

## CHAPTER 1

# Seeing the World Through Our Eyes

To fully comprehend why we have such strong negative reactions to seemingly minor daily disruptions one must understand how the autistic population perceives the world. We will look at the core “issues” of autism from the perspective of someone who lives it daily. Actually I don’t like using the term “core issues” because it seems to have a negative overtone. Let’s instead view them as “core character traits.” It is paramount that you the reader should not misunderstand the word “autism” to truly appreciate the insights this book will offer. On the television and in the media autism mostly carries a negative connotation. It is a “disease,” “disorder,” “lifelong burden,” and, my favorite, an “epidemic.” Many people have a stereotypical view of an autistic individual as a non verbal child who rocks incessantly, huddles in a corner flapping their hands, and seems to wail when asked to do something. Society has not fully accepted the higher functioning person with autism and Asperger’s as an individual who despite looking physically “normal” does have limitations and special needs. I find this especially true in the school system. So many parents have lamented to me that, despite a diagnosis of autism, their child is not seen as “autistic” because they are doing well academically and therefore isn’t offered the reasonable accommodations necessary to provide a safe learning environment for them. When I am called in

for consultations due to “behavioral issues” by the school, most often these behaviors are the direct result of a lack of understanding of the child’s particular needs as well as an incorrect understanding of what autism truly is.

News reports describe the insurmountable obstacles parents face, and the need to find a cure along with stopping the spread of autism. Every now and then a news story breaks about some incredible feat of an autistic individual and it seems more of an aberration to the world than a true measure of the gifts and capabilities all individuals on the spectrum have. There is an almost obsessive drive to purge autistic traits out of these children so that they can act “normal” and successfully integrate with society. For a culture that embraces diversity, yet singles out autism as something that must be eradicated from the face of the world, this is counterproductive. Autism is more of a cultural difference than a disorder. The autistic population is rising dramatically. Perhaps one day we will outnumber the non autistic population.

I like to tell my audience that people with autism are like tigers. A tiger’s natural environment where they are content doing what comes naturally and instinctively to them is the jungle. You can put us in the circus and train us to jump through hoops—for that is what is expected of tigers so that they fit in an environment not their own. Still a tiger is a tiger and has natural instincts that at best may be subdued or dormant for a while but can break forth at any time. People shouldn’t be shocked when a wild animal such as a tiger suddenly and without warning snaps and attacks its trainer. Children on the spectrum are expected through much intervention to adapt themselves into a foreign world that goes against their natural “nature.” It is no surprise that tantrums, meltdowns, and bad behaviors “break forth” without any reason apparent to the non autistic bystander. Understanding our thought processing differences will help you, the reader, better anticipate the outside influences that may create an extreme response despite the best behavioral plan or interventions.

## Is autism part of an evolutionary process?

Why is autism on the rise? Every species must adapt in order to ensure its survival. What if nature is trying a new experiment by creating a blend of autistic and non autistic traits to create a new race of beings to ensure mankind's survival? Could you imagine a world where people said what they meant and meant what they said? Where honesty and truth abound? Our world is standing on the brink of extinction from terrorists, radical extremists, and an indifference to the abuse of our planet's natural resources. In generations yet to be born a blend of autistic and non autistic character traits in each human being may just ensure our continuity as a species. It is human emotion that may lead humanity to extinction. If you do not believe this then read about American life in the 1950s and the Cold War with Communism. I still remember air raid drills in 1966 for predicted atomic bomb attacks by the "Reds" (Soviet Union). Society became so paranoid about mass extinction it influenced every fiber of its being. People began building personal bomb shelters, magazine advertising catered to nuclear preparedness, and children were taught and drilled in the school system on how to survive a nuclear holocaust. Both the Soviet Union and the United States began building up its arsenal of weapons of mass destruction out of sheer fear the other side would attack. I collect items from Cold War America, including booklets, advertisements, and trinkets to increase the odds of surviving such an attack. Logic and reason took a backseat to raw emotional fear. No wonder the children of that era who became teenagers in the 1960s rebelled against authority with their famous mantra, "Make love and not war."

I collect these items as it is my way of understanding how being non autistic and slave to emotions can be a greater disability at times than having autism. It is comical to behold items that would not help the individual in any way during an atomic war, despite their claims, but people's emotions clouded logic and they bought these items to ease their anxiety. The McCarthy hearings (or witch hunt) during that time accused a lot of innocent people, including celebrities, of

being Communist sympathizers, based not on hard evidence but on hearsay. Many people's careers were permanently destroyed as a result. This would never have happened in a dominantly autistic society.

