
Humanism and Raising an Autistic Child

by Jeremy Kridel

Our son, “S,” is autistic. Ten years old as I write this, S was never typical. He started reading words when he was two. He could use a computer when he was three. He was easy-going about change, and was relatively at ease in large groups of people.

He also repeated kindergarten. During the second go-around, he spent nearly half the year back in a developmental preschool so he could learn how to walk in a line and wait at a door.

S wasn’t the stereotypical autistic child—not that there is such a thing. Nor is there any particularly proper or characteristic response to an autism diagnosis for one’s child. S has been receiving therapeutic services since he was two years old, so we didn’t much worry about the diagnosis of “severely autistic” when he was four, but it can be catastrophic for other families.

Our catastrophe came later.

S spent kindergarten through third grade in public school. That setting—the large numbers of students, the noise, and the inflexible environment—was increasingly difficult for S. There were numerous disruptions in S’s attendance, and he spent more and more time outside the mainstream classroom. My wife left a job with our local Jewish Federation because of calls to pick up S from school early. During third grade, S’s agitation increased, with regular tantrums while going to or from school. He could only hold himself together so long before falling to pieces. We lived in fear of the phone ringing during the school day.

When he was one month shy of his tenth birthday—after brief periods of behavioral therapy, two years of medication adjustments,

four tries with various ADHD medications, an ever-present anti-anxiety medication, an anti-psychotic medication, and a stint on a drug study—S became violent. He became increasingly angry, and spent almost an entire day in a state of constant aggression, except when we gave him a medication that helped him sleep. We hoped sleep would allow him to “reboot” his system.

The first thing S did when he woke up? He gave a blood-curdling screech, and then kicked me. Then he kicked, hit, and scratched himself and us for two hours.

We took him to the ER (the autism specialist’s office made it quite clear there were no emergency appointments, but we could come in September) and waited for hours as he scratched, kicked, punched, smacked, and pulled hair. He attacked himself, my wife, my sister, the medical staff, and me. It took eight nurses, my sister, nitrous oxide, and me to hold him in place for blood tests. He was diagnosed as psychotic.

I never dreamed I would be afraid of a nine year-old.

There is a first time for everything.

II

S was admitted to a “pediatric stress center.” That’s a euphemism for a suicide and drug-overdose monitoring and counseling

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unit for teenagers. No shoelaces. No belts. No drawstrings in waistbands.

S was nine. The next youngest child was thirteen. S's screams the first night shook kids in other rooms out of their beds.

During May 2014, S would spend more than two weeks in these kinds of facilities. The first stay seemed to help; anti-psychotic and ADHD medications were changed, and he was calmer. But he regressed. He never returned to his third grade class: we didn't want to risk him harming other children. And, of course, we couldn't find a doctor.

Within a week of his release, S was violent again. We went to a different ER, one at a dedicated children's hospital. That hospital no longer had any inpatient psychiatric facilities.

S was turfed to a private facility. Though they knew on admission he lacked basic self-care skills, they didn't change his clothing or bathe him, wouldn't work with his behavioral therapist, couldn't figure out how to give him his medications, and wouldn't let us much past the lobby to help with any of this.

That's where S turned ten.

The day before S was scheduled to be released, while we were visiting him during the not-quite-daily visiting hour—hour, not hours—he threw a handful of metal bangles my wife had been wearing.

They landed squarely behind my ear. I couldn't see or hear right for about a minute.

The facility nevertheless released him the following day, because throwing metal at your father's head isn't "acute" behavior. But as luck would have it, the staff's inability to give S medication actually did help: he stopped getting the heaviest of the medications he was taking. It turned out that they were doing more harm than good.

We changed S's physician for his autism care and, since his tenth birthday, he has taken

only one medication at a time—an anti-anxiety medication. He's doing much better. But mental health hospitalization left its mark. S refuses to leave home most weekends if we talk about it in advance. If we drive by a hospital, he objects loudly that he is "all better now." Every time he emits even the smallest shriek, I worry we'll be headed back to the ER.

And, of course, there's the guilt of having institutionalized your kid for his tenth birthday. Dad-of-the-year award-winning material, that. (I'm still waiting for my plaque.)

III

So, as Humanists, what do we do in this situation?

We don't obsess over *why* S is autistic. There is no clear cause of autism. Obsessing over *why* is unhelpful with the *how* of the present, and pathologizing S doesn't help us love him as he is.

And no, vaccines did not cause S's autism.

I can't tell you what you should do in this situation. I can tell you what we did. It could probably have been done better, but I'm not in the business of turning back clocks.

We refused chaplaincy services everywhere we went. We turned to friends and family with varying degrees of success.

