

Spurring innovation in AAC technology through collaborative dreaming and needs finding with individuals with developmental disabilities who use AAC

Elizabeth R. Lorah¹, Stephen MacNeil, Tara Zimmerman¹, Tracy Rackensperger, Christine Holyfield,¹ Nicolette Caldwell¹, Eduard C. Dragut, Slobodan Vucetic

¹University of Arkansas, Fayetteville, AR

²Temple University, Philadelphia, PA

³University of Georgia, Athens, GA

Abstract

Millions of individuals who have limited or no functional speech use augmentative and alternative communication (AAC) technology to participate in daily life and exercise the human right to communication. While advances in AAC technology lag significantly behind those in other technology sectors, mainstream technology innovations such as artificial intelligence (AI) presents potential for the future of AAC. However, a new future of AAC will only be as effective as it is responsive to the needs and dreams of the people who rely upon it every day. AAC innovation must reflect an iterative, collaborative process with AAC users. To do this, we worked collaboratively with AAC users to complete participatory qualitative research about AAC innovation through AI. We interviewed 13 AAC users regarding a) their current AAC engagement; b) the barriers they experience in using AAC; c) their dreams regarding future AAC development; and d) reflections on potential AAC innovations. To analyze these data, a Rapid Research Evaluation and Appraisal was used. Within this paper, the themes that emerged during interviews and their implications for future AAC development will be discussed. Strengths, barriers, and considerations for participatory design will also be described.

Keywords: Augmentative and alterative communication, participatory design, artificial intelligence

Spurring innovation in AAC technology through collaborative dreaming and needs finding with individuals with developmental disabilities who use AAC

The philosophy and history of the disability justice movement has long recognized the importance of empowering people with disabilities to advocate for what they know is best for themselves and their community (Charlton, 1998). Almost 30 years ago, Charlton (1998) proclaimed the slogan “Nothing About Us Without Us” to capture the essence of the disability justice movement, demanding independence, empowerment, and self-determination for people with disabilities. This slogan has been adopted by millions of people worldwide who are nonspeaking, or who experience intermittent, unreliable, or insufficient speech (Zisk & Dalton, 2019; Donaldson et al, 2021) and benefit from the use of augmentative and alternative communication (AAC) technologies (e.g., mobile technologies with communication apps, speech generating devices) to exercise the human right to communication (Light et al., 2019; Williams et al., 2008). With this principle, the disability justice movement broadly, along with the AAC field, recognized the need for participatory research that included those people with lived experience of having a communication disability and using AAC to substantively influence decision-making and advancement within the field.

Of critical importance to innovation in AAC is a participatory research approach in which people who use AAC are meaningfully involved in the design, development, evaluation and innovation of AAC technologies. In particular, research is needed in this area that fully embraces a participatory research framework, being grounded in the fundamental notion that people who

use AAC should be at the core of decision making. Fittingly, using a participatory research framework, people who use AAC are empowered as collaborative co-creators of knowledge, breaking down the barriers between researchers and AAC users and bridging the research-practice gap. This is essential to establish relevant and sustainable technologies and interventions (Connery & Salsberg, 2023; Douglas et al., 2022; MacNeil & Holyfield, 2023).

Despite these clear advantages, a participatory research paradigm has been largely under-represented within the field of speech-language pathology broadly (Connery & Salsberg, 2023), and within the field of AAC specifically (Dee-Price et al., 2021; MacNeil & Holyfield, 2023; Walsh et al., 2024). In the AAC field, proxy-report from family and support people has often been used rather than making participation in the research process accessible for people who use AAC (Walsh et al., 2024). When people who use AAC have been involved in AAC research and development, their involvement has almost exclusively been limited to serving as research participants (e.g., participating in focus groups or interviews), rather than as consumer research partners who can influence every aspect of the research process (with a few notable exceptions such as McNaughton et al., 2008). Involving people who use AAC as research partners maximizes their participation by involving them in all stages of research including deciding the topic, developing the questions, designing the research, identifying methods for data collection and analysis, interpreting results, and disseminating findings (Connery & Salsberg, 2023; Wallerstein et al., 2017).

One specific area that is ripe for research using a participatory research framework is the use of artificial intelligence (AI) to improve AAC technology design. Cutting-edge AI presents enormous potential for the future of AAC. Components of AI such as machine learning, computer vision, and natural language processing present an array of AAC innovation

opportunities such as customized word prediction, automated visual scene displays, vocabulary capture tools, and voice recognition of dysarthric speech (Sennott et al., 2019; Holyfield et al., 2023). In fact, recent research and development has explored avenues for leveraging AI with promising early results (see Cai et al., 2022; Cai et al., 2023; Holyfield et al., 2024; Valencia et al., 2023). For example, recent research has demonstrated the benefits of “context-aware” AAC that integrates communication partner speech input to enhance communication efficiency for both people with severe motor impairments (Cai et al., 2022, 2023), as well as young children on the autism spectrum (Holyfield et al., 2024). Given the widespread availability of AI tools at this time and their potential, as well as the limitations of existing technologies (Light et al., 2019; Ripat et al., 2019), it is urgent to consider and apply them to the innovation of AAC technologies.

However, a new future of AAC technology will only be as effective as it is responsive to the needs and dreams of the people who rely upon the technology every day (Williams & Holyfield, 2024). In fact, there is some evidence in other areas of healthcare that AI, though applied in an effort to improve technological support, can at times exacerbate problems rather than alleviate them (Babic et al., 2021; Singh et al., 2020). Participatory research is urgently needed to ensure that AAC innovation reflects an iterative, collaborative process with people who use AAC, including them as partners and co-designers of AAC technologies (Gottgens & Oertelt-Prigione, 2021; MacNeil & Holyfield, 2023).

