autism through many lenses

ISSUE 9

autistic, adult, brown and STILL INVISIBLE

Strategies & Techniques for TEACHERS

THE Importance of Mentors

CREATING a **Sensory-Friendly** WORK STATION

> AUTISTIC SELF-ADVOCATE CAROL GREENBURG HELPING KIDS SUCCEED

HELPING KIDS SUCCEED IN A BROKEN EDUCATIONAL SYSTEM



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Autistic Self-Advocate Helping Kids Succeed in a Broken Educational System

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LETTER FROM THE EDITOR

his summer my family and I moved to a different state, which means not only new schools for the kids to attend but also a whole new special needs school system for my son Jacob. Yup, just when I thought I finally had things figured out, we had to start all over, and boy, are things different in this new county we are living in. While Jacob will not get all the services he did in his old school (they don't exist here), we feel we have put together a wonderful TEAM that seems to really want to help him succeed, which gives us faith that everything is going to be okay. I'm still crossing my fingers and toes though ... you know, for good measure.

I am not sure why or when navigating the educational system became so hard, but there is no doubt that it is! No one seems to know that better than Educational Advocate and Consultant Carol Greenburg. In this issue, Carol, who is autistic herself, shares her personal experiences with her son Arren (who is also on the spectrum) and how they have been suing their school district every single year. Read Carol's story and learn why she feels her own autism is the very thing that helps her to be such a good advocate, allowing her to keep her clients in the school conference rooms rather than court hearing rooms.

If you think things are only bad in the good ol' US of A, then you need to read our ZOOM IN

My Bella making a wish for a great last year of middle school.

essay titled "A Right to an Education" by a young nonverbal autistic teenager in France. "My life would be rather simple if people would consider me as a person rather than a thing to eradicate," types Nicolas Joncour. This piece will bring you to tears and make you realize just how far we have to go to change the way the world views autism. A definite must read!

Doing his best to help with that vision by changing the way TEACHERS TEACH is autistic professor Dr. Stephen Shore in Part One of what will be a series for ZOOM called "SWAT: Special Ways and Techniques for Educating Students with Autism for Maximum Academic and Social Inclusion." In this issue, Stephen presents his thoughts on the idea of chunking information and time management. If you are a teacher, or know someone who is, PLEASE HAVE THEM READ THIS PIECE!

We asked, "If you could let a teacher (past or future) know just one thing about yourself (if



you are autistic), or your autistic child (if you are the parent), what would it be?" and our ZOOM Facebook community really came through. You can add their answers to Stephen's article when you hand it to your teachers. Seriously, the responses are that good.

We also included a very special feature that takes the theme of education in a different direction and touches on a subject that, unfortunately, we need to shine a light on. In "Autistic, Adult, Brown and Still Invisible," instrumentalist, Grammy Award Winning music producer, writer, father, entrepreneur, and autistic self-advocate Michael Buckholtz shares what it is like to be a black autistic man in today's society. Michael shares how hard it is to leave his house every day and how, while others SEE him through the broad lens of "the standard black stereotype," when it comes to conversations about autism, he and his brown sisters and brothers suddenly become invisible. Things will not change until more people are aware, so we hope you will read Michael's essay and share his words with others.

On a closing note, this issue #9 marks the beginning of our 3rd year publishing ZOOM. I think I can speak on behalf of Sharon Cummings and everyone else who is part of our ZOOM family when I say that we have learned just as much putting it together as you have reading it ... if not more. We are so grateful to the autistic



Keeping with our family traditions of making a wish on the first day of school is Jacob, 10th grade.

individuals who contribute by offering their advice, their insights, their talents, and their time. We couldn't do this without you!

Until next issue,

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



ho am I, you ask? Well, I'm a musician ... that just happens to be on the autism spectrum. I'm a multi-instrumentalist. I've worked on and helped produced a few multi-platinum-selling, GRAMMY-winning albums, worked at some record labels and toured the world. I'm a military veteran. I'm an author. I'm a contributing editor for an awardwinning entertainment magazine. I'm an awardwinning entrepreneur. I'm a father. According to family stories passed down to me from my parents and theirs, I'm a mixture of many ethnicities, possibly American Aboriginal, Arab,

Caribbean, German and Spanish. Clearly, I'm multiethnic with brown skin. In today's societies, that's called being 'black.'

Most would see this description and may-

be think, 'This person seems to be doing rather involved in me leaving the house, to do basic well for himself,' and you would not be wrong to things, is an undertaking of epic proportions. surmise that. Those accomplishments were (and Still, on top of all that, I am afraid someone will continue to be) a combination of a conscious call 911, saying they 'saw some black guy' driveffort to maintain an optimistic approach to life, ing, walking, shopping, standing, pointing, etc., and I'll be targeted by police because of somemuch hard work (no task or routine too menial), one's learned blind fear or hatred. The way I'm targeted education, many mentors (both real and virtual), multiple levels of experiences, tons of treated keeps me hypervigilant. It's like living mistakes and sometimes painful sacrifices. What under occupation. Life under these conditions is many do not see are the multiple mental, emooverwhelming and exhausting, but I manage. I tional and societal gymnastics I must master in feel I've become stronger because of it and more order to stay alive in a world that continues to compassionate in spite of it. teach its citizenry that peoples with brown skin are less valuable than those who are not. Contrary to popular belief, black, brown, Afri-

can-American, multiethnic folks on the spectrum feel deeply and know how to love. While some Look, I'm just a musician. I want to create musical memories. I'm pro human race. I'm anti-hate. in the media seem to enjoy quoting dubious I'm pro peace and love. None of these feelstudies claiming nearly all brown peoples are prone to criminality, I choose to focus on actual ings are a stretch for me. In many ways, much facts, like my own life. For those people who of what I feel is amplified by my neurological condition, causing the need for me to completely care about me in a heartfelt way, I never forget shut down and tune out, sometimes for days, them. Loyalty is a big deal with me. In fact, I've loved one woman for the past seven years. Like from information overload. me, she's proudly on the spectrum. She is fiercely loyal and protective of me, as I am of her. She Regardless, my regular routine is to over prepare for leaving my house. For starters, I dare has a fantastic sense of humor, is way smarter

not leave my ID (my papers). My auto registration and insurance is strategically tucked into the passenger side visor, overhead, so when I'm stopped by police, my hands will be in clear view and up in the air. I do not dress according to today's fads. I'm either casually dressed (no ripped jeans or sagging pants), or I'm in a suit and tie two days during the week. I rehearse, out loud, the exact wording for responses to questions I may get from people in authority so as to remain neutral and pleasant. I'm used to being profiled, considered threatening or followed (when shopping or in public), but it increases

"I'M MULTIETHNIC WITH **BROWN SKIN. IN TODAY'S** SOCIETIES, THAT'S CALLED BEING 'BLACK.'"

my anxiety, making me simply want to hurry and leave wherever I am. The nervous behavior just makes some think I'm up to something when that's not the case. The planning



In New Orleans on The Autism Society's 47th National Conference panel with keynote speaker and New York Times Best Selling Author, of the book 'NeuroTribes', Steve Silberman (far left) and (left to right) Alex Plank, Jeff Staley, Chloe Rothschild, Lindsey Nebeker and John Newman-Miller.

than me and has an especially pleasing tone of voice. Yes, her voice. That detail may not seem important to many, but as an audible learner and lifelong musician, the impact of tones on my nervous system is massive. Her voice literally calms me. I can listen to her non-stop. It's pretty awesome. There's nothing in the world more powerful than loval love, and I've found it.

