# *How Ableism Impacts People Who Need and Use AAC*

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Hi everyone, I'm thrilled to be here with you all at the AAC Research Summit as this is my first time at a conference about AAC. This session, "How Ableism Impacts People Who Need and Use AAC," is very personal for me so this will be less of an academic presentation replete with citations, graphs, fancy slides, et cetera. So let's get started. I was born with a neuromuscular disability. Ever since I was a child I encountered and experienced ableism, but I didn't have the word for it. Teenage years are already totally embarrassing for everyone and on top of that I had such rage against the microaggressions and blatant discrimination due to my disability along with gender and race. I felt so alone and angry. It wasn't until I was in my twenties when I started to read disability studies and sociology that I had a better framework for understanding how the world operates. Learning about systemic ableism as a form of oppression was a turning point. I realized that not only was the physical world never built for me, but the entire sociopolitical apparatus is centered on normative bodies and behaviors that uphold white supremacy and hypercapitalism deeming disabled people as deviant, unproductive, and less than human. With eugenic legislation such as medical-assisted dying or the rationing of ventilators that happened during the early part of the pandemic, and by the way we're still living in a pandemic and I hope all of you in the audience are wearing a mask because it would be fucking ironic to have a conference on AAC where many attendees may be high risk, without the decent act of masking that will reduce the risk of transmission which could be deadly or debilitating to the person next to you, disabled people have resisted for millennia efforts to eliminate us and erase our culture. As a writer, editor, community organizer, columnist for Teen Vogue, and founder of the Disability Visibility Project, it has been my mission to amplify the stories of disabled people and tell my own in order to leave evidence of our lives that no one can deny. Much of my life story is about interrogating and dismantling ableism through my work. I have been a wheelchair user for most of my life with a visible disability that I could not hide from. Being part of the disability community for decades, I had no idea I would become a user of AAC. This June is the second anniversary of one of the most horrific and traumatic times of my life. I was hospitalized because I had a punctured lung, aspiration pneumonia, and was malnourished after struggling to eat due to weakness with swallowing. I tried so hard to keep what I had but I came to a breaking point. After several weeks in the ICU and almost dying several times, I came home from the hospital with an irrevocably altered body. I was a cyborg before, but now I am like fuckin' RoboCop. I was left with an even more disabled body which was the latest iteration from my progressive disease leaving me unable to eat, drink, or speak. So many things are inserted into my body such as catheters, a tracheostomy, and a feeding tube into my stomach and intestine. I had to endure all of these new visitors because without them I would die. Communication access was one of my earliest priorities and I texted friends for recommendations from the hospital before I was discharged. A friend connected me to CommunicationFirst and one person from the organization suggested a text to speech app that I am currently using. While it has its limitations like any form of AAC, I liked that I could use it on my smartphone. One struggle after I got home was reconfiguring my body to the environment. It took me a long time to get myself situated back in my wheelchair where I had to get my ventilator tubing supported and find the right clamp that could fit my phone next to my joystick since I will need it close to me forever. My phone was important to me in the Before Times but now it is a vital appendage allowing me to communicate with the world.

Right now I'm still dealing with the trauma and health-related issues with my new body. I miss my voice. I was a really funny, witty speaking person. Just ask my fellow presenter and friend Lateef McLeod who knew me in the Before Times. I am still a funny, witty person but the way I express my personality through speech will never be the same. As I tried to adjust to my new body I had to adjust to the way I presented myself to the world as a nonspeaking person. I had a new disability identity and was part of a new segment of the disability community. It was a bit intimidating being an outsider who is slowly easing into a new world, a new way of being while still mourning what once was the norm.

On top of that, my personal care needs became more intensive requiring a team of attendants working 24/7 which was a major change that impacted my everyday routine and privacy. In fact, my personhood itself has changed. I don't even know who I am in the world. In those dark, quiet moments when my mind wanders, I tried to make sense of everything. For the first year, I stayed home primarily fearful of something happening to my ventilator while outside. I used to wear turtlenecks all the time and couldn't anymore because of my trach. I had to get new clothes even though I wasn't ready for any social outings. Slowly, I took small trips around my neighborhood, visiting my favorite cafe where I got my usual latte. My sister would gently tip the cup into my mouth, I swirled the warm, creamy delight in my mouth and spit it in a paper cup. I discovered that with my weakened throat, when I tried to take a small sip, latte came out of my throat from the hole in my trach. When I discovered latte coming out of my throat, soaking the shirt with pale foamy elixir, my sister and I were grossed out but we cackled. And when I say I cackled, I expressed it with my body and facial expressions. I didn't have the time to type HA HA HA THAT WAS FUCKING WEIRD on my phone because it would have taken too long and the moment came and went in a nanosecond.