We took each day as it came; we did what we needed to do. We met with school officials and healthcare providers to develop a new plan. We went to work when we weren't in meetings or visiting S. We tried to care for ourselves as best we could. We spent extra time together, ate a lot of comfort food, and tried to accept help whenever it was offered. The last of those is important, and in retrospect we would have benefitted from asking for and accepting more help from more people.

Over time, with a change from an individualized program in our local public school to about forty hours per week of health insurance-

paid therapy, S has gotten better. He's gained the ability to express himself, he can manage some of his anxiety, and he's learned some functional skills in the world.

Our parenting has become a much more short-term affair since S's hospitalizations. The planning horizon shortened after May 2014. It's not, "I wonder if/where he'll go to college?" It's instead, "where will he go if insurance stops paying?"

So in part, we do what we've always done. We embrace S's difference. It's what makes him who he is: he's clever, he's funny. He's affectionate. I know, it sounds like he's not, but this is also a kid who randomly walks up to us, says he loves us, and gives us hugs and kisses. S was like that before his hospitalizations, and sometimes he's like that again now.

Embracing S's difference is not about extending him all the leeway he demands. He has a bedtime. He has meal times, and he has to eat at the table. He has to clean up his messes. He has to take a bath and brush his teeth. But it takes longer for him to develop those skills, which means we do more than other parents of children who are the same age to bridge skill gaps.

We also try to make sure he has the therapies he needs to develop skills to navigate his world. For S, this means Applied Behavior Analysis ("ABA"), which focuses on incentivizing desired behaviors. There's dispute over whether and to what degree ABA is the best possible therapy, but often there aren't other choices.

In its earliest forms, ABA did some bizarrely coercive things like attempting to enforce eye contact. S's therapists don't do that. He's learned to buy items in a store, sweep a floor, brush his teeth, tie his shoes, button his pants, zip his coat, use a washer and dryer, and fold shirts and towels, and has improved his use of commonly accepted means to express himself. It's hard to argue with success, and S tells us he enjoys his therapy time.

Embracing S's difference, it turns out, is an evidence-based affair. It is rational for us to do it, because his difference won't change. It is about seeing his unique value, his personhood, and finding ways to allow him to reach as much of his potential as he can. It is a fundamentally humanist thing, because to be a humanist is, essentially, to accept and work within the world as it is for a world we want to see, while finding the inherent value and dignity in each person.

IV

Rabbi Sherwin Wine wrote, "Courage is not an introspective victory. It is an act of will." (*Staying Sane in a Crazy World*). Courage is accepting the facts and choosing from the options that are real. It is getting up day after day and trying to move forward, knowing that the only things that will happen are the ones you and the others in your life can work up to accomplishing.

For our family, courage is not about being unafraid. Courage is about persevering when the hard times come and we want to hide in bed or beg off the day and wallow in our tears. Courage is about remembering that we have an obligation built from love to take care of another person who needs us more than his peers need their parents. Courage is about planning.

Our courage is not optional. Fortunately, most days, we have no trouble finding it.

But then there are days like the one after I started to write this article. A day when S gave me five hours' sleep and then was very much inside himself most of the day, chattering endlessly and nervously about *Bob the Builder* and *Sesame Street* and *Angry Birds Seasons* and the change of seasons and the end of November and the beginning of December and going home and not going home and eating cake and not eating lunch.

It was a day when S was asked to play a game of team tag at the park and I had to decline for him, because I knew he would be unable to quickly learn the rules; he suddenly tagged one of the kids, only to run off and never return

to the group again. It was a day when he was afraid to walk across a bridge he usually runs across at the playground. A day when every dog he saw sent him cowering (he's desperately afraid of all animals except fish). A day when S displayed fewer social capabilities at ten than the two year-olds playing on the toddlers' playset alongside him.

A day, in short, when I thought I was a laughable fraud for trying to write this article.

Those are the days when courage is simply not crying in public—not because I'm sorry for myself, but because, as the co-owner of S's therapy center has said, "cute at four, weird at fourteen, criminal at twenty four." What happens when my wife and I are gone? I don't care about someone remembering me; I care about someone remembering that S needs care, because there is dignity simply in being a person.

Sometimes, courage is remembering to update your estate plan. Or gritting your teeth

and filing an appeal when insurance benefits are denied. Or taking your kid to the park when you're not quite sure how that's going to go that day, because his head is in a place that has you worried and he's given his hands names and says they're going to hit people, but his favorite thing in the world is to swing, and he can't do it by himself.

Courage is figuring out what needs to be done, picking a piece you can do, and starting there. It's calling for help when you can't do it yourself. Sometimes help is family or friends, or just going to work on Monday hoping you don't get a call from school. Sometimes it's a therapist. And, candidly, sometimes help is an anti-depressant.

Individual courage is not always enough. Sometimes making it through the day is its own achievement; sometimes, even that takes help from others. On those days, courage is getting up and continuing on.

It's everyday courage; but it's not courage every day.



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