Even though, autistic, male, adult, brown, compassionate, loyal and productive people, like me, exist, we remain invisible. We're, summarily, not considered

(brown autistic men or women) when regular conversations are being had concerning autism, how broken social and justice systems uniquely impact our emotional, mental and physical wellbeing and what it's like for us to experience loving loyal relationships, such as friendships and marriage. We're just like anyone else, but time and again brown autistic peoples are forgotten, seemingly viewed through the broad lens of 'the standard black stereotype.'

Maybe there's the view that we couldn't possibly be interested in sharing our experiences. Maybe,

because we've been publicly dehumanized and mischaracterized in front of people for so long (helped along by corporate media, politicians and some social elites), many are unable to show compassion for a people they perceive as dangerous and destructive, making some feel unsafe and believe that we're responsible for bringing down their quality of life, materially.

"EVEN THOUGH, AUTISTIC. MALE, ADULT, BROWN, COM-**PASSIONATE, LOYAL AND PRODUCTIVE PEOPLE, LIKE ME,** EXIST, WE REMAIN INVISIBLE."

Whatever the apprehension, our stories need to be told. I'm also savvy enough to know much of this behavior isn't as intentional as it is societally learned. As the renowned educator Jane Elliott

bluntly points out, "Racism is learned. It can be unlearned." Until such a time, I and my brown multiethnic autistic brothers and sisters will have to remain vigilant in the hope that enough people will someday say, 'Enough. We see you. Let's talk. Let's learn.'

(The above essay was edited and shared with permission. To read the unedited version in its entirety, please visit the author's website Hot Mike's Music Industry Chronicles.)

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SPOTLIGHT ON SUCCESS

JENNY PALMIOTTO Created a Conference with HEART

BY: CONNER CUMMINGS

Editor's Note: On October 8-9, hundreds of guests will come together to attend the third annual Love & Autism event, a conference aimed to inspire and bring awareness to the fact that every individual, even those diagnosed with autism, deserves to be loved and have high-quality relationships in life. The woman behind this event is Dr. Jenny Palmiotto, CEO of The Family Guidance & Therapy Center of Southern California. Our very own autistic self-advocate Conner Cummings was able to ask Dr. Palmiotto a few questions about this conference of the HEART and why it is so important to the autism community.

CC: Why did you start the Love & Autism Conference?

Dr. P: Love & Autism: A Conference with Heart came about when I found myself just tossing out every conference brochure sent to me as professional in the autism field. Honestly, everything was about behavior, behavior, behavior. I just grew tired of it. I'm a lifeCC: After the conference is over, are there ways to still get the help or tools we need to practice what we learn?
Dr. P: The most beautiful thing about love is that it's available to us at

long learner, and I wanted to continue to grow, so I decided I would create a conference that focused on the things that were important to me. I believe

"Compliance is not **the goal** in life; **love** is."

that the primary goal in life is to love and be loved. This doesn't change when you are born with neurological differences associated with autism. Love is an innate human need, yet in my experience many current treatment models don't prioritize love. Compliance is not the goal in life; love is.

CC: Tell us a favorite story about how this conference led someone like me to find real friends or true love.

Dr. P: The first thing that comes to mind is a conversation I had with an autistic teen named David in 2014, our inaugural year. Prior to the conference, he shared, "I think it's Love vs. Autism, not Love & Autism. It doesn't seem that people show us love." I remember feeling an acute loss of breath at this very sad disclosure. I simply said, "David, I hope your life proves you otherwise." The very next year, David was a speaker on the young spectrum panel. He spoke of not only finding the courage to make friends but also of developing a healthy autistic identity. Basically, he learned to love himself. This was so

profound. It's moments like these that I realize we are on the right track at Love & Autism.

that it's available to us at all times. We can always make small shifts to love deeper, whether that means loving others or ourselves.

CC: Communication comes in many forms ... words from our mouths, typing, movement, or a mixture of all. How does the Love & Autism conference greet someone's individual needs?

Dr. P: Love & Autism attempts to create a space where all participants can be included in any way they are comfortable. We offer network-





ing rooms, quiet spaces, movement rooms, and badges where people can identify their preferred interaction level. We always open our conference with a collective experience that brings

the group together in an active way. We do this because, at the end of the day, we want our participants to feel loved and valued. Although we are all very different, we all need to feel a deep sense of belonging in our lives. With that being said, the ways we create connections and improve relationships happens in many, many forms. We have various speakers

who will present using different communication styles: music, dance, storytelling, art. Breakout sessions will include relationally-based discussion on communication, including healthy communication within marriage, canine companionship, the power of human touch to connect, creating connection through RPM, and RDI's experience-sharing language for deeper connection. We want people to be able to see, feel, hear, and experience the love at Love & Autism.

CC: For autistic individuals, speaking and shar-

"The most beautiful thing about **love** is that it's **available to us at all times.** We can always make small shifts to love deeper, whether that means loving others or ourselves." ing their words, their feelings, is so important. How do you choose the speakers?

Dr. P: Great question. This is so important to me. We don't have many rules at Love & Autism, but one of them is to save the majority of main stage speaking spots for autistic people that align with our message. One of my own perseverations is

reading blogs and books written by autistic selfadvocates. I create my top 10 list each year and ask each speaker to be "raw, honest, real" with our audience. At first I was so shy to make these connections. Now I've found that many people reach out to me and share about the amazing things that they are doing. Now, it's just hard to narrow it down! **CC**: Can you share with us your next goals or vision for the Love & Autism conference?

Dr. P: We are a few weeks away from Love & Autism 2016, so I'm barely thinking about 2017. We're a really small organization that just wants to do great things. Alex Plank of Wrong Planet has been instrumental in helping me develop this year's event. Wrong Planet is also one of our sponsors. This year, I'm excited to get our local chapter of ASAN involved with designing some of our autistic-friendly spaces. We'd like to continue to grow Love & Autism in many ways and continue to invite a diversity of perspectives, including autistic people, clinicians, researchers, community leaders, parents on the spectrum, and of course people that check more than one box. I'm so open to suggestions, and that is what has led me to find so many of our wonderful speakers. I know some readers of Zoom Autism Magazine know people that would be perfect for Love & Autism. Truly, reach out. Email me at jenny@familyguidanceandtherapy.com. Love & Autism is part of a larger grassroots movement that hopes to change the dominant discourse about autism. This event would not be where it is today without amazing people letting me know of how they are living the core values of Love & Autism.

CC: What do you want to leave our readers with that you feel is important?

Dr. P: We are all worthy of love, and each of us has value. Every day is an opportunity to love better, live better. You can always start with yourself and give yourself the gratitude you deserve for being a lovable person.



Conner Cummings is an autistic self-advocate, Project Coordinator/Staff Photographer for ZOOM and has a law in Virginia named after him ... Conner's Law. In addition, Conner has a

passion for Disney, photography, ice skating, writing, learning foreign languages and piano. Follow Conner and read more of his insightful writing on his popular Facebook page Conquer for Conner.

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Creating a Work Station on a **BUDGET**!

