CURRICULUM INQUIRY
2019, VOL. 49, NO. 4, 373-386
https://doi.org/10.1080/03626784.2019.1664255

Am I the curriculum?

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ABSTRACT

When we consider disability and the curriculum, we usually mean preparing professionals to work with people with disabilities or including students with disabilities. Here, I provide a personal description of these ideas colliding. It's Fall 2017, and I'm taking a course on Augmentative and Alternative Communication (AAC). That means it's about disability, or really, about certain services for people with disabilities. My classmates are studying to be speech language pathologists. I'm Autistic, and I use AAC part time because I can sometimes, but not always, speak. I'm the first AAC user to take this class. As we go through, the professor keeps saying how much they're learning from me, as an AAC user. So: am I the curriculum or the student? Am I both? Could I be a teacher? As I work on and eventually publish my class project, an overview of AAC use by speaking autistic adults, am I the object of research or the researcher? Am I both?

KEYWORDS

Augmentative and alternative communication, autism, disability studies, student and teacher experiences, higher education, personal essay

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It's Fall 2017, and I am taking a class on Augmentative and Alternative Communication (AAC). My classmates are studying to become speech language pathologists, associated with the American Speech Language and Hearing Association (ASHA). I'm here because this class counts as an elective in the neuroscience program, because I can't always talk and use strategies like typing to communicate when I can't talk, and because I want to know what professional curriculums have to say about people like me. Academic institutions usually consider disability as something negative to remediate or hide (Connor & Gabel, 2013), and while that's not how *I* conceptualize my status as an Autistic and proud part-time AAC user, I don't automatically trust any field to view me as a person. I want to know what they're saying about me, and to consider the curriculum critically. Am I, perhaps, the curriculum?

When they are being broad and inclusive, ASHA says:

> AAC includes all of the ways we share our ideas and feelings without talking. We all use forms of AAC every day. You use AAC when you use facial expressions or gestures instead of talking. You use AAC when you write a note and pass it to a friend or coworker. We may not realize how often we communicate without talking. (ASHA, n.d.b)

By that definition, everyone is an AAC user, including me. But in practice, that's not what we mean when we talk about AAC. If we want to talk about passing notes to friends or co-workers, or about teens texting each other in the back seat so they can have a conversation their parents don't hear, it won't be in

Perspectives on Augmentative and Alternative Communication/Of the ASHA Special Interest Groups[1], or *Augmentative and Alternative Communication*.

When we talk about AAC, we're talking about how people whose disabilities affect communication use these other strategies, because they (we) have to. We're talking about Stephen Hawking controlling a computer with his cheek, or a child pointing to pictures to tell their teacher what they want for snack today. We're talking about specialists supporting communication through any means a disabled person can use, arguing with other professionals who focus on speech and incorrectly view alternatives as a last resort that might inhibit speech (Romski & Sevcik, 2005). And maybe, just maybe, we're talking about me.

I'm Autistic, and I have intermittent speech – sometimes I can talk, and sometimes I can't (Sparrow, 2017). I text, both when I can talk and when I can't. As a teacher, I answer questions on index cards and leave them with my students. I write on white boards, both with and without speech. I have communication applications on my iPad.

Is all this AAC?

Maybe. When someone we think of as “using AAC” texts, that's still AAC (Williams, Beukelman, & Ullman, 2012). But I can talk, sometimes. What if *I* start texting because I can't talk right this minute?

Is that still AAC?

Am I the curriculum?

I'm by no means the first person to wonder if I might be the curriculum, just as much as I'm a student. Students of colour at white institutions become the curriculum too – the diversity curriculum. They are expected to educate normative peers about their “diverse” identity, while also being told how they aren't like the others in their “diverse” group (Gaztambide-Fernández & DiAquoi, 2010).

It's not the same for me, of course. I'm still white. But it's relevant. I'm registered with disability services at my university, to protect my right to use … the topic of this class. Three AAC users will present as part of our curriculum. We're told it's important to learn from them.