What would our world look like if everyone kept to their scripts, for instance, airlines always leaving on time or being honest and announcing delays in a prompt manner? My speaking takes me all over the country so I fly a lot. It is so frustrating to be waiting at the gate for your departure, noting the departure time has passed, but the monitor board still displays the original and now incorrect departure time. You ask the airline representative behind the gate counter what the new departure time will be and generally they respond by saying they don't know. You ask for some timeframe for the delay yet receive a well rehearsed phrase that is cold and impartial. Someone has to know, don't they?

Wouldn't it make more sense during the pre-flight safety briefing by the airline attendant if she no longer stated that in case of water landing (let's be brutally honest and say what you really mean... crash) your seat cushion doubles as a flotation device, and instead gives clear concise instructions on how to use the parachute and open the windows which act as emergency exits located in each row? A society predominantly autistic would familiarize themselves with emergency escape procedures well in advance of the flight. If you were an unlucky passenger not familiar with this critical knowledge your fellow autistic passenger would be prepared to give you a discourse on proper evacuation procedures. To minimize the casualty rate in such catastrophic events an autistic society would engineer planes that complement our need to script out every scenario including disasters. Basic logic will tell you that four emergency exits for a plane that holds 230-plus people, with only a 90-second window to escape, is eerily reminiscent of the lack of enough lifeboats to hold every passenger on the Titanic. To up the survival statistics autistically engineered planes would give every passenger an equal chance of beating those odds by adding in structural features which take into account the fact that accidents may happen (due to our need to script for just about every contingency). I constantly question the

non autistic rationale of so few exits for so many airplane passengers but I keep getting the answer, “You can’t worry about the unknown, so just don’t think about it.” When I ask fellow passengers what they would do in the event of an impending crash, overwhelmingly the response I get is, “Well I would just put my head between my legs and kiss my behind goodbye.”

I challenge you to contemplate the real disability here. What is worse? The emotional distress of the mere thought of a disaster that makes one unable to plan for the unexpected so that they resign themselves to dying in a fiery ball of flames, or the individual who analyzes planes crashes and comes up with viable options to increase their survival in such an event and isn’t even selfish with this knowledge, using it as “small talk” to engage their fellow row mates? Trust me, right now if I engage others while waiting in airports with Domsday crash scenario scripts I am seen as a lunatic, but if the plane were really going down and I stood up saying I knew how to improve our odds of surviving I bet I would be seen as a savior.

## The importance of scripts

Our need for having everything to follow scripts (a pre-set pattern of events) for even the most mundane daily life skills such as getting dressed or brushing teeth seems mind boggling to an outsider. Routines and rituals govern our every activity. I will elaborate much more on this in Chapter 4, but for now let’s note that in many instances our staunch refusal to break our pattern or routine collides with the non autistic mindset that “variety is the spice of life.” My non autistic husband is forever trying to persuade me to try a new dish when we go out for dinner at the same Italian restaurant. As sure as the sun rises each morning I always order the same thing, noodles Alfredo. I marvel at how he truly enjoys reading each entrée selection and then creates difficulties for himself because according to him there are so many dishes he would love to try and he can’t make up his mind. Annoyingly I have to script in ten extra minutes on these dining excursions just for his indecisiveness over menu selection. Apparently to the non autistic population trying something new

just to “excite” the palate seems pleasurable due to the thrill of the anticipation of unknown and unexperienced flavors. He is quick to remind me that, “You don’t know what you are missing.”

I retort with an expression I have learned that goes, “If it isn’t broken then don’t fix it.” To me bland is beautiful and, since I am happy with my dinner selection which is very pleasurable to my taste buds, there is no need to deviate from what works for me.