While little participatory research has been conducted to examine this specific area of AAC innovation (i.e., innovation with AI), a number of qualitative studies have examined the perspectives of people who use AAC and their everyday communication partners by including them as participants in qualitative research, in order to inform research and practice. One area of

qualitative research has focused on the lived experiences and perspectives of family members (most often parents) of people who use AAC. A recent qualitative meta-synthesis, (Berenguer et al., 2022), as well as a recent comprehensive scoping review (Kim & Soto, 2024), have systematically summarized the experiences and perceptions of caregivers of children using AAC. Both reviews highlighted the challenges with implementing AAC within the family unit including multiple and competing demands on caregivers, disconnects between home and school communication needs, and emotions associated with implementing AAC at home. There were also challenges reported related to service providers who either lacked knowledge in AAC, or who failed to include parents in the AAC evaluation process. Related to the AAC technologies, parents indicated a need for high and continuous levels of support and training in AAC technologies, as well as challenges related to high costs and funding demands. Overall, caregivers highlighted many difficulties with adopting and implementing AAC at home, and both reviews emphasized the need for collaborative AAC service provision that empowers family members to make decisions throughout the AAC assessment and implementation process (Berenguer et al., 2022; Kim & Soto, 2024).

While parent perspectives have been the most frequently researched partner perspectives within the qualitative AAC work, some research has also examined the perspectives of other important communication partners such as speech-language pathologists (e.g., Moorcroft et al., 2022), special education teachers and paraeducators (e.g., Biggs & Hacker, 2021), and peers (e.g., Lorah et al., 2021). This body of work has revealed stakeholder perceptions of advantages, as well as challenges, for implementing AAC technologies (Biggs & Hacker, 2021; Lorah et al., 2021; Moorcroft et al., 2022).

Importantly, a number of qualitative studies have also examined the perspectives of people who use AAC (e.g., McKelvey et al., 2022; Rackensperger et al., 2005). Ripat and colleagues (2019) performed a meta-synthesis of the published qualitative literature that investigated the lived experience and meaning ascribed to AAC technologies by people who used AAC and their familiar communication partners. Among the advantages of technologies, people indicated that they promoted decision making, increased independence and communicative competence, supported the expression of personality and identity, facilitated engagement in meaningful activities, increased social participation, empowered users, and helped to counter stigma. Despite these advantages, findings also highlighted challenges surrounding the inefficiency of communication using AAC technologies (i.e., slow, effortful), the lack of naturalness (i.e., limitations in voice quality, slow interaction impacts communication), and negative societal responses (Ripat et al., 2019).

Clearly, it is of utmost importance for the AAC field moving forward to capitalize on the advantages (e.g., empowerment, social participation, reducing stigma), while working to counteract the challenges (e.g., inefficiency, lack of fit between user and technology, limitations in voice quality) experienced by people who use AAC in everyday life. Accordingly, recent research investigating the experiences and needs of adults who use AAC has highlighted the importance of the “nothing about us without us” slogan introduced earlier in this paper (e.g., Andzik & Chung, 2022; McKelvey et al., 2022). Specifically, Ripat and colleagues (2019) conclude (emphasis added), “Given the rapid advances in technology, it is important that service providers and industry partners with individuals with complex communication needs to develop [AAC technologies] that address the reported shortcomings of existing devices. Removing environmental and societal barriers to the use of [AAC technologies] with unfamiliar

communication partners and improving the design of [AAC technologies] particularly by *involving people who use AAC and their communication partners in all design stages*, are vital steps towards improving the communication experiences of people with complex communication needs” (p. 77).

Our research team has endeavored to do just this regarding the innovation of AAC technologies with cutting edge AI. Our team for this project included an individual who used AAC, the fourth author, who helped lead conceptualization and implementation of this qualitative study. We also worked to gain input from individuals who use AAC directly, rather than relying on proxies, to share their ideas and experiences. The aim of this participatory research was to gain the perspectives of people who use AAC about: (1) the needs they experience when using their existing technologies, (2) the dreams they have for future AAC technologies, and (3) their attitudes toward incorporating AI into AAC technology in new ways. The results of these interviews were then used, in real time, as part of a larger project that aimed to develop low-fidelity prototypes incorporating cutting edge AI into AAC features (see Holyfield, et al., 2024).

Methods

Participants

The Human Research Protection Program provided ethics approval prior to the commencement of this study. Participants were recruited by direct or indirect contact with individuals who use AAC and their everyday communication partners via word of mouth, emails, or postings to social media sites. Individuals were eligible to participate in the study if they reported (a) being 18 years of age or older, (b) having developmental disability, (c) using AAC technology on a regular basis (i.e., most days) for at least the past 2 years. Participants also all

were required to participate independently in the creation of their interview responses. The participants for this study included 13 AAC users. All participants gave verbal and informed consent to participate at the beginning of the interview and received a gift card as a “Thank you” for their participation. All participants reported using a variety of high-tech, low-tech, and no-tech communication methods, and all participants primarily used AAC to communicate and had been doing so for years. Table 1 provides more demographic information about participants.

Materials

The materials included a University owned laptop computer and Zoom video conferencing server. Sessions occurred either in person or via Zoom, but were always recorded and stored electronically through Zoom services. All data were stored electronically in a Box folder only accessible to the researchers. During the interviews, the interviewer used a Microsoft Word document on a University owned laptop to take notes and perform the rapid analysis, which was also stored in the Box folder. The rapid analysis document was completed at the end of each interview or immediately following video/transcription review.

