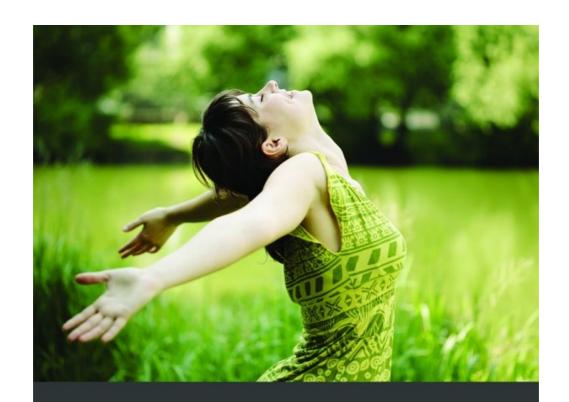


Empowering Females
with Asperger Syndrome

Aspergirls

RUDY SIMONE

FOREWORD BY LIANE HOLLIDAY WILLEY



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"I can highly recommend this book to all Aspergirls and their parents, family, partners and professionals, as well as to all *members* of our community. With humor, love, liking and respect Rudy opens our eyes to the World of the Aspergirl, providing powerful insights on love, learning, sex, career, marriage, having children, friendships, puberty, diagnosis, emotions, health, ageing and more. For each topic there are sections of advice for the Aspergirl and her parents. These sections will also be very helpful to clinicians. For too many years we have missed Aspergirls due to our current understanding of Asperger syndrome being largely based on a male presentation. Rudy generously provides, through deep personal insight and her interviews with other Aspergirls, a broader definition and understanding, one that will help bridge the gap between Aspergirls and the non-spectrum population."

—Dr. Michelle Garnett, MPsych(Clin) PhD MAPS MCCP, Clinic Director and Clinical Psychologist, Minds & Hearts: A Specialist Clinic for Asperger's Syndrome and Autism

"Aspergirls is an extraordinary read. It is an affirmation of the movement towards understanding AS in females, and a celebration of the culture of AS womanhood. Simone writes with passion, honesty and truth—sharing both the challenges and the joys of a woman's life on the spectrum through her own observations and the voices of other women. It is rich with stories and strategies to be read and re-read as reminders, mantras and as a map for embarking on the journey of being a woman with AS. Above all, it is a much-needed book about permission, empowerment, and, as Simone so eloquently states, moving beyond the mutism. Bring all your color, girls, and paint the world!"

—Shana Nichols, PhD, Licensed Psychologist, Researcher and Clinical Director of ASPIRE Center for Learning and Development, and co-author of Girls Growing Up on the Autism Spectrum: What Parents and Professionals Should Know About the Pre-teen and Teenage Years

Aspergirls

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To Mike W. Who gave me a different lens to look through

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I would like to sincerely thank the women who participated in the making of this book, as well as their partners and parents. I was honored by your trust, and I hope I've done it justice.

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FOREWORD

I was not diagnosed with Asperger syndrome (AS) until my daughter was diagnosed. This was almost fifteen years ago. At the time, few people I knew had even heard of pervasive developmental disorders, much less AS. Happily, much has changed since then. These days, I would imagine virtually everyone remotely interested in human behavior or current events has heard of Hans Asperger and his "autistic like" patients who struggled with non-verbal communication skills, peer interaction, limited but intense interests (and yet, higher than average IQs), strong verbal skills and an awesome ability to recall details and facts. Asperger syndrome is a media darling which shows up everywhere from the red carpet of Hollywood to the smallest school district's special education discussions. Google the term—you'll see what I mean. While it is stirring for those of us with AS to see all of this attention being focused in our direction, many of us remain without a formal diagnosis, particularly if we don't have a Y chromosome. Females, from the littlest of girls to the eldest of ladies, continue to fly under the radar of proper diagnosis, eventually landing in worlds where they don't belong. schizophrenia, obsessive-compulsive disorder, Neuroses. personality disorder, oppositional defiant disorder, anxiety issues, social phobia—these are familiar diagnoses for women beyond a certain age who struggle to make sense of the environment, society, relationship rituals and the like. Not that these diagnoses are completely off base. The chances are very good that any mix of those comorbid factors also lay on a lady's genetic code. The problem is many counselors and doctors seem unable to see AS crouching in the middle of the huddle. Why then (many of us ask) does a diagnosis of AS remain a guy's thing? Why do researchers still report that AS affects males three to four times more often than it does females, despite top psychologists in the field, such as Tony Attwood, Judith Gould and Lorna Wing, trying to reframe our thinking from "AS does not affect females" to "how can we

recognize AS in females?" I tend to think part of the reason is straightforward enough. Many women with AS are leery about coming forward with the suspicion they may be an Aspie because, as much as many of us like to say it isn't so, a diagnosis of any kind brings with it a heap of stereotypes and prejudice. Simply put, it is downright difficult to tell the world you are a square peg jamming yourself into society's round hole

I am in awe every time a woman on the spectrum shares her experiences. I am indebted. And I am relieved to know that each day, more and more Aspie women are joining web forums, small group discussions, and friendship circles, to share advice on how to navigate the neurotypical world map. A voice here or there might not be heard, but the collective voice of women willing and able to share—wow. That's a loud chorus that can't and won't be ignored. Rudy Simone's book, *Aspergirls: Empowering Females with Asperger Syndrome*, has a lead role in that chorus, and will serve as an important catalyst to encourage contemporary thinkers to have the realization that a significant number of females do, in fact, have AS.

Simone's book is part memoir, part research review, and part user's guide to AS. The writing style flows smoothly from the page, making it an eloquent, yet relaxed and informal, and always very informative, read for anyone interested in life outside the box of normal. Couple this with Simone's fresh and spot-on voice perfectly capable of expressing what life with Asperger syndrome is often about for women on the spectrum, and you have a superb read on your hands. Superb reads are great for the mind, but essential for souls hoping to move toward an understanding of things new, things different and things worth cherishing.

I identified with just about everything in this book. Page after page brought me closer to my own feelings as I highlighted sentences and earmarked pages to share with others. I was especially touched when I read the personal vignettes which Simone includes. People on the spectrum

often say they appreciate and deeply respect the experts in the field, but no one can tell it like it is better than those who walk the spectrum walk. All the women who shared their experiences for this book are doing more than walking the walk. Their insight is invaluable to the community. Simone does an excellent job of incorporating others' words with her thoughts, and then rounds everything up with practical advice for growing and enjoying life.

Simone coins a new word in her book—"Aspergirls" is what Ms. Simone calls women with AS. I like it. My daughter said the term sounds like a superhero. Fine by me, and, I suspect, fine by Ms. Simone. I don't think anyone could read this book and not come to the conclusion that women who manage to come through the gauntlet of AS with any measure of success are indeed super *and* heroes. But like every hero, women with AS are bound to be susceptible to some sort of Kryptonite. Simone takes on these poisons one by one. Bullying, self-esteem, anxiety attacks, melt-downs, sex, guilt...the list goes on, but never without supportive insight aimed at assisting the downward falls with a myriad of suggestions and positive images that will refuel the reader's desire to get up and carry on with one's head held high and one's spirit moving in a comfortable direction.

New books are always exciting, but only a certain few have staying power. *Aspergirls: Empowering Females with Asperger Syndrome* is here to stay.

Liane Holliday Willey, EdD

Author of Pretending to be Normal: Living with Asperger's Syndrome, Asperger Syndrome in the Family: Redefining Normal, and editor of Asperger Syndrome in Adolescence: Living With the Ups, the Downs and Things in Between

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CHAPTER 1

IMAGINATION, SELF-TAUGHT READING AND SAVANT SKILLS, AND UNUSUAL INTERESTS

It is known that people with Asperger syndrome love information, but why? Information gives our thoughts an anchor, it gives us an identity and is something we can control. We don't have to charm it, take it to lunch, or impress it. It is ours to do with what we will.

We have a voracious appetite for it. We don't want to wait for kindergarten for the words on the page to reveal their meaning. We also don't want to wait for our first lesson to evoke music from the magical instrument standing in the corner. And often, we don't have to.

I learned how to read from "Sing Along with Mitch Miller" records. One day I picked up *The Cat in the Hat* and I could read the words, they just suddenly made sense. (Widders)

My own process of learning to read was logical and quick. I remember asking my mother to show me the alphabet, and since "A was for apple and B was for boy," etc., I learned the sounds of the letters. By the time she finished going over the alphabet minutes later, I picked up a book and I was off. Most of the Aspergirls I interviewed were self-taught readers and many had similar experiences with maths, music, and design.

I'm a spatial-mechanical savant. I have CAD (computeraided design) for a brain. I can build electronics and machines from scratch with no background. (Andi)

This skill levels off as we get older. I believe that this early ability to read and comprehend above our years (hyperlexia) gives some young Aspergirls an air of intellectual maturity

that tricks people into thinking we possess emotional maturity as well. It also hides autism by shielding our deficits.

Some Aspergirls are less language-oriented and, of course, some of us do possess learning disabilities such as dyslexia. But verbal or visual, learning difficulties or not, throughout our lives, much of what we want to know will be self-taught, even if we attend college. We like to teach ourselves just about anything we're interested in, not only because of impatience but also because we have our own methods for ingesting and comprehending. We might not "get it" from other's instructions, particularly verbal ones, and we take information in, in our own way.

Almost everything I know is self-taught. I was a very fast learner at school but had low exam grades due to dyslexia so I was written off. I have taught myself statistics, chemistry, sewing, embroidery, and welding. (Sam)

Some people, like author Bill Stillman (2006), believe that children with autism have a "God connection"—that their deficits are compensated by a higher spiritual awareness which gives them access to knowledge and gifts. Experts tell me that people with AS have a higher-than-average IQ...yet we don't always project practical intelligence. When we're young we may be called "little professors," but when we get a bit older, we're more like "absent-minded professors." What has been lately proven, is that children with Asperger's have a higher rate of *fluid intelligence* than nonautistic children (Hayashi et al. 2008). Fluid intelligence is the ability to see order in confusion, to draw inferences and understand the relationships of seemingly unrelated things. While we may not have higher crystallized intelligence (the ability to use acquired knowledge and skills), this may explain why we sometimes just "know" how to do something, like solve complex maths before we are taught, or build electronic gadgets.

I can fix or reproduce things, including devices and clothing, after just looking. (Dame Kev)

I do not mean to say that we are all blindingly smart; if you are an Aspergirl without any "zone passion," and you have no savant skill, you are not alone.

What really makes me uncomfortable is when Aspie campaigners couch that "leave us alone" argument in the myth that *all* AS people are super intelligent mathematician science savants and some sort of master race. That makes me feel, as an Aspie who doesn't have any of that, I'm a double fail—I fail at being normal, and also fail at being AS. (Polly)

But those who fall into the slow learner category may do so for any number of reasons—from sensory processing difficulties; shutting down under pressure or around others. Dyslexia, dyspraxia and selective mutism can all play a role in making a smart girl be misinterpreted.

I lived in my own sweet little bubble. I ignored most of what was going on around me. I couldn't read out loud (selective mutism), so the teachers all assumed I couldn't read at all. They wanted me to read low level books, but they were really boring, so I had to sneak upper level books in the classroom and library. I got into trouble if caught with one of my contraband books. (Widders)

I was not in special ed but they always assumed I was stupid. I always had to prove myself and was frequently invisible. (Ann Marie)

Not comprehending things the way other people do is fine in academia because we can usually find our own methods, but in social situations, this same tendency plays out differently—we can't always impose our own rules and priorities on others. We can't research people in everyday conversation the way we research information from books. It is not uncommon for us, when we're young, to ask too many questions of others, which makes them uncomfortable. If we could set the tone, we would probably be more comfortable, but we can't so we shut down. This becomes most noticeable in the teenage years when

conformity begins to be of the utmost importance. (We'll talk more about this in Chapter 9.)

It is often said that those with Asperger's have little imagination and do not engage in imaginative play as children. I think this is erroneous and may be a hindrance to identifying those with Asperger's who do possess a vivid imagination. Just because we like to arrange crayons by color or alphabetize our toys doesn't mean we don't want to use them. But the stories I made up in my head were far more interesting than the ones I could enact with my dolls—rigid, unconvincing bits of plastic.

The diagnosed Aspergirls I interviewed have varying degrees of creativity and imagination, from "none" to "extremely vivid." We all seem to start out by copying what we admire and some will stop there, at being great emulators.

I can remember music from beginning to end after hearing it only once or twice. I started violin at age five and played entirely by ear for years. If my teacher played the piece I was supposed to learn, I could play it back to her and just had to refine the technique. (Heather)

Put a pencil in my hand and I turn into the human copy machine. (Bramble)

Others have created their own works of note.

Orchestral pieces of mine were being played by people all over Europe when I was only 14. (Kylli)

My painting skills are completely self-taught. Everything I have learned is a consequence of personal research and self-directed study and reading. That is all I do. (Camilla Connolly, Australian artist and Winner of the 2009 Waverley Art Prize)

Another reason that autism may be overlooked is that our obsessions do usually fall under the heading of "normal" girlhood things, like books, music, art, and animals. It is the rapacity with which we enjoy them and the passion they inspire in us which is taken to a new level. While it took me a

few years to begin to write original stories, songs, and essays, I read as if my very life depended upon it. I would fake being sick so that I could stay home and read. I'd bring snacks into my room in the morning because I knew I would not want to stop and take any breaks for food. I would have peed in my room if I could, just to not have to stop reading.

Why do we read with greed? (Or play, or design, etc.?) We want to fill our minds with knowledge the way others want to fill their bellies with food. Information replaces confusion, which many of us experience in interactions with others. It is a place to focus, apart from all the external stimuli in our homes, schools, shops, etc. It is completely within our control how much we want to let in, unlike dealing with people, who are unpredictable and uncontrollable. (Even those of us who are in our own bubble, who don't read or seem to look outward much, may have a rich internal world and not yet have such a need to connect.)

Information fills a void as we don't seem to have much of an identity of our own when we're young. We feel a sense of urgency to learn and create and you can't really create anything until you've taken in enough understanding of what already exists. In *Thinking in Pictures*, Temple Grandin (2006) says she learned how to draw engineering designs by copying another draftsman's drawings. She soon began to create her own highly complex works without any formal training.

Obsessive activity is an illustration of the incredible focus that we possess, and teachers, doctors and educators are beginning to realize this is an asset—something to be cultivated and not discouraged. As Temple says, we have to work with our strengths not our deficits. This is a key to the kinds of workers and innovators we might be in our future. But there are practicalities to attend to. When we are in *the zone*, we do have a hard time with taking breaks, going to the toilet, eating, drinking, grooming, getting fresh air, or exercise. It can also impinge upon getting a job, going to work, and other crucial activities. Is it really just executive dysfunction

causing this behavior—not knowing when to stop? Or is there something more?

It is the only time I experience a unified sense of self. Nothing else matters. (Camilla)

When engaged in my passion I lose all sense that there is anyone else on the planet or that time is passing. It is like another dimension. (Heather)

One of the differences between young girls and boys with Asperger's seems to be that our unusual interests are not as unusual and may seem more practical to an observer. If a girl reads voraciously, this is not as jarring or strange to a parent or physician as being fascinated with the different types of plane engines built between 1940 and 1945. But what might not be realized is that behind our bedroom door, we may be reading the same book 124 times, because we are obsessed with it. Some Aspergirls do border on trainspotting.

I was obsessed with limestone cave formations. I never had any interest in cartoons or fantasy. (Kes)

I liked baseball and memorized statistics with ease. (Kiley)

I could name every car on the road before I was two. (Pokégran)

Another difference between Aspergirls and NT girls is that the latter do tend to grow out of these childhood passions and into more so-called age-appropriate activities. We will still engage in the same activities all our lives. But this isn't necessarily a bad thing. For, if Mozart wasn't obsessed with music, would not the world be the lesser for it? Temple, Einstein, even Dan Aykroyd have changed the world with their Aspergian ways. I'm sure we have had many women scientists, novelists, etc., who have contributed to culture and progress because of AS focus and diligence, but we'll never know for sure about the past. The future, however, is a different story and we may be the ones to write it. You may be one of the first *openly* autistic women to front a famous rock band, be a best-selling novelist,

director, etc. Some of those women may be found right here in these pages.

ADVICE TO ASPERGIRLS

Do not let peer pressure dissuade you from doing what you love and what you are good at. Life is about making a contribution, not about being popular and fitting in.

Executive dysfunction—knowing how and when to start or stop an activity—does figure into the experience for many of us. Once we get going on something, we often do forget to eat, groom, bathe, go out, have fun; even going to work or school is an unwelcome interruption to our "zone activity." Get into the habit of taking breaks for hygiene, nutrition, and exercise. This is for your own mental and physical health—you must keep that Aspergirl machine finely tuned. This will also help increase your confidence when dealing with the outside world.

Don't worry if you don't have a savant skill—even if you spend your time in a passive activity, that may translate into a marketable skill later on. For example, an obsession for watching movies could be channeled into film school and later, a career as editor, critic, or actor. Do try to turn a passive passion into an active one. And do take at least a passing interest in other things. The more you know about life, the more informed your passion will be and the more you will feel comfortable with a variety of people and situations.

ADVICE TO PARENTS

Praise and encourage your daughter's passions, whatever they are, for therein lies her comfort, her security, her happiness, and possibly her genius. There also lies, most likely, the key to her future career.

Do not criticize her for being a bookworm, or being obsessive. She wants to please you but she can only be herself, successfully. She can try to be someone else, mirror what she thinks people want to see, but that's not who she really is. She is your gift and you are the caretaker of this special person. It is difficult at times but it is also a privilege.

On the other hand she might not have any obvious talents. A professor with AS that I interviewed said she has no savant skills, however, navigating the world of higher education for so long proves that she possesses the focus and diligence which I list as Aspie gifts. Your daughter will develop and unfold and her area of interest will appear.

CHAPTER 2

WHY SMART GIRLS SOMETIMES HATE SCHOOL

Despite a love of learning and an appetite for information, Aspergirls do not all enjoy school the way others might think that they would. For some, school is too slow; too restrictive, for we are often unable to read what we like or study in the areas of our passions. Social issues are yet another minefield to navigate, and an obstacle on the path to our desire—to learn as much as possible as quickly as possible.

Most of the Aspergirls said the same thing—with few exceptions, school was boring and they were bullied. *Bullying* is something that will come up throughout this book and throughout the lives of many Aspergirls. Unfortunately, it seems to be intrinsically tied to formal education. Bullying happens when someone is different and is seen as a threat in some ways, yet seen as weak in others. Aspergirls fit that bill perfectly. To a young and innocent child, bullying is a shock and often turns the world from a safe and happy place to a complete nightmare. For a spectrum child, it can be the beginning of lifelong post-traumatic stress disorder (PTSD).