I share this story as an example of the new reality of being a nonspeaking person in a world that privileges speaking and hearing as primary ways of communicating. I'm now in a world where time is slowed down, conversations I used to have for five minutes, fast, speaking excitedly over each other, laughing, interjecting, snorting, would take thirty minutes to type.

As I slowly and bravely started resuming my social life, by the way, my work life never stopped, I noticed some major changes in the way I relate to people and how others perceive me. In conversations with groups of people, I don't say as much as I used to. I made people laugh and felt the vibe when I'm connecting with someone. That still occurs but in a stilted, extended way that gives me anxiety and pressure to keep up with normative speaking speeds and patterns. Even with my family when we're eating dinner together and guffawing about something, by the time I type a banger of a remark, they already moved on to another subject. And even when I play what I wrote it feels like a womp womp of a comment. Do I feel left out? Yes. But am I trying new strategies that will bend normative speaking speed to my new disabled speed? Hell yeah.

In one on one conversations, there is so much I want to say and most of my friends are patient with me when I type a response, but there are times it takes minutes. I worry about them losing interest while they wait for me. My conversations have fundamentally changed.  I find myself saying less, skipping certain parts of what I want to say, and becoming more succinct instead of my old days of words tumbling out of my mouth like a waterfall of hot wisdom. When it's complete strangers the calculus changes. I have to explain that I am non speaking and pray that they don't freak out, filled with pity, or impatient. I am now constantly editing, thinking of what to say, typing furiously while editing on the phone, and editing my social interactions at times, limiting the full glory of my filthy humor and gigantic ego. Y'all are missing out and you don't even know it, ha ha ha. Oh see what I did there, I type ha ha ha to simulate actual laughter and while it works to some extent, it feels robotic and hollow to me. I miss laughing and all the sounds I can make that you will never find in an AAC glossary. And maybe that's internalized ableism that I have to work through, the same way I had to work through it throughout my life. Internalized ableism forced me to work harder and achieve more as if that would give me respect, credibility, and equality with nondisabled people. And I know this intellectually, that I don't give a fuck anymore about what nondisabled people think of me but right now, I'm still working through the internalized ableism of speaking while simultaneously mourning the loss, which is hella real, valid, and very typical of the disabled lived experience.

The essay Six Ways of Looking at Crip Time by Dr. Ellen Samuels resonated deeply with me in the Before Times so much that I included it in my 2020 anthology *Disability Visibility*, and it resonates more deeply now from the vantage point as a newly nonspeaking person. Dr. Samuel writes, quote, "For *crip time is broken time*. It requires us to break in our bodies and minds to new rhythms, new patterns of thinking and feeling and moving through the world. It forces us to take breaks, even when we don't want to, even when we want to keep going, to move ahead. It insists that we listen to our bodyminds *so* closely, *so* attentively, in a culture that tells us to divide the two and push the body away from us while also pushing it beyond its limits. Crip time means listening to the broken languages of our bodies, translating them, honoring their words…being a crip vampire spins me back into that whirlpool of time travel. I look 25, feel 85, and just want to live like the other 40-somethings I know. I want to be aligned, synchronous, part of the regular order of the world Like the leaves just now turning as the year spins toward its end, I want sometimes to be part of nature, to live within its time. But I don't. My life has turned another way. I live in crip time now." End quote. Since this is a prerecorded video, I cannot tell the audience's reaction to the quote but I fucking love this essay and encourage you to follow Dr. Samuels' work. To crip something is in my opinion, to bend, compress, twist, subvert, and imbue disabled wisdom into systems, institutions, and cultures. As I've done before as a physically disabled person, I will now crip the world mightily with the multiple perspectives I have as a disabled nonspeaking ventilator-dependent, high-risk Asian American woman. Whew, that's a mouthful and something I should put in a business card. It takes a tremendous amount of labor to crip the world, but I'm not alone. I am slowly becoming more involved with the AAC-using community, which includes a cross section of numerous disabilities, like speaking with you today at this conference, but more importantly, the power of community is more important than any software update to my text to speech app or another new intervention. I was friends with Lateef McLeod before I became nonspeaking and I am lucky that we have become even closer friends. I interviewed him several years ago for my podcast and was influenced by the audio story he produced and created for Making Contact Radio as a storytelling fellow. It encouraged me many years ago to apply for the same program. Lateef isn't my mentor or AAC doula, he is my friend, my homie, and that is invaluable in a world that is designed to isolate, marginalize, and silence us.