Procedures

All participants were contacted by the research coordinator following expressing interest either via email, word of mouth, or via an online recruitment link, pre-interview to arrange a date and time for the interview to occur. The research coordinator also contacted the participants post-interview to provide them with the gift card. Participants were also asked to complete a demographic survey, though completion of this survey was not compulsory. Prior to the interviews, the research coordinator provided access to the interview questions for any of the AAC users who requested it. Verbal consent occurred at the onset of the interview.

Consistent with participatory research (Connery & Salsberg, 2023) and design partnerships, an individual who used AAC was included as an integral member of the research team who was involved in designing this study, identifying methods for data collection and analysis, participating in interviews, and interpreting results. That individual who uses AAC, the fourth author, led the interviews of most participants (8/13). Each interview lasted no longer than one-hour in duration and included at least two members of the research team, who were responsible for completing the rapid analysis following the conclusion of the interview. On two occasions, the interviews occurred in a focus group format that consisted of three to five AAC users. As is consistent with participatory research, the interviews were flexible and iterative (Walsh et al., 2024). While they followed a semi-structured interview guide, if a participant decided to describe an area of the interview in more detail than another, they were given the space to do so, while keeping the interviews limited to the one-hour maximum length. Members of the research team who use AAC reviewed the questions from the semi-structured interview guide and provided feedback based on their lived experience of having communication disabilities and using AAC. Modifications were made to the overall number, content, and wording of the questions based on this feedback before beginning the interviews. Each participant was interviewed one time and during each of the interviews, one member of the research team assumed the role of interviewer. Participants responded using the AAC systems described in Table 1. Participants were given adequate time to answer questions, and the interviewer's role was only to provide the prompt and affirmative responses such as verbal confirmations and head nodding. Each question was prompted only after a lull in conversation occurred and the participant confirmed they were finished answering the previous question. The following questions served as a guide for each of the conversations:

- 1) Describe your current use of/engagement with AAC technologies? For example, consider a typical day, what kinds of AAC are you using? What is/are the setting(s) in which it is used? What functions does the AAC serve?
- 2) What challenges do you have or see with existing AAC?
- 3) What “dreams” do you have regarding future AAC developments?
- 4) Reflect on possible AAC innovations.
- 5) Do you have any other comments regarding AAC and its use?

Data Collection and Analysis

This study used the rapid analysis qualitative method (Vindrolas-Padros & Johnson, 2020) to interpret and derive insights from the interviews with AAC users. Traditionally, a qualitative research approach requires long periods of time between data collection, analysis, and dissemination, and as a result, there is a long delay in the translation of research into practice. This is problematic when real-time data are needed to inform implementation, such as in applied health, clinical, and educational settings, Lewinski et al., 2021; Nevedal et al., 2021; Vindrola-Padros & Johnson, 2020). In these service delivery settings, delays to render findings may make findings out of date (Taylor et al., 2018). This is especially the case when technology is evolving at such a rapid pace that a one-year delay in data collection could render the results obsolete. As the results of user interviews in this study were being used to develop real-time AAC features, leveraging AI innovations, any delays in data interpretation and analysis had to be avoided.

As previously mentioned, this study was the first phase of a larger project sponsored by the National Science Foundation to explore the use of AI technology in the development of AAC features . Given the accelerated timeline of the overarching research program a rapid analysis (Vindrolas-Padros & Johnson, 2020) was deemed as the appropriate design choice so that the

results could be quickly analyzed and used to develop AI features in real time, to then be tested with users before the end of the grant period. When using rapid analysis, researchers can minimize time needed for data analysis by avoiding the use of transcription services and instead, delivering real-time findings immediately following a structured interview (McNall & Foster-Fishman, 2007).

The phases of the rapid analysis were consistent with those outlined in Taylor et al., 2018 and were as follows a) data collection: interviews were analyzed first, then focus groups; b) transcription: during and immediately following data collection audio recordings were transcribed by a third party and checked for accuracy by two authors, it was from these transcripts that all direct quotes were obtained ; c) ordering: interviews, then focus groups were analyzed first; d) data management and review: at least two researchers completed an analysis of one interview transcript inserting them into The Rapid Research Evaluation and Appraisal Lab (RREAL), described below; e) interrater reliability was assessed for each RREAL form, by researchers reviewing the content in each other's matrices; f) summaries and findings were combined and checked; g) and finally, researchers reflected and discussed their data and interpretation (Taylor et al., 2020).

The Rapid Research Evaluation and Appraisal Lab (RREAL)

At the end of each interview session or immediately following video review/transcript of an interview session, at least two members of the research team completed a Rapid Research Evaluation and Appraisal Lab (RREAL)(Vindola-Padros et al., 2021). Transcripts were also used to supplement interview review due to articulation difficulties with interviewees. Within the RREAL, researchers noted basic interview information (i.e., date, participants, etc.), the content of the interview (i.e., the questions asked during the interviews), common themes that occurred

in the interview, application ideas, and surprising findings. The use of the RREAL sheet supported data triangulation (Vindrola-Padros, 2020). Data triangulation occurred through the examination of these different interview sources, across the interviewees, and through the identification of common themes across researchers (interrater reliability). Interrater reliability was 100% across RREAL forms. The RREAL sheet facilitated real time data collection, synthesis, and reporting (Vindrola-Padros, 2020) allowing for subsequent phases of the larger project, which involved the development of low-fidelity prototypes of AAC innovations leveraging AI, to occur quickly.

Results

In total, 26 RREAL forms, from the interviews/focus groups were synthesized and analyzed. The results of the rapid analysis are presented in Table 2 and indicated three overarching themes and eight subthemes related to the questions that were asked. The first was related to current technology used and those pain points associated with its use. The second was hopefulness for the future of AAC technology and dreams related to features and functionality. The third related to concerns for the ethical use of AAC in the future of AAC technology.