I'm also told how much the professor and my classmates are learning from me. My situation may be somewhat similar.

Does that make me a teacher?

Or am I the curriculum, too?

The question of my position – student, curriculum, or teacher, as well as researcher or object of research – is one of identity. I want to know where I, an Autistic person who uses AAC some of the time, fit as a graduate student in an AAC class and a researcher doing work on AAC. Like Yergeau (2013), I combine scholarship on my topic of AAC with my relevant experiences. There may not be a concrete thesis, because there are no simple answers. Instead, this narrative spirals.

So, do my varied communication supports, ranging from writing on index cards to dedicated iPad apps, count as AAC? Am I the curriculum?

> Augmentative and alternative communication (AAC) is an area of clinical practice that addresses the needs of individuals with significant and complex communication disorders characterized by impairments in speech-

> language production and/or comprehension, including spoken and written modes of communication. (ASHA, n.d.a)

No clinician addressed my communication needs. I wonder why it needs to be clinical. Is it because ASHA is an organization with a clinical focus, or because disability is usually associated with the medical and the segregated? We never really discussed what "significant and complex" meant, if it should really be "significant and/or complex" when applied to one person. I assume "can't talk" is significant. A full explanation of how my speech works and doesn't work is complex, though perhaps not in the way they mean.

> AAC uses a variety of techniques and tools, including picture communication boards, line drawings, speech-generating devices (SGDs), tangible objects, manual signs, gestures, and finger spelling, to help the individual express thoughts, wants and needs, feelings, and ideas. (ASHA, n.d.a)

I use a speech-generating device, sometimes. It's what my accommodations letter used to say I got. My iPad has Proloquo4Text, designed for literate people who can't speak, and my laptop has eSpeak, which wasn't really designed for AAC but works for Mandarin Chinese. I use them least, but I use them. That makes me an AAC user, right?

My professor thinks I'm an AAC user, the first one she's had in her class. I believe it – I know I'm the first person at my university to get AAC use as a formal accommodation. They put it in their system for me, three times now as we've updated the wording.

We talk about the meetings and paperwork involved in getting AAC to students. I think about my meetings with disability services, ensuring my right to the topic of our class. So, am I the curriculum? Probably. But where do I fit?

> AAC is augmentative when used to supplement existing speech, and alternative when used in place of speech that is absent or not functional. (ASHA n.d.a)

Is my intermittent speech, my Schrödinger's[2] speech that is neither present nor missing until I collapse a wave function of possibilities into a single answer by observing my speech abilities of the moment, supplemented by other communication methods? Sometimes. Teaching, I write on the board, even when I can speak. Writing alongside fluent speech puts me in that broad category of nonspoken communication but not the (clinical) accommodation for disability.

Is my writing or typing "used in place of speech that is absent or not functional"? Sometimes. I still teach when I can't speak, writing on a white board or an index card.

Is it augmentative or alternative when I type as a teacher in an online classroom? There is no audio in the classroom, so my Schrödinger's speech remains unobserved, both working and not. Typing here is neither clinical practice nor formal accommodation, but I'm not the first to answer limited speech with online teaching (Lance, 2002).

Is my AAC augmentative or alternative? Yes. That's why it's AAC. You wanted to know which? I'd like to know too. I don't think the definitions were built for people whose speech varies from zero to fluent-seeming.

> AAC may be temporary, as when used by patients postoperatively in intensive care, or permanent, as when used by an individual who will require the use of some form of AAC throughout his or her lifetime. (ASHA n.d.a)

Is it temporary or permanent when I don't always need AAC, but the reason for my sometimes use is forever? These definitions weren't built for me, either.

Do my classmates spend so long wondering about precise definitions of where they fit (or don't)?

Am I the curriculum? Am I a student? Schrödinger is back, and observation isn't providing a single answer now.