I was not a classic autistic; I had no learning deficits. I was a happy, eccentric child whose Amadeus-like laughter filled the school halls and classrooms and who was tolerated if not well liked. To keep me busy, my kindergarten teacher gave me the other kids' papers to grade. It was absolute torture for me to listen to my classmates struggle with *See Jane Run*, so when my turn came, to make up for lost time, I read as fast as I possibly could—which was pretty fast. It made all the other kids giggle. Five- and six-year-olds can be much more tolerant than older kids. My uncoolness was my coolness.

Later, from about second to sixth grade, I wrote plays and gave out parts to my friends, performing them in and out of school. I had a good singing voice and wrote my own solo when the teacher gave the one Christmas solo to someone else. I had many friends...until adolescence.

All at once, my idiosyncrasies became very uncool, almost overnight. My social *deficits*, which prior to that point had just been *differences*, became glaring holes in my persona. At first I was merely ostracized, losing friends one by one, but then, the threats began. By this time I had no one to sit with at lunch so I usually spent it hiding somewhere. I developed ulcers first, by age 12. The main perpetrator of all this torment, a classic bully, announced that she was going to beat me up and that I couldn't avoid it. After a year or more of baiting me with hints of future physical pain, she finally made good her threat and I was badly beaten in front of a very large crowd of cheering kids, mostly older teenagers.

Physical fights became an almost daily probability. I went from obsessive reading to obsessive pushups to strengthen my weak limbs. Singing and laughing—my two favorite things—were supplanted by mutism and crying. I developed very low self-esteem and PTSD. And as anyone who's ever been bullied can tell you, once the air around you is poisoned, you are a target for everyone; from the strongest to the weakest, they will all want to take a shot at you.

How does a girl who was once a gifted and *popular* student fall so far? Home was dysfunctional, and I'd already become mute and withdrawn there, long before I did at school. My teachers may have noticed, but as is often the case, the bully was more popular with teachers than I was. Kim wasn't a know-it-all like I was; she didn't appear sullen and awkward, but instead, was confident and gregarious. It is possible, if not likely, that some teachers thought I had it coming.

Teachers, more often than not, either can't or won't protect you. While a good teacher is an incredible gift to a child's life and mind, a bad one is a force for destruction. The bullying started in my first year of kindergarten which was in 1985. We were all sitting in our chairs at our assigned tables and working on an art project when I felt this extreme need to stand up and spin around and around in circles and stare up at the ceiling. The teacher grabbed me by my hair and dragged me into the coatroom where she began to beat me with a ruler. She told me I had been disruptive to the class. The students could see through the little window of the coatroom door and thought it was funny. After this incident the children started to torment me on a daily basis. It started off with name calling, but then quickly progressed to kicking, punching, pulling of hair, biting me; things of that nature. After being held back twice, I was given tests. I was then enrolled into a gifted and talented program during the summer months, held at a different school in a different district. It was only during these months of school that I ever felt that I fit in with other students. (Brandi)

Having AS means you have both talents and deficits—recognition of both is important, but even when a girl is diagnosed it doesn't necessarily mean she will thrive. I don't think individualized education plans (IEPs) existed when I was in school, but from what Aspergirls tell me, they don't always do what they are set out to do.

I had a gifted IEP. Middle school and high school were hell—bullying from students and teachers, no one to turn to. I spent years dealing with severe depression. Everyone ignored my problems because I had good grades. (Andi)

Again and again throughout the conversations with Aspergirls I heard stories that echoed my own. For some the bullying started earlier or later, but it almost always starts. While bullying happens to both males and females on the spectrum, girls, particularly, can be judgmental. Dr. Grandin advocates that some gifted children with autism should be allowed to skip high school and go right to college and I couldn't agree with her more. We flourish much better in an environment where the emphasis is on academic achievement and not

socializing. Of course we need to learn to socialize, but through shared interests with like-minded individuals, not by being thrown to the lions. Emotionally, we *require* an atmosphere of tolerance and non-judgment.

With NT girls, you just don't know what the game is about. They have a coldness that can turn to meanness. (Widders)

With diagnosis or an IEP we might end up in special ed or some other place where some well-meaning individuals watch us like hawks, which we do not like. Barring learning deficits like dyslexia it is our emotions that really need the extra care. Our intellect will do just fine if you give it something to play with and let it go. (Reminder: I am referring to high-functioning individuals.)

Even if you are not bullied at school, it can still be very lonely. The reason many adults with AS like to be alone is because we simply get used to it, starting at an early age. I know we all have a fight-or-flight reaction to others, but I think that is an acquired response, even if it is acquired very early on.

I get let out of class early to avoid the crowds and I don't have to eat in the lunch room. I hope I find a friend. Someone who understands me. (Megan)

Experiences in school (grade school particularly) differ from one Aspergirl to the next and certainly from one school to the next. The soul of a school is comprised of its people. We are all individuals and there is no blanket remedy for any of these situations. Some Aspergirls thrived in the days before diagnosis, scrutiny, IEPs and special ed, partly because they were left alone, and partly because bullies were not allowed to conduct their reign of terror.

In Catholic primary schools in those days it was Aspie Paradise. Schooling was strict, formal and predictable. I thrived. It was expected that children would work hard, obey rules and be kind to one another. (Pokégran)

Aspergirls do not thrive under scrutiny, if it has just the slightest bit of hostility in it. Whether from our peers or teachers, if we are looked at with an unfriendly, intimidating, or threatening eye, we fold. Alone, we are talented, graceful, witty, and smart, but under such circumstances we curl up like hedgehogs. We're as sensitive emotionally as we are physically and the bullying becomes a vicious cycle—when the perpetrators see what an effect they're having, they redouble their efforts. Some of us get backed into a corner and keep retreating until we are out in the parking lot...then we just keep going. In other words, we quit. Some of us older Aspergirls went from gifted student to high school or college dropout. Instead of getting PhDs, we let PTSD stop us at our GED (General Equivalency Diploma or General Education Diploma). Quitting is better than allowing someone to bully us to death. We feel powerful when we leave a bad situation, for it means we are taking control, something very important to an Aspergian. But the problem comes in the future, when we realize we are 42 and never got that degree, or didn't get as high a degree as we should have. Our temporary feeling of triumph will come back to bite us in the backside again and again.

We, or at least our parents, have the power of choice. If you are not doing well, another school might provide a dramatically different experience.

Public school was a struggle. I was bullied, teased; I was shy and slow. I had difficulty reading due to dyslexia. High school was a private international school, and I was encouraged to grow as an individual. I did well there. (Jen)

ADVICE TO ASPERGIRLS

Socializing is a big part of the school experience, just ask anyone who has ever had to sit alone at lunch every day. Try to find friends who will accept you as you are, rather than trying to hang with the cool kids. But do make the most of the learning opportunities. While you may want to run straight home after school, joining extracurricular activities might put you in touch with people with similar interests; you may find another Aspergirl in the drama or science club. There are many more of us around than previously thought. Do not suffer in silence and risk eating and psychological disorders—keep searching till you find a friend who understands AS and your issues.

I hear from people on the spectrum all the time who are being bullied at home, at school, and at work. They are often afraid to speak up or to make waves for fear it will get worse. There is nothing worse than being bullied. Being bullied will result in shattered nerves and poorer mental and physical health. Aspergirls, you need advocacy and protection, but you also need to stand up for yourself. That includes seeking help and advocacy, not necessarily confronting the bullies directly. There are a number of resources out there which provide strategies for dealing with bullying and gossip, including my employment book Asperger's on the Job (Simone 2010). There are also websites with steps to follow. Get help. Tell your parents you won't go back to that school until the bullying stops. My own daughter was being ridiculed at a school she went to, so I home-schooled her and then took her across town to a better one once I found it. She's not autistic, but the point is, every parent should have a zero tolerance for bullying when it comes to their child.

Look yourself, or ask your parents to look for a school for Aspies. My dream school would be an all-Aspergirl school and although I do not know of one at this time, I think it is inevitable that one will soon exist.

Some of the Aspergirls I interviewed were bullied and abused by parents. If your parent bullies you, find another relative to protect you. If you have difficulty describing what is going on, write it down and give it to someone who is in a position to assist you, someone you trust. Abuse is not something you should have to tolerate. Protect yourself, feel no guilt, and get help!

ADVICE TO PARENTS

Your child is smart—you know that and they know that, but teachers, peers, administration, and counselors might not see it. Many people equate Asperger syndrome with intellectual impairment and that is one of the risks of disclosure. On the other hand, she may be obviously smart and it isn't any fun to hear other kids struggling with See Jane Run while you're already on Dickens. If your child is gifted, she might need a special program or some challenge in her life. Remember however, that she may seem quite mature in many ways but she is autistic and she will be fragile and childlike in others. Letting her be moved up a grade or two might not be a good idea if she feels intimidated by older kids. Happiness achieved through being allowed to be herself is more important than academic achievement, for it is the foundation on which the latter will be built.

There are schools specifically for kids with AS. Keep checking as this is a topic that is exploding and I'm sure it is only a matter of time before there are some all-girl Aspie schools.

Regarding bullying

Parents—you *must* protect your children even if part of that protection means teaching and encouraging them to stand up for themselves. But there are times that bullying is health- and life-threatening and intervention is needed. Don't be afraid to make waves when there's so much at stake. Just because a school says it has a zero tolerance policy for bullying doesn't mean it's true. Don't be afraid to switch your daughter's school. She may balk at the idea even if she hates her current school because she doesn't like change, but if she's in danger of either academic underachievement, social isolation or bullying, you might want to seriously consider this option.

CHAPTER 3

SENSORY OVERLOAD

There are a million triggers lurking everywhere, waiting to set us off, steal our peace and sabotage our calm. Sights, sounds, smells, touches, and even tastes can drain us mentally, physically, and emotionally. Why do things that others barely notice send us into a tailspin—literally? I personally subscribe to the "Intense World" theory of autism (Markram, Rinaldi and Markram 2007). Markram states that we are hyperfunctional as opposed to hypofunctional. People used to think that autistics felt less, felt nothing, were less than human in some ways. Actually the opposite is true—we feel everything, we smell everything, we hear everything...and we sense things others can't. There is no heterogeneity in autism, so some people might not experience this; a couple of the Aspergirls said they felt very little as children. But most will agree that we feel things "too much." I'm reminded of Lucy's character in *Dracula*: "I hear mice in the attic stomping around like elephants." We fixate on little tiny things that other people barely notice. Not because we are neurotic, not because we are attention-grabbers, but because those things are jumping out at us.

The Aspergirls I interviewed gave me quite a long, long list of what sets them off. Here's just a small part of it:

Loud social situations, traffic, standing in queues, perfume, fluorescent lights, clothing labels, background noise on phone, music in shops, when someone is fiddling, cigarettes, air fresheners, babies crying, vacuums, bathroom ceiling fans, sirens, fire alarms, fireworks, yelling/arguing, car horns, power tools, loud music in cars, TVs everywhere, commercials, cell phone ring-tones, if two people talk to me at once, too many items on shelves, cities, wind, cold...

The list was much *much* longer, but you get the general idea. But knowing what triggers we have is not the same as knowing what it feels like, or why. I think that most people who are not on the spectrum think of a sensory *trigger* as more like a phobia. A windy day makes you anxious not because of an irrational fear, but because trees are swaying, their leaves swirling, branches waving chaotically. The sound of wind is loud, distracting, an unpredictable assault on the ears. The wind pulls your hair and whips it into your face and eyes; it tugs on clothes and aggravates the skin—this is sensory overload.

Sensory processing disorder is a separate syndrome, but it's part of autism's package deal. Most if not all of us will have it to some degree.

SOUNDS

A cuckoo clock goes off unexpectedly. Two people carry on talking while a third doubles over and puts her hands over her ears—why? It is not, for most of us, a problem with the ears but a processing difference. Despite our legendary ability to focus, or perhaps because of it, we tend to need to address one noise at a time, so if we are on the phone, the television must be muted. If we are in conversation, the radio must be off. If someone is fidgeting while I'm trying to speak on the phone, they have to leave the room or they have to stop. Even the most minor movement and sound is a distraction.

Typical sounds that others can filter out, drive me to distraction...and shatter into shards of disorienting pain. (Stella)

Our sensitivity to sound as well as touch strongly affects our sleep habits and many of us can't catch 40 winks without earplugs and noiseless, heavy blankets. Because we have minds like recorders, even hearing a song before bed means it might play over and over again, robbing us of our rest. We have to limit what we take in and we must be selective.

A lot of these triggers, perhaps all of them, exist only in relation to our lack of control over them. If I'm running the

lawnmower and making a racket, that is okay, but if my neighbor is, that's a different story. This can make us seem like control freaks to others, and a bit hypocritical to boot. After all, some of us play in rock bands, or love heavy metal. But that means that we are *prepared* for it. We can handle an onslaught of sound for a time, but preferably a time, place and sound of our choosing. Hence, therapy for sound sensitivities may involve playing recordings of sounds that upset you and controlling the interval and volume until you get used to it and it no longer bothers you.

SIGHTS

We all know that Autistics and Aspies have an aversion to fluorescent lights because they flicker and hum at a rate we can detect even when others can't. But there are many other visual processing difficulties, such as from too many objects or people in motion. The objects in a grocery store aren't in motion but we are, causing a maelstrom of images in our minds that make us dizzy like we're riding the scrambler at the county fair. Grocery stores are hell on earth for autistic children and grownup Aspergirls don't like large shops any better—and yes, they can still cause us to have temper tantrums. We'll take a small boutique over a department store any day.

Recently I spent a day walking and exploring the historic city of Boston. By the end of it, even though I'd worn ear plugs and shades and had paced myself, I had taken in too many things for my brain to process. I had unnecessary images and sounds in my head that needed releasing. As I tried to sleep, these pictures played in my mind like a kaleidoscope, each one appearing and then morphing into the next. It was so vivid and full-color that it was like looking at a movie screen. While it was happening, my temperature shot up to a fever. My body was frantically working to "rid" itself of this invasion as if it were a virus. This went on for an hour or two before it slowed and I was able to sleep. Sometimes we just can't get rid of unwanted images so we may be quite selective about what we want to see. Other people might see us as being

fussy, difficult to please, oversensitive, and they may hesitate to invite us out anywhere for fear we won't like it. They just don't understand the intensity and repercussions of so-called normal stimuli.

I can't watch a lot of movies because of the imagery. I don't like having the images stuck in my head for eternity. I made the mistake of watching *Hostel* once, and to this day I could draw the worst scenes in it direct from memory. (Andi)

SKIN SENSITIVITY

The Aspergian need for soft fabrics and a firm touch is well known. We all have aversions to certain products and fabrics, though what those are vary from one individual to the next. Uncomfortable, fussy clothing is a torture for most people with Asperger's, not just females, but females have more fashion choices and may be expected on some level to wear fussy things. If you don't believe me just go to any shop: ruffles, strings, lace, polyester, wires, straps. We don't like fussy and we don't like frilly. Some of us like soft, tight undergarments like camisoles and leggings, to keep cold air off our skin. Others may only wear loose-fitting things. Always soft.

Little autistic kids are supersensitive to clothing and may not be able to tell you. It has always been fashionable for little girls to be dressed in "baby doll" outfits, with puffy sleeves that have elastic bands at the arms and thighs. Those clothes are torture; by the end of the day those elastic bands cut into flesh. Crocheted baby blankets do nothing to keep us warm at night but we can't tell our mothers because we are still nonverbal, so we freeze. When we're older, our mothers don't dress us but we are "dressed" by societal expectations, the uniforms of our positions, and by available fashions and fabrics. Currently it's much better for Aspergirls than it was decades ago, say in the 1950s and 1960s. At least we aren't expected to have a stiff bouffant and wear heaps of nylon and wool, but we still have a lot of fashion hurdles to deal with, for

example, pantyhose and high heels, swishy dresses, scratchy shirts, binding bras, and pinching trousers. We usually hate the cold, so we wrap ourselves in layers of soft, warm, frumpy clothing rather than something more becoming. Aspergirls are notorious for dressing for comfort before style. This can give others the perception that we don't care about our appearance, that we're unfeminine, a bit lower-class. While we want to be found attractive, we can't see ourselves as others do and we can't sacrifice comfort for acceptance. When we find something that fits, is comfortable, *and* is fashionable, it's like finding the Holy Grail.

We only like tight hugs, but those aren't appropriate in all situations so we'll avoid polite hugs people seem to enjoy giving each other. I always wonder how European Aspies deal with all those kisses on the cheek. They make me rub my face like a five-year-old boy after Aunt Mildred slobbers on him. This is also easy to misperceive as being cold and unaffectionate. We are affectionate when we want to be and particularly when we can control the amount of physical pressure involved.

PSYCHIC SENSITIVITY

That is not a misprint. I believe that in some cases, our senses are heightened and are almost animal-like. We sense things. Many people think that those with AS are psychically blind but I do not agree. Again this may be more germane to females, as psychic sensitivity (woman's intuition) is somewhat split along gender lines anyway. I think, similar to our sense of humor, we miss the obvious and see what is not obvious to others.

I have what some call psychic experiences and always have. To me, it seems perfectly logical. After all, there is the need to communicate and when your brain doesn't want you to communicate "normally," it seems to compensate in this way. (Dame Kev)

I can tell you that I dreamt of 9/11 hours before it happened and also had a vision of the 2004 tsunami when I was in

Thailand, ten months before it occurred. I'm sure you won't believe that, but you might agree that cats and other animals can sense earthquakes, even though that too is not proven by science. Just because science can't prove it—yet—doesn't mean it doesn't exist.

I believe that this is a large part of why we have difficulty getting along with others. If someone is smiling and saying one thing but psychically we are hearing something completely different, we will get confused and want to run away. This often conflicts with appearances and what others tell me, causing me to doubt my own intuition. I usually turn out to be right. A more cynical person might call it a self-fulfilling prophecy. The misperception of this sensitivity is that we are hard to get along with...paranoid.

Sensory problems affect us everywhere. They make dating difficult: "Is this new guy gonna think I'm a freak if a siren goes off and I have to cover my ears and flee?"; they affect employment: "Do I really want to spend \$300 a year on itchy nylons?"; and everything else as well: "I'd like to go out but it's too noisy/cold/windy..."

The fallout? We stay home a lot.

ADVICE TO ASPERGIRLS

Stress and sensory overload need to be looked at as a total package. Environmental sensitivity will always exist for most of us with AS but our reactions to triggers can be managed through taking good care of ourselves in general. You must take good care of your body and your nerves so when that cart rolls by with the squeaky wheel, or the fire alarm goes off, you may jump but you won't fall to pieces. What can we do?

