



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

Final Report

May 2025



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Introduction

This final report is submitted to the Association of University Centers on Disabilities (AUCD) to fulfill contractual agreements between AUCD and the Oregon Health & Science University's University Center for Excellence in Developmental Disabilities (UCEDD) and its partner, CommunicationFIRST.

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 report will be structured according to the deliverables proposed in the contract. The process of developing recommendations involved the following:

1. Conducting a survey of AAC users and others regarding existing known peer support models both inside and outside the AAC community
2. Identifying and presenting different peer support models and discussing 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 this report on our findings and recommendations for a national plan

This report meets requirements set out in the AUCD-OHSU contract.

- It is actionable, practical, and realistic
- It addresses the goal of the project and proposed solutions
- It identifies future partners in implementation
- It factors in the needs of and barriers faced by marginalized communities
- It can be immediately acted upon and/or sets forth clearly the prerequisites to implementation



Objective 1: Partnership Group

1.1. A full roster of confirmed National Partnership Consortium and Steering Committee members, along with their affiliations, roles, and contact information

The AAC Peer Support Project established a nationwide Consortium of approximately 60 individuals who represented more than 30 different organizations (see Appendix B1). 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 others with expertise in AAC and peer support.

The AAC Peer Support Project was implemented using a consensus-based approach that included a core administrative team from the OHSU UCEDD and CommunicationFIRST, as well as a steering committee led by three AAC users that gathered input, guidance, and direction for the project from the 24 AAC users in the Consortium through regular meetings. Final outcomes of this project, therefore, are the results of consensus from the Consortium. The majority of this report represents perspectives and priorities of AAC users. Appendix B2 lists the AAC users who participated in this year-long project.

Full Consortium meetings took place monthly. The Consortium also formed six workgroups, which met weekly to conduct the work of the project. The workgroup leadership and members are listed in Appendix B3.

Appendix A describes the roles and responsibilities that Consortium members could choose for participation. These roles were presented to the potential Consortium members as soon as the project began and whenever new members were recommended so we could optimize on national representation and participation by the AAC community.

Objective 2: Governance and Management Plan

This project adhered to the management plan laid out in the initial proposal. Appendix C lists the organization, meeting dates, and meeting handouts that were working documents during this project.



2.1. Schedule of National Partnership Consortium and Steering Committee meetings

The Consortium met monthly. Steering Committee meetings took place when they could convene a majority of AAC users. Meeting dates are provided in Appendix C1.

2.2. Minutes and notes from National Partnership Consortium and Steering Committee meetings

Steering Committee agendas were developed by the leaders. They reported their work and progress at the Consortium meetings. Copies of all slides presented at the Consortium meetings are provided in Appendix C2.

2.3. Written monthly reports of project activities using progress report template

Written reports, using the Progress Report Template, were provided to AUCD during the initial 10 months of this project. AUCD was provided copies of each monthly report. Appendix C3 includes the monthly progress reports for the initial contract. External reports of project activities were shared in monthly email updates provided to Consortium members who requested them (see Appendix C4).

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, interact with others, and to be meaningful members of their communities.

An estimated five million people in the United States experience disabilities or other conditions that impact their ability to rely on speech alone to be heard and understood. Some are born with limited speech or no ability to speak, and some experience speech-related disabilities at later stages of life. Communication is not a luxury, but an



immutable part of life and a fundamental right. Unfortunately, far too many children, working-age persons, and older adults who require AAC tools and support to express themselves are denied it based on biases grounded in the notion that those of us with little to no understandable speech are unintelligible, lack language, or have little to say, do, or contribute.

People who need AAC form a diverse, inclusive community. They may have a variety of congenital, developmental, or acquired disabilities, including co-occurring intellectual, cognitive, physical, neurological, and psychological conditions. It is important to acknowledge that historically and to this day people who need AAC are disproportionately and incorrectly identified as having significant cognitive disabilities. However, cognitive disabilities are not predictors of significant speech disability, nor is significant speech disability indicative of cognitive disability. People who cannot rely on speech alone to be heard and understood experience widespread bias and discrimination from not being seen, heard, or counted, regardless of the cause or age of onset of their disability or condition.