BY JACOB AND SHARON FUENTES

🚹 alvin Coolidge once said, "The only difference be-U tween a mob and a trained army is organization." To me, this quote is game-changing. What I've learned in my professional and personal life is that success depends on synchronization and harmonization of efforts. Bottom line: organization is the staple ingredient to keeping my family in sync, especially when it comes to my autistic son Jacob.

mare

Jacob is one of the smartest people I know, but, like many autistic individuals, he tends to have some executive functioning problems. The thought of getting organized is just too exhausting to him, and yet he thrives on it. A place for everything and everything in its place is what he needs in order to feel in control. So, with this in mind, every school year we put together what we like to call a homework/work station, a comfortable and creative space dedicated to him (and my daughter Bella too).

Our homework station addresses many of Jacob's potential challenges when he sits down to do his homework. We tackle sensory and possible attention/focus issues with just a few easy inexpensive items and ideas. The end result is an environment that not only is conducive for work but also allows Jacob to feel in control and successful.

To help get you started on creating your own budget-friendly homework/work station, we broke down the different areas of Jacob's, what it is about them that he finds helpful and where you can find similar type products. Remember: what works for Jacob may not work for you or your child. Also, the links we include are by no means products that we are recommending or getting paid to promote. We are just including them to help get you started.

If you already have a homework/work station, or should you choose to make one after reading this article, send us the pictures so we can share with others. Email your pictures with short captions to zoomautism@gmail.com.

MAGNETIC DRY ERASE BOARDS AND CORK BOARDS

From reminders to make sure he has everything he needs before heading off to school to inspirational and fun messages, these boards keep us organized and on task. If something is changing, such as rehearsal after school, it gets written on the board as a visual reminder.

Why Jacob says it helps: "I can put reminders for tests and the perfect scores I got on said tests because I remembered."

Where you can find it: You can find these types of boards in almost any size and shape everywhere. If space is an issue and you do not have room for separate boards like we use, why not try this twoin-one option that costs only \$11 on Amazon.





BODY BALL

This is a new addition to our workstation and one that is a huge hit... at least it is now! At first Jacob did not want to try it out as it's an exercise ball, and as he said, "Mom, I'm trying

to do homework, not work my core muscles." But after I told him about all the research I found about how therapeutic and relaxing exercise balls can be, he gave it a try. Now he is hooked!

Why Jacob says it helps: "I can bounce and roll around on it, which is enjoyable. But what I really like to do is read while sitting on it. It really is relaxing. And besides, who doesn't like a giant bouncing ball?"

Where you can find it: I found our body ball at Walmart for only \$8.



HEADSET OR NOISE REDUCING HEADPHONES

A lot of Jacob's classes are now online, which means homework is online too, and headphones really help with his focus. They also help with outside stimuli.

> *Why Jacob says it helps:* "They are headphones, Mom. It's self-explanatory."

Where you can get it: We have had these in the picture forever, and they are fine, but I am thinking about getting these wireless ones with their own stand instead. They can be found at Office Depot and cost less than \$20.

FIDGETS

Fidgets can be very effective and helpful selfregulation tools. Almost anything can be used as a fidget to help relieve stress or increase focus and attention. My boy tends to prefer metal items and magnets. If he is sitting at a desk, he is bound to have something in his hand!

Why Jacob says it helps: "I like how the metal



feels. It's cool and calming to me."

Where you can find it: We find a lot of affordable small desk toys that we use as fidgets at Office Playground.com. They have a huge line of magnetic items that Jacob says are a must have!

PERSONALIZED MOUSE PAD



So this one is not really a NEED item, but it is a FUN one that makes Jacob happy just seeing it and truly customizes his workspace. Who can blame him? A personalized mousepad with your picture on it is just plain cool!

Why Jacob says it helps: "It's my face on the body of my favorite Mystery Science Theatre 3000 character with BOTS... need I say more?"

Where you can find it: You can have a mouse pad made at most online photo shops, but we made ours through VISTA Print. It cost less than \$10 and was one of Jacob's favorite

MAGNETIC POETRY KITS

Years ago we started using magnetic poetry on our refrigerator to help get Jacob's creative writing juices flowing. You see, while he is very imaginative, he used to have problems getting started. So every day I would put up a random sentence on the fridge, and he would need to add onto it. It was a fun game we played and a great way to help him warm up to writing. While he doesn't really need any help in that department now, we still use these magnetic poetry kits to communicate with each other. Be it words of encouragement on test day or something to make him smile, it is a wonderful addition to our workstation.

Why Jacob says it helps: "It doesn't really help me anymore, but I do enjoy reading what Mom





comes

up with. Although I wish she would get some different kits that would allow me to reply in a more interesting manner."

Where you can find it: Shh ... don't tell Jacob, but I just ordered this really cool new kit with famous movie one-liners! Frankly, my dear, I think he will give a damn! LOL!

The Right to an Education

BY NICOLAS JONCOUR TRANSLATED INTO ENGLISH FROM FRENCH BY: LAURENCE LE BLET, NICHOLAS' MOTHER

decent life in France is practically impossible for an autistic student, especially if you are nonverbal like me. In special schools there is no real education, and the psychiatric hospital remains the norm. As my mother encounters more and more difficulties to enroll me in a normal school, the only solu-

tion to an equal opportunity is maybe to leave France. I want to go to university to study the Holocaust as people with disabilities are still destined to horrific fates.

My hope is to study history

and the Holocaust, a subject that has intrigued me for almost six years. Specifically, Operation T4, which is the eradication of the people with disabilities by the Nazis. Perhaps the Holocaust interests me because I feel the discrimination in relation to my disability. The eyes of others are like deportation camps without return for me.

Without my mother I would likely be in a psychiatric hospital. The right to education definitely remains the domain of utopia. The more I grow, the more I realize I do not have my place in society. I have to fight to deserve to dream. My disability, autism and dyspraxia, makes me look like a mentally-challenged person. People talk to me as if I am a small child, and they watch my gestures as if I am a monster.

The reality is that all their looks are like the slam of a cattle wagon door. My connections towards the victims of Operation T4 are very strong, and my reality joins their fatal destiny. I have faith that helps me, and God gives me so much love that I do not feel alone. I think I have the right to denounce my condition and my social discrimination as long as I would suffer of it. The right to a dignified life is my fight, and I recently joined the ENIL Youth Network to create change. Nonverbal autistic people demand recognition of their right to a real education.

"A decent life in France is practically impossible for an autistic student, especially if you are nonverbal like me."

My life would be rather simple if people would consider me as a person rather than a thing to eradicate. I want my intelligence to be recognized without having to meet the low expectations

of people who doubt me. The peculiarity of my disability is that I understand very well what kind of people I have to deal with. The inability to defend myself makes me vulnerable to all attacks. Not being able to express oneself orally is a very hard way to live.

People do not consider my written prose without doubt. Not even my relatives who do not understand autism. To be recognized, mentalities must change, and the way we move, having no eye contact and no speech, shouldn't exclude us from living a fulfilled life. For this to happen, we need the right to education, an education which mustn't be negotiable and should be accessible to all.

•••



Nicolas Joncour is a 16-year-old nonverbal autistic student who types. He lives in France and is homeschooled and in mainstream school for a few hours per week.

Follow him on Facebook and visit his blog.

"My life would be rather simple if people would consider me as a person rather than a thing to eradicate."



