



**A National Partnership to Advance Peer Support  
Models for People Who Need  
Augmentative and Alternative Communication (AAC)**

Executive Summary

May 2025



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## **WHAT IS THIS PROJECT?**

The AAC Peer Support Project emerged from funding from the U.S. Administration for Community Living, implemented through a contract between the Association of University Centers on Disabilities (AUCD) and the Oregon Health & Science University's University Center for Excellence in Developmental Disabilities (UCEDD) and its partner, CommunicationFIRST, between February 2024 and March 2025.

Our goal was to advance the use of peer support models for people who use or need AAC through the creation of a nationwide, comprehensive, consensus-based approach. We were tasked with answering: (1) What peer supports exist for AAC users now? and (2) Can we create a nationwide resource for developing peer support models for people who use or need AAC?

The process of developing recommendations involved the following:

1. Conducting a survey of AAC users and others regarding existing known peer supports both inside and outside the AAC community
2. Identifying and presenting different peer support models and discuss their outcomes
3. Conducting a systematic literature review
4. Identifying barriers and opportunities, with attention to multiply marginalized communities
5. Examining models, approaches and activities for AAC advancement
6. Building consensus on initial findings and recommendations
7. Drafting a final report on our findings and recommendations for a national plan



## Objective 1: Who Are We? Partnership Group

The AAC Peer Support Project established a nationwide Consortium of approximately 60 individuals representing over 30 organizations (Appendix A). The Consortium is composed of AAC users, individuals from multiply marginalized communities, service providers, family members, educators, representatives from disability rights and self-advocacy organizations, AAC manufacturers, and other experts.

Full Consortium meetings took place monthly. The Consortium formed six workgroups, which met weekly to conduct the work of the project. Appendix B lists workgroup membership.

The AAC Peer Support Project implemented a consensus-based approach led by a core leadership team from the OHSU UCEDD and CommunicationFIRST and a steering committee led by AAC users that gathered input, guidance, and direction from the AAC users in the Consortium. Final outcomes of this project are the results of consensus from the Consortium. The majority of this report represents perspectives of AAC users.

## Objective 2: Governance and Management Plan

This project followed the management plan laid out in the initial proposal.

## Objective 3: Conduct Comprehensive Review and Analysis

### 3.1. Results of the survey of AAC users and their peer support preferences

#### 3.1.1. Who uses or needs AAC?

Anyone who cannot rely on spoken or sign language alone to be heard and understood, regardless of age, cognitive ability, or community language, requires AAC to express themselves. Please see the CommunicationFIRST website for more information on who uses or needs AAC.

#### 3.1.2. What is AAC?

The American Speech-Language-Hearing Association defines augmentative and alternative communication, or AAC, as “all of the ways that someone communicates

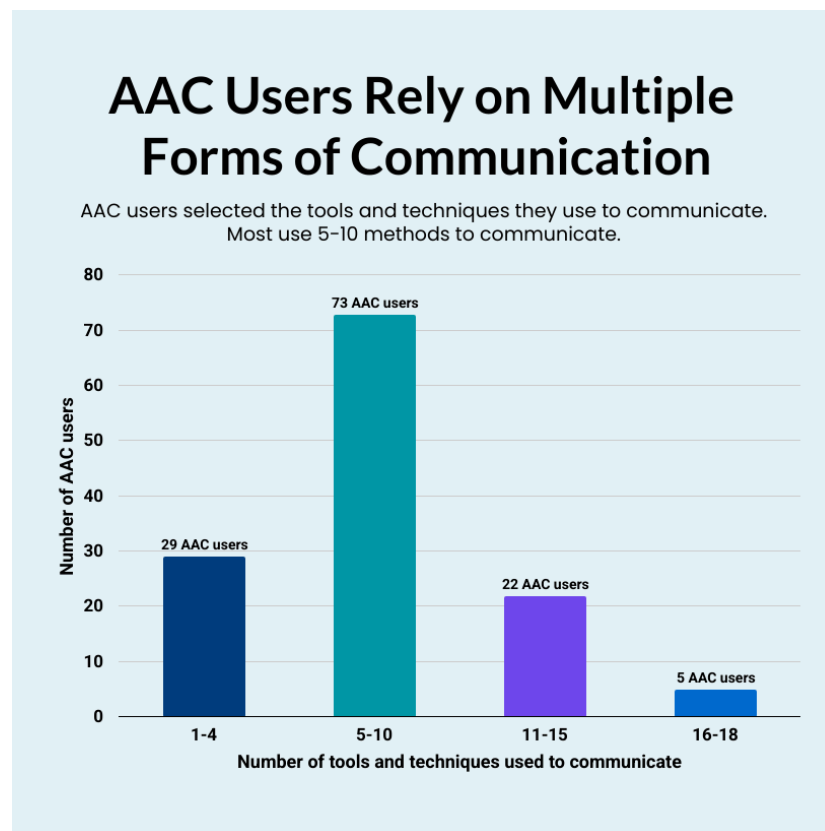


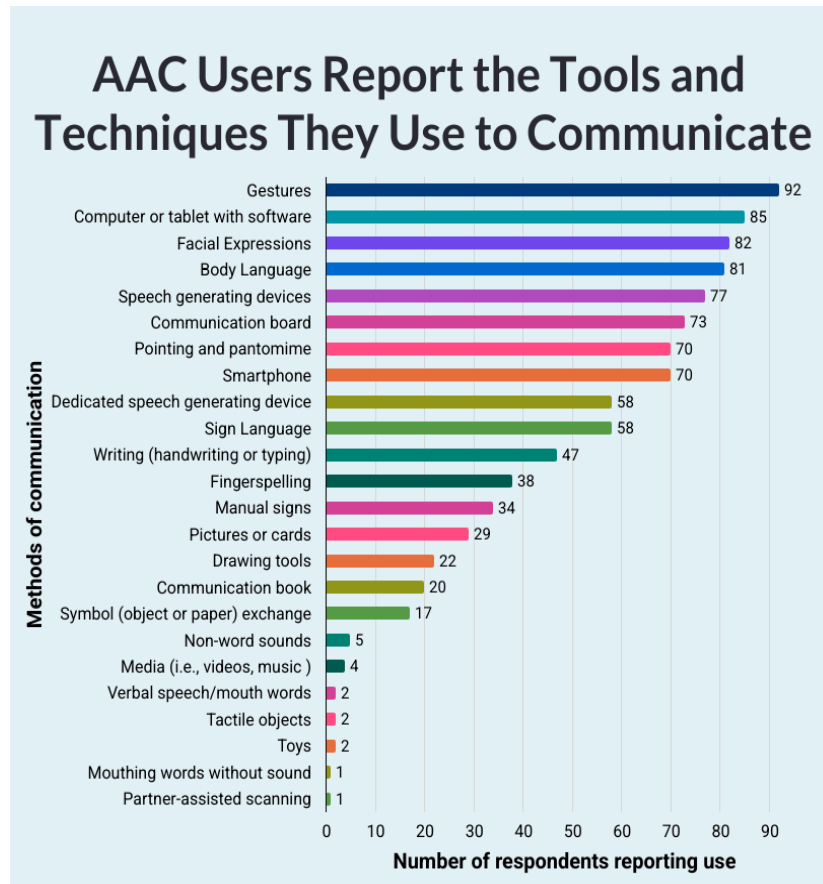
besides talking.” AAC is any tool, method, or support used by a person who cannot rely on speech alone to be heard and understood by others. AAC can come in many forms, such as alphabet boards, speech generating devices (SGDs), gestures, eye gaze, facial expressions, vocalizations, brain-computer interfaces, handwriting, and other tools or supports. People may use AAC all the time, most of the time, or episodically. People of all ages can use AAC. Virtually all AAC users use multiple types of AAC. This is referred to as an “AAC system,” or sometimes “multimodal AAC.”