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 when their ability to vocalize is either temporarily or permanently interrupted. AAC is not only a means of expression, and it is so much more than technology. It is a process that includes message sharing between partners using many forms, and is based on the needs and preferences of the AAC user.

Virtually all AAC users use multiple types of AAC to communicate, to be understood, and to participate in society. This is referred to as an “AAC system,” or sometimes “multimodal AAC.”

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

The project completed a survey that was distributed to AAC users throughout the U.S.



to learn what forms of AAC they rely on for expression. In total, 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.

In the following pages we present charts that list AAC tools and techniques and the number of respondents who indicated use for each one. Below we describe what the tables tell us.

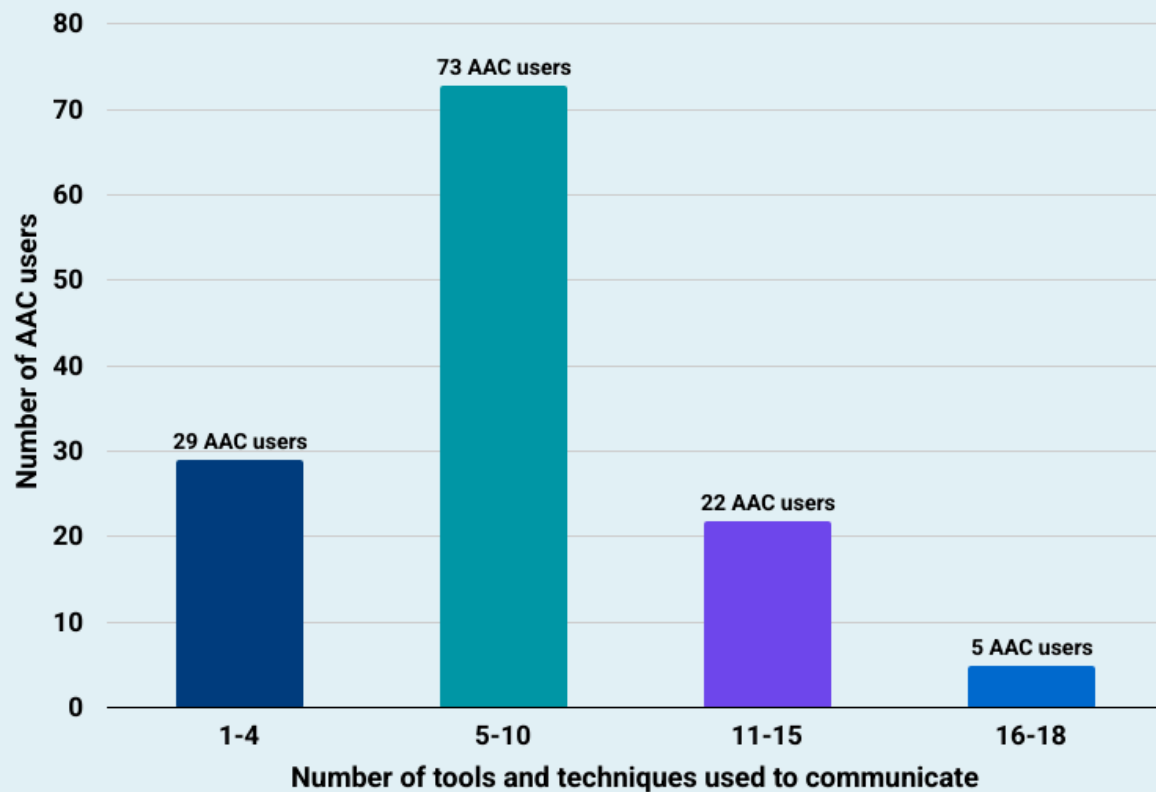
Only six people reported use of a single form of communication. The remaining respondents indicated that they use at least two ways to express themselves. The majority of respondents reported using between 5-10 tools and techniques to communicate. Twenty-nine respondents reported using between 1-4 tools and techniques, twenty-two reported using 11-15 tools and techniques, and five reported using 16-18 tools and techniques.

