

# ZOOM

autism through many lenses

ISSUE 11

Learning to  
**DRIVE**

A Welcome to the  
Autistic Community  
*from ASAN*

The “**SEX** Talk”

NEW LAW ADDRESSING  
*Elopement*

ARTIST, CONSULTANT & AUTISM SELF-ADVOCATE

**KIRSTEN LINDSMITH**

**VIEWS THE NON-AUTISTIC WORLD  
THROUGH AN ANTHROPOLOGICAL LENS**





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ISSUE 11

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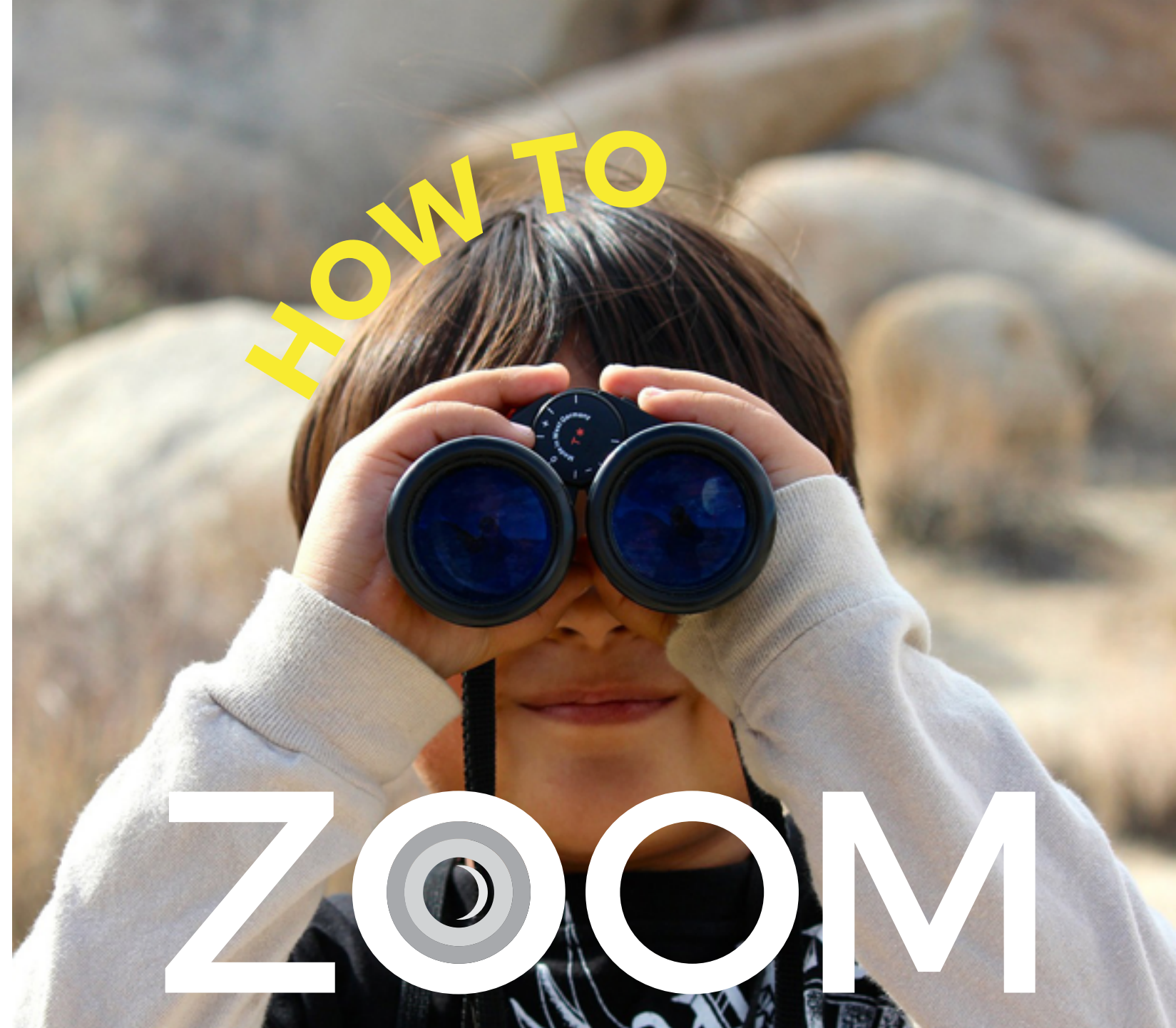
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See what some of our Facebook readers had to say...

**“ Glad I just found this page. I love reading the personal comments.”**

- Kelly M.

Don't forget to follow us on Facebook so that you can be a part of our discussions too!

**Coming Next Issue:** Creating a culture of INCLUSION in our families, schools and community!





## LETTER FROM THE EDITOR

**R**ecently, my 16-year-old autistic son Jacob accomplished a huge milestone ... taking an online driving course so that he could get his learner's permit. To be perfectly honest, he was in no rush to do this, but I gently nudged him to take the course. My thinking was that if he got his permit and chose to continue afterwards to get his real driver's license, great. If not, well, that would be great too, for at least he would have an official form of identification and some knowledge about traffic safety. He eventually agreed and signed up for the course.

One of the biggest surprises to us both was how difficult the course was for him. His peers referred to it as an easy A, yet for my boy, it was anything but. But he drudged through, and yes, I use the word drudge because that paints a very vivid picture of what it was like for him. There were all of these exceptions to the rules that, excuse the pun, drove him crazy. Not to mention, the pictures of crashes and cars on fire were enough to keep even me from wanting to drive again.

While Jacob started off anxious and frustrated, eventually, I began to see something else ... a hint of excitement! He started asking me to physically show him where things were located in the car. As he sat behind the wheel of my vehicle, I saw a real sense of independence come over him. Sure, it was sad to see my baby growing up, but

it was even more thrilling to see him overcome his own fears and tackle this new accomplishment. And accomplish he did. He passed the course and received his learner's permit! Will Jacob continue to learn to drive a car? I think he will ... eventually. For now, he still needs to practice some of the skills that he will need in order to be successful doing so. If you are not sure what skills those might be, then you will want to read our article titled LEARNING TO DRIVE in this issue. This piece paints a very realistic picture of some of the challenges that autistic individuals may face when it comes to driving and offers some personal insights from autistic adults who have been there.

The theme of this issue is "shining a light on some very hot topics," which is exactly why we included the editorial THE IMPORTANCE OF TALKING ABOUT SEX. We know this may not be the most comfortable subject, but it is perhaps one of the most important! Whether you are the

*Even when Jacob was just a little baby he enjoyed being behind the wheel.*



parent to an autistic individual, an educator or an autistic adult, we encourage you to read this piece and explore the resources included.

Our cover story this issue is an incredible piece by the very talented Kirsten Lindsmith, who talks about being autistic in a world that was certainly not designed with autistics in mind. Her article THE CULTURE SHOCK OF AUTISM is eye opening, and the drawings she allowed us to include are magnificent. It is a MUST READ for sure.

There is so much packed into the pages of this magazine that we know you will want to save this issue as a pdf and perhaps even print it out to keep. It's that good and that full of resources.

Lastly, we could not have done this issue without the autistic individuals who candidly contributed their personal life experiences with us. We are sincerely grateful that they have allowed us to share their insights with you, our readers. We think you will be happy they did, too.

Until Next Time,

Sharon Fuentes  
Editorial Director/Co-Publisher & Founder  
ZoomAutism@gmail.com



*From the safety of our driveway, in a parked car, Jacob practices sitting in the driver's seat.*



# Autism & Learning to Drive

**L**earning to drive a car is often looked at as a step towards independence. Autistic individuals can certainly learn to be safe, defensive drivers if they choose to do so, but for some, the desire to drive alone may not be enough. There are some aspects of driving that may give autistic individuals additional challenges. This article will break down some of these areas as well as offer first-hand perspectives from several autistic adults.

## Physical Coordination

The physical abilities most often associated with safe driving include strength, range of motion of extremities, and trunk and head/neck mobility. While power steering and brakes (and other vehicle adaptations) may assist drivers, maneuvering a vehicle still requires a great deal of physical coordination. Proprioception, the ability to move your limbs without looking at them, is also vital for driving. For example, a driver must be able to keep his eyes on the road while simultaneously adjusting his arms and hands on the steering wheel and applying the appropriate amount of pressure to the pedals to maintain speed. For those who need to observe their limbs to successfully accomplish tasks, they would have to look down at their feet, for example, every time they want to change from gas to brake or stare at their arms if they want to make a right-hand turn. This type of distraction can make driving nearly impossible. The good news is that coordination and proprioception can be improved with practice much in the same way a concert pianist can play incredibly complex music with her eyes closed because she has trained the muscles and proprioceptive sense of her fingers to be precise enough for the task.

## Be Mature

"When I was 15, I started Drivers Ed, and I did not take it seriously enough and nearly got into a serious accident. Once a person with autism is mature enough, it would be wise to take the intermediate step of using a simulator or a driving game to get the feel of what challenges are present when driving. Learning to drive should be a more gradual process; [start] in an area that is less congested and poses fewer challenges. Also, from my own experiences, I have to make myself more aware of my surroundings when driving. As for sensory, this is something that needs to be addressed before a person with autism goes on the road."

**:: John Miller, autistic self-advocate, special education teacher, public speaker and author of the book *Decoding Dating*.**



## Keep Your Opinions to Yourself

“I LOVE to drive. I grew up on a farm and my dad needed me to be able to drive vehicles and tractors, so I learned from a very young age. I avoid riding as a passenger, though, and I dislike having passengers in my car because they always have opinions about how fast I should be going.”

:: **David Finch**, author and inspirational speaker, co-founder of Front Range Center for Neurodiversity



## Perception Skills

Perception is the ability to filter out the unimportant matter from all the messages received by your senses and then apply the important information to the task or situation at hand. When driving, perception of dangerous or hazardous situations is critical as is the ability to recognize potential problems and anticipate what might happen so that one can be ready to react accordingly. The problem is that many autistics have a natural affinity to see every little detail but may not be able to see the general ‘big picture’ or need extra time to process all the messages that they are receiving. This is where virtual reality driving simulator programs, role playing and lots of practice may be very useful.

