



Creative Intervention

An Autistic Letter to a Neurotypical Friend

ELSBETH DODMAN

Dear David,¹

I'm sorry I haven't written to you in a while; springtime came and before I could turn around the trees were green again, the sun high and hot, and it was August. I wonder if time knows its own flow or if it's just as surprised to be here as we are.

I got a chance to watch that TV show you recommended – the one with the Autistic doctor. You know I don't really watch that much TV. I usually just watch the same old movie for those first five minutes over and over again. I can barely sit still for a full episode, but I tried really hard this time because people kept recommending it to me. Because you kept asking me to. It still feels novel to see an Autistic character on TV. I remember when I first started educating, nobody had heard of autism, now we have our own caricatures on prime-time television. I must admit, most of the books on autism I read when I was younger were written by doctors or people with letters after their names. Strange to read about myself in a cold, pathological way – to see my life broken down into case studies and diagrams and clinical-speak. I think after a while you get used to hearing your story spun out as pathology; your pieces broken down into “behaviors,” “skills to work on,” and “deficits.”

After a while I left the textbooks alone. There's only so much you can take, David. Only so many hours you can sit with a book and see the parts your parents highlighted as they found you somewhere in between the pages of medical-speak. I left them and found the books that parents wrote. Their journeys “through” autism, their “struggling” to “overcome” their child's diagnosis, them “reclaiming” their child, all with rave reviews from other non-Autistic writers about how brave and honest they were to talk about their child's life in such intimate detail – my life and all its intimate details – and what their child's diagnosis meant for them. I left those books behind after a

¹ Guest editors' note: Elsbeth has been writing short essays as letters addressed to a man named David as a way to start a conversation about autism issues and the experiences she's had. In real life David was one of Elsbeth's drawing teachers. None of her letters have ever been sent to him.



mother recounted her story of therapy where she and other parents held their Autistic children tightly while screaming, “Don’t you understand what you’ve done to us? Don’t you understand you’re tearing this family apart?” I didn’t want to find myself in between those pages even though I held the story in my heart. Stories live with you, David. Once you read them, they become a part of you forever.

I watched the doctor TV show. I saw parts of my story, but in stilted glimpses through the lens of someone else. It was like an outsider who has never been to your country telling you very confidently what it’s like to live there in bold stereotypes without any of the nuances. You’d forgive yourself for being a little cynical.

Humans are storytellers. We share our history, our traditions, and our experiences. All in a shape with a beginning, middle and end. Stories are important, David, and narrative has power. “The horse kicked the man” or “the man allowed the horse to kick him” – each creates a reality, and the speaker gets to shape it. We create truth. We build worlds on words and expect people to live in them. I live in them.

Autism is all about stories, David, and who gets to tell them. It’s about voice with a capital V and who has one, physically and metaphorically, and it’s all about whose Voice gets to be heard. Here it comes, David, the greatest irony of autism. They want you to communicate – preferably to speak if you can manage – it’s a parent’s fondest dream to hear your voice but you still don’t get a seat at the table to talk about autism. You don’t get to be the narrator of your story because you’re still Autistic. Voice or not. Unreliable, disabled, stupid. You don’t get to have a say in autism policy. You don’t get to have a voice in what autism best practice looks like. You don’t even get to see people like you on boards or committees. Your participation is almost an afterthought, David. Autistic people are optional in autism issues and in autism stories. You worked hard for your voice, but you don’t get to use it. Someone else gets paid to play you in the story of your life while you and your friends face high unemployment rates and crippling poverty – and that depiction is how everyone sees you. It might even be how you grow to see yourself.

“You have autism? Just like Sheldon from that show!”

All your hard work – that hard-won voice – and it amounts to precious little. The same people who beg for their child to say “Mama” will sit on a committee or in an online group and tell you that because you can talk you aren’t Autistic enough to talk about autism. You’re only one person. “You cannot possibly speak for the whole,” they’ll say, without tasting the irony that they do it every single day. They’ll turn away from you and away from their own hypocrisy. The high bar they set is one that they themselves can’t live up to! What difference does it make if I can talk? What does it matter if I can’t be a part of the conversation? Why did I work so hard? What was it for?

Oh no, David – you do not get to give us language and then ask us to only give you comfortable words. You do not get to give me a voice and then tell

me to listen quietly. There's a reckoning of words waiting if you think that's the way this story will play out. I'm not interested in sitting with my hands out waiting for the promised trickle down of awareness and services. I want to build that future with my own hands.