Theme 1: Existing AAC Technologies are Cumbersome and Disconnected

End users indicated that existing AAC technologies were cumbersome and disconnected—from one another, the people who use them, and the environments in which they were used.

Subtheme 1: More than one AAC is Required

The majority of advanced AAC communicators reported using more than one AAC technology, often switching between devices during communication, evidencing the disconnection between technologies. For example, many AAC expert users reported using a keyboard and a combination

of mobile and dedicated devices. Several AAC users switched between keyboards and the laborious typing of personalized responses, to the use of preprogrammed phrases. Several users relied on predictive keyboard technology. Finally, users reported utilizing unaided AAC, such as gestures when appropriate and able, to supplement the use of aided AAC systems. While the majority of AAC users could rapidly alternate between multiple devices, they reported this to be cumbersome.

Subtheme 2: Disconnect Between AAC Technologies

One AAC user spoke of the disconnect between AAC technologies and the environments in which they were used as he discussed situations in which AAC technologies left his communication needs unmet, “...some other times my communication needs are not met are as follows: Lying in bed; having dinner at a restaurant; watching movies, especially at a theater with 4DX technology; chilling on the couch watching TV, or at an event where there’s a lot of physical activity where using my Accent is not feasible. This is not an exhaustive list, but a quick overview. Most of these are solved by using my phone or a combination of my natural dysarthric speech, ASL fingerspelling and simple hand gestures, or a tapping system when people don’t know ASL.”

Subtheme 3: Communication is Slow

Regarding the cumbersome nature of existing technologies, slow rate of communication with existing AAC technologies was a challenge reported by almost all participants. Specifically, contributing to fast-paced conversations created tension with communication partners who often became inattentive as they waited for the AAC users to type or select a response, ultimately contributing to communication breakdowns (i.e., partners having difficulty understanding the AAC users ’message). While the following quotation reveals how one expert AAC user

developed a strategic competence to combat this challenge (i.e., a pre-programmed phrase to inform communication partners to be patient), it also demonstrates the challenges with slow communication methods with existing technologies. One interviewee stated: “I told [name redacted] that I needed some way to stop people to tell them that I had something to say. [Name redacted] and I came up with this sentence: hang on a second, please. I'm typing what I want to say. We programmed a button to say this on my main page. having that sentence available to me was life changing...”

It was further reported that current AAC systems were often physically cumbersome and disconnected from the people who use them. The size and positioning of technologies disrupted intimate moments with communication partners and the natural flow of conversation. One AAC user noted that the screen of the device can interfere with her ability to make eye contact and look at communication partners during exchanges. This makes reading facial expressions difficult, which is a natural and important part of a communication exchange. Participants expressed the desire for high-tech communication options that they could use beyond the traditional tablet- or computer-based interface. As one participant cleverly stated: “It's time to start thinking about communication outside of the ‘box’.” This statement corresponded with them gesturing to the outline of their AAC device and clarifying that was the box they wanted communication options outside of.

Given the cumbersome and disconnected nature of existing technologies exemplified by the preceding quotations, participants also had ideas about innovations for the future of AAC technologies.

Theme 2: The Future is Smarter, More Responsive, and More Connected

Participants reported they would like AAC technologies to be smarter, more responsive to the environmental context, and more connected (i.e., less separated from the person using AAC, the environment, and other technologies).

Subtheme 1: More Accurate Predictability is Needed

Regarding dreams of technologies that would be smarter and more responsive to the environmental context, AAC users described technologies that could learn about them and more accurately predict the things that they would need to communicate. Many users dreamed of smarter devices that would use context from the environment around them to provide quicker and more individualized and responsive communication options. For example, if a user took the same bus to work every day, the AAC device could predict the information that they would need to communicate to the bus driver based on the time of day and location of the individual. For example, one user dreamed future AAC might include "... facial recognition software. Like if I make a sad face, it will recognize the context and give me possible things a sad person would say." Further stating "It would be also cool if the AAC was listening to the other person. Like if they asked me what my favorite baseball team was, the AAC would automatically present choices of the baseball teams."

Additionally, many users expressed a desire for smarter devices that could learn their speech sounds or words, and automatically program them into device buttons or predict more complete or accurate spoken phrases. In a conversation between two interviewees, one user said: "So I think hopefully with AI they can take our voices and store and adjust it so that it can be spoken on our AAC devices... maybe AI can understand our verbal pronunciation and make messages out of it." The second user agreed, asking: "What if an AAC system could understand my speech, so I only have to speak, it could understand, then say it in a more intelligible way?"

Subtheme 2: Communication Should be Faster

AAC users reported a desire for technologies that supported genuine connections with communication partners, through technologies that were responsive to the needs of the user and aware of the environmental context. One AAC user hoped about their future AAC device, by integrating input from communication partners, that: “It could let you say whatever you wanted to say very quickly (in 1 or 2 seconds). because that's a challenge of it takes the user a few seconds to type in what they want to say, and the listener may not be patient enough to wait a few seconds.”

Subtheme 3: There is a Need for Better Integration with Non-AAC Apps

AAC users hoped for technologies that could more seamlessly integrate with non-AAC applications, such as games or work documents. For example, one interviewee wanted a feature in his video game that would allow him to communicate the six most common phrases he used while playing that specific game. Finally, they reported a desire for smarter high-tech features such as projecting screens, haptic holographic keyboards, and wearable glasses that could be integrated into their AAC experience. One participant reported, “The next big medium is virtual reality which will definitely change the way we interact with others as we know it. I hope AAC methods can be built into VR technologies in the ground level and be in the minds of developers before people who have complex communication needs and significant physical challenges get left behind, and it takes decades to have reasonable accommodations when we can solve the issue right now with awareness and training of innovators in the field.”