Exercise

Many of us are more in our minds than in our bodies, and we think just because we focus on work or hobbies 14 hours a day and are tired, that we have exercised. We haven't. Try things that integrate the mind, body, and spirit—yoga does that and might appeal more to an Aspergirl than an aerobics class, with

its oft-obnoxious music. Yoga works on releasing chi and channeling it into parts of the body where it is blocked—including the brain. When I was teaching yoga I was much more mentally and physically calm. Martial arts or dance might work; pilates, or a mini-trampoline—it's repetitive and you don't have to join a gym, just buy one. Exercise bikes and ellipticals are also tools you can keep at home. Aspergirls are not gym-goers. We don't like the atmosphere, and there's too many strangers for us to feel comfortable, especially with all the emphasis on the body, but we can still work out. Try jogging, skating, or jumping rope.

Diet

Diet is important—stay away from chemicals, sugars, and any processed food. There are more stringent autism-specific diets as well, including the gluten-free, casein-free (GFCF) and the specific carbohydrate (SCD) diets. We'll talk more about that in Chapter 19.

Therapies

These are being developed all the time for people on the spectrum, not just for social skills but also sensory issues; usually some form of cognitive behavioral therapy (CBT).

Equipment

Sunglasses or colored lenses, hats, earplugs, iPods, comfortable clothing, and a squishy toy in your pocket can prevent overload before it happens. Take water and anything else you need to keep yourself hydrated and nourished when out and about.

Make informed choices

Make informed choices about what you're going to do and where you're going to do it. I've moved a lot but always live near an open field, park, lake, or ocean. This is because, even before AS awareness, I knew that I needed to have visual quiet as well as auditory stillness. For the last few years, particularly, I have avoided cities and places that I know will

flood me with sights and sounds that I am unable to process in "real time." You might like the *idea* of living in New York City but you might not be able to handle the constant sensory overload of it.

Some people create *sensory rooms* to regulate themselves if they feel a meltdown coming on or to recover from one afterward. Sensory rooms have special lights, smells, sounds, temperatures, and textures which you choose yourself to provide deep soothing input to your individual senses.

ADVICE TO PARENTS

If there are distinct triggers that you know of then try to avoid them. There are literally countless triggers everywhere we go. Watch for signs of physical and emotional discomfort in your child and don't expect them to just "get over it." Remove the source or remove them from the source. Sensory triggers are real and strong aversions, not just petty annoyances. They can leave us feeling sick and depleted. Work on getting the various therapies that help us minimize our reactions to triggers.

If you have a young Aspergirl and need to take her shopping, let her get used to stores a little at a time, one or two aisles at most. Let her identify markers along the way—where her favorite foods are, so she'll be able to fathom it better the next time she comes in. Hats and sunglasses will help, earplugs and iPods for older girls. Though they may make it hard to communicate with her the benefits will outweigh that inconvenience.

CHAPTER 4

STIMMING, AND WHAT WE DO WHEN WE'RE HAPPY

What happens when we experience sensory or emotional overload? Well, different things. Sometimes we get migraines, nausea, sometimes we have meltdowns, and sometimes we just *stim*.

I hate the word stimming. First of all I think it sounds creepy and weird, second of all it's a misnomer. Stimming is short for self-stimulatory behavior, but that's not exactly what it is. Stimming is simply something we do to *soothe* ourselves when we are upset, anxious, overloaded, or in pain; to release unpleasant feelings or energy. A student of eastern thought might say we have blocked *chi—life force*; energy.

Stimming behaviors typically include rocking, swaying, twirling, spinning (yourself or objects), humming, flapping, tapping, clapping, finger flicking, and so on. I'm sure there are many, many more. Soothing stims happen because someone or something is pushing our autistic buttons.

Little kids stim when they're bored, which makes them anxious; they stim when they've had sugary things with artificial coloring because it makes their bodies feel twitchy. They stim because the supermarket has too many items in it and the lights hurt their eyes. They stim when grownups are yelling and they stim when other kids are mean. They stim from the million and one triggers that are all around.

As adults, we stim when the rent is due and we're short, or we need new tires, or we have to get up early and go some place and don't know exactly where it is or what to expect. We stim because we have to go to dinner with...(gasp!) people. We stim when we're lonely and sad. We stim thinking about any stressful activity we might have to engage in.

The earliest stims I remember doing were spinning tops and rocking on my horse—all socially acceptable for little girls. Like Donna Williams, I also remember watching the patterns in the air but in my case, in the darkness when I closed my eyes. Red and white circles swam against the blackness, and it was infinitely entertaining and soothing. When I needed to change it up, I pressed my eyeballs or squeezed the sides together to make a whole new burst of swimming circles. That is one stim I don't do anymore. Now, all grown up, I hum tunelessly; after giving a lecture, I have to run through the parking lot to my car. I don't care who sees me. If I'm very stressed, I'll put my hands on either side of my head and squeeze and rock. It's better than having a meltdown or getting an ulcer.

We stim from sensory issues, and we stim from anxiety and social or emotional issues. When you read this list of stims, I want you to keep in mind that the women speaking are of all ages, and some are highly successful and/or educated:

Bounce on a ball or trampoline, play with toys, flap my arms, rub certain fabrics, bite my nails, rock (side to side or back and forth), spin things; kick my feet in patterns, drum rhythms on surfaces, face-rub with the back of my left wrist, wriggle constantly, tap thumb and forefingers together, pace, sway, and shift from leg to leg, whisper things I've memorized, finger flick, wiggle my fingers, or rub them together. Rock on heels while in public, hum monotonically, sing, repeat things, talk to myself, rub my belly; pet my dog, stare at clouds, watch favorite movies repeatedly, match my breaths with each syllable in a sentence.

Autistic people have an innocence, a childlike quality, regardless of age or education. This is very obvious when we are anxious and upset.

I'm a very tactile person (to materials and objects, not other people!), so I tend to soothe myself by touching either a material that I like—book-bindings in leather for example; or an object that I like—an action figure out of

my personal collection, or some of my son's stuffed animals. (Siv)

By the time we grow up, we know what isn't acceptable to do in public but sometimes we forget ourselves.

In public, if I am getting overwhelmed I will jiggle my leg or tap my fingers—small stims which are probably somewhat annoying to others, but don't mark me as a complete loony. (Polly)

I don't consciously realize I'm doing it. In public, I try to sit still if I'm worried what people think of me. I've embarrassed myself a few times, especially in restaurants where people tend to stare. (Andi)

But there is a trade-off to self-control. Not stimming when you feel anxious means you're not releasing the build-up of tension and you risk having a meltdown, or migraine, or acquiring a tic. Sometimes my eyes or mouth will twitch and that is totally involuntary. Some tics are semi-involuntary. I had a vocal tic when I was little—I made a clicking noise in my throat. Perhaps that is a perseveration. *Perseverations* are gestures, movements, or repetitive rituals we cannot stop ourselves from doing and so straddle that line between tic, stim, and ritual. I didn't know anyone could hear my clicking, so I didn't try to contain it. I suppose it was in lieu of rocking or something more noticeable, but the trouble was, it was noticeable and I didn't know it until my best friend said "What is that stupid noise you always make in your throat?" I was horrified and found the will power to stop. I'm sure it was probably replaced by nail-biting or something else that was fairly socially acceptable. The trouble with repressing stims is that we tend to pick up destructive habits, or else we just internalize our anxieties and pains instead of releasing them as they happen.

My mom saw me rocking one day in the kitchen when I was young and said "What's wrong with you? You retarded?" After that I started bouncing my feet off the foot board, driving my little sister in the bottom bunk crazy. In public I'm a mess. I pick at invisible hairs, clean

dirt out from under my nails over and over, and fidget with everything I'm wearing. Picked up smoking at 20, having a hard time beating that one. (Bramble)

Our emotions are raw, immature, childlike. Nowhere is this more apparent than when we get excited. I asked the Aspergirls if they "stim" when they're excited and I got the following list—they are very similar to our anxiety stims; but they happen because of an overflow of positive emotion:

Dance for joy, laugh out loud, flap my hands or arms, say "yay" and "yippee" like a little kid, jump up and down, ball up my fists and shake them, clap, can't stop laughing, pace back and forth at full speed, skip, sing, speak in a high squeaky voice.

A lot of my obsessions tend to be media based (certain TV shows/movies, for instance) so if I'm at a particularly good bit, I might have to pause it, have a quick run, and then continue. (Polly)

Many of the Aspergirls mentioned a high-pitched laugh or squeak when happy, and a childish tone of voice. I do think this display of exuberance is more germane to girls and is relatively socially acceptable for us and so we are lucky in some respects. How socially acceptable depends on the situation and the mindset of the people we're with.

When everyone's in a goofy mood, nobody seems to point out my quirks so much. (Dame Kev)

People don't seem to mind, and some seem to enjoy things more because I get really excited about them. (Andi)

Some parents put their Aspergirls in dance or other classes to channel that energy into something more constructive or socially acceptable.

My mother insisted I use all of that energy for something productive. The solution was dance, martial arts, tennis, fencing, or any type of sport that forced me to learn to channel that exuberance. It also helps keep me from jumping on someone unexpectedly for a wrastle. (Dame Kev)

Others haven't found acceptable outlets so they've learned to suppress or channel "happiness stims" into something less noticeable, often after being made fun of or criticized.

I noticed I was different as a teen when someone said "What's wrong with you?" I was jumping up and down at the time. At some point I got into the habit of keeping my hands clasped and held in front of my waist when walking. When I'm happy, that morphs into thumb twiddling. I'm not sure when I got into those habits. They're less noticeable though, I think. (Elfinia)

The more I learn about Asperger's, the more I realize how much of who I am (and was) was constantly being covered: "Don't do that, don't look that way, be polite," etc. I am hopeful for myself now and for my kids to understand themselves and to love those differences. I am also bringing back some of the old stims which were taken away from me—jumping on the tramp, spinning tops, clapping. (Jen)

Stims are harmless, usually—recently, a favorite song came on the iPod (I didn't know my daughter had put it on for me) and I flapped my hands in excitement, which is fine except I was driving on the thruway. It caused me to lose control of the car for just a moment—I had not been aware of that tendency prior to that incident.

It makes it difficult to go out and have fun when we know that if we are just ourselves, people will think we're strange. Fear of ridicule is just one more thing that keeps us isolated. Others' misperceptions might be that we're immature, mentally challenged, or that we're acting silly on purpose to attract attention. Since we are often stoic, when we're happy and exuberant, it can be misconstrued as flirting.

ADVICE TO ASPERGIRLS

We do develop some control over when, how and where we "release chi." How much you want to stim in public is up to you. I realize that perhaps there are some things better left in private. But if I'm not hurting anyone or causing a loved one terrible embarrassment, I will let it all hang out. I jump up and down, flap, clap, skip, talk in a high squeaky voice, and laugh gleefully. Since I've allowed myself this freedom of expression, I feel healthier, I feel happier. I love all of these things about myself. My facial tics have almost completely gone away except in times of extreme stress.

I tell people that I may rock or flap or whatever to alert and educate them about what autism/Asperger's really is. Recently I flew on a plane and there was turbulence. I explained to the person next to me that I needed to rock because I was scared. After the bumpy ride was over, I asked if it was weird for her to see. "No," she replied, "I almost wanted to join you."

I don't want to spend a lot of time in environments or around people that can't handle the real me. But I do realize some of you are in jobs or communities that are a bit straight-laced. Let your hair down when you can. Make sure that at least some of the time, you can let it all out, or from what other Aspergirls tell me and from my own experience, you will damage yourself—your nerves, your psyche, and you will diminish your potential for happiness. Smile and stim. Stim and smile. Sure is better for you than smoking.

ADVICE TO PARENTS

You don't want your daughter to draw attention to herself for being strange, and you don't want the other kids to make fun of her so you might find yourself being a bit strict and critical of these types of demonstrations.

If your child is engaged in an anxiety stim then try to figure out what is bothering her and fix or eliminate it. Maybe she has sensory overload. Maybe she needs some intelligent conversation or engaging interaction. Maybe she needs to be given a challenge or a chore. If you're around others maybe there is someone who is giving her an unpleasant feeling.

Yelling at her for acting this way is just going to make her feel ashamed, and if it's a happiness stim she's doing it'll ruin the joy of the moment. Help her to channel it into something useful, constructive and socially acceptable. If you daughter likes to jump up and down, buy her a trampoline; if she likes to twirl, get her dance lessons; if she likes to hum, encourage voice lessons or joining a choir. Tapping can be channeled into drumming and so on.

Being embarrassed about whether or not your Aspergirl is going to stim in public is no different than worrying about what your fellow church-goers will think about her pierced nose. It's about your vanity to some degree; your reputation. But she is who she is. God (if you believe in God) gave her to you to nurture and to protect and also to let flourish.

If her stims are self-injuring, that is something else entirely. Most of the Aspergirls I spoke to only self-injured when on the wrong medication, when benign stimming was discouraged, or when there was some serious psychodrama going on in their young life, such as abuse or bullying. Find out the source. Don't be too quick to medicate without thorough research, whether it's garden-variety stimming or self-injury. We'll talk more about medication later.

CHAPTER 5

ON BLAME AND INTERNALIZING GUILT

Lists of Asperger traits say that we have difficulty with eye contact, which makes us look guilty to the uninitiated. I think there's more to it than that. I think we internalize a lot of guilt along the way.

In addition to the embarrassment of having our stims pointed out to us, we will have all of our other idiosyncrasies pointed out as well, one after another, starting when we're young—by our families, our friends, our teachers, and everyone else who might be a witness. We are blamed for our erratic and often uncontrollable behavior. Even those who were well behaved were blamed for social awkwardness and botched interactions. Because we never knew what we did wrong, a profound sense of confusion, alienation, and *guilt* crept into our psyches, displacing normal childhood emotions.

I displayed many autistic behaviors. It was assumed I *knew* I was acting weird, and did it deliberately. I. Just. Did. Not. Get. It! (Polly)

During my early home life I was not diagnosed and my symptoms were overlooked. I was told to "buck up" or "stop it" if I was having problems with school and social interaction. (Brandi)

If there is no diagnosis then there is a vacuum—a hole in which to pour speculation and fill with labels.

School counselors thought I was a brat. I went to many psychiatrists and took many tests and was diagnosed at 12. (Riley)

Diagnosis still doesn't always stop the people around the Aspergirl from thinking that she is somehow reacting to things

"on purpose." Families and communities, out of ignorance or sometimes jealousy, will often accuse her of faking reactions, drawing attention to herself, or even choosing to have meltdowns. Parents who are supportive may end up sharing blame and receiving criticism themselves from other family members who may not take the time to read about and understand AS.

My daughter was diagnosed very young. Ever since I can remember, my family thought we were too indulgent and that she needed stricter discipline. They could not understand how we could "allow" her temper tantrums, and how we could allow her to not socialize with others. As she grew, the family changed the way they treated her. They went from feeling she was a spoiled child to treating her almost as if she were retarded. When her cousins get together to socialize, they never include her. My mother was afraid of her, and was uncomfortable being alone with her. (Deborah)

It's bad enough if a little boy acts like a wild thing in public but "girls should know better" how to behave.

I would meltdown and my parents would threaten to commit me if I didn't quit. (Naga Empress)

Blamed for lots of social interactions going wrong. Never understood what I did most of the time. They would just say "You know what you did!" I never did. (Elfinia)

The potential fallout to this, on top of having AS, is having a life-long guilt complex; becoming apathetic to even trying to have friendships or relationships; and being fairly easy to goad into things. We often, as children and as adults, try extra hard to please and not to make waves, but somehow we always end up "causing problems." We may try very hard to behave. We think that if we are very, very good, people will like us and all will be well. I see this all the time with adults with AS at their jobs. They try not to make waves, but still they get accused of things and they don't understand it.

When puberty hits things get worse instead of better. We might start engaging in the very behavior of which we are accused. If everyone says you're a troublemaker, you've nothing to lose by actually making trouble.

I lived in a very controlling, hostile environment. Everything I did was watched under close eye with immediate criticism. Nothing I did was right. I was not allowed to do much. I displayed social avoidance, selective mutism, horrible eye contact, soft, slurred speech, rocking, constant fidgeting. Being that I am a female this was all considered shyness, then they chalked it up to puberty, then it was being a young adult. I was always told, "You'll grow out of it." (Elle)

But of course we never do grow out of it. One of the things that has recurred throughout my life is a feeling that I should be doing better, that I should be able to handle a job/relationship/life/whatever, better than I am. Every time someone walked out of my life—whether friend, boyfriend, husband, boss, etc. they always said "You're strong, you'll be just fine." But I did not feel strong. I felt incredibly flawed and vulnerable and just couldn't figure out why. I knew my mind was strong, and I knew I wasn't insane, or at least I hoped. I had doctors and counselors list my various behavioral problems, most of which, in hindsight, fall onto the list for AS: fear of change, emotional immaturity, obsessive behavior, need for control, inflexibility, depression, self-absorption. But rather than symptoms they sounded more like judgments, as if knowing what the problem was I should therefore, be able to change it—because I'm obviously intelligent. Needless to say, I didn't stay with those counselors very long. I came to the conclusion that there was nothing wrong with me, there was something wrong with everyone else. That worked for a while, until I had a daughter, and she also had the same observations, with a few more of her own thrown in, for example weird; socially awkward. I felt utterly alone. Then I discovered Asperger's.

Once we receive the diagnosis, whether through the efforts of a perceptive doctor or our own investigative work, there is definitely relief; a laying down of our burden. But that burden gets picked up again and again, every time someone asks "Why can't you just?" or every time we simply just *can't*. New situations will constantly arise that push our sensory buttons, cause us to panic, trigger meltdowns, etc. Knowing you have AS is not going to fix all these things, nor is it going to make you suddenly socially adept. And not everyone you meet is going to realize you are on the spectrum, so they are going to be measuring your behavior with a non-autistic yardstick.

There is always going to be some internalization of blame. Most of us, whether we care to admit it or not, have a considerable amount of embarrassment and shame to contend with—for not being able to handle the little day-to-day, ordinary experiences that other women seem to manage just fine. Whether that means holding down a job or a conversation; growing friendships or savings accounts, as a group it is safe to say that we struggle with these things.

We feel guilt for another reason—Asperger's is not an obvious, life-threatening condition like cancer or some other horrible disease or situation, and we know it. We look "normal"; we are often extremely smart. Some of us may not have any learning deficits at all, others do but they're usually not obvious, for example dyslexia. When others tell us to "deal with it" we wish that we could, and part of us thinks that we *should*. But telling a person with Asperger's to just "get on with it" is like telling a person in a wheelchair to take the stairs if they want to get to the second floor.

Men have their own pressures but women, who are expected by society to be capable, multi-tasking, high heel wearing, doyennes of manners, etiquette and the sharp retort, will feel it in their own special way.

ADVICE TO ASPERGIRLS

Some family members will read all they can about Asperger's and get behind you 100 percent. Some won't lift a finger to try and understand. They may think they've got you all figured out and they won't want to hear anything that challenges their assumptions and makes them examine their own behavior towards you. Most will fall somewhere in the middle. If you're older and your parents are elderly they may not be mentally prepared at this stage to believe that you're autistic and that they never noticed it.

