"If you've met one person with autism, you've met one person with autism."

- Dr. Stephen Mark Shore

While looking at theoretical research is an important process in understanding ASD (including challenging misconceptions and stereotypes), listening to personal narratives of individuals on the spectrum is exceedingly powerful. The following is a collection of life stories and experiences shared by people on the ASD spectrum.

1. The Art of Autism: (blog, collection of narratives, art exhibit)

<u>Autism Unveiled: Voices On The Spectrum</u> is a six-week project where individuals on the spectrum were invited to share their experiences alongside ASD. Through the collection of personal narratives via blogging, individual struggles and successes were shared and then expressed through art. To encompass their entire experience, each individual was asked to provide a few words they felt accurately represented their identity. The purpose being that of 'more than' - they are more than just someone with ASD.



Image Credit

(*Note: Some individuals chose to describe themselves as "Autistic" - despite the problematic and oppressive nature of the lack of person first language, the narratives in themselves are extremely powerful. Additionally, in most cases when "Autism" or "Autistic" is included in their self-identified descriptions, it is referred to last - again, signifying the importance of 'more than'.)

https://www.youtube.com/watch?v=RpUQxa6JWWw

The following are a few examples of the personal narratives shared as part of the *Autism Unveiled* project. For a comprehensive list of blog posts shared via this project, see <u>88</u>

Personal Narratives: What Life Is Like On The Spectrum.



"My autism is the reason I'm in college and I'm successful. It's the reason I care," <u>Jacob Barnett</u>, 16-year old physicist

I am Jake

<u>Jason Cantu</u>, a college graduate, almost lost his life last year. He tells the story and illustrates his life with maps.

<u>Jason: college graduate, actor, artist, radio-dj aka</u> Captain Retro. #Autistic





"We will have true inclusion the moment we are able to accept another person for who they are even if they are completely different from us," Gee Vero, Germany Gee:woman, mother, partner, artist, writer, public speaker #Autistic. I am

<u>Michael Whary</u> made a video for parents of newly diagnosed children for his Eagle Scout badge – watch it in his blog.

Michael: Eagle Scout, honest, easy going, focused and #Autistic

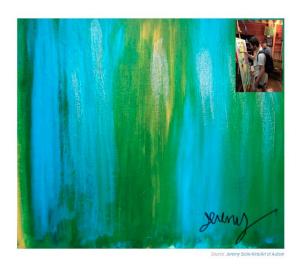


(*Credit for all above images & personal quotes*)

"Autism is a neurological variation (a neurodiversity) that occurs in about two percent of the population and is classified as a developmental disability. Autism has no socio-economic class, gender, race, country, religion, personality or profession. The purpose of the project is to show the diversity of the population" (*The Art Of Autism*).

In response to the *Autism Unveiled* exhibit, Michael McCutcheon (blogger for MIC) challenges misconceptions and stereotypes ('myths') commonly associated with ASD in his article <u>Eight Portraits of People With Autism That Shatter Stereotypes About The Spectrum</u>: "It tells a very different story about what living with autism is like than the one that's made its way through popular culture." The following are examples of McCutcheon's disruption of misconceptions.

(**Note: Information taken directly from article.)



Myth: Autism makes it impossible for kids to achieve their potential.

Many people with autism view it as a special part of who they are."The world would be drab if we were all the same," writes Jeremy Sicile-Kira, who also has synesthesia, a condition where senses mix, like seeing colors while listening to music, because of differences in brains wiring. Research shows that people with autism are almost three times more likely to have synesthesia. "Really, if it were not for my autism, I would not see the beautiful colors that I see everywhere, even in dust," he writes.

Myth: Being on the spectrum has no benefits.

Research shows that many people with autism have unique abilities, whether it's incredible pattern recognition or attention to detail, compared to the general population. Nik Sebastian is an artist living in Pennsylvania who specializes in faces. "Details like laugh lines, moles and supposed imperfections ... are more beautiful to me by far than any airbrushed Hollywood star," he writes. "I feel that autism is what allows me to see minor details that most others don't seem to notice."





Myth: People with autism don't process emotions.

People on the autism spectrum actually process emotion and sensory inputs quite intensely — it's just how they process them is different. "It's not that I don't understand something, it's that I don't know how to respond to it," writes Amanda LaMunyon. LaMunyon, who lives in Oklahoma, started painting when she was 7 years old, a year before she was diagnosed with autism spectrum disorder. Research shows that people on the spectrum actually have intense emotional experiences, it is just their coping strategies — how to deal with those emotions — that can be difficult. But they are anything but emotionless.

Myth: People with autism aren't aware of how others see them.

People with autism can be greatly affected by others' lack of understanding. "One of the biggest challenges I face is the view of autism held by many people I meet," writes Kati Mills. "It shocks people that I am happy with my neurology." Mills, who lives in Arizona, titled her self-portrait "Secrets." When she was younger, she struggled socially. It was only as she got older and found a social group that understood and accepted her that she began to feel less alone in the world and became proud to be part of the autistic community.



Source: Kati Mills/Art of Autism



Source: Kateri Michaels/Art of Autism

Myth: People with autism are unemployable.