I open my textbook. We're to write reflections on each chapter, guided by questions the professor provides.

> For most of you who read this book, daily communication is so effortless and efficient that you hardly think about it when you interact with others face to face, over the phone, through email, by texting, or through social media. You probably do not remember the effort that you initially expended as an infant and toddler to learn to speak because now these processes are largely automatic. Usually, you just "talk," formulating your messages and executing speech movements as you express yourself. (Buekelman & Mirenda, 2013, p. 3)

For most of you. Most. Not all, and not always. And even here, I am odd: email, texting, and social media are as effortless and efficient as suggested. My Schrödinger's speech, however, can collapse anywhere from "none" to the apparent fluency of "most" readers and *still* not meet my communication needs. Where do I fit?

Don't get me wrong. I appreciate the specification that this is most readers, not all readers. Non-existent exceptions don't need specification. But, if "The purpose of this book is to introduce you to people who rely on AAC, to the AAC supports that they use to meet their communication needs, and to those who assist them" (Buekelman & Mirenda, 2013, p. 4), then we exceptions are still the other, and we must be introduced to ourselves. The "you" of the expected reader is still not the "them" of the expected AAC user. We're not the same. Then, the remainder of the introduction reminds me of autism essays in their use of numbers to illustrate the importance of a subject readers already care about (Yergeau, 2010).[3] Who are you trying to convince? I know AAC is important. Anyone who dropped $84.95 for our textbook knows AAC is important.

Rhetoric and disability studies invade my reading of my clinically oriented textbook. I let them in. After all, I'm the sort of person who'd follow Yergeau's (2013) style, asking if I am the curriculum instead of if I am my mind, as I consider my place as a part-time AAC user in an AAC class.

One of the three major purposes of the text is to introduce readers to people who need AAC, another is to introduce the supports they (we) use, and I am one of three students in an AAC class using this text.

> Am I the curriculum?

We are assigned videos to watch and then discuss with our classmates. One line, from one video, sticks in my mind.

> Sometimes we find ourselves on the floor or under a desk because that's where somebody wants to be. (Carroll & Mintun, 2013)

I am a graduate student, going for a doctorate in neuroscience. People in my lab don't just know to look for me under a table. They know which table I'll be under with my laptop and headphones, with whatever I'm reading, with the wearable sensor I'm sewing back together because it got ripped up in testing this morning and we need it again this afternoon. I've sat under that lab table in meetings with my major professor.

That's *me* they're talking about.

I point this out in my reflection. If sitting on the floor or under tables is the example provided to explain that there are no “behavioural prerequisites” for access to communication, for AAC, doesn't that mean people have been denied AAC for sitting on the floor or under a desk? If that never happened, there would be no need to explain: yes, you can get on the floor or under a desk, if that's where the AAC user wants to be. I remember Julia Bascom telling me about the expectation that autistic children must be table ready – sitting still, at the table, making eye contact – in order to learn (Bascom, 2011).

Augmentative and Alternative Communication is a blended class – half face to face at the bottom of campus, and half online, with meetings on Google Hangouts. The first online meeting, I can't speak.

I log in to Google Hangouts and message the professor to let her know I'm typing that night. Questions are directed at my classmates to see how they're understanding the material. Not so much at me. Is she reducing expectations on my communication, because even my rapid typing is slower than speech? Or is she talking around the person who can't talk? I don't know, but I notice. I am reminded of an AAC user quote in my textbook: they are “talking behind, beside, around, over, under, through, and even for” me (Musselwhite & St. Louis, 1988, as cited in Beukelman & Mirenda, 2013, p. 6). I don't read these experiences as an outside observer. They resonate: I have been there. I am there now, in my AAC class.

I contributed more writing on the side board in graduate math courses than I do meeting online, with a chat box, for a class *about* alternative communication methods. Am I a student, or am I the curriculum?