### 3.1.3. What AAC tools and techniques are currently used in the U.S.?

The project distributed a survey to AAC users across the U.S. to learn what forms of AAC they rely on. 135 AAC users responded to this survey. **This is the largest survey conducted to date in the U.S. to collect this information.** Survey results should drive recommendations surrounding AAC use (including policy, advocacy, training, purchasing and distribution, personnel preparation) in the future.

We present charts that list AAC tools and techniques and the number of respondents who indicated use for each one.





#### 3.1.4. What is Peer Support?

Peer support is complex and dynamic. We view peer support less as a program or model than a series of activities or actions that people mutually engage in. Peer support can occur naturally or in structured ways. One form is not superior or more impactful than another. What matters most is the content and the opportunity to access peer support in a timely manner to address the participants' needs and preferences.

Peer support amongst disabled people validates personal disability narratives, builds upon individual strengths, and challenges peers to develop understanding and skills in areas they have less experience in.

Peers are people who have contextually relevant social status and roles in common. Establishing and defining the specific aims of peer support can help to define the peers. It is important to understand who is driving and leading a peer support model and who is present during the activities because their values or interests may differ from the peers.



AAC users can benefit from peer support in many areas, such as higher education, employment, and recreation. Therefore, rather than recommending a single peer support model, we propose applying the core principles, definitions, and visualizations defined by this Consortium to a flexible framework of peer support activities that will vary based on the goals of the activity.

### 3.1.5. Proposed basic values of peer support, which are the foundation of our definitions of peer support

- Peer support can be offered, received, and is reciprocal
- Peer support is about being seen, heard, and valued
- Each person belongs to many different and diverse peer groups
- Peer support can be one-time, episodic, or ongoing
- Peer support can be brief or comprehensive, depending on the availability and expectations of the persons needing the support and the skills and responsibilities of the persons offering support
- Peer support disrupts oppression
- Peer support recognizes and sustains community as comprised of acts of belonging and sharing, not mere coordinates on a map
- Peer support spurs pride and a sense of resilience in ourselves and our community, spelling it out, and taking action

### 3.1.6. Organic Peer Support

Consortium members developed an understanding of organic peer support, which refers to informal support among people who relate to one another through experiences, strengths, challenges, or backgrounds. The term "organic" emphasizes that these support systems develop naturally, with limited external organization, however it may branch off from formal support services.

Key characteristics of organic peer support:

- **Informal:** No formal power hierarchy.<sup>1</sup>
- **Natural:** Develops spontaneously among people with shared experiences.
- **Mutual:** Support is reciprocal, with each person helping one another.
- **Non-professional:** Support is not provided by trained professionals, but by peers with similar experiences.

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<sup>1</sup>There may be an administrative structure if needed for ensuring practical tasks are accomplished consistently.



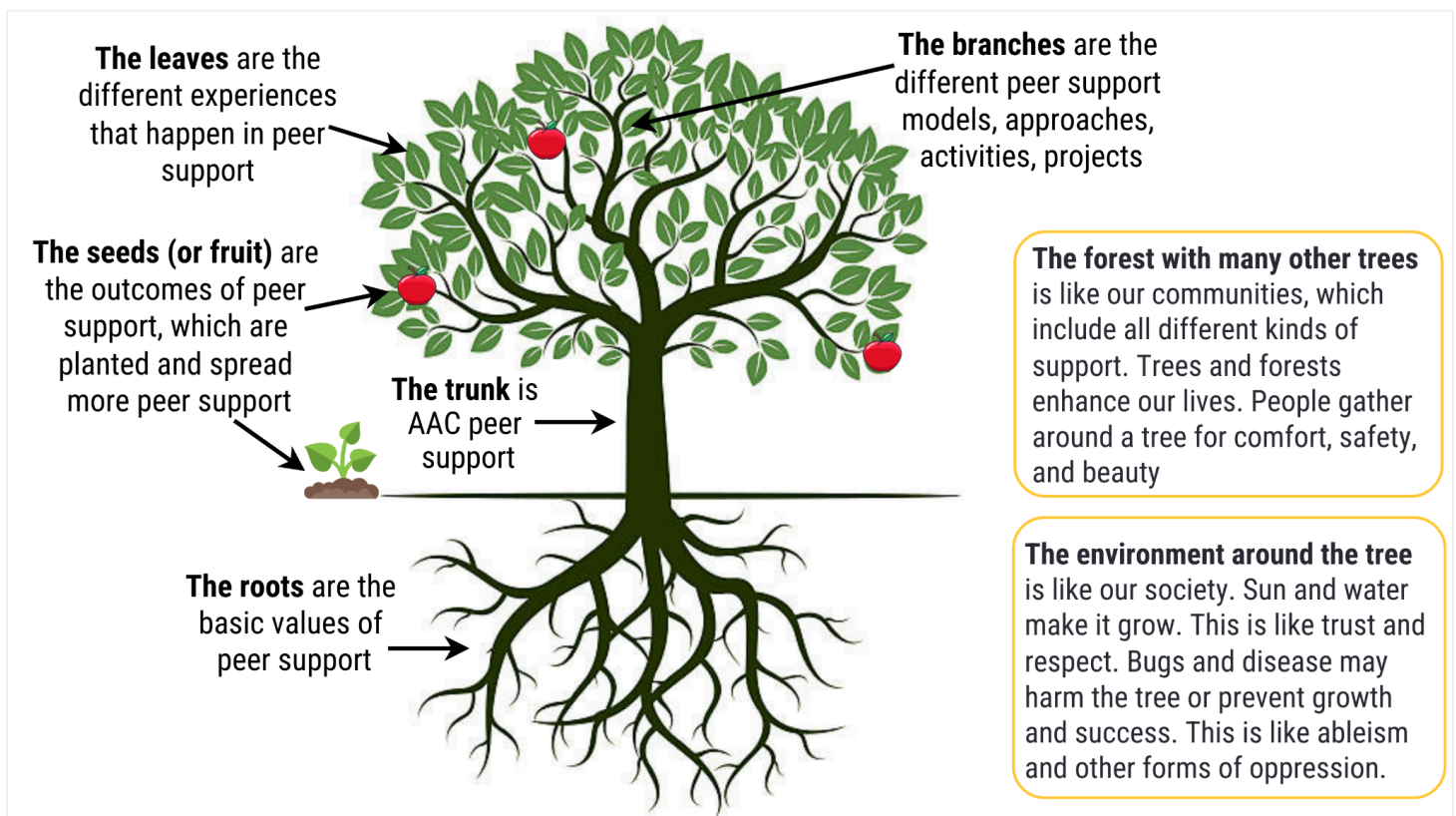
## 3.2. An analysis of the existing activities & approaches that can be applied to an AAC support model.

