Priorities for Future AAC Research and Development

White Paper Summary of Papers and Discussions at the
Future of AAC Research Summit

Organized by the NIDILRR-funded Rehabilitation Engineering Research Center on Augmentative and Alternative Communication (The RERC on AAC)
in collaboration with CommunicationFIRST
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Priorities for Future AAC Research and Development

Background

Communication is a fundamental human right – one that is often taken for granted. Yet, there are more than 5 million Americans, more than 97 million people worldwide who cannot rely on speech alone to be heard and understood[1], including children and adults with developmental disabilities (e.g., autism, cerebral palsy, Down syndrome, intellectual and developmental disabilities), acquired conditions (e.g., brainstem stroke, cerebral vascular accident, spinal cord injury, traumatic brain injury), and degenerative disabilities (e.g., ALS, dementia, muscular dystrophy) (Beukelman & Light, 2020). Without access to effective communication, these individuals are severely restricted in their participation in all aspects of society – education, employment, healthcare, family life, and community living (Arvidsson et al., 2015; García et al., 2020; Hiersteiner et al., 2014; Smith et al., 2020).

Augmentative and alternative communication (i.e., AAC; strategies and techniques to enhance communication such as signs, gestures, picture exchange systems, alphabet boards, speech generating devices, mobile technologies with AAC applications) offers tremendous promise to enhance communication, increase participation, and improve quality of life for people who cannot rely on speech alone to be heard or understood (e.g., Kasari et al., 2014; Morin et al., 2018; Peters et al., 2024; Pope et al., 2024; Romski et al., 2010). However, this potential can only be realized if people have access to effective AAC and have meaningful opportunities to learn language and literacy skills and to participate in education, employment, healthcare, and community living (Donaldson et al., 2021; McLeod et al., 2022; Williams, 2024). Unfortunately,

- Only 22% of school-aged children who would benefit from AAC have been seen by an AAC specialist (Binger et al., 2021)
- Only 10% of adults with disabilities who need AAC, have access to AAC (Hiersteiner et al., 2014)
- More than two-thirds of children with multiple disabilities and more than half of children with intellectual and developmental disabilities spend a majority of their day in self-contained classrooms or separate schools, away from their peers and outside the general education curriculum (US Department of Education, Office of Special Education Programs, 2024).

[1] We recognize the power and importance of the language that we use to talk about people who need and use AAC. We respect the right of every person to describe themselves in the ways that they choose. In this paper, we have used the terms proposed by CommunicationFIRST, a nonprofit organization in the United States with the mission to protect and advance the civil rights of people who use AAC. Specifically, we use the terms, people who need or use AAC and people who cannot rely on speech alone to be heard and understood.

- Up to 90% of individuals with developmental disabilities who need or use AAC have limited or no opportunity to participate in literacy instruction and enter adulthood without acquiring functional literacy skills, undermining their participation in society (Foley & Wolter, 2010).
- Less than 5% of individuals who need or use AAC are employed full time (McNaughton et al., 2001, 2002); only limited numbers secure part-time work (Shattuck et al., 2012); and these positions typically involve low wage jobs (Taylor & Seltzer, 2011).
- People who need or use AAC are severely restricted in community participation, resulting in social isolation, increased loneliness, and reduced quality of life (Arvidsson et al., 2015; Donaldson et al., 2021; García et al., 2020; Hiersteiner et al., 2014)
- 45% of individuals who cannot rely on speech alone to be heard and understood report that they have been victims of crime, maltreatment, or neglect; 71% of these individuals have been victimized multiple times and 97% knew the perpetrators (Bryen et al., 2003).
- Hospital patients who cannot rely on speech to communicate experience 2-3 times more preventable adverse medical events (e.g., medication errors, falls) compared to individuals without communication disabilities, leading to poor health outcomes and increased mortality (Handberg & Voss, 2018; Happ et al., 2015; Hemsley & Balandin, 2014; Zubow &Hurtig, 2013). These communication failures result in over 600,000 preventable adverse events annually, at a projected healthcare cost of $6.8 billion per year (Hurtig et al., 2018).

Action is urgently required to effect positive change.