Theme 3: Ethical Considerations for AAC Use

The last component of the interview required AAC users to reflect on possible AAC innovations. During this portion of the interview many users reported a distrust on how data

would be used if given permissions for context aware or predictive AAC. However, interviewees discussed that there were steps that could be taken to increase trust in data sharing, and that they would be willing to share data if they saw clear benefits and trusted the people who were collecting and using the data. As one AAC user put it: “If people weren’t incentivized to use me for money, I would be less worried.” At which point another AAC user chimed in: “And if you were being paid for your data.”

Subtheme 1: Data Protection

Users also indicated that they wanted power over features that were collecting and using data and when that was occurring. One reason shared for this was concern over consent issues related to the use of data collected from their communication partners. For example, if a device were context aware and used communication partner speech to produce predictive phrases—how could the partner provide consent prior to the communication episode. In particular, interviewees expressed concern over less familiar communication partners being recorded (particularly video recorded) without their knowledge or permission. Interviewees also discussed that being able to disconnect and make their communication private would be important to them in intensely personal situations. One interviewee stated it was important for them, “To be able to communicate during sex in a private method.”

Subtheme 2: Authenticity of Communication

A final concern related to the authenticity of communication and whether AAC user communication would be considered genuine if it relied on predictive text or artificial intelligence for generative purposes. While this technology has been available in mainstream technology for sometime, such as with “Google Mail”, it has not been leveraged to its full potential for AAC devices. Despite its use in mainstream technology, AAC users expressed their

concern in authenticating the originality of the message. For example, if AAC interpreted communication partner speech and offered reasonable options for responding, how could the AAC user make sure the communication partner interpreted the exchange as authentic when it was generated by AI? One AAC user had specific concerns that the use of AI to generate messages would undermine his intelligence in the eyes of communication partners. One participant reported, “Case in point Simple AI Technology such as spell and grammar check would benefit AAC users with speaking, but would that take away from the respect for the person’s inherent intelligence? Especially since that is a real battle for many people with disabilities.”

Summary

While AAC users reported difficulties with their current systems, they also reported that they are often clear and easy to edit, they provide helpful prediction by saving previous text that were previously communicated. They also reported that their current AAC does provide many options for communicative purposes and that they are often (but not always) easy to switch between, as needed. They are hopeful for the future of AAC as new technologies seem to be making the world more accessible. AAC users remain optimistic as to the future of AAC.

Discussion

The adults with developmental disabilities who participated in the current study all used high-tech AAC as their primary mode of communication, indicating the benefits existing AAC technology provides. Still, all of the participants stated clearly that they have communication needs and desires that are currently going unmet with existing AAC technologies. Participants reported that existing AAC technologies were cumbersome for them to use and disconnected from them, the context in which they communicate, and the other digital platforms within which

they communicate (Theme 1). For instance, AAC users discussed that they were often unable to participate in fast-paced interactions (Subtheme 3), that there were places and context from which their primary technology was not useful (Subtheme 1), that their AAC technology was not well connected to the world outside of it (Subtheme 2), and that communication was too effortful (Subtheme 3). When considering the future of AAC technology, participants discussed concerns about privacy, who would have access to their data, and to what end (Theme 3). The participants wanted transparency around if and how their data were being used (Subtheme 1), wanted assurances that their data used to make AAC smarter was being protected (Subtheme 1), and wanted compensation as appropriate (Subtheme 1). Participants also expressed concern that communication partners may question the authenticity of their messages if smarter, AI-based AAC was being used (e.g., to support prediction) (Subtheme 2). Important as their concerns were, participants' concerns were outweighed by their excitement for the possibilities for the future of AAC that they believe will be smarter, more responsive, and more connected (Theme 2). Participants discussed a range of opportunities for AI to be integrated into AAC technology to improve their lives. Examples of ideas included offering quick and low-effort communication options predicted with environmental information (Subtheme 2), integrating the context outside of the communication device into the communication device (Subtheme 1; Subtheme 3), and improving the ability of AAC technology to learn from them and adapt to their needs to better support them such as by providing personally relevant prediction (Subtheme 1).

Previous qualitative research has gathered important information from people with developmental disabilities who use AAC about their needs and priorities (Ripat et al., 2018) as well as those of their families (e.g., Berenguer et al., 2022) and the professionals in their lives (e.g., Moorcroft et al., 2021). Recent research and development have also begun to explore

opportunities for AI to improve the AAC technology user experience (Cai et al., 2022; Cai et al., 2023; Holyfield et al., 2024; Valencia et al., 2023). The current study extends existing research by using qualitative methods to understand the dreams, needs, and concerns of people with developmental disabilities who use AAC toward the innovation of future AAC technology, such as through the integration of AI. The current study also extends previous research and development efforts by, in addition to including individuals with developmental disabilities who use AAC as participants, taking a participatory approach to include a person who uses AAC as a major contributor to the project and as the person interviewing the majority of participants.

Implications for Researchers and Developers

People who have developmental disabilities and use AAC offered valuable insights in the current study. However, the study was limited in size and scope, so strong guidelines for future research and development cannot be established. Still, researchers and developers should take a use-inspired approach to AAC innovation in which they listen to the dreams and work to address the needs of the people who rely on the technology every day to participate fully in life. Researchers and developers should consider the effort required and lack of connectedness felt by people with developmental disabilities when they are using existing AAC technologies. Researchers and developers should also consider their excitement toward future technology that is smarter, more connected, and more responsive to them through the integration of new AI capabilities. When doing so, careful consideration should also be paid to the concerns AAC users expressed about data privacy, and the ways in which they expressed they would feel more comfortable in sharing their data.