### 3.2.1. What is AAC Peer Support?

AAC Peer Support is a community where AAC users come together in a safe space to share their positive and negative experiences. It is built on trust and respect, fostering open and honest communication, and involves sharing ideas, activities, and frustrations to manage life's challenges and validate all forms of communication. Key elements are:

- **Reciprocity:** Mutual exchange of support and understanding.
- **Connection:** Building friendships and a sense of belonging.
- **Empowerment:** Encouraging independence and interdependence.
- **Shared Experiences:** Learning from each other's lived experiences.
- **Flexibility:** Engaging in both structured and organic activities.
- **Trust and Respect:** Essential for open sharing and successful group dynamics.

Consortium members described AAC Peer Support with an image of a tree picture and a Word Cloud.







Below are the key facilitators to AAC Peer Support proposed by the Consortium.

**Consider meeting format.** Meeting virtually is crucial for many AAC users, but it is not accessible or preferred by all. Offering a variety of options enables broader participation. However, consistency and predictability in scheduling are also important.

**Get the word out.** To facilitate AAC Peer Support, messages about its value and availability need to be shared broadly and through multiple channels.



**AAC users need support to access peer support.** Consortium members stated that people with significant disabilities may need assistance to access peer support in both virtual and in-person settings. Those supporting AAC users must be informed about both the value and availability of AAC Peer Support.

**AAC users told us how to make AAC Peer Support happen:**

*“Treating AAC users as AAC experts, whether or not we’re also researchers or professionals has been key.”*

*“I feel that we are all on equal footing in that the AAC users have our lived experiences, as do the professionals and all are valid and should be respected.”*

*“I can honestly say that this Consortium has been the most accessible meeting I have attended, and it is not even close.”<sup>2</sup>*

*“I felt like everyone had time to be heard and talk.”*

*“Helping people relax in peer support meetings is important. They communicate and participate more. Using AAC is so much work and you constantly feel like you cannot keep up.”*

*“Laughter is very underrated.”*

### 3.3. Completed Schema (scoping review of existing peer-support approaches needed for the AAC community)

A full understanding of the current literature is needed to identify research gaps, inform future studies, and guide the development or adaptation of AAC Peer Support models. There are 3 aims to the literature review:

Aim 1: Describe the models and settings of peer support for AAC users.

Aim 2: Identify the populations involved and roles of stakeholders.

Aim 3: Summarize reported outcomes and identify research gaps.

## C. METHOD

This review followed the PRISMA framework for scoping reviews (PRISMA-SC; Tricco et al., 2018), our protocol is available on Open Science Framework (OSF; Quinn et al.,

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<sup>2</sup>The Consortium adopted accessibility and discussion guidelines that prioritize AAC user perspectives and respect their communication access needs (Appendix K).



2025). The initial search yielded 1,309 articles. We extracted information from each study to describe the literature.

## **D. RESULTS**

Fifteen studies met the eligibility criteria to be included in the scoping review. Most studies used qualitative designs (53%) or quasi-experimental designs (20%) and focused on adults (60%).

### **Aim 1: Describe the models and settings of peer support for AAC users**

Peer support was delivered in a variety of ways, often online, and included activities like instruction, group discussion, peer counselling, mutual self-help, and shared social experiences. Common activities included semi-structured or unstructured discussions (each reported in 47% of studies), followed by education/instruction (40%), mutual self-help (27%), and peer counseling (20%). Fewer studies incorporated structured exercises (13%), developing goals or treatment planning (13%), or networking (7%).

Peer support took place online (40%) and in-person (40%), with fewer using blended approaches (13%). Nearly half (47%) included synchronous activities, while others used asynchronous formats (20%) or a combination of both (20%). Half of studies did not specify total number of sessions (53%) or total duration (47%).

The most common peer support contexts included online forums or groups (33%), recreation (13%), group therapy (13%), and camps (7%). Some programs utilized a combination of small and large group activities (7%), while others involved dyads (13%) or small groups of 3–20 participants. However, a large portion of studies (53%) did not report group size, indicating variability or gaps in reporting.

### **Aim 2: Identify the populations involved and roles of stakeholders**

The most frequently included populations were individuals with cerebral palsy (40%), aphasia (27%), traumatic brain injury (13%), and autism (13%). Other groups included individuals with ALS, Down syndrome, deaf/hearing impairments, intellectual and developmental disabilities, dementia, and speech-language delays, each appearing in 7–13% of studies.

Most studies (80%) did not report race or ethnicity, although a minority included participants who were Black, Indigenous, or People of Color (13%) and/or Hispanic or Latino/a/x (13%). Similarly, only one study reported on participant income or



socioeconomic status, and two studies (13%) included multiply marginalized people. This suggests that the current literature is not representative of the AAC user population, and points to a need for research that is consciously inclusive of racially, ethnically, and linguistically diverse individuals.

Age data were inconsistently reported, though programs included participants under 12 (7%), ages 13–18 (13%), ages 31–50 (27%), and 51–65 (20%). This indicates a need for more age-diverse research, particularly in middle childhood and adolescence.

Peer mentors or facilitators were included in 27% of studies, and communication partners were included in another 27%. Program leadership was most often provided by a professional facilitator or instructor (40%), while others were peer-led (13%) or co-facilitated by professionals and peers (7%). Individuals who use AAC were involved in program evaluation (27%), program delivery (20%), and program design (13%).

### **Aim 3: Summarize reported outcomes, barriers/facilitators, and identify research gaps**

Only 27% of included studies specified outcome measures. The most frequently reported domains were social connectedness (13%), communication outcomes (7%), and program fidelity (7%). **No studies reported outcomes related to autonomy, leadership, advocacy, or service access.**

Several gaps were evident. Key demographic variables, including race/ethnicity, socioeconomic status, and gender, were often not reported. Most studies failed to include younger children or adolescents, and only 13% included multiply marginalized AAC users. These gaps highlight a need for greater inclusion and reporting transparency in future AAC Peer Support research.

### **3.4. A report addressing whether peer support models for AAC device users can be developed, and, if those peer support models will help more people use AAC devices.**

A total of 135 AAC users across the U.S. were surveyed about what peer support or mentorship from AAC users they had experienced or would like to experience.” **This is the largest AAC user survey ever conducted in the U.S.** 64% of AAC users received peer support when learning AAC. 94% of these respondents stated they wanted more AAC Peer Support. 78% of those who did not experience peer support when learning



AAC stated they would like to, or were unsure. Five themes were identified in the responses:

1. Mentoring Support to Improve Self-Advocacy Skills
2. Validation of the People Who Use AAC's Identity
3. Guidance in Improving AAC Skills
4. Advocacy for the AAC Community
5. No Need for Peer Support

Most respondents desired AAC Peer Support, and wanted it most in the areas of increasing self-advocacy and AAC skills. Future AAC Peer Support programs can be designed with these goals in mind.

### 3.4.1. Evaluation of Outcomes for AAC Peer Support Activities

With data in hand demonstrating that most AAC users value AAC Peer Support, especially for increasing self-advocacy and communication skills, it became imperative that a framework be developed to evaluate AAC Peer Support activities.

