The Narrow Bridge

PRESS

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Jacob Raphael's Presentation

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Oh boy, how am I supposed to follow up on something like that? How is someone supposed to follow up the words of their father; a man who not only raised you, but also helped you 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 putting up with me sticking around a decade or so after I should've moved out.

With the ice now properly broken, let's get down to brass tacks. Aside from the time we spent making stories, I think the first memories I had with my father were during our various "daddy adventures." These were usually trips to downtown Washington, specifically the assorted Smithsonian museums, where I could stare, enraptured, at dinosaur bones or a real-life World War II bomber on display. During our walk to the Metro station, we'd regularly pass an ad for a paint company--Sherwin-Williams, I think--that depicted the world being covered in red paint. I distinctly remember that the paint in the ad was red. I asked my dad about it once, and he explained as best he could that it was an advertisement, something designed to get people to buy the company's products. I remember wondering just how the world being flooded with stinky, sticky paint was supposed to get people to buy a product.

I suppose I've always been curious, at least in my own way.

It was only natural that I'd eventually start to wonder what, exactly, made me

different. And make no mistake, I could tell there was something different about me since at least elementary school. For one, playing with my parents was different from playing with other kids. Guided by Dr. Greenspan, Mom or Dad would let me lead whatever madcap adventure I'd cook up during that play session, whether that involved pirates, mummies, or Robot Playmobiles teaming up to help a town or some strange, squid-shaped alien taking power away from wealthy cretins. Whenever I'd play with the other kids, however, they'd keep hijacking the story and take it in directions that I didn't want it to go. And they'd always call me out for poking a Power Ranger or Teenage Mutant Ninja Turtle action figure to make it fall to the ground after some imaginary attack, a habit I picked up from assorted toy commercials. I suppose, in retrospect, it wasn't fair for me to expect kids who played just for fun to hold a candle to two grown adults who'd been professionally trained by a world-leading child psychiatrist in play.

More than that, things that didn't bother other kids tended to get under my skin. Trying new foods for example, even if it was something as simple as chicken or hamburger, was an intimidating proposition that required me to fight my own revulsion. Keeping track of a conversation in a crowd of people talking required a lot of focus as everything blended into a single monotonous droning.

And then there were the appointments. While I know that most other kids had the occasional doctor or dentist appointment, the ones I went to felt different. Part of it was just how many I had. 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 upwards of an hour or so away from our new home in the Baltimore suburb of Pikesville. There were even times when I'd have three a week. The appointments themselves could be anything from trying to parse words spoken into my right ear when others were spoken into my left ear to picking out the differences between two pictures.

Several words and phrases also tended to pop up repeatedly at my house that just didn't show up either at school, on TV, or at others' homes. Words like

“spectrum,” ICDL, DIR, Floortime, and, of course, autism. “Autism” seemed to appear everywhere in our house. On books, on newsletters, in Word documents, and even in the occasional piece of junk mail.

It reached a boiling point around sixth grade or so—give or take—I asked my mother what was “wrong” with me and if it might have anything to do with “autism”. By then, I was starting to put the pieces together (no pun intended) and recognizing that I might be connected to autism somehow, at least in some tangential way. It all felt like a math problem that I could answer if I just knew the right formula.

Turns out the connection between me and that mysterious word was a little more straightforward than I thought. But yeah, that was when I learned about my “origin” story. I don’t think I need to repeat what my father has already stated up here. The loss of my limited vocabulary, the visit with specialists, my alleged future in an institution, my father’s despair, and, of course, meeting the famous Dr. Greenspan. Finally, I’d been shown the answers to the math problem.

Unfortunately, those answers ended up making me feel more foolish than satisfied. It’s one thing to know that you’re autistic. It’s another to understand *what* autism is and what it means to be autistic, especially back in the early 2000s. While I personally have a better understanding of what the condition entails these days, the word didn’t hold much meaning to me when I first learned it. When I asked mom what autism was, she responded that it was a “developmental disorder,” and she’d use things I did when I was “little” as examples of “symptoms.”

One time, I made the mistake of bringing up that I was autistic at my middle school. My teacher's response was 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 have been a bit more understanding.

While the school itself didn’t specialize in educating neurodivergent children, its unique approach to teaching, not to mention the very small class size, meant that it attracted its fair share of children who had learning differences of their own. One kid tended to flap his arms, likely due to his own sensory issues. Another kid

was very open about having Tourette's syndrome.

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.

So, I looked up autism on Wikipedia--which was slowly becoming my go-to for concepts and ideas that I didn’t fully understand--and its precise, detached descriptions did little to clarify what it meant *to be* autistic, only that autism was related etymologically to “auto,” or by oneself. Amidst the technical jargon and assorted, confusing notes on history, however, I did notice that little phrase again: “sensory and developmental disorder.” Even with a middle-schooler’s limited vocabulary, there was something inherently sinister about the phrase, if not the word “disorder” itself.

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?” What should I expect if I tell someone I’m autistic? Did I come off as weird if people didn’t know I’m autistic? Would it help if they knew I was? And I couldn’t really get answers to questions like that with the resources I’d thought to consult.

During the Passover holiday, there’s this traditional anecdote shared about four sons: one wise, one evil, one foolish, and one who doesn’t know how to ask. That last one was me, at least when it came to the autistic condition. I didn’t know how to ask about what sort of relationship I should have with autism. At least not in as many words.

Unfortunately, "because of this did the Lord do for me when I came forth out of Egypt,” the line you’re supposed to give the son who doesn’t know how to ask, didn’t cut it. There was no easy answer to the questions I didn’t know how to

ask, and even if there were, there was no one to give it.

