Speech is Simply Exhausting

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Hi everyone, my name is endever* corbin. I'm a multiply disabled semispeaking autistic self-advocate in my thirties, and my pronouns are they/them/theirs or xe/xem/xyrs. I'm a white nonbinary person with greenish hair that's shaved on the sides, wearing tinted glasses and a KN-95 face mask. It's such an honor to present here today; thank you all for taking the time to participate in this summit.

Today I will focus on my personal experiences regarding meaningful participation in society as an AAC user, the importance of self-determination and interdependence in defining and enacting meaningful participation, and how all that relates to my research priorities. I hope you will keep in mind that anything I have to say is skewed by the privileges I hold, so please continue to seek out more and more AAC user points of view on this important topic.

I think some of you know my history with AAC. But to provide context for everyone else, I should explain that due to many years of going to speechcentric SLP services as a kid, I spent a couple decades pushing myself to use mouthwords as my primary communication method. To people who didn't know I was autistic - myself included! - I think those mouthwords even passed as fairly normative.

But the cost was high. You may know of the three types of autistic speech Zisk and Dalton outlined in their 2019 paper: one, intermittent speech, two, unreliable speech, and three, insufficient speech. I experience all of those to some degree, but above all my mouthwords are simply *expensive.* Alyssa - that's Dr. Zisk to most of you - myself, and our colleague Tuttleturtle, are working on introducing this notion of "expensive" speech to the academic community as a fourth common autistic speaking experience that typically goes unobserved by listeners. Together we define *expensive speech* as that which, [quote] "may be effective but has a significant cost in terms of energy, cognitive resources, or other internal resources, affecting what is available for other or later skills or tasks” [end quote]. I am so excited to have partnered with Alyssa and Tuttle on this definition, because I think what we’ve settled on really nails what I’ve been trying to describe about my mouthwords for a few years now. Speech is deeply exhausting.

So as you may imagine, in many ways AAC has massively decreased my cognitive load when it comes to communication, opening up more resources I can utilize for meaningfully participating in other activities. When I have access to multiple means of communication - not just speech but also high tech AAC, low tech backups, and ASL, I am far more able to join in on conversations I want to be a part of. A social environment that respects my need to regularly switch modalities supports my ability to show up and participate authentically.

Here’s what meaningful participation looks like for me… It means talking with my friends, whether that’s using symbols or spelling or signs. It means caring for my cat, using our own little language of echoes, hums, mid tech AAC, and meows. It means advocating for my needs and my rights in healthcare settings, doing the best I can to manage my co-occurring conditions while living in the community. It means pursuing my favorite leisure activities and engaging in my special interests. It means asserting my queer identities and connecting with peers in that community. It means being an advocate and an activist. It means informally mentoring peers who may be roughly where I was 10 years ago: forcing speech to my detriment. It means giving presentations to academic, professional, and community audiences. And it absolutely means doing research. It means doing my best to make my hope, that kids growing up in the future will have increased access to AAC, into a reality. I want them to have multiple means of communication that work for their bodies and brains, open doors to authentic relationships and equitable standing in society, and leave as much energy and cognitive resources as possible left over for whatever they want to spend them on.

And that list of whatever they want to spend them on might look nothing like mine. Even everyone in this room probably has different priorities for your own meaningful participation in society - some may overlap with mine, some may not. Maybe your priorities are paid employment, or formal education, or living in your own place, or training a service dog, or raising children, or learning to drive, or taking the 10 o'clock train to your favorite museum every Saturday so that you can sit somewhere silent and stare at something beautiful. Or maybe even more likely, your priorities are things I haven't even considered, because I am not you. I'm not those future kids growing up, who I so desperately want to have increased access to communicative choice and autonomy. I just want myself, y'all, everyone, and especially them, to have a better chance to choose and express priorities for ourselves.

I'm definitely getting at the idea of self-determination here. We each find joy and purpose in different activities because we are individual people, with different life experiences, couched within various cultural backgrounds. Self-determination is part of what *makes* participation in society meaningful. Now, it should be noted - and I think David is going to touch on this, too - self-determination does not, or at least should not, imply or necessitate independence. Disability communities have taught me that the idea of independence is a myth that serves to uphold ableism and other oppressions. The reality hidden beyond the myth is that every person is *interdependent*. We're all part of a human ecosystem, a vast network of give and take and need and support, just as much as we are part of our local biome.