#### *3.4.1a. Communication performance is not the only goal*

The primary goal of AAC Peer Support may not be increased communication or use of AAC. Rather, individuals should define their own goals.

*“Sometimes it [a goal in AAC Peer Support] isn't to get better at using AAC. We can measure participation/engagement in any form, including just showing up or following up. Measuring AAC use might not make sense and puts pressure on the user who might just be showing up to have company and relieve isolation.”*

#### *3.4.1b. Participation and engagement*

We recommend that metrics of participation and engagement be used to evaluate peer support outcomes. This should be a broad and inclusive measure because there are many ways AAC users express themselves, such as attending, being eager to attend, putting events into schedules, taking initiative to be prepared for events, nonverbal expressions, participating in conversation, simply observing, watching meeting recordings or reading notes.



### 3.4.1c. The “I matter” factor

Perhaps one of the most important and least defined evaluation metrics identified is the *I matter* and *we matter* factor, meaning the sense of feeling valued and that one belongs. Consortium members shared what *I matter* meant for them:

*“I think it can feel to be encouraged, like you've been heard, like you've had the opportunity to be yourself, accepted as you are.”*

*“When people wait for me to respond, I feel respected. When people ask me what I think, I feel valued.”*

*“I feel like I matter when I feel like I have had a voice in discussions and when my contributions have been respected. I feel like I have been understood when I receive positive reinforcement. Or when I have given a different opinion or suggested a different focus... just as anyone, AAC user or not, appreciates.”*

### 3.4.1d. Measuring effectiveness of AAC Peer Support through self-assessment

One of our key recommendations is that evaluation of AAC Peer Support activities must be conducted from the lens of AAC users, recognizing that AAC users should be trusted to express what is important to them, what is working, and what is not working. Outcome measures should be determined by the peers; outcomes defined by others are antithetical to peer support. This may be accomplished by asking what impact AAC Peer Support had before and after engagement to determine if the experience is meeting expectations. Example questions<sup>3</sup> include:

- What do/did you hope to get out of this peer support activity?
- What are/were your goals for engaging in this peer support activity?
- Do you think this peer support activity will help/has helped you meet your goals?
- Was this peer support activity what you expected? Why/why not?
- Are you able to participate in peer support activities regularly/as much as you want? Why/why not?<sup>4</sup>

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<sup>3</sup> Questions were posed by AAC users. They need to be available in alternative and accessible formats for all individuals.

<sup>4</sup> It is vital to consider and investigate factors that motivate and prevent the individual's engagement or participation, such as availability of support, transportation, accessibility, cost, etc.



Any tools for evaluating peer support must be personalized and adapted to each participant's accessibility needs. Factors related to accessibility must be considered when establishing and evaluating peer support as initial and ongoing access is required to achieve any desired outcome. People offer and receive peer support in a wide variety of ways and methods must be adapted as needed. Similarly, settings and personnel will have distinct approaches, limitations, and strengths, which will impact evaluation efforts.

A self-assessment tool was developed with Consortium input that is designed to encourage reflection following a peer support experience. The statements could be rephrased to establish individual goals or structured in a survey format. This qualitative approach to data collection can inform scholarly research while maintaining the emphasis on person-centeredness. Additional survey, ethnographic study, and related qualitative methods can be considered in the future.

Self-assessing goodness of fit and effectiveness in AAC Peer Support activities			
<b>Individual effects: I Matter/We Matter</b>	I got this	I want this but I didn't get it	I don't want this
I can be myself			
I am accepted for who I am			
I feel respected			
I feel valued			
I feel like I matter			
I feel like my opinion matters			
I feel included			
I'm not rushed or pressured to communicate			
People are comfortable expressing themselves			
We listen to each other			
If we disagree, we work through it			
<b>Individual effects: Connections</b>	I got this	I want this but I didn't get it	I don't want this
I feel less lonely			
I feel like I belong			





I have more friends			
I am part of a community			
I spend time with people like me			
I spend time with people I trust			
I spend time with people I respect			
<b>Individual effects: Communication</b>	I got this	I want this but I didn't get it	I don't want this
I am a good listener when others speak			
I am respectful of other people's communication (their method or tool, style, and/or skill level)			
I understand myself (I know how I feel and I know what I like and don't like)			
I can express myself better than I could before			
I learned new ways to use AAC			
I got better at communicating using AAC			
<b>Individual effects: Personal growth</b>	I got this	I want this but I didn't get it	I don't want this
I have more self-esteem or self-confidence			
I feel good about myself			
I can advocate for myself or speak up for myself			
I helped someone else with problems in their life			
I got help with problems in my life			
I got support to achieve my goals			
I met my goals			
I built leadership skills			
I am resilient			
I am satisfied			
I am confident			
<b>Characteristics of the experience that are likely to increase participation</b>	I got this	I want this but I didn't get it	I don't want this
There is a good structure and organization			





I know what to expect from the experience			
We meet or communicate often (at least once a month)			
We always meet at the same day and time			
There are guidelines that encourage everyone to participate			
This is a good fit for me			
I'm getting what I want out of the experience			
I look forward to participating			

### *3.4.1e. AAC Users Define Success of Peer Support Activities*

The AAC users in the Consortium were asked to describe what success in peer support means to them by finishing this sentence: *A peer support experience is successful when...* Below is a selection of their responses.

*"All people involved in the peer support gathering, model, or group feels valued, validated, and everybody gets something that they can utilize outside of the peer support."*

*"The peers get what THEY want out of it whether or not that goal is shared by (or even comprehensible to) the professionals around them."*

*"An AAC Peer Support experience is successful when a person who use AAC can acquire guidance, community acceptance, or camaraderie from other people who use AAC."*

*"I feel a greater sense of engagement, empowerment, hopefulness, and belonging than how I felt before the peer support experience. I do understand that these are feelings that are difficult to quantify but that makes them no less valuable than other data points you plot on a graph."*

*"When I feel empowered I can take on difficult tasks. When I feel engaged I do not feel isolated or lonely. Using AAC is challenging at times but meeting with AAC peers we are all on the same page, or dynamic display, whatever the case may be."*

*"I have multiple ways to finish this sentence: ...I ask a Direct Support Person (DSP) to help me fix an issue I'm having with my communication device, and they follow my instructions that I had programmed on my device. ...I glean new communication techniques from fellow AAC users while attending meetings and AAC Socials. ... a group meets at a set time and day routinely. ... I look forward to an "AAC Social." ... I successfully communicate to a stranger using my communication device. ... I make*



*students laugh while I'm speaking to their class. ...I get my doctor to understand what I need."*

### 3.5. Legal frameworks report with findings and recommendations

There are a number of federal funding sources based on federal legislation that can be used to support AAC Peer Support activities and realize our proposed recommendations. These recommendations are provided within a legal framework. Funding sources could be (1) sustainable and continue year to year; (2) multi-year funding for peer support and similar purposes. We do not identify all sources of federal funding, nor is this list government-wide in scope. We believe that conducting such a comprehensive review would be beneficial.