## Executive Functioning Skills

Executive functions consist of several mental skills that help the brain organize and act on information it receives. These skills enable people to plan, organize, remember, prioritize, pay attention and both begin and complete tasks. They also help people use information and experiences from the past to solve current problems. As you can imagine, driving requires many executive functioning skills. A driver needs to know how to plan a route and follow it without becoming disoriented. He or she also needs to understand when the car needs gas or service or what to do if things don’t go as planned. What if a road is closed? What if it starts to rain? Sustained attention is also critical when driving. The average commute is around 20 minutes, and the driver must remain alert the entire time. Many distractions can and WILL compete for the driver’s attention – a cell phone ringing, sirens from a police vehicle passing, a passenger in the car singing. For safety’s sake, a driver must be able to prioritize and determine that which requires attention and tune out all other distractions as needed.

## Driving Is a Social Act

Driving requires following the rules and cooperating with other drivers. Obeying rules is generally not a problem for autistic individuals who may take comfort in the structured black-and-white thinking. The problem is that many rules, when it comes to driving, fall into the grey area and require flexibility and taking context into account. For example, if a yellow light means that you are supposed to slow down, why do so many drivers speed up to get through it? Cooperating with other drivers involves reading nonverbal social cues. On the road, that happens through the “gestures” drivers make through the motion of their cars — by changing lanes boldly or hesitantly, for instance. Those motions amount to signals flashed from driver to driver so routinely that most people are hardly aware of the messages being sent, but someone on the spectrum may not intuitively receive them. Another aspect is how a person reacts to the emotions of other drivers. How do you react if another driver shouts at you or uses a rude gesture? Will the driver respond appropriately if pulled over by police? How would the autistic individual respond if other drivers were not abiding by the rules of the road as precisely as he believes they should? These social and emo-

## Find a Laid Back and CALM Instructor

“I did not yet have an autism spectrum diagnosis when I was learning to drive. I also have panic attacks and am stereoblind. I don’t remember the name of my first driving instructor. I only remember that he lost patience and yelled at me when I started getting anxious. My first driving lesson ended with a dangerous panic attack and meltdown. My parents fired the mean driving instructor on the spot and replaced him with a guy named Hawaiian Bob. Hawaiian Bob was the perfect driving instructor. He was very laid back and calm. If I made a mistake, he would quietly tell me how to correct it, and he gave me detailed, concrete instructions for how to handle all the situations that happen while driving. To this day, if I start to get stressed out behind the wheel, I just think to myself, “what would Hawaiian Bob do?” I highly recommended that any Autistic person learning to drive find an instructor like Hawaiian Bob and avoid driving instructors like the mean, angry first one I had.”

:: **Katherine Hall**, autistic self-advocate



tional situations must be considered before getting behind the wheel.

There are many drivers out there who do not have an autistic diagnosis but do have problems in these social areas, and sometimes, no matter how much you prepare, you just don't know how you will react until you are in the situation. It is for this reason that every new driver should practice, practice, practice so that the physical act of driving comes so naturally that any additional energy can be used to deal with the unknowns.

While we have pointed out many critical skills to consider, it is always important to remember that no two individuals are alike and that there is no set rule to determine when someone is ready to drive, regardless of autism-related challenges. Just because a person may not have the desire or ability to drive now, doesn't mean he won't in the future.

...

### Driving When You Are an Anxious Person

"For years, there have been conflicting motivations in my mind for wanting to get a driver's license. Of course, I've wanted to be able to drive myself anywhere, but I've also pressured myself because I thought I was supposed to, or should, get a license just like most people my age. However, driving has always been difficult for me with the anxiety I felt from urging myself to get a license as well as the anxiety I feel in simply getting behind the wheel of a car. At first, driving was an amazing new experience, but that changed when I moved into more populous areas. I tend to tense up whenever I'm driving; therefore, my reaction time isn't very fast. The unpredictability of drivers (especially in Virginia), coupled with my Asperger's-induced anxiety, makes me very nervous in heavy traffic, and I feel unsure of my abilities. Therefore, even though I've driven for at least four years with a permit, I'm still getting used to driving. I've been waiting to retake my driver's test since I've passed the written exam, but fear of failing, like I did on my first test due to simply not stopping all the way at a stop sign, has partially prevented me from taking the test again. However, with assurance that the test won't be as difficult as I've imagined it to be (I often imagine things as worse than they really are), I plan to take it again soon."

∴ **Thomas Wiese**, autistic self-advocate





# A Welcome to the Autistic Community



By **Ilanthe M. Belisle Dempsey**



An illustration by Anabelle Listic (taken from ASAN handbook cover).

In 2014, the Autistic Self Advocacy Network released *Welcome to the Autistic Community*. This handbook welcomes newly-diagnosed autistic people and autistic people who have just learned of their diagnosis to the Autistic community. It addresses the most common questions that people may have about their diagnosis, emphasizes that they are not alone, and celebrates their new identity. The handbook is written entirely in cognitively-accessible plain language. The main content of *Welcome to the Autistic Community* is divided into ten sections:

- **What is Autism?**
- **What Does It Mean?**
- **Am I OK?**
- **More Alike Than Different**
- **Positives**
- **Am I The Only One?**
- **Where Are the Other People Like Me?**
- **What Are My Rights?**
- **Resources**
- **What Does My Future Look Like?**

Many autism introductory resources talk about autism like it's a disease rather than a developmental disability. They aren't written with autistic people in mind; often they're geared towards parents or teachers. It's incredibly alienating if your first introduction to being autistic is something written about you without bothering to talk directly to you. Even if you do manage to find good resources, they're often written in jargon-filled, cognitively inaccessible language. Resources for the autistic community should be written in language that all of us can understand, including those of us with intellectual and other disabilities. That's why our handbook is written in accessible plain language, addressed directly to the autistic reader.

To date, *Welcome to the Autistic Community* has been downloaded over 362,000 times. Last year, we adapted the handbook into a short, animated video, and I had the incredible opportunity to be the voice-over narrator. This was an important moment for me. In order to understand why, let me tell you a bit about my world before the handbook was published.

I didn't start identifying as autistic until I was 20. Before then, I'd had autistic friends tell me yeah, you're definitely one of us, but I was so scared of being perceived as a liar or an attention-seeking hypochondriac. I spent a straight year reading whatever scattered information I could find about autism written by autistic people. It wasn't easy.

There were no resources like *Welcome to the Autistic Community* in 2012. There weren't any introductory-level guides that weren't targeted at non-autistic parents. There wasn't an FAQ for autistic people who weren't diagnosed in childhood. Research is my strong suit, and even so, my search was hardly turning up anything accessible.

This is why *Welcome to the Autistic Community* is so important. It's a concise, plain language starting point. Before I was diagnosed, I spent over a year pouring over articles and blog posts written by autistic people, trying to answer the very questions posed by the sections in the handbook: What does it mean to be autistic? Am I disabled? Where are the other people like me? Autism isn't as straightforward as some other diagnoses. All autistic people have traits in common, but the way those traits manifest can be completely different from person to person, not to mention that sometimes those traits, taken as a whole, all seem like they have nothing to do with each other. After all, why would





Click above to view Welcome to the Autistic Community video.

the fact that I can't seem to color without snapping crayons in half have anything to do with my tendency to absorb and parrot "catchphrases" from people around me? Without the framework of autism, I felt isolated. I couldn't figure out why school and social situations were so much harder for me. It took me 20 years to find my way; *Welcome to the Autistic Community* is an expedited entry point. It helps reveal the invisible lines that connect the dots of all these different experiences.

Joining the autistic community is about more than just meeting other autistic people. You're suddenly privy to a new, vast landscape of

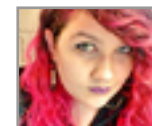
**"Resources for the autistic community should be written in language that all of us can understand, including those of us with intellectual and other disabilities."**

information. I suddenly had words for things I'd experienced but had never known how to convey, like "neurodivergent" and "stimming." You find out that lots of things that you always thought were specific to only you are actually traits that you share with a lot of people, people who have made resource lists and FAQs. You start reading resources shared by the community that link to other resources or use these new words and ideas. Suddenly, everything starts making sense.

I can't reach back to my younger self to say, "Hey, you're not just making it up. I can explain everything." What I can do is share *Welcome to the Autistic Community* with anyone and every-

one who's in the same place I was – full of questions, seeking straightforward and optimistic answers.

*Welcome to the Autistic Community* was written by and for autistic people. It's available for free as a PDF download from ASAN's website, and a closed-captioned video adaptation is available on our YouTube channel. Nothing About Us Without Us!



Ianthe M. Belisle Dempsey is ASAN's Publications & Communications Coordinator. She has been an outspoken anti-oppression activist for the past decade and has a degree in theatre/film studies and history from Illinois State University. Her current independent research projects include the theory and development of a unique body of Autistic theatre performance, among other topics. Ianthe has had pink hair for the past 7 or 8 years and has no intentions of changing that anytime soon.

# Learning to Run Toward Your Fears

BY RUSSELL LEHMANN

I have come a long, long way in life. 14 years ago, at the height of my distress, I was pretty much non-verbal. I was too afraid of the outside world to speak to anyone other than my parents. I stayed inside my house as much as possible, clinging to my parents' sides, terrified of any external stimuli, such as the doorbell ringing, the TV being on, or the microwave going off. I was a prisoner inside my own body. I would have multiple meltdowns every day, curling into a ball in the corner of a room, just crying for hours. I could barely take care of myself.

Now, however, I'm an internationally known author, poet and motivational speaker who travels the country, spreading a message of hope, awareness, understanding and acceptance about autism and other disabilities.

The amount of personal growth I have experienced has been astronomical. The catalyst behind this growth is not due to some pill or "cure" but rather to pushing myself outside of my comfort zone daily. Every single day I take every chance I can to push my mental abilities to the test, whether it be pushing myself to the limit at the gym, initiating a conversation with a stranger, placing myself in the middle of a loud crowd to expand my sensory processing capabilities, or just simply making full eye contact

with an individual I'm talking to.

I do this not only to further grow and develop into the best person I can be but also to conquer the remaining demons that I do still deal with. I happen to have not only autism but also anxiety, depression, OCD and a previous battle with anorexia. If I were to stay inside my comfort zone and not push myself out into the extremely frightening outside world, I would eventually regress back to where I was 14 years ago.

My progress in life may seem like a miracle on the surface; however, everybody and anybody can attain this type of personal development. My advice? Run toward, not away from, your fears. Fear, first and foremost, is nothing but opportunity disguised as risk. Behind every single fear in your life is a wondrous reward that you will only attain if you push through what frightens you. It is a fact that when you push yourself outside of your comfort zone, your chance for personal growth increases exponentially.