After this online class meeting, I read her comments on my first reflection, made earlier in the day. She wants to know: might I be willing to share my perspective as the student under the desk with my classmates? She'd love it if I could elaborate in our class meeting. She didn't ask me about it in class. (She didn't ask me *anything* in class that night. What I typed, I initiated.)

Did she avoid asking me this in class so I could refuse without my classmates knowing I'd been asked? Was it a nod to privacy about an insight that is, after all, rather personal? Or did she fail to ask me in class because *I couldn't talk*?

What's past is past. I can't share the thought in our class meeting, which has already happened. I post my comment to the class forum instead. My classmates appreciate my perspective as the person under the desk, having seen children they work with punished for acting as I did and still do.

Am I the curriculum?

We'll all have individual class projects, and I've been filtering possible topics through my experiences. Autism research, I know, is heavily focused on children. A brand-new systematic review on AAC research for autistic adolescents and adults shows this holds for AAC too (Holyfield, Drager, Kremkow, & Light, 2017). I'm frustrated, but not surprised. Can I do something with autistic adults and AAC? I've squeezed into a single dorm room for the night with as many autistic adults who sometimes use AAC as they've found adult participants in autism specific AAC research – four (Holyfield et al., 2017). (I slept under the bed. It was cramped.) This is *pathetic*.

I can do something with this, but I'll be making myself the curriculum even more than I already was. And will I be the researcher, or an object of research? Can I be both?

Back on the class forums, we discuss communicative competence and how we understand it. We need to know the language we're using. That's linguistic competence. We need our communication systems to be in working order, and we need to know how to use them. That's operational competence. We need to navigate cultural norms. That's social competence. Finally, we need to be able to communicate within whatever restrictions we're dealing with, or help others deal with those same restrictions. That's strategic competence (Beukelman & Mirenda, 2013).

My classmates, who are both studying to be speech language pathologists, of course answer with the perspectives they come from: teaching students with communication disabilities. Teach language. Keep systems in good repair. Teach social skills.

Me? I'm a part-time AAC user who sometimes speaks two languages. Communicative competence for AAC looks like communicative competence for my year in Tianjin, China: knowing the language isn't enough. I need a functioning communication system – regardless of language, speech will only cover me sometimes. I've been in social skills groups. They tried to teach me how to blend in, but that didn't work. At most, I made it into the uncanny valley. I can't perfectly adopt mainstream Chinese communication norms any more than the mainstream neurotypical ones in the US. I need strategic competence to explain *why* my communication looks weird, so people still talk to me. It's about communicating within restrictions. Chinese isn't my first language. Speech isn't working. Typing is slower than speaking. The restrictions I need to work within vary between study abroad and AAC, but they overlap. My Chinese language AAC options that year didn't come with speech generation. I passed my tablet to a classmate to read my screen aloud, or I emailed the teacher what I typed after class. How does communication work, given my options?

My classmates are again grateful for my insights. My professor is again learning from having an AAC user in her class. Are my stories the curriculum?

This isn't to say every reading, every video, every experience makes me ask if I'm the curriculum. I was never a young child learning to use AAC at the same time as I learned to use language. I never had AAC use as a goal in an individualized educational plan (IEP). I was a different kind of IEP student: International Engineering Program. I don't ask if I'm the curriculum when we learn about setting measurable goals, like asking questions using a speech-generating device. I'm not the curriculum when we learn about eye gaze and switch systems, or when I discuss something relevant I learned in the brain computer interfaces class I'm also taking this semester.

I could do something about controlling computers with brain signals for my project. My project needs to be professionally relevant to me and related to AAC, but it doesn't need to be original research. My classmates aren't doing original research in a massive literature gap the way I'm considering. As a neuroscience student in an engineering lab, taking my *second* course using brain computer interfaces, a project on AAC by controlling computers with brain signals is absolutely relevant outside this one classroom. And while there is plenty of research on these systems, the only reference to them in *Augmentative and Alternative Communication* is in passing (Roark, Fried-Oken, & Gibbons, 2015). They weren't mentioned in *Perspectives on Augmentative and Alternative Communication* at all in 2017, though they are now (Huggins & Kovacs, 2018).