- Centers for Medicare and Medicaid Services (CMS)
- The U.S. Department of Education (ED)
- The Administration on Children and Families (ACF)
- Administration for Community Living (ACL)
- State Councils on Developmental Disabilities
- Private Foundations and non-profit organizations

### 3.6. Initial list of resources and information

The project compiled a list of peer support models, projects, approaches, and activities within the U.S., provided by Consortium members and their networks (Appendix C).

### 3.7. AAC Key/preferred terms

Terminology used to describe AAC users is important because language shapes perceptions, influences attitudes, and reflects respect for individual identities. The Steering Committee discussed the list below with the AAC users on the Consortium. Preferred terms will differ among individuals and will evolve as societal perspectives shift over time.

- |  |                                    |
|--|------------------------------------|
| • AAC users                              | • People using AAC                 |
| • People who need or use AAC             | • Individuals who use AAC          |
| • People who cannot rely on speech       | • AAC communicators                |
| • Individuals who utilize AAC            | • Augmented communicators          |
| • Individuals using AAC                  | • Augmentative communication users |
| • People with communication access needs | • Alternative communication users  |



- Speech device users
- Assistive technology users
- Individuals using AAC
- Users of assistive communication device

## Objective 4: Endorse a Nationwide Comprehensive, Consensus-Based Peer Support Model for Advancing AAC

This report was endorsed by the Steering Committee. All activities were conducted through a consensus-based approach with AAC users and members of the Consortium. It meets the requirements set out in the AUCD-OHSU contract to establish nationwide, comprehensive recommendations for advancing AAC with peer support activities.

### 4.1. Recommendations

AAC Peer Support activities alone will not ensure successful and effective AAC acquisition and use. In addition to supporting AAC Peer Support activities, it is critical to provide support for AAC advocacy, legislation and policy. This must include **AAC user-led** training for professionals, mentoring opportunities provided by AAC users in schools, homes, and employment sites, evaluation of activities by AAC users, and funding for sustainability. Below we list 10 actionable, practical recommendations.

**Recommendation #1: Establish a Center of Excellence for AAC Peer Support.** This center will serve as a national leader in development, implementation, evaluation and dissemination of AAC Peer Support activities, and will enhance collaboration among networks. The center should focus on developing and evaluating peer support activities, policy advocacy to improve communication access and the availability of AAC Peer Support, and strengthening AAC Peer Support activities through technical assistance.

**Recommendation #2: Build a core leadership team composed of AAC users, family members, and professionals to ensure the Center's initiatives are aligned with community needs.** Maintain existing advisory committees to direct the center's activities and evaluate peer support projects.

**Recommendation #3: Create a mechanism to provide community mini-grants that sustain AAC Peer Support activities and incubate novel programs.** Establish a means to distribute mini-grants for initiatives that sustain AAC Peer Support projects, reduce access barriers, and develop new programs. For example, mini-grants can be provided to reduce travel costs, develop extension activities to sustain relationships built



during AAC camp, fund peer support activities in states where Medicaid waivers do not support AAC services

The Center of Excellence for AAC Support should provide technical assistance for writing and administering mini-grants. The grant review committee should include members who use AAC and their families. There is a precedent at the OHSU UCEDD Community Partners Council, which provides mini-grants to community organizations.

**Recommendation #4: Increase inclusion of people who need AAC in multiply marginalized communities by conducting *community engagement studios* to address support needs.** A Community Engagement Studio (CES) is a model for engaging community members in collaborations between professionals, AAC users, and their networks that focus on evaluating program components through listening sessions. The CES approach can identify successful features of AAC Peer Support activities to accommodate the unique needs of these populations.

**Recommendation #5: Develop an Implementation Toolkit for AAC Peer Support.** We recommend developing an Implementation Toolkit consisting of resources, practical tools, and self-assessment checklists to increase accessibility of peer support activities for anyone interested in starting, maintaining, funding, or evaluating AAC Peer Support activities. A Toolkit could direct the uptake and sustainability of peer support activities and likely lead to more successful acquisition of and effective use of AAC.

**Recommendation #6: Create family-centered peer support activities.** Peer support is needed among families and others who support AAC users (i.e., paraeducators, direct support professionals, nurses). Family-centered approaches like those in AAC camps, provider organizations, and Family to Family Networks should be utilized to enable participants to connect with peers.

**Recommendation #7: Establish a repository for AAC users who are interested in being peer mentors within AAC Peer Support activities.** Many people who need AAC have never interacted with an AAC user. We recommend creating a repository of AAC users, detailing their locations, tools, techniques, and availability to connect, modeled after networking efforts like the U.S. Society for AAC (USSAAC) Speakers Bureau and the PRC-Salttillo (AAC manufacturer) Ambassador Program.

**Recommendation #8: Create an AAC Peer Support hub to increase means to find AAC Peer Support activities.** A virtual hub similar to the Commit to Connect Champions ([committoconnect.org](http://committoconnect.org)) and Patient Connect ([polygonhealth.app](http://polygonhealth.app)) should be



created that lists contact information for peer support activities. The hub should provide information on a wide variety of AAC Peer Support activities.

**Recommendation #9: Host a bi-annual conference about AAC Peer Support.** An online or hybrid conference should be convened with three goals: (1) Offer training and consultation to AAC users and their networks; (2) Provide networking opportunities; (3) Set implementation, dissemination, advocacy, and policy priorities.

**Recommendation #10: Implement a rigorous evaluation framework using outcome measures specified by the AAC community.** Evaluation of AAC Peer Support activities must be conducted from the lens of AAC users. Evaluating participation, engagement, and goodness of fit can provide useful outcome measures.

## 4.2. Outcomes and Outputs

It is vital to acknowledge that this project was considered pivotal, positive, and far reaching to many Consortium members. **This is one of the greatest collaborations that has been witnessed between academicians and community members in the AAC field to date.** We highlight several outcomes of the project.

**Guidelines to establish communication equity.** These guidelines for holding virtual meetings between AAC users and speaking people will be shared in many venues (Appendix E).

**Creating an AAC identity.** A number of AAC users stated that their participation in this project helped them with self-advocacy and creation of their AAC identity. Many stated that they were empowered by the work and the meetings were a form of AAC Peer Support.

**AAC agency.** A number of AAC users stated their opinions, turns in a conversation, and value were acknowledged and valued in this project. They said the communication power dynamic was flipped, making the AAC user the expert, creating a new sense of AAC agency.

**Valuing the messages of AAC users.** In this project, AAC users' messages were prioritized, which is in contrast to most AAC users' experiences interacting with people who rely on speech. This created confidence and meaningful participation.

Appendix D lists additional outputs that resulted from this project.