If you had a rough start in life, and were unsupported, I was going to tell you not to let it cloud your mind, prejudice it against people, because there are good people out there in the world, and you will find them. But the truth is, every person you meet in your life will have good and bad traits, positive and negative qualities. Some will have more good than others. Some will see things in you that they admire, that they resonate with, and others will see your so-called weaknesses as an invitation to criticize, bully, etc. Some will want to befriend you, nurture you, and even protect you, while others will exploit and abuse. Some people may do both things at varying times. I have lived for many years with this condition and my own family still doesn't get me. Although they know I have something to do with AS awareness and education, they will praise me in one breath, question my Aspergian behavior in the next.

The best thing you can do is believe in yourself and know that there is good in most people. You can bring it out in them if you know how to. A tuning fork, when you strike it, can make a guitar string resonate with the same note if it's close enough in pitch. You are special, you have special qualities, and you can bring out similar qualities in other people. You can spur them to examine life from a perspective that they contain within themselves, but rarely bring out into the light. You are here for a purpose and a reason. You grace the world with your presence, and there *will* be people who appreciate you. As you get older I hope that your confidence increases rather than decreases and that you don't shut yourself away in

your bedroom as so many of us do, watching films or reading books every night because we know what the world consists of and we don't like it. If you don't like your immediate environment—town, city, etc. perhaps you need to get creative and decide where you can put yourself to do the most good (once you're old enough). Don't let the rat race get you so down that you end up in the "rut race"—an even worse game where you are just spinning wheels and spending time.

Hopefully your family are supportive. If they aren't, I know how difficult and lonely it is to exist in a household where you are made to feel the black sheep. It's funny, but a dysfunctional family, if they don't know they're dysfunctional, can make *you* feel like the dysfunctional one because you don't fit in. I firmly believe that most of the psychological problems that seem to come with AS have more to do with non-acceptance, bullying, and blaming than anything else. Someday you will be able to leave and have your own family and you can set the tone for your house—one filled with light, love, games, creativity, reading, humor, and whatever else you want...even if it's 15 ferrets and a llama.

ADVICE TO PARENTS

First of all, don't blame yourself or your husband because your daughter is an Aspergirl. Second, don't blame her. You have a gift and a blessing on your hands.

It's funny, I think all moms who genuinely love and care for their children think that anything that's not perfect with their child is somehow the mom's "fault." I had a terrible virus in the first trimester of my pregnancy. I beat myself up over this for months. What if I hadn't worked in the doctor's office...maybe I wouldn't have gotten sick...or maybe I shouldn't have worked but just stayed home and taken care of myself... You can make yourself crazy with guilt sometimes. But I came to realize life is what it is. With age comes wisdom. I had no real control over my daughter's outcomes. And shame on me for ever thinking that she is less of a person for her "disability."

With or without Asperger's, I couldn't love her more, and she is the perfect being God intended her to be. Shame on doctors and therapists who put blame on others for their children's not fitting into the mold of normalcy. People with labels are no more or less. They count as much as we do, and bring so much color into what could be a very boring black and white existence. I think it is important that parents of children (young or adult) understand that. (Deborah Tedone, director of Square Pegs/Asperger's Support Group)

Your Aspergirl may be difficult at times, and she may seem like she wants to be left alone (this can result in being left to fend for herself far too often) but she *needs* nurturing—in the form of food, understanding, safety, and advice. She needs these things as much as your non-AS children, if not more so, but may get less attention because of her solitary ways. Don't let this happen.

She has enough confusion in her life already. Blame and guilt should not be part of the legacy that she carries for they most assuredly will result in other, psychological conditions (autism is neurological, not psychological, as many still think). These, in turn, may obscure AS and cause doctors and therapists to treat the symptoms rather than addressing the source.

Your daughter's battle with sensory issues, social issues and prejudice may be life-long. Give her a good start by embracing her idiosyncrasies, even if she doesn't like it when you embrace her physically.

CHAPTER 6

GENDER ROLES AND IDENTITY

Gender roles have annoyed me since puberty, when all my childhood girlfriends started paying more attention to their looks than to books and started acting nicer to boys than they did to me. Since then they have bothered me in ways too numerous to list. Whether it is the fact that all commercials for cleaning products feature women and that every single movie trailer has a male voice-over, I have issues with society's assumptions and reinforcing stereotypes.

Splitting AS traits along gender lines may seem unnecessary to many on the spectrum because we tend to be androgynous creatures—in mannerisms, behavior and, mostly, in essence.

I think gender roles are a load of BS. I didn't understand gender when I was young, and had issues with bullying because of it... I don't understand femininity. In my mind, stereotypical women seem boring, petty, materialistic, and completely irrational. I'd rather be interesting and outcast. (Andi)

Our androgyny shines through our feminine shells. Many times I've been accused of being either a transvestite or a lesbian and that has also happened to my Aspergirl peers.

In high school, girls treated me like I was something else, not boy, not girl, just an *it*. (Elfinia)

In my mind, in my self-perception, I have a male identity as well as a female one and can visually picture my male self.

I have never felt female or able to be "one of the girls." I actually feel as if I am half male and half female. (Camilla)

I discovered that, in fact, most if not *all* Aspergirls have similar perceptions about gender. Our anima and animus seem to be of equal influence and power. For some it manifests in

obvious ways—being the breadwinner in a relationship, or allowing children to live with their father while she pursues her career. For others it manifests sexually; although most of the Aspergirls are heterosexual, a substantial number said that their partner's gender didn't matter. Mostly it manifests as frustration, and disinterest in society's expectations at what being female means. As usual, we march to our own drum.

I was probably seven when I was one shot from beating a boy at table hockey. I saw the look on his face that he could lose to a girl. I scored. I have never backed down from a guy. Nevertheless, females do not make much sense to me. When one plays with girly-girls, heaven only knows what the game is about—I certainly never figured it out. (Widders)

Though we may not feel particularly womanly, others will still see us as such and measure our behavior against nonautistic females, when in reality I feel it would be more appropriate and fair to measure our behavior against a man's—after all, men are not expected to be socially adept, or have an abundance of nurturing feelings. This would be a much fairer standard of measure and other Aspergirls agree.

Women are typically measured by how well they can multi-task, regulate their impulses, smooth over conflict and soothe other people's emotions. People say women are equal to men, but they still expect women to carry far more of the burden for other people's happiness than they are conscious of or care to admit—this magnifies ridiculously for spectrum women. (Stella)

Another aspect to being a woman is the amount of grooming we may be expected to do. I once read that the average female spends thousands of hours of her life—hundreds of days—getting ready to go out. That just seems silly to us. While basic hygiene is not a gender issue, how "decorated" society expects us to be is—makeup, hair products, lotions, potions, etc. We'll talk more about that in Chapter 8.

I will never buy lots and lots of shoes. I have no understanding why anyone needs that many shoes, or would even want them. Makeup makes me want to claw my face off, I can't/won't wear it. (Elfinia)

It's not just gender identity that we may struggle with—it's identity in general. It does seem to be a trend, for some of us, to have a changeable personality either based on our current role model, or changing interests.

I have exhibited that well documented chameleon-like nature that is spoken of in relation to women with AS. I do not have a clear or typical sense of self. (Camilla)

Are we just impressionable or are we true *chameleons*? Does this changeability stem from a mind hungry to experience life from many angles, a dissatisfaction with who we are, or really just not knowing who we are? When I was a child I wanted to see, be, and do as much as I possibly could. I read and later traveled voraciously to seek this out. I remember that I always felt like an empty vessel that needed to be filled with experiences so that I could craft an identity out of them. Other people, throughout my life, seemed like they already had identities and therefore, seemingly, had less need for experiences.

I even picked up accents quickly, as if searching for an ethnic identity as well. I was once fired from a hostess job in New York. I picked up a Hispanic accent from talking to kitchen staff and the boss thought I was an illegal immigrant. When I lived in England, I had a full-fledged British accent.

Alien to our gender, to our culture...and to our species? The term *alien* has often been used to describe the Aspergian experience. Some of us felt not only like we weren't particularly female as children but also like we were not from the same planet as everyone else. This is a good part of the reason so many of us love sci-fi and fantasy. The books of C.S. Lewis and J.R.R. Tolkien gave me hope that there were other worlds, places where I would fit in. The very first record I bought was "Space Oddity" by David Bowie. I related to his

character, his persona, although I was only six years old at the time. I felt like I was literally in the wrong world and particularly in the wrong family; that there had been some sort of terrible mistake. And I am by no means the only Aspergirl who feels this way—virtually every single one of them said that they never felt that they "fit in."

I still love X-Men. When I was younger, thinking of myself as being like one of the mutants (without the super powers) made me feel like even though I was different, I could live with others. (Dame Kev)

ADVICE TO ASPERGIRLS

Most of us don't really need any advice in the gender department, just validation...our anima/animus seem pretty balanced and that is something to be proud of. If kids make fun of you, just know we've all been there, and the kinds of kids who make fun of us in school usually end up right where they started—same place, same mentality. People who really know who they are, are lucky in some ways, but they are perhaps less challenged to grow. We have a thirst for knowledge; our personalities will develop if we don't hold ourselves back.

If our sense of who we are changes with our interest, maybe being a chameleon *is* our nature. I do believe that we each have core identities which will run throughout our lives, no matter what externals change. Each woman that I interviewed for this book had a distinct voice and character and it was easy for me to see that they had strong personalities even if they can't see that themselves all the time.

As far as identity and what is normal, everything that constitutes society is a construct. I learned that in Sociology 101 (Basic Sociology) but I saw it firsthand when I traveled around the world. What's polite in one place is offensive in another. Some cultures read right to left and back to front. While there is no Asperger homeland, no mother ship, that means to a large extent we are free to create our own culture, our own rules, and our own environment. As one Aspergirl,

"Stella," said, "Barring anything dangerous or unsanitary, do whatever it takes to cope."

It is important to identify for yourself some core values, and to look to a higher source to find them—whatever that means to you. It may be a superhero or it may be a religious figure. It may be a character from a book. We learn social behavior by emulation. To look at the popular kids and try to act like them means that we might find ourselves with a whole new set of behaviors and morals that are not our own. Choose wisely.

ADVICE TO PARENTS

Dads, the great thing about having an AS daughter is she will be more likely to want to help you fix the car and build a fort than help Mom cook dinner. This is a trait that may be overlooked because she's in her head so much and is so solitary much of the time.

Being a goofy but intellectual tomboy is normal in our world. Similarly, if she wants to decorate her room like Rivendell and can't get her nose out of her fantasy books, understand she feels that she doesn't fit in with this world. Who's to say why this is? As the saying goes, we are in this world, but we don't have to be "of it." This world is not of our making, so it's no wonder we want and need to make our own.

This can result in a type of restlessness, a craving for experience and identity. It could result in lots of stops and starts, whether in the areas of employment, education, or even geographic location. If you daughter seems to be losing herself, she's probably emulating...again, this is normal, but if she's behaving in a way that is inconsistent with her usual code of conduct and ethics, you might want to find the source and help her replace it with a more appropriate role model.

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CHAPTER 9

FRIENDSHIPS AND SOCIALIZING

I once saw a plaque in a British pub that said "Forget about our enemies. God save us from our friends!" Whoever said that must have been an Aspie. For we love our alone time. We love not having our peace wrecked by nonsensical conversation and meaningless activity. But at the same time, most of us also crave companionship and fun. It's complicated. People with Asperger's have a fight-or-flight reaction to all social contact. We want to be accepted for who we are but it is difficult to be yourself around others when you can't relax. Adrenalin kicks in, so if we don't run away, we might hog everyone's attention, do a little song-n-dance, or standup routine, then afterwards go home and have an afterparty meltdown.

I do not do social chit chat. Everything has a purpose and is about analysis. I do attend social gatherings occasionally but I pay with emotional overload and a meltdown or migraine the following day. (Camilla)

Because of this, and all the other myriad communication and sensory issues we contend with daily, we usually find friendships very difficult to maintain—and so we choose to fly solo. This plays out a little differently for Aspergirls than for our male counterparts—when was the last time you heard the phrase "lone wolf" applied to a female? Women who have no friends are simply weird, suspect—cat ladies. While it is plausible and acceptable for a man to be a loner, women are assumed and expected to be social creatures, arranging weekly margarita nights with girlfriends or having a phone surgically attached to our heads. According to the media and the myths of popular culture, girls can't even go to the bathroom alone,

much less the mall. The reality is, whether we want them or not, most Aspergirls have few or no friends.

Our difficulties usually start in school. Other girls may make fun of us for our unfashionable looks and withdrawn or unusual mannerisms. Once you've been bullied, it gives you a glimpse into the darker side of human nature that other people may rarely, if ever, see. That is something you never quite forget, even if you learn to get along with people and see their good side later in life. It can prevent you from ever getting truly close to people, for you come to believe that what constitutes popularity is not something of any deep or lasting value. If we can find those who will take the time to get to know us, it is possible to cultivate a close peer relationship or two in school.

I had a best friend from fourth to ninth grade (she moved out of state). All other friends have been transient. (Widders)

I was bullied from the first day of school until the eighth grade. After that I made one friend. Many people find me interesting (at least at first) but I try to keep them away because I don't want people in my life. (Siv)

We cultivate or maintain "appropriate don't relationships." When we're younger we may be attracted to older people because of our intellectual maturity and hyperlexia, but as we get older, we may feel more comfortable with younger people because we don't mature emotionally. As adults we find people our own age boring and lacking in similar interests. For example, new sounds in the form of alternative music are incredibly important to me/us, but many people my age still listen to what they did when they were teenagers or else they have migrated over to country music the way old people migrate to Florida. They dress old-fashioned and wear their hair in styles they deem "suitable" for their age. To me they just seem staid. When I attend a rare dinner party, it is a short matter of time before all conversation starts to sound like the teacher from Charlie Brown ("wah wah, wah wah wah wah"). No matter how nice or intelligent

everyone is, I just want to go home, put on my tutu and roller blade. I simply have great difficulty finding people who are open and youthful, yet mature and experienced in a way I relate to.

I am a mother and yet my room looks like a child's room with a single bed, my teddy, my elephant collection, and little trinkets and things. I live like a kid. I also feel as if my emotions are both rudimentary and somewhat extreme. I am prone to tantrums and meltdowns. I feel out of my depth around adults unless it is special interest related. I am 47. I suppose I look my age, although I dress like a university student. (Camilla)

Ironically I like teenagers more now than I did when I was one. I've caught up in some ways—shop at the same stores they do, listen to the same bands, and like most of the same films. I am now, at first glance, *cool*. Yet after a few minutes of conversation, our intellectual and neurological differences become apparent on both sides. I find them unripe and preoccupied with hair. They find me shocking, strange and amusing...sometimes intimidating because of my bluntness. And in many ways they've passed me by again—I still want to watch children's movies and play games while they are enthused about boys and their future.

I find joy in computer games, in films like Harry Potter and Star Trek, and it seems that some people find me a bit childish because of this. I like to talk about it a lot as well. (Siv)

I don't *think* that I look, act and feel younger than I am, I *know* I do. I'm not irresponsible, just hyper and active like a younger person is. I have a lot of younger friends. I don't have any problems in particular with people my own age, save that I sometimes think they are boring. (Dame Kev)

As a person on the spectrum, I do have both compassion and empathy for many people, but that is not the same as friendship. There are people I like, those I admire, those whose

company and conversation I enjoy in small doses, but I do not enjoy doing the things that women are supposed to enjoy doing with each other—shopping, movies, lunching, etc.

I am eccentric and well loved, I have a good sense of humor and am a good mimic. But I cannot feel connection with others in a manner that lasts over space and time. Many mistake my one-on-one "intensity" for some kind of special friendship "intimacy." I operate at a depth most people do not. (Camilla)

Because of our myriad sensory and social issues, many Aspergirls socialize only with their partners and children, because they understand us. We have control over what activities we will do with them. A friend who invites you to an event may not fully understand your reticence and concerns if they don't take the time to read and research AS.

There are times that I look at other people and wonder what its like to have friends but my husband is my best friend; we have an AS son and we all have a ton of fun together. (Nikki)

School and work gives us a pool from which, by odds, we might meet someone we connect with. But once we're out of school and especially if we're out of work, we can be quite isolated.

I am a little lonely. It's always been hard for me to make friends and I have spent a lot of time inside the house the last few months, living at my parents'. At this stage, where academics stops structuring life for me and I have to structure it myself, it's been very difficult to work up the self-motivation to even leave my bedroom. (Stella)

The only place I meet new people is at work. I don't have many friends, but I also don't actively try to make new friends. (Jen)

We have to get creative and seek out kindred spirits if we want friends. Special interests and group activities give us somewhere to go, *if* we can afford to go out at all (many of us

spend our lives in financial straits). But we're still Aspies and may have a hard time taking that step to conversation.

I have *no* friends! I have tried joining clubs, going to lessons, and all the usual palaver, and it doesn't work. Say it's a knitting class...at the end I've learned to knit, but I haven't met anyone or spoken to anyone much. If I have had a conversation, it was probably pretty forced. (Polly)

I go to local film industry events and I see the same faces over and over again and get comfortable with some of them. This makes them acquaintances, though, not friends. My life isn't stable enough for *hanging out with the girls*-type friends—no money for one thing, plus too much stress to just hang and be casual. (Anemone)

Facebook, Twitter, and other internet tools can be extremely helpful in maintaining at least some semblance of a social life. They don't cost money, and since a large majority of us express ourselves better in writing than in conversation, it is possible to conduct fairly meaningful relationships online.

I don't do well in person, but the internet has served me well. I can be the me that's stuck inside my head here...I am on one particular message board a lot. That's my home! I have lots of e-friends but locally I have no one. (Elfinia)

Online socializing avoids the group setting while, at the same time, gives us a feeling of being part of a community. Some find the growing sense of community among those with Asperger's means it is possible to have several friends that are also on the spectrum. It feels really good to talk to those who understand, to whom you do not constantly have to explain yourself. The other edge to the sword is that we may develop an "us and them" mentality.

I long ago stopped trying to be close friends with nonspectrum people and only have friends I understand and who understand me. (Pokégran) Younger Aspergirls have more need for "real world" friends, someone to sit with at lunch, play with after school, and share experiences with. This may impact our lives even more than our male counterparts—female friendships are based far more on social skills than male ones, which have more to do with shared activities or interests than conversation. The loneliness a young Aspergirl feels means that she might not be too discriminating.

I would take whatever friends I could get. Often kids who didn't speak English. (Olive)

While it is true that some Aspergirls just don't want friends and are happy being alone, the thing I have found in my research is not so much an innate lack of desire for friends, but an acceptance of the fact they will never have them.