Failure is another factor of life that we all need to embrace. If we were to never fail, we would never know what we need to improve upon, and we would never be aware of what we are truly capable of. When there is a chance you may fail at something, you either succeed or you learn. There is no losing when it comes to

**"Fear, first and foremost, is nothing but opportunity disguised as risk."**

failure. Think of failure as a trampoline: You are going to fall, but you will bounce back better because of it!

I chose to become a self-advocate and speaker in order to help others not have to go through the unnecessary pains and struggles I've been put through. I take pride in being a voice for the unheard, for I know how frustrating and challenging it is to go unnoticed. I'm honored and humbled to be able to give hope to families and parents who are concerned with their children's future, just as my parents once were.

I have a raging fire within me to help others succeed no matter what obstacles or hardships they

may be faced with. I sincerely hope this article aids in this all-important endeavor of mine.

...



Russell Lehmann is a 26-year-old autistic award-winning motivational speaker, poet, author, and disability advocate. He sits on the Nevada Governor's Council on Developmental Disabilities and is a board member for the Autism Coalition of Nevada, chairing their statewide Youth Advisory Committee. He is also the Youth Ambassador for the mayor of Reno, Nevada, Hillary Schieve. Visit Russell's website at [www.TheAutisticPoet.com](http://www.TheAutisticPoet.com) for contact information, motivational videos and booking information.



# Nothing to Me

BY STIANO QUADRACCI

## I ran.

Up mountains, into valleys.

I met trees that told me stories.

I told these stories to my tribe.

## I explored.

Into caves, across seas.

I met birds that told me stories.

I told these stories to my friends.

## I loved.

Sensitive creatures, beautiful nature.

I met souls that told me stories.

I told these stories to my family.

Then some people told me a NEW story.

They said I was primitive, achieving no goals,  
leaving no legacy.

They taught me  
a new way.

The new way was to buy things.

They told me to strive for wealth, to rise from  
my primitive existence of running and exploring  
to an enlightened state of wanting and having.

That wealth would make me happier  
than before.

That having and owning more things would  
fulfill me.

I MISSED my stories.

I MISSED running.

I MISSED exploring.

I MISSED loving.

I MISSED my tribe.

I MISSED my friends.

I MISSED my family.

The things I bought were nothing to me.

Then I remembered a story.

The one I am telling you now.

I left my things behind.

I walked outside, and I started running.

Then I began exploring.

Then I loved every kind soul I met.

I FOUND my tribe.

I FOUND my friends.

I FOUND my family.

## And I found you.

*Stiano Quadracci is a 16-year old autistic student and poet.*

"I wrote *Nothing to Me* so that the reader could realize (either spiritually, intellectually, etc.) that doing things and experiencing life is what's important and what creates happiness. In Western culture, lots of value is placed on owning things and being wealthy. Owning things and possessions is not happiness, and it just causes suffering."





# THE Culture Shock *of* Autism

BY KIRSTEN LINDSMITH

I am an autistic woman. I've also been working in the autism community for over seven years now. I've worked with people from every corner of the spectrum, and I've seen autism from many angles. Despite the unfortunate and often explosive philosophical divide between autistic advocates of neurodiversity and nonautistic pro-cure caregivers, I've noticed an attitude that unites nearly all of us in the autism world: the disabling aspects of autism are directly tied to culture and expectations.

Sometimes I find that parents will react to this idea defensively, saying that this only applies to the "high functioning" among us. But for every parent who reacts with despair, I meet another who muses that potty training her nearly adult son with sensory and motor issues would be much easier if the family had a Japanese squat toilet.

Personally, I believe that many of the disabling aspects of autism are related to context.

For example, a hallmark of the autism spectrum is impaired social communication, yet many of these social difficulties don't cause the same problems when autistic people are socializing with each other. Things like autistic conversation style, topic choice, and nonverbal communication can seem strange and even alienating to nonautistics but feel perfectly fine to other autistic people.

This is because the natural result of autistic traits creating a distinct style of communication is a uniquely autistic culture.

I first heard the analogy for culture as applied to autism from Dr. Stephen M. Shore. He said the reason he feels he and his wife understood each other so well when they first met is that they both knew what it felt like to be cultural outsiders—he being on the autism spectrum, and her having just immigrated from China.

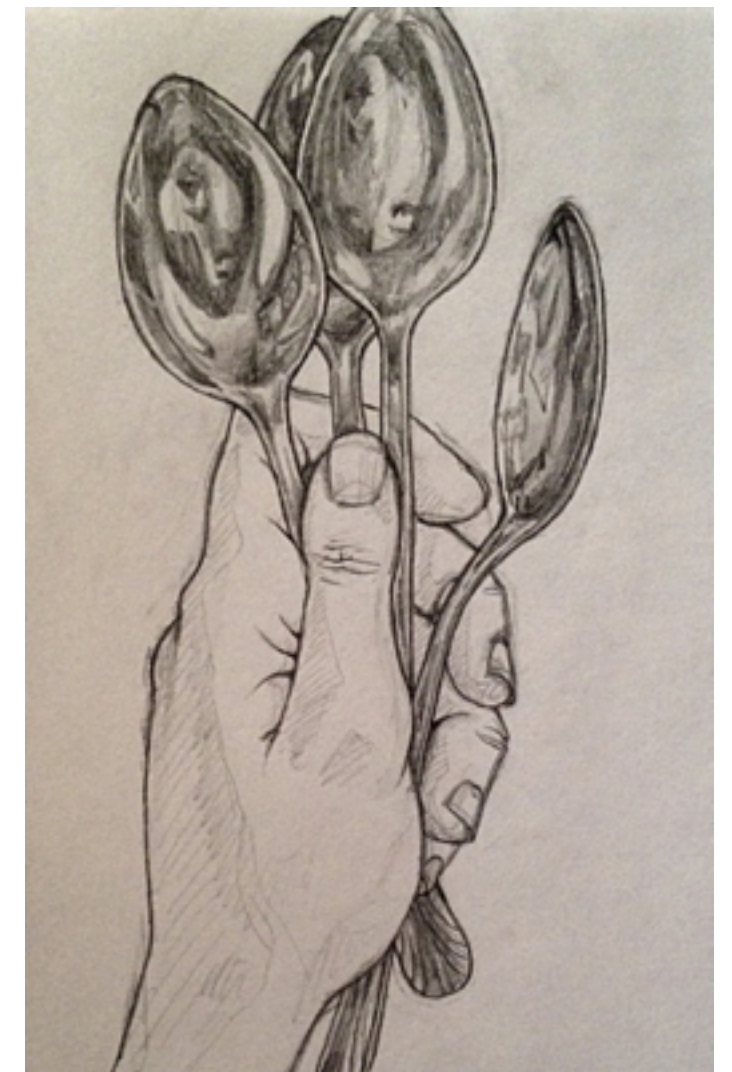
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*Photos of Kirsten's drawings throughout this article have been provided and shared with permission by Kirsten Lindsmith. For more of her artwork visit her website.*

Autistic people often talk about feeling like they were born on the "wrong planet." Not only do we have the unifying experience of feeling like cultural outsiders, but we intuitively follow our own cultural rules.

Of course, there are infinite reasons why social communication is difficult for autistic people (motor processing issues, for example). Also, in certain ways, connecting and maintaining relationships with fellow autistics can be even harder, and reaching out to others at all is a complex topic in and of itself. But there's a reason why autistic people actively seek to create "safe spaces"—like ANI's Autreat—where we can be our own autistic selves, comfortably blending with an autistic majority.

Once upon a time, when I was dating a nonautistic man, I remember he had a lot of trouble feeling comfortable hanging out with me and my mother. The first time he met her, he said to







me as we left, “That was so stressful. Why were you arguing? It sounded like you were agreeing!” Surprised, I dug deeper and realized that he was thrown off by our natural autistic conversation style. My mother and I had been talking about some scientific topic we both found exciting. Thus, our conversation was essentially what my ex would come to refer to as “shouting facts at each other.” I was having fun, but my ex was as uncomfortable as I was when I struggled to make care-giving small talk with his nonautistic family.

It’s not that my natural conversation style is “disabled,” because it’s perfectly functional with other neurologically diverse people.

To quote the blog Autism Through Cats, “We’re disabled by the way it’s socially acceptable to wear strong perfume that makes us feel ill but it’s not acceptable to cope with stress by rocking.”

The neurodiversity movement defines autism as not only a pervasive developmental disability but also a constellation of traits that describe a particular type of person. In short, autism is a way of being. Some of these traits can be very disabling, some can be gifts, and some can be neutral, just an aspect of human diversity.

I’ve found that the most successful way to improve my social skills is to study autism and allism (nonautism) as though they are two different cultures. Why do autistic people socialize in this unique way? What functions do the hallmarks of nonautistic culture serve?

For example, some key traits of autism that affect social communication are lack of self-awareness, impaired cognitive empathy, weak central coherence, information-centered conversation, sensory-processing differences, perseveration and inertia, social scripting, and trauma-induced social anxiety.

Conversely, some of the key traits that define nonautistic culture are other-centered conversa-

tion, intuitive real-time cognitive empathy, unconscious nonverbal signal processing, indirect speech, and intuitive conformation via social norm abstraction.

I’ve now spent several years studying nonautistic culture through an anthropological lens, and it’s improved my social skills immensely.

For example, many autistic people struggle with small talk, not only participating in it, but understanding it. Nonautistic people, often disabled by their overly strong central coherence,

struggle to break abstraction down into details in order to explain its purpose—“It’s how you get to the more in-depth stuff,” “It’s how you break the ice,” “It’s how you get to know someone.”

It wasn’t until I started studying human culture academically that I learned the purpose behind small talk. The answer was so obvious, I felt a little cheated that nonautistic people had so failed to explain

this to me. But I guess I can’t fault them; they’re products of their neurology as much as I am.

My favorite definition is the one from Desmond Morris’s book *Peoplewatching*. Morris is a



**“ I’ve found that the most successful way to improve my social skills is to study autism and allism (nonautism) as though they are two different cultures.”**





zoologist who focuses on human animals, creating a unique flavor of anthropology. He refers to small talk as the human grooming display, saying it is “like the social grooming processes of monkeys and apes,” serving to “demonstrate vocally our pleasure at the meeting” by “paying compliments, showing concern, and showing pleasure.”