## Heightened senses impact our ability to navigate social settings

Most individuals with autism are very content with this seemingly narrow approach of avoiding new experiences, particularly in a society where everything is so unpredictable and constantly changing, often without any logical basis behind the change. Many individuals with autism have heightened senses so it is very common for us to experience sensory integration overload or difficulties in areas overlooked by non autistic people. The tongue is a sensory organ divided into sections where certain taste buds pick up on salty, sweet, sour, bitter, etc. Something as simple as spaghetti sauce may feel as spicy as jalapeño peppers to an autistic person with sensory issues. Once while at a church picnic I was sitting with a family who had a child with Asperger’s Syndrome. This child was doing very well running around with three other children chasing butterflies. Seeing as it was a warm day one of the other mothers offered these children a cold drink, which happened to be ice cold soda pop from the picnic cooler. The boy with Asperger’s Syndrome, who was seven years old and very thirsty, impulsively took a big swallow of this beverage and almost immediately went into a full meltdown. No one around, including his mother, knew what triggered this catastrophic reaction as he normally enjoyed drinking soda pop. Initially they assumed he was upset because either he didn’t get served first, or that the wrong cup was used, and on and on they micro-analyzed what minor detail may have prompted his wailing. The mother attempted to quiet him down by offering him a new cup and new can of soda, which only escalated the situation and intensified his self stimulating.

I knew immediately just by his non verbal reactions that this was a sensory issue so I ran up to him with a small cool, not ice cold, juice box which I placed in front of his face. He immediately grabbed it and began drinking. Within a few minutes he was calmed down.

I explained to the mother all about heightened senses and how sometimes the most mundane of things that non autistic people take for granted may not be so to the autistic population. In this young boy's situation it was the temperature variation of the soda fizz that became a sensory nightmare to him. Although he drank soda before it had never been that cold and the bubbly sensation of the fizz became unbearable. As a result for the rest of the picnic that little boy became fearful of all foods out of his comfort range and refused to eat or drink anything else while there. Of course I am not advocating that we should stay locked up in our rooms for ever to avoid unpleasant experiences in life. I am merely pointing out that seemingly ordinarily sensory sensations can be unbearable to individuals with autism. Actually, sensory overload has been perfected into a cruel means of torture. Throughout history various empires and regimes perfected the means of non lethal torture by employing methods that led to such sensory overloads as to cause insanity in the prisoner who was subjected to it for prolonged periods. So when individuals on the spectrum are subjected to sensory overloads without any means of escape from the stimulation it is a similar form of non lethal torture employing sensory overload methods.

A parent forcing a child with autism to go into a department store during the Christmas holiday season, even if it is just for five minutes to "teach" them to learn to deal with sensory situations they must encounter as adults someday, seems cruel to me. I have actually witnessed such a situation and the end result was the child going into a full blown meltdown. I have complete empathy for that child because I have tried repeatedly to "train" myself to endure shopping during the busy holiday season (to no avail) by using a script complete with navigational maps, communication phrases, and back up plans for everything from an out of stock item to running into someone who knows you and wants to chat. The totality of the

large mass of people squeezing themselves down crowded aisles, the pungent smell of overly used perfumes and colognes, the same Christmas music playing over and over again, and the noise and flashing tree lights increases my anxiety level to the point where after just a few short minutes I end up running out of the store in a panic mode every time.

I live in a small town with only one major department-like store. Even if I don't shop for Christmas presents I will still have to frequent the store during holiday season to purchase regular household commodities. To complicate matters even further I am mesmerized by colorful shiny objects. The Christmas decoration aisles teeming with a vast array of shiny tree ornaments, garlands, and tinsels act as a siren beckoning me to come closer. The power of this lure is equivalent to the power of pheromones, and I ignore caution, scripts, common sense, and the rising sensation of sensory overload just so I can stare at these objects close up. Although I am focused entirely on the ornaments it doesn't mean that my body isn't registering sensory issues. By the time I refocus back to the shopping at hand I am close to a sensory meltdown, my anxiety level is critical, and I didn't even recognize it at the time because of this narrow focus.

Avoidance of shopping is not an alternative but I have to realize my limitations that can't be dismissed. I have learned to compromise. I shop when there is a greater probability of low people volume, like when the store first opens, close to closing time, and Sunday mornings when many of our local town folk are in church. When possible I ask my husband to go to the store for me and I hand him a shopping list. I am asked why I don't just use sensory reduction devices such as noise cancellation headphones, sunglasses, or a hat with a big brim to help reduce the impact of sensory triggers. Wearing such an ensemble into the store feeling and looking anxious will only serve to draw attention to me from the undercover security people looking for shoplifters. I have also found that when wearing sensory assist devices like the sunglasses and a big brimmed hat, despite my looking down at the floor to avoid seeing people, someone who knows me always ends up touching me or tapping me on the



shoulder sarcastically asking if I was deliberately trying to avoid them. Then they delight in engaging in small talk about subjects I have no interest in listening to, such as their Christmas shopping plans or ideas. That subjects me to a longer exposure time to sensory triggers. As an adult, a person with high functioning forms of autism has the distinct disadvantage of looking “normal” so therefore can’t be seen as autistic by society. And as I stated before, to the general population autism conjures images of individuals rocking, flagrant hand flapping, and engaging in bizarre behaviors, so any individual not engaging in such behaviors must be lying about being autistic. Even people who know I have autism will still feel slighted if I apologize and explain that I cannot chat with them at the moment due to sensory issues and then curtly say my goodbyes and walk away.