I only have a few acquaintances and one friend, really, who I don't see that often. Yes, I've given up for the most part. I don't know how to initiate or sustain friendship. If I call someone I think they will see me as weird/childish in mannerism. (Elle)

In lieu of human friendship, many Aspergirls allow only fourlegged, furry, or feathered friends into their hearts. All but a few said that her pets were her closest companions.

Animals are people who are easier to get on with and befriend than humans. They are honest and accepting. Their needs and demands are simple, understandable, and easy to meet. They don't play mind games. (Pokégran)

As much as we feel alienated at times, we also alienate others. One of the ways we do this is by shutting out those who don't share our passions. I tried to get my teenage best friends to be as obsessed with Tolkien and music as I was but they bonded together in their hunt for more "normal" pursuits (i.e. jobs and boys), and I was left behind. I felt incredibly hurt, though I'd really left them no choice *but* to exclude me, since I made my contempt for their preferences obvious.

I tend to put people on a pedestal and then they fall off very quickly when I find they don't share one of my narrow interests even though they pretended to in the beginning. I feel betrayed by their lie. (Sam)

We have short-term memory issues so while we might be vehemently angry at someone for a while, we can quite literally forget why we were so mad after a time. This may cause us to go back again and again to the same unhealthy friendship or relationship, with the same patterns of behavior and expectations, until something quite dramatic happens—enough to lose empathy completely and close a door forever.

Doctors and the diagnostic manuals are telling us that we are not cultivating "appropriate peer relationships" but in light of all these things it makes sense. We seem, feel and act younger than our age but it is not appropriate for us to "hang out" with teens or children. Other people our age bore us or we can't relate to them. We have a tendency to stay at home. Once we're of post-education age, and especially if we're out of work or in the wrong job, it means our options will be decreased and limited, and that it will be difficult to have a large or typical number of friends.

Some of us are okay with that.

I was always unable to connect but didn't feel lonely. (Kiley)

ADVICE TO ASPERGIRLS

If you have confidence in yourself, that confidence spills over into your social skills and into the social arena. People sense when you know your worth and they respond to it. It helps to be validated but even before validation comes belief in self and in one's own thoughts and abilities.

I am a Lord of the Rings lovin', Renaissance Faire going, comic book reading, typical geek. Probably before I was even five I knew I'd never fit in; knew I was different and just decided "to heck with it" and embraced my

geekiness. Being a nerd is one of the things I really love about myself. (Elfinia)

If you are truly happy alone, then you are lucky, for it is peaceful and you definitely have more time to engage in your passions, whether they be writing books or painting pictures or just hanging out watching British period films and kung fu flicks. But, I want you to please take some time to ask yourself if you are truly happy, or if, like many, you've simply given up. I've been there. Until very recently I'd become resigned to a life alone, where I'd eventually die alone and my body would lay partially eaten by rabid squirrels until some pesky Jehovah's Witness came to my door and saw it through the window.

But then an old friend came back into my life, regaling me with tales of food and fun and people and drink and music and dance and it made me angry that I'd let life get me so down that I basically laid down and said "I quit!" I was using work as a shield, keeping myself cruelly busy and then every night I'd sit alone, watching movies, pretending that I'd had a full enough life; that this was okay.

I disclosed Asperger's to this old friend and asked if I would be given acceptance and leeway for sometimes unorthodox behavior. To my delight, this friend has now read up on AS, asks thought-provoking questions and tells everyone about this great gal he knows that has Asperger's. He in turn, shares what he has learned with others and is educating the world in his own small way. He has accepted me completely although he does challenge my boundaries. He is now my partner. Other friends have not been so understanding, but that is no reason to give up.

If you want more friends, *do something about it*. Don't give up. Use your interests and strengths and visualization skills to figure out how to go about it. It's important to understand that you can still be friends with people who don't passionately share all your interests. This is how we broaden our horizons. You may also have to leave your room, unless you are okay with cyber friendships only. They may not strengthen your

face-to-face skills but they are a good place to start and you can develop some rapport with people in this way. Safety first—don't give out addresses, real names, etc., to people you meet online. In addition to chat rooms and forums, there are software programs which enable you to video-chat with friends for free as long as you both have a camera. You get much more of a sense of a person if you can see them while speaking. I find this to be true—for although eye contact can be difficult I find it hard to discern a person's intentions from their voice, and find reassurance in faces...and *kind* eyes. Again, follow safety rules.

Another thing about the internet is that because people can and do say whatever comes to mind, it is not a full picture of someone. People can take on other personas and mislead you. I frequently find a phenomenon called "internet balls" on forums, where people say things that they probably wouldn't say in person. Be yourself and be tactful—if you do eventually want to meet someone you've met online, you want to have given them a glimpse of the real you, a complete picture, just as you would want from them.

Don't throw a friend away because you don't like or agree with 10 percent of their behavior and don't give people a small window of time to perform to your expectations. There is no human piece of perfection that will meet all our criteria. We have control issues and we need to know what to expect, but give yourself and your friends a little room to maneuver and to mess up without judging too harshly. For we do judge, don't we?—both ourselves and others.

As far as maturity goes, as long as you are addressing your needs and the needs of those who depend on you, especially children, then carry on wearing those Wonder Woman pajamas.

ADVICE TO PARENTS

Like the parents in Roald Dahl's *Matilda*, there are some who don't understand their daughter's bookish ways and solitary nature. They might think that if they push their daughter out of

doors and into the waiting arms of other kids (who often have fists and throwable objects at the end of them) that the girl will benefit more from that. There is a time and a place for socializing but she's better off seeking out like-minded kids rather than defaulting to whomever is available in her neighborhood.

Young people with AS have told me that social skills training has really helped them. Explore the options in your area, through your local autism services, school, and therapists. There are also books on body language, etc.

Find clubs or activities she'll enjoy, for example if she's a science geek, find out if there are clubs or activities at her local science museum. Pursuing intellectual things that make her happy will bring her into contact with kindred spirits and like-minded souls and then socializing will come almost naturally.

Some parents take away internet privileges from their AS child thinking that will get them out into the world. I don't recommend that...the internet is our favorite link to people, organizations, and information, and "real world connections" can be made from it. There are lots of ways to make a living online as well and you must work with your Aspergirl's strengths, not against them.

If your daughter is unhappy and doesn't have enough friends, you and other family members can take an active role. If you know someone your daughter might get along with, it couldn't hurt to arrange a meeting. You have to trust your own instincts, as long as it's someone she'd like and not someone you'd like her to like.

I meet friends through my husband or through other family members or long time friends. Often, those are the friendships that last longer. It may be an odd thing to say, but it is like the people who know me well screen the person to see if we might get along. (Dame Kev)

One mother, Deborah, started an AS support group to give her and her daughter a chance to meet others with AS in their area.

That's what I call being proactive! Maybe you already have a local group you could attend. Give it a chance, you have nothing to lose and everything to gain.

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CHAPTER 11

EMPLOYMENT AND CAREER

There are various pitfalls and challenges in the workplace specific to those with Asperger syndrome. Not least of all is getting a job in the first place. There is no magic bullet, but there are several dozens, if not hundreds, of techniques, strategies, and points to know about AS and work. The main problem for most of us is that we have a hard time holding onto jobs for social reasons. I cannot stress enough how important it is to work with your strengths and acknowledge your triggers—things that push your autistic buttons—so that you choose the right career path. (To that end I created the Personal Job Map which can be found in Asperger's on the Job (Simone 2010).) The areas we want to work in run the gamut from painting, drawing, design, music composition and performance, writing, architecture, engineering, physics, to medicine. Nobody I have ever interviewed said it was their lifelong aspiration to be a secretary, sales girl, or waitress, but that is often the type of position we find ourselves in, especially if we do not get a degree. Those jobs don't require degrees, but they do require people skills—the thing we lack the most. If a person with AS can work in the field of their passion, their obsession, their "zone activity," they will be much more apt to want to go to work and be much more fulfilled as a person.

Financial stability is important to everyone, male, female, AS or NT; however, I think it is in some ways most crucial for an Aspergirl. Many Aspergirls remain single out of choice, limiting household financial income. She is also left without "male protection"—you know, the physical presence that keeps mechanics and plumbers from taking advantage. She will be at the mercy and whim of others if she cannot stand on her own two feet. If you have money, you can buy and/or live in the kind of environment which is crucial to your sensory

issues—i.e. a quiet house as opposed to a cheap and noisy apartment building. You can pay for yourself to go places and not have to rely on a partner. Feeling powerless and ineffectual is a huge part of female AS and poverty will only increase that feeling.

Aspergirls often know when they're quite young what they want to do and with the right support they may achieve it. They are more likely to have a satisfying career if they can stick out their degree.

I always wanted to be a librarian. I am a specialist in cataloging and have worked as a librarian for 20 years. Today I work with a wide range of material, from medieval manuscripts to eighteenth-century collections. Time and place cease to exist, when I'm working with my collections. (Siv)

I work in the media, and it was my first choice. I'm an autistic person who communicates for a living, and relishes the irony! I got a job with my current employer straight out of uni and I've stuck with them ever since. I'm very, very grateful, because the organization I'm with has quite a high population of Aspies (whether they know it or not!) and is very tolerant of eccentricity. (Polly)

For those whose aspirations are of an artistic or musical nature, it is very hard to make a living at those things, but it is not impossible. One of the pitfalls of this kind of career is often the lack of financial stability. You may also feel that you have not been given your just deserts; that your music or art is not being recognized for its worth. There is an awful lot of subjectivity in artistic careers and often our progress may be impeded by poor social skills, which may frustrate us. The other thing about these types of careers is that you have to do something else for money until you get established. Most of us won't want to go to college full time and get a time-consuming career in something else when we just want to paint or sing for a living, so we will start in those dead end jobs such as waitressing that require people skills and possibly end up in

them as well. That means obscurity, poverty and very high stress levels for most of us.

I write in the hopes of writing something that will sell, including a major research project on the evolution of culture. I have been on welfare for close to 12 years of my adult life. (Anemone)

My first choice from age five or so was to be an artist. I'm now a successful artist in Australia, also a speaker on ASD (autistic spectrum disorder) issues. I work in isolation and live reclusively but successfully. I sell my work, represented by commercial galleries and have won awards. However, over the years I had many menial jobs for periods of time. I usually left jobs after a year or so because I could not cope. (Camilla)

I went to college for music but was soon singing professionally so I dropped out. When my band broke up, I became a waitress, secretary, receptionist, hostess, babysitter, housewife, and telemarketer and just about everything else that could possibly mess with my sensory and social issues. The list is much longer than I care to recall. Never again did I reach the heights of success as a singer as I did at the age of 18 to 19. It took 20 more years of struggle before I finally gave up. All the while, I burned through a string of countless meaningless jobs that did nothing for my self-esteem, that did not utilize my gifts, and that wreaked havoc with my Asperger's, or else my AS wreaked havoc with them. And although I've found success in the last few years as a writer and consultant, if I had to do it over again I would have finished my degree and avoided the menial jobs. It sometimes takes a hard lesson to get us back on track.

I am not currently employed. I have had over 30 jobs. Fast food worker, dishwasher, nanny, PCA (personal care assistant), mental health worker, behavioral technician in an inpatient psych unit, production worker, sanitation worker, press operator, bartender, retail associate, housing support specialist, caretaker/housekeeper, nursing

assistant, program assistant, and teacher's aide. These are all I can remember. I'm now a graduate student. (Brandi)

Getting a degree is a crucial part of success for most of us, as is working with our strengths. But it is no guarantee. We must also work on our deficits or we will have a hard time securing a satisfying position.

I hate cleaning. It's so mindless. And what a cruddy end for a person with a university degree: Custodian? House cleaner? Gads, the shame! I am not currently employed. I have not been successful at maintaining a job for more than four months. (Heather)

As I state in my employment book, most Aspies want to go to work, do their job and go home, but it's not that simple. People set the tone of our experience. That is why many Aspergirls try to circumvent working with others, by working from home, or with animals:

I don't work. I stay home and home-school my son. I just can't deal with people for long hours. (Nikki)

I love being a groomer. I feel an affinity with my dog and the ones I groom as well. I feel like I'm a part of their world, like a mother wolf. (Elfinia)

I've talked a lot about intellectual challenge and fulfillment, but of course not every Aspergirl is a creative genius. Some like simple and repetitive work.

At the age of 13 I decided to be a dental hygienist. I love the repetitive work of removing deposits from teeth. The hard part is working with the people attached to the teeth and all of the personality issues that arise. (Jen)

Aspies can burn very hot and cold on hobbies and vocations, so it is good to stay in the area of your passion so that it will hold your attention and focus for a long time, and you will be paid to be "in the zone." If you do not find work in one of your areas of obsession, you will probably be distracted, bored, depressed; you may even find you become physically sick. We need our obsessions. They give our psyches an anchor, they

give our thoughts ritual and routine which we know is extremely important. Without them, our thoughts will just float about in the breeze like a stray balloon, not going anywhere, never really getting lift-off.

I get so stressed being with people all day and not being able to pursue my interests. I stay up until the wee hours feeding my interests and get little sleep. (Widders)

Temple Grandin says to people on the spectrum "sell your work not yourself" and she is right—but how do you do that in a culture where personality sells, and the psychometric or *personality test* is often a required step toward getting a job? The so-called personality test exposes our social and cognitive differences (not necessarily deficits) and could cause a person with Asperger's to lose a job before they get it, before they have a chance to show what they're made of. Career satisfaction, and lowering the number of people with autism who are out of work or underemployed, comes down to recognition of our talents, acceptance of our deficits, and utilization of our strengths.

It doesn't matter anymore that you are a dedicated, hard worker with a good work ethic. They would rather have someone talkative and outgoing. I've never held a job longer than a year. Currently I am unemployed and because of the economy I will have to take any job that I can get whether it is appropriate for my personality or not. (Elle)

I know this question is meant for adults, but I'll answer anyway. I do worry about getting a job... I don't know how I'll handle the interviews. I have a very hard time looking people in the eye, especially strangers. (Megan)

Underemployed and overqualified most of life. Worst aspect about AS. (Michelle)

Disclosure—when and where to do it, if at all—always comes down to a cross between personal choice and necessity. Partial disclosure is another option—asking for individual accommodations rather than disclosing the fact you have AS.

Some of us see it as our duty to disclose, to spread awareness of what AS means. But disclosure, even full disclosure which incorporates discussion and literature, is no guarantee of accommodation or true understanding. That's why many of us opt for self-employment as artists, writers, lawyers, etc., or work in Aspie-friendly fields such as engineering and software developing, where our quirks will hardly be noticed.

Getting the right education in your field, making good choices and not giving up on being a useful part of society is so important, especially for naïve Aspergirls. If we don't make things happen *for* us, things tend to happen *to* us...

I've been working at renaissance festivals and living in a tent or my car. Used to traveling to a new show every two months with other social outcasts. Two years ago I was in a bad car accident (rear ended while waiting to make a left turn in a 70 mph zone) That left me with 11 herniated discs, fibromyalgia, and no car. I found myself stuck in bed in a little shack. I've been floating (homeless) for five or so years now. (Bramble)

As I stated in the Introduction, I actually think that problems with employment and the economy are why more people are being diagnosed. The high cost of living, having to work longer, harder and having more competition to get jobs as well as hurdles like the personality test mean that we are smacked in the face with the realization that we are not coping as well as we should be and we want to find out why.

ADVICE TO ASPERGIRLS

It is possible for an Aspergirl to have a thoroughly satisfying career. You must work within one of your areas of passion, get through your degree or training as best you can (hopefully with enough help) and then find a position with at least some autonomy, prestige and enough intellectual challenge. At the same time, you must respect your sensory needs.

To a large extent it is true that social skills count more than actual work ethic in many jobs. There is social skills training, in the form of books, groups, therapy, etc.

There are jobs you can do alone, with little social contact, and there is also the option of self-employment. Business owners and the self-employed often struggle but there is both peace and satisfaction in doing what you want and being your own boss. But self-employment can have its own set of difficulties, including financial instability, multiple and varied responsibilities (e.g. even if you're an artist you may also have to be your own secretary, marketing person and accountant) and too little social contact to help you grow that aspect of yourself.

Those who are stay-at-home moms, too, seem happy and fulfilled. However, to hope for and rely upon the thought that a man will support you is just not practical. Most men these days can't afford to support a woman even if they wanted to. An Aspergirl must face the world with the aim of supporting herself, being fulfilled and not needing anyone else to support her—especially in the United States, where benefits are very hard to come by and have several hurdles, all of which seem to have the aim of humiliating you and eroding self-esteem.

If you have an inclination toward the arts, I do not want to discourage you, but take it from one who has been there—you must get qualifications and have two or three back-up plans that are virtually as appealing as your main goal. Follow your bliss, get as much education as you can, and have two or three "Plan Bs." This is *not* a cop-out, this is called being smart, for just because you don't have a safety net, doesn't mean you won't need one.

Not every Aspergirl is a creative genius. You might find that the routine and predictability of being an accountant provides the surety and tranquility you require. And not everyone hates being a cashier—some with high-functioning autism (HFA) and AS like the scripted life of the checkout counter.

Work is an interruption into our routine—but new routines can be made. Meal planning, sleep aids, and constructive use of time spent out of work will ease the transition.

Take the time to get to know yourself and really be honest about what you want and what you can handle. If you are going to work with a job coach, make sure they have an indepth understanding of AS. You and/or they can read my book employment (Simone 2010) get to a the many social. understanding of emotional environmental issues at play. There are others too: Roger N. Meyer's Asperger Syndrome Employment Workbook (2001) and Sarah Hendrickx's Asperger Syndrome and Employment (2009) are both excellent.

Make financial stability and independence your passion and seek it with the same legendary focus and diligence with which you do almost everything.

ADVICE TO PARENTS

Do encourage your Aspergirl to get the highest qualifications she can in her field of interest, as well as social skills training and whatever other practical applications she needs help with. As we discussed in the previous chapter, education is fraught with several difficulties in itself, but it must be navigated if your daughter is going to fulfill her potential. An Aspergirl's happiness depends on a combination of meaningful work, limited friction, freedom to create, and lots of control. On the other hand don't push too much—our passions change and just because we are fascinated with space doesn't mean we want to be an astronaut. Aspergirls need to find work that works with their AS traits but doesn't push their autistic buttons.

Many Aspergirls will be frightened of work. She will try her hand at a job and find that she is not fitting in; she may get bullied or just feel really uncomfortable. It is frustrating for parents when their 18-year-old is still living at home (or their 38-year old) and they just can't seem to find a job that works. It is not that your daughter is lazy—it is so difficult to explain to someone who has not lived through it, but feeling like a black sheep, feeling awkward, uncomfortable, scrutinized, having our rituals and routines interrupted, not having control over our environment, all these things make finding a job we

like incredibly difficult. Your patience will likely be tested. The usual milestones will probably happen, just not as quickly as you might hope or expect. Do your best not to be angry at your daughter for finding it hard fitting into the world of work, but be supportive and discuss with her what her dreams are, and what the possibilities for making them happen involve.