In addition to the valuable content that people who use AAC provided us in this project, researchers and developers could also consider the approach taken to gather it. The field of

human-centered design has well developed methodologies and tools that AAC researchers and technology developers could leverage to great effect to more meaningfully include people who use AAC with developmental disabilities in the process of designing and evaluating technological innovations (Dee-Price et al., 2020; Göttgens & Oertelt-Prigione, 2021; MacNeil & Holyfield, 2023; Muller & Druin, 2012). Such participation is critical to improving outcomes (Connery & Salsberg, 2023; Douglas et al., 2023; Quintero, 2020; Walsh et al., 2024; Williams & Holyfield, 2024). This study adds just one example to the few currently available (e.g., McNaughton et al., 2008) of research and development work in which people who use AAC are members of the research/development team rather than serving as participants. Researchers and developers should take deliberate effort to meaningfully include more people who use AAC as part of their teams as it may be hard to underestimate the impact of taking a participatory research and design approach. In our case, it is impossible to know whether we heard information from participants that we would not have heard otherwise if a person who uses AAC did not help develop the interview questions and lead most of the interviews. But it is unlikely there was not at least some positive impact of this participatory approach on the insights we gathered.

Limitations and Future Research Directions

There are many important limitations to the current study and opportunities for future research to build upon it. First, millions of people with developmental disabilities use AAC technology (Light et al., 2019); in this study we heard from just 13 of them. As such, the generalizability of the findings of the current study are limited. Future research should continue to include people with developmental disabilities who use AAC to share more of their dreams and insights and should provide detailed information about participants. In addition to including

participants who use AAC, future research should also consider gathering insights from individuals who abandoned AAC technology because it was not meeting their needs. These insights may provide valuable information about opportunities to innovate future AAC technology that results in increased uptake. Second, only limited demographic information about the participants was gathered, and due to the rapid analysis used, quotes and insights were not assigned to specific participants. While it is important to share detailed information about participants to better inform readers, time was a major consideration highlighted by our team member who uses AAC. She knew that the questions that could be asked and answered in a reasonable amount of time for a one-time interview or focus group was limited. To be able to dedicate more time to hearing from end users about AAC technology innovation, we asked limited demographic questions. Also, due to the fast-paced nature of technology innovation and our team goal toward iterative research and development, we conducted a rapid analysis of the data which limited the level of detail provided. Future research should include more demographic information to allow for a richer analysis of the information gathered. Future research should also conduct more in-depth analysis to provide more detailed information about each participants' specific views toward each interview question. Third, our research team included individuals with developmental disabilities who used AAC but did not include an individual who had an intellectual disability, and the interviews included just one individual with an intellectual disability. This is a major limitation of this study. People with developmental disabilities who have an associated intellectual disability stand to benefit immensely from new capabilities in AI (Holyfield et al., 2023). They are also a group who do not always find existing AAC technologies accessible to them (Light et al., 2019). Therefore, it is critical that future research and development meaningfully includes people who use AAC who have intellectual

disabilities, both as team members and as participants. For practical strategies for meaningfully including people with developmental disabilities on a research team, please see Forber-Pratt (2024).

Conclusion

The future of AAC technology is bright due to the burgeoning capabilities of AI, and the potential for those capabilities to be integrated into AAC technology for it to more effectively support the people who use it (Holyfield et al., 2023; Sennott et al., 2019). Individuals with developmental disabilities who use AAC reported some concerns with a smarter future for AAC technology, but overwhelmingly participants dreamt of and were excited about the future. Yet, despite the incredible new capabilities of AI, a brighter technological future is not guaranteed (Babic et al., 2021; Singh et al., 2020). AAC researchers and technology developers must partner with people who use AAC and engage them meaningfully in all aspects of the technology innovation process, not just to consult on initial ideas or as research participants to evaluate already completed AAC designs.

Acknowledgements

This project was funded by a Track H Convergence Accelerator grant (Award Number 2236352) from the National Science Foundation.

Conflict of Interest: The authors declare no conflict of interest.

Table 1

Participant Demographic Information

Participant	Stage of Adulthood	Race	Developmental	AAC User	Primary AAC Used
			Disability Type		
1	*Adult	White	Physical disability	Full-time AAC user	Tablet with Predictable
2	Adult	Black	Physical disability	Full-time AAC user	Dedicated device (PRC-Saltillo) with LAMP
3	**Young adult	White	Physical disability	Full-time AAC user	Tablet with Apple Notes
4	Young adult	White	Physical disability; Intellectual disability	Full-time AAC user	Dedicated device (Tobii- Dynavox) with Word Power
5	Adult	White	Physical disability	Full-time AAC user	Dedicated device (Tobii- Dynavox) with Word Power

6	Young adult	White	Autism	Full-time AAC user	Tablet with Proloquo4Text, Proloquo2Go, Flip Writer
7	Young adult	White	Autism	Part-time AAC user	Tablet with Proloquo4Text
8	Young adult	White	Autism	Full-time AAC user	Tablet with Flip Writer, word processor
9	Young adult	White	Physical disability	Full-time AAC user	Dedicated device (Smartbox) with Grid 3
10	Young adult	White	Physical disability	Full-time AAC user	Dedicated device (Smartbox) with Grid 3
11	Young adult	White	Physical disability	Full-time AAC user	Tablet with SpeechAssistantAAC, Proloquo2Go
12	Adult	Black	Physical disability	Full-time AAC user	Tablet with Proloquo2Go, Proloquo4Text