The dreaded, illogical How are you? isn’t just an empty question, even though Morris himself admits the answer doesn’t matter. It’s the asking that matters. Small talk is a social display, communicating what we are about with whomever we’re talking to, and recognizing their unique experience as fellow human beings. When you say “Hi, how are you?” to your cashier at the grocery store, you’re not pretending

that you care about his well-being; you’re showing that you recognize that he exists as an equal to you with his own experience. I’ve found that cashiers treat me much better now that I

say “Good. How are you?” instead of just “good.”

Yet social adaptation should be a two-way street. All too often the burden is placed entirely on autistic people to communicate correctly, to change themselves to suit their nonautis-

tic families, friends, coworkers, and romantic partners. It takes two to communicate, and it takes two to have a communication problem. Accurate, mutually-beneficial communication is always an act of compromise, no matter who’s involved.

“Social adaptation should be a two-way street. All too often the burden is placed entirely on autistic people to communicate correctly, to change themselves to suit their non-autistic families, friends, coworkers, and romantic partners.”

If you are not autistic, it’s your responsibility to communicate your needs to the autistic people in your life. That means telling your husband that him writing a letter to your boss doesn’t help and you just want a back massage or telling him about your day if he forgot to ask instead of thinking that it means he’s not interested. It also means reminding yourself, again and again, that every time you struggle when interacting with autistic people, you’re getting just a small taste of what it’s like for them to interact with the entire world.

Autistic culture isn’t inherently disabled or wrong. It’s just different. What’s really disabling is fighting an uphill battle against a world that doesn’t accept you when being autistic is already hard enough as is.

Autistic people are disabled by the fact that our normal behaviors are seen as rude, crude, or antisocial. Our intentions are misinterpreted, our natural body language is seen as wrong or lacking, our emotions are misread, our sensory needs and pains are dismissed, our conversation structure is viewed as self-absorbed, and our expressions of empathy are read as uncaring.

Even if we don’t always come out and say it, we all know that the autistic minority has to adapt to an alien culture that won’t adapt to us. That’s just the way the world works. When you play the game of social integration, you win or you die.

After all, there’s a reason why the mainstream philosophy is to drill autistic kids with eye contact and handshakes. The physical pain and psychological trauma of autistics is secondary to the minor confusion of nonautistics when those nonautistics are the ones with the power to arrest us, hire us or fire us.

We live amidst a neurotypical majority in a world where everything from clothing to infrastructure is designed without us in mind.

In short, it’s disabling to be autistic in a neurotypical culture. And sometimes the most important thing you can do as a nonautistic ally is to remember that.



Kirsten Lindsmith is a consultant, artist, and autism advocate. She is a member of the board of advisors for the Yale Child Study Center’s Initiative for Girls and Women with Autism Spectrum Disorder and works in collaboration with NYU’s ASD Nest program for NYC public school students on the spectrum. She lives in Brooklyn and maintains a blog where she writes articles about ASD-related topics.





# Lessons from Yoda on Achieving Goals

BY ANDY JACKS

“No! Try not! Do. Or do not. There is no try.”

In Star Wars Episode V: The Empire Strikes Back, Yoda challenged Luke Skywalker to believe he could use the force to mentally pick up his spaceship from the swamp. Luke ‘tried’ but didn’t really think he could do it. So guess what? You got it. He didn’t do it.

Yoda was making a specific and really important point that we all need to remember. If we are just trying, then we are not really envisioning our success and, therefore, won’t achieve it. Even more so, if we don’t convey this attitude to others, then they are likely only ‘trying’ to learn instead of actually learning.

Later in the movie, when Yoda lifts the spaceship on his own, Luke says, “I don’t believe it.” Yoda replies, “That is why you fail.” Wow.

This is where VISION comes into play. SEE your goal in your mind so you KNOW what you are trying to achieve. BELIEVE it can happen. Have the attitude that you WILL DO IT. Not only will it help you focus and accomplish that goal, but also, others will see that attitude in you and follow your lead. Confidence is contagious.

Think about your next goal in front of you. It could be working out more, reading a new book, or helping a child master a new skill in the classroom. If you tell yourself, “I’ll try to get it done,” you are fooling yourself. Do it or don’t do it. Make up your mind. Once you decide, put

everything into that direction. Let it go or make it happen.

Trying is not doing; it’s just pretending.

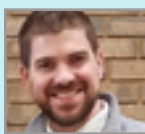
Trying is not committing.

Trying is not believing.


How far are you willing to go to achieve your goals? We should see it in your eyes. You know that look—the look of someone who knows what they are going to do. That look conveys that it doesn’t matter what obstacles present themselves. It doesn’t matter what failures or setbacks occur along the way. This...is...going...to...happen.

**Be confident. Believe in yourself. Do.**

The above is an edited version shared with permission by the author. [CLICK HERE](#) to find the original.



Andy Jacks is the enthusiastic and award-winning principal of Ashland Elementary School in Prince William County Schools. Through his leadership, Ashland has led the use of technology, engaging instruction, and social media, resulting in one of the highest performing schools in the division. Mr. Jacks can often be found celebrating with students or providing motivation by cheering, “Believe in yourself and be you!” In addition, Mr. Jacks serves on the board of directors for the Autism Society of Northern Virginia. He advocates for those with special needs in his school and in the community.

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BY ED ZETLIN & MARK FRIESE



# Elopement

I have a twenty-two-year-old neurotypical daughter and a twenty-year-old son with autism spectrum disorder. As different as they may be in many respects, the one word in common for them that brings me to my knees is elopement. For my daughter, it would make me sad not to be included in her secret marriage, but for my son, it is an earth-shattering fear of him wandering away to an area of danger. Elopement, the act of leaving a safe area and entering one of potential danger, is a great fear for many families. Almost half of kids on the autism spectrum, according to Disability Scoop in 2012, have “wandered away from a safe place.” Disability Scoop’s 2012 research showed that this act of elopement had resulted in more than one hundred deaths.

A new law, known as Kevin and Avonte’s Law, was recently passed to address elopement. Named in honor of two autistic boys who perished after wandering, this law provides funding to the Department of Justice of two million dollars annually, allowing them to issue grants to law enforcement agencies across the country for tracking devices, training and other resources to address wandering. The grants will also fund training for schools and others responding to emergency situations. Technology programs would also be included and made available to families who have members that may wander.

This is a great step to making the world safer for our family members with disabilities. Providing resources, training and support and making tracking devices available will hopefully, hopefully will save more lives. These incidents unfortunately are far too common. This new legislation will provide additional resources to hopefully make them less frequent and save lives.

Other steps families can take to protect their children from the dangers of elopement:

- If your child has elopement issues, make sure people that interact with him/her are aware of this situation. This awareness should include caregivers, teachers and health care workers. It is also important to record this in your Individualized Education Program (IEP) so that people dealing with your child are aware of your child’s tendencies to wander.
- Document the wandering incidents. There may be similar triggers that can be avoided in the future to reduce the chance of wandering.
- Make sure that your child knows where to go for help. This would include security staff, the police department, etc.

- Understanding the protocol of the environment you are in is also important. If it’s a school situation, what are the wandering policies? How would you be notified if your child had a wandering incident? Could providing additional documentation for a doctor or therapist help provide a reasoning for sounder security measures for your child?

...

*Edward Zetlin has a solo practice in the areas of elder & disability law, guardianship/conservatorship, public benefits, estate planning and estate administration. He serves on the Northern Virginia Autism Association Board and is an Adjunct Professor of Law at the Washington College of Law of American University.*

*Mark Friese is the founder of Special Needs Financial Advisors, based in Washington, D.C. With over 100 years of combined experience, they help to navigate the many aspects of planning with special needs family members.*

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Conquer for Conner



THE  
IMPORTANCE  
of  
TALKING  
ABOUT  
SEX



Drawing by Kirsten Lindsmith

*Did the title of this article make you cringe?  
If so, then it is even more important that you  
keep reading.*

When it comes to the subject of sexuality, many people can become quite uncomfortable. While we may not like talking about it, like it or not, all humans are innately sexual beings. It is not a choice or an option – sex is a natural biological drive we all experience, just like thirst, hunger or the need for sleep. While the degree to which one feels or experiences these sexual drives varies, having a diagnosis such as autism doesn’t make the natural urge go away.

Before we go any further, it is important to point out that when we use the terms sex and sexuality, we are referring to so much more than just the actual act of having intercourse. Sexuality encompasses the sexual knowledge, beliefs, attitudes, values, and behaviors of individuals. It deals with anatomy, physiology, and biochemistry of the sexual response system as well as with roles, identity, and personality. Individuals who understand their own bodies, their rights and experiences may find it easier to communicate their needs and have them respected. For this reason, it is vital that every person, regardless of their neurology or disability, be given access to sex education.

Without proper education, we may be setting up our autistic loved ones for a life of victimization. While this may sound overly dramatic, there is now research that backs up this thinking. A 2014 study conducted by York University in Toronto found that autistic individuals were at greater risk for sexual abuse than those that were neurotypical. The study acknowledged that the reason why those on the spectrum had a significantly higher victimization rate was because autistic individuals were more likely to have gained their knowledge of safe sex and appropriate sexual behaviors from television, internet, and pornography as opposed to teach-

OBJECTIVES TO  
SEX EDUCATION  
TALKS

- To provide accurate information
- To foster self-esteem, self-determination and self-protective skills
- To develop healthy attitudes and clarify values
- To teach skills needed to achieve mutually satisfying relationships
- To develop responsible behavior and teach skills for preventing pregnancy and sexually transmitted infections



## RESOURCES ON PUBERTY AND HUMAN DEVELOPMENT

- **Healthy Body Toolkit – FREE** online resource
- **Ready, Set, Grow!: A What’s Happening to My Body? Book for Younger Girls** by Lynda Madaras & Linda Davick
- **The Care and Keeping of You: The Body Book for Younger Girls** by Valorie Schaefer
- **On Your Mark, Get Set, Grow!: A “What’s Happening to My Body?” Book for Younger Boys** by Lynda Madaras
- **The Boy’s Body Book (Third Edition): Everything You Need to Know for Growing Up YOU** by Kelli Dunham

ers, parents or friends. The lack of quality sex education leaves many open to misinformation and possible abuse.