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# Appendices

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## Appendix A: AAC Peer Support Consortium Roster

The AAC Peer Support Project Established a Partnership Consortium With Significant Representation of<sup>5</sup>:

### People who use AAC

- **Bob Williams** (CommunicationFIRST)
- **ender\* corbin**
- **Jan Staehely** (Community Research Liaison, OHSU)
- **Jordyn Zimmerman, M.Ed, MB** (CommunicationFIRST)
- **Lateef McLeod** (CommunicationFIRST; ISAAC; OHSU)
- **Tracy Rackensperger, Ph.D.** (Public Service Faculty Institute on Human Development and Disability, University of Georgia)
- Alyssa Hillary Zisk, Ph.D. (Admin, Ask Me, I'm an AAC User; AAC Research Team Lead, AssistiveWare)
- Anastasia Wilson (Waisman Center LEND; Headstrong Art)
- Chloe Rothschild (Autism Society; The Arc National Council of Self-Advocates)
- Chris Klein (ImpAACT Voices)
- Donnie Denome (Autistic Self Advocacy Network)
- Esther Klang (Accessibility tester)
- Grant Blasko (TASH)
- jorja harper t schall
- Kevin Williams (AAC Advocate; Community Organizer; Independent Researcher)
- Linda Akagi (Research Assistant, Portland State University)
- Mateo Moreno
- Michael Fondacaro (USSAAC member; founder of Beyond the Chair)
- Otto Lana (Center on Youth Voice, Youth Choice)
- Patrick Regan (President-Elect USSAAC; ISAAC LEAD Committee; Coordinator of Activities and Events for Bridging Communities Through Alternative Communication)
- Rick Reese (Aphasia Community Center, Inc.)
- Thanh My Diep
- Tim Jin (CA DDS Self-Determination Program)
- Tyson Renze (Bridging Communities Through Alternative Communication)

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<sup>5</sup> **Bold** = Core Leadership

**Bold & Italicized** = Steering Committee



#### Providers/organizations who could propose potential users of AAC

- **Tauna Szymanski, J.D., M.P.A.** (CommunicationFIRST)
- Brain-Computer Interface system participants (OHSU)
- Carrie Luce, OTR/L & Noelle Birky, MS, CCC-SP (Community Vision AT Lab)
- Jill Tullman, MS, CCC-SLP (Augmentative Communication Specialist, Jill Tullman and Associates)
- Lisa G. Bardach, MS, CCC-SLP (Speech-Language Pathologist, ALS of Michigan)
- Maura English Silverman, MS, CCC/SLP (Executive Director National Aphasia Association)

#### Nonprofit community-based service provider organizations

- Allie Tasche (Autism Society of America)
- Carrie Luce, OTR/L & Noelle Birky, MS, CCC-SP (Community Vision AT Lab)
- Maura English Silverman, MS, CCC/SLP (Executive Director National Aphasia Association)

#### Direct support professionals

- Rachel Acevedo, MPA (National Alliance for Direct Support Professionals)

#### Self-advocacy organizations

- **Bre Mercier, B.S.** (CommunicationFIRST)
- Amy S. Goldman, MS, CCC (USSAAC)
- Amy Hanreddy, Ph.D. (Professor and Chair, Department of Special Education, California State University, Northridge)
- Chloe Rothschild (Autism Society; The Arc National Council of Self-Advocates)
- Donnie Denome (Autistic Self Advocacy Network)
- Grant Blasko (TASH)
- Kevin Williams (AAC Advocate; Community Organizer; Independent Researcher)
- Morgan K. Whitlatch (Director of Supported Decision-Making, Center for Public Representation, Partner in the Center on Youth Voice, Youth Choice)
- Patrick Regan (President-Elect USSAAC; ISAAC LEAD Committee; Coordinator of Activities and Events for Bridging Communities Through Alternative Communication ("BCTAC"))
- Teresa Moore (Self Advocates Becoming Empowered)
- Theo Braddy (National Council on Independent Living)
- Tim Jin (CA DDS Self-Determination Program)



### Youth and adults with ID/DD

- **endeavor\* corbin**
- **Jan Staehely** (Community Research Liaison, OHSU)
- **Lateef McLeod** (CommunicationFIRST; ISAAC; OHSU)
- Alyssa Hillary Zisk, Ph.D. (Admin, Ask Me, I'm an AAC User; AAC Research Team Lead, AssistiveWare)
- Chloe Rothschild (Autism Society; The Arc National Council of Self-Advocates)
- Chris Klein (ImpAACT Voices)
- Darrius Frazier (Council of Autistic Advisors (CAA); Autism Society of America)
- Donnie Denome (Autistic Self Advocacy Network)
- Grant Blasko (TASH)
- Mateo Moreno
- Otto Lana (Center on Youth Voice, Youth Choice)
- Sophie Korpics (Institute for Community Inclusion, UMB)
- Teresa Moore (Self Advocates Becoming Empowered)
- Tim Jin (CA DDS Self-Determination Program)

### Families

- Jill Jacobs (National Association of Councils on Developmental Disabilities)
- Rebecca Reese (spouse of AAC user; Aphasia Community Center, Inc.)
- Tamara Bakewell (Oregon Family to Family Health Information Center)
- Tina Moreno, MA, SLP-CCC, ATP (Speech-Language Pathologist, UCP Cleveland LeafBridge Alternative Education Program)

### Related service providers, including Speech Language Pathologists (SLPs).

#### Occupational Therapists (OTs), and Physical Therapists

- **Melanie Fried-Oken, Ph.D.** (OHSU, Principal Investigator)
- **Emily Quinn, Ph.D.** (OHSU)
- Carrie Luce, OTR/L & Noelle Birky, MS, CCC-SP (Community Vision AT Lab)
- David Niemeijer (AssistiveWare)
- Jill Tullman, MS, CCC-SLP (Augmentative Communication Specialist, Jill Tullman and Associates)
- Kirk Behnke, M.Ed., ATP (Training and Implementation Services Specialist, PRC-Salttillo)
- Lisa G. Bardach, MS, CCC-SLP (Speech-Language Pathologist, ALS of Michigan)
- Tina Moreno, MA, SLP-CCC, ATP) Speech-Language Pathologist, UCP Cleveland LeafBridge Alternative Education Program)



### Educators

- **Melanie Fried-Oken, Ph.D.** (OHSU, Principal Investigator)
- **Emily Quinn, Ph.D.** (OHSU)
- **Tracy Rackensperger, Ph.D.** (Public Service Faculty, Institute on Human Development and Disability, University of Georgia)
- Adrianna Noyes, PhD, CCC-SLP (University of Wisconsin)
- Amy Hanreddy, Ph.D. (Professor and Chair, Department of Special Education, California State University, Northridge)
- Gloria Soto (Project AAC for ALL at San Francisco State University)
- Jennifer Seale, PhD, CCC-SLP (AAC Program Director, Waisman Center, University of Wisconsin-Madison)
- Samuel Sennott, Ph.D. (Professor, Universal Design Lab Director, College of Education, Portland State University)
- Tawara Goode (Georgetown University National Center for Cultural Competence)
- Terri Wofford, MS, CCC-SLP (Associate Lecturer with the Wyoming Institute for Disabilities; Manager of the Wyoming Assistive Technology Resources)
- Tori Gilbert, SLPD, CCC-SLP (West Virginia University Center for Excellence in Disabilities)
- Vicki Casella (The Bridge School)

### Others in their support system

- **Rachel Benson, MSW** (OHSU)
- **Sarah Fjeldstad, MSW** (OHSU)
- Adrianna Noyes, PhD CCC-SLP (University of Wisconsin)
- Allison Cohen Hall (Institute for Community Inclusion, Umass Boston)
- Amy Szarkowski, PhD (Senior Research Fellow, Institute for Community Inclusion, University of Massachusetts Boston)
- Jennifer Seale, PhD, CCC-SLP (AAC Program Director, Waisman Center, University of Wisconsin-Madison)
- Lew Golinker (Assistive Technology Law Center)
- Mary Sowers (National Association of State Directors of Developmental Disabilities Services)



