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How to Model AAC

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In the last fifty years augmentative and alternative communication (AAC) technologies have become increasingly more accessible to people with complex communication needs (CCN). AAC is usually described as various icon-based or text-to-speech programs and devices that speak the words of a person with CCN. With the increased accessibility of AAC devices, individuals with CCN have gained the tools, independence, and confidence to express themselves more than previously possible. The passage of the Americans with Disabilities Act in 1990, which acknowledged the civil rights of people with disabilities, and the Olmstead Act in 1998, which granted individuals with developmental disabilities the right to live in the community, created new opportunities for disabled people to be engaged in the public sphere: making connections, sharing their perspectives, and contributing their talents. With these new opportunities for engagement and self-expression—the result of social as well as technological shifts—people who use AAC have been able to succeed in education, in their professions, and in building new relationships.

Despite the obvious advantages of AAC systems for enhancing the communication of people with CCN, there remain disparities in awareness, inclusion, and education that have hindered the technology's potential impact. AAC involves a blended approach of technology and supportive tools to enhance communication. There are multiple modalities that incorporate each individual's strengths and needs to achieve unique communication goals. However, this variability poses challenges when customizing AAC training plans and navigating additional hurdles of access, economics, and adaptability. An *AAC role model*, as a person who already uses AAC, helps bridge the divide by providing encouragement and advice on implementation strategies. Potential users may find it helpful to have AAC role models to emulate as they go through the challenges of daily life. These role models, or AAC mentors, exchange knowledge and experience with their mentees, promoting self-advocacy and leadership. The epistemologies cultivated in the AAC mentor-mentee connection can be applied to focus areas such as educational challenges, professional obstacles, friendship building, and romantic relationships. Harnessing the perceptiveness and discernment of an AAC mentor follows the tradition of epistemological innovation that originated in the disability community. As Cassandra Hartblay (2020) explains in the article

"Disability Expertise: Claiming Disability Anthropology," people with disabilities use their knowledge or disability expertise to navigate through a society where they encounter instances of ableism and marginalization. Disability expertise should come from people with disabilities themselves, developing a personalized approach to guide interactions in the world. AAC mentors draw from their life experiences to cultivate their disability expertise, and this knowledge not only benefits themselves, but it also assists their mentees and drives innovation that will affect future generations of people who use AAC.

Until recently most, if not all, individuals with CCN were victims of a long history of extreme marginalization. With the advent of capitalism, it was deemed inappropriate for people with impairments to live in regular society if they were not going to be economically productive. Because of this, disabled people were rounded up into almshouses and later institutions. Susan Schweik (2009) explains in her book *The Ugly Laws: Disability in Public* that nineteenth-century American cities passed laws barring people with disabilities from being seen in public. The police during this time harassed and arrested disabled street peddlers and threw them into almshouses—designated for the old, the maimed, and the distressed—which degenerated into abusive medical institutions. These institutions housed disabled people in horrible conditions, a situation also cataloged in *Disability Incarcerated: Imprisonment and Disability in the United States and Canada*. In a chapter entitled "Self-Advocacy: The Emancipation Movement Led by People with Intellectual and Developmental Disabilities," Mark Friedman and Ruthie Marie Beckwith (2014) discuss the way individuals with the most severe disabilities were relegated to the neglected corners of institutions, where there was little supervision and horrendous abuses occurred. It is in these shadows that many people with CCN lived, since they could not advocate for themselves for a different outcome. The innovation of AAC technology became instrumental in allowing people with CCN to advocate for themselves.

The introduction of AAC technology continues to revolutionize self-expression. The technology was developed in the late 1950s and 1960s, leading to some of the first AAC speech-generative devices. These devices became available to those who needed and could afford them in the 1970s (Wendt, Quist, and Lloyd 2011). AAC provided a reliable avenue for people with CCN to express themselves, sometimes for the first time. However, some people have always struggled in learning how to use their AAC adequately. I argue that people might find it easier if other people who have CCN, and are more adept at using their AAC devices, illustrate how these tools can be utilized more effectively. AAC mentors can be adviser figures to those who are experiencing a challenge with their devices by sharing knowledge and expertise with them. The AAC mentor and mentee develop a knowledge base together as they attempt to solve life challenges and obstacles.

One challenge AAC mentors can assist young people with is education. Many children with CCN struggle in using their AAC devices because they must learn

to communicate with them while also trying to excel in their education. Those who feel overwhelmed by these extra challenges might find it helpful to see older people who use AAC proficiently. A few scholarly articles have pointed out the benefits of AAC mentoring in schools, although it is not yet common. In "Mentoring as a Communication Coach in a Public School Setting," Catherine George and Faye Warren (2012) focus on Warren's work as an adult who uses AAC and mentors students newer to the technology in the Orange County Public Schools in Orlando, Florida. Warren attends class with students who use AAC and encourages them to communicate more often with their devices. Students who use AAC see her accomplishments and are motivated to emulate some of the things she does. Warren's most productive sessions with the students occur when teachers give the students preplanned discussion topics or show-and-tell activities to complete before Warren arrives in the classroom. This engagement of the students assists with her primary goal as a mentor, which is to get them to use their AAC devices in conversation with her. Because of the benefits of mentoring, schools should provide funding for these programs, so that more students with AAC can gain knowledge and skills from the experience.