So now you understand why it is important to keep talking openly and honestly about sex, but perhaps you are not sure what you should be talking about. There is so much information out there, and we have integrated many of these wonderful resources (including ones specifically for adult autistics to access on their own) in the sidebars throughout this article. We have also incorporated several personal insights from autistic individuals throughout this piece to offer different perspectives. Lastly, we offer below a few key points for family members or educators to consider before having the ‘SEX TALK’ with a loved one.

### DO NOT TAKE HAVING SEX LIGHTLY

*Sex is a very serious issue, especially for individuals with autism. Lust is very different from love. You must recognize the difference between the two. Lust is based solely on physical attraction. Love develops over time, often from a friendship. Many things must be considered prior to having sex with someone. Unwanted pregnancy, STD’s, HIV/AIDS, Hepatitis. How well do you really know this person to risk all of those things? Do NOT take this lightly. NEVER be forced into having sex. Don’t get into a dangerous situation by going somewhere with a stranger or casual acquaintance. Trust your gut instincts.*

– Anita Lesko, autistic self-advocate, public speaker, author and certified Nurse Anesthetist

### BEFORE YOU BEGIN

It is imperative that you think ahead and be proactive about sex education. Thinking about what you are going to say will also keep you more calm and allow you to be supportive. Gather multiple instructional mediums in advance so that if one thing is not working, you can try another. Be ready to break larger areas of information into smaller, more manageable blocks. Be concrete; use facts and figures. A lot of individuals on the spectrum can relate better to facts than the usage of euphemisms and non-concrete ideas. (In other words, no using phrases such as “the birds and the bees.”) Be ASK-able and open so that the autistic individual feels comfortable coming to you with questions instead of going to another source that may not be as reliable. And if you don’t know the answer to a question or need a bit of more time to figure out how you should reply ... just let your loved one know that. The more honest and direct you are, the more willing they may be to come to you.

### NOT READY FOR A RELATIONSHIP YET

*My parents have always been very open and honest about sex. I feel comfortable going to them with just about any question, much to mother’s chagrin I’m sure. While I feel I am intellectually prepared for a girlfriend and a relationship, emotionally, however... Heck No. I’ll Wait! – Jacob F., Autistic Student, 16-years old*

### TEACHING SELF-DETERMINATION IS A MUST

No means no, or does it? Many times, without even realizing we are doing it, we send mixed

## RESOURCES FOR AUTISTIC ADULTS

*The following resources are written by autistic adults, contain adult-themed subject matter and are shared here to empower other autistic individuals and the adults who support them. Any views or opinions found in these resources are solely those of the authors and do not necessarily represent those of ZOOM.*

- **Relationships and Sexuality**  
A free downloadable handbook produced by Autism NOW, a national initiative of The Arc, and the Autistic Self Advocacy Network.
- **Sex, Sexuality and the Autism Spectrum by Wendy Lawson**  
A resource that gives a sensitive, honest, respectful treatment of sex and sexuality for autistic people written by an openly gay autistic adult.
- **Decoding Dating: A Guide to the Unwritten Social Rules of Dating for Men with Asperger Syndrome (Autism Spectrum Disorder) by John Miller**  
A short book written from the view of someone with autism with lots of practical advice.
- **The Aspie Girl’s Guide to Being Safe with Men: The Unwritten Safety Rules No-one is Telling You (1st Edition) by Debi Brown**  
This straightforward and honest book is written by an autistic woman who bravely shares her own first-hand experiences to keep all women, not just those on the spectrum, safe.



## RESOURCES ON SEXUAL ORIENTATION AND IDENTITY

- **Trans Bodies, Trans Selves: A Resource for the Transgender Community**, edited by **Laura Erickson-Schroth, MD, MA**
- **Mermaids**  
(Website for family and individual support for teenagers and children with gender identity issues.)

### WHEN IT COMES TO SEX, TAKE THINGS SLOWLY

*The important thing about sex is you need to be comfortable with your partner and communicating your needs, including “I don’t want it right now.” I recommend taking things slowly – in steps. You must be acclimated to discussing anatomy and sexual terminology with your partner, then slowly figure out what kind of touching feels good and what touches to avoid, then gradually get comfortable being together in various stages of undress. It is a good idea to figure out how to apply a condom ahead of time by practicing putting one on a banana! The main goal of sex is that it should always be a fun and relaxing experience for you and your partner.*

– Katherine Hall, autistic self-advocate

messages to our autistic and disabled loved ones by insisting they comply. Dave Hingsburger offers a wonderful explanation of this in his article “The Ring of Safety: Teaching People with Disabilities to Be Their Own First-Line of Defense.”

“Imagine for a second that it is chore night for Denis at the group home. The staff approaches and asks him if he wants to do the dishes, and Denis says, ‘No.’ If you believe that the staff should first pester and then force Denis to do the dishes, then you also believe that ‘no doesn’t mean no.’

The problem is that staff and parents often don’t discriminate linguistically between choice and demand. In the scenario above, the issue is not the chores, the issue is not the fact that Denis needs to pull his weight in the group home, the issue is not “testing,” nor is it a power struggle.

This issue is that the staff asked Denis if he wanted to do the dishes. Denis thought that this was a question and that, therefore, he had a choice. His choice was clearly no. In teaching to non-comply, the staff must learn to distinguish questions from demands. In this way, the individual learns to assert her/himself in areas where there is a choice.”

The ability to say NO is a step towards self-determination and self-advocacy. It is also the first line of defense against a possible abuser. It sends the message that you understand the rules and that if the other person breaks them, they will be in trouble.

### TALKING ABOUT GENDER IDENTITY AND SEXUAL ORIENTATION

Although our society teaches us that there are only two genders—male and female—there are really many genders. Just as many of our loved ones are considered to be out-of-the-box thinkers, some may not be able to fit neatly into one specific male or female category. If we want

our autistic loved ones to have a healthy, positive sense of themselves, your sex education talks need to be fully inclusive and respectful to sexual orientation and gender identity. Conversations should normalize possible attraction to both genders and empower individuals to adopt the sexual identity that best fits their self-concept.

### TALK OPENLY BEFORE CONSIDERING HAVING A RELATIONSHIP

*Put discomfort and preconceptions aside, and openly answer questions and talk about concepts like desire, feelings, consent, self-advocacy, contraceptives and speaking up for oneself. In my book, I discuss the importance of whether a person is ready for a relationship. I’m of the mind that most people with autism are not ready for a relationship until adulthood. They need to think of what is entailed in a relationship.*

– John Miller, autistic self-advocate, special education teacher, public speaker and author of the book *Decoding Dating*.

### SOMETHING TO REMEMBER

It is important to remember that every person is different, so you may have to keep trying different sex education approaches at different times. We encourage you to start early and keep the conversations going, even if you think that the message is not being received. IT IS! Every person has her own timeline and way to process information. You know how this may be an uncomfortable conversation for you ... chances are that it is just as uncomfortable for your autistic loved one.

...



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# BUY 'ER SOME DONUTS OR SOMETHIN'

RETOUCH BY DAVID FINCH

David Finch is a humorist, inspirational speaker and author of the acclaimed New York Times best-selling memoir, *The Journal of Best Practices*. David's essays have been published in the New York Times, Huffington Post, and Slate, and he contributes to Psychology Today. To book David for your next event or to contact him in person, please visit his website.

I was standing in the humble lobby of Temple Grandin School — a private school for children with autism spectrum conditions, located in Boulder — holding two large boxes, each filled with a dozen assorted donuts. I hadn't been asked to come for a visit; this was just an awkward self-invitation sweetened with glazed icing and chocolate long-johns. I wasn't a guest so much as a geek bearing gifts.

Apropos of the circumstances, I was greeted by a behavior analyst whom I'd met on previous visits. She seemed surprised to see me and delighted to see my donuts. Without inquiring about the occasion, she invited me to set them down in the kitchen. "I'll round 'em up," she said.

In little groups the students paraded in, prowling for the donuts and voicing their selections with no less authority than a Manhattan business executive ordering her coffee. That's what I love about young people: when informed that a visitor has brought donuts for all, their sole concern is not "Why?" or "Who?" or "May we have one?" but rather, "What kind did he bring?" — which is arguably the only pertinent question one could have about donuts. This is especially true for most of the students at Temple Grandin School, whose minds naturally value the assertion of parameters. Like me, they don't simply want a donut; they want one specific type of doughnut — offer them anything else, and you're only wasting their time.

Being the adult, I pretended to wait patiently while the variety of donuts diminished. With only a couple marble glazed remaining, I was squar-

ing my shoulders and preparing to lunge into the scrum when a teacher wrapped her arm around me and escorted me to her classroom. "There's someone I want you to meet," she said, motioning for a young man to follow. I didn't catch his name, but I swear it sounded like ham. In the throes of donut anxiety, it's hard to make sense of anything.

"Hey," I called back to the kitchen, "save me a marble glazed!"

Halfway through his teen years, it seemed Ham had been involved in many soured romances that at first had seemed promising but which had left him feeling heartbroken and perplexed. Ham, nevertheless, carried himself with a cavalier determination to find a girlfriend. Apparently, having written a book about relationships, I was now being mistaken for someone who might be able to help.

"Tell me what you mean by 'get a girlfriend,'" I said, keeping one eye on the single marble glazed remaining.

This seemed a ridiculous question to Ham, who repeated himself slowly and loudly, as though he were addressing a disoriented foreigner: "I want...to get...a girlfriend. Girls...don't want...to be...my girlfriend."

Oh, Ham, I thought. How to tell him that virtually no girl wants to be anyone's girlfriend?

It wasn't Ham's appearance or personality that was getting in his way but rather his logic: having a girlfriend seems fun, so I need to find one to call my own.

"Are there any girls you currently enjoy spend-

ing time with?" I asked.

"No."

"Are there any girls you wish you could be getting to know? Maybe someone who's pretty or cool, but just out of reach?"

"No," he said. "Not really."

"But that 'having a girlfriend' thing, though. Am I right?"

"Yeah."

I knew exactly where he was coming from. When I was Ham's age, a girlfriend was what I desired more than anything. It practically didn't matter who as long as she was attractive. I didn't have much in the way of personality requirements either, so shallow were my intentions. Now approaching forty, and understanding the complications of relationships, my pursuits are considerably less ambitious: give me a donut, marble glazed, and a quiet room to eat it in.

There's only so much advice you can give a person named Ham, so I spoke in the most generalized terms possible: Girlfriends are not a commodity; girlfriends are a privilege. They can be earned, they can be forged, but they cannot be acquired — at least, not from the catalogs I read.

