Crossing the Communication Chasm
By Melissa Crisp-Cooper

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[David]: Our next speaker is Melissa Chris-Cooper. She is a writer, adventure seeker and advocate. She uses many forms of AAC. She is an associate director of participant experience at the Arc San Francisco. Before joining the Arc, she helped develop educational and policy material related to health care for people with disabilities for the Office of Developmental Primary Care at UCSF. Melissa and her husband, Owen, live in Oakland, California with two opinionated black cats. Together, they love to travel and eat good food. So, Melissa.

[Melissa Crisp-Cooper]: Thank you for the opportunity to speak on reducing social isolation. For those of us who cannot rely on spoken words to have fluid conversations. For a brief visual description. I am a middle-aged white woman. I use a power wheelchair with a purple frame. I am wearing a dark purple jacket with white flowers and a rose-colored shirt. I use she/her pronouns.

Before I venture too far into this topic, I would like to offer two disclaimers. First, this talk will be largely based on my own experiences, observations, and perspectives as someone who uses different forms of AAC. Since I did not want to be the sole voice on this important topic, I asked a friend for her thoughts. Yet, we in no way represent everyone in our varied community. There is an extremely limited amount of formal data capturing stories of social isolation among AAC users, but many of us can describe feelings of loneliness being unheard or ignored in spaces not designed to meet our communication needs.

My second disclaimer is personal. Talking about how my communication disability affects my relationships and how I am often seen by society is not my favorite topic. It challenges my self-perception as a capable, fierce, snarky, insightful woman. I usually have a tight grip on this vision of myself so I can continue to advocate, find joy, and get through the day. Talking about the wide chasm between how I see myself and the external societal perceptions of my life and my abilities to think and communicate complex thoughts, forces me to confront my own vulnerabilities and my own internalized ableism. I do not like admitting that I feel left out of conversations at work, or that a small wave of dread rolls through my brain when I must introduce myself to strangers.

Life with a significant disability has taught me to be flexible, resourceful, creative, and empathetic. Yet on days when I don't have the physical or emotional energy to make myself understood by unfamiliar communication partners, I would love to trade in my scrambled speech for an upgraded debugged version of my voice. I envy people who connect over quick conversations, or can recount stories at parties or in loud, crowded restaurants.

My friend Denise Jacobson wrote about a similar sentiment in her guest blog for the Columbia University Irving Medical Center, titled Time to Speak. My journey growing up with disability affected speech. Denise says: I might be committing an infraction against the disability movement and ethos of disability pride by blatantly admitting that if I could change one thing about my disability, it would be my cerebral palsy affected speech.

Technology has made social inclusion both easier and harder. The ability to send a detailed email to a new connection, or a quick text to a friend has opened so many doors. Meeting my husband on an online message board for people with disabilities changed the trajectory of my life. The chat feature has improved the accessibility of virtual meetings. Technology, however, has also sped up the pace of communication. It can be hard to take up space and time in a conversation. When you perceive that others are ready to move on to a new topic, or your typed response relates to a comment made by your coworker five minutes ago.

Like many AAC users, I rely on different forms of communication depending on the situation. The complexity of my message, or the familiarity of the listener. Each method has strengths and drawbacks in terms of social inclusion. My go to communication method is my voice. Perhaps this is because my internal monologue, this constant flow of thoughts running through my mind, is fluent and generates high speed, complex messages. I can imagine a world where conversations skip along with speed and ease. For me, using my voice in real time, on good days with patient or familiar communication partners is often the best way to express myself.

Talking to the rest of the world can be a lonely, deeply frustrating experience. I tend to censor my words to convey my message and meet the needs of the listener. This can both leave a lot unsaid and create missed opportunities for someone to truly hear my thoughts or get to know me. Instead of taking the time to travel through a conversation with me, some listeners become antsy and impatient. They question my competence and send other subtle messages of ableism to cross this communication chasm.

I need listeners to understand that I have a world of thoughts in my head, and that I have a basic human need to communicate these thoughts. Using my voice to communicate with someone might be asking them to travel in a slow lane of a bumpy two-way street. But if they are patient and willing to go on the journey, we will eventually reach the destination.

Some of us are lucky enough to have partners or assistants who can voice our communication. My husband, for example, has years of practice decoding my speech and volumes of context about my life. But we both have jobs and separate identities outside of who we are as a couple. Using someone else to voice your words can be tricky in many social situations. The focus tends to be on the person speaking. Private conversations are challenging. You probably don't want your mommy voicing on a first date.

Paired communication supporters are often difficult to find, train, and retain. More funding for well-trained, qualified support would go a long way to solving this problem for presentations or complex messages to a new communication partner. I will pre-type my thoughts into my AAC.

Using AAC helps me communicate, but this method has inherent drawbacks. This robotic voice might be unscrambled and easier to understand than my voice. Yet this is not my voice. The monotone AAC voice named Heather does not inject my emotions or my humor. She does not giggle in the middle of a funny story, or sound aggravated when I am mad. Heather does not fully reflect my personality.

Heather, like Violet, my wheelchair is another piece of technology between me and you. One more thing that highlights how differently we interact with the world. About 18 months ago, I found myself in a whole new social and professional context. I started a new job. My road to full time employment was long and lined with potholes. Many potential employers had a hard time crossing the distance between the clear words they read on my resumes or cover letters, and the jumbled words spoken during interviews. Employment for anyone with a communication disability has the potential to reduce social isolation and increase personal networks.

At work, I am the sole person in a leadership role with a significant communication disability. Learning to communicate with my colleagues was a long process. My coworkers assumed all forms of communication were difficult, so I was left out of conversations. I missed group chats, was left off text chains, and hid in my office for most of the day. I said the bare minimum at meetings.

Gradually, communication became easier. I developed new strategies. My office mate has become an excellent re-voicer. I have more confidence in my ability to predict levels of comprehension and the best communication method for the situation or audience. It took me a little over a year to feel like an insider at work.

One of my colleagues organized staff improv classes. My instinct was to shy away from this social activity that relied so much on communication. But I needed a way inside the circle. My colleague and I met before the first class to talk about how to adapt the skits so I could fully participate. They have been a great way for my colleagues to get to know my personality on a level deeper than just abbreviated, work related functional speech. After one class, a colleague remarked, I didn't know you were funny.

Our organization offers adults with developmental disabilities a variety of supports and services. Many of our non-speaking participants also face communication barriers. They don't have access to appropriate AAC devices, trained support staff, or vocabulary so they can talk to their peers.

I have so many wishes regarding decreasing social isolation for myself, our participants, and the wider community of AAC users. I wish for an investment in technology that fully adapts to the needs and preferences of each user and funding for well-paid, highly qualified communication supporters. I wish for stronger employment policies and employers who recognize our skills and talent, even when initial communication might be bumpy. I wish all AAC users had access to devices, vocabulary that went beyond functional needs, and community that aligned with their intersections and interests. I wish communication partners assumed competence and learned the art of being patient listeners. Wishes take time and advocacy to be realized. I can keep using all my methods of communication to create a world where all AAC users are valued and included