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AUTISTIC SELF-ADVOCATE CAROL GREENBURG **NEGOTIATING THE EDUCATION SYSTEM** FOR HER SON AND OTHERS



BY MARIPAT ROBISON

arol Greenburg is an autistic self-advocate, the owner of Brooklyn Special Needs Consulting, LLC., the New York City-based educational advocacy and consulting company. She is a contributing editor to The Thinking Person's Guide to Autism, past Regional Director of the Autism Women's Network, and the former editor of many Star Trek novels. Carol's teenage son Arren is also on the spectrum. I first met Carol at IMFAR in Atlanta, where she was busy tweeting info to her (over 5,000) followers. She is brilliant, engaging and an outstanding mom and friend.

MP: When was your own diagnosis?

CAROL: I was in my early forties. My son Arren (pronounced R-ren) had been diagnosed two years earlier, when he was three and a half. When I did a little research on autism, I was continually promised by all these websites that my child thought very differently than I did, was in a totally different world than I was, and to be prepared to enter that different world. I did, and it wasn't a different world at all. It was the same one I'd been living in for a long time. I was really shocked that not everybody else lived

in it. A lot of autistic adults do get diagnosed after their children, but a lot of things fell into place thinking about my family.

MP: What were the circumstances of Arren's evaluation?

CAROL: We had put Arren in a Montessori preschool. He's always been very laid back, just a happy person. All of a sudden, he was having a meltdown at school every single day. The minute he came out the door to us, he was fine. They recommended having him evaluated, and I thought, why can't the world just accept him the way he is?

They told me he had Autism Spectrum dis-

order. I remember saying: he's autistic, that's for life, now what are we going to do? I had to think about this in a constructive way, and even though I was scared, one thing I thought of was that he's so much like my dad. My dad's a pretty good guy, so this is not the worst thing that could happen.

Arren, my dad and I have always had in common this loathing of being patronized. If someone expected performance on demand, like if a teacher of Arren's asked, "What color is that fire truck? Is it blue or is it red? Arren wouldn't answer because it's a ridiculous question. The fire engine is red. He can see that it's red. Furthermore, he knows that the questioner knows that it's red, so there's no need for him to provide that information since it is already known.

MP: How have you negotiated the education system for Arren?

CAROL: We have been suing the district every single year to get reimbursement for what's called a Unilateral Placement. We opted out of anything they could offer because everything

"Why can't the **world** just **accept him** the way he is?" they were offering was not appropriate for him. The only place that was clearly appropriate for Arren (he's been there since he was about 4) is the school he's in, which is a completely private school. It's not a school that's funded

by the state; it's private and reserved for autistic students. This school has no funding from the government.

When you do Unilateral Placement in New York (and throughout the whole country, really) placing a child independently in a private, nonpublic-funded school, you have to prove that nothing appropriate exists and that the school you've chosen is appropriate. In Special Ed talk, it's called Prong 1 and Prong 2. Prong 1 - "Is what he is being offered appropriate for him?" If the answer is no, you go to Prong 2. In a case where you're suing, "Is where you have him an appropriate setting?" If the answer is yes to that, you've got a pretty good case. We've always had a pretty good case.

MP: You started Brooklyn Special Needs Consulting in the beginning of 2008. Why?

CAROL: A very close friend of mine was diagnosed with cancer the same week her son was identified as "somewhere on the spectrum-ish." He had been asked to leave his preschool as my son had. She called me up, told me about her cancer and said there was no way she could fight on both fronts. I said, okay, I can't deal with the cancer. You do that, and I'll deal with his education.

I felt that even though I had no experience advocating for autistic kids, I would be better than nothing, and what I found out about three months in was that there were lots of people trying their darnedest to get him services, and they weren't very effective. I seemed to be able to get him services that other people weren't getting and setting up meetings that other people weren't able to get.

Once, I went to pick him up while his mother was having a medical procedure because his bus had not yet been decided. They hadn't ponied up with a bus, which is such a basic thing. If you don't have a school bus to take you to school, then you literally do not have physical access to an education. So my son and I went to his school (I was the emergency contact), and there I was, holding the two little boys' hands on the playground, listening to this absurd assistance principal trying to bond with me over the difficulty of getting a bus. He was saying, "Oh, it's so impossible, and I've been calling," you know, casting himself as the hero.

And I just had it, and I said to him very loudly, "Yeah, it is a shame that you can't get the bus, and you know why it's a shame? It's a shame because when this goes to due process, as I suspect it will, somebody's going to get flooded with phone calls. I don't think it will be the district, and I don't think it will be the Office of People Transportation. I think it's going to be YOU. You're going





to be the one that gets ALL the phone calls about why this kid can't even get a bus." I was talking reasonably but loudly in front of the staff so that they could hear, and he was looking more and more uncomfortable, and I said, "It's a shame you don't have more power in this situation."

That night, the father called and told me that he didn't know what I said, but his son would have a bus starting the next day. He also told me I should consider doing this professionally. That's when I started with Rights Law Training, and my priority was my friend's son because I had promised her. After she died, I felt like I was able to help, and I wanted to continue doing that with other kids, so that's when I opened Brooklyn Special Needs Consulting.

MP: How did Rights Law Training help?

CAROL: To be trained as an advocate at that time, there was very little in the way of instruction except for the wonderful people at rights law, who did educational advocacy. They had an advocacy book and they conducted workshops, but there is no formal certification, even now, for a non-attorney special education advocate. If you're a special education attorney, you're a lawyer. If you're a lay advocate, there's no one accreditation. I think they're working on one.

When I started practicing, there were a lot of people who hung out a shingle as an advocate because they had a kid with special needs. They thought that meant they knew what they were doing, but very often they were just fighting their own battle over and over again. They'd go into an IEP meeting with their backs up, and everybody would be screaming and yelling, and they wouldn't be getting anyone to turn the volume down. And the most important thing is trying to deescalate because these situations start off pretty escalated. Trying to deescalate is very hard to do, and most parents weren't really able to do that. They saw a kid being treated badly, they got mad and weren't sure how to negotiate something that everyone could live with. That's what I wanted to focus on. Principal negotiation, conflict resolution. I always say now, try to keep things in the conference room and out of the hearing room. It is my autism that helps me as an advocate in so many ways – the whole delayed reaction phenomena – because I can just keep a straight face and listen to people.

MP: How did you become involved with the Thinking Person's Guide to Autism (TPGA)?

CAROL: I knew people online who had autistic kids, and one of the people I knew, Sharon daVanport, was coming to NY to speak at BlogHer on the panel "Busting Myths about Autism." Sharon is an autistic with autistic children. It turned out that she couldn't make it to NY, and as I had experience speaking (in my former career as an editor for Star Trek novels), I offered to go on for her. It was a great panel, and I met Jan Byde Myers and Shannon Des Roches Rosa. A couple of months later, Shannon got in touch with me and asked if I was interested in being an editor, and I've been there six years now.

MP: What can you tell us about attending the International Meeting for Autism Research (IMFAR) conferences? As a self-advocate, what kinds of changes have you seen over the years?

CAROL: My first IMFAR was in Toronto in 2012. There were very few actual autistics there then. I went again in 2014 and then this last one in 2016.

There are a lot more autistic bodies now. People MP: How can we help autistic kids succeed in seem less surprised when I get up and say, "I'm the current educational system and infrastrucautistic, and here's my take." They used to be ture? quite taken aback. It seems to be more inclusive in the sense that it used to be a private club for **CAROL:** The current educational infrastrucscientists, and now it has grown in that they are ture is really broken. The Individuals with trying to include more autistics. This year there Disabilities Education Act (IDEA) is a very good was a majority autistic panel; all but one particilaw, but what has happened is that the governpant was on the spectrum. I never would have ment has said, "In order to adhere to the law, dreamed of that back you must give a free in 2012.