Autism in the media isn't for Autistic people. It's for you, David.

Autistic people do not get to tell their stories or shape their truth – be it on TV, or in politics, or on committees. The truth we wear – the truth we are made to shoulder – is shaped by parents, by service providers, by people with letters after their names, and sometimes by a non-autistic man on TV who gets paid very well to wear my skin without ever having to live a day in it.

Governments will create plans and sign your name, famous people will star in shows about your life, and caregivers will make agencies under your banner – claiming space in your community before shutting the door behind themselves. They will speak for autism and disregard that autism is already speaking. We live and die by their choices. It's not just about stories, David. This isn't a game for you to tune in next week. It's shaping a truth that will determine my life. Will accessible housing be available? Will we hire more Educational Assistants in schools? What about supports for Autistic adults? Are we addressing the lack of mental health supports in our country? Will we tackle the unemployment rate faced by Autistic people? Will we acknowledge the ableism that informs our society? The ableism that informs our services? Will we change the narrative we keep telling ourselves about disabled persons so that disabled persons can have the audacity to live and celebrate our lives?

I found my Individual Education Plan in a binder in the basement. It read like every other clinical report about a girl named Elsbeth – someone I'd come to find in highlighted textbooks and in memoirs. The report dictated my education and the supports I was supposed to get in school, and I'd never even seen it before. I didn't even know what it said, but my name was on it. The individual was divorced from the Individual Education Plan.

It all goes back to that story we tell ourselves about how developmentally disabled people are too stupid to have anything to say – about anything – and that the people who speak for them are heroes for doing it. Disabled people don't have a thought in their heads. They're retarded and we can't expect anything from them. Elsbeth is slow. It's faster if we make choices for her. So, they do. They still do. They still are! If you're not in the room, a government, an agency, a decision maker can shortchange you and say it was for your own good. They can write a blank check, sign your name and call it fair. They still do!

So, if you paint me as suffering, I will spend my life suffering and hating myself for a diagnosis I cannot change. If you call me retarded, then I must be too retarded to be considered reasonable – even when I'm right. If you say you grieved for the “normal” child, you could have had then my life is a funeral procession towards the empty grave of a girl that never existed. If you colour me unskilled then how can I get someone to give me a job? If your

book says you overcame autism then I am to be overcome – something wild with claws and teeth to be conquered and tamed. You cannot pretend to be surprised when I start to see myself as that wild thing instead of a real girl.

If you say you reclaimed me, brought me back from autism's grasp, then I have no agency in my own body or in my life. I will be a shell of a person waiting for a savior instead of recognizing my effort and my personhood. And if my savior never comes, am I condemned? What kind of life is that? What kind of hope do I have if you paint being disabled as the worst-case scenario? If all you can see in me are "deficits" then I grow to love myself in spite of you – claws and teeth and all.

If you tell my story for me then that will be the truth I must wear – and it will fall to me to disprove it, to work every damn day, David, to be even more! Or else I drown in it. And if the people you say you speak for have to clean up after you, then really, what good are you to them?

I'm not saying that actors can't ever pretend to be disabled or that the TV show I watched was no good. Sometimes it's those first few shaky steps that ease society's bend towards moral justice. Change rarely happens all at once or is born perfect from the forehead of the gods. You're trying, and that's important. And an actor's whole job description is pretending to be something they're not – spies and doctors and superheroes – but in a world where Voice matters, where your stories have real life consequences, where your voice comes with a privilege and mine does not... is it ethical? Do you not owe me more, especially when you're profiting from my existence? Would it not be better to hire Autistic actors? Autistic writers? To give Autistic people the chance to tell our stories and be visible, to show our truth, to shape our realities? To be authentic and have the audacity to be happy in our Autistic lives?

Who would it hurt to show disabled people as empowered? Who is injured by disabled people being seen as credible enough, competent enough, to have truth – and to be worthy of telling it? What do we stand to lose by having Autistic people seeing themselves as champions of their own stories, as authentically themselves, as capable? Happy with ourselves? Would it wound you to see our lives as something more than a voyeuristic spectacle – as inspiration porn for you to jerk off to in prime time and feel better about yourself?

Or are you afraid that our real stories will uncover some uncomfortable truths about your comfortable society? Are you afraid you might come face to face with yourself in our stories and that you won't like what you see staring back at you? That you might have to get up, turn off the TV, and help us tear down the barriers that keep us from fully participating in society. Are you scared about the amount of work there is to be done?

It is a lot of work. But it's still worth doing.

Sincerely, Elsbeth.