

The problem with the term “low functioning.”

So, I wanted to share about my time volunteering in the after-care program at a school for kids with developmental disabilities (mostly autism and Down Syndrome). Here are some of the things I learned and observed about the autistic students in the program:

Every single autistic student was wildly different in their needs, abilities, personalities, and strengths. All of them would probably be categorized as “level 3,” meaning requiring very substantial support in everyday life, but that honestly doesn’t reflect how individual all of their needs and abilities were.

One kid, named Matt, was functionally nonspeaking and was extremely easily overstimulated & overwhelmed. He had a hand-biting anxious stim that had caused severe visible scarring and bruising on the back of both of his hands. He had aggressive meltdowns frequently, and often destroyed classroom materials. He was also incredibly intelligent and therefore easily bored by the conspicuous lack of intellectually stimulating activities in the after-care classroom. He could read, and clearly understood everything and everyone around him. He also had perfect pitch and was mind-blowingly talented at playing piano and creating original compositions on the classroom keyboard by layering recordings over each other. The songs he made were absolutely beautiful, and extremely complex.

One student, named Ethan, developed a friendship with me. He was very gentle in nature, and had a great sense of humor. He had functional speech, most of which was scripted. His processing speed and executive function was very slow, and it took him a really long time to organize his thoughts, body motions, and words in order to express himself. He really liked to play hangman, and had a great love for words and reading, though he couldn’t always say all the things he wanted to say. His favorite conversational scripts were about basic safety rules, but there were some really creative ones, too. One example was:

Ethan: take your helmet off in space?

Me: nooooo....

Ethan: you might...

Me: you might die! It’s too cold in space, and there’s no oxygen!

And then, after a few other scripts, I’d flip it around.

Me: can I take my helmet off in space?

Ethan: no!

Me: why not? What if I really wanted to?

Ethan: too cold!

Me: and then what might happen?

Ethan: might die!

Another student, named Kayla, was entirely nonspeaking, but made noises and used a tablet to express her thoughts and needs. She often had meltdowns and would pull teachers' hair because she was easily overwhelmed and couldn't communicate her needs effectively. She was also clearly intelligent and aware of what was going on around her, and often laughed and made jokes in her own unique way, without words. She sometimes poked the teachers and play-wrestled with her aide for fun, smiling all the while.

And there was Garrett, who was highly verbal and communicative, and who really liked to discuss basketball and the personal lives of the teachers. He had a great memory and remembered the names of the teachers' cats, sisters, husbands, brothers, etc. as well as all of their relationships with each other and events that happened or were coming up. He happy stimmed by clapping his hands and rocking back and forth. He also liked to have fun in conversations by insinuating something obviously untrue about the person he was talking to, then insisting upon it while smiling and happy stimming. An example was:

Garrett: you're going to buy me dinner tonight!

Me: oh, really? I wasn't aware of that.

Garrett: yes, you are. You are going to buy me dinner!

Me: what if I don't want to buy you dinner?

Garrett: you will!

And that was that. It's always important to remind people that the level of support and assistance an autistic person needs in daily life doesn't tell you anything about what areas they need help in, what their personalities are, or what their talents and joys are. When autistic self-advocates talk about how autism is a spectrum, and how every autistic person has specific needs that are more nuanced than labels like "low functioning," we're talking about Matt, Ethan, Kayla, and Garrett. We're talking about ourselves, and we're talking about every single other autistic person.

Matt is not “low functioning” when he sings and plays the piano like someone playing Carnegie Hall.

Ethan is not “low functioning” when he comes up with creative hypothetical scenarios and discusses them with other people.

Kayla is not “low functioning” when she gives her aide a sly smile and slowly reaches over to arm wrestle him as he waits and laughs.

Garrett is not “low functioning” when he gossips with the teachers about their spouses and children, as if he’s known them his whole life.

No human being can be reduced to such a broad and demeaning label. And honestly, their “level 3” or “very high support needs” designation doesn’t really tell anyone much, either. That’s because autistic people are all unique individuals, not imaginary copy-pasted stereotypes.

~Eden 🐸