Valuing neurological diversity in the workplace and the unique potential of people on the spectrum is an idea that advocates believe deserves greater attention. "We have thoughts, feelings and ideas, and we have gifts to share," writes Kateri Michaels (who uses a pen name). Michaels drew this self-portrait at 17. She writes that she often keeps her diagnosis private, concerned that it will negatively affect how people see her professionally (Michaels is an optometrist). Research shows that people with autism spectrum disorder face can face major employment hurdles and discrimination.

Myth: Autism is just a disability.

Simply labeling autism a "disability" doesn't tell nearly the whole story.

"Autism is not a disease, and autistic people are not mentally challenged," writes Aarti Khurana, whose daughter, Amrit, has autism. Khurana describes how, when her daughter was first born, she hoped they would have a conventionally normal life. But as the first few years went by and her daughter never spoke, she worried that that would never happen. In time, she realized that everything she was experiencing with her autistic daughter was normal. It was just a different kind of normal; it was normal in the world of autism — and that was just fine.





Myth: Autism is something that desperately needs to be cured.

While autism comes with its difficulties, it's not something that many people would want to be cured of. "Society's inability or refusal to understand us does not make us broken," writes Chelsea Dub. "To 'fix' my autism would radically change who I am." Dub, who attends Ball State University, describes how she felt incredibly alone growing up, and that, as she grew up, many people misunderstood her different way of thinking as deficient. Many advocates aren't looking for a cure for autism. Rather, they want people to prioritize recognizing the value that people on the spectrum bring to our culture.

Myth: Autism is a condition that some people just have to bear.

Autism isn't necessarily something people are suffering through."My autism makes things shine," writes Mike Allcock. "Playing the piano makes me very happy... Playing Beethoven is like your feelings — all of them — exploding." Allcock, who is 16 and from the U.K., was non-verbal until he was 10. According to his bio, he was first diagnosed on the spectrum at 2 years old. His parents were told to put in him in a special education program and that they shouldn't expect much. Now, Allcock is an accomplished pianist, and a year ago, he started painting for the first time. It's past time to let the myths and misconceptions about autism go, and help other people know what it really means to be autistic — what it means to just be unique and different.



To view the entire collection of **Autism Unveiled** artwork, please visit the gallery of self-portraits.

"Autism is my destiny. Destiny is to seek – not to fight against. We may call the same word 'destiny' as 'luck' or 'fate'. If autism is my path, let me walk it well, let me understand my life walking my path,"

- <u>Tito Rajarshi Mukhopayday</u>

2. Carly's Voice: (blog, video)

"My name is **Carly Fleischmann** and as long as I can remember I've been diagnosed with autism.I am not able to talk out of my mouth, however I have found another way to communicate by spelling on my computer **(and yes that is me typing on the computer by myself).** I used to think I was the only kid with autism who communicates by spelling but last year I met a group of kids that communicate the same way. In fact some are even faster at typing than I am.

Last year a story about my life was shown on ABC news, CNN and CTV here in Canada. After my story was played I kept on getting lots of emails from moms, dads, kids and people from different countries asking me all sorts of questions about autism. I think people get a lot of their information from so-called experts but I think what happens is that experts can't give an explanation to certain questions. How can you explain something you have not lived or if you don't know what it's like to have it? If a horse is sick, you don't ask a fish what's wrong with the horse. You go right to the horse's mouth." (*Carly's Voice*)

Carly loves to write and has recently published a co-authored <u>biography</u>, sharing her own personal experiences alongside ASD. Her blog *Carly's Voice* serves as an online hub for sharing her narrative (including recommended resources).

Below are two videos depicting 'a day in the life of' Carly. Unlike other 'simulations', Carly's Cafe was entirely written by her and was produced with the help of her family.

<u>Carly's Cafe: Experience Autism Through Carly's Eyes</u> https://www.youtube.com/watch?v=KmDGvguzn2k

<u>Carly's Voice: Incredible Medical Stories (Appearance on *The Doctors*)

https://www.youtube.com/watch?v=D2BocHID1eM</u>

3. In Our Own Words: Living On The Spectrum: (blog, collection of narratives)

In Our Own Words serves as a hub for a collection of personal narratives from individuals with ASD. There is a multiplicity of stories here, showing the true diverse nature of the ASD spectrum. The following is a poem featured on the *In Our Own Words* blog, sharing one man's experiences living on the spectrum - breaking through the normative 'mould' society constructs for individuals with ASD:

Only If You Knew Me - Kerry Magro

If you knew me...

You would know I was nonverbal at 2 and a half

You would know I was diagnosed with autism at 4
You would know I got kicked out of two preschools
You would know I had extreme sensory-integration difficulties
You would know I would lash out to get attention when I couldn't communicate on my own
You would know I twirled my hair

You would know that when I was in school, my peers labeled special education "wrong" instead of "special"

You would know I spent hundreds of hours a year in therapy to get to where I am You would know I spent hundreds of hours being bullied because of my diagnosis You would know that being institutionalized was a possibility.