To deal with the Christmas decoration aisle issue I have a small live evergreen tree as a potted plant trimmed out with shiny garlands and colorful balls and electric lights in my parlor. It stays up all year round allowing me to “admire” it whenever I am home, thereby diminishing the craving somewhat at Christmas time to deviate from my script to view the store’s Christmas displays. It is portable so if I should have visitors it can quickly be moved out of sight when out of season so that I don’t “embarrass” my husband.

Luckily with today’s interventions for sensory issues there are techniques that help us to cope with being in an environment that is overstimulating and children learn coping strategies to help handle many of those situations. What is sometimes overlooked, though, is the fact that all human beings have sensory limitations of one sort or another. In an attempt to normalize the child with autism, however, there is a tendency to force them to endure, even if by the technique of desensitization, environments that exceed their sensory capabilities rather than working a compromise, such as visiting a shop during non peak hours when sensory impacts would be minimal. Although every waking activity of ours revolves around scripts, sensory issues can completely dominate and ruin even the best devised script. Remember it is not about what the shoppers will think about you or your autistic child; it is about successfully navigating a life skill

task without having a catastrophic reaction. Know your individual's limitations and work within them and attempt to override them for society's benefit. It is O.K. to be different in today's world.

## Growing up undiagnosed with autism

Seeing as I was diagnosed as an adult with autism I am frequently asked how I managed to grow up without any formal professional interventions. Did I follow scripts and what happened when scripts weren't followed? I consider myself very fortunate, having been only diagnosed in 2005 at age 44. I was born with autism and early home movie footage shows that at age two I was already engaging in very prominent stimming. I reached those early childhood development milestones rather slowly but by age three my vocabulary just exploded and I was not only bilingual but acted as a translator between my mother, who spoke very little English, and my father, who didn't speak German. My mother is quick to say that I was a good child but just "stubborn, set in my ways, quirky, but able to spend hours entertaining myself playing with the same toy." Looking back now it is easy to see why. My mother was born before World War II into an aristocratic wealthy family and raised me in traditional German culture. She had non breakable routines, used scripts, schedules, was very punctual, and I was taught formal etiquette where I always addressed individuals by their title such as "Mrs. Smith," or "Aunt Gisela." Everything was black and white, concrete. I referred to my parents as "mother" or "father," not mommy or daddy. Back in the 1960s the German people were more reserved and stoic. Emotions weren't something that was displayed in front of others. Every aspect of daily life was regimented, scripted, and very punctual.

I remember being around six years old and watching my mother doing laundry and asking her why she ironed towels, pillow cases, and undergarments. I was told it was a "rule" taught to her by her mother, therefore something that must be followed. There were a lot of time-honored child rearing non negotiable rules imposed on me. I like to say somewhat jokingly, "I know there is a God because if

you have to grow up being undiagnosed as autistic the ideal parent who would somewhat understand our needs would be a German one.” What was culturally instilled in my mother translated into an environment where I flourished, and was seen as “normal.” Being raised German was as close to being raised autistic as possible in a non autistic dominant world.

I had no behavioral issues until I entered kindergarten when it became mandatory to integrate with other children and accept social customs considered the norm. About the only time my behavior became explosive at home revolved around feeding times when I was still a baby. My mother delights in recalling the time I taught her about attention to details. I was about one year old and the routine for breakfast consisted of putting me in the high chair at the same time every morning and immediately serving me my porridge. It was always the same breakfast with the same apple sauce on the side. It was what I liked so my mother never felt the need to “push” different breakfast choices. This one time my mother accidentally made my cereal too hot to eat but didn’t notice it till after she placed me in the high chair. Obviously not wanting to scald my mouth, she refrained from placing the bowl on the high chair tray and began to blow on it in front of me to cool it down. This breach of what in my brain became to me a routine was traumatizing. It wasn’t that I was tantruming but I didn’t understand why there was such an abrupt “change” in my being fed breakfast. She went off script. I began wailing, screaming, and flailing my limbs all around me. My poor mother desperately tried, in vain, to hurry cooling down the cereal. Twenty minutes later my “outburst” had me so worked up that I turned beet red and was unable to breathe, therefore unable to eat breakfast at all. She said after that “incident” she always paid attention to the little “details” and made sure never to put me in the high chair till the food was ready to be served. Other than incidents where she realized there was a break in structure or routine she claims I was a model child albeit set in my own ways. The issue wasn’t that I was acting willfully, but that my script and routine were interrupted.