2024 has been one freaky trip so far. I turned fifty in March which was mind blowing because I didn't expect to reach this age. Doctors told my parents I wouldn't live past eighteen so I grew up never imagining what grown up old ass Alice would look like. And this is why visibility, being able to tell our stories and controlling our own narratives is why I do what I do. As I face the two-year anniversary of becoming a nonspeaking cyborg kraken, the ableism continues and in fact is greater now with my additional disability.

No matter how hard I try, the medical industrial complex is my kryptonite as I crip time and try to work on myself and heal. With all the rich and deep connections I have with the disability community and the privileges I have, I am still seen as a noncompliant, unruly, and disposable subhuman patient. I thought the weeks being in the ICU were terrifying enough, but wait, there's plenty where that came from. In January I went to the emergency room because my feeding tube became clogged and my abdomen became rigid and tender. I tried to wait it out over the weekend until I could have it replaced on Monday with interventional radiology (IR) but the pain was too much. I was admitted to the ICU until they could find someone in that department to change my tube. A day later, they whisked me to the radiology department. There was so much I needed to say about my pain before and during the procedure but I couldn't. My phone was not allowed in the room because of their infection control protocols and my caregiver, who could read my lips, could not join me. I wish you could sense the terror of not having your AAC for two hours or even a minute. It was an act of violence to my bodily autonomy since my AAC became an extension of my body. When the IR technician was setting up the sterile field, the only thing he said to me was "Sorry, this will be cold and sting" as he disinfected my abdomen. Frantically, I tried to mouth the words to the nurse to tell him to be careful because my abdomen is in sharp pain. She could not understand me and told me to stop moving when I writhed in pain bursting into tears as he swabbed my abdomen. The nurse said I could have pain medication and administered Versed; the ICU nurse who accompanied me to IR administered multiple doses of Fentanyl throughout the procedure to no avail. Throughout the 2 hour procedure, both nurses wiped tears that kept rolling down my face, advising me to take deep breaths and relax. This only compounded my anger and frustration resulting in tachycardia. I cried so much due to acute pain during that procedure my eyes became swollen. Upon return to the ICU, my heart rate was over 200 beats per minute chalked up as "anxiety." The ICU team further defended the lack of communication access, a right under the ADA, due to the need to maintain a sterile field in IR which meant I could not write anything down or use my phone as if it was my fault for being a non-speaking person. Healthcare providers know how to work with all kinds of bodies. I have no doubt someone could have figured a solution that would not endanger a sterile environment for procedures and surgeries. However, the ICU care team intimated it was an impossibility which I found disappointing. This is an example of medical ableism, it reduced me to a small, powerless, and insignificant organism during this process. I wanted to scream, beg, and wail and tell people how much pain I was in. I was in the hospital for only two days and it left me shaken and vulnerable. This is one way ableism impacted me as an AAC user. I retreated from life for a few weeks and became enraged that this happened not just to me but for other AAC users. I filed a patient complaint with the hospital and have yet to receive an official response.

Based on what I just told you about my two years as a nonspeaking person, I am not interested in your recommendations or opinions. This is just me telling you my truths, that ableism is baked into our society and AAC users face many challenges in public life. But we belong in public, holding court in conversations, doing our thing, our access needs respected, and being our full selves unapologetically. I am a baby AAC user and probably shared things that have been covered in conferences like this. While I am still evolving and discovering new aspects of life without speech, I believe AAC users can collectively bend conventional modes of communication, practice crip time, teach speaking people to slow the fuck down, and have us centered for once instead of at the margins. That's my dream so that other newbies don't have to experience what I did. Thank you.