Communication technology is used by the majority of respondents: 85 people reported using computers or tablets with software, 77 people use speech generating devices with 58 others using dedicated speech generating devices, and 70 people use smartphones. It is important to note that no-tech techniques, such as gestures, facial expressions and body language, were reported 352 times, and low-tech options, such as communication books, boards, toys, cards or pictures were reported 179 times. This indicates the diversity of tools and strategies that are used by people who rely on AAC.

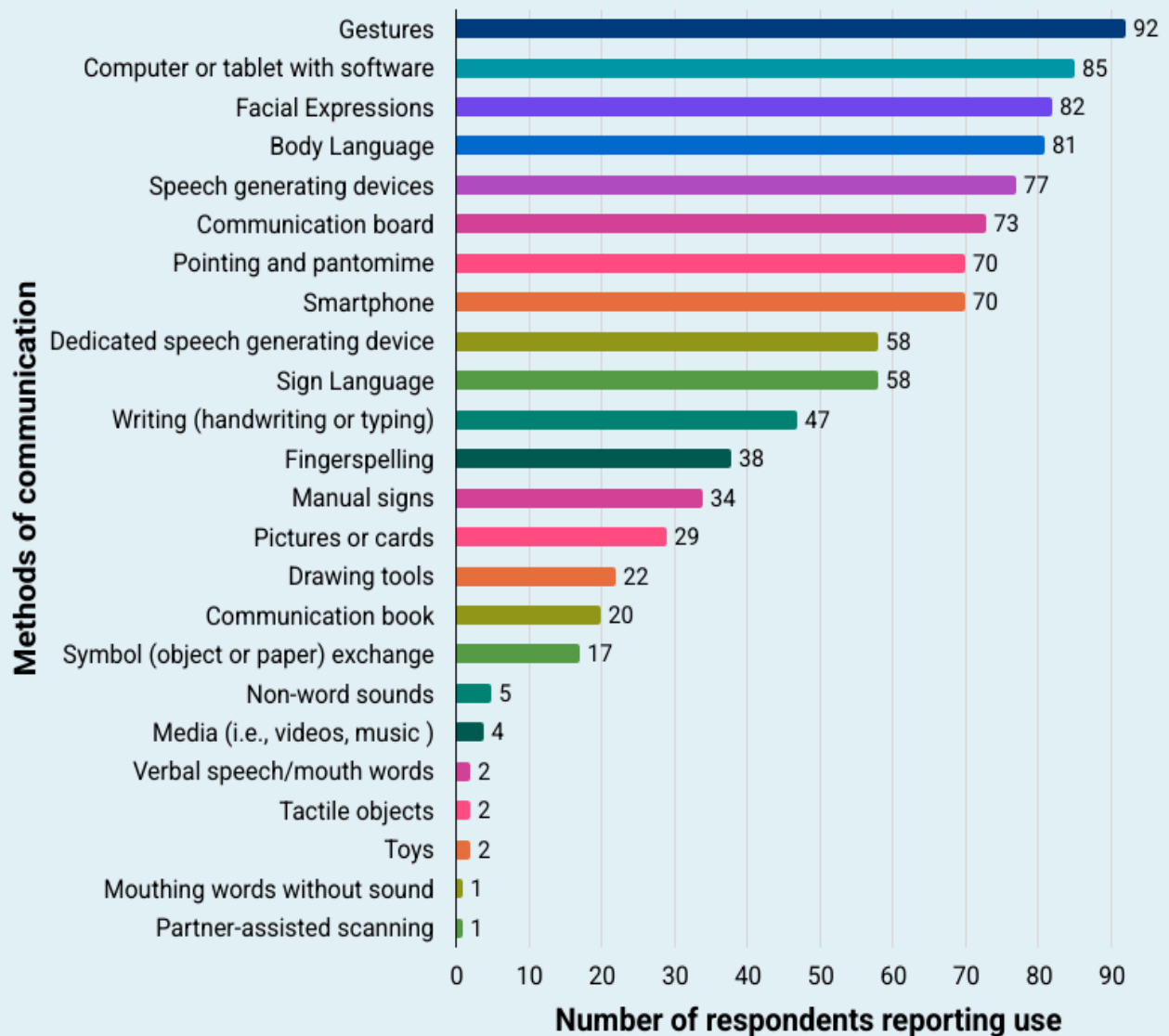


AAC Users Rely on Multiple Forms of Communication

AAC users selected the tools and techniques they use to communicate.
Most use 5-10 methods to communicate.



AAC Users Report the Tools and Techniques They Use to Communicate





3.1.4. What is Peer Support?

Peer support is complex and dynamic. It can occur naturally or in more structured ways, and one form is not necessarily superior or more impactful over 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.

We view peer support less as a program or model than a series of activities or actions that people mutually and trustingly engage in to lend and receive various forms of support to others. Many of the terms we positively associate with peer support can also be used to describe the values we believe peer support should exemplify, as well as the value-added outcomes we believe peer support can reasonably and demonstratively yield.

Peer support is one of the best ways for a disabled person to grow in their self-advocacy: we can look up to peer leaders and role models, learn from how they self-advocate, and aspire to that kind of advocacy ourselves. Peer support amongst disabled people validates personal disability narratives (including experiences of ableism and other oppressions), encourages and builds upon individual strengths, and challenges peers to develop understanding and skills in areas they have less experience in. Self-advocacy is perhaps strongest when it involves building community with other disabled people, working together to form a base of power that can have a real impact on our personal lives as well as on the societal structures that shape us.