Dispelling the myth that non verbal individuals with autism must possess low cognitive function, I cannot stress enough that whether someone is verbal or non verbal the thought processing is the same, so this book is applicable to the entire autism spectrum and not just to the higher functioning and/or Asperger's Syndrome group. A child or adult with autism who is non verbal may not be able to "talk" to us using the spoken word but they communicate their frustration through behavior. All behaviors are a form of communication. I still encounter within the general population the belief that non verbal individuals with autism have low I.Q.s and minimal, if any, reasoning capabilities. The contents of this book will enlighten those of you who interact with anyone on the autism spectrum, whether severely autistic or very high functioning.

## "Scripting": the golden rule in autism

It is important that you the reader understand what I have coined as the "golden rule of all people with autism," as it directly clashes with the non autistic mindset. This rule is something all individuals with autism follow whether they are aware of it or not. Simply stated the golden rule is: "We need every second of every minute of every hour scripted."

Anyone who has encountered an event where something went off script for an autistic individual, unplanned or otherwise, will surely tell you it didn't go smoothly. We have this compelling need for order as well as an intense drive to structure our day into timetables or schedules. We create "scripts" of how the day or event is to unfold according to an orderly plan that we devise in our head. Unfortunately, though this plan is flawless in our minds we don't seem to communicate that plan to those around us until it collides with a non autistic agenda. Living in a dominantly non autistic world that seems to thrive on spontaneity is almost incomprehensible to a person with autism. The natural world isn't chaotic or random, it is orderly, predictable, and adheres to a predetermined timetable (or as I like to view it, "script"). The natural order of things dictates that

we are born, live a life span, and then die. To break this routine, script, or order of things would result in absolute chaos and severe mental anguish, as succinctly portrayed in every zombie movie ever produced. Even seemingly unpredictable random weather events like thunderstorms follow strict patterns governing weather such as fronts, air masses, clouds, etc. To us changing the natural order of things we are used to is as distressing as waking up one morning and suddenly finding out the world has been taken over by zombies.

## GOING OFF SCRIPT

Going off script is equally as terrifying as jumping out of an airplane without a parachute. Why is it so terrifying? Is it a fear of the unknown?

If so, why then when someone tries to explain to a person with autism that a change is just about to occur and what to expect, is there either still strong opposition to this abrupt change or intense negative reaction. Reassuring phrases such as “Don’t worry, it’s taken care of,” or “It will be fine” offer little if any consolation.

In a nutshell it is about losing control of our immediate environment where things can happen that we have no script for. It is a primal need for safety, and we manipulate the environment around us to achieve predictability because of this intense anxiety of the unforeseen. This dominates our every waking moment. Going off script is losing control and losing control puts us at the mercy of “chance” which is random, unpredictable, and offers no sense of self security. We script to feel safe. This starts at an early age even if the child is unaware of why they are doing it. Scripting to navigate our way through today’s society becomes even more critical because we have to counterbalance how today’s society doesn’t even follow its own scripts or take into consideration how breaking their’s affects us. Case in point is going for a doctor’s visit. How many times have you had an appointment for say 11:00 am and you end up waiting 45 minutes before being seen just because there are a lot of patients that day? I have witnessed quite a few fellow patients getting upset and complaining to the receptionist that their wait time is affecting

their schedule and they have to be either back at work, or picking up the kids, or at other appointments they can't miss. I see their frustration and I have empathy for them, for this is what it feels like for us when we go off script. The anxiety that accompanies this feeling seems to cast a sense of doom and gloom over the remaining day because the predictability that we had predetermined in our brains by careful scripting has been shattered and we are out of control of our environment. I cannot emphasize enough how paramount scripting of everything from major events to daily life skills such as meal time or bedtime routines is critical to our sense of well being and if you are the one doing the scripting you cannot deviate from that once it has been communicated to the individual. Let me give you a perfect example of a very common easily overlooked breach of staying on the script you created for the child with autism.

