The Narrow Bridge
PRESS

Sentra Health Autism Roundtable

Presentation by Jacob Raphael

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OPENING

Creating stories together

This is the second time I've spoken after my father, and it may be even more daunting than the first time around. After all, this is the person who not only raised me but helped me learn how to communicate with a world seemingly not designed to do so. I guess a thank you would be as good a place as any to start. Thanks, Dad, for everything. From helping me learn the ways of the world, to letting me add my own voice to *A Miracle of the Heart*.

Though I suppose the two of us are just getting back to what we used to do best: creating stories together.

GROWING UP

Play, stories, and school

If you've read *A Miracle of the Heart*, you'll know that play was how my parents got me to open up. My childhood overflowed with Legos, Playmobil, and other assorted toys. While I wasn't allowed to watch Power Rangers or Teenage Mutant Ninja Turtles, I'd have recognized them on the spot, considering how often we played with their toys. When I learned to talk around age three, these play sessions evolved into little stories about cowboys, superheroes, and/or spacemen teaming up to fight big snakes or other such evildoers.

Around kindergarten or so, I was introduced to the wild world of Pokémon and, by extension, video games. For a period of roughly six months, I dedicated every moment I could to playing Pokémon Yellow on a Game Boy Color that I carried around with me like a stuffed animal.

Which isn't to say that the physical play stopped. Far from it. It's just that now the stories would include Pokémon or other such craziness. Dad and I would also occasionally play video games online whenever he wanted to try and join me in my new hobby. I can still remember sitting on my father's lap, playing some computer tank game.

He even tried to incorporate one or two Pokémon into our play sessions, with limited success.

As the years went on, and elementary school became an increasingly painful experience, our play sessions became a balm. Even as every single one of my friends left that school for greener pastures, my father was still waiting for me at home to play after a long, long day.

Even as I endured the mockery of my peers, and the intentional ignorance of my teachers, I reassured my folks that I was having a decent enough time at my current school. At some point, I'd concluded that school wasn't something to be enjoyed, but endured.

My folks would eventually catch on to what was happening when Mom asked me how school went one day. Instead of the "alright" I typically gave, I let slip "not well." And despite trying to change the subject, Mom did eventually get me to talk about how much I disliked school. Mom and Dad started looking for somewhere else for me that very night.

When my parents mentioned the idea of switching schools, I will admit that, in spite of how much I disliked school life, I was anxious about the whole thing. The new school wasn't Jewish and was a good half hour away from our safe little Baltimore suburb of Pikesville. And while I was miserable at the school I went to, I trusted the devil I knew more than the one I didn't.

In the end, however, this change turned out to be for the better. At the Greenmount School, students were given a level of respect and autonomy that kids at my elementary school couldn't have dreamed of.

GROWING UP

Something I was good at

It was in this sort of environment—where creative freedom was truly respected—that I came to find something I had a talent for. You see, for a very long time I wasn't ever "good" at anything. Even with assistance from Lindamood-Bell-trained professionals and Harry Wax, the developmental optometrist who helped with my eye tracking, keeping up with my peers when it came to, well, *everything,* was hard. Every time I felt like I'd acquired a solid grasp on whatever math concept or grammar rule was being taught at any given time, we'd move on to the next one without much ceremony.

And don't get me started on gym. Ignoring strength and speed, the most important traits someone needs for any sort of team sport are clear communication and solid hand-eye coordination. I don't think I have to be the one to tell you how short in supply those are when you're autistic.

While these problems didn't really go away when I transferred schools, they were diminished. Aside from the usual suite of sports games that were offered after school, Greenmount also offered improv. I don't remember if I was overtly interested in improv, or if my folks signed me up, hoping it would boost my confidence, but I found myself genuinely enjoying the weekly sessions in the school's auditorium. The theater games we played reminded me of assorted stories I'd make up with Dad. I even agreed to be in the two plays that Nancy, the woman who organized the whole thing, was putting on—abridged versions of *John Henry* and *The Tempest*.

And after a few months of hard memorization work and practicing what we'd do for each scene, opening night came. I repeated everything there was to say, the movements that we practiced, ignored my nervousness, and bowed. Later, after my fellow actors and I left the stage, I received compliments not only from my own parents, but from other teachers, and even other parents. And that was when it started to crystallize for me: I was good at something. There was something in this world that wasn't a source of frustration and confusion. Something that I even enjoyed. From that exciting first night, I realized that I had a skill, even if that skill wasn't necessarily one that got good grades. I was good at acting. Later on, I realized that it wasn't just acting. Once I'd gotten a decent grasp on the whole grammar thing, I realized I actually enjoyed writing quite a bit.

DISCOVERING AUTISM

The first clues

I suppose I bring all this up because stories are a part of me, and stories, or at least the stories that my parents and I would make up together, were how I first came to realize that there was something different about me.