I could do something with this. Work on brain computer interfaces for an AAC audience, not an engineering audience, would be easier than work in the middle of a gap in the literature. I wouldn't be the object of research, and it would connect my projects from two classes.

There's an element of choice to next textbook readings. I need to choose one chapter from the section, “Augmentative and Alternative Communication Interventions for Individuals with Developmental Disabilities.” Individuals. Why don't I see people write “abled individuals”? People without disabilities get to be people. We're individuals. It's like we're not supposed to band together and notice patterns in our experiences. Noticing patterns is for researchers determining what's “wrong” with us and how to fix it, not for “individuals” where meeting one (or being one) isn't allowed to tell us much. “Individuals” is professional speak.

In any case, I'm considering potential projects as I choose my chapters. The brain computer interface research I've seen is done with abled adults, or adults with acquired disabilities. Nothing in the developmental disabilities section will help with that. Brain computer interfaces don't appear in the index, nor do other key terms – there might not be anything relevant in the book.

Thinking about AAC for speaking autistic adults, I’m focused on people who have language, just not always speech, or not always sufficient speech. I don't need the chapters on emerging communicators, teaching language, or teaching literacy. The general overview of AAC for people with developmental disabilities includes an autism section, which is the most relevance I'll get for either project topic. I read that chapter.

I quickly regret this decision.

Throughout my textbook, I appreciate the short, relevant quotes from AAC users. This chapter's overviews of AAC for people with cerebral palsy, intellectual disabilities, and deaf-blindness all include quotations from AAC users with those disabilities. Autism? Not so much. We do, however, get Temple Grandin quotes about thinking in pictures and overload. Neither of those are about AAC, and she doesn't use AAC.

We also get this gem. Clara Clairborne Park, referring to her daughter with autism, writes:

> As she grew, the problem of her speech took precedence over all the others. It was through speech that she must join the human race. (Park 1982, as cited in Beukelman & Mirenda, 2013, p. 212)

I would like to point out that this is literally a book about augmentative and alternative communication, or things which are not speech being used to replace or supplement speech. What is this doing here? Requiring speech, specifically, to be part of the human race contradicts the entire point of this book. And people thinking of autistic people as not quite human is an ongoing problem. Ivar Lovaas, the pioneer of ABA, the most common therapy “for” autism, straight up said we weren’t human and talked about creating people from scratch when working with us (Chance, 1974). Even modern research tends to imply that we lack humanity (Yergeau, 2013).

The autism section also discusses “ends” of the autism spectrum with the need for educational, behavioural, or community supports going together with co-occurring intellectual disabilities at one “end” and shy, eccentric people who can live on their own, marry, have jobs, and have kids on another “end.” That's not how this works! That's not how any of this works! The authors should know that, since they mention our often uneven skills later in the chapter (Beukelman & Mirenda, 2013)! Is it that hard to believe that non-speaking people could live alone, that people with intellectual disabilities marry, or that shy, eccentric people with jobs could need AAC or be unable to live alone, knowing that we develop in ways the neurotypicals consider “uneven”?

Here, I am not the curriculum. I'm an autistic AAC user, but … I'm not here. I have intermittent speech, where I can say the words I want *but not always*, and I need AAC. There's the usual emphasis on early intervention, which I escaped, but no plan for adulthood like cerebral palsy gets. I'm an adult. Where am I?

I note my concerns with *just this one bit* of the textbook in my reflections and in an online class meeting. I paste the terrifying implication that autistic people aren't part of the human race if we don't speak, must speak to be human, into the chat box that accompanies our meetings.