The advice sank in quickly, which is something else I love about my fellow people of the spectrum — they tend to be knowledge sponges. Still, Ham was stuck on a particular stumbling block: how does one go about getting a girlfriend?

"Simple," I said, eyeing the worsening donut

situation. "Stop trying. Instead, focus on meeting interesting people. When you find one, be available to his or her friendship — that's all. If the friendship evolves and she's a girl, well, then you've got a shot."

Some kids were now approaching the kitchen in search of seconds. Unacceptable! I thought as my anxiety reached fever pitch.

"Just gotta be yourself," I added in a rush.

"But what do I do then?" asked Ham.

"No one really knows, man," I said bee-lining for the kitchen. "Buy 'er some donuts or something! Good luck!"

I drove back to my hotel still cursing the kid who'd snatched up the last marble glazed. That's easily one of the things I like least about young people: they hog all my donuts, even though their lives are carefree and awesome. I called my wife Kristen to see if I could find some sympathy, but she was in meetings and wouldn't be able to chat for a few more hours. "Okay," I said as she hung up. "I'll wait." There were other people I could have called, I suppose, but none would have pretended to care as much as she would have.

On the passenger seat, my donut boxes rattled and slid around, one empty, the other occupied by the four doughnuts that nobody ever eats: two cake, one powdered, and one mushed-in custard nonsense. I could have settled for any one of these, but eating a donut wasn't the point. I knew which donut I wanted more than anything, whether it was available to me or not.





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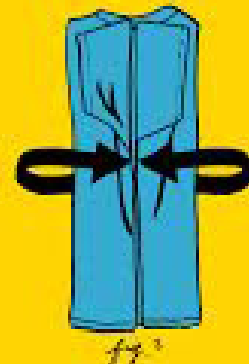
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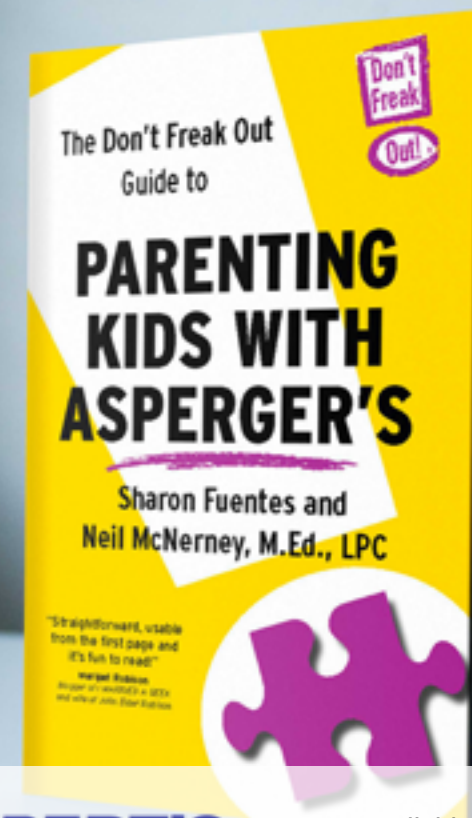
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## CUMMINGS AND GOINGS

**S**o many important topics in this issue. So many significant meetings Conner and I are fortunate to attend. Many conferences Conner and I speak at, not because we are experts by any means, but because hopefully we give the audience some food for thought so to speak. Conner says that his all-time favorite thing to do (besides Disney, of course) is to read his written words, to speak in front of the state house and senate. He especially loves to speak at our nation's capital. We had the honor of speaking in February at the Autism Society of America's Day on the Hill. We were able to speak with amazing advocates from all around the United States. There are so many critical topics to advocate for, and as long as Conner wants to speak his written words, we will continue to advocate as he states "Conner's style-Conner's way."

Two important topics in this magazine for us personally are driving and sex/relationships. These two subjects are areas that we are relating to right now in our lives, and we are



looking forward to learning together with you. Conner has created his own 'Circle of Support.' This was a topic at an ARC of Northern VA meeting. It resonated with us. Conner wrote his own list of people he can trust that, at this time in his life, he wants involved in some form of his life. People he can reach out to when he has questions or needs advice. People he feels he can count on. A few people I felt he did not have a close relationship with, and we discussed. He felt otherwise, so they remain. One person on the list has a mutual love for Disney, one he said taught him to laugh, one has taught him more than just school books, one really listens to him, encouraging him to speak whichever way he wants. One is his mom's best friend, and he said that "he could call her and there is nothing she cannot or will not do." Those are just a few of the reasons why he made his choices. The number of people in your support group is up to you, and it can change at any time. It can be family,

*Conner learned to drive our mule on West Virginia trails. He loves to drive through creeks and up mountains, enjoying nature along the way.*



*Conner's Political Circle of Support group coming together from across the U.S. to advocate on behalf of the Autism Societies "Day on the Hill"*

friends, teachers, counselor's ... anyone who has touched your lives. He will be reaching out to this list of people to discuss. Each person has a specific purpose for why they are on the list. He has said that, after we speak to these people, he may make a few changes to the list. He stated, "perhaps they are not ready to be on the list yet." Conner says that he trusts these people because of 'his feel.' He looks through their eyes when they speak, and, as he says, "eyes do not lie; words do." This circle of support list will grow as he grows and change as he changes

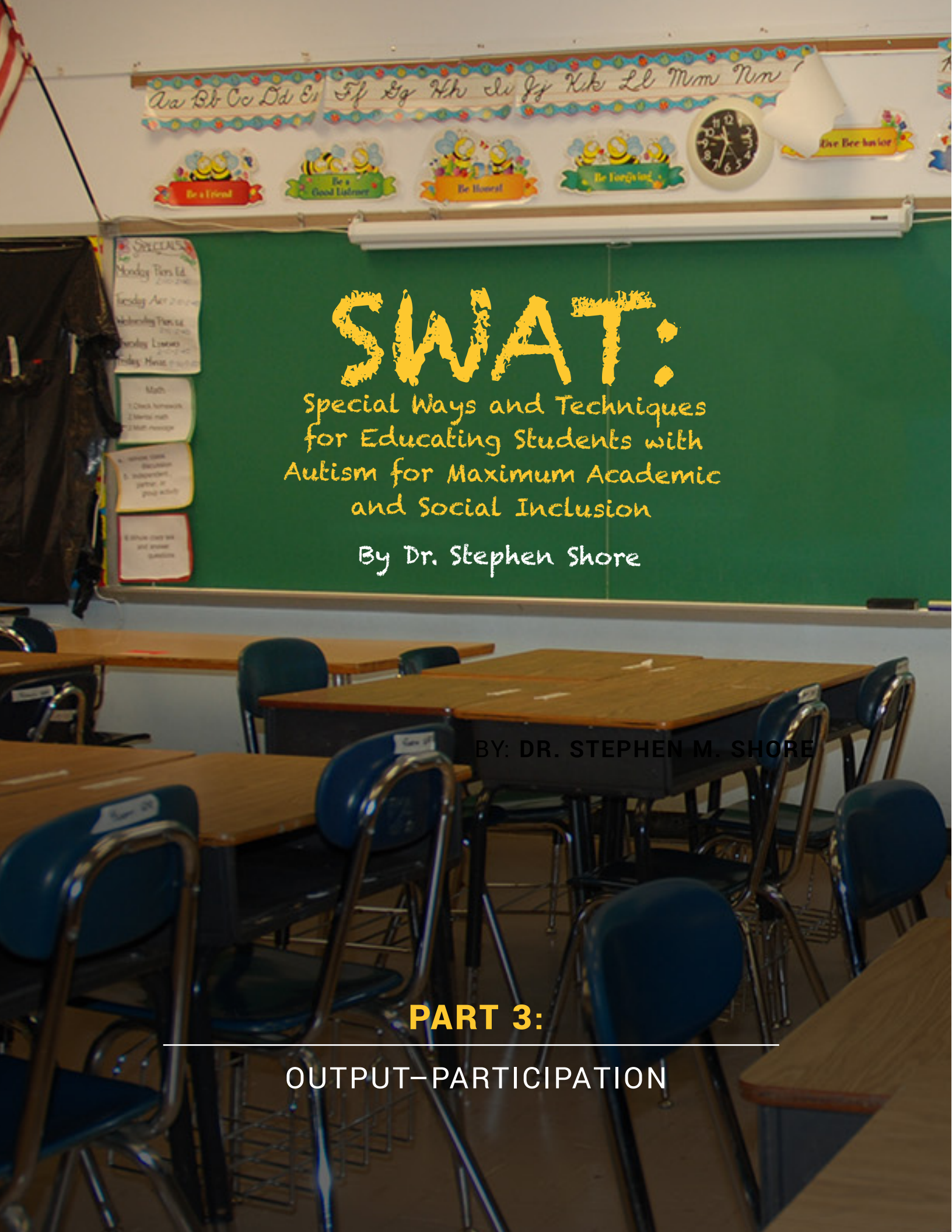
– or maybe not! Feel free to reach out to us if you have any questions and are thinking about possibly starting your own Circle of Support!

Warmest regards,

*Sharon*

Sharon Cummings  
Executive Director/Co-Publisher & Founder  
ZoomAutism@gmail.com





# SWAT:

Special Ways and Techniques  
for Educating Students with  
Autism for Maximum Academic  
and Social Inclusion

By Dr. Stephen Shore

BY: DR. STEPHEN M. SHORE

## PART 3: OUTPUT-PARTICIPATION

**H**ow is it that my student, who has such a hard time with writing assignments, manages to excel in class participation and discussion? While I understand the need, and can often successfully develop accommodations for students who are at grade level, how can I meaningfully include those individuals who are just unable to perform at the same level as everyone else? The past two articles in this series discussed the first 5 of 9 curriculum domains. We looked at Size or Quantity of information that students are expected to process and addressed the challenges of Time, whether providing additional amounts or focusing on Management of time. We also examined strategies for providing Levels of Support, Input of information, and adjusting levels of Difficulty based on the abilities of students with special needs.

Part 3 of this series examines strategies for providing needed Output and different techniques for helping students engage in meaningful Participation in class even if they are unable to complete the same tasks or activities as everyone else.