Play, in particular, was the first clue. Guided by Dr. Greenspan, Mom or Dad would let me lead whatever madcap adventure I'd cook up during that play session. Whenever I'd play with the other kids, however, they'd keep hijacking the story and taking it in directions that I didn't want it to go. In retrospect, it wasn't fair for me to expect kids who played just for fun to be as good at it as two grown adults who'd been trained by a world-leading child psychiatrist.

There were also the appointments. While I knew that most other kids had the occasional doctor or dentist appointment, the ones I went to felt different. Once or twice a week, I had some form of therapy or specialist to go to, typically at places with names like "The

Spectrum Center." Many were an hour or so away from home. The appointments themselves could be anything from trying to parse out words spoken into my right ear while others were spoken into my left ear, to picking out the differences between two pictures.

Lastly, there were words that tended to pop up around the house and at the aforementioned appointments that never made their way into the stories my father and I would tell. Words like "spectrum," "ICDL," "DIR," "Floortime," and, of course, "autism." The word "autism" seemed to appear everywhere in our house. On books, on newsletters, in Word documents, and even in the occasional piece of junk mail.

I eventually asked my mother, outright, if there was something "wrong" with me, and if it had anything to do with "autism."

It turned out the connection between me and that mysterious word was a little more straightforward than I thought. That was when I learned about my "origin" story. The loss of my limited vocabulary, the visits with specialists, my potential future in an institution, my father's despair, and, of course, meeting the famous Dr. Greenspan. I finally had the full story.

DISCOVERING AUTISM

Searching for answers

Unfortunately, at that time, I didn't really know what to do with that story. If nothing else, I lacked context for what autism *was*. You didn't really hear it that often, especially back in the early 2000s when I was trying to figure all this craziness out. Back then, I hadn't really heard the word outside our house or at a couple of the places we went for therapy. When I asked Mom what autism was, she responded that it was a "developmental disorder," and she'd use weird things I did when I was "little" as examples of "symptoms," such as just picking up rocks and letting them fall to the ground, and letting a bookcase fall on top of me.

One time, I made the mistake of bringing up that I was autistic at school. My teacher responded that "Autism is a type of mental retardation." The student next to me immediately teased me with a "Haha, you're a retard." You'd have thought the woman could be a bit more understanding.

When I mentioned the idea that autism was a form of mental retardation to my parents, they reassured me that autism was a "sensory and developmental disorder." While repetition may help with understanding in some cases, it most certainly didn't here. Once again,

I was missing a piece of the puzzle.

So I looked up autism on Wikipedia, and the precise, detached descriptions the site is known for did little to clarify what it meant *to be* autistic, only that autism was related etymologically to the Greek *autos*, meaning "self."

Amidst the technical jargon and assorted, confusing notes on history, there was that little phrase again: "sensory and developmental disorder." Even with my middle-schooler's vocabulary, I could sense something sinister about the phrase, if not the word "disorder" itself.

But even if I could get a straight answer about autism from my parents, my teachers, the TV, or the internet, none of them could have answered the real questions I had. Questions like: What did it mean *for me* to be autistic? What kind of relationship should I have with being autistic and autism in general? Should I refer to myself as "being autistic" or "having autism"? How should I approach my own story of being autistic? And I couldn't really get answers to questions like that with the resources I'd thought to consult.

So I'd have to find those answers through my own lived story. And based on that story so far, I understood that being autistic was why sounds were either inaudible or so loud they hurt my ears. It was why I knew a part of me was in pain, but articulating *where* exactly I felt that pain, or what *kind* of pain I felt, was such a challenge. It was why trying new food was a constant, endless battle between my embarrassment and my gag reflexes. It was why tags on shirts constantly itched and nagged. It was why it felt like everyone else had a basic understanding of what to say in any given social situation, but I didn't. It was why math homework seemed to take me hours longer than most of the other kids. It was why I went to this or that specialist for everything from hand-eye coordination to allergies.

In other words, it was why life was just a little harder.

DISCOVERING AUTISM

Something I survived

Society tends to treat "disabilities" or disorders as character flaws of the person dealing with them, and autism is no different. And without any guiding voices or approachable tales related to autism, it became a source of shame for me. Something to be hidden and only revealed to those who needed to know, or those I absolutely trusted. Something to be medicated, treated, and willed out of existence, hence the endless procession of specialists and therapists, not to mention the regimen of Strattera and Zoloft I started around that

same time. Even the explanation of what happened when I was a toddler seemed to support that conclusion: I didn't talk, didn't connect with the outside world, but then, thanks to the hard work of both my parents and myself, I did. All because I was autistic.

> *Autism was something I survived. Not something I lived with.*

Don't get me wrong. I doubt this was my parents' intention. They really did just want what was best for me. But that's the conclusion I came to in my confused, insecure mind. The world hardly treated being autistic as something worthy of respect or dignity, so I didn't either.

Consequently, I didn't really know how to discuss being autistic, even with those I was comfortable sharing such facts with. I would always just say it as a confession and then assume that that confession was enough to make the proper impression. Or at least hope that they'd use this new information to accommodate my sometimes off-kilter character. In retrospect, I may have put a bit too much faith in others knowing what autism was. After all, if I barely understood what autism was, how could I expect others to?