On May 13-14, 2024, a national meeting of AAC stakeholders (The Future of AAC Research Summit) was convened to share the state of the science in AAC and determine priorities for future AAC research and development to improve outcomes for people who need or use AAC. The Summit was organized by the Rehabilitation Engineering Research Center on Augmentative and Alternative Communication (The RERC on AAC [https://rerc-aac.psu.edu] funded by the National Institute on Disability, Independent Living, and Rehabilitation Research) in close collaboration with CommunicationFIRST, a national advocacy organization, run by people who use AAC, with a mission to protect and advance the civil rights of people who use AAC (https://communicationfirst.org/).

The Summit brought together a wide range of AAC stakeholders, including people who use AAC, families, AAC service providers, researchers, mainstream technology developers, assistive technology manufacturers, professional organizations, and representatives of federal agencies (e.g., National Institute on Disability, Independent Living, and Rehabilitation Research; National Institute on Deafness and Other Communication Disorders; National Institute of Mental Health; U.S. Department of Education; Interagency Autism Coordinating Committee; Office of National Autism Coordination, etc.). The Summit was a “first of its kind” event, organized in full collaboration between people who use AAC and researchers.

The two-day event included papers presented by people who use AAC and papers presented on the state of the science in AAC as well as opportunities for discussion among all participants to identify key priorities to advance knowledge, expand technology solutions, build greater capacity in AAC, and improve services and results for those who need or use AAC. Across all of the papers presented at the Summit and the discussions among stakeholders, there was a consistent call for a paradigm shift to inclusive research, development, training, service delivery, and outreach where people who use AAC are involved in meaningful roles every step of the way. The following sections provide short summaries of the priorities identified at the Future of AAC Research Summit. More detailed discussion of the state of the science, barriers encountered by people who need and use AAC, and future research, development, and training priorities are available in a special issue of the peer-reviewed journal *Augmentative and Alternative Communication* (March 2025). This issue is a "first of its kind" scholarly publication; all papers in the special issue involve people who use AAC as authors or co-authors with researchers in the field.

Inclusive Research and Technology Development

Like much of the disability-related research conducted to date, historically, research and development in AAC has been driven by researchers and technology developers. Studies have been developed and conducted, and results have been disseminated, with minimal, if any, involvement of people who use AAC other than as research participants to be studied. There is no question that this research and development has led to some important advances, but it has often failed to address the most pressing needs of people who need or use AAC and their families.

Historically, the research grant structure has also failed to include the perspectives and priorities of people who use AAC. Instead, research priorities have typically been set by funding agencies with input from university-based researchers and other professionals; and grants have been reviewed by panels of researchers with no input from those who use AAC. This structure has resulted in funding for some important research and development projects that have contributed to improved outcomes. However, too often, funding decisions have been driven by the interests of the research community rather than addressing the urgent unmet needs identified by people who need or use AAC.

A consistent theme across all the presentations and discussions at the Summit was the critical need for a paradigm shift toward inclusive research and technology development that involves people who use AAC as partners. Inclusive research and technology development is an equity-based approach that involves people who need or use AAC in meaningful roles as partners in every step of the research and development process, from conceptualization of the problem to implementation to dissemination and tech transfer.

Recognizing the lived experiences and expertise of people who need or use AAC ensures that unmet needs are addressed as priorities and that results are meaningful and impactful. Participants at the Summit emphasized that individuals who use AAC should be involved not just in qualitative studies or participatory action research, but rather across the continuum of research from exploration and discovery to intervention development and

evaluation to large scale implementation science and across the continuum of technology development from proof of concept to proof of product to proof of adoption.

Participants at the Summit also called for changes to the research grant system to ensure meaningful involvement of people who use AAC in setting priorities for federal funding and reviewing grant proposals to determine their significance and assess their potential impact on the lives of people who use AAC. Participants acknowledged the contributions of past research and technology development in AAC but underscored the need for much more rapid and substantial advances to ensure effective communication and participation. To this end, they emphasized the importance of setting AAC research and development as a funding priority, the need to build greater research capacity in the field, and the need to devote greater support to "high risk high reward" projects to accelerate advances in the field and impact the most pressing problems.