13	Adult	White	Physical disability	Full-time AAC user	Tablet with LAMP
----	-------	-------	------------------------	-----------------------	------------------

Note:

**Adult: 27 and older*

***Young Adult ages 18-26*

Table 2*Themes, Subthemes, and Examples*

Themes	Subthemes	Examples
Existing AAC technologies are cumbersome and disconnected	More than one AAC is required	Use of keyboards and grid displays; mobile and dedicated devices
	Disconnect between AAC technologies	AAC devices are not always available, in all circumstances
	Communication is slow	AAC communication cannot keep up with fast-paced conversations
The future is smarter, more responsive, and more connected	More accurate predictability is needed	Communication could learn more about users, improved predictability
	Communication should be faster	Use of predictability could make communication faster
	There is a need better integration with non-AAC apps	Use of AAC apps to communicate within video gaming systems
Ethical Considerations for AAC Users	Data protection	Data collected from communication partners needs to be secure
	Authenticity of communication	Concerns about whether communication leveraging AI would be considered authentic

References

Andzik, N. R., & Chung, Y.-C. (2021). Augmentative and alternative communication for adults with complex communication needs: A review of single-case research. *Communication Disorders Quarterly*, 43(3), 182–194. <https://doi.org/10.1177/1525740121991478>

Babic, B., Gerke, S., Evgeniou, T., & Cohen, I. G. (2021). Beware explanations from AI in health care. *Science*, 373(6552), 284-286. <https://doi.org/10.1126/science.abg1834>

Berenguer, C., Martínez, E. R., De Stasio, S., & Baixauli, I. (2022). Parents' perceptions and experiences with their children's use of augmentative/alternative communication: A systematic review and qualitative meta-synthesis. *International Journal of Environmental Research and Public Health*, 19(13), 8091. <https://doi.org/10.3390/ijerph19138091>

Biggs, E. E., & Hacker, R. (2021). Engaging stakeholders to improve social validity: Intervention priorities for students with complex communication needs. *Augmentative and Alternative Communication*, 37(1), 25–38.
<https://doi.org/10.1080/07434618.2021.1881824>

Cai, S., Venugopalan, S., Tomanek, K., Narayanan, A., Morris, M. R., & Brenner, M. P. (2022). Context-aware abbreviation expansion using large language models. *arXiv preprint arXiv:2205.03767*. <https://doi.org/10.48550/arXiv.2205.03767>.

Cai, S., Venugopalan, S., Seaver, K., Xiao, X., Tomanek, K., Jalasutram, S., ... & Brenner, M. P. (2023). Using Large Language Models to Accelerate Communication for Users with Severe Motor Impairments. *arXiv preprint arXiv:2312.01532*.
<https://doi.org/10.48550/arXiv.2312.01532>

Connery, A., & Salsberg, J. (2023). Exploring participatory health research and its application to speech and language therapy research practices. *International Journal of Language & Communication Disorders*, 1-12. <https://doi.org/10.1111/1460-6984.12994>

Dee-Price, B.-J. M., Hallahan, L., Nelson Bryen, D., & Watson, J. M. (2020). Every voice counts: Exploring Communication Accessible Research Methods. *Disability & Society*, 36(2), 240–264. <https://doi.org/10.1080/09687599.2020.1715924>

Donaldson, A. L., corbin, e., & McCoy, J. (2021). “Everyone deserves AAC”: Preliminary study of the experiences of speaking autistic adults who use augmentative and alternative communication. *Perspectives of the ASHA Special Interest Groups*, 6(2), 315-326.

Douglas, N., Hinckley, J., Grandbois, K., Schliep, M., Wonkka, A., Oshita, J., & Feuerstein, J. (2023). How a power differential between clinicians and researchers contributes to the research-to-practice gap. *American Journal of Speech-Language Pathology*, 32(2), 803–810. https://doi.org/10.1044/2022_ajslp-22-00207

Forber-Pratt, A. J. (2024). Advancing and Expecting Inclusive Research. *Inclusion*, 12(1), 30-39. <https://doi.org/10.1352/2326-6988-12.1.30>

Göttgens, I., & Oertelt-Prigione, S. (2021). The application of human-centered design approaches in health research and innovation: a narrative review of current practices. *JMIR mHealth and uHealth*, 9(12), e28102. <https://doi.org/10.2196/28102>

Holyfield, C., MacNeil, S., Caldwell, N., O'Neill Zimmerman, T., Lorah, E., Dragut, E., & Vucetic, S. (2024). Leveraging communication partner speech to automate augmented input for children on the autism spectrum who are minimally verbal: Prototype Development and preliminary efficacy investigation. *American Journal of Speech-Language Pathology*, 1–19. https://doi.org/10.1044/2023_ajslp-23-00224

Holyfield, C., MacNeil, S., Vucetic, S., Dragut, E., Rackensperger, T., Lorah, E., Caldwell, N., Karnes, A. (2023, January). *Is the current state of natural language processing the future for AAC?* [Poster Presentation]. Annual conference for the Assistive Technology Industry Association, Orlando, Florida.