And that was my relationship with autism well after I'd graduated middle school, moved from Baltimore to Atlanta, graduated high school, gone on a gap year to Israel, graduated college, and worked an assortment of jobs to support myself while I tried to figure things out.

Which isn't to say that I had stopped growing as a person. My years with the Habonim Dror youth group left me with a deep appreciation for social justice. Later on, during college, I developed a genuine friendship with a combination metalhead and nerd. And being around the motley crew that was his friend group left me with a growing respect for others' imperfections. Eventually I became interested in looking into autism more. But there was still that apprehension at what I'd find. So, as with so many tasks you should do sooner rather than later, I just never got around to it.

FINDING MY VOICE

Autistic voices

Fast forward to 2020, and the COVID pandemic happened. As you can imagine, I had quite a bit of free time on my hands. So I figured I might as well bite the bullet and look into autistic voices. Not the voices of parents or specialists, but of autistic folks themselves.

I'm thankful I did finally bite that bullet, because even the surface-level digging I did changed how I looked at autism. A lot of the articles, essays, and even webcomics I read articulated just how the world wasn't designed to help autistic folks in ways I hadn't really thought about. Such as how people couldn't wrap their heads around the fact that sometimes even interacting with others was harder for autistic folks than they'd think. Even the memes gave me a deeper appreciation for what it meant to be autistic in this world. To quote one, "the 'high functioning' label says more about neurotypical comfort than about the autistic experience." Autism started to feel like something that didn't have to be a disadvantage, or at least that there could be some push and pull between society and me, and that others could at least try to see where I'm coming from.

I also took it upon myself to read some books by autistic writers. John Elder Robison's *Look Me in the Eye* comes to mind. While the book may have aged poorly in its use of the "Asperger's" diagnosis, there's a charm and authenticity to it. Robison not only talks about how people would constantly demand that he "look them in the eye," but also about his misadventures as a child and his experience as a father and a working member of society. I also appreciated his propensity for troublemaking, at least in his youth. He drank, he played practical jokes, he carried firearms, and he was even a roadie for the band KISS for a bit while in his 20s. In one particularly memorable scene, he shot a venomous snake that was just outside of his room while staying at a motel in Florida.

A quote from Robison I quite like is:

> *"Asperger's is not a disease. It's a way of being. There is no cure, nor is there a need for one. There is, however, a need for knowledge and adaptation on the part of Aspergian kids and their families and friends."*
>
> JOHN ELDER ROBISON, *LOOK ME IN THE EYE*

The book that has really stuck with me, though, is Donna Williams's memoir, *Nobody Nowhere*. In it, she discusses how she endured ridicule and confusion from her family as a child, not to mention her struggles to find a place in this world. What resonated with me the most were the visceral descriptions of things that I had trouble putting into words.

> *"I came to learn that all behavior had two definitions: theirs and mine. These 'helpful' people were trying to help me 'overcome my ignorance,' yet they never tried to understand the way I saw the world. It seemed so simple to them. There were rules. The rules were right. I obviously needed their help to learn them."*
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> DONNA WILLIAMS, *NOBODY NOWHERE*

I would eventually go on to the Meetup social media site looking for gatherings for autistic folks, and actually managed to find a group that I've continued to meet up with over the years. While I'm not as close with some of them as I am with other friends, others have become close and dear to me in their own ways.

TODAY

What I've learned

All of these experiences made me realize just how much I, and other autistic folks, have to put up with. The world is loud and confusing. Everyone expects you to know the intention behind their words while being as vague as possible. The rules change all the time, and you're expected to keep up. Also, why do people expect you to look them in the eye? I know that it shows that you're paying attention to them, but there have to be other ways.

I've also become much more comfortable and open when it comes to talking about being autistic with others, especially those whom I may have just met. Earlier this year, I actually admitted that I was autistic, flat out, on a first date. Ten or fifteen years ago, I could never have imagined confessing that sort of thing to someone I'd just met for the first time, much less on a date.

It's taken me three decades to become more comfortable in my own skin and with my own unique qualities, and I'd like to think that I've learned a thing or two along the way. For one, going to occupational therapy or doing Floortime will only help someone navigate the world. If you truly want someone who's autistic to be happy and feel like they're a part of it, you have to find people they can connect with, whether those people are neurodivergent or neurotypical. More than that, find people who are okay with who they are, autism and all. It will be hard, but they're out there; I've met them. A good place to start would be with the off-kilter folks. Those who are into the kinds of weird things they're into. I can't

guarantee it's a surefire approach, but it's as good a place as any to start. At the very least, have voices they can listen to who are autistic themselves. Because I've learned that there are three major things that help someone feel like they're a whole person: having a history, being able to embrace their story, and having a community.

I've come a long way and still have a way to go.

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ABOUT THE SPEAKER

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