For the first time, as I'm saying, *no, this one bit of how you talk about me is just bad*, I get pushback, not comments on how enlightening my perspective as an AAC user is. That quote about joining the human race through speech is from 1982, after all. (The textbook was revised in 2013, and the authors decided it was still appropriate.) Maybe the quote meant a broader idea of speaking that includes AAC. (One, that wouldn't make it OK. Two, that's unlikely given that it's from 1982. I can point to the year too.) Maybe I'm not like the child this parent is talking about. (My perspective is enlightening the rest of the time, but I guess I'm not quite like the people I represent. It happens to other minorities (Gaztambide-Fernández & DiAquoi, 2010).) Somehow or other, I have misinterpreted the quotes. (I *am* autistic, after all, which supposedly means I can't really understand other people's narratives (Yergeau, 2013).) Or maybe, just maybe, this is about the tension in who holds disability expertise: professionals, or the people they practice on (Connor & Gabel, 2013). Insights about what it's like to be an AAC user are safe. Telling professionals they're *just wrong*, not so much.

This is one more thing to consider as I choose my project. As an Autistic AAC user writing about AAC for autistic people, I *would* be studying my own community, and my expertise could be contested for this reason, even if I'm *also* a researcher. It's tricky, but I can do better than an autism section that quotes a parent with a speech obsession and an autistic animal sciences professor who doesn't use AAC.

I could do the brain computer interface project. There is plenty of relevant work in the engineering literature, but not in the AAC literature. Academic silos are a thing. Moving knowledge between them might not be as good as breaking the silos down, but it's useful. As far as my neuroscience programme is concerned, this would probably be the more strategic project choice. But I can't really do that. I have to get in and challenge the narrative while there isn't much about AAC for autistic adults.

I know what my guiding questions will be for this semester's project:

> What aspects of communication are autistic adults who use AAC part time attempting to address with their AAC use? How can we (either the AAC users or any parents, teachers, or other professionals supporting them) select AAC strategies to support these needs?

That's me. It's not *just* me, of course, none of this has been *just* me, but it is me. I just made myself the curriculum, and possibly the object of research, even more than I was before. I never could leave my identity at the door.

My professor is impressed with how many tangentially relevant sources I find, given the gaping hole around AAC research on autistic adolescents and adults (Holyfield et al., 2017). I read through what Holyfield found. Looking beyond autism, I find research based, at least partially, on the priorities of adults who use AAC. They, like me, want more from their systems than developers or clinicians realize: we want situational flexibility, ease of programming, and foreign language speech output, thank you (O'Keefe, Brown, & Schuller, 1998).

I find citations to back up my claim that I'm working in a massive, gaping hole in the literature, justifying my use of research that only partially applies to my work. I find that AAC users who can speak don't get much attention (Niemeijer, 2015), and I already know about the lack of work for autistic adults (Holyfield et al., 2017).

Then, at least partly because of how little there is in the literature about AAC and autistic adults (Holyfield et al., 2017), my professor suggests I could submit my project for publication, or present it at a conference. I'd already thought about it, but confirmation from a professional that this project could be publishable is both comforting and terrifying. It means the gap I thought I found is really there. My focus on speaking autistic adults takes two gaps in the literature and intersects them to make a double-extra gap. A double-extra gap I'm sitting in, just spent the summer writing about sitting in (Hillary & Harvey, 2018). Inclusive education – I made it into the classroom – is turning into inclusive research – I'm pointing to a spot where more work could go, and starting to fill it.

But what is my position while I write about people like me? I remember my difficulties with expectations of distance and impartiality, that I rejected writing about the erasure of queer autistic people (Hillary, 2014). Was I the researcher, or the object of study, then? Am I the researcher, or the object of study, now?

I wrote "I" and "we" about Queer Autistic people before when talking about how we are erased. I am one. But with multiple "others" to consider, be they researchers from my position as a Queer, Autistic, part-time AAC user, or any of those identities from dominant perspectives expected of researchers, pronouns are an issue. I'm not so certain I want to write "I" and "we" now.