## **Appendix B: AAC Peer Support Workgroup Members and Leadership**

### **Workgroup 1: Peer support models within the AAC field**

Leadership/steering committee co-leaders: Lateef McLeod & Melanie Fried-Oken

- Alyssa Zisk
- Becky & Rick Reese
- Jan Staehely
- Jill Tullman
- Kirk Behnke
- Mateo Moreno
- Michael Fondacaro
- Terri Wofford
- Tina Moreno

### **Workgroup 2: Peer support models outside the AAC field**

Leadership/steering committee co-leader: Jordyn Zimmerman

Co-leader: Amy Goldman

- Allie Tasche
- Maura Silverman
- Samuel Sennott
- Tamara Bakewell

### **Workgroup 3: Evaluation of AAC Peer Support activities**

Leadership/steering committee co-leader: Bob Williams & Bre Mercier

Co-leader: Jennifer Seale

- Amy Szarkowski
- Darrius Frazier
- Grant Blasko
- Lewis Golinker
- Lisa Bardach
- Morgan Whitlatch
- Noelle Birky
- Otto Lana
- Patrick Regan
- Rachel Acevedo
- Samuel Sennott
- Thanh My Diep

### **Workgroup 4: Presentations to the Consortium**

Leadership/steering committee co-leader: endever\* corbin

Co-leader: Jill Tullman & Patrick Regan

- Kevin Williams
- Kirk Behnke
- Lewis Golinker
- Linda Akagi
- Samuel Sennott
- Jordyn Zimmerman
- Lateef McLeod
- Lisa Bardach
- Michael Fondacaro

### **Workgroup 5: Strategies for inclusion of diversity and underrepresented communities**

Leadership/steering committee co-leader: Bob Williams & Bre Mercier



Co-leader: Theo Braddy

- Tracy Rackensperger
- Anastasia Wilson
- Gloria Soto
- Grant Blasko
- Jenny Sichel
- Kevin Williams
- Morgan Whitlatch
- Otto Lana
- Tim Jin

**Workgroup 6: Systematic review/metanalysis of peer support**

Leadership/steering committee co-leader: Emily Quinn & Rachel Benson

Co-leader: Alyssa Zisk

- Amy Hanreddy
- Anna Noyes
- Lateef McLeod



## Appendix C: Peer Support Models, Projects, Approaches, and Activities

List of peer support models submitted by the consortium:
AAC Peer Support Project <a href="https://bit.ly/AAC_PeerSupportProject">bit.ly/AAC_PeerSupportProject</a>
AAC Research Learning Communities AAC Social Portland State University
American Association of People with Disabilities (AAPD) Summer Internship Program <a href="https://aapd.com/summer-internship-program">aapd.com/summer-internship-program</a>
ACES Program Temple University <a href="https://disabilities.temple.edu/news/2025/01/aces-communication-program-ramps-2025">disabilities.temple.edu/news/2025/01/aces-communication-program-ramps-2025</a>
ALS of Michigan (1: ALS support group, 2: Lectures, seminars, presentations 3: Support for patients and family, 4: Support for caregivers, 5: Bereavement support) <a href="https://alsofmichigan.org">alsofmichigan.org</a>
Alanon/Nar-Anon <a href="https://nar-anon.org/find-a-meeting">nar-anon.org/find-a-meeting</a>
Aphasia Community Center AAC group chat <a href="https://aphasiasarasota.org">aphasiasarasota.org</a>
Aphasia Support groups <a href="https://aphasia.org">aphasia.org</a>
Ask Me, I'm an AAC User <a href="https://facebook.com/groups/456220758119314">facebook.com/groups/456220758119314</a>
AssistiveWare AAC zoom chats (AssistiveWare's private adult AAC users community)
AssistiveWare AAC Users Community Facebook group <a href="https://facebook.com/groups/192898234141275">facebook.com/groups/192898234141275</a>
Augmentative and Alternative Improvisation (private group led by a Consortium member who is an AAC user)
Autistic Self Advocacy Network (ASAN) Autism Campus Inclusion (ACI) Academy <a href="https://autisticadvocacy.org/aci">autisticadvocacy.org/aci</a>
Bridge School Self Determination Program <a href="https://selfdetermined.bridgeschool.org">selfdetermined.bridgeschool.org</a>
Bridging Communities Through Alternative Communication (BCTAC) <a href="https://bridgeschool.org/outreach/bctac">bridgeschool.org/outreach/bctac</a>



Camp ALEC <a href="http://campalec.com/home">campalec.com/home</a>
Camp Chatterbox <a href="https://facebook.com/p/Camp-Chatterbox-100064405853508/">facebook.com/p/Camp-Chatterbox-100064405853508/</a>
Camp Communicare, LLC. <a href="https://facebook.com/AACcommunicare">facebook.com/AACcommunicare</a> ; <a href="http://aaccommunicare.com">aaccommunicare.com</a>
Camp ImpAACT-Ellis Center <a href="http://elliscenter.org/camp-impaaact">elliscenter.org/camp-impaaact</a>
Camp McYack <a href="http://jcisd.org/special-education3/camp-mcyack">jcisd.org/special-education3/camp-mcyack</a>
Camp SPEAK AAC (1: children 2: parents of children) <a href="http://campspeak.org/">campspeak.org/</a>
Camp TALK <a href="http://camptalk.org">camptalk.org</a>
Cancer Support Community Greater Philadelphia <a href="http://cancersupportcommunity.org/">cancersupportcommunity.org/</a>
Children's Hospital Colorado (1: First Steps Camp, 2: Talking with Technology Camp) <a href="http://childrenscolorado.org/doctors-and-departments/departments/audiology-speech-learning/first-steps-camp">childrenscolorado.org/doctors-and-departments/departments/audiology-speech-learning/first-steps-camp</a> <a href="http://childrenscolorado.org/doctors-and-departments/departments/audiology-speech-learning/camp">childrenscolorado.org/doctors-and-departments/departments/audiology-speech-learning/camp</a>
Communication Access Connect <a href="http://disabilityvoicesunited.org/interchange/communication/communication-access-connect">disabilityvoicesunited.org/interchange/communication/communication-access-connect</a>
Community Autism Peer Specialist (CAPS) Program <a href="http://phillyautismproject.org/community-autism-peer-specialist-caps-hub/">phillyautismproject.org/community-autism-peer-specialist-caps-hub/</a>
Community Vision (1: AAC Social Group, 2: AAC Play Group ages 0-5) <a href="http://cv-atlab.org">cv-atlab.org</a>
Family to Family Health Information Centers <a href="http://mchb.hrsa.gov/programs-impact/programs/f2f-health-information-centers">mchb.hrsa.gov/programs-impact/programs/f2f-health-information-centers</a>
ImpAACT Voices (1: Virtual Hangouts, 2: In-person events) <a href="http://impaaactvoices.org">impaaactvoices.org</a>
ISAAC online chats <a href="http://isaac-online.org/english/news/pwuaac-online-chats/">isaac-online.org/english/news/pwuaac-online-chats/</a>
Jill Tullman and Associates AAC Peer Support groups (1: Preschool and school aged, 2: young adults)





