think so. Name it, and some fear dissipates. But don't throw stones with your bafflement of someone's differentness. I assure you, if they're at all like me, they try harder than you'll ever know to keep their metaphorical ball properly inflated to last through the whole game. Keeping balls in the air is tiring, and most of the time deflation is inevitable. You may occasionally hear or sense a metaphorical “Pppffttlll.”

Yes, my Asperger's shows.

I'M okay with it. I ask certain people: Why does it bother YOU so much?

# Life as an Autistic School Teacher

*by Lesley Baird*

I am a special education teacher, and I have also worked in various programs for adults with disabilities. All my life I have been drawn to people who are different, either by physical challenges, developmental delays, or anyone who happened to be quirky— anyone who marched to their own drum beat. Up until the age of 56, I assumed I was neurotypical.

In the winter of 2016, the year my whole understanding of who I am changed, I was preparing a lesson for my 9th grade English students. It was a small, pull out class for students who were not able to work at their best in a general education classroom. Since two of my students were diagnosed with ASD and one I felt sure was also on the spectrum, I decided we would read Mark Haddon's *The Curious Incident of the Dog in the Night Time*. This would hopefully be an opportunity for the class to get a better understanding of what autism is. While looking for some background information to introduce the concept, I discovered a list of traits typical for women on the autism spectrum. Over the years I'd taken some of the online tests just to see how I'd turn out, but I never took them seriously. But this list—it was a life changer! I had nearly all of the traits! At this time I had been having a difficult time with paperwork, and this was not ingratiating me to my boss, so I shared my ah-ha moment with the school's autism specialist. He recommended that I get evaluated as soon as possible. I was lucky to get a diagnosis within a few months, and I realized that I have more in common with many of my students than I ever would have imagined!

I read incessantly on autism in both adults and children. Some books I read repeatedly because they are so interesting. The more I understand autism and its so many nuances, the more I understand my students. A few years back I worked with a group of teen aged boys who were severely affected by autism. One, who I'll call Peter, was a small, wiry African American who was nonverbal, had a smile that could melt the sternest of hearts, and he loved basketball. He was very shy, but he and I hit it off. I could watch him shoot baskets all day – he never missed! I counted once – out of 100 shots, he made 99! However, he was unpredictable, and might turn and punch me in the face with no warning. (For reasons known only to the administrators, they took these kids to a brand new building they'd never seen before, and introduced them to a brand new staff they didn't know. Not the best idea, as anyone who knows about autism would agree!) I recently read a description of a woman's reaction to sensory overload—she'd find sometimes a huge fit of anger strikes her and she wants to hit someone. She feels it in her hands, and has to really hold herself back at times. When I read this, I understood exactly what had been going on with Peter. I always knew it wasn't anything personal, and seeing this phenomena described by someone else was a satisfying experience. Years later I ran into Peter at a different school where I briefly worked. I went to say hi to him. His smile was the same as always, and he had grown a beard—so grown up! I wasn't sure he remembered me until a couple of days later when I felt someone

touch my hand. I turned, and there he was, his eyes saying “Hi, Miss!” It was such a privilege to work with him!

My employment history has been rocky, to say the least! After college I wanted to “work with people,” just like everyone else in my graduating class. Eventually I discovered human services. I worked in a day program for adults with disabilities. I LOVED it! The pay was rotten, but my then husband was doing fine, so I settled in and did my work. I set up a computer lab to train people in data entry. No one had ever attempted this before. I begged and borrowed to get equipment, and soon got things running smoothly. One gentleman designed the cafeteria menus every day, and another (who was quadriplegic and non-verbal!) kept a database of fuel consumption for the agency's fleet of vans. This job lasted a long time, though too frequently my mouth got me into tight spots—like many Aspies, I have a talent for saying the wrong thing at the wrong time to the wrong person.

Eventually, I moved to a new area, got divorced, and gave serious thought to what I wanted to do with my life. I could make more decisions with only my interest in mind, and I pondered what would be satisfying, and would pay the bills. I considered nursing and teaching, the two professions I swore I would never work, being a liberated woman of the late '70s. I chose teaching because I'd loved working with adults, and I imagined that helping kids might bring them more opportunities not available to the adults I'd worked with.

First teaching job: Alternative school in Holyoke. It lasted seven months, then the school population dropped to nearly nothing, and I was laid off. The school closed shortly thereafter. Then I worked at Westover Job Corps, which I enjoyed, and I learned more about street gangs than I ever imagined. I got to know quite a few kids and I learned a lot from them.

Unfortunately, verbal abuse from other kids and lack of support from administration forced me to resign. I worked part time in a DYS facility for girls (and was not asked back due to not being a good fit); I worked for a month at another alternative school in Holyoke where I was let go due to not filling out my very first lesson plan correctly. There was something seriously fishy with how that job ended ... it took me months to get any kind of understanding about it. Meanwhile, I subbed, was left without income once summer arrived, got a summer job, but before it began my car got repossessed! I spent my last \$300 on a clunker, worked the summer job, and got paid roughly a month after it ended. That fall, I worked in a public school—and was laid off by spring. The following year I worked at another alternative school; I wasn't asked back because I raised my voice to a student. The year after that was the year of my “epiphany,” and although I struggled with paperwork and organization, I was sure I'd be asked back. I wasn't. Due to organizational skills (executive function), and not being social enough with the other teachers. (Social skills: What, they wanted work to be a party?!) I'm not at all sure how my current job will work out. I disclosed during my interview, because by this time I felt if they knew of my eccentricities up front, that might lead to better understanding. I have a great relationship with my supervisor, but I really HAVE struggled in relationships with co-workers. I love originality, and don't see the value of doing exactly what the other teachers are doing. Nonetheless, I'm working on being more open to collaboration.