Could I get published writing "I" and "we" about autistic AAC users? Sure. I've done it, writing about teaching as an AAC user. Some journals explicitly welcome autistic perspectives, or perspectives from the spectrum. *Autism in Adulthood* does. I'm even editorially encouraged to do it. I'm just not certain I *should*, this time.

I'm noticing that the *Perspectives on Augmentative and Alternative Communication* pieces by AAC users are usually about their personal experiences of AAC use (Green, 1997; Hyatt, 2011; McLeod, 2011; Staehely, 1997), while professionals may present broader research and recommendations (Braddock, Hilton, & Loncke, 2017; Farrall, 2013; Mirenda, 2013). The people making the kinds of suggestions I want to make call AAC users "they" and couldn't do otherwise on their own. Claiming AAC use won't get me credibility as a serious researcher any more than claiming my autism would. Even when we are published in the same venue, we belong in the separate space (Connor & Gabel, 2013) of discussing our experiences alone.

So I write my article using "they," "them," and "their" to talk about speaking autistic AAC users. I still tell readers who I am in the body of my paper – I won't lie.

> The first author is a speaking Autistic person who uses AAC some of the time and discusses their own AAC use publicly.

Of course, I use "their" to talk about myself, too, since I'm non-binary. There's probably something interesting about identity in that, too – the "they" of distance as contrasted with the "they" of asserting who I am. It's not a first-person pronoun, but I'm using the same pronouns for both myself and the group I'm discussing. I may yet wonder more about that, but it's not why I'm writing about Autistic AAC users with "they." I want to be clear that my own AAC use isn't the topic of the paper, that this *isn't* just about me. It's about rhetorically showing my position as a researcher discussing a whole group, not just myself.

There are more ways of showing my position than pronouns alone, of course. Do I discuss my own AAC use at all? I do in other contexts, but I'm less than certain I should here. And if I talk about myself, do I cite myself? I've written about AAC before (Hillary & Harvey, 2018). And I know of a sometimes AAC user with cerebral palsy who references her own AAC use, and her prior work on AAC, in one of her papers (Bryen, Chung, & Lever, 2010). But what happens once I get my paper in front of a reader?

Autistic people are often thought of as not understanding our own experiences (Grace, 2012; Yergeau, 2013). *My* claiming personal experience isn't necessarily the same as Chung doing so (Bryen et al., 2010), or even Kerschbaum (2014) doing so. It isn't just that emphasizing myself as an Autistic AAC user won't get me credibility. It's that it risks *losing* me credibility as someone who can accurately discuss anyone's experiences, including my own. Autism essays, after all, are non-autistic (Yergeau, 2010).

And citation choices tell readers what work our arguments are built on. Do I *want* to claim my arguments are built on my experiences?

In theory, self-citation could be neutral, just pointing to relevant work that happens to be mine (Hyland, 2003) as a citation for a public description of AAC use by a speaking autistic AAC user, which I am. Or it could show my credibility as someone who already has researched and published in my focus area (Hyland, 2003), in theory. I don't think citing my blog, or my twitter, where I talk about my part-time use of AAC, will give me much in the way of professional credibility as an AAC researcher or as an autism researcher. I don't even think a properly researched chapter on teachers who use AAC will do that.

An editor says I don't need to worry about this – I should write the best paper I can, whether or not I speak to my own experiences, and self-citation is a normal thing when we write about the same topic more than once. And she's right, in theory. I want to be able to believe I could write about my experiences, admit to writing about my own experiences, and be taken seriously as writing about a *common* need, with recommendations people should take seriously if they want to support autistic people.