CHAPTER 13

HAVING CHILDREN

Some of us want the companionship and love of a family while others live in fear of it; if we can barely take care of ourselves how shall we support another human being? Having children should never be entered into lightly whether or not one has Asperger's. But when one does, all the inherent issues are compounded. Having kids means saying goodbye to peace, quiet and solitude, our favorite things. There are social functions we'll have to attend, from school plays to play dates to parent—teacher meetings. We'll be expected to be caretakers; to be mature adults who make mature decisions, to be selfless; all things we might struggle with. We won't look like most other mothers, act like other mothers or feel particularly motherly. The very name "Mom" is something we may balk against, for it denotes a one-size-fits-all picture of womanhood that doesn't fit us.

I am avoidant of marriage and having children. I don't want to be out of control of my own body. I don't want to have to be "switched on" at all times as a mother. (Kes)

I do not have children, and I do not intend to. I wouldn't want to be responsible for raising a child. I have a hard time keeping track of myself as it is. (Shannon)

I loved being pregnant; I felt so beautiful. I loved nursing my babies. I enjoyed enriching their language and worldview. I had three children. Other parents often asked me to watch their children, too. (Widders)

I've often said that the whole teddy bear and balloon image of infancy that we find on everything from wallpapers to announcement cards should be replaced with urine, excrement, vomit, and blood, for that is what giving birth to another human being was about. It wasn't pretty, it wasn't fun, and having a baby messed with every sensory, social, and control

issue I ever had. In addition, I was a pretty self-absorbed person, and having to subjugate my own needs to address another's first, was something I did not like. On one occasion my daughter and I were on a train from California to New York, when she was just two years old. She was playing with a boy and the boy's grandmother looked at our two cherubs and asked rhetorically, "Don't you just love being a mother?" I honestly and bluntly replied, "No, I don't." For a moment the woman got a look of sheer horror on her face, as she slid her bottom further from me, and over to the seat by the window, where she craned her gaze as far away from me as possible. Clearly she had just put me in the category of serial killer. I laughed to myself, and wondered at the ability of some people to lie to themselves.

She didn't ask me if I loved my daughter. If she had, I'd have said yes. It was being a mother I disliked, for I found it ridiculously demanding. From the moment she came out, screaming, tugging at my flesh, breaking the stillness of my small San Francisco apartment, filling it with horrible smells, my baby was an Aspergirl's worst nightmare. I laugh as I write this because she knows how much I love her, and knowing my sensory issues, she is now quick to turn off the music before speaking or to shush the dogs when I'm writing. But when she was a baby, I couldn't even watch a film without her crying or screaming, which violates rule 14 of the Aspie code of ethics: thou shalt not interrupt my movie!

In a strange twist of irony, my daughter is not autistic, but she was very un-cuddly as an infant and toddler. She was the one person I wanted to hug but she pushed me away, and when she did so, my attachment to her decreased. I became very Spock-like in my attitude to child-raising, and I don't mean Dr. Spock. I erroneously assumed that she did not need or even love me. I thought her father, who by this time had left me, might be more to her liking. For a time I left her in his care, until my strong feelings of connectedness to her returned. When they did, it was very powerful and sudden. My daughter says that she experienced a similar detachment and revival of

feelings towards me at virtually the same time. I had moved overseas and she was sent to live with me.

I have a son, age ten. He lives with his father in a town far away. He visits me 5–6 times a year. I think that is for the best. I love him, he is the joy and meaning of my life. (Siv)

When my daughter returned to my care I was, once again, a very devoted mother and a good caregiver. Despite eccentricities, my need for ritual and routine meant that things were fairly conservative, safe and predictable in our house. When we got into a schedule and a flow, it lasted for a long time and my daughter was able to settle in. I enjoyed being a single mom more than a married one, because I didn't have to share control with anybody.

I'm happy, single, have a two-year-old son; a fantastic relationship with him. Wouldn't want to be with anyone. Motherhood is the best thing in the world. (Kylli)

Our need for control, sensory issues, and our love for learning usually means that our children read or get read to a lot, and a limited amount of television. Our sensitivity to foods and additives means that they eat nutritiously, with little junk. They get exercise and fresh air. From what I've learned from other Aspergirls is that we make unconventional yet conservative moms; strict, safe, logical, protective, and intellectually stimulating.

As a result of control issues and distrust of school systems, we may want to home-school our children. Later in my daughter's life, when she was age seven, I home-schooled her for six months because she was not intellectually challenged at our local village school in North Wales. We started every day with *Bewitched*, followed by singing lessons and art. But we also covered all necessary subjects including math, reading, writing, geography, social studies, and science. My daughter was a straight A student once back in school. Of course, it had to be the best school, with the friendliest, most creative atmosphere I could find, not just what was convenient. At one

point I took four buses a day across town to get her there and back while I was juggling university and part-time work. Other Aspergirls I talked to home-schooled their kids as well or were active in their education.

I was smart enough but never got the help that I needed. I am now home-schooling my three AS boys. (Naga Empress)

Despite trying very hard, I always had the sense that what I was doing was never enough. Pre-AS awareness, my daughter had to witness my many transformations. As I was trying to figure myself out, she had to go on that journey with me, since my spiritual journey often took physical form. She had visited or lived in 14 countries by the time she was 14 years old. Other mothers had more money, more patience, more stability, and never seemed as stressed as me. They talked to each other in playgrounds, they met each other for coffee. I was never invited.

Once my daughter cried "Why can't you be normal like other moms?" That hurt. I'd been singing opera very loudly in the car. Apparently other moms didn't do that.

On the positive side, having an emotionally immature but smart mom meant that my daughter had someone to play with; someone to not only watch *Chitty Chitty Bang Bang* with, but to sing all the songs as well. It meant we moved to New Zealand because we loved the scenery in Lord of the Rings. When she was a teenager, we shared clothes. We listened to much of the same alternative music. But then she grew up and I didn't. I still watch kid's movies and sing the songs, but I do it by myself now.

She is now at college and far away, completely on her own. There is a part of me that knows she benefited from having an Aspie mom. There's another part that wishes I'd had a diagnosis and some support so that she might have had more geographic and financial stability. But I think I did a good job. She is compassionate, would never bully, has a wonderful open-minded outlook on life, is pretty nonjudgmental and is

very good at social skills. That she definitely did not get from me. I am living for myself again and I have to say I like it!

While most Aspergirls I spoke with also don't have a particular affection for babies, the ones that did have children loved them very much and many found great joy, friendship, and camaraderie in their kids.

I have no feelings of motherhood but I love my two children. (Sam)

Their house is a muse-um, when people come to see-'em, they really are a scre-am, the Aspie Family. I've never been in the household of an entirely spectrum family but I should imagine it would be a great place, filled with evidence of esoteric interests, models of our galaxy, books stacked to the ceiling, and animals running rampant.

At the beach or park, we dig in the sand (or dirt), explore around and just do whatever makes us feel calm and happy. At Nana's, we play games with the numerous cousins, sing and dance. (Dame Kev)

We explored the woods, dissected electronics we dragged home from the dump, and examined road kill. We went to museums, made costumes, and started a 4-H club for dog training. We read each other to sleep every night. I was a stay at home mom for 12 years and I loved every minute of it. I am responsible, but very immature and hanging out with kids is a great way to pass time. (Widders)

Having more than one Aspergian in the house compounds some of the issues.

I thought my son was going to give me a kiss on the cheek and instead he pulled my face to his and bit me on the top lip. (He's seen me my husband kissing me and I think he misunderstood.) In a way, there was a double meltdown. He had a meltdown because I screamed at the top of my lungs and flailed around. He ran into his room and raged among his toys. I cried, went into the kitchen and tossed a bunch of leftovers from the fridge onto the

floor. I went into a corner of the kitchen and rocked for a minute when I realized what I'd done. After a few minutes, he brought in one of the toys that calms both of us down and we played together for a little bit before I cleaned stuff up and got him ready for bed. (Dame Kev)

Some of us thrive in our families, and in our protective environment...and as stated can have surprisingly conservative and traditional outlooks on family. So what happens if the marriage ends? Losing the support of our partner is a shock to any mother, but in our case, we may lose the family's sole breadwinner, our all-important social and environmental buffer, and the one who took care of all the things we could not. We now have to be both mommy and daddy, with all that encompasses.

My husband was a lawyer. He left me with the kids and little money (later he took them from me). Meanwhile another man "fell in love" with me. Months later, I had twins, a boy and a girl, but he left too. I was now a single mother of five, with no job experience who now had to work for a living. By the time I got home from work, I was not up to the challenge of motherhood. I have spent the last 16 years trying to pull my life back together. I think one can say that I am a fabulous mother in a vacuum, but I really suck in real life. (Widders)

Our struggles with our children do not end when they reach adulthood. They can still push our autistic buttons and be some of the most demanding people in our lives. Even though they know we're autistic, they still want us to be parents and to meet their needs.

Generally one of my children (ages 29, 27, 21, two 16s), will start demanding something from me that I can't give them and they won't let up. I ask for privacy but they follow me through the house into my bedroom. They won't leave me alone and I get so wound up until I finally totally flip out. Anybody else, I can generally escape from. Don't think badly of my children. They are capable and bright, but they all have such strong personalities.

They blame me for everything that went wrong in my marriage with their father. Because I lost so much in the fight, they think I am incompetent; because I ended up so poor, they think I am low class. He took them from me and wouldn't even let me have supervised visitation for years. It was terrible and my children have a lot to work through. They thought I was bad, but they are learning more about me now. (Widders)

The dichotomy of being emotionally immature yet intellectually sound; of being logical and regimented yet having executive dysfunction, is something that is difficult for others (social workers and Family Court judges for example) to get their heads around. We are at times suspected of being bad parents. A few of the women I spoke to had been investigated by Child Protective Services. At least two had their children temporarily taken away based on suspicion of inadequate parenting only, not on any evidence. Both were exonerated of any wrong-doing.

ADVICE TO ASPERGIRLS

We are lucky to live in a world where it is no longer unusual or undesirable to be a single lady or a childless couple. Don't worry about justifying your choices to anyone—it's your life. For those of you who do want a family, a few words of caution: Remember that having a built-in universe is great for a while. But those children will grow up and they will move on, especially if they do not inherit your Asperger's. While you will probably like the idea of being able to live for yourself once again, if you have relied too heavily on them for companionship and meaning in your life, you will be left completely without a social circle. This is empty nest syndrome taken to the nth degree and can be quite devastating. All of a sudden you have no one to watch films with, or go shopping with, etc. You then realize how alone you've allowed yourself to become. Unless you are totally happy being totally alone, try to find some friends before that happens.

If you think you do want children and don't have them yet, research very carefully what that will mean financially, socially, sensorially, and emotionally.

If you do have children, remember that if they are nonautistic they might have expectations that you do not naturally understand or anticipate. For example, it was pointed out to me *after* the fact that I should have gone out of my way to see my daughter in her prom dress or help her move into her dorm room. Both times I assumed my presence was neither wanted nor needed. There have been a myriad of instances in our lives where I simply did not know what was expected of me. And because I do not have girlfriends and am not close with my sisters or mother, I have had no one to tell me what I "should" do on such occasions. Seek help and advice from nonautistic women if you have nonautistic children. They may give you more insight into some of the milestones and events that your child might want you to acknowledge and commemorate.

Also, don't forget the hugs. Even if you don't like to hug, find a way that works for you. It is so important.

ADVICE TO PARENTS

For those of you who are worried about grandchildren, don't. We Aspergirls can make great, if somewhat unorthodox mothers. However, if you see there are "gaps" in the parenting services we provide, for example if we don't see the necessity of spending \$100 every two months on hair appointments and manicures, or trick bikes and hockey gear, maybe you can step in and, without guilt-tripping us, provide some of the information and encouragement we might need in order not to miss out on anything important.

Do not pressure your Aspergirl into getting married or having children if she doesn't want them. We may never have nurtured ourselves properly and may have to do quite a bit of that before we can devote ourselves to nurturing another. We might just not want those things, full stop. And there's too much at stake to go into motherhood or marriage half-heartedly.

CHAPTER 17

TEMPER MELTDOWNS

Both males and females on the spectrum have temper meltdowns. While violence is less acceptable in today's society than it used to be, there is still a part of our collective psyches that sees being hot-headed as a normal part of being male. A woman who flies into a rage is merely unstable, crazy...psycho. If it happens in public, people would certainly think she had a psychological problem. Unless she is non-verbal and/or obviously challenged, autism would not even be considered as a possible underlying cause.

We see girls who have trouble regulating their impulses not as having a disability, but as being non-compliant or drama queens. In other words, it is a behavior problem and discipline issue. (Stella)

I've witnessed others' temper meltdowns and thought their reaction was hyperbolic to the situation. Yet my own tantrums always seem justified. I'm sure they thought theirs were too. Why do we do it? Why can't we stop ourselves? It's not like we wake up in the morning and say "I think I'll have a meltdown today," it just happens. What sets off our rage can be multi-factorial, from a combined sensory, social, and emotional experience, such as going to a party with loud music and lots of people; or trying to exchange a faulty product in a loud store with an uncooperative salesperson attending you. A sudden change in lifestyle or routine can also be difficult—for example when you move, are on holiday, or start a new job or relationship. These meltdowns are an outpouring of rage, and when you scratch beneath the surface of rage even a tiny bit, you find pain. Pain which builds up in cumulative, often combative, frustration.

I feel a surge of anxiety and body sensations that build throughout the day...then they burst. These meltdowns as much as I hate to admit it are quite comparable to a tantrum that a child has in a store when he/she is told they cannot have the toy. (Brandi)

When a temper meltdown is building, the feeling is not usually as heavy as before a depression meltdown. It's more like an extreme tension; an electricity. In my case I feel angry, agitated, sometimes dizzy; I'm not breathing right. When I speak, if I can speak, I may be sarcastic and scornful. You might not even be able to tell it's coming until right before. Then clouds gather in my head, and you can see it in my eyes —Hurricane Rudy is imminent. It is unleashed very suddenly and I might have little or no control over it. A temper meltdown can mean public tears and outrage; yelling, swearing, and being vicious. We might say things we don't mean but at the time they seem true. We can be scary when we rise up, when all of that bottled anger and frustration finally finds its vent. It's destructive and chaotic. I once wrote a song called "Velvet":

I'm so scary, call me Carrie White, you heard hell hath no fury.

This line was based on my meltdowns and how I reminded myself of the character from the Stephen King novel who could destroy with just the power of her wrath.

We are emotionally raw like children. And like children crying "not fair," one of the many things that can trigger a temper meltdown is the feeling that we are being taken *unfair* advantage of.

During a break between classes at college, I caught a friend cheating at gin rummy. The game wasn't serious, it was to pass the time, nothing else. I had a violent meltdown, punched him, then I fainted. Others there said he never threw a punch back or tried to defend himself, he was just stunned. I remember the meltdown, but not the fight. I came out of it with an EMT (Emergency Medical Technician) standing over me. (Dame Kev)

Injustice can also start the fire burning—when we feel others are being taken advantage of. I loved vigilante films like those of Clint Eastwood and Charles Bronson when I was a kid, because I hated to see wrongdoers get away with stuff. (I've since learned about karma, or I'd probably be sporting a poncho and nunchuks today.) When I was 14, I found out my friend's father was making her have sex with him. I tried to hide her at my house but he came after her and I flipped. I wanted to kill him but I took it out on his car instead, hitting it with my bare fists. I felt no pain but afterwards I saw it was dented all over.

We are more susceptible to meltdowns when we're *hungry*. Children in supermarkets—famous example. Too many items, lights, people going by, music, chatter...and all that food. Restaurants are another likely setting.

I can have a meltdown when I go without eating for a while. I once threatened to throw rocks at peoples heads if the line didn't "f-ing move." (Elfinia)

I went to a taqueria and I wanted an avocado tostada and they wouldn't make it for me. I got annoyed that there was nothing there that I could eat because I am a vegetarian. I started crying in front of everyone and ended up feeling really sick and horrible for the rest of the day. I also threw up. I will often throw up after having meltdowns. (Olive)

Having a meltdown when we're being *falsely accused* makes us look dangerous or unhinged, and merely strengthens others' negative opinion of us.

About a year ago my son was attending a YMCA kids workshop, where a counselor suspected there may have been physical abuse to him by my hand. It seemed so horrible that the place I took him to for emotional help was having this suspicion. I was so offended at the false accusation that I lost it, becoming very verbally aggressive and abusive to the staff; I spoke in this weird sarcastic tone, which only reinforced their suspicions of

me. My son was taken away by Child Protective Services to a foster home and I didn't see him for a month. I did not even realize that what I was doing would result in police and court intervention. (Ann Marie)

The more outrageous the accusation, the greater the rage meltdown will be. Unfortunately rage only implicates us, makes us look guilty to the person who does not understand Asperger syndrome.

Getting *ripped off* can be another impetus. Sales pitches that promise one thing and then deliver another; customers that refuse to pay; people who borrow something and don't return it.

The worst temper meltdown I've had in recent years was at a woman I was doing some gardening for. She decided she only wanted to pay me half of what we agreed on, but she waited until I sweated for many hours in the hot sun before she told me. I screamed and bawled like a baby at the injustice of it. Half the neighborhood heard. (Tandy)

Social/sensory overload:

I have tantrums when I find people stupid and annoying or when too many persons surround me and I am in a situation where I can't leave. My biggest tantrums lately have been at work at meetings. The head of the library has had special talks with me about this. I'm quite frightening at these times and there is no way of stopping me. (Siv)

Temper meltdowns may be childlike but if you are 18 years old, according to the law you are an adult and should behave like one.

Workmen coming, going, banging around and overwhelming paint smell stinging my nose—all of this change, all of this stimulation, and none of it under my control. I felt helpless, raw. I didn't think. I just struck my dad in the face. My boyfriend called the police. They kicked open the door, and tackled me to the floor in our

foyer. I panicked, the sounds and sensations in my head static, trying to find a home like a radio dial between channels. I must not lash out. I must retain speech. If I don't the cops won't understand. Why? Why can't I stop? That's what I keep asking myself. That's the shame, fear, anxiety, and pain...I was taken to a mental health facility and upon being deemed harmless, released. No one needs to tell me that violence is unacceptable—physical or otherwise. I know Asperger syndrome is not a get-out-of-jail-free card that exempts me from responsibility for my own actions. (Stella)

Meltdowns can be triggered by *touch*, whether painful touch, for example from dentists; but even from those who are supposed to be pampering us, like hairdressers, massage therapists, and manicurists.