Let's say you are in the process of preparing dinner, which will be macaroni and cheese and find that there isn't enough cheese for the dish. Seeing as the grocery store isn't that far away you decide to "run to the store" to pick up the needed ingredient. Since there is no one else who can watch your autistic child, who we will call "Timmy," it is obvious he will have to accompany you to the store. To a non autistic child it is easy to say, "Come on, Timmy, get your coat, we have to go to the store to get a few things." Other than some possible protesting about not wanting to leave his preferred activity Timmy generally complies. If Timmy is autistic, however, usually a phrase like that will result in what I call the "But what if?" syndrome.

It starts with, "Come on, Timmy, get your coat, we have to go to the store to get some cheese for dinner." Typically the conversation will unfold like this: Timmy starts right in with, "But what if we get to an intersection and there is road construction and we get detoured and you get lost?"

You reply by telling him you know another route to get there. He then asks, "But what if we get to the store and find that they don't have the cheese you want?" Again you tell him that you would buy a comparable brand or type of cheese that would not affect the quality

of the dinner. Timmy is growing visibly more anxious with every response to his questions.

He becomes relentless, asking numerous “But what if?” questions. Many mothers have told me that they feel Timmy is just stalling because he doesn’t want to go to the store. While this may be a tactic employed by non autistic children it is not so for the autistic child who is desperately communicating to you that they need more scripting for this trip to the grocery store. The “But what if?”s even if they seem far-fetched to you, convey his need to plan and script various potential scenarios that logically could occur even, if only as a remote possibility, so that he has alternate scripts he can count on as a back up plan should your script be altered by the unforeseen. Timmy doesn’t feel safe even in your presence without these back up scripts because he doesn’t know how you would respond to going off script unless you communicate that upfront with him before you set off on the excursion. Despite your best intentions you can’t pre-script everything perfectly and there will be times when scripts don’t go according to plan. Taking the time to allow Timmy to ask his “But what if?” questions will serve to calm him down because scripting is one of our major coping strategies for dealing with the non autistic world. It makes us feel somewhat safe and in control even when we are in a situation that is out of control. It is a natural part of autistic childhood development where we begin to develop the skills that will create coping strategies for the unpredictable events that life will throw at us as adults by having alternate scripts to fall back on in just such a case.

To ease the “But what if?” syndrome try communicating the anticipated event succinctly and clearly. Let’s rephrase the announcement of having to go to the store in such a way Timmy isn’t compelled to grill you with 101 questions. This is how the conversation should unfold in such a way that Timmy has a workable script that has been clearly defined and spelled out for him by you:

Timmy, I have to go to the store to buy some cheese. I was gathering all the ingredients for tonight’s meal preparation and I realized I needed two cups of shredded

cheddar cheese and I only have one cup left in the package, which is not enough. There is no one else here to watch you while I am gone so you must accompany me to the grocery store. We will get our jackets from the closet and put them on because it is cold outside. You will sit in the front seat next to me in the car. We will go down our street, turn right onto Main Street, and follow that 2.3 miles till we reach the grocery store I always shop at. After parking the car you and I will proceed into the store, walk down the bakery aisle all the way back to the dairy case where they keep the cheese. I will pick out a package of cheddar cheese needed to complete the two cups called for in the recipe. This store always carries on hand many different brands of the shredded cheese we need so it is highly unlikely they will not have what I need. Should, however, this be the case my back up plan will be to pick up a brick of cheddar cheese and shred the cheese myself on our cheese grater when we return home. Seeing as we are in the dairy section I will also pick up a carton of milk and a dozen eggs because we only have enough of both ingredients at home to make breakfast for three days and our weekly grocery shopping day is five days away. We should be back home within the hour unless there is heavy traffic but bring your (use your child's favorite stim tool that calms them down when they get anxious) Darth Vader action figure just in case our timeframe goes over one hour due to unforeseen road construction detours.

