To Include Us in Our Own Worlds, AAC Is Not Optional

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My name is Ren Koloni, and I use they/them pronouns. I'm a fat white nonbinary person with dark brown hair, half of it shaved, half of it in a long braid. I'm wearing glasses and rocking slowly back and forth. I share these words with you now from lands historically cared for by the Doeg people. I pay my respects to them and the other peoples, including the Piscataway, Nacotchtank, Manahoac, and Monacan, that shaped and stewarded the land on which I have lived and learned as an uninvited settler on Turtle Island.

I'm an autistic, multiply disabled crip with some access to speech, and I communicate most effectively by typing, but in a world that privileges audible speech, it pays to have ways to be heard, not just seen. Since I can't stand the text-to-speech voices that are available to me, expressing my words for me aloud today is my wife, M.

Here's the good news on the state of AAC: we have a lot of really great strategies already, and even in their current state, we know they change lives. There's plenty of things that we could be doing better:

1. We need to be thinking about expanding our strategies for visual orientation and organization to support people who struggle to read or to think quickly, easily, clearly, or normatively, for reasons ranging from dyslexia to low literacy to dementia to brain fog. Images and design are powerful tools for enabling communication, but they will fall short of their full potential without input from the people who are using them all day, every day to decide how they want to say what they have to say. But we also need to make sure that there's plenty of nonvisual options, too. What options does someone with low vision have when they need AAC? How can we

incorporate the many and various sensing strategies of our community, inclusive of both sensory limitations and sensory expansiveness?

2. We've got to make AAC voices expressive. We need to be able to use tone and emotion and sarcasm, to be comforting and solemn at a funeral or raucously funny around our friends. We should also have the option to express a range of cultural identities. There's no voice that expresses that I'm a proud intersex transgender person and Appalachian, so why bother? Right now, a meeting with multiple people who use speech-generating devices is bound to have more than one person with the exact same toneless or permanently chirpy voice. We deserve to carry social, cultural, and personal identity in our voices as much as anyone else does.

3. We also need to understand and put into action the best practices to train and support not only people who use AAC across many disabilities and backgrounds, but also the people we come in contact with… which should be everyone. A lack of awareness from people who have unconditional access to speech is a huge part of what makes it difficult or impossible to use AAC in public life: I am dismissed and ignored, and I may end up forcing speech when doing so is painful or exhausting, or otherwise suffering humiliation, discrimination, or harm in silence. And that's what it's like for me *with the privilege* of having some access to speech. Everyone needs to know about AAC, not just so that they can use it if they need it, or refer their friends and family to it, but also so that AAC users can interact with them without being treated with disrespect or dismissal. AAC needs to be normal. I should have known that I could type to talk when I needed to when I was a kid. My mother, teachers, doctors, and friends should have known, too.

But those ideas are all set dressing compared to the actual biggest problem here: access. The majority of people who *could* give us access to AAC don't, and won't. They believe that we can't use it, or that we don't have anything to say, so there's no point in trying. Or that we can speak sometimes, so it's not a big deal, we can force the speech out if we *really* need to. Or maybe they think it's just too expensive or time-consuming, not worth the money or effort—and of course, whether they realize it or not, that means they think *we're* not worth the money or effort, and we pick up on that attitude.

None of these excuses should mean inaction. Communication is a human right. Every single person has the unalienable right to say anything and everything they want to say, whenever they want to say it, and, correspondingly, the unalienable right to get the support they need in making that happen. But this right to communication and self-expression *is* being alienated, thousands or even tens of thousands of times a day. (We literally *don't know* how many people need AAC in this country, let alone how many need it but have been denied access to it.)

This is almost certainly at its worst in institutions, where people without access to speech are some of the last disabled populations who have yet to be freed and supported in their communities. And we just don't know the extent of the damage this does, let alone what to do about it. We don't know how many people are suffering and unable to tell another human soul, unable to so much as keep a diary. We don't have any data on the lasting traumatic effects of not being able to communicate, but we have enough understanding of trauma in general to know that it must be horrific and totalizing. There are people right now who are not only unable to say things like *no* or *I am hungry*, but also *My favorite color is blue because it reminds me of the ocean* or *I feel wrong when this person talks to me, but I don't know how to ask for help and I'm honestly scared that I might deserve to feel this way* or *Isn't the sky beautiful right now? Look at the way the clouds part for the sun, the way the pinks and oranges bloom like watercolor* or *There's a sharp pain in my back and I'm really nauseous and I think I need to go to the hospital but I am scared about how they will treat me when I get there* or *I want to learn to read so I can write poetry, can you help me?* or any number of other things that come up in the course of being human.

This kind of isolation is beyond almost anything we can currently imagine. It is clearly and dramatically distinct from the violence of solitary confinement, domestic abuse, or colonialism, and yet the lessons we have learned about the pain and damage these kinds of violence can wreak on the human nervous system and psyche can and must be applied here. Ultimately, though, we won't be able to fully understand its developmental, cognitive, psychological, physical, and social effects without speaking directly to the people who lived through it.

To do this, we must give everyone who has been denied access to communication the tools to tell their stories, to speak their minds, and to be a part of their own worlds. It’s our ethical responsibility as humans, and also our legal responsibility, according to the Olmstead decision in 1999: people have a right to live in their communities, but being deinstitutionalized is not always enough to fulfill this right. We are not living in community if we cannot communicate with our communities.

Even once we are able to access both AAC and our communities, we have to recover from the trauma of being denied AAC. For example, many of us have to relearn, or learn for the first time ever, how to say no, or how to have an opinion. Many of us have to learn for the first time that we have the right to be human. This will be painful, arduous, complicated work. But it is necessary, and it is possible.

In trauma studies, by learning from survivors of the Holocaust [and other genocides], of war and displacement, and of domestic abuse, incest, and rape, we have come to understand that telling our stories and being witnessed is the only way to durably and meaningfully heal from trauma. And that witnessing *cannot happen* without both robust, language-based AAC *and* an understanding of the best ways to support us in recovering from this unique trauma, as people with a variety of disabilities, from a variety of backgrounds.

To be denied expression of the self should be unimaginable, but it is not. It is happening. It is our responsibility as researchers, as advocates, as people to not only imagine it, but to find out why, how, where, when, and in what ways it happens—and to make it right.

To all who are here in the spirit of making the world a better one for AAC users, you have my gratitude. May this gathering provoke both knowledge and action.