But my point about self-determination perhaps comes down to this. Though it's one key to building meaningful participation, it's a pretty hard thing to accomplish - particularly in this ableist society - if we don't have options for robust communication that are consistently accessible to our brains and bodies. Now, hopefully y'all understand AAC doesn't always mean a device and doesn't even always mean language - rather, disabled humans have been coming up with creative ways to communicate for probably as long as we've existed. Nonlinguistic gestures, facial expressions, and mouthsounds can also be communicative. So I definitely don't mean that being, quote, "fluent" on a high tech system or something is a prerequisite for self-determination or meaningful participation. But as someone who felt so helpless and trapped when I thought speech was the only option, and so useless and lonely when I couldn't pull it off - I do think that being able to choose between communication methods that are more effective for me is what has most built my ability to shape the course of my own life. And that's a large part of what makes my participation in society meaningful to *me*.

So, how does this all fit into research? Well, maybe one big reason I'm talking to you today is the research I've helped with. And as I said, doing that research is one way I feel I can be part of the world. But let's look at the question of how AAC technology and AAC research more broadly can move forward in a way that supports the self-determination and meaningful participation of all AAC users.

Communication technologies, modalities, and learning methodologies that currently exist can certainly be improved to meet the needs of more disabled people, supporting us to live full lives. Even for those of us that have been given access to really great fits in terms of devices, apps, or light tech supports - that are feature-matched to our needs - yes, I think even we have long wishlists of what our communication supports could do better! So I really appreciate AAC developers that work closely with actual AAC users to continually improve their products to meet a wider range of needs. And I think we have a long way left to go in so many ways, including meshing technological advancements with disability studies in a way that can make the cyborg aspects of our identities increasingly tangible.

But so many people are still out there who haven't even had a chance to try the communication supports that already exist. They can't afford it, or their insurance won't cover it, or their caregivers are against it, or the language used in their community isn't incorporated, or their speech therapist doesn't know much about AAC, or everyone thinks they are “too young”, or for that matter, “too old”. Or maybe, like in my story, they're still undiagnosed, or simply don't seem (from outsider points of view) to need AAC at all. So my passion for research for the immediate future is exploring and deconstructing the artificial barriers to AAC access that are established or maintained by ableism and related oppressions. I want everyone who struggles with speech - no, every disabled person period - no, every single human - to have an opportunity to explore multiple robust, culturally and linguistically appropriate, queer-friendly AAC options. I don't want there to be such a thing as too poor, too young, too articulate, or too, quote, “diverse”, for the technology we already have. No such thing as too disabled, or not disabled enough, to communicate our own goals for meaningful participation in society. Every. Single. Human.

I know, that’s a long way off, too! So I’m very grateful to be here today and to be able to share that vision with you. What I’d like to leave you with, beyond that endpoint I’m personally trying to work towards, is a sliver of how we might get there. And that, pulling back to what I mentioned earlier about interdependence, and this Summit’s theme of collaboration, is participatory research. I won’t present the details of participatory research models here, in hopes that you either are already well versed or will become curious enough to learn more later. But can we talk about how crucial participatory research is for this field?

As AAC users, we may have limited, if any, access to a literal voice based in our throats. Moreover, full language may have been withheld from us for most of our lives, and our words may still often be physically removed from our reach by people in power… And even for those of us who currently have consistent access to robust communication systems, our perspectives (even on our own lives!) may still be disregarded, no matter how tenacious our efforts to communicate or how fierce our efforts to self advocate.

So the idea that AAC-related fields of study and innovation would perpetuate this enforced “voicelessness” should strike everyone here as deeply ironic, if not deeply unjust. Yet this is the reality. So many research studies are still stuck focusing solely on family and professional views on AAC, without even including AAC users as research subjects, let alone working with us as equal partners and co-authors. This human ecosystem of academia is only beginning to explore how much can be accomplished when AAC users are involved as full collaborators.

I assert that AAC users’ real voices - that is, our words, perspectives, communication, and self-advocacy, however we choose to share them - are in fact crucial to this field. They’re as crucial to research as they are to exercising self-determination in each of our lives. We, AAC users, participating as equal partners, are what can make AAC research more meaningful… Not just meaningful to me or to you. Meaningful for all those kids coming after us. Remember? *I want them to have multiple means of communication that work for their bodies and brains, open doors to authentic relationships and equitable standing in society, and leave as much energy and cognitive resources as possible left over for whatever they want to spend them on.* That means it’s up to us to break down all the artificial barriers to AAC created by ableism. And it means doing it together.

Thank you.