MP: What do you see as your role or mission in attending?

CAROL: I can't touch the expertise of some of the researchers, but I have the expertise of personal experience and the expertise of raising an autistic son. That's

what I try to bring to IEP meetings, what I tell parents to bring to IEP meetings. You have to respect these people because they bring something to the table, but you also bring something to the table.

MP: What do you think is missing from current research projects?

CAROL: There's very little we know about older autistics. Research into causality should not be getting most of the money. Research into services for living, breathing autistic people should be getting most of the money. First of all, we don't even have statistics on how many autistics there are in the United States. They have that in Britain; we don't even have that baseline data. If you can't do that, then you can't figure out why the unemployment rate is so high among autistics. And if you can't do that, you can't figure out what might lead to higher

employment among autistics.

"It is **my autism** that **helps me** as an advocate in so many ways."

appropriate public education, but we're not going to increase the funding on that." Good luck finding the money! That puts the districts into an impossible situation, and that's where the tendency to demonize districts comes in. It's not all because somebody's evil and they want to deny your

child services. It's because there's rationing. There's no money, and the money that is available is getting rationed to the people who make the biggest fuss – not just the people who sue, but also the people who know their children's rights and who can advocate for their children.

...



Maripat Robison is an international speaker and writer, leading workshops on loving someone with autism. A retired television executive and magazine publisher, Maripat has raised two neu-

rodiverse kids and is married to John Elder Robison. Maripat is the author of the popular blog and forthcoming book, I Married a Geek.



PART 1:

CHUNKING OF INFORMATION AND TIME MANAGEMENT

Although nonverbal and recommended for institutionalization at two and a half years old, Dr. Shore's parents advocated on his behalf and provided (what we today would call) an intensive home-based early intervention until speech began to return at age four. Stephen Shore did eventually end up in an *institution of sort – but in higher education as a professor of special education at Adelphi University.*

Focusing his efforts on promoting fulfilling and productive lives for individuals on the autism spectrum, Dr. Shore is an internationally known consultant, author, and presenter on issues related to the autism spectrum. This article (Part One of the SWAT series) focuses on educational strategies for promoting success both in academics and social interaction from a viewpoint within the autism spectrum.

've got six students with special needs on my roster of 27 students. How do I teach to all of them while making sure everyone's academic and social needs are met? They didn't teach this to us when I was getting certified. With the beginning of a new school year, conversations like this are being heard across the nation. Often it may seem like a SWAT team is needed to sort things out to make sure all students are given an equal chance of success for their education. Rather than Special Weapons and Tactics, we will examine a set of Special Ways and Techniques for maximizing educator efforts in promoting both academic and social inclusion for students of all abilities.

Educators lost in an ocean of potentially thousands of curriculum modifications may find parsing these adaptations into nine categories to be helpful. It's important to understand all students as individuals with unique strengths and challenges; therefore, modifications of academic material and delivery may be needed as well as customization to student needs. Although commonalities exist within individuals with autism and between other categories of special needs, there is also great diversity. When you've met one person with autism, you've met one person with autism.

Size or Level of Difficulty **Ouanity** Support

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

Size or Quantity of Information: Adapt the amount of material the student is expected to learn or complete.

Taking the idea of modification one step further, For example, reduce the number of questions and in the interest of more complete inclusion, on a quiz given each Friday from 10 to 5. Often perhaps the entire class could take two quizzes this will work; however, a possible extension to of 5 questions every week. In this way there is this modification could be to see if the student only a single curriculum delivered in a single can achieve success completing 5 questions on way that has expanded accessibility to more Tuesday and another 5 on Friday as perhaps the students. This technique addresses the goal of individual really needed a reduction in chunkmelding the adaptation to regular instructional ing of information to process at a given time. routine and benefits everyone else as well. Additionally, this strategy elevates the modifi-



cation to an accommodation where the student is now doing the same work as everyone else instead of half the amount.





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

Time: Adapt time allowed for learning, task completion, testing, or assist with management of time.

Although the most common strategy for time is to provide more of it, often the student with autism is challenged with executive function of managing time. A common support would be to set up a schedule using pictures and/or words depicting intermediary steps – as might be needed for a course paper – culminating in the final deadline. An extension to this strategy would involve providing the entire class with this schedule to benefit everyone.

In the case of a long-term paper, the concept of managing time can be reinforced for the entire class by dividing a bulletin board into columns with each section dedicated to each step along the way to completion. As students complete their steps towards completion, their work gets posted on the board. In addition to being a strong visual reference of individual and class progress, pupils, parents, principals, and others all appreciate seeing student work hung up on the wall.

Taking the idea of time management a step further, perhaps I would ask the person with autism if he would like the job of bulletin board monitor. That student would be in charge of making sure student work is posted in the correct column. If needed, additional support customized to the needs of the student can take the form of working in pairs with another student, hand-over-hand assistance from a paraprofessional, the teacher, a classmate, or whatever is needed. In this way, the student most in need of support in time management receives it, the

modification is worked into the teaching routine of the class, there's the potential of greater social interaction, and the entire class benefits from having an easy-to-access reference to the progress of their work.

We have looked at two of the nine domains of curriculum modifications where adaptation allows the student a chance of success in education equal to everyone else, much like eyeglasses provide an equal chance of all students seeing the board in front of the class. The examples provided emphasized how adaptations originally for a single student with autism or other special need can be incorporated into instruction for the entire class for the benefit of all students. The concept of SWAT will continue in the next ZOOM issue with exploration into the other domains of curriculum adaptation, meaningful inclusion when the student is unable to perform at the same level as his classmates, and the concept of Least Restrictive Environment in terms of promoting student success.

...



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"Dear teachers, past, present, and future: You underestimate me. Because my body does not obey my mind. Because I can't speak in a way that demonstrates my understanding. Because I can't sit still or look at you and pay attention. Because my body language is a completely foreign language to you, you mistakenly believe it is expressing disinterest, stubbornness, defiance, lack of engagement, and inability to learn. Don't underestimate me. You can learn as much from me as I am learning from you. And I AM learning." ~ Michelle Jones

"I wish someone had noticed and empowered my different mind instead of writing me off as stupid, difficult, unmanageable, or attentionseeking. I wish someone had taken the time to read between the lines and figure out what my verbal scripts meant. I wish someone had advocated for me instead of everyone being against me. And above all, I wish I knew what autistic was so that I knew I was more than just stupid, difficult, etc." **~ Em Martha Feightner Heil**

"This is a deep one for me, so my reply will be broken up into two:

Dear teachers of elementary school past: I needed you to be my social advocates through the bullying, crying fits, and low grades. What? You're finding this out now? Well, I couldn't voice it back then because I didn't know I was autistic back then. Just that I was different. While most of you did do a good job with helping out with grades, academics don't mean a thing on the playground, where I needed you most. You can't say you didn't know because you had access to an IEP. You can't say you didn't know because you labelled most of that behavior as problematic. If only I could go back and show you what I've become now, but alas, there is a reason they call it the past ...