So, I'd have to find those answers through my own lived experience. And based on my lived experience, I understood that being autistic was why sounds were either inaudible or so loud that it 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 struggle of fighting my own embarrassment and gag reflex. 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. Society tends to treat "disabilities" or disorders as a character flaw of the person dealing with them, and autism is no different. And without any guiding voices or genuine sources for answers, autism 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 me, I did. All because I was autistic.

Don't get me wrong. I'm sure this wasn't my parents' intention when they took me to assorted specialists and therapists. They really did just want me to be able to take part in the outside world as much as I could. But that's the conclusion I came to in my confused, insecure, adolescent mind. The world hardly treated being autistic as something worthy of respect or dignity.

So, I started to distance myself from autism, or at least, tried to make myself

seem weird in a “cool” way. I’d hang around the “cool” kids, endure their ridicule, in hopes that, somehow, that would endear me to them. Later, in high school, I’d always be the one to make jokes and push boundaries but I never had much in the way of actual connections. I tried so hard to associate with those who weren’t weird or off-putting that I never actually made genuine friends. Though I suppose it didn’t help that we’d recently moved down to Georgia and that I was a new kid in a new school in a new state.

It didn’t help, either, that I didn’t really know how to discuss being autistic, at least 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 impression. Or at least hope that they’d use this information to help them accommodate my sometimes off-kilter character. In retrospect, I may have put a bit too much faith in others—especially those I’d perceived as older or wiser--understanding what autism was. After all, if I barely understood what autism was, how could I expect others to?

Which isn’t to say that I hadn’t stopped growing as a person. My years with the Habonim Dror youth group left me with a deep appreciation of social justice. A few years later, I developed a genuine friendship with a combination metal head and nerd. And being around the motley crew that was his friend group left me with a growing respect for others' imperfections. That said, it did take a little while for me to make that connection between my own differences and those of others I’d come to appreciate and understand.

I also avoided “digging deeper" longer than I should have when it came to autism, being autistic, and my childhood. And while shame was certainly a piece of my reluctance, I also had a distinct dread that came with the idea of approaching anything that related to autism. It was a topic that I had such a confusing and uncomfortable association with that I felt a genuine apprehension at starting that sort of research.

And then the Covid pandemic of 2020 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 get around to doing something I probably should've done years ago: look into autistic voices. Not the voices of parents or specialists, but of autistic folks themselves.

I'm thankful I did finally bite the bullet, because even the surface-level digging I did at first changed how I looked at autism. A lot of the articles, essays, and web comics I read articulated just how the world wasn't designed to help autistic folks in ways I hadn't really thought about. Or at least how people didn't wrap their heads around the fact that sometimes even interacting with others was harder for us than they would 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. 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. Not books by parents of autistic children, but books by autistic individuals themselves. John Elder Robison's "Look Me in the Eye" comes to mind, for example. While it may have aged poorly concerning his use of the "asperger's" diagnosis, there's a charm and authenticity to the book.

Robison not only talked about how people would constantly demand that he "look them in the eye," but also about his misadventures as a child and his time spent working on special effects for the band Kiss as an adult. I also appreciated his propensity for troublemaking, at least in his youth. He drank, he performed practical jokes, he carried firearms. In one particularly memorable scene, he shoots a venomous snake that was just outside of his room while staying at a motel in Florida. It's so easy to fall into the myth that autism is something that leaves you permanently innocent. I say this as someone who loves his horror movies and his drinking.

The book that really stuck with me, though, was Donna Williams's memoir, "Nobody Nowhere." In it, she discusses how she endured ridicule and confusion from her family early on, 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. "Anything I took in had to be deciphered as though it had to pass through some sort of complicated checkpoint procedure… It was a bit like when someone plays around with the volume switch on the TV." And that was how the world could be, and still is, sometimes; some things are perfectly understandable to a painful degree, and others are difficult to decipher.

Another quote that comes to mind is "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."

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

All 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 without getting any memos. It's hard to know what people are truly thinking when texting is the primary form of communication in this day and age. And, why do people expect you to look them in the eye? I know that its shows that you're paying attention to them, but there have to be other ways. Or at least an understanding that that's not the *only* way to show that you're paying attention.

I also became much more comfortable and open when it came to talking

about being autistic with others, especially those whom I may have just met. I recently admitted that I was autistic, flat out on a first date a while back. I could have never imagined confessing that sort of thing to someone I'd met in person for the first time 10-15, much less on a date.

After so many years, I found the answer to a question I didn't know to ask. It wasn't a straightforward line, but a complex, confusing collection of life lessons and discussions with others. I've come to learn that having community and history, having those with whom you can relate and discuss the issues you face daily, is, in some ways, almost as important as knowing how to interact with the world at large. Experts can help folks who are autistic to better interact with the people around them, but having others who understand you outside of professional settings is as nice a place as any to start with building an identity of one's own.

It's taken me three decades to become more comfortable in my own skin and with my own unique qualities. Which isn't to say I still have a ways to go. That said, I'd like to think that I've learned a thing or two along the way. For one, going to occupational therapy and other such things will only help in navigating the world. If you truly want someone who's autistic to be happy and feel like they're a part of the world, you have to find people who they can connect with, whether they be neurodivergent or neurotypical. More than that, find people who are okay with who you are, autism and all. It will be hard, but they're out there, I've met them. A good place to start would be to find the off-kilter folks. Those who are into the kinds of weird things you're into. I don't guarantee that is 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. Because I've learned that there are two major things that help a part of something: having a history and having a community.

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

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Find out more about David and Jacob and order copies of "A Miracle of the Heart: A Father and Son's Autism Journey at www.narrowbridge.us