Kim, J., & Soto, G. (2024). A comprehensive scoping review of caregivers' experiences with augmentative and alternative communication and their collaboration with School Professionals. *Language, Speech, and Hearing Services in Schools*, 55(2), 607–627.
https://doi.org/10.1044/2024_lshss-23-00117

Lewinski, A. A., Crowley, M. J., Miller, C., Bosworth, H. B., Jackson, G. L., Steinhauser, K., White-Clark, C., McCant, F., & Zullig, L. L. (2021b). Applied rapid qualitative analysis to develop a contextually appropriate intervention and increase the likelihood of uptake. *Medical Care*, 59(Suppl 3). <https://doi.org/10.1097/mlr.0000000000001553>

Light, J., McNaughton, D., Beukelman, D., Fager, S. K., Fried-Oken, M., Jakobs, T., & Jakobs, E. (2019). Challenges and opportunities in augmentative and alternative communication: Research and technology development to enhance communication and participation for individuals with complex communication needs. *Augmentative and Alternative Communication*, 35(1), 1–12. <https://doi.org/10.1080/07434618.2018.1556732>

Lorah, E., Holyfield, C., & Kucharczyk, S. (2021). Typical preschoolers' perceptions of augmentative and alternative communication modes of a preschooler with autism spectrum disorder. *Augmentative and Alternative Communication*, 37(1), 52–63.
<https://doi.org/10.1080/07434618.2020.1864469>

MacNeil, S., & Holyfield, C. (2023, November). *AAC by and for the people: Adopting human-centered design practices to inform AAC design* [Oral presentation]. American Speech-Language-Hearing Association Conference, Boston, MA, United States.

McKelvey, M., Weissling, K. S., Lund, S. K., Quach, W., & Dietz, A. (2021a). Augmentative and alternative communication assessment in adults with amyotrophic lateral sclerosis: Results of semi-structured interviews. *Communication Disorders Quarterly*, 43(3), 163–171.

<https://doi.org/10.1177/15257401211017143>

McNaughton, D., Rackensperger, T., Benedek-Wood, E., Krezman, C., Williams, M. B., & Light, J. (2008). “A child needs to be given a chance to succeed”: Parents of individuals who use AAC describe the benefits and challenges of learning AAC technologies. *Augmentative and alternative communication*, 24(1), 43-55. <https://doi.org/10.1080/07434610701421007>

Moorcroft, A., Allum, J., & Scarinci, N. (2021). Speech language pathologists' responses to the rejection or abandonment of AAC Systems. *Disability and Rehabilitation*, 44(16), 4257–4265. <https://doi.org/10.1080/09638288.2021.1900412>

Rackensperger, T., Krezman, C., McNaughton, D., Williams, M.B., & D'Silva, K. (2005). When I first got it, I wanted to throw it off a cliff: The challenges and benefits of learning AAC technologies as described by adults who use AAC. *Augmentative and Alternative Communication*, 21(3), 165–186. <https://doi.org/doi:10.1080/07434610500140360>

Muller, M., & Druin, A. (2012). Participatory design: The third space in HCI. In J. A. Jacko (Ed.), *The Human-Computer Interaction Handbook* (3rd ed., pp. 1125–1153). CRC Press.

Quintero, C. (2020). A review: Accessible technology through participatory design. *Disability and Rehabilitation: Assistive Technology*, 17(4), 369–375.

<https://doi.org/10.1080/17483107.2020.1785564>

Ripat, J., Verdonck, M., Gacek, C., & McNicol, S. (2018). A qualitative metasynthesis of the meaning of speech-generating devices for people with complex communication needs.

Augmentative and Alternative Communication, 35(2), 69–79.

<https://doi.org/10.1080/07434618.2018.1513071>

Sennott, S. C., Akagi, L., Lee, M., & Rhodes, A. (2019). AAC and Artificial Intelligence (AI).

Topics in Language Disorders, 39(4), 389–403.

<https://doi.org/10.1097/tld.0000000000000197>

Singh, R. P., Hom, G. L., Abramoff, M. D., Campbell, J. P., & Chiang, M. F. (2020). Current challenges and barriers to real-world artificial intelligence adoption for the healthcare system, provider, and the patient. *Translational Vision Science & Technology*, 9(2), 45-45.

<https://doi.org/10.1167/tvst.9.2.45>

Valencia, S., Cave, R., Kallarackal, K., Seaver, K., Terry, M., & Kane, S. K. (2023, April). “The less I type, the better”: How AI Language Models can Enhance or Impede Communication for AAC Users. *In Proceedings of the 2023 CHI Conference on Human Factors in Computing Systems* (pp. 1-14). <https://doi.org/10.1145/3544548.3581560>

Vindrola-Padros, C., & Johnson, G. A. (2020b). Rapid techniques in qualitative research: A critical review of the literature. *Qualitative Health Research*, 30(10), 1596–1604.

<https://doi.org/10.1177/1049732320921835>

Wallerstein, N., Duran, B., Oetzel, J. G., & Minkler, M. (2018). *Community based participatory research for Health: Advancing Social and Health Equity*. Jossey-Bass Inc.

Walsh, M., Harman, I., Manning, P., Ponza, B., Wong, S., Shaw, B., Sellwood, D., Anderson, K., Reddihough, D., & Wallen, M. (2024). Including people who use augmentative and

alternative communication in qualitative research: Can you hear us? *International Journal of Qualitative Methods*, 23, 1-13. <https://doi.org/10.1177/16094069241234190>

Williams, M. B., Krezman, C., & McNaughton, D. (2008). “Reach for the stars”: Five principles for the next 25 years of AAC. *Augmentative and Alternative Communication*, 24(3), 194–206. <https://doi.org/10.1080/08990220802387851>

Williams, K., & Holyfield, C. (2024, May). *Future of AAC technologies: Priorities for inclusive research and implementation* [Oral presentation]. The Future of AAC Research Summit, Arlington, VA, United States.

Zisk, A. H., & Dalton, E. (2019). Augmentative and alternative communication for speaking autistic adults: Overview and recommendations. *Autism in Adulthood*, 1(2), 93–100. <https://doi.org/10.1089/aut.2018.0007>