Confusion can be another cause; panic, or extreme fear. I recently left my wallet at a security gate at an airport. Traveling with two emotional support dogs and a laptop, I wasn't traveling light. I got confused and left my wallet on top of the security scanner that your carry-ons have to go through. Once on the plane, checking for my wallet, I flew into a panic, pulling things out of my bag, throwing them onto the seat. I pushed my way off the plane with little regard for others' physical boundaries. I kept myself from full meltdown because of fear of airport security and being thrown off the plane. I asked my fellow passenger, once the wallet was found and returned to me and we'd settled in for our flight, what it was like to for her to observe the situation.

I could tell something was wrong with you, but I couldn't tell what. You were all over the place, your eyes were far away. I was trying to tell you something, to talk to you, but you couldn't hear, you just kept saying "I need my wallet" over and over again. I felt helpless. (Nancy)

"Helpless" is definitely the feeling others have when witnessing a meltdown. If one is not vested in the situation (or on a plane) one can just walk away. But if you live with someone and have to deal with them on an ongoing basis it is bound to have an affect on your relationship with that person and their own mental health.

Once she starts melting down I feel helpless; there's not a whole lot of comfort I can bring. It's scary. She is no longer accepting any sort of advice—it's like white noise. It's like trying to affect a wave, it's coming after you; what do you do? You dive underneath to avoid getting pummeled by it and then you just brace yourself for what's to come. You still want to help but you have to wait for the storm to pass. Afterwards you feel drained. (My partner, Mike)

ADVICE TO ASPERGIRLS

The day I figure out how a person with Asperger's can avoid meltdowns is the day I win the Nobel prize. But let's not assume they are inevitable. Be as scientific about your meltdowns as you are about everything else—*Cause/Solution*. Know your own triggers—make a list. Refer to it often and add to it when you discover a new one. Share this information with partners or parents.

Shopping puts us in a precarious state. Always take snacks and water, have breaks, don't try to navigate too many shops in one day. If you have a new supermarket to fathom, be sure to do it a few aisles at a time, don't try to buy a week's supply on your first trip. And don't go hungry!

While some Aspergirls I spoke to never had pre-menstrual syndrome (PMS) (also called PMT or pre-menstrual tension), others turned into a raging Medusa on a monthly basis. PMS can make us susceptible to meltdowns of either the depression or temper variety. Eating healthy helps. Avoid high sugar and salt foods and too much alcohol. There are holistic supplements for PMS, such as evening primrose oil, that help with symptoms. Birth control, while it regulates periods, can make an already sensitive Aspergirl insane, so if you decide to take it watch your state of mind. If you start feeling seriously depressed and moody, it might be the pill. Find a lower-dose pill and see if that works or talk to a good obgyn (Doctor of

Obstetrics and Gynecology) for an alternative. We are products of hormones, our state of mind the result of chemicals. Do your best to harness your mood so that is doesn't take you on a Disney World-sized emotional ride.

Be aware that you are not the only one being affected by your meltdowns. It is hell for us but it is also really difficult for those around us; family and even strangers may be upset and shaken by what they see. Even though we feel like we are completely alone when it happens, we are not. Children particularly are affected and just because they seem to get "used to it," they don't—it's bound to affect them. Communicate as much as possible, explain what it is and why. Other people will feel less guilty or complicit if they realize it is a product of autism and not something they did or didn't do.

Do what you need to do for their sake and also for your own. If antidepressants help, take them; some girls go to online forums, al-anon (organization for families and friends of alcoholics), others to counselors. Do what it takes to protect your own sanity and also that of your loved ones.

ADVICE TO PARENTS

If your daughter, whether she is little or not, is having temper tantrums in supermarkets or other superstores, she has sensory overload. Too many items for her mind to process, with music playing, people going by and chattering. The first time you take her to a new store, tell her you are going to visit the first two aisles. Let her find where her favorite foods are in those aisles. Those will be markers; the next time she goes, she'll feel more at home in those aisles—she will have conquered them already and can grab the jar of peanut butter with triumph. The next time you go add two more aisles. This is not practical when you have a big shop to do, so don't do it then. Do it when you have some time to show her the ropes. If she is very little, get her some funky sunglasses to cut down the glare from the lights and bring her fave soft toy.

If your daughter is having temper meltdowns *at you*, you of course want to look for the sensory causes, hunger, etc., and

then ask yourself what you are doing to upset her. Are you criticizing or instigating; making her feel guilty for being herself, blaming her for something she says she hasn't done? Pull back and remember to always use positive reinforcement with your Aspergirl. Of course I'm not suggesting you cater to whims and allow her to manipulate you with tantrums. She has to learn there are consequences to losing her temper, and if you take away a privilege when she does, she'll learn. But start while she's young—it won't do any good to threaten her with not seeing *SpongeBob SquarePants* if she's in her twenties. And when she's young she's more receptive and her character is developing.

I once heard an elderly English lady say "Manners are the oil that make society run smoothly." It's a good rule to follow, autistic or not, but the visual aspect of it is something we can latch onto.

As with depression meltdowns and stimming, an outlet for her energy and a soothing quiet environment when she needs it are essential. Drugs are a last resort.

CHAPTER 18

BURNING BRIDGES

I burn bridges. That was a side effect of being undiagnosed and unaware of Asperger syndrome. When things didn't work out on a job, or with a friend, with a city or even with a country, I would leave it. As I said earlier, for a while I developed a mindset of there's something wrong with the world, it isn't me, and that made it not only easy to leave flawed situations behind, but imperative. This is not always a bad thing. Some places and people are bad for you. Some situations are more progressive, healthier for mind and spirit. But when you've circumnavigated the globe twice, are middleaged and are still burning bridges, it's perhaps time to take stock and see what's what. Figuring out I had Asperger's made me want to dig my heels in and deal with every situation, but of course, that's not good either. I had and still have to learn what to keep and what to throw in the goodwill bin.

Burning bridges and starting again is such a defining feature of my life I thought that I'd ask other Aspergirls if they do the same and all but one said that was a defining characteristic of hers as well.

When things get so bad I can't take it anymore, I up and leave, burning every bridge behind me. The phoenix is a personal symbol of mine for that reason. Burn it all and rise from the ashes. (Bramble)

This shows up in the Diagnostic and Statistical Manual of Mental Disorders (DSM) criteria as subtext, neatly hidden inside "failure to develop peer relationships"—we do develop them briefly, but then we toss them away.

I feel like I am getting revenge when I burn a bridge. I think "that person will be really lost without me; they took me for granted and did not realize how much I helped them." (Ann Marie)

Burning bridges is a sort of psychic pyromania. We get angry at somebody or some thing, and we want to let them know that we don't need them anymore—that we never really did need them. When we burn a bridge, we are saying that we are the ones with power over our lives. The trouble with this is that it is usually done in the heat of the moment. When we are more cool-headed, we realize that we still want to shop at that store, or we still want to see that friend, or we do need that job after all. Like pyromania, it feels good at the time, empowering, but it is usually irreversibly destructive.

Burning bridges is often the result of depression meltdowns. The clouds won't lift so we seek new horizons, a new stage on which to perform our play.

I get depressed, get very low, kick out at everything and everyone. Hate my life, hate myself, hate the people around me. I get out of it by changing as much around me as possible—quit a job, leave a relationship, sell my house, etc. (Sam)

It is often the end result of temper meltdowns. We get very angry at a place, person, or thing and resolve never to deal with them again. Sometimes, after a temper meltdown, we can't—because we are banished outright or our embarrassment is too great to revisit the situation. Burning bridges is triggered by many of the same things; it's the last straw of being misunderstood—we get sick and tired of people not getting us, taking us for granted; not showing us the love and appreciation we feel we deserve. We don't learn from our mistakes as easily as others, partly because we have memory problems. We often may not remember why we got angry at someone. We might forgive and forget until it happens again and again...instead of protecting ourselves all along, we remain vulnerable and then blow up, once and for all severing a connection.

If I don't like a situation it's so much easier to just walk away, avoid it and never look back. Usually it's just a relief but then if I'm avoiding someone I have to worry about running into them so it can add some stress too. I have a really bad memory so after some time has passed, if I run into someone, I'm just like nothing ever happened. (Nikki)

Burning bridges affects our family lives—we may leave husbands or parents; siblings; friends that let us down; people who we feel have used us. This causes us to pour the proverbial kerosene and strike the match.

It seems to happen quite a bit. Mostly when the empathy give and take shuts down. (Dame Kev)

Burning bridges is triggered by injustice—we do not want to patronize or support any ideology, institution, or person that goes against our strongly held ethics and views. Burning bridges affects employment. We have bad experiences on the job, so often, particularly when we're younger, we will leave a job abruptly without giving notice.

I am definitely a bridge burner! I could probably have stood to give my two weeks notice at the last couple of jobs. I left with no notice and that made it extremely hard to find that next job. (Elfinia)

As a person of a certain age who has had the benefit of seeing history repeat itself in my life, over and over again, I can see that burning bridges is, for lack of a better phrase, bad karma. When I blow up a bridge to a place or element of my past, I merely stumble upon a similar village a little further down the road. The climate may be different, the language also, but the story will play out very similarly.

As an Asperger's consultant, I often hear people with AS who are fed up with their life experience put the blame solely on others. They think that they can change their luck by changing jobs, towns, etc. Sometimes you can, and while you should always seek out your ideal environment, at the same time, if you are leaving in haste and bitterness, be warned, history will repeat itself for you too. You have to leave a situation mindfully and as graciously as you possibly can. If you don't believe in karma, I'm sure you can at least believe in references and recommendations—by behaving this way, you

will have none of those. It can also affect your reputation and make it harder for people to entrust you with their friendship.

Burning bridges is closely related to the *pre-emptive strike* which many of us are also good at—quit before you are fired, dump them before they dump you, leave before things get messy. We do develop a tendency to sense trouble ahead. We learn to read the signs the way cats feel earthquakes coming and birds know winter is on its way. Cynics may call it a self-fulfilling prophecy.

Sometimes our bridges get burnt for us when our meltdowns get particularly bad. I have read that females with Asperger's tend to be a little more prone to physical temper tantrums than their male counterparts. I would say, based on observation and interviews, this might be true. I'm not entirely sure that males burn bridges as well. I don't think that they do it as often. I believe, based on my own experience, that it does sometimes coincide with PMS; enough to see a correlation. As our bodies are cleaning house, so do our psyches. PMS makes us more temperamental, more apt to say things, not necessarily that we don't mean, but that we might not say at other times.

I need to clean house a lot, metaphorically speaking, to cope, to keep the clutter in my personal life down. (Anemone)

I believe also that this tendency of self-imposed change may throw doctors off the Asperger's scent. We normally do not like change. For example, we hate it when our supermarket gets torn down and a new one put up, because we have to remap it and re-learn what triggers will be lurking there. Burning a bridge, on the other hand, is something in our control. It's our way of saying we don't need a store at *all*. Of course sometimes we are not right, and we can regret it later.

My life is a series of burned bridges. At the time, it feels as if I am *right* and that I am standing up for what I believe in. Often I am. I have, however, learned in the past decade that I can be very black and white in my thinking. (Camilla)

ADVICE TO ASPERGIRLS

Sometimes, in the throes of a meltdown particularly, we cannot see *any other perspective* but our own and this reflects what I've been trying to say about our lens. It is often about *how* we are looking at something in the moment, not what we are looking at. Now I know that as a person with AS, you have probably been gossiped about, bullied, taken advantage of and it has built up and built up and then finally, like steam, it finds its vent. That is why it is so important to learn how to stand up for yourself tactfully and with strength as you go through your life.

Most of the people and situations you will encounter in your life will have a mix of attributes, and as stated earlier, it is about resonating with and bringing out the higher qualities of those people and situations. We get blind-sided. We have bad memories. People can fool us and hurt us over and over again, till we get fed up. One trick you can try to avoid disillusionment, to avoid being blind-sided, is to have a list of traits you need to remind yourself of, every time you see a person—for example: "This is Sally, she's my co-worker. She's a nice person but she doesn't always tell the truth. Therefore, don't believe everything she says." That way you are on your guard and you are not shocked and horrified when she lies to you for the umpteenth time and you figure it out too late.

You can do the same thing with places. "This is Best Buy. It is a big, loud store. I need to eat before I go and bring water, earplugs, and sunglasses or a hat with a visor. Some of the salespeople are helpful, some are not. I will remain calm and only speak to those who seem happy to assist me."

If you do leave a situation, it is important to try to leave things with people, jobs, etcetera on the best terms possible so that your conscience is clear, so your new start is a fresh one, and there won't be any guilt or other ties pulling you back into the old situation. Remember the three Rs: references, recommendations, reputation. You may need all three at some point, untarnished, to get what you want.

ADVICE TO PARENTS

Watch for the warning signs that a bridge is about to be burnt. Mainly they comprise excuses, apathy, criticisms, and complaints. If she needs a little incentive to get through college or stay in a job, try to find something. It may be more valuable to just sit down with her and find out the source of angst or dissatisfaction and see if there's anything that can be done about it.

What if it is you she wants to burn the bridge to? You'd have to start by asking yourself why—why would your daughter want to leave you behind? What did you do that was so terrible? To again refer to M.J. Carley's book (2008), many of us will be angry at our parents for not recognizing that we were different and had special needs. Carley says it is important that we forgive our parents, because they probably weren't bad parents, they were just normal people and had no frame of reference at the time for understanding. Talk to her about this. Apologize if necessary.

Children only want to be loved by their parents, no matter what their age. It means a lot to me that my mom, at the age of 73, has begun to turn the television sound off when I visit, instead of shouting things at me over the commercials. If you and your daughter are younger than me and my mom, I'd suggest you make a real effort to get to know her; her likes and dislikes, and what she wants and needs from you. It will not be good for either of you to be estranged from one another.

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CHAPTER 21

ON WHETHER ASPERGER SYNDROME IS A DISABILITY OR A GIFT, AND ADVICE FROM ASPERGIRLS TO ASPERGIRLS

In order to determine whether AS is a disability or a gift, I have to ask myself if I am truly disabled. Of course I prefer differently-abled. We are overly-abled in some areas, superenabled even. We can read books and understand anything written better than most, but can't follow social conversation. We can dismantle computers and install hardware, but we can't find our way around a supermarket. We can monologue for ages on our special interests, but can't spend an hour in conversation without getting a migraine or having a meltdown. We can paint pictures and design things of astonishing beauty, but can't be bothered to fix our own hair. We can write novels, but can't make an imaginative supper.

Some people think that AS only exists in relation to others, that if everyone were on the spectrum they wouldn't feel disabled. I agree that I'd feel less odd, but I'd still have many sensory issues, and I have a hard time listening to other Aspies monologuing without getting brain-strain. I have also hurt the feelings of others on the spectrum because they, like me, are very sensitive and I'm blunt.

Many now agree that if you remove the autism, you remove the gifts. While of course we don't want to see people suffer with extreme autism, the thought of eradicating it through things like genetic selection is sad and frightening. While there have been many times I've wished I'd never been born, it is annoying and insulting when well-meaning people say "I'm sorry" when I tell them I have Asperger's. If it weren't for Asperger's and obsessions there would be no Theory of Relativity, no *Magic Flute*, no Microsoft...and no *Ghost Busters*. Here's what the Aspergirls had to say about having Asperger's.

I'm a lucky person in this respect, because I have a measured and recorded very high IQ and have made a career as a specialist. This has also made me good at passing as a person without difficulties to the outside world. People close to me, like my ex-partners and my son, know that I have great disabilities in taking care of myself and my home, for example. But nevertheless, I would never ever want to change or be more "normal." I get so much out of my special interests, my collections, and am easily stimulated and satisfied in most ways of life. I see AS more like a large part of my personality, and I can't think of myself without it. (Siv)

Even the social isolation has benefits, in that one can be free of the dominant thought to see things uniquely. (Widders)

When it comes to educational pursuits and intellectual ability, I think AS is a wonderful gift. I can hyperfocus. I like tedious tasks. I adore logical problem solving. My brain might hold the technology of the future. However, when I look at my life and realize I've never been in a real relationship, I can't attend most social events, I'm the easiest person to take advantage of, and the populated world in general completely overwhelms me, I realize I'm not like other people. The funny thing is, if the rest of the world was just like me I don't think I'd feel disabled at all. (Andi)

I have gifts—a great mind, insights, the capacity to paint and draw. It is also a disability. I cannot work with others without conflict and worry, confusion and exhaustion. (Camilla)

Over the years I've noticed, as I became more "normal"/less visibly autistic, I have much less focus than

I did. I suspect that my visual memory is less sharp because I rely on and practice language more often than my first language. Get rid of the disability and you also get rid of the gift. (Stella)

When I read about the possibility of determining what causes AS, I experience concern that there is an imperative to change it. In my mind determining the cause is only useful for knowing whether a person has it and then offering that person every opportunity to be valued for their own specific "diamonds" and assisting them with the "shit." As far as changing it, forget it...as hard and painful as my life has been, I would not want to be normal. (Tina)

It's important to realize that how much AS is a disability depends on everyone else and how inclusive they feel like being. (Anemone)

I know others see it as a gift, and have real gifts because of it—savant skills, amazing talents born of special interests, amazing ability to visualize or design or hyperfocus. But I don't have any of those, and for me, AS is a disability. In the Aspie Rights area, there's the growing ideology that AS people be allowed to just live and not be cured and not have prenatal testing trying to weed out AS from the gene pool. I don't know how I feel about that... I don't like the idea that if a parent knew they were going to have a child like me, they'd abort, but at the same time I don't know I'd wish the life I've had on that child anyway. (Polly)

I see it in the same light as astigmatism. People with astigmatism need glasses to see properly. People with AS need different tools so we "see properly" in a world full of people without AS. (Dame Kev)

In this day and age, due to the social demands of society (being flexible, being outgoing and assertive, etc.), AS will usually be seen as a disability. Perhaps in a different day and age where our other traits (such as dependability, able to do repetitive things all day, being alone) would be much more valued, then it would have been considered a gift. (Elle)

I think Aspies have always contributed to society in their way. (Jayne)

ADVICE FROM ASPERGIRLS TO ASPERGIRLS

I asked the Aspergirls what advice they'd give to others. This list is the result:

Get a diagnosis.

- Be proud to be different.
- Study and work in your field of interests, and AS will not stand in your way.
- Cultivate your talents and try to turn them into a marketable skill.
- Be yourself. That way you'll be found and liked by all the other people like you.
- You can be happy with Asperger's or miserable with Asperger's. I've tried both. I prefer happy.
- Autism gives us perseverance, not just to become enthralled with special interests, but to *succeed in life*.
- If you are having a crummy day, check out a chat room. You might feel alone but you are far from it.
- You have Asperger's, Asperger's doesn't have you.
- Choose men very carefully.
- Find a companion who is truly unconditional.
- Revel in solitude.
- Don't worry about what others think. It's just between you and your best self. Success is closing that gap.
- Listen to other people's observations. If they tell you they have doubts about a person or situation, they're

probably right. It's a bad idea to trust intuition you don't have, and it can get you seriously hurt.