### 9 DOMAINS OF CURRICULUM MODIFICATIONS AND DELIVERY



From Cole, Horvath, Deschenes, Ebeling, and Sprague, 2000

**Output:** Providing alternate ways for students to demonstrate mastery of material.

The flip side of input, the ways subject or skill mastery can be demonstrated, is only limited to the imagination of both the instructor and student combined. For example, responses can be typed, spoken, pointed at using an assistive communication device or even received through drawing mind maps. The following is a helpful example of modifying output and how one student, Abraham, advocated for this accommodation.

**Assignment:** Make an annotated list of the components of the electronic music lab, including their functions, and how they are connected. Abraham waited until the other students left and then directly disclosed having ADHD, something that greatly slows his writing and makes his penmanship all but illegible. He then

stated his resignation to accept a failing grade due to those challenges... or... could he draw a map of the electronic music studio depicting the same information?

I could have taken the stance that, as a junior in high school, Abraham should be writing simple paragraphs and, therefore, should drop the course in favor of taking a developmental writing class before returning next year as a senior with improved writing skills. However, something told me to let him draw a map of the studio as he suggested he clearly understood and could work his way around the equipment with greater facility than the other students and, in some ways, better than I. Abraham's map clearly demonstrated that he had mastered the electronic music lab.

Clarity of assessment goal(s) is vital. If measuring content knowledge is the objective, the instructor must remove undue barriers to success; otherwise, the student having greatest



subject and skill mastery potentially receives the lowest (read invalid) grade in the class. On the other hand, if I wanted to evaluate Abraham’s writing, it would be incumbent upon me to remove the physical barrier of writing by allowing him to use a scribe, speech-to-text software, answer verbally, or another means of response.

**Participation:** Requires making needed modifications to keep the student meaningfully involved – possibly through a complementary activity.

As mentioned in part 2, there may be times when modifications to coursework or activities do not allow the students to participate in the same way as everyone else. However, the student can remain meaningfully involved by engaging in a complementary activity.

For example, suppose a nonspeaking yet very vocal student is included in a chorus class. In other words, the student may vocalize, but meaning has yet to be derived from these sounds.

(Please note that the term “nonspeaking” is used where many would classify the student as nonverbal. That is because verbal communication involves more than just speaking. For example, there are many people on the autism spectrum who are unable to speak, yet provided with assistive communication devices, the nonspeaking individual often communicates as well as or even better than her peers. Perhaps “nonverbal” should be reserved for when a reliable means of communication with the person on the autism spectrum has yet to be discovered.)

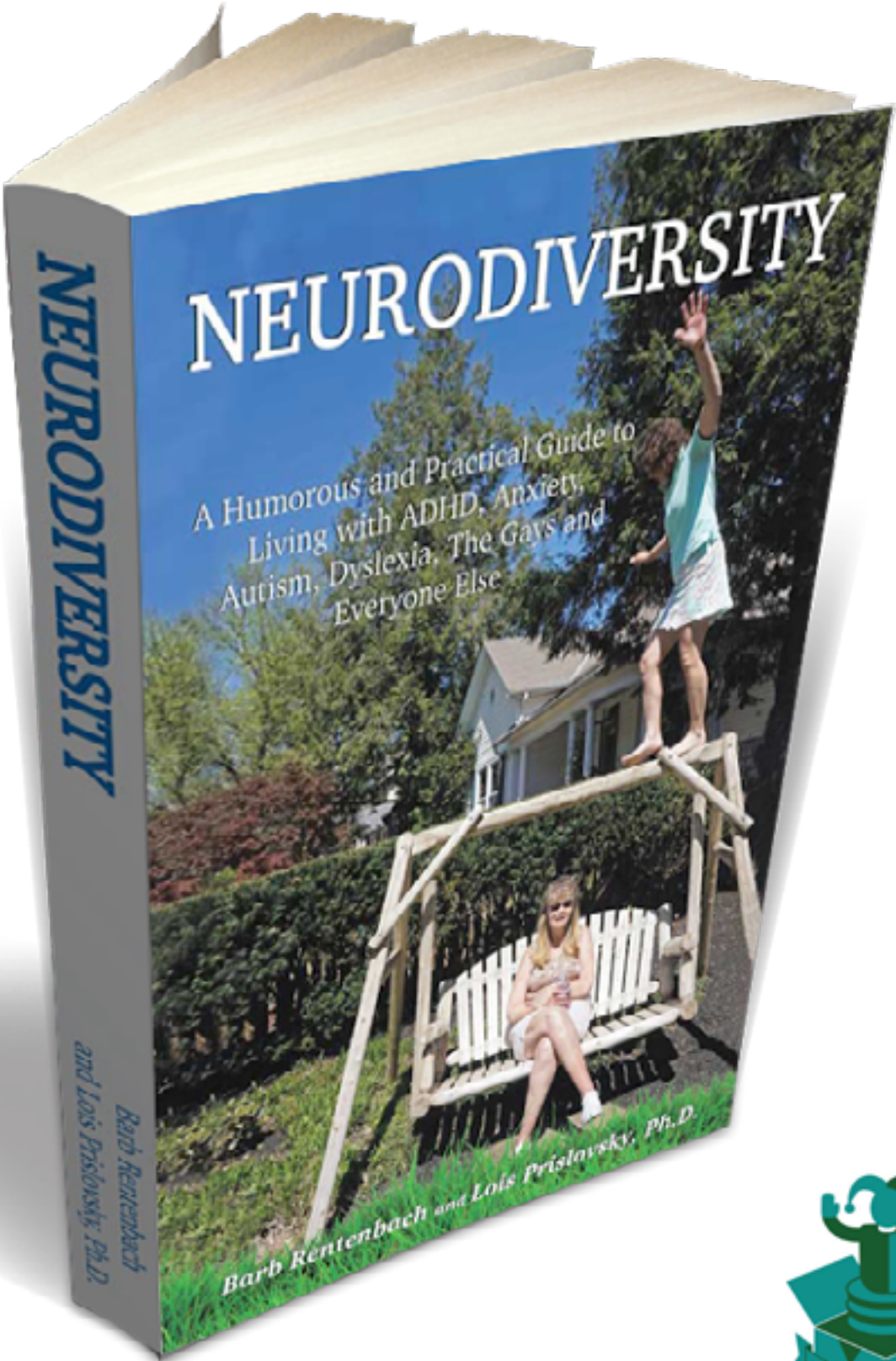
Often this student needs to walk about the rehearsal space. She does not try to elope or escape, but rather, she paces the perimeter of the room. When moving in this fashion, the student is mostly silent. These frequent,

somewhat random vocalizations make meaningful inclusion challenging as this student has difficulty standing in place, maintaining pitch, rhythm, and other aspects of singing in a choir. Perhaps there are body to environmental issues related to sensory processing or other reasons that can be interesting to ponder.

However, reframing the situation away from what the student can’t do to focusing on what the student can accomplish will be helpful. Since this individual needs to pace, finding ways to engage that behavior may be fruitful. Some possibilities employing the need to move may include keeping tempo on a percussion instrument or improvisational movement to the music where the student may have an unexpected skill. Another idea might be to have the student march about the auditorium carrying a flag relevant to the music. Finding other students to volunteer to engage in these activities as well will keep the individuals with special needs from being isolated.

In this way, the student’s need to move, the challenges of singing in a group, and the need for meaningful participation are addressed in such a way that there is mutual benefit for the individual with special needs, the other students, and even the audience during performance!

We have looked at 2 more out of the 9 domains of curriculum modifications where adaptation of output successfully allowed a student to demonstrate his level of mastery in the electronic music studio. For those students, unable to perform at the same level as their classmates, we examined how what might have been considered a disruptive or challenging behavior of vocalization and movement can be reframed into a strategy for meaningful involvement in a choral performance benefitting all involved. The next article in the series will examine the remaining two domains of curriculum modification – alternative activity and substitute curriculum.





# “What skill/goal do you want to accomplish that you have not yet met?”

“I want everyone to know that they should celebrate what you set as your goals but remember that we all have the exact same value as human beings. When you say that the reason why you deserve to be respected, the reason why you fight ableism is because you have proven your “intelligence,” because you have a degree, because you work and pay taxes, you are not fighting ableism, you are being ableist. Those are accomplishments as defined by the worst of capitalism, controlled by non-disabled people. It is defining WORTH through perceived productivity. Some of us will never be able to “accomplish” any of those goals.” - **Amy Sequenzia**

“I want a full-time job. I have two part-time jobs, but I want a full-time job doing something with numbers that I am good at.” - **KF**

“I want to be able to be in a crowded room, like a party or event, and talk to people. I am working on social conversation, and I want to live it.” - **MB**

“I am a performer. I play the guitar, and I sing. I also play the drums. I want to be able to write my own music. Lyrics can be harder for me.” - **JH**

“World Domination! Just Joking. What I really want is to be Governor one day. I plan on graduating high school and then going on to university where I will study Political Science and then obtain a law degree. These are some hefty goals, but I know I can do it.” - **JF**

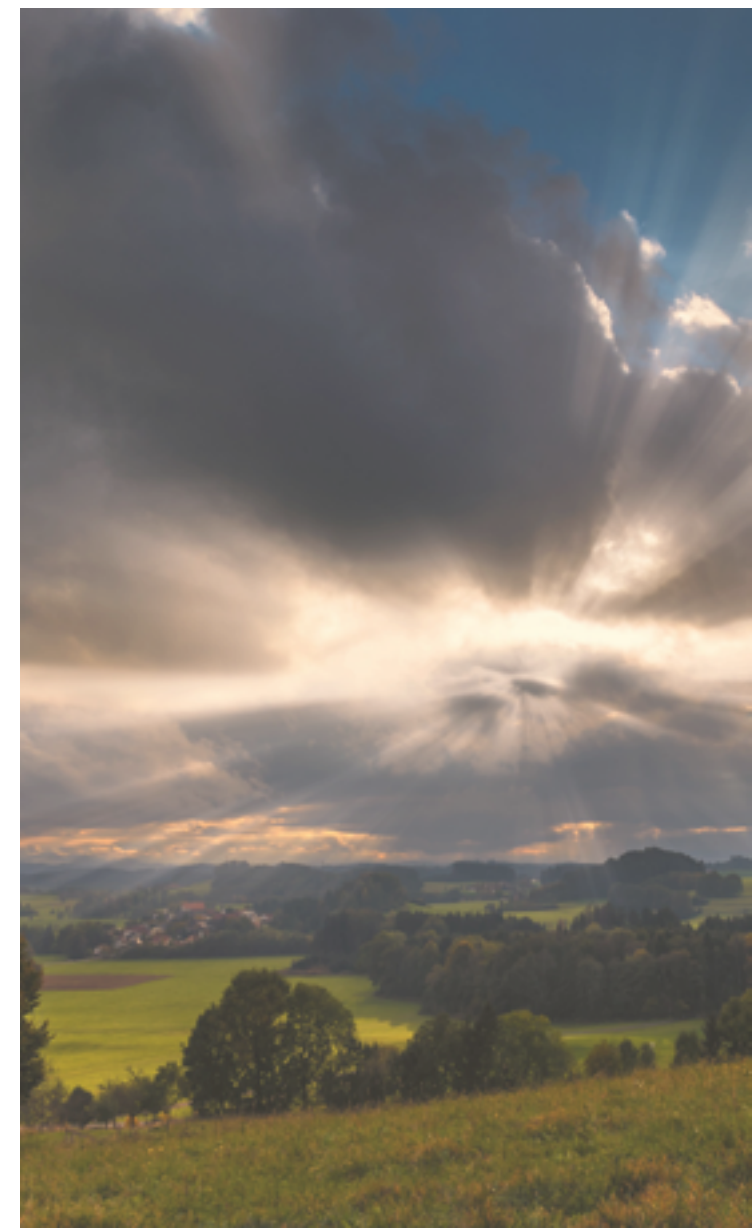
“I want a job. I apply at local places. I am qualified, but I am not hired.” - **SM**