This will go a long way to minimizing the “But what if?” questions because you scripted in the details in such a way that Timmy now has a working visual in his mind of how the trip will unfold and what to expect. But please don't commit the following most common mistake: “You know, while I am here I might as well just grab a shopping cart and pick up a few other things.” Almost instantly Timmy's anxiety level sky rockets and he becomes visibly distressed. Why? It is because you went off script. You said you were only



going to the store to buy three things: cheese, eggs, and milk, and now you have altered this script by deciding to shop for other items. This impulsive decision then creates a domino effect where every element of the original script also changes in essence, leaving little Timmy without a working script which destroys his inner sense of control and feeling safe. Timmy had a mental picture of just how long it would take to reach the dairy case, what aisles would be traversed, using the express check-out lane requiring ten items or fewer, which is much quicker than the regular check-out lanes, driving home before the rush hour begins, and an overall timeframe of one hour or less. Now how can he revise this script on such short notice? He has to contemplate how much longer will we be in the store shopping for the other items. Will there be more than ten items, which will force us to use the regular check-out lanes which are usually very busy with shoppers pushing shopping carts overflowing with hundreds of food items, and who have a tendency to utilize the slowest check-writing skills imaginable, which serves to further delay our exiting the store? Will this extra time translate into driving home during rush hour? If so, how much longer will this supposedly one hour or less trip last?

He may understand that sometimes going off script for unforeseeable reasons is the reality of life but in this case you, his mom, just completely disregarded his need for predictability, destroying his inner sense of preservation, and without the working script which you spelled out to him before leaving the house he is literally lost. Timmy understands this going off script was a choice made without forewarning him and not an event beyond his mom's control. A sense of helplessness will set in, creating a tendency to lash out verbally or behaviorally out of desperation. Deciding to shop for a few more items may seem like only a minor infraction of a predetermined script to someone without autism but to us going off script anywhere in the script is just as unnerving, whether it is being broadsided while driving by another vehicle or having Mom decide to add in some last minute shopping. To Timmy it is earth shattering.

Our need to script is one of our core traits that we cannot eliminate or diminish the importance of. You will never go wrong by explaining in detail what is to unfold clearly, succinctly, and with contingencies added. It will go a long way in gaining our trust and having us feel relaxed around you.

## HATING SPONTANEITY

There are many reasons why we prefer to be more solitary creature than social butterfly but one is our distrust of being around non autistic individuals because they are spontaneous, willing to sometimes “go with the flow,” alter plans midstream, and generally don’t mind not adhering to agreed upon timetables. During my teen years I made several attempts to establish friendships with other girls my age. The early 1970s heralded the invention of large indoor shopping malls compared to the individual stores congregated in a plaza. It became the socially accepted norm for teenage girls to spend their free time shopping at the mall. I have accompanied different female peers on numerous outings and social functions where they decided on an impromptu side trip to the mall in search of just one article of clothing before continuing on to our activity. I was always told, “This won’t take long.” I believed them because we agreed upon an arrival time to whatever function we were going to that night and I wanted to fit in with my peers socially so I subjected myself to their whims. Without fail they always seemed to lose track of time and constantly we ended up arriving late. To complicate matters further they would have to explore each clothes rack just out of curiosity.

My script for shopping tends to be more of a mission with a specific target in mind with no deviations. If I need a new shirt I go into the store straight to the racks that offer shirts, look for the section that carries my size, and I thumb through the available section. I like to wear similar styles and colors so if that rack contains nothing that I want I exit the store. It seems senseless to “browse” the aisles in hopes of seeing something that may act as a substitute. In the company of these girls I would grow increasingly distressed over timeframes that now did not match the arrival time for the

function we originally agreed upon. This ruined my script so badly I could not enjoy the evening because I could not overcome the late arrival and subsequently I became very distrustful going with anyone anywhere because I could not count on them staying on time.

Even to this day, whenever possible my non autistic husband and I will take separate vehicles when attending the same social function because despite our predetermining a set time to leave he may be having such a good time at a party that he wants to stay beyond our allotted time, or he may take too long to get ready before we leave for the event, causing us to be late. My need to follow a script is so intense that in order to avoid a scene over this, because I get very visibly anxious rapidly (it is obvious to everyone around me), we take separate vehicles, which means my script stays intact even if he changes his. About the only time I feel comfortable going someplace with another person is if we are taking separate vehicles. It is all about staying on script and the lengths we go to to ensure that.

## DEALING WITH GOING OFF SCRIPT

It is important to realize that we will all have the unexpected happen to us in life that takes us off script and sometimes back up scripts will fail, so having an immediate calming tool available to handle the anxiety will help us deal with calming the raging sense of helplessness we feel when our scripts fail. Non autistic people are no different from autistic people in this regard because they also use various “tools” to calm their anxiety when faced with the unexpected. Have you ever found yourself commuting home from work on a Friday evening and running into a complete traffic standstill because of someone else’s auto accident up ahead that caused the highway you were traveling on to be closed until the emergency medical services vehicles arrived? With no exits close by you are stuck waiting it out without any workable timeframe of when traffic will be allowed past the accident site. How do you handle your frustration and anxiety in that situation? Some commuters will turn the radio on to a station that plays relaxing music, others may take out a book to read while

enduring the wait (I have actually seen people in neighboring autos read the newspaper when I was in this situation), still others may light up a cigarette. They are all calming tools very similar to our use of stim tools to ease anxiety when faced with unforeseen events.