But if you also knew me...
You would know I graduated grade school
You would know I graduated high school
You would know I graduated college
You would know I received a master's degree
You would know I have a job

You would know I consulted for a major motion picture
You would know I live independently

You would know I consult to help parents who have children with autism You would know I am a national speaker, life coach and author You would know I have had a girlfriend

You would know I love my family, my friends and the autism community out there
You would know that I'm Kerry, and no matter what autism means or doesn't mean I'm being
the best me I can be
Only if you knew me...

4. My Autism & Me: (video)

13-year-old Rosie shares her experiences alongside ASD, specifically Asperger's Syndrome: "Although it can be a problem, I wouldn't swap my autism for anything. It makes me who I am and I just wouldn't be the same without it. For instance, I think it gives me more imagination." Additionally, Rosie introduces other children with ASD to share their experiences: "These children tell their own stories in their own words to give a vivid and moving insight into what it's like to have autism."

https://www.youtube.com/watch?v=ejpWWP1HNGQ

5. The World Needs All Kinds of Minds - Temple Grandin: (video)

"Temple Grandin, diagnosed with autism as a child, talks about how her mind works — sharing her ability to "think in pictures," which helps her solve problems that neurotypical brains might miss. She makes the case that the world needs people on the autism spectrum: visual thinkers, pattern thinkers, verbal thinkers, and all kinds of smart geeky kids."

6. How I Learned To Communicate My Inner Life With Aspergers - Alix Generous: (video) "Alix Generous is a young woman with a million and one ideas — she's done award-winning

science, helped develop new technology and tells a darn good joke (you'll see). She has Asperger's, a form of autistic spectrum disorder that can impair the basic social skills required

for communication, and she's worked hard for years to learn how to share her thoughts with the world. In this funny, personal talk, she shares her story — and her vision for tools to help more people communicate their big ideas."

7. How Autism Freed Me To Be Myself - Rosie King: (video)

"'People are so afraid of variety that they try to fit everything into a tiny little box with a specific label,' says 16-year-old Rosie King, who is bold, brash and has ASD. She wants to know: Why is everyone so worried about being normal? She sounds a clarion call for every kid, parent, teacher and person to celebrate uniqueness. It's a soaring testament to the potential of human diversity."

Parental Narratives:

8. Bill & Chris (Son) Challenging Stereotypes of Autism: (video)

In an interview, Bill and his son Chris give insight into Chris' journey alongside ASD (specifically as a son and as a learner). Bill and his wife made the decision to open their own education centre, with a focus on Applied Behavior Analysis (ABA): "...we began teaching Chris. I thought to myself, if he's happy, if he stops hurting himself, you know, if I could hug him - that would be the greatest gift in life...we continued against all odds and he got better."

Bill shares the most important support/strategy to use when living and working alongside someone with ASD: **love.**

https://www.youtube.com/watch?v=Go485342t7g

9. Autism Daddy: (blog)

Although not a personal narrative, 'Autism Daddy' shares the daily experiences of his son with ASD. Autism Daddy uses a quirky sense of humor to make light of challenging times and he continuously shares his thoughts regarding ASD. Through regular blog posts, he gives insight into his son's life - the challenges, but most importantly the successes.

"I'm a 45 year old neurotypical dad with a 12 year old son with severe, non-verbal autism (NOW ALSO WITH EPILEPSY, AN ADDED BONUS!!). My wife is an Autism Mommy Rock Star! However, she didn't like me RANTING about autism on Facebook to our friends & family. So I created this Page to rant about autism & epilepsy while celebrating my son who I affectionately call "the king":-).

I LOVE my son, but I don't love his autism. He was given a raw deal. He has severe autism and it gets in his way with EVERYTHING. So this page will be 75% comically ranting & complaining & telling it like it is and 25% inspirational & warm & cuddly & feel good stories... Ok, maybe more like 80 / 20...:-)

All people are welcome on this page regardless of their backgrounds or beliefs. And you are welcome here if your kid is low functioning, high functioning, Aspergers, etc. But always remember the place where I am coming from. Severe, low functioning non-verbal autism. Just remember this. I have an 11 year old son whose receptive & expressive language are at an 18 month old level and they have been for years. So that's the autism that I am writing about.

I want this autism page to be (for the most part) free from all the debates i see on a lot of other autism pages about whether certain vaccines cause autism, whether Autism Speaks is good or evil, whether this treatment is better than that treatment (trust me we've tried them all), whether using meds on our kids is good or bad, etc, etc.

The mission of my page has become to talk about and try to laugh about all the unpleasantries of this crazy world of autism. I couldn't really find a FB Page or blog that wasn't all sunshine and rainbows. I couldn't find a place where people actually b****** and complained about autism.

So, this is a place to tell it like it is, not to sugar coat things... I talk about poop on here A LOT, and complain about my kid's crazy stims and bizarre sleep schedule. If you don't like people laughing about poop and shouting hallelujah when their kids FINALLY fall asleep, then this might not be the page for you.

Also, please remember that this is my page and on it I'm sharing my story of my life with my wife and my only child with severe autism. Sometimes I'll write something in an attempt to help/teach others in this similar situation. And sometimes you may not agree with everything I write about, and that's ok, but just remember that I'm posting as a 45 year old dad, not some sort of autism expert..."