I can't believe it. Too many people think autistic people can't even understand what it's like to be ourselves (Grace, 2012) and think we can't tell non-autistic audiences what they would *want* to know about our experiences (Yergeau, 2013). Sequenzia and Grace (2015) anthology, *Typed Words, Loud Voices*, while not purely about autistic AAC users, addresses the problem that too many autistic AAC users are positioned as not *really* communicating. Because of this, I don't believe I can *both* write about my experiences and be taken seriously as documenting a pattern deserving further attention. Even my textbook, typically so good about including AAC user perspectives, doesn't quote an autistic AAC user. It quotes a parent, and it quotes Grandin, and *neither* wrote about AAC (Beukelman & Mirenda, 2013).

As an Autistic AAC user, I'm supposed to be an object of study. If I'm not going to be the object of study, I have to be hard to mistake for an object of study. There may be expectations that we explicitly filter our research through our own experiences (Kerschbaum, 2014), but those expectations are exactly what I'm trying to avoid here. That means my experiences with AAC are not to be considered, except for the unavoidable filtering of my research through my own knowledge.

While seeking information relevant to their own AAC use helped inspire the current project, they are not discussing their own AAC use in this paper. (Zisk & Dalton, 2019)

I'm not citing myself. Never mind that avoiding myself entirely is *hard*. *Typed Words, Loud Voices* is a big source, given the number of autistic contributors it had (Sequenzia & Grace, 2015). I can't ignore it entirely just because I have two essays in there and did the cover art. I can, however, stick to the pieces by other speaking autistic AAC users.

So I do. I find public writing by speaking autistic people who use AAC, enough to write my paper without referencing my own experiences. It's the way not to just be an "individual who uses AAC," or an "individual with autism," segregated into sharing my experiences alone. It's the way to avoid problems resulting from being perceived as not quite like the others in my group at the same time as I'm educating others about my group that would make it easier to dismiss any parts of my perspective that challenge standard positions (Gaztambide-Fernández & DiAquoi, 2010).

After all this, I'm still not sure where I fit. A year later, I'm back in the AAC classroom, presenting "my perspective" but really talking about part-time AAC use in general. A year and a half later, my paper is published, and I've *still* seen it shared as "my perspective as an AAC user," including by people who've commiserated with me about how we only get to have fascinating insights, not real challenges to professional knowledge. Am I the teacher or the curriculum? Was I a student? Am I a researcher? Am I an object of research? I think it's all of the above, but I also think that I'm not really supposed to be here.

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Notes

1. *Perspectives on Augmentative and Alternative Communication* was one of the ASHA Special Interest Group publications. These publications merged as of 2016.
2. Erwin Schrödinger was an Austrian physicist who worked in quantum theory. He proposed the thought experiment known as Schrödinger's cat to illustrate an issue with one interpretation of quantum mechanics, when applied at everyday scales – the issue where a cat would, under that interpretation, be simultaneously alive and dead until observed, at which point the cat's status collapses into one state or the other. Calling my speech Schrödinger's speech is a reference to Schrödinger's cat – my speech is either functional or not (or maybe it's both?), but I definitely don't know until I check.
3. The AAC textbook and the typical autism essay both use statistics, such as the number of people whose disabilities make AAC relevant, the portion of children diagnosed as autistic, or the eugenicist "cost" of disability, to illustrate the importance of AAC and autism. These tend to relate to the importance or effect of our disabilities on *other people*, rather than the importance of disabled people ourselves.

Acknowledgments

I would like to thank Dr. Elizabeth Dalton, the professor for my Augmentative and Alternative Communication course, for her support and encouragement as I took her class and as I continue to work on this topic. The awkwardness of being a student, a teacher, and the curriculum is about systematic issues interacting with my identities and not her teaching. I would also like to thank Dr. Melanie Yergeau for her major influence on my style, and the anonymous reviewers for their helpful suggestions about my manuscript.

Disclosure statement

No financial conflicts of interest exist. No other conflicts of interest exist.

Funding

This work was not supported by any grants. The author was supported by a graduate tuition scholarship and Ryan Institute for Neuroscience Fellowship while completing the work.

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