Dear teachers of the future: Let me tell you something you're probably not going to hear in any of your teachers' college courses: 'A child

"If you could let a teacher (past or future) know just one thing about yourself (if you are autistic) or your autistic child (if you are the parent), what would it be?" isn't an IEP, and an IEP isn't a child.' Don't let bullet points on an IEP dictate what a child can and cannot do because at the end of the day, autistic children are human and can live up to their potential like any other child." **~ Theo Howe**

"Just because I'm not making eye contact doesn't mean I'm not listening. Getting in my face and/or yelling at me doesn't get my attention or respect. In fact, my behavior will probably escalate, which doesn't benefit anyone!" ~ Sarah Bradley Morris

"Don't mold me in your image. Just because I disagree with you doesn't mean I'll kill you in your sleep. How can anyone learn if we're all parroting your opinions? Saying "this is wrong, fix it" does nothing to help me understand the assignment. Try teaching me the concept first. If I still don't get it, try another tactic rather than doubling down and using the method that didn't work the last five times. Your double standards appall me. The boy who talks about groping is funny, but my off-color humor is shocking? Your favorites can do no wrong, but I'm a bad person for wanting disability accommodations? No one is fooled at your feigning to like me." **~ Emma**

"She knows a lot more than she will express to you." **~ Patty Zayas**

"I wish any of my teachers would have noticed that I'm autistic and got me the help I needed as a kid. I'm about to have a career as a teacher starting this fall. I hope that my autistic students feel safe in my class. I hope their parents and other school staff don't force me to try to make them act neurotypical." **~Karin Gomez**

"Sigh. Social skills. They need to be taught. By the time I 'mastered' (right!) peer-level concepts, I was in graduate school ... plan for a future, for opportunity, respect special interests and allow us to use those to fulfill curriculum goals (i.e., trains and math-multiplying mileage and cars and food consumed during traveling). Intervene as soon as bullying appears. One grade I had a class angel, who I later called my peer angel. Pair students together. Remember kindergarten? Strength in numbers? Include, include, include. In sixth grade my teacher saw that not only was I picked last, I was often not even picked. He taught me how to hold and swing a baseball bat. Fifty years and I still celebrate running to first base." **~ CarolAnn Acorn**

"The teachers that truly care about helping a child close gaps - their future changes for the better. But it takes a special teacher who is passionate about making a difference in that child's life. They are the equivalent of heart surgeons in the medical field." ~ Diana Lewkowicz

"As a person with Asperger's Syndrome, I have been able to connect with children on the autism spectrum through Boost! Summer Program, an activity group for children on the autism spectrum. As can be attested by the teacher of the group, a child really likes me. Also, a parent told me that her child really likes me. These children feel comfortable with me. I see myself as a role model to these kids. I truly enjoy this experience." **~Jessica**

"For my children on the spectrum: They are capable of more than you know. They may not always arrive at the answers traditionally, but they do arrive. Thank you to the teachers that embrace this truth and accommodate for it. Blessedly, more of you have been that way than not. And for myself: I was not merely shy or clumsy. My mind worked in a different way than any of us could put a name to. I may have gotten by quite well academically, but there were struggles socially, emotionally, and physically speaking, where further attention was warranted. More than the praise for the A's, I needed someone to notice I was friendless, selfconscious of my motor skills, and often drowning in depression. But what's done is done. It's all water under the bridge, and I'm glad to say that I am coming into my own now and raising autistic beauties. Recently recognizing autism in myself is truly helping in doing so."

~ Marisa Ulrich

"On behalf of a child ... I need to see something from all 180 degrees before I recognize it in new contexts, but you might not realize it because I sound like I understand. A new context = need someone to help me make that explicit connection. Otherwise, I might get it, I might misapply it, or I might miss it entirely."

~ Kelly Warriner Smith

"My autistic twins are 4, so I'm just starting this school adventure. But if I had any real hope for their future teachers, it'd be that they truly believed in them. My kids are little geniuses, trapped in bodies they sometimes can't control. If you really get to know them, their likes/dislikes, and join them in learning/playing, they'll blow your mind. Patience, awareness, understanding, and love are all necessary for a solid relationship, and you have to form a relationship to get them to open up."

~ Michelle Parker

"He matters! He is not a textbook anything, and his individuality needs to be respected and cherished! Also, he doesn't need to learn slang to fit in!" **~Davona Wilson**

"Dear teachers ... thank you for everything you do. I may not know how to show you I appreciate the patience and creativity you provide every day, but it's working. Thank you for believing in me and knowing that I can do it, even if it takes multiple times showing me. I know I don't always look like I am listening, but I am. Most of all, I am thankful that you have faith in me to succeed and that I am worth your time, energy, love, and understanding."

~ Debra Gomez







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4 Easy Tips to Make the Transition Back to School Easier BY JAMIE E. CARTER, PH.D. AND AHNA I. O'SHAUGHNESSY, M.A.

THINK ABOUT YOUR CHILD'S SENSORY

THINK ABOUT YOUR CHILD'S SENSORY ISSUES.

Many autistic children have sensory issues. When you are planning for the transition to school, you will want to think about ways to lessen the impact of sensory concerns. For instance, when you are buying back-to-school clothing, think about the types of fabrics and fasteners that your child prefers. If your child is sensitive to noise on the school bus or in the cafeteria, find out if noise-cancelling headphones would be permitted. If your child is sensitive to smells, pack a small sachet in her backpack for her to use as needed.

MAINTAIN A ROUTINE.

Ozonoff, Dawson, and McPartland (2002) note in their book *A Parent's Guide to Asperger Syndrome and High Functioning Autism* that maintaining consistency in the home and classroom, by way of having the same rules and expectations in both settings, can make transitions easier. If possible, inform your child's teacher of your rules at home so that the teacher can carry over the same expectations in the classroom and vice-versa. Additionally, using the same scripted phrases across both settings to establish routine or react to specific behaviors makes for easier transitions. For example, when your child becomes upset, you and the teacher might both want to say "count backwards from ten."

USE PICTURES AND STORIES.

Remembering that "a picture is worth a thousand words" can help you find ways to prepare your child for the upcoming change in routine and environment due to school beginning. If you are able to take photographs of the school, classroom and/or teacher, you can hang them on the refrigerator or make a small book about school. Additionally, you might want to use one of Carol Gray's Social Stories® to explain the upcoming transition. If your child will have some of the same classmates as in previous years, you might want to look at prior year photos of the children and review their names and discuss what your child knows about them. For example, you might want to say, "Here's Tyler. You two used to show each other your Pokemon cards, and maybe you can do that again this year."

TEACH YOUR CHILD TECHNIQUES TO MANAGE EMOTIONS.

Teaching your child relaxation and calming strategies to use at home and in school to help remain calm can go a long way in easing the transition. You will want to practice these well in advance of the beginning of the school year so that your child can easily perform them as needed. A variety of techniques can be used to deal with anxiety. These include deep breathing, progressive relaxation, counting down from 10, or squeezing a stress ball. Teach one or more of these techniques to your child when he is calm and can focus on learning the technique. You will then be able to cue your child to use the technique when you see that he is becoming upset.



Dr. Carter is a clinical psychologist.



Ms. O'Shaughnessy is a psychology associate.

They are the authors of PREP for Social Success: A Guide for Parents of Children with Autism, which is available exclusively through Amazon Kindle. You can follow them on Twitter: @Prep4SocSuccess and on Facebook.

