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Being the Curriculum

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Cover Page Footnote

I would like to thank Frank Menniti, who ran journal club, for asking me to give the autism presentation – systemic awkwardness is not the fault of the individual, and asking me to give that presentation was likely his best available choice. I would also like to thank Ranjita Dhital and Kai Syng Tan for their work on the Neurodiversity in/and creative research summer programme 2021, where I had the opportunity to discuss and refine my ideas related to this work. Finally, I would like to thank Michelle Dawson, an autistic autism researcher whose tweets about autism research led me to quite a few of the neuroscience-related papers I cited in this paper.

Being the Curriculum

Alyssa Hillary Zisk

It's late January 2018, the start of the spring semester, and the journal 'club' for my neuroscience program is focusing on developmental disabilities. The purpose is to have the neuroscience graduate students engage with peer-reviewed academic articles, discussing them together, and the topics rotate each semester. Since this 'club' is also a class, the first few weeks often consist of longer presentations introducing the topics. This semester, we're going to start with introductory presentations for a few different disabilities: one chromosomal, one single-mutation, and one with complex genetics (thankfully not fully known—right now, that knowledge *would* be used for eugenics). The professor running the class will bring outside experts into our class to give these presentations for Down syndrome and for Rett syndrome. He asks me if I want to give the presentation for autism, knowing that I'm autistic.

Do I want to? It's complicated.

On one hand, I wouldn't be the first student to give this kind of introductory presentation, in lieu of presenting on a single paper. One of my classmates spoke about Parkinson's. She was asked because she'd been a physical therapist for people with Parkinson's, not because she had it herself. Somehow, I don't think these are quite the same.

On another hand, I'll be on display as the curriculum if I give this presentation. I use augmentative and alternative communication part time, because I can speak some of the time but not all of the time. That's not the kind of accommodation that can actually be kept private. I could theoretically use my text-to-speech tools for class participation as needed without telling anyone why. My needs still wouldn't be private, just the reason for them. However, in practice my classmates do in fact know I'm autistic. I'll be on display as an example of the neurotype we're discussing. (Would leaving someone else to give the presentation change that, once the professor decided autism would be one of the three examples at the start of the semester?)

On an imaginary third hand, the hand that wins the day: I want *nothing* to do with sitting through the presentation most ‘autism experts’ would give. Thank you, no. If I don’t give this presentation or get excused from the day, then there’s a very real chance of my conspicuously and defiantly throwing myself into a wall . . . again (Hillary 2019b). I am a person, now, autistically, in your classroom and in your conference hall, while neuronormative experts discuss “optimal outcomes” and “loss of diagnosis” as if they were the same thing. At the American Academy of Arts and Sciences, I was not given the opportunity to be a speaker. When these assumptions were spoken as fact, I took my natural stimming, which can include bouncing off the walls, up a notch—instead of gently bouncing my back against the wall, I threw myself hard enough for the vibrations to be felt near the stage from the back of the auditorium where I was standing, repeatedly.

But a flat stretch of wall is a bit harder to find in our conference room turned classroom than it was at the American Academy of Arts and Sciences. And even if I manage not to attend the hypothetical presentation by someone else . . . my classmates will still attend. What will they internalize? I don’t want to know, but I won’t escape finding out: I’m already out as Autistic. After whatever presentation someone else could give, I will still be out as Autistic, and my classmates will have internalized . . . something . . . about what that means. Will they decide I’m unlike their understanding of autism and thus Not Really Autistic, or that I *am* like their understanding of autism and therefore Too Disabled To Understand? I don’t want to know that, either.

So, it’s time to go be the curriculum. What do I want a bunch of neuroscience students to know about autism, that fits in an introductory presentation? How do I talk about the very real differences, about a very real experience of disability, in a way that my classmates trained in neuroscience, often trending more towards basic biology than I do, won’t decide they need to therapize me in class? And yes, it’s a concern. At my orientation for this PhD program, I had a professor tell me, “no flapping.” (Obviously, I didn’t listen. I typed back, “yes flapping!” and flapped more.) How do I give knowledge that a neuroscience class will interpret as sensible science, without either continuing the systemic epistemic violence of ignoring autistic people as knowers (Ymous et al., 2020) or making a self-narrating zoo exhibit of myself (Sinclair, 2005)? Also: why is it *my* job to walk this tightrope? *What is this tightrope doing in science to begin with?*

I tell them about models of disability, including not only the medical model but also the scientific model (Gosling, 2008), because my classmates are scientists. They need to know pushing for technological changes to our bodyminds is not, in fact, a neutral position doing only good.