aac-therapy.com
Let's Talk Communication Access Initiative letstalkinitiative.org
Ohio University Sparkles Cheerleading facebook.com/OHIOSparkles
Oregon Family Support Network ofsn.org
Parent to Parent p2pusa.org/
Peer-Mediated Learning vk.vumc.org/assets/files/resources/psiPeermedstrategies.pdf
PRC-Salttillo employment prc-salttillo.com/careers
PRC-Salttillo Toastmasters AAC Club toastmasters.org/Find-a-Club/07990786-prc-salttillo-toastmasters
Rainbow Kids familyconnectionssc.org/rainbow-kids
SHARE Cancer support sharecancersupport.org
SHIBA - Senior Health Insurance Benefits Assistance shiba.oregon.gov
Tele-STELLA ohsu.edu/oregon-center-for-aging-and-technology/stella-family-studies
Traditional Healthcare Workers - Peer Support Specialists oregon.gov/oha/ei/pages/about-traditional-health-workers.aspx
USSAAC awareness committee ussaac.org/about-us/committees
USSAAC Speaker Connection speaker.ussaac.org

## Appendix D: Outputs from the AAC Peer Support Project



1. The AAC Peer Support Project webpage:  
<https://www.ohsu.edu/university-center-excellence-development-disability/augmentative-and-alternative-communication-aac>
2. An article written about the project in the June 2024 newsletter of the International Society for Augmentative and Alternative Communication (ISAAC):  
<https://isaac-online.org/wp-content/uploads/The-ISAAC-Communicator-June-2024-June-28.pdf>
3. An article written about the project, highlighting Bob Williams and Lateef McLeod in the US Society for AAC (USSAAC) on-line magazine, SpeakUp!:  
<https://ussaac.org/speakup/articles/aac-peer-support-models/>
4. Two-hour webinar for the October, 2024 virtual conference for ISAAC:  
<https://conference.isaac-online.org/event/a-collaborative-aac-peer-support-model>
5. Two posters for the AUCD conference held November, 2024 held in Washington, D.C. and the Assistive Technology Industry Association (ATIA) conference held January, 2025 in Orlando, FL.:  
[https://www.ohsu.edu/sites/default/files/2024-11/AUCD2024\\_Poster\\_AAC%20Peer%20Support%20Experiences\\_final.pptx.pdf](https://www.ohsu.edu/sites/default/files/2024-11/AUCD2024_Poster_AAC%20Peer%20Support%20Experiences_final.pptx.pdf)  
[https://www.ohsu.edu/sites/default/files/2025-01/AUCD2024\\_Poster\\_AAC%20Tools%20and%20Techniques%202025.pdf](https://www.ohsu.edu/sites/default/files/2025-01/AUCD2024_Poster_AAC%20Tools%20and%20Techniques%202025.pdf)
6. International AAC Peer Support Webinar hosted by Assistive Technology Industry Association (ATIA) in June, 2025:  
<https://www.atia.org/path-lms/?pathPage=%2Fatia%2Fcourses%2F106597>
7. Two abstracts (for poster and presentations) submitted to the American Speech-Language-Hearing Association for the 2025 ASHA Convention, to be held in Washington, DC in November, 2025.



## Appendix E: Guidelines for the Prioritization of AAC Users in Group Discussions

### Developed for the 2024-2025 AAC Peer Support Project Virtual Consortium Meetings

- **Schedule meetings at least two weeks in advance** whenever possible. Share agenda, meeting topics, and any questions to be addressed in the meeting to participants at least a week in advance so people have time to prepare responses.
- **Accept that there will be pauses**, and lean into any discomfort you might feel while people are preparing messages in real-time.

Most AAC users communicate more slowly than people who can use speech fluently. Continuing to speak while an AAC user is typing disrupts their concentration and often results in the conversation moving on before they have a chance to contribute.

- **Pause to ask whether anyone has additional thoughts** before switching to new topics. We recommend around a minute.

Because of the time it takes to construct responses, AAC users may be forced to react to meeting topics at a later time, such as via e-mail or a prepared message at the next meeting. This practice doesn't enable collaboration or participation in productive discussion and decision making or sharing points of view. Being sure to pause gives AAC users the opportunity to indicate they have something to add before moving on.

- **Take time to learn and look for individual signs that a person might want to contribute** to the conversation. Not everyone can nod, raise a hand, or otherwise gesture that they want to speak, and the raise hand or reaction features in virtual meetings are not accessible to all. If it's not clear whether a meeting attendee is preparing a response, one might ask something like, "Are you typing?" or "Are you composing a message?" Also, be aware that mute/unmute and other virtual meeting functions are not accessible to all.
- Groups may offer the opportunity for participants to **share their preferred communication style** (e.g., chat, SGD, speech) or describe their cues that they wish to speak. Be mindful that some consider this additional communication a tax on their time and energy. This should be offered as an option, not a requirement.



Other accessibility considerations for the group include whether there should be audio descriptions of people/slides, whether folks should say their name before commenting, and are there specific content warnings people need.

- **Offer multiple means of giving input** (email, survey, chat, instant message, etc.) whenever possible, and invite input before and after meetings. Asynchronous communication permits AAC users to take their time to formulate their responses.
- **Assign a dedicated chat reader.** Many people are not physically able to use chat, or it may be too challenging while managing multiple screens. Participants who rely on Chat for message generation should have their message read aloud. Participants should include a note if they don't want their message read out loud, for example, "Don't ROL."

Whenever possible, chat readers should read messages in order or provide context for the message they are reading. For example, refer to a previous message when reading a response: "Tom is responding to Jerry's comment about friendship, and he says..."

- **Offer support.** Zoom has many features for meeting participants. We've condensed instructions for some of the most helpful features into this document [W Zoom Meeting Participant Controls.docx](#) (up to date as of 2024). Tell participants how and to whom they may communicate any other access needs they may have before, during, and/or after the meeting.

Virtual meeting hosts should take time to learn Zoom accessibility features like captions and interpretation to provide support to participants as needed and ensure the meeting flows smoothly. We prioritize the perspectives of AAC users. We will seek AAC user input first.

- A **discussion moderator** will be selected. Speaking people will raise their hands (physically or using the Zoom feature) and wait to speak until called on.

If a discussion goes off topic, or if a speaking person is taking up too much time, the moderator will notify the person first by private chat, then aloud. We can put these topics in a "parking lot."

- **Access flexibility** is key, which means an accommodating spirit and willingness to adapt to the needs of the group members. Accessibility measures for one person can



be insurmountable barriers to others. Groups should prepare for these inevitable tensions and adjust as much as possible. For **additional tips** on meeting with AAC users, please see: <https://communicationfirst.org/best-practices-for-online-meetings/>

### Meeting Roles

- Managing multiple duties in virtual meetings is challenging. Roles that meeting facilitators/hosts should consider assigning include: developing an agenda, managing a waiting room, introducing agenda topics at the start of the meeting, reviewing group guidelines, leading discussions, reading chat messages aloud, moderating discussions, sharing a screen, note taking, timekeeping, providing in-meeting accessibility support.