It is important to examine who is considered to be a peer. The Consortium came to an understanding that 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 further define the peers. It is expected that there are circumstances in which AAC users and non-AAC users are peers who offer support. For example, an AAC user may give and receive peer support from non-AAC users in a bereavement support group, whose members are peers as it relates to the shared experience of grief, but other AAC users are best suited to engage for peer support around navigating physical and societal barriers experienced by AAC users.

However, peer support models for the AAC community should not focus solely on AAC-related support. AAC users can benefit from peer support in many other areas such as higher education, employment, and recreation. Therefore, rather than recommending a single peer support model with predefined outcomes, we propose applying the core principles, definitions, and visualizations defined by this Consortium to peer support activities. The application of these constructs will vary based on the goals



of the activity. While there is no one-size-fits-all approach, developing a flexible framework that outlines key considerations for establishing peer support will provide valuable guidance to diverse groups.

It is equally important to determine if peers lead support efforts, are involved in support efforts, and the degree to which there might be family, friend, or paid support involvement. We have identified three types of peer leadership: peer-led, professional/instructor-led (not a member of the peer group), and co-facilitated. 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.

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

Within a formal definition of peer support, Consortium members developed an understanding of organic peer support as a slightly different concept with proposed key characteristics. The Consortium emphasized the value of organic peer support opportunities that have flourished into peer support networks. It is important to expand and build on these approaches.

Organic peer support refers to informal support networks among people who relate to one another through experiences, strengths, challenges, or backgrounds, fostering empathy, understanding, trust, self-expression, and mutual aid. This type of support often emerges within communities, social groups, or online forums, where people share common interests, conditions, or life experiences. The term “organic” emphasizes that



these support systems develop naturally, with limited formal structure or external organization. Organic peer support can branch off from and complement formal support services, providing an additional layer of connection, confidentiality, and understanding.