Communication is at the very core of human existence. Lack of access to effective communication has a devastating and enduring traumatic impact. Given the magnitude of the consequences, research and development is urgently required to ensure that all people, including those who cannot rely on speech to be heard and understood, have access to the fundamental human right of communication. To that end, participants called for dedicated, federally-funded collaborative AAC centers to advance research, technology development, training, and dissemination to improve outcomes for people who need or use AAC.

Future Research Priorities in AAC

Participants at the Future of AAC Research Summit identified the following priorities for future research to advance knowledge and improve outcomes for people who need or use AAC:

- Collect demographic data to accurately identify the full population of people who need or use AAC (across ages and disability groups), track their access to AAC services and supports (or lack thereof), and monitor outcomes.
- Document societal barriers that limit the communication and participation of children and adults who need or use AAC; determine strategies to dismantle these barriers; and evaluate outcomes, including research to:
    - Reduce racial and ethnic disparities and inequities in access to AAC systems and services
    - Circumvent delays in access to AAC systems and services for infants, toddlers, older children, and adults who cannot rely on speech to be heard and understood to reduce trauma and the negative sequelae of these delays
    - Ensure access to effective instruction to increase literacy and educational opportunities
    - Reduce maltreatment of people who need or use AAC and inequitable treatment through the judicial system
    - Address social isolation and its impact on physical and mental health of people who need or use AAC; investigate trauma-informed approaches to intervention

    - Increase employment opportunities and improve outcomes for people who need or use AAC
    - Reduce institutionalization of people who need or use AAC
    - Ensure access to effective patient-provider communication to support healthcare
    - Increase AAC competencies among educational, medical, and rehabilitation professionals to ensure high quality evidence-based AAC services
- Develop and evaluate AAC interventions to maximize language, literacy, and communication outcomes for individuals who need or use AAC, including
    - Focus on early intervention starting in infancy to circumvent the negative sequelae of delays in AAC services
    - Conduct longitudinal research to investigate how individuals who need and use AAC develop (or recover) language skills, including more advanced skills
    - Investigate effective literacy instruction leading to the development of the advanced literacy skills required for higher education and employment
    - Investigate the impact of literacy (text) on language learning
    - Explore implementation science to close the gap between research and practice so that people who need or use AAC receive effective instruction
- Explore personalized / precision AAC interventions adapted to the needs and strengths of people who need or use AAC and their communication partners; determine which AAC interventions work best for whom under which conditions
    - Focus on the needs of those individuals who are not well served by current AAC interventions, including those with significant motor, sensory perceptual, cognitive, and linguistic support needs
- Investigate strategies to support meaningful employment, education, and community living for adolescents and adults who need or use AAC
    - Determine strategies and techniques to best support the development of self-determination and agency by people who need and use AAC; explore models of interdependence
    - Explore the integration of multiple modalities to meet the breadth of communication needs across contexts and communication partners
    - Investigate intervention to build the linguistic, operational, social, and strategic skills to support effective communication and participation in society
    - Evaluate the effects of mentoring programs developed by and for people who use AAC
- Evaluate techniques to teach communication partners to interact effectively with people who use AAC, tailored to their support needs
    - Conduct scaled up evaluation to improve communication access across education, healthcare, and community settings
    - Increase public awareness
- Conduct implementation science to support uptake of current AAC research and close the gap between what we know is possible and what typically occurs in the lives of those who use AAC.

Priorities for Future Development to Improve Technology Solutions

Participants at the Future of AAC Research Summit identified the following R&D priorities to improve technology solutions for people who need or use AAC:

- Improve the design of AAC technologies to maximize the power of communication and reduce learning demands for AAC users and communication partners
    - Consider the motor, sensory perceptual, linguistic and cognitive processes that underlie human computer interaction and develop user interface designs driven by the needs and skills of people who need or use AAC
    - Consider the ways in which people learn and recover language in designing AAC technologies
    - Explore techniques to improve alternative access for individuals with minimal movement
- Explore mechanisms to increase the agency of individuals who need or use AAC in their interactions and AAC systems
    - Develop technologies that prioritize identity-related features (e.g., access to personalized voices, interests, vocabulary, languages, dialects, accents, emotional expression, intonation)
- Investigate technologies that leverage AI to learn from and alongside people who need or use AAC; develop adaptive systems that evolve based on user interactions and that respond to qualitative and quantitative shifts in needs and skills over time
    - Explore applications of computer recognition to support multimodal communication (e.g., vocalizations/ speech approximations, gestures, facial expressions, etc.) by people who need AAC
    - Explore the integration of physiological data to support communication partners in understanding communication signals especially those of individuals with significant disability-related support needs
    - Develop context-aware AAC technologies that incorporate data from communication partners, the physical environment and task, and the AAC user to support communication
    - Investigate applications of AI to adapt tasks and activities to accommodate the needs and skills of people who need or use AAC and to support their participation in education, employment, healthcare, and community living
    - Leverage technologies to support language development and communication of people who use AAC (e.g., providing auto-captioning or AAC modeling) and reduce demands on communication partners to provide these supports
- Develop AAC technologies to support robust and efficient communication and participation in education, employment, healthcare, and community
- Explore applications of virtual reality, augmented reality, and extended reality (VR, AR, and XR) to improve trainings for communication partners and to provide opportunities to practice strategies

    - Develop tools to empower people who use AAC to develop their own trainings for preservice and inservice professionals and for communication partners
    - Develop technologies to support emergency preparedness for people who need and use AAC
- Improve accessibility of mainstream technologies to reduce the need for retrofitting; establish federal standards to ensure equitable access to technology for those with the most complex disability-related support needs (e.g., motor, sensory perceptual, cognitive, linguistic)

Capacity Building in AAC

The participants at the Summit also highlighted the extremely limited numbers of researchers, technology developers, and educational and rehabilitation professionals with expertise in AAC. They noted that an extremely limited number of people who use AAC are currently carrying a significant burden for advocacy in the field. Participants identified the following priorities for capacity building to address these problems:

- Investigate techniques to improve AAC preservice and inservice training of service providers in AAC
    - Prepare professionals to work collaboratively with families, provide culturally responsive / family-centered services, and support anti-ableist initiatives
    - Evaluate the effects of inclusive training that involves people who use AAC in personnel preparation
- Build competencies in inclusive research and technology development among graduate students in the field and among current AAC researchers, technology developers, faculty, and service providers
    - Evaluate the impact of inclusive research and technology development
- Develop and evaluate ways to build greater leadership capacity in the community of AAC users
    - Investigate strategies and techniques to support self-determination and greater agency
- Promote greater public awareness of the impact of AAC for individuals who need or use AAC.

Summary

For many people, daily communication is so effortless and efficient that it is taken for granted. However, this is not the case for the more than five million Americans, 97 million people worldwide, who cannot rely on speech alone to be heard and understood. Without access to effective communication, these individuals are extremely limited in their participation in all aspects of life. AAC offers the potential to enhance communication and increase participation for people who cannot rely on speech alone to be heard and understood. However, that potential has not yet been fully realized.

Future research and technology development is urgently required to:

1. dismantle societal barriers and reduce disparities that limit access to AAC systems and services for children and adults who need or use AAC;
2. determine which AAC interventions work best for whom under which conditions to promote language, literacy, communication, participation, and self-determination for individuals who need or use AAC across the life span;
3. leverage technical advances to improve AAC technologies so that they maximize the power of communication and reduce learning demands for people who need AAC, including those with the most significant disability-related support needs and their communication partners; and
4. increase leadership capacity in the community of AAC users and increase capacity in AAC research, technology development, training, and service delivery.

The following actions are imperative to reduce social isolation and improve outcomes for children and adults who need or use AAC:

1. AAC research, development, training, and services must be a funding priority;
2. People who need or use AAC must be partners in all aspects of research, technology development, training, and policy making; and
3. Funding support must be provided for inclusive centers to advance AAC research, development, training, and services.

These actions are required to ensure that people who cannot rely on speech alone to be heard and understood have access to the basic human right, the basic human need, and the basic human power of communication.

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