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What Is the Every Student Succeeds Act (ESSA)?

n December 15, 2015 President Obama signed into law the Every Student Succeeds Act (ESSA). ESSA represents a true bipartisan effort to update the No Child Left Behind Act of 2002. Specifically, the law addresses the following:

- It ensures that states and school districts will hold schools to account for the progress of all students and prescribes meaningful reforms to remedy underperformance in those schools failing to serve all students.
- It excludes harmful "portability" provisions that would siphon funds away from the students and schools most in need and maintains dedicated resources and supports for America's vulnerable children, including students with disabilities, English learners, Native American students, homeless children, neglected and delinquent children, and migrant and seasonal farmworker children.
- It ensures that states and districts continue the work they've begun this year to ensure that all students, including students from low-income families and students of color, have equitable access to excellent educators.

The Disability Community was particularly concerned about states using standards that would reduce standards to an overly simplified level for special needs students. The new law

requires meaningful goals for the progress of all students, including special needs students. States must set ambitious targets to close student achievement and graduation rate gaps among subgroups of students in order to meet their goals. If there are schools where too many students consistently fail to reach the goals and other indicators set by the state, school districts will provide them with tailored interventions and supports that are proportionate to the needs of those schools and the students they serve.

The Autism Community actively participated in the drafting and passage of the Act to assure that students with Autism receive an education tailored to their needs but with an emphasis on achieving their highest potential.

...

Edward Zetlin has a solo practice in the areas of elder \mathcal{E} 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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CUMMINGS AND GOINGS

Conner, Chloe Rothschild & Ron Suskind from @Life Animated

his summer, Conner and I were fortunate enough to be able to attend the Autism Society of America's National Convention in New Orleans. Conner was one of the photographers, and his task was to take pictures of our personal journey at the convention. The choice of which sessions to sign up for was difficult as there were so many I wanted to attend, all conflicting with each other. Every session we were able to go to was informative and worth attending. A few that stood out for us were led by some of our friends. Chloe Rothschild's "Strategies for Living with Autism, Road Bumps and All," was insightful, and Jonathan Murphy along with his mom Jodi of Geek Club Books had the room laughing and learning while he shared his story – what a great combo! We even got to attend the renewal of wedding vows from Anita Lesko and Abraham Talmage Nielsen as they discussed romantic relationships.

The final day was scheduled as a keynote by Steve Silberman, but he suggested instead that he host a panel of self-

Conner, Alex Plank & Sharon





advocates talking about topics of their choosing. Alex Plank, Jeff Staley, Chloe Rothschild, Lindsey Nebeker, John Newman Miller and Mike Buckholtz were all on the panel. All questions were directed to and about people on the spectrum. They covered a multitude of questions: What are the most damaging misconceptions played out in the media? Tell us one thing you wish people knew about Autism. What role does the internet play? Why should we care (or have discussions) about life experiences from brown peoples of Aboriginal, African and multiethnic decent? What changes can be made to facilitate employment and financial security? What are the most important things that neurotypicals can do to become better allies?

You could hear a pin drop in the crowded auditorium as we all listened intently to what each of these six amazing individuals had to say while making us in the audience think 'out of the box.' As, one-by-one, Steve called on them to answer questions, I heard Conner sitting beside me answering as well. I realized that I wanted to hear more of what Conner had to say, so I started taking notes so that I could ask Conner the questions later and discuss the panel's answers. Each individual on the panel was just that, an individual, uniquely different from the others, representing the wide spectrum.

The best part for me was that Conner was so interested and wanted to continue the discussion in the best way he learns ... what we call a business plan. Conner's wrote on Steve Silberman's FB page, "I enjoyed so much my friends Chloe & Lindsey on the stage answering questions, and now I have five new friends on the panel. Me and my mom will be discussing today my own thoughts and what I heard from you."

Steve Silberman and the panel not only closed the event with one of the most informative and inspirational sessions we had ever attended, but also, Conner and I learned tools that will foster conversations for months to come. And we got to see a little bit of New Orleans with friends, too.

Warmest regards,

Sharon

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

Sharon, Steve Silberman & Conner





Conner & Lindsey Nebeker



Elizabeth Roy @ASNV, Conner, Jodi Murphy & Jonathan Murphy

THE IMPORTANCE OF MENTORS

BY: CHLOE ROTHSCHILD

y name is Chloe Rothschild. I am a young adult who is kind, creative, caring, helpful, a great friend, and I have autism. It is my honor to have been asked to talk about a topic that is very near and dear to my heart: mentoring. Mentoring has truly positively impacted my life. I've also gotten the opportunity to see mentoring help impact both my own life and the lives of others.

One of the great things about mentoring is that it helps both the mentor (person mentoring) and the mentee (person being mentored). In my experiences, both parties learn from each other. This makes mentoring and being a mentee very rewarding.

ZOOM Autism Magazine asked me to interview a good friend and mentor of mine, Dena Gassner. Dena is an individual on the spectrum, mom to a son on the spectrum, a PHD student at Adelphi University and a professional who works in the field. Dena has experiences being both the mentor and mentee. I asked Dena some questions about mentoring; here were the questions and her answers.

CHLOE: When did you first become interested in mentoring and why?

DENA: I became committed to mentoring after I experienced the difference mentoring could make in a life. Stephen Shore took me under his wing. No one could ever compete with his level of super mentoring! Thousands benefit from his mentoring and are sharing that space under that wing with me!

CHLOE: Mentoring can be a life-changing experience for both the mentor and person being mentored. How has mentoring changed your life?

DENA: Just before my diagnosis, I met Stephen. His encouragement and that of Tony Attwood helped me be more fear-

We sat at a table in a public restaurant with horless about seeking my diagnosis. Also, for many rible lighting. I took my napkin and unscrewed years Stephen was my only link to autism and the bulb, and she looked at me like she had just a way to reconnect with my identity. Knowing met her long lost sibling. Such a look of recogninot only that I was autistic but also how I expetion, affirmation and acknowledgment! rienced the world differently and how others experienced my ASD gives me critically needed **CHLOE:** How does mentoring others make you self-awareness for success. That process began feel? with Stephen, each year at conferences.

CHLOE: What has mentoring or being men-

tored by others taught you?

DENA: I enjoy the moment when an autistic has an "aha" moment of understanding and connection. Also that moment when they realize they're not the only person who sees, feels, and experiences the world in the way that they do. And I hope I give them courage.

CHLOE: What is one of the most rewarding experiences that you have experienced while

"I'VE HAD QUITE A **Journey** TO THIS PLACE OF WHOLENESS, AND I COULD **NOT** HAVE DONFIT **ALONE**."

mentoring someone?

DENA: Watching you grow has been one of my favorite experiences, and we're both a work in progress! And I love that once, I met a woman who was fairly reluctant to meet me. She was rejecting her identity and didn't think I could help.

DENA: It's one of my greatest joys. It's one of



Chloe with her Mentor and friend Dena

my purposes in life. I've had quite a journey to this place of wholeness, and I could not have done it alone.

Also, I want the pain I've experienced to teach and serve others.

CHLOE: Do

you think that mentoring is a two-way street (that you learn

from the person you are mentoring as you are teaching them)?

DENA: Always. You've taught me so much about interoceptive issues in autism. Others have each left a place on my heart. Last month I went to a wedding for a former client, and the maid of honor was one of our aspie friends. Seeing such long-term relationships come from my work is always wonderful.

CHLOE: What is your favorite part of mentor-ing?