“Public speaking for me is very difficult. I can speak in small groups, but large groups really intimidate me. I get tongue-tied, and I feel my cheeks turn red. I would love to overcome that.” - **HO**

“I want to write a book. I want to write about my life and help other families.” - **LW**

“I want to be a lawyer. I am in college. I have a way to go, but I will be an attorney and a good one.” - **TA**

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# Believing EVERY Step of the Way

BY MARYANN GIVEN

**B**efore my son Tommy's diagnosis of Autism, I cheered him on as he walked at 8 months old and eagerly explored his world, saying things like "He sure is independent! No one tells him what to do!" I saw his strengths and admired all the traits that would soon be viewed as part of a disability where having one's own agenda is a negative.

The word Autism temporarily cast a shadow over my joy, causing me to question his future and turn to others for answers. Suddenly, Tommy's boundless energy, curiosity, and tireless exploration were considered disadvantages when he was unable to conform to the demands of classrooms or rules of society. But when I viewed Tommy with my heart, I saw so much more. I saw an athlete in the making who could

impressively climb fearlessly to great heights and walk or run incredible distances without fatigue.

Tommy's obsession with Disney videos was also not honored by many. People would advise me to turn them off; instead, I bought him more. I saw how much they meant to him, and I chose to follow his lead.

Tommy's big brother Paul also showed us who he was at a very young age, intensely interested in animals of all kinds, determined to save the planet. We encouraged his passions, providing every opportunity to allow him to become who he was meant to be. We treated Tommy in this same way. We provided every opportunity for Tommy to pursue his interests, to use his gifts for his own agenda. Like his natural ability to run.

Tommy has always been a runner. He used to run away, but now he runs in races! When he was 14, he seemed ready to try running daily, as a sport. My husband and I felt like it was time to help him turn something he was compelled to do into something positive, so we helped him start a daily jogging routine. Tommy worked hard, day by day, and progressed steadily. There were many challenges and setbacks, but I believed each step of the way that anything was possible, and I saw the positive changes the sport brought Tommy with each new success. Ten years and many races later, Tommy has become a very elite runner. His impressive marathon and half marathon times have earned

him the title Road Racer of the Year in Ottawa for the past three years. He is a T20 Para-athlete who began international competitions in 2016 and just returned from a three-week stay at the Olympic Training Center in Chula Vista, California. World Championships 2017 and Paralympics 2020 are real goals! I burst with pride, yet fear all the challenges ahead. And still I follow his lead as he shows me what is possible for him.

Tommy's life is unfolding in its own way—unique and always true to his interests. I believed he would always show us what he needs, and he has—just like his brother, who is now a biologist researching birds. Both Tommy and Paul have shown us who they are, bit by bit, and have taken us on an adventure, discovering who they are.

Tommy sometimes calls me "Lucky Mommy." I sure am lucky. I have the honor of parenting two unique young men who work hard and

make the most of every opportunity provided to them.

I don't know what lies ahead for Tommy. I can't plan his life for him based on what I think is best or any preconceived notion. I am merely witness to his path unfolding, fostering opportunities, supporting his choices and success. I may indeed cheer for him at the Paralympics one day. Yet I may not. Only he can show me what is meant for him. He may not follow the agenda of a typical person, but he will always follow his own agenda with me as his biggest cheerleader. There will be disappointing moments—there have been many already. But my son Paul has and will also experience disappointments. I feel blessed to understand that the challenges both of my sons experience are inherent to being human and even more blessed embracing the unique path each of them has blazed for themselves as they find their way.

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# Creating Bonds of Friendship

BY SCOTT KRAMER

I received an initial autism diagnosis in 2007 and an official documented diagnosis in 2010. Afterwards, I went to various nonprofits in the Greater Chattanooga, TN area, asking each if a support group for autistic adults existed. The general response was “We don’t have anything like that here. Good luck to you.” I became tired of these responses. I reasoned that other individuals were on the autism spectrum besides me, and I wanted to socialize with these like-minded individuals. I chose to do something about it. On December 31, 2010, I founded Greater Chattanooga Aspies (GCA).

I did not have a mentor, so everything for the first couple of years was by “trial and error.” I

came close to closing GCA a couple of times; however, I did not. If I had, I may have never seen GCA become what it is today or see what it can become in the future.

In the fall of 2015 during the North Georgia Autism Conference, an adults breakout session occurred where many parents, adults, and other interested individuals wanted to know if I could replicate the success I had with the Chattanooga support groups in North Georgia. I replied, “Why not?” Suddenly, I had support groups in two different locations in two different states (Tennessee and Georgia).

In Spring 2016, my wife, April, and I gave a talk on “Intentional Relationships” at the Chattanooga Autism Center Conference for a standing room only audience. At the end of the presentation, parents wanted to know when we would be giving workshops. It was then that April and I realized we were on to something.

Shortly after the conference ended, I sensed that GCA was becoming too big. I needed something that would allow people access to information quickly. Thus, I started the GCA website and GCA Newsletter. An executive director of a local nonprofit became my personal mentor. He suggested that GCA needed to change its name to reflect that my program was a resource center of information to the Greater Chattanooga and North Georgia autism communities. So, Greater

Chattanooga Aspies became the GCA Centre for Adult Autism.

Toward the end of 2016, the Autism Society of Georgia (ASG) approached me about joining its Board of Directors and chairing its Adult Advisory Board. After going through the vetting process and asking many, many questions, I was more than satisfied with the direction ASG wanted to go in regard to adult autism. I joined the Board of Directors and the Adult Advisory Board. Also, I joined the board with the Virginia Tech Center for Autism Research (VTCAR). VTCAR’s director and I realized that Southwest Virginia and North Georgia were similar, so we have been discussing how GCA’s model can be used in that area of the country as well.

As a Georgia resident, I advocate for myself and for others in Greater Chattanooga and the North Georgia autism community. Last year, I began advocating for myself and others in a political environment as well. I had never done that previously and avoided politics in all possible ways. One evening in early 2016, April and I were having a conversation. She mentioned how politics affects everyone, so I went to the Georgia State Capitol in 2016 and began talking with legislators. I was scared...very scared. I thought talking with these individuals at any level was next to impossible. Communication challenges are common for adults on the autism spectrum. I was no less different. In speaking to these legislators, I realized that they are human beings like you and me. They have feelings and emotions. They are real. I went to Autism Awareness Advocacy Day last year and this year and attended Employment Advocacy Day this year. My state senator now sees me as his “autism go-to person” because I developed a relationship with him as his constituent. Plus, I did not allow my communication challenges to interfere with what I wanted to accomplish.

Lastly, after an extensive search on “adult autism conferences,” I realized that the only ones that existed were in the San Francisco Bay area and in London. Nowhere else. I founded the Inaugural Tri State Adult Autism Symposium

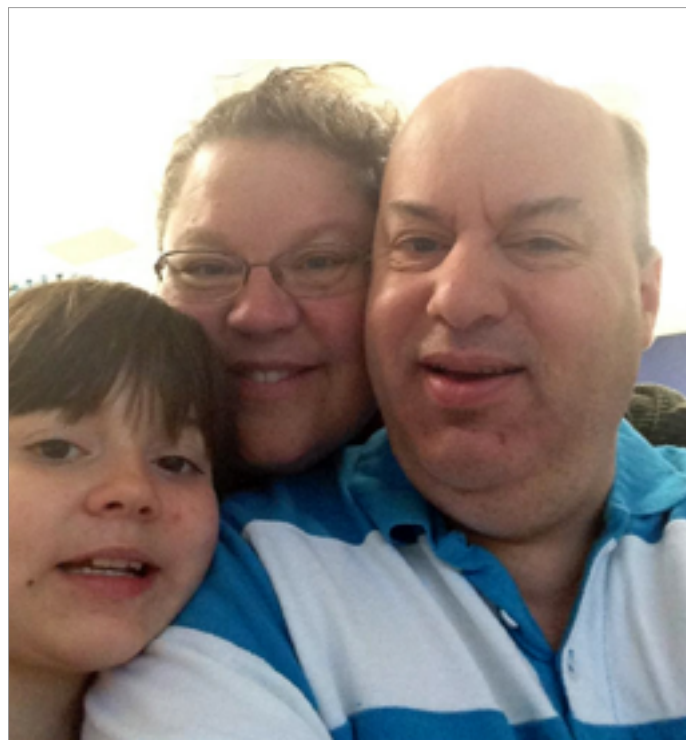


Conference, which will focus totally on adult autism issues. I am billing this as “the first adult autism conference east of the Mississippi River.” The Symposium will be taking place on Saturday, July 22, 2017 in Chattanooga, TN.

The conference will be unlike any other autism conference as multiple social networking opportunities for autistic adults will occur. A welcome reception and dining-out event will take place the afternoon and evening before the Symposium. Another event takes place the evening following the Symposium. The focus of all of this is to create bonds of friendship.

I am proud of how far I have come as an autism advocate and self-advocate. Just as people change from one lifespan stage to the next, GCA and I changed right along with it. I’m excited to see what the future holds for us both.

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