I tell them about language and autism: not how our speech and language are supposedly “wrong,” but how it works. Here is hyperlexia, which nominally just means early, self-taught reading. In practice, hyperlexic people are almost always autistic. Here is echolalic communication, where people re-use relevant quotes (or parts of quotes) to communicate. Echolalic communication is not an oxymoron. It’s part of gestalt language acquisition (Manning & Katz, 1989), it’s not unique to autism (Peters, 1977), and it works, much the same way non-echolalic communication does (Prizant & Duchan 1981; Prizant & Rydell, 1984). This isn’t news; autistic people could have told you this if you asked, and these references are older than I am!

The neurological findings related to autism are the slides I go through fastest. Yes, this is a neuroscience course. No, this isn’t what I actually care that my classmates learn. I need them to know that exclusion is a bigger problem, that dehumanization is a bigger problem, than anything our brains are doing differently. I need them to know that social issues occur in a social environment, aren’t a problem located within a single person, are related to neurotypical peers recognizing quickly that we are different and deciding that they don’t want to interact with us (Morrison et al., 2019; Sasson et al., 2017).

I need them to know: if you’re going to do autism research, while understanding how autistic people actually work is useful, it’s not the most pressing concern. Instead, the most immediate need is for you to remember that we are human people who do things for human reasons, and to be wary of building on work from people who literally said we weren’t people in the psychological sense (Chance, 1974). We count as people (Gernsbacher, 2007). If neurotypical cognition tends to work one way, and autistic cognition tends to work another way, it’s not correct to call the neurotypical way “how human cognition works.” Because fun fact: several neurocognitive quirks we learned about in our degree are actually quirks of neurotypical cognition, not of human cognition in general, and we were not taught this in class.

I learned elsewhere that the McGurk effect, where mismatches between visual and auditory cues can lead to a person ‘hearing’ a sound other than the one that was made, is reduced in autistic people (Feng et al., 2021), years after I was the only person in my neuroscience class the effect *didn’t* work for. (And yes, the researchers noting that it’s a weaker effect in autism are framing this as a deficit. Even though the effect being weaker means we’re more likely to hear the sound that was actually produced. Make it make sense, please.)

I learned elsewhere that autistic people are, effectively, harder to bribe (though this is somehow a theory of mind deficit?) (Hu et al., 2021). I learned elsewhere that Weber’s “law,” about the smallest difference most people can perceive between stimuli, is not actually a law because it doesn’t hold for autistic people (Hadad & Schwartz, 2019). One could argue that the discussions of how these processes actually work for autistic people *do* belong in a course on autism, or in a course on neurodivergent psychology. However, the failure to specify that the way these processes generally work for neurotypical people is, in fact, *neurotypical* psychology rather than *human* psychology excludes neurodivergent people from “how cognition works.”

Human cognition doesn’t all work one way. Researchers taking their intuitions about their own cognition (our own cognition), using their introspective understandings of how they think and perceive (our introspective understandings of how we think and perceive) to guide hypotheses of how cognition and perception might work is, I think, a reasonable thing. I even do it: my experiences of thinking without visual mental imagery guide my guesses about how cognition without visual mental imagery, or aphantasiac cognition, might work in general. The use of intuition is not the source of the problem. The problems come from a combination of factors:

- The researchers who make hypotheses about cognition based on this introspective intuition are usually neurotypical.
- Neurodivergent people face barriers to researching neurodivergent psychology (when neurotypical people get to research neurotypical psychology without issue).

- Neuronormative intuitions are prioritized over neurodivergent ones, even about how neurodivergent cognition works.

See also: arguments about the reality and importance of visual mental imagery. It turns out some people have it and some don't, but people really wanted to show that cognition either requires mental imagery. So am I, an aphantasiac person, merely executing a program and not thinking, as in Searle's thought experiment (1980)?

I know different minds work differently. As an autistic, aphantasiac teacher, I try to keep this in mind. But do others remember that my mind exists (do they believe my mind really, truly, exists as a mind?) as they teach about how minds work? Yergeau says they're getting used to not existing, in rhetoric (2013). I'm not convinced I exist either, in neuroscience. Do I have to exist, to be the curriculum?

Author's Note: The presentation took place one semester later than the main events of "Am I the Curriculum?" (Hillary 2019a), which is not needed to understand this piece but does address similar themes. The follow-up events to "Am I the Curriculum?," however, largely occur after the main events of this paper. Reflections on a variety of systemically awkward experiences in my neuroscience PhD program continue to the present.

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Alyssa Hillary Zisk (they/them/theirs) is an autistic researcher, sometimes but not always an autism researcher. They recently completed a PhD in Interdisciplinary Neuroscience at the University of Rhode Island. Alyssa is broadly interested in disability and communication, neurodiversity and representation, and the overlap of queerness and neurodivergence. Just like they are sometimes but not always an autism researcher, Alyssa's research on disability and communication is sometimes but not always related to their own experiences.