DENA: By sharing my multiple experiences as a mom, autistic, advocate and educator, I try to

help others find their paths. I want them to feel worthy of support and love.

CHLOE: If you were to give someone else advice about mentoring, what would you tell them?

DENA: Don't help too much. Guide them in pondering, thinking, considering but don't give them all the answers. I think that particular one has been a little distressing for you when we work together, but in the long run, making your own decisions has been powerful for you, right?

CHLOE: How have you seen mentoring change people?

DENA: I've seen the love that happens and the joy of friendship. I was inspired by just such a

"BY **SHARING** MY MULTIPLE EXPERIENCES

AS A MOM, AUTISTIC, ADVOCATE AND

EDUCATOR, I TRY TO HELP OTHERSFIND

THEIR PATHS."

friendship with Stephen, and that's why I'm back in graduate school and going for my PHD. It's urged me higher in my professionalism. I take more risks. It's helped me to feel loved and to enjoy loving and supporting others.

CHLOE: Is there anything else that you would like Zoom readers to know about mentoring?

DENA: Programs need to foster opportunities, space and leadership development to create mentors. Scholarships for conferences and learning opportunities are ways to cultivate future leaders.

I want to thank Dena for letting me interview her. I also want to thank her for taking me under her wing and mentoring me. She has encouraged me and taught me so many things. Dena has been there for me through the good, the in between and the harder moments. And she has done so without judgment. Dena just listens. This is one thing that makes men-



Dena with her Mentor, Dr. Stephen Shore



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toring so special, at least for me. I've had the opportunity to have many mentors in my life, including Dena. I consider myself to be so blessed to have the opportunity to have Dena Gassner as a friend and mentor.

•••



Chloe Rothschild is a young adult living with autism. She is a self advocate, writer, and presenter. Chloe is a member of the OCALI (Ohio Center for Autism and Low Incidence) Advisory Board.

Chloe is also the managing editor for the Autism Research Institute Adult's with Autism eBulletin. In her free time, she enjoys spending time with her family and friends, doing art projects, and more. Chloe loves making a difference by sharing about autism from her perspective.



Learning to Look at Your Child Through ABILITY Lenses

BY RACHNA SIZEMORE HEIZER

y autistic son has attention and language processing issues, which meant that schools often assumed he was incapable of learning. School staff regularly wanted to keep him apart from his non-autistic peers in order to work on what he did poorly – communicate and pay attention. They never stopped to consider what he did well – how social he was, his passion for all things musical, his ability to observe a situation and figure out how to survive in it, his ability to memorize and remember EVERYTHING. No one talked about that. No one even noticed.

Last year, in 7th grade, my son was invited to play his guitar and sing at Unplugged, the acoustic show hosted by the high school theater department. He was one of only six middle schoolers to ever be asked to perform at Unplugged in 19 years.

HOW DID WE GET HERE FROM WHERE WE BEGAN?

First and foremost, I learned to look at my child through ability-focused lenses. Too often we [parents] are worried about all the things our children CAN'T or WON'T do, and we forget to nurture the things they CAN or WANT to



do. Look at your child with ability, not disability, in mind, and then talk about them that way when talking to the teachers. If we don't do this, we cannot expect our schools to do this. Show educators WHY they need to treat your child like they treat everyone else, as human beings whose potential is being developed rather than human beings whose deficits are being addressed. My son is a brilliant musician but will probably never pass a state standardized test. Regardless, his school is now very invested in his future because NOW they see that he has a path to a productive life, pursuing his passion.

The second thing you have to do is be persistent, trust your instincts and work as hard as you expect others to work. I realized my son had a passion for music but had no idea he was good at it. Nevertheless, I started trying to find him a music teacher. It took us three teachers before we found one willing to truly teach my son music, and it took our willingness to sit in on lessons to help with communication where needed for my son to grow as much as he did.

In November 2013, my son, then age 11, stood on a stage on the National Mall in Washington DC in front of a crowd of thousands and, with his crooked half grin, asked the audience, "you all having a good time today?" And as the crowd roared, he strummed his guitar and sang. In the crowd were four of his former and current teachers, with tears in their eyes, watching the boy who could only read at a kindergarten level rock out in front of thousands who loved him. And no one there doubted his ability.

•••

"Show educators WHY they need to treat your child like they treat everyone else, as human beings whose potential is being developed rather than human beings whose deficits are being addressed."



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SPOTLIGHT ON SUCCESS

Louder than Words

BY: ADRIENN SALAZAR

hen I was 12 years old, I decided that music was what I wanted to do for life. My mission was unclear, but I knew I wanted to teach someday. My mom, who I adore, made it clear very early on that if you have any kind of talent, it is a gift and you must share it! So I did. I sang in numerous choirs, played in orchestras, taught summer camps, and so on. Teaching really fit me, and I enjoyed what I was doing.

I started working for the Loudoun County After School Strings program, where we offered group classes to 4th and 5th graders. I had at least 25-30 kids in my class. Some tall, some short, some loud, some quiet. But one boy always stood out. His technique on the violin wasn't the best, but he never missed a class and was always ready to play.

One day after class, his mom stopped me and asked if I would be interested in teaching her son privately. "But I have to tell you," she said, "he has autism." I remember trying to figure out the meaning of that word in my head. What is autism? Ah, I thought, there is nothing I can't

A few talented individuals from Children of the Rainbow playing @ Stone Tower Winery in Virginia





Jesse & Amanda making beautiful music for an Autism Society event

handle. I always love challenges. I agreed, and Jesse started lessons with me. Little did I know that he wasn't the only one who would be learning!

Jesse and I learned to communicate through music.

If he did not have a good day, I would sense it at the beginning, so that day we would just play our "favorites." We even invented a game called "name that tune." He would play 4 notes of a song, and I had to guess the song and start playing it on the piano. Good times, good times! Over the years his technique improved. I learned what type of songs he liked, and he learned that practicing will make him better.

The word got out, and I started gaining more autistic students. No two students would be alike. At times they impressed me with their talent and incredible minds, yet other times I would be frustrated because I felt I could not get through to them. As one of my favorite and highly quoted German poets, Heinrich Heine said once, "When words leave off, music begins." I made a decision, and so the "Children of the Rainbow" productions was born. I recruited all my students and musician friends, and we practiced in my small living room for hours. At times there were more than 20 kids. But our first charity concert was on the way, and we were all excited. I felt like a rock star, full of energy! I composed most of the music, arranged it, conducted, and played along with my students on stage! I remember sending in the first check to the Autism Society of Northern Virginia. A donation of a little more than \$300. Not much, but the feeling was irreplaceable!

Our group continues to have more and more musicians every year, and of course, Jesse is always there. This year, Jesse proudly led the violin section. He started college this August, but he continues to come for lessons and will always be a part of my production.

I am so thankful to my students and musician friends who, year after year, volunteer their time and passionately play at our fun-

music school in Eastern Loudoun County, Virginia where everyone will be welcomed, and music is louder than words!



"When words leave off, music begins."

draiser events. As for me, I will continue to teach music, regardless of race, disability or age. I am currently working on opening my

Adrienn Salazar is an accomplished music educator specializing in strings and music theory. Mrs. Salazar is a member of the Loudoun Symphony and the Pro Arte Chamber Orchestra of Greater Washington. Inspired by some of her wonderful students, she began an annual fundraiser concert for autistic children called the "Children of the Rainbow" concert series.

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