Looking back on so many past jobs, I remember doing some really odd things. I've been known to make random (and not always appropriate) comments, I've been unexpectedly friendly to some (the autism specialist I worked with last year told me he knew I was Aspie from the moment he met me!) while I've been not so friendly with others—I was recently told that I'm unapproachable. One time I decided to teach a particular book after my supervisor had recommended something else. With a better knowledge of my nature, I can completely see that most if not all my mistakes of the past were more likely than not expressions of autism.

The one thing I would like to change in schools is to educate the general education teachers, parents, and other neurotypical adults in a child's life. So many genuinely don't get ASD students. I've heard them saying “He's just doing it for attention,” when a kid picks his nose to give himself a nosebleed. (Actually, he does it so he can go home and play computer games. All you need to do is ask, and most kids are happy to explain themselves! Getting the parents to understand this would be helpful – if there's no computer games, he'll be more likely to stay in school!) Other things I've heard include “He's just lazy,” “She could do better if she'd only try” ... we need to teach empathy to adults who work with kids on the spectrum. Why is the student “lazy”? Is the work too difficult? Too easy? One student would do absolutely nothing unless it was related to The Wizard of Oz, his topic of interest. I gave him as much input as I could when choosing reading material—some would say I'm coddling him, but if he's not willing to work on a teacher's terms, why not work on his terms when reasonably possible?

There is so much to learn about autism, and so much to share with the neurotypical world. I hope to focus much of my work on older students and young adults. How do they get from the basement computer to the working world? How do they learn to live on their own? What kind of housing is available for older adults? How do we make the corporate world more autism-friendly? These, and so many more questions, must be answered if we are hoping to have a society where neurotypical and neurodiverse can happily coexist.

# My Autism Life

*by Linda*

I'm a forty-eight-year-old woman with ASD. On September 16, 2016, I was diagnosed with Asperger's Disorder. When I was six years old, I was misdiagnosed with a Nonverbal Learning Disability. However, My current psychiatrist noticed some Autism traits in me, for which she sent me for a developmental evaluation with a neuropsychologist. Therefore, the test results came back positive for Asperger's Disorder.

I rock myself to self-soothe and I have a fixed interest in stuffed animals (sharks), which I use to comfort me when I isolate myself.

I have special abilities in music and math, I'm a walking calendar, and I have excellent abilities to memorize dates and birthdays. I'm fascinated with sharks. I have an Associate of Arts Degree in Chemistry. I graduated with honors. The work I do presently is medical accounting and medical coding. I hold two coding credentials. I've been married for twenty-three years and we have three cats.

The ASD diagnosis gave me more insight into the problems I had as a child and now as an adult. I didn't understand my level of discomfort in social situations. I like to isolate myself in order to shut down my senses when I feel overwhelmed. For example, I was in my neuropsychologist's office with my husband and I thought he was tapping, but the doctor said that he was not tapping. She said that there was construction three offices down the hall. The neuropsychologist also said it was sensory stimuli ASD which I was experiencing. I have always felt different from my peers. For example, I started playing the flute when I was eight years old, and reading music too. I have difficulty recognizing social cues and gestures. For example, when I was in high school, I was working for a bakery and I didn't realize my supervisor was angry at me until I was written up. In conclusion, it was a sigh of relief to find out that most of my social and communication problems were due to ASD in my life situations.

I have three lovable cats: Tigger, Midway, and Bo. Tigger always finds away to get into trouble. All three cats are from the same litter. My husband and I got the cats when they were four weeks old. I named the cats: Tigger, because he looks like a tiger with gray and black stripes, Midway—black and white fur—aircraft carrier from World War II, and Bo, a big robust cat with black and gray coloring. The cats provide comfort when I'm stressed.

Tigger knows how to open doors ever since he was a kitten. He's a Hubble, amazing cat. The cats' ears have incredible sensory functions and also the cats' whiskers have the same abilities. The walls have ears, which brings back good memories of life. I love to hear the cats purr. It brings happiness to me. In summary, I absolutely love my cats.



# How Being a Female with Asperger Syndrome/ASD Has Affected Me Vocationally

*by Michelle*

As I am a late-in-life diagnosed adult on the autism spectrum I spent most of my life not understanding why I had such difficulty gaining and maintaining employment. Now with my diagnosis and subsequent self-education about Autism Spectrum Disorders, I understand how the autism played its part in this kind of “glass ceiling” that I kept bumping up against. But the other half of the scenario is the ablest attitudes and prejudices of non-autistic people—this unwritten assumption that everyone MUST fit the mold, and if they do not, then they deserve to be harassed and excluded.