It is important that little Timmy should understand at an early age that while scripting is very beneficial in helping us deal with daily life there will be times when things don't go as planned, so it is of the utmost importance to have a calming technique available for those times when we can't remedy the problem and must just endure it. Wailing and flailing limbs in this situation will not make him feel any less anxious and is socially unacceptable in public, especially as an adult. I have seen non autistic drivers in vehicles around me get so enraged because their timetable was interrupted by the highway accident that they constantly beep their horns, shout obscenities, and make obscene hand gestures to anyone glancing their way. That is also totally socially unacceptable and perhaps if they became more autistic-like and used calming stim tools, like the socially popular stress balls you can squeeze or worry stones to rub in the palm of your hand, it might decrease the incidents of road rage plaguing our roadways.

The point is that, understanding how important scripting is to our inner sense of well being, every autistic individual should brace themselves for going off intended scripts through no fault of their own frequently throughout life, and prepare for them by having calming tools on hand to use in these circumstances when there is no alternate script to fall back on. I am an individual who once behind the wheel of a vehicle begins to fret over possible but highly unlikely scenarios that would cause me to be late in my expected arrival time before I even leave the driveway. I have a GPS navigational system which gives me an estimated arrival time as well as alternate routes should the one I plan on be detoured due to road construction, or I take a wrong turn, or I am unsure of the directions. It helps in reducing the anxiety of unforeseen circumstances, but I carry a road atlas as well just in case the GPS system malfunctions or is out of satellite range as a back-up script to follow. With new roads being added frequently and old ones changing names even

road atlases become outdated and inaccurate quickly. Despite having both of these countermeasures I have on occasion found myself hopelessly lost trying to find my final destination point, whether due to erroneous directions, auto accidents, or road detours.

For times such as these when my back-up scripts fail and I feel a sense of panic for going off my timetable I carry a special CD to play that calms me down. Gregorian chanting is very calming when I feel anxious. Somehow just the tone of the chant seems to ease the mental anguish I am experiencing. I don't play it regularly as that will over time desensitize me to the calming effect it offers. I have such a CD in every vehicle I drive, and I carry one with me when I am a passenger in someone else's vehicle, along with a portable CD player with headphones so I don't bother the driver with my music should I need to resort to it. Because I am stressed when faced with an unscripted driving occurrence and not in control when someone else is driving I don't want to "share" my music with others in the vehicle. I want to listen to it uninterrupted to calm down and I like the volume high enough to drown out all extraneous noises so all my brain registers is the soothing music. Headphones allow for that. Playing that CD when someone else is driving at a volume low enough where one can talk over the music can aggravate the anxiety I am experiencing with something as benign as the comment, "That is really pretty music," because it interrupts my concentration on internally calming myself down. I have found that, at least as an adult, when I am in a stressed out situation in the presence of someone else they feel obligated to attempt to calm me down with reassuring phrases that only incite my anxiety such as, "Don't worry, this too shall pass," or try to divert my focus onto something requiring thought, which is too demanding on me at that moment. Blocking everything out, including people, to focus on Gregorian chanting allows my brain to decompress and function more clearly. For me it isn't an option but a requirement when driving scripts go awry. I have many tools and techniques to utilize when faced with various other script malfunctions.

Realize that when we are working on self calming techniques we need to be able to focus on gaining control of our anxiety

without the distraction of someone trying to converse with us at that moment unless we initiate conversation. Help your child with autism begin to recognize what calming tools and/or techniques work for those times when things go off script, and they will have to endure through the unscripted situation. Have whatever special stim tool or calming technique that works for your child available in the vehicle so that they can self soothe when the unforeseen occurs and things go off script. It is the goal of every parent of an autistic child to be able to have their child self regulate their behaviors in public as an adult. Going off any script can cause explosive, even rage-like behaviors, if distressing enough, so it is important to help the child understand that things in life will not always go as scripted and they must learn to cope with the help of stim tools or calming techniques when scripts fail.