- Find ASD women mentors.
- Don't worry too much, there's usually no need.
- Be as tolerant and understanding of others as you can.
- Learn assertiveness techniques.
- Simplify life.
- Life is not about being someone else's perfect anything.
- Don't be worried about social stigma. Fight false media messages that autism means being less of a person.
- Get fit, exercise regularly, and eat carefully.
- If you feel too uncomfortable conforming to a role, change your role.
- Read a lot, not just about Asperger's.
- Don't care so much about what people in school think of you. You'll never see them again in your life after you graduate.

My advice is, be vulnerable *and* courageous. Just as eye contact contains too much information, "life contact" seems to as well. AS disables us when our extreme sensitivity becomes inverted, ingrown and morphs into a shell of protectiveness and exclusion. A burgeoning cultural awareness is happening with the arrival of films, books and news stories about Asperger's. Tell your own story.

ADDITIONAL TOOLS FOR PARENTS

CHAPTER 22

GIVE YOUR ASPERGIRL SOME BALLS: BELIEF, ACCEPTANCE, LOVE, LIKE, AND SUPPORT

Most of the information in this book is aimed directly at Aspergirls. I'd suggest moms and dads re-read all the "Advice for parents" sections on a regular basis because you will be challenged throughout your lifetime and you will forget things that you learned, to make room for more as the years go by.

I'm a fan of things that are easy to remember, so I've come up with this handy dandy acronym, which reiterates some key points even without explanation. It sums up what I've been trying to tell you throughout the book.

The best thing you can give your Aspergirl is some BALLS: Belief, Acceptance, Love, Like, and Support.

BELIEF

Because AS is classed as a disability many people put more emphasis on the *can't* than the *can*. Inherent in having Asperger's is a lot of self-doubt and confusion so you need to bestow within your child a sense of belief that she can be anything or do anything that she wants. Believe in her dreams, her goals, her opinions, and in her intelligence. If you believe her and believe in her, then she leaves your house and enters the world with a much more solid platform than she would otherwise.

Also, if she is older and is just now diagnosed or is self-diagnosed, you might not initially believe it possible that she has Asperger's. Don't waste time and energy trying to make her doubt the diagnosis. Let the verdict settle and then read all you can.

While parents may be willing to believe the diagnosis, often other family or community members may shake their head in disbelief and refuse to accept that she is autistic. They think that autism is an "either/or" situation. Educate everyone. She doesn't need the job of convincing people on top of everything else.

If she is self-diagnosed, while you should encourage and attempt to get an official opinion, treat the prospect seriously. When an Aspergirl first realizes she has AS, she has a true Eureka! moment. Following that, she will have months, perhaps years, of learning to accept AS and what it means to her. Your rebuttal of her self-diagnosis is going to do no good whatsoever unless you have firm proof or evidence to the contrary.

ACCEPTANCE

You must accept and acknowledge the impact of Asperger's on her life. If she tells you she can't handle studying, working, or living or whatever under certain conditions, those limitations should and must be respected. She's not doing or saying it for attention or special concessions, she's reaching out for understanding. While pushing boundaries is important, small supported steps are much more effective than being thrown in the deep end.

Those at the highest-functioning end of the spectrum, while less affected, still have autism. You must accept that. For those of you who have had success with diet and other means getting your child's autism "downgraded" to Asperger's, you still have to educate yourself about AS and accept the challenges that come with that situation.

Accept that she has Asperger's. Accept her for who she is. This will minimize the chance of comorbid psychological conditions and increase her chances for positive self-esteem.

LOVE

Obviously if you as a parent don't love her, then there's going to be a part of her that will always feel like she doesn't deserve to be loved—basic psychology. Of course you probably do love your daughter. Yet, how many of us follow the words with "I love you, but..." This kind of talk says that love is conditional; that we would love them more if they were less this or more that. You must love her. For if you do not, what sort of hope has she got in this world? She will be looking for something to fill that emptiness. It might be an activity, it might be drugs, most likely it will be a man (or woman) to fill the void. Finding love is hard enough when you have autism, much more so when you have never had it at home and really don't know what it is. While this is important for boys I believe the consequences for girls are potentially dire. Many Aspergirls said they had been in abusive relationships early in their dating lives. Many of us have lost our virginity in inappropriate and unsatisfying ways because we did not value ourselves. Many of us have married the wrong man because we did not know what love was; what it felt like to be loved. If we aren't loved by our parents we are very likely to partner with someone who carries on the tradition our parents started.

LIKE

To like someone is more important than to love them. When you like your daughter you let her know that she's likeable, and we with AS have a hard time with that. We're not socially accepted, and we have all these issues that make us difficult to deal with sometimes. How many of us love someone in our family but do not like them? You must find a way to understand your Aspergirl, to see things from her point of view. Without that understanding and perspective, you will never know her and if you don't know her, how could you possibly like her? She will have a hard time making and keeping friends. It will be so much easier for her if she believes and knows that she is likeable; that it is a question of finding the right playmates as opposed to changing herself to fit in. Do not try to make her. Aspergirls get told by everyone from parents to job coaches that they should "fake it" to fit in. Imagine going your whole life faking your personality. Who could keep that up for long?

One of the difficulties a parent may have truly liking their daughter, might stem from the fact that because she is not demonstrative, the parent may feel that she doesn't like them.

When she was younger, I felt as though she didn't like me. She was not affectionate, stiffened if I tried to hug her and turned her cheek if I tried to kiss her. She hated to do things that I enjoyed doing, like shopping, small talk, being with friends or family. With time and education, I learned not to take offense over these things. I have had to learn how to talk to her in a way that was not offensive to her. She would take everything we said very literally, and would often say things that were very random. I think most moms think of their daughters as extensions of themselves. It took time to learn and understood that she is not me. (Deborah)

SUPPORT

It is possible and likely that an Aspergirl will take longer to leave your house. The bird will fly the nest eventually, but if you push her out too soon you do so at her peril. She may seem mature for her age when she's little but when she is older, she will be emotionally more vulnerable than her peers. She doesn't learn from her mistakes as readily. She will be naïve romantically. She may have a difficult time finding and keeping employment. She can and she will, with help and effort, be successful at all those things but it may take a bit more time.

Her health may suffer from a lifetime of PTSD, poverty (with resultant stress and poor diet), depression from loneliness, GI issues, etc., so you can see how absolutely crucial it is not to shove her out into the world and expect the same progress from her as from non-Aspergian girls.

With a nonautistic child you can expect certain milestones to occur in their lives on a fairly straightforward timeline. With an autistic child, you take each milestone when the child is able to get there. With a nonautistic child, you can allow her more freedom when

she demonstrates she is mature enough to handle it, the whole *roots and wings* thing. An autistic child will not be able to defend herself against the unscripted, multifaceted world that awaits her outside of her home until older. If the wings come, it won't be until much later. (Deborah)

We need support—moral, emotional, and sometimes financial support. Many Aspergirls have a hard time supporting themselves, so she might be coming to you for money or she may still live at home, and I know that's hard for you too. But we often have nowhere else to turn; government welfare and disability agencies are largely clueless. In New York state, if I wanted help I'd have to go to the Office of Mental Retardation! Since people with Asperger's have a higher-than-average IQ, and being mentally retarded connotes an IQ of 70 or less, we will be turned away at the door. There's a lot of misunderstanding and stigma attached to Asperger's because of lack of awareness. With nowhere else to turn, we often have to rely on our loved ones. If we do not have a partner, that can mean parents; even elderly ones.

The less stigmatized we feel, the more confident we feel, and that translates into the ability and wherewithal to seek employment and assume our place in the world at large.

CHAPTER 23

THOUGHTS AND ADVICE FROM PARENTS OF ASPERGIRLS

I'm not the parent of an Aspergirl. For this chapter I enlisted the aid of Deborah Tedone, Director of Square Pegs/Asperger's Support Group for Adults in Rochester, NY. Deborah says so eloquently what all parents of AS girls need to hear.

WHAT IS THE BEST PART ABOUT BEING THE PARENT OF AN AS GIRL?

The best part about being the parent of an AS girl is that God loved me enough to entrust such a sweet, beautiful, unique being into my care. I think what I love most about being her parent is that I truly love her honesty, her brilliance (and I'm not exaggerating), her innocence, and her fierce determination to beat this world despite *its* imperfection. I respect her. I trust her. I thank God every day for her!

WHAT ARE THE BIGGEST CHALLENGES?

There are many, but not because of her, necessarily, but because of the world. When she was very young, the temper tantrums were very challenging. We didn't know what to do to help her. She couldn't communicate to us what was wrong. She would also do things that were not age appropriate, such as demanding to wear two different shoes to school at the same time, when in Junior High. It hurts to see her not treated well by others. It tears my heart apart when I hear others picking on her or calling her names. Other people's ignorance and self-centeredness can make me very, very angry. I have spent many tears praying for people to be less cruel to her. So, so many examples. The first time was when she was three, she was sitting in the sand box in our back yard. She liked the

feeling of the cool sand on her legs on hot days. When I went inside to answer the phone, I went back outside (maybe 4–5 minutes later) to find the neighbor-boy pouring buckets of sand over her head, and laughing, calling her a retard while he did it. She just sat there with her thumb in her mouth, blankly staring. When she was 17, we stood in line at a grocery store she worked at a few hours a week. The cashier didn't see us in her line, but she was talking about my daughter to the cashier in the next aisle, loud enough for us to hear. Things like, "What planet did (she) come from...what a retard!" She turned white when she saw us in her line. I was furious, and ready to go to her supervisor. But my daughter asked me not to, and simply, flatly stated, "Don't worry about it. People talk about me like that all the time. They just don't know any better."

WHAT ADVICE OR WORDS OF ENCOURAGEMENT WOULD YOU GIVE TO GIRLS WITH AS?

Don't ever be embarrassed or ashamed of who you are. And just as important, try not to spend too much energy trying to be something you're not. You are a special gift from God to the world. It's easy to be "average" but it is a blessing to be unique.

WHAT ADVICE WOULD YOU GIVE TO PARENTS OF GIRLS WITH AS?

- Moms and Dads—educate yourselves!!! Educate your family!!! Educate your child's teachers!!! She can't do it, it's up to you.
- Don't expect your daughter to be you. Don't try to stamp your personality on her. She will be who she is, she won't morph into a replica of you. I think that's important.
- Never blame her, your spouse or yourself for her Asperger's. It is no one's fault, it's just the way it is.
- Don't let your feelings get hurt because of her need for solitude, she doesn't crave it as an escape from you,

- rather as a need to stop the world from spinning so fast and to survive in her own world.
- Be very careful of your advice to her. She will be very literal, and she will remember everything you say. Choose your words carefully and wisely.
- If you have other children, don't play favorites. That will only cause deep-rooted resentment.
- Love her for who she is, not for who you would like her to be. Enjoy the girl she is and the woman she becomes.
- You can discipline a nonautistic child using complex reasoning skills. You cannot discipline an autistic child in the same way, he/she would not understand complex reasoning skills. My daughter danced to a different drum than her nonautistic peers. We had to embrace her uniqueness and not squash her individualism. It did no good whatsoever to "punish" her for tantrums, or to "explain" things to her. She is wired differently and to expect the same rules/procedures to work for her would be futile.
- You are not alone. If needed, look for Asperger support groups in your community to help her and you cope with life's challenges. (Deborah)

APPENDIX

Appearance/personal	Intellectual/giftedness/education/vocation	Emotional/physical	Social/relationship
habits			_
Dresses comfortably	May have been diagnosed as autistic or	Emotionally	Words and actions
due to sensory issues	Asperger's when young, or may have been	immature and	are often
and practicality.	thought of as gifted, shy, sensitive, etc. May	emotionally	misunderstood by
Will not spend much	also have had obvious or severe learning	sensitive.	others.
time on grooming and	deficits.	Anxiety and fear are	
hair. Hairstyles	Often musical, artistic.	predominant	cold-natured and
usually have to be	Often musical, artistic.	emotions.	self-centered;
"wash and wear." Can	May have a strong interest in computers,	More open to	unfriendly.
be quite happy not	games, science, graphic design, inventing,	talking about	Is very outspoken at
grooming at all at	things of a technological and visual nature.	feelings and	times, may get very
times.	More verbal thinkers may gravitate to	emotional issues	fired up when
	writing, languages, cultural studies,	than males with AS.	
Eccentric personality;			talking about
may be reflected in	psychology.	Strong sensory	passions/obsessive
appearance.	May be a self-taught reader, have been	issues—sounds,	interests.
Is youthful for her	hyperlexic as a child, and will possess a	sights, smells,	Can be very shy or
age, in looks, dress,	wide variety of other selftaught skills as	touch, and prone to	mute.
behavior and tastes.	well.	overload. (Less	Like her male
Usually a little more	May be highly educated but will have had	likely to have	counterpart, will
expressive in face and	to struggle with social aspects of college.	taste/food texture	shut down in social
gesture than male	May have one or many partial degrees.	issues as males.)	situations once
counterparts.		Moody and prone to	overloaded, but is
May have many		bouts of depression.	generally better at
androgynous traits		May have been	socializing in small
despite an outwardly		diagnosed as bipolar	doses. May even
feminine appearance.		or manic depressive	give the appearance
Thinks of herself as		(common	of skilled, but it is a
half-male/half-female		comorbids of	"performance."
(wellbalanced		autism/AS) while	Doesn't go out
anima/animus).		the AS diagnosis	much. Will prefer to
May not have a strong		was missed.	go out with partner
sense of identity, and		Probably given	only or children if
can be very		several different	she has them.
chameleon-like,		prescriptions to treat	Will not have many
especially before		symptoms. Will be	girlfriends and will
diagnosis.		very sensitive to	not do "girly" things
ulagilosis.		medications and	like shopping with
			1. 1.
		anything else she	them or have
		puts in her body so	gettogethers to
		may have had	"hang out."
		adverse reactions.	
Appearance/personal habits	Intellectual/giftedness/education/vocation	Emotional/physical	Social/relationships
Enjoys reading and	Can be very passionate about a course of	Will have mild to	Will have a close
films as a retreat,	study or job, and then change direction or	severe	friend or friends in
often sci-fi, fantasy,	go completely cold on it very quickly.	gastrointestinal	school, but not once
children's, can have	Will often have trouble holding onto a job	difficulties—e.g.	adulthood is
favorites which are a	and may find employment daunting.	ulcers, acid reflux,	reached.
refuge.	Highly intelligent, yet sometimes can be	IBS, etc.	May or may not
Uses control as a	slow to comprehend due to sensory and	Stims to soothe	want to have a
stress management	cognitive processing issues. Will not do	when sad or	relationship. If she
technique: rules,	well with verbal instruction—needs to write	agitated: rocking,	is in a relationship,
	down or draw diagram.		
discipline, rigid in		face-rubbing,	she probably takes in
certain habits, which	Will have obsessions but they are not as	humming, finger	very seriously but
will contradict her	unusual as her male counterpart's (less	flicking, leg	she may choose to
seeming	likely to be a "trainspotter").	bouncing, fingeror	remain celibate or
unconventionality.		foot-tapping, etc. Similarly physical	alone. Due to sensory
Usually happiest at			

home or in other	when happy: hand	issues, will either
controlled	flapping, clapping,	really enjoy sex or
environment.	singing, jumping,	strongly dislike it.
	running around,	If she likes a male,
	dancing, bouncing.	she can be
	Prone to temper or	extremely,
	crying meltdowns,	noticeably awkward
	even in public,	in her attempts to let
	sometimes over	him know, e.g. she
	seemingly small	may stare when she
	things due to	sees him or call him
	sensory or	repeatedly.
	emotional overload.	This is because she
	Hates injustice and	fixates and doesn't
	hates to be	understand societal
	misunderstood; this	gender roles.
	can incite anger and	This will change
	rage.	with maturity.
	Prone to mutism	Often prefers the
	when stressed or	company of animals
	upset, esp. after a	but not always, due
	meltdown. Less	to sensory issues.
	likely to stutter than	
	male counterparts	
	but may have raspy	
	voice, monotone at	
	times, when	
	stressed or sad.	

Will usually be very proud and protective of the gifts that Asperger's/autism has bestowed, but would like to be more at ease in the world and suffer less.

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SUMMARY OF SOME MAIN FEMALE/MALE DIFFERENCES

- Usually a little more expressive in face and gesture than male counterparts.
- Better at mirroring than males and so may mirror many different types of personalities. Hence females may not have a strong sense of identity, and can be very chameleon-like, especially before diagnosis.
- Will have obsessions but they are not as abstruse or unusual as her male counterpart's and tend to be more practical (less likely to be a "trainspotter").
- More open to talking about feelings and emotional issues than males with AS.
- Less likely to receive early, correct diagnosis because the criteria are based on male behaviors/traits. (Hans Asperger studied males only.) More likely to be diagnosed as bipolar or manic depressive (common comorbids of autism/AS).
- Physical gestures/behaviors when happy more expressive than males: hand flapping, clapping, singing, jumping up and down, running around, dancing, bouncing—this pertains to adult women as well as girls.
- Adult females are prone to both temper and crying meltdowns, even in public, sometimes over seemingly small things due to sensory or emotional overload. Hunger/food issues seem to be a common trigger. Adult males not prone to crying.
- Tends to receive less tolerance and more expectation from others, because she appears more adept.
- Like males, she will dress comfortably, but may be thought androgynous, as she may have an aversion to makeup and complicated hair and clothing styles.

- Less likely to stutter than male counterparts when stressed or upset; although both may have a raspy, choked, or monotone voice, or suffer mutism at those times.
- Females are generally better at socializing in small doses. May even give the appearance of skilled, but it is a "performance." Like her male counterpart, will shut down in social situations once overloaded.
- More likely to keep pets for emotional support but not always, due to sensory issues.

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WEBSITES

www.help4aspergers.com

Rudy Simone's official website.

www.aspie.com

Offers visitors a variety of opportunities to connect with Liane Holliday Willey, EdD, Aspergirl extraordinaire, generous human being and internationally acclaimed speaker and author on the subject of Asperger syndrome. Articles addressing Aspie relationships; articles for parents, caregivers and teachers; lesson plans; poetry; a pet therapy blog; interesting articles from other sources; PowerPoint presentations, and a FAQ section.

www.autismhangout.com

News, videos, webinars and programs all about autism and Asperger syndrome. A marvelous resource passionately run by Craig Evans.

www.camillaconnolly.com

Camilla Connolly is a successful Australian artist living in the small town of Murwillumbah, northern NSW. She has held many solo and group exhibitions and her work is held in both private and public collections nationally. Camilla was formally diagnosed with Asperger's syndrome in 2009, and often lectures publicly on Asperger's syndrome and women and girls in Australia.

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The website of one of the original Aspergirls, a true pioneer and one of my favorite human beings. You must read one of her books and see her speak if you really want to understand the wondrous nature of Asperger's and autism.