Throughout my life, I have quit or lost jobs due to characteristics of my Asperger Syndrome/ASD that employers and/or co-workers misinterpreted or took issue with and attributed these things to nefarious motivations: I have been criticized for “not being a team player” because I come to work to work, not to socialize, and because I need quiet and solitude to get my work done because of my sensory sensitivities. *(Ironically, I make an excellent addition to teamwork because of my fresh perspective and ability to brainstorm creative ideas, but due to my sensory sensitivities it is very difficult for me to participate when more than one person is talking at once. So I require a simple accommodation: Instead of informal, unstructured meetings where cross-talk takes place, I need a more formal structure where participants stay on task and minimize the social cross-talk).* I have been called “insensitive, tactless, or blunt” because I misunderstand social dynamics or fail to comprehend vague, indirect hints, and because I speak plainly and from a logical, solutions-oriented perspective rather than from an emotional one. *(Perhaps if the general public were more aware of differences in communication styles these type of misunderstandings and the subsequent hurt feelings that arise could be mitigated).* I have been accused of “being negative” because I am always pointing out ways to make improvements *(something that I actually thought was being helpful and would be appreciated because it demonstrated that I have my employer’s best interest in heart. I was quite shocked to learn that neurotypicals interpreted this as pointing out flaws! It seems to me that they are the ones being negative to interpret my information in this way).* I have been accused of “being argumentative” because I ask too many questions and because I need to understand the “why” behind things in order for the policies or procedures to make logical sense to me. I have been told that I am “being difficult” or have gotten written up for not following directions because I was confused or derailed by semantics. I have been deemed “incompetent” because I have a different learning style and/or learning curve. Employers have concluded that I am “not committed” or that “I don’t like my job” because I had to take too many sick days because I suffered from migraines *(which I learned post-diagnosis are a function of my sensory issues overwhelming me. Pre-diagnosis, I wasn’t even aware of “sensory issues” so I had no clue what caused my migraines or how I could manage my sensory environment in order to*

*minimize their occurrence. I think this knowledge, alone, has made a tremendous difference in my life, and I am convinced that I would have had been more successful vocationally had I only had known this information sooner).*

I am very sensitive to smells, loud noises, bright or flashing/flickering lights, or increases/decreases in temperature. My sensitivity can cause migraine headaches, nausea, irritability, and impairs my performance. Because I now understand that I'm sensitive to these things, I try to avoid them wherever possible. An example of work environment smells that cause me great distress include coworkers who heavily wear perfume and/or make up, or who drink coffee, smoke cigarettes, or are dog owners and who come to work with these smells on their breath, body, or clothing. If I am required to work closely with such a person when they are training me) I tend to lean away from them to avoid the smell. The co-worker tends to take offense because my body language is telling them that I think they smell bad or that I don't want to be with them, thus my opportunity to connect interpersonally is hindered. Also, the smell and the resulting migraine headache or nausea that it causes me tends to distract me from even being able to focus on what I'm supposed to be learning or doing, thus my work performance suffers.

If I end up working in an environment where the climate cannot be controlled, and it's too warm or too cold for me, this also impairs my concentration and I can become very irritable and I might end up snapping at people when they interrupt me or break my concentration that I am struggling so hard to maintain. (This, of course, further alienates me). The same scenario can happen in an office with fluorescent lights that need to be changed (i.e., lights that blink or hum), or in a place where the noise level is just intolerable for me. It's important to note that what is or is not tolerable for me is very different than what is or is not tolerable for the average person. And this threshold can vary based on my level of stress or the quality of my sleep, nutrition, or wellness. For example, if I am coming down with the latest cold germs that are circulating around the office, even "regular office socializing" can be too much noise for me, and people end up thinking that I am a stick in the mud when I hush them or won't engage in their conversations.

Most people cannot relate to what I'm going through. They seem to think that I'm being deliberately rude or difficult if I haven't disclosed my diagnosis, or they think that I am making excuses, or seeking attention or special treatment when I do disclose my diagnosis. None of this bodes well for my interpersonal relationships with my co-workers and supervisors. I have overheard co-workers talk about me to new staff and refer to me as "she runs hot and cold," which I have learned means that they perceive my mood or friendliness to be inconsistent. So it seems that once people have formed an opinion about me they influence new staff's opinions of me in this way, so I don't ever get a fair chance to outgrow an unfavorable impression...*(this, of course, causes my anxiety to increase, which in turn further hinders my focus. Thus a downward spiral begins)*. Then, it isn't long before I am called into my supervisor's office and told that it just isn't working out and given the "it's just not a good fit" speech.

Of course, all of this is very frustrating for me because it feels like I am being gas-lighted because I am so misunderstood, and this causes me a great deal of anxiety. Every job I have had, I started out with the greatest of enthusiasm and the desire and intention to do well, but soon this social miscommunication or cultural clash comes into play and then the people I work with get irritated with me. Often times this irritation turns into passive-aggressive hostility towards me. I understand that this hostility is a type of peer pressure that is intended to change my behavior; but what is not clear to me is exactly when and what I have done wrong, or how I ought to have behaved. So I am at a complete loss to know how to please people. If I ask them (even when I have disclosed my diagnosis) I am met with attitude and comments like, “Oh, come *on*, you *know* what you did!” So this just increases my anxiety, which in turn, increases the likelihood that I will make even more social faux pas because everything I do requires specific attention and focus...nothing comes naturally to me...and the more anxiety I have, the more it interferes with my ability to focus! So I end up in a rapid downward spiral that I don’t know how to pull out of. I end up getting fired or I quit. And then I end up being heartbroken and depressed for several months and too discouraged and demoralized to even consider applying for another job. *(So then the gaps in my work history persist, which further hinders my employability)!*

My Asperger Syndrome/ASD has even hindered my job search process because of my literal thinking: Until very recently, I didn’t understand that the ad is just a “wish list” of what the employer would like potential candidates to possess, so if I did not have every single one of the qualifications and job responsibilities listed then I would not apply because I thought that I was not qualified for the job. I am sure I would have been more successful vocationally if I had only known this simple fact sooner! And to think of all the frustration and low self-worth I could have been spared if I had only known this years ago! I’ve developed a cognitive distortion that I am worthless (despite the fact that I have four college degrees and made Dean’s List almost every semester) because I would search thousands of jobs and very seldom find any that I thought I was qualified for. Because volunteer organizations would gladly talk me on board because they are happy to train a person if they are missing a few skills, all these years I gave my labor away for free instead of spending that time earning a paycheck because I believed that no one would bother to pay me for my labor.