Mentors should also encourage young people who use AAC to excel in school, since education leads to more opportunities. With education, specifically a college education, AAC users gain the qualifications for occupational and organizational opportunities in the community. It is important for young students who use AAC to be engaged throughout their education careers. Young students need older mentors for advice not only on educational challenges but also on challenges they may have with their teachers, aides, or fellow students. A mentor can give a student advice on social issues such as how to make friends or how to navigate negative experiences such as bullying. These are just some of the ways a mentor can provide crucial information to a student who shares their AAC educational experience.

Another way mentors who use AAC assist their mentees is with professional challenges. Disabled people in general have a low employment rate, and for people who use AAC the employment situation is even more severe. When a young person who uses AAC completes their education, they may need guidance navigating the job market. They need advice on aspects of work such as searching for appropriate jobs, applying for those jobs, preparing for job interviews, and preparing for inaccessible work conditions or even an ableist work culture. The AAC mentors have experienced their own professional successes and challenges. With their advice and knowledge, young people who use AAC can avoid some of the professional mistakes the mentors themselves made.

When AAC users broaden their presence in the workforce, possibilities for others blossom. With people who use AAC occupying more career positions, it becomes more common for people who use AAC to be seen as professionals. And when this cultural shift happens, it will allow younger AAC users and their

families to envision more for their professional futures. Rising expectations will also allow people who use AAC to demand more from their employers. They will advocate for accessible and anti-ableist work environments that are conducive to AAC communication, and to the flourishing of other disabled people.

Besides advice on professional relationships, people who use AAC need mentorship on how to navigate social and personal relationships. AAC users often have challenges building social relationships because of their unique mode of communication. Interacting with someone who communicates at a slower speed with an electronic speech-generative device is sometimes disconcerting for nonusers of the technology, which makes them reluctant to engage with people who use AAC. This reluctance puts the onus on people who use AAC to make others comfortable talking with them. AAC users feel pressure to initiate communication with temporarily able-bodied people. Mentors who use AAC can prepare their young mentees on ways to store instant phrases on their AAC devices along with other strategies for being more responsive. They can advise their mentees in ways to be "approachable" and assertive when meeting new people and forming new relationships. Friends are important for everyone to have, and if people who use AAC learn how to form meaningful friendships early in life, it will serve them well.

People who use AAC also need more knowledge about maintaining their existing relationships. Some people who use AAC grow distant from family and friends due to their responses to disability. Because of the historical stigmatization of people with disabilities in society, people can be ashamed and embarrassed to have a disabled person in the family. It would be good for those family members to see people who use AAC handling their business proficiently and professionally, and contributing to society. A mentor who uses AAC serves not only as a role model for students and mentees but also as an example to family members of what those students are capable of.

Mentors who use AAC can also advise their younger mentees in navigating romantic relationships. Engaging in romance has always been challenging for people living with disabilities in modern Western society. This society has a long history of secluding disabled people in institutions or in their homes, rather than seeing and engaging with them in the community. Disabled people have historically had fewer opportunities to date and build romantic relationships. For people who use AAC to speak, it can be more difficult to navigate the social norms of dating, especially since they do not have many opportunities to practice these skills. In "Sexuality and Intimacy for People with Congenital Physical and Communication Disabilities: Barriers and Facilitators," Darryl Sellwood, Pammi Raghavendra, and Paul Jewell argue,

> Relationships and sexuality have been identified as two of the essential factors that contribute to quality of life for adolescents with cerebral palsy. Forming sexual

> identities and learning the etiquette of relationship building usually occurs in youth through socializing with peers. However, people with physical and communication disabilities often lack adequate sexual and relationship education in their youth. Adolescents who use AAC often lack opportunities to discuss essential topics for their development such as sexuality, intimacy and relationships with peers and support workers. The participants in Collier et al. expressed strong feelings of being deprived of information about healthy relationships, opportunities for experiencing intimate relationships and being able to express their own sexuality. The participants perceived that support workers, parents and doctors saw them as asexual and as a result, not in need of such information. (2017, 237)

People who use AAC have many challenges regarding dating and sexuality as a result of the dominant culture thinking they are asexual and dismissing their sexualities. In an effort to alleviate these challenges, a mentor can advise about what worked and did not work regarding dating and expressing sexuality. A mentor might even describe the intricacies of navigating intimate scenarios with partners, whether they be disabled or able-bodied. This know-how can only come from another person who uses AAC. A person outside the AAC user community will not have the same insight or historical knowledge about such romantic situations. A temporarily able-bodied person or a disabled person outside the AAC community has limited knowledge about how to approach someone romantically using an AAC device. It is important for people who use AAC to discuss these issues with each other and expand the knowledge base for the community.

Mentors and mentees exchange knowledge about life challenges through their camaraderie as fellow AAC users. The path is still not clearly defined for what people who use AAC are supposed to do in society, or who they are supposed to become to contribute to their communities. With AAC mentorship relationships, mentors and mentees can collectively invent new ways to live and strive in an ever-changing society. There is no denying that AAC mentorship can improve the lives of young people who use the technology. AAC mentorship programs need to be widely known, encouraged, and funded by educational and community institutions so that more students have the chance to benefit.

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