My husband and I had long ago discovered that there seems to be an inverse relationship between my quality of mental well-being and my employment status. So we agreed that I should stay home and focus on my well-being by indulging my creative interests and volunteering so that I am in the best shape possible to raise our children. This lifestyle decision is often met with scorn from our parents, extended family members, and even neighbors who accuse me of being a “play-girl” or “selfish” and accuse my husband of being my “sugar daddy” because of how outside the social norms our lifestyle is for the times that we are living in. I fear that this reputation that this intolerant gossip has earned me also hinders my employability if you consider the six degrees theory.

Despite their claims to not discriminate (as employers declare in their application paperwork), employers actually do discriminate throughout the entire hiring process:

It could be argued that the way employment postings are written is discriminatory against people with ASD because of our language impairment. When job postings utilize industry-specific jargon or acronyms, people with ASD are excluded from receiving valuable information about the job, and due to our propensity to avoid ambiguity, we would be inclined to not even apply for a job if we didn't completely understand what the responsibilities and qualifications entailed.

Another way in which hiring practices are discriminatory against a person with ASD is in the resume screening process because negative assumptions are made about a candidate's work ethic if there are gaps in employment, or if the candidate has several jobs that were only held for short periods of time. I know this because as a member of the PTO, I was selected to serve on my town's public school system's search committee for a new Middle School Vice Principal where I was privy to the selection process. So I now understand why I seldom even get called to interview despite how many jobs I apply for. I had been told "it's a numbers game" but in fact it is truly a brick wall because I have held many jobs for very short stints of time and I have big gaps in employment. So if my resume is being automatically dropped from consideration because of those gaps, it won't matter how many times I apply, my resume will never get considered.

If I do happen to get lucky and get called to interview, I seldom get called back for a second interview or offered a job. I believe this is because the very nature of the job interview process is very biased against anyone with an Autism Spectrum Disorder or an anxiety disorder because of the need to maintain eye contact, the need to be succinct, and the need to social multi-task and not get derailed by semantics. Even the open-ended nature of interview questions and the non-specific way in which they are asked is biased against literal-thinking candidates with an ASD: The standard "Tell me about yourself" question deceived me for a long time before someone quite recently pointed out to me that what they are really saying is, "Please summarize your employment history in two minutes or less." Because interviews always begin with the obligatory small talk, I never recognized this question as being part of the interview and I just assumed it was a part of the small talk exercise. So when asked this question, I would go on and on about my family, and the things that I like to do in my spare time (much as one would do when meeting someone for the first time in an exchange to get to know one another). Often I would leave interviews thinking, "All we did was small talk...how are they going to know if I am a good fit for the job when they never bothered to ask me anything about my work experience and my qualifications?" If employers want to be fair about interviewing candidates with ASD, then they need to give parameters for open ended questions ("I want to know about your work history, not about yourself"), explain how they want the question answered (in two minutes or less), and be specific by asking exactly what they mean ("Summarize your employment history or tell me how you meet our qualifications").

Some interview practices are also discriminatory against candidates with ASD, such as the public school job interviews (by committee) in my area that do not allow the candidate to take notes, and they ask multifaceted questions that are not written down. They score based on a rubric system. Due to my deficient short-term memory and my weakness in processing auditory information, I usually end up forgetting one or more parts of an interview question. Because of my deficits in processing speed, short-term memory and auditory processing I am at a distinct disadvantage, which results in a poorer interview performance, lower rubric score, and thus decreases my candidacy for the position. Also, the interview by committee process is an added hindrance to a candidate with ASD because there are so many facial expressions to have to contend with, and when people shuffle their papers and make noises moving in their seats it adds to the distraction factor. Thus making it even more challenging for a candidate with an ASD to perform well in the interview.

I have discovered that disclosing my diagnosis (for the purpose of getting a reasonable accommodation for the interview process) results in the presumption of incompetence and the underestimating of my abilities, which results in a lack of opportunities from potential employers or volunteer organizations. I am a lot more capable than people are willing to give me credit for once they become aware of my diagnosis. I believe that this is due to the fact that the general public is still too uninformed about the entire autism spectrum, so when they hear the word “autism” they automatically think of the misinformation and rhetoric that Autism Speaks has been publicizing since 2005. So in effect, I am “handicapped” by the rhetoric and stigma because it interferes with my ability to find work or volunteer positions at an appropriately challenging level for my abilities, so I am confined to underemployment (if I am fortunate enough to find employment at all).

## Why I was Just One of the Guys

*by Rachel Samuels*

By the time I first entered a non-traditional school, I knew the importance of looking like the other girls. The outfit I wore, embroidered blue jeans, tank top, and pastel velour jacket matched the styles of my female classmates. My hair, of course, was a little different, but the wild curls were tamed in a way that wouldn't make me stand out. I didn't know I was on the spectrum back then, but I knew that I had never fit in with my age-mates. This time, I thought things would be different.

Everyone was nice to the new student. They went out of their way to make me feel included. I was a novelty to them, and an adorable one. I don't remember all my classes that day, but I remember the final class period: Art. This was the year of the Big Pig Gig in Cincinnati. Pig designs were showing up everywhere. (You can still see some on display in parts of Cincinnati.) Our class didn't try to make a full-sized piggy. Instead, we had little ones, about sixteen inches tall, and two feet long. I had never worked in a group project before. It was nice to be included in the process of implementation, even if five or six children huddled around a pig that size got awfully crowded. Somehow, even though the pig was decorated in pink swirls and white flowers (it was a fancy birthday cake), the group I entered consisted entirely of boys. When we went to mix more paint, Richard and I got to talking, or rather, he asked riddles, and I answered them correctly. "If a boat has six rungs each a foot apart, and water covers two rungs, if the water rises four feet, how many rungs are underwater now?" "Wouldn't the boat rise with the water?" "What kind of key opens no doors?" "A monkey. Donkey, piano key." I continued to match him riddle for riddle, with no penalty for thinking out loud. "You're clever, Rachel," Richard said. I had already seen how some of the other boys, mostly the geeky ones, followed his lead.

In a school for the gifted, nerdiness was cool. By keeping pace with one of the leaders, I made a place for myself in the pack of kids. I also discovered a love of puns. The boys and I spent hours each day trying to outdo each other with tasteless wordplay. Wordplay is the type of humor most likely to be valued by Aspies (Hans Asperger, 1944). Other types of humor usually involve understanding human behavior, and rely on facial expressions and body language. They also require an understanding of situational appropriateness. In other words, some humor relies on concepts that can take Aspies years to grasp. Making fun of that is just mean. Wordplay, on the other hand, is language-based. It relies on words, meanings, and sounds. Because Aspies often take pride in our facility with words, this type of play works for us.

While the boys and I cracked puns, and cracked up, Victoria sat off to the side. I never figured out why she didn't join us. Looking back, she was eleven: at such an age, many girls stop hanging out with boys, a species they deem to be immature. They also try hard to be cool and

sophisticated, whatever that means. I was no exception, and always tried to be mature. I just saw no reason not to have fun too.

Unlike many Autistic females, I never had a problem with feminine dress codes (Simone, 62). I mean, I get the idea that some clothing is uncomfortable (I can't stand collars), but I don't see any reason to wear guy clothes when I prefer dresses. I liked, and like, dolls, flowers, cute animals, and such. I have always been extremely feminine. Despite this, I hung out mostly with boys at Sunday school. The girls there had become obsessed with Football. (I think they meant the cute players, I'm not sure.) They liked to gossip and to talk about clothing. I tried that last one at least once. The girls were discussing bared midriff shirts. They mentioned that some of them were wearing such things under their outer clothing. I was confused about what they were saying, so I said "I'm wearing one too" and proceeded to show them my training bra. They were kind enough to inform me of the difference before they went back to discussing even more topics that I didn't understand.

Such experiences are not uncommon among preteen Aspie girls. Female friendships at this age are cliquish and change rapidly, which causes distress and confusion even for neurotypicals. For Aspies, it's insanely hard to understand. (Atwood 81) Male friendships are easier to interpret. If a boy gets mad at another boy, they fight. They don't turn all their friends against the victim in a way that teachers can't even see. In most cases, they wouldn't fight a girl that way, at least not one as small and fragile as I was. More to the point, while girls tend to talk (and shop, yuck), boys tend to play. I could wrap my head around activity-based friendships easily. The boys and I were happy to build things. I wasn't so crazy about the racecars we built, but wilderness shelters were fun. (Why don't girls like to get dirty? It washes right off.) I learned to play Magic the Gathering (yes, I am a Nerd, thank you) because the boys in my set played. I never aced that game, but I became competent and it gave me something to do when rehearsal ran long.

But I still wanted to hang out with the girls. I always knew that I was supposed to, and there were places, such as health class, where the kids had to separate by gender. I sat with the girls there. Victoria made sure there was a place for me, but I'm sure that I appeared odd to them. I tried to remember eye contact, but I'm sure it looked forced. Conversation, idle chitchat did not come naturally to me, nor did I enjoy it when they pointed out how I was different. That was tough, because they told me to act a certain way. "Rachel, aren't you a little old to skip in the hallways?" Emily asked. I heard that for the order it was, and saw it as a way of excluding me. That wasn't the only way she tried to order me around. In the end, I asked the assistant principal to stage a meeting between the two of us so that I could explain how upset Emily made me. She stopped bullying me at that point, but she also stopped talking to me. I coexisted with the other girls there, but that tolerance never blossomed beyond mild liking on either side. I tried, but I just couldn't figure out the rules of female interaction in middle school. In the end, I spent time with boys, because they, at least, made sense.

# Untitled

*by Rebekah White*

Hello! My name is Rebekah White. I live in Danvers with my parents and dog, a Maltese named Hobbes. I also have a sister who just graduated from college. I am 25 years old and attend UMASS-Lowell majoring in meteorology and work at the coffee counter at Barnes and Noble.

I was diagnosed with Asperger Syndrome when I was eight years old and in the third grade in 1999. When I was diagnosed, Asperger syndrome was a fairly new diagnosis, only becoming official a few years before. As a result, not much was known about Asperger's by either my parents or my teachers. My mom has even told me that at the time I was diagnosed there were only three books out about Asperger's. My teachers were forced to go to training about Asperger's, as well as my mom helped my teachers learn about Asperger's and especially how it affects me. Therefore, it was a learning curve for everyone.

Soon after I was diagnosed, I got an aid in school. I had an aid from third grade until eighth grade where the aid would be with me during each class and also help me with my classwork. I even remember that when I had my first full time aid in fourth grade, I thought it was strange to have a person with me all the time while I was at school. I didn't realize it at the time, but my aid would be very good for me, because I would be protected from any bullying from my classmates.

In the eighth grade, it was decided that I was doing well enough where I would not need an aid in high school. In eighth grade, I had a shared an aid with another boy in my classroom who I had been friends with.

High school, however, was difficult for me without an aid. I remember on my first day of high school, I got upset by some of my classmates. It was in science class and I remember getting really upset and ended up going to a new place where I would spend a lot of time.

At my high school, there was a place where people with disabilities and/or learning difficulties would go for support. It was called CIL, or Center for Individualized Learning. There were great people there who helped support me all through high school through the difficult times. I would go there to do my school work when I couldn't stand to be in the classroom or during free time. CIL was a place where I could cry when I got frustrated, or just to escape when I needed to get away.

In high school, when my classmates realized there was no one there to watch out for me, they took advantage. Coming from a small town, Lynnfield, we were all in the same school from fifth grade onward. Therefore, we all knew each other well, including what could drive me nuts. Many of my classmates knew from middle school that I did not like talking when we were supposed to be quiet because I would shush them. This was one way my classmates would get a reaction out of me. In high school however, another common thing people did



started to bother me. Gum chewing/popping started to drive me nuts. In high school, you were technically not allowed to chew gum in class, however my classmates never listened to that rule. Also, it was very popular to pop your gum, a lot. These actions, started to bother me a lot, and would elicit a reaction whenever someone chewed loudly or would pop their gum. I am now fairly sure that I have something called misophonia which is a hatred of a sound which for me is caused by gum popping. With misophonia, different triggers can cause a reaction, but for me, it was mainly gum popping.

However, their favorite method of getting a negative reaction out of me was aiming spitballs at me. This would be done when the teacher had their back turned and therefore would not see who did it for me, and I would have no idea either because I sat at the front of the class. I would have difficulty in remembering names of classmates, and therefore, even if I had a good idea of who did it, I could not easily identify who it was. I would often be the one to get in trouble for yelling at my classmates instead because I would be what the teacher saw, not the action that caused my reaction. I, however had much support from my teachers and the people in CIL and the assistant principal. There was just so much that they could do because no one would speak up for me. I even tried switching classes my freshman year to get out of a couple of my worst classes, but only one of the classes improved, and got worse in the other. I ended up regretting the decision to change classes, but before I changed, I thought it would be a good idea.

As high school went on, I matured and was able to react less and less to the bullying. This was also helped by getting into more difficult classes where the students were more serious, and my classmates maturing. I was able to learn how to control my emotions as well. I believe though, that being a woman, and the emotions that come with that did come into play with my reactions. I feel that being a woman was one reason for being bullied, but also was an advantage for me because being a woman. I would mature faster than the boys and learn how to internalize my emotions better.

I discovered this when I went into college. I graduated high school in 2010 and immediately started college. I discovered through my maturing and not knowing my classmate that socially, college was much easier to deal with. I still struggled with the sound of gum popping, but I would not react anymore, and my classmates would not intentionally do it to get a reaction out of me. I have struggled on and off in college academically, but at least I have not dealt with the bullying I dealt with in high school.

To any girls who may be dealing with bullying, I would say to get support from your teachers and any support your school may offer. They may not be able to do much, but it alerts them to what may be going on and why you may be reacting. Realize, though, that you will mature and handle it better before they do.

# Growing Up with Asperger's Syndrome

*by Suzannah McWilliams*

My name is Suzannah McWilliams and I was told I have Asperger's Syndrome as a senior in high school. I also have a cognitive disability meaning that I have difficulty learning new concepts and learning a lot of information very quickly. I had a terrible time growing up with these disabilities in the 1970s and 1980s. I had terrible difficulty making friends and connecting socially with my peers, and as a result got bullied and screamed at growing up. I started getting bullied in first grade, and it continued all the way through high school. I also got yelled at because I exhibited inappropriate behavior at times and often had to have things repeated when learning new concepts.

As a result of this extensive mental stress, I developed a speech impediment, which became so bad I could hardly speak when I graduated from high school. I also developed obsessive psychotic thinking which I couldn't get rid of or control. I almost became suicidal in high school but somehow made it through.

I have been in therapy and on psychotropic medication for most of my life and am psychologically very healthy now. In fact, I am now in the best place in my life that I have ever been, but it took 46 years of terrible emotional stress to get here. I think that my mother and God helped me deal with such a stressful childhood and get to such a wonderful place in my life currently. I'm a very strong person psychologically and am very proud of myself for my accomplishments despite such challenges. I care for myself and respect myself a lot, and I am very thankful for that.

## After This Diagnosis Has been Much Better, Though Life through a Mirror Also Held Beauty

*by Yvonne*

I was diagnosed with autism last year at the age of 52, and PTSD around age twenty. Decades of work on PTSD issues didn't solve some problems in spite of a lot of hard work. I've lost some major life opportunities, but felt my way along for decades; I have also met some of the wonderful people of the world. I fortunately have some good building blocks in place now, but am very glad for the new work on autism in women.

I think that my particular flavor of autism contributes many strengths that actually help me get through difficult times; I can only speak for myself here. I've actually built my connection to things I love to help myself get through, just hoping that the painful areas—mostly somehow related to connection to humans—would somehow improve in the future. The intense love I have for certain complex systems, and ability to contribute, have helped me keep going through some very bad times though. Systems, be they in IT, human group dynamics, or nature, can be fascinating and beautiful things; there is always something more to learn. Is music perception connected to system understanding? Have you ever felt that trees, in some fashion, might sing?

Discovering my autism has been an intense journey this year. Last winter it was mentioned that an elderly relative might have Asperger's, and after a full five minutes of Googling, it was, well, really pretty obvious. Luckily, in there I found a page with a list of female traits, and in what was probably the most transformative five minutes of my life, my childhood practically popped right out of the page. More reading led to more possible matches in my family. So many unexplained, unsolved family issues and difficulties; suddenly one explanation made sense of it all.

A YouTube video of an autistic girl "stimming" was a shock too; her finger fluttering matched what my brother called my "finger picking." Unfortunately he may have untreated autism too. As I remember these events from forty or so years ago, he had frequent rages. He couldn't tolerate my fingers or my voice, he was "in trouble" for random things at school that I never understood, he didn't finish high school, he refused to go on trips in the car. All may have been partly due to sensory issues; there is no way to go back and find out. There was physical violence, which I believe partly led to my later PTSD diagnosis; I was also bullied in school, and sensory sensitivities I had to noise, in the noisy chaotic classrooms, cannot have helped. At home I was eventually told to sit on my hands so my parents didn't have to cope with his rages; my fingers were to be still—apparently a common issue for autistic kids. I may have been lucky to able to focus so intently on distractions for myself though, and stayed in school and developed a love of learning.

My memories of elementary school are very spotty. (I am not good with linear event memory, but rather seem to remember grouped concepts fairly well.) Strong early school memories are of being scared to look up at people, staring at floor patterns instead, drawing and doodling, and playing with my pile of wonderfully soft eraser dust from the tan one that I ground up on my desk.

In the present day, I'm trying to make connections between these memories and what I read of physical and emotional issues of autistic folks in research abstracts. I tense my muscles far too much during everyday activities, and have damaged some joints as a result. I have inconsistent trouble with proprioception, and do not seem to be feeling my muscle knots like many people do. I'm wondering... can a lack of needed stimming lead to later musculoskeletal problems? Has anyone looked into this before trying to stop stimming in thousands of children? Exercise helps me, massage helps, maybe I will get a rocking chair; I do hope that in the future, though, researchers will work to determine what truly helps long-term quality of life for people who naturally stim.

Eye contact is mentioned as a difficulty in both PTSD and autism, so it was easy to blame the PTSD for all of it through decades of therapy from my twenties to last year. A terror of being looked at in school likely correlated to situations where I might have eye contact and leaving was difficult; I thought it was from the violence. To avoid the electric shock feeling of eye contact in high school and college, I doodled, took notes, drew. How much really was due to PTSD, and how much to autism? I've thought on this, and considered how those issues improved over time. In my twenties, I intentionally worked to better learn to predict other people's moods and intentions, mostly in relatively safe settings like martial arts classes. The new people weren't like my memories of my brother, but also the shock became less frequent over the years though I can't directly connect anything. I took public speaking opportunities, met many wonderful people who tolerated people with some differences. I can still have strong discomfort from eye contact and find it distracting and tiring. Perhaps the electric shock feeling was a quick, strong fear that I couldn't identify; my emotions can take days to figure out initially. Eye contact is now much less of a problem—a very major improvement in quality of life.

If 1 in 38 children are autistic per the South Korean study, how did so many autistic girls and boys learn to pass in prior periods without ubiquitous notice? In my case, I was extremely quiet, focused on academics, and had a one similar friend whose dad was also a technical type. We played with model horses, organized their societies, spent hours admiring their colors and shapes. Fantasy books we loved often included creative models of societies. Social interactions between nonhumans and humans were particularly fascinating to me; I'd identify with the nonhumans quietly. I later took classes in math, animal behavior, evolution, cross-cultural anthropology, psychology, geography, ecology, but always kept improving my models of people. I actually like socializing for a bit now if the model fits, especially if the conversation can be scientific in some way. Normal folks can be tough!

Having a diagnosis has been crucial in learning to identify social overload situations for myself, a work in progress now at least. Loud, informal groups are the worst for me; the rules are obscure, speed of interaction high, and the volume can get way too high unpredictably ... That's been a major problem; I leave feeling a failure, as I believe I *should* enjoy such situations, and actually can sometimes—but I suspect self-awareness of my limits is one of the first things to go offline. So I avoided interviews for available career moves without understanding why, avoided dating people I liked in favor of people who maybe didn't notice when I wasn't there. (I am still trying to figure that out; I really wish there were guides for therapists in helping people like me.) I'm trying to learn to treat myself better in ways I have needed for decades.

Assuming this was all PTSD left me unable to help myself effectively in such situations; I often blamed the wrong invisible factors. My best guess used to be that undiscovered, underground lakes of trauma were somehow affecting me in situations that must have been similar to past forgotten traumas ... lurking, able to drown me if I didn't stay alert. About five years ago, learning the word "dissociation" helped. Having a word helps one not feel crazy and alien, but not having the cause correct prevents one from helping oneself effectively. Shutdowns may have a similar brain mechanism to dissociation; if the brain senses a harmful overload, perhaps the cause doesn't always matter.

Social support helps healing from PTSD greatly; this is very commonly discussed in studies on PTSD: social connections increase resilience to PTSD, connection to the therapist helps healing from PTSD, group therapy can help PTSD. Unfortunately the few researchers I have read who are working on autism and trauma, seem to be hypothesizing that autistics may be innately more prone to PTSD after trauma. Maybe their neurology is just more prone to PTSD, maybe it's this neurotransmitter or that one...

I have not found any studies connecting the basics how social autism (apologies if I've just plain missed such studies; I'm not a professional at this, just a very fast reader with lots of years to read behind me). If your social connection bandwidth is flaky but you don't know that, and therapists know nothing about your autism, how can your reactions not be misinterpreted by the (latest) therapist you're hoping will help you (this time)? Are you intellectualizing and avoiding? Say what you are feeling! Eye contact, emote! Time after time, I would have reactions alone, but not while interacting, so trust didn't improve beyond a certain point, and I'd feel I'd failed over and over. I feel very fortunate that I at least kept exercising and found interests and people with whom I could connect so strongly—at least over common interests, and to some extent interpersonally—over some of those years.

My inner experience feels important to mention here. I will try to explain the cryptic "mirror" reference in the title of this article for anyone who is puzzled! As a child, I remember having an "inner world" but also needing to interact with the "outer world." Heartfelt, spontaneous reactions were not safe too much of the time, I needed to examine my actions and words beforehand, and got much faster at this over time. I eventually came to feel that I was interacting with my "model" of the world rather than the world almost all of the time, but no

one else talked about this sort of thing. “I” was partly separate from the world; “I” was too slow to respond directly, intuitively; so I learned to look at a model of cognitive understandings, or perhaps a mirror image of the world. The “mirror” was my early word for this feeling, from perhaps early teen years. I would quickly analyze situations with people in various ways, and respond to that understanding, which is based upon a combination of intellectual and emotional learning (though my emotional side is much, much slower to learn, so my cognitive side seems to take up the slack a lot). I believe this learned response approach might be called “scripting” in autistic children—but adults can get much better at it. I am so glad to see specific help being offered to autistic kids! Cognitive-level processing still delays me too much in complicated social situations, but I have learned more and more over the decades about different people and ways to have decent relationships, even if not intimate.

I have also tried to examine my own motives and reactions from an early age. I remember believing as a child that harm done to others by family members was done due to their lack of self-understanding, so I was very strongly motivated to be try to fair about my emotional reactions. This was an intellectual approach, and identifying emotions has been a lifelong effort—but I have made progress. There were also perhaps fewer memes from the outside world that fit the inner world of autistics than “neurotypicals” generally benefit from, without realizing how much they are benefitting. I hope that having more and more autistic people work on, identify, and explain their inner experience—perhaps in images too—will help future generations of autistics identify their own inner experience. I have been finding autistic bloggers extremely helpful.

My inner experience feels important to mention here. As a child, I remember having an “inner world” but also needing to interact with the “outer world.” Heartfelt, spontaneous reactions were not safe too much of the time, I needed to examine my actions and words beforehand, and got much faster over time. I eventually came to feel that I was interacting with my “model” of the world rather than the world almost all of the time, but no one else talked about this sort of thing. I also tried to examine my own motives and reactions from an early age; I remember believing as a child that harm done to others by family members was done due to their lack of self-understanding, so I was very strongly motivated to be try to fair about my emotional reactions. This was an intellectual approach, and identifying emotions has been a lifelong effort—but I have made progress. There were also perhaps fewer memes from the outside world that fit the inner world of autistics than “neurotypicals” generally benefit from, without realizing how much they are benefitting. I hope that having more and more autistic people work on, identify, and explain their inner experience—perhaps in images too—will help future generations of autistics identify their own inner experience. I have been finding autistic bloggers extremely helpful.

Recently I began to examine my difficulty in direct social connection again after my autism diagnosis. I think there are several parts to it; one issue is that words are not my native internal language. My thinking is conceptual; this is very flexible and good for math and abstract understandings, but maybe not as efficient for quick verbalizing, and it can take me a

long time to verbalize inner thoughts or concepts; emotions can sit there like bubbles with no way in. Words feel more like an external appendage that I am using, in a sense, and writing or reading works much better than listening or speaking for me.

Might different neurotypes have different topologies of thought, of where the “self” is formed in the brain or exists in the interplay of verbal areas with nonverbal areas? (This is probably best discussed in a pub and drawn on a napkin, like talking about string theory... for those of us with no real background in the anatomy, chemistry, and physics involved.)

Talking at normal speed with eye contact is so intensive for me that my inner thoughts easily vanish, though I did not realize this in many, many therapy sessions and other relationships. I am generally paying a lot of attention to the other person, which feels very complicated. Having at least a reasonably good reaction from the person I'm talking to is important to me, being “normal” used to be a safety issue, although I have gravitated toward contexts where I like the “normal” in recent decades, but socializing is still hard work.

Developing the skill of staying in contact with my inner reality while interacting with a person, now that I am aware of my issues with this, is also hard work. In therapy now, I can luckily forget eye contact, speak quite slowly, and it's ok and a relief. This has let me feel present, like the “inner me” is in the same world with other people finally, or at least a little more reliably. Writing was a bridge in discovering all this; I can write in the quiet at home, and began to share it in therapy.

Regular massage has been helping me connect with tight, feelingless deep muscles, and other sensory issues, for two years now. It confirmed for me that I wanted to get officially diagnosed, as joints were harmed. Feeling safe in one's body is crucial to quality of life, and feeling safe with some contact with others is wonderful.

Through intuition, some wonderful people, and luck, I have made my way into a programming career in a calm workplace with wonderful geeks. I value the contributions we make. I feel that my abilities with systems, education, plus high “fluid intelligence,” are likely related to my autism, and get me through. Perhaps more focus on such positives would lead to more undiagnosed autistic people becoming motivated to examine a possible source of both gifts and problems, and getting help. Volunteer activities in environmental work and other communities have also helped me connect with committed people over shared interests; we love our work and support each other. In my memory of the first tree I worked to pollinate, in a bucket forty feet up amidst a world of life that we cannot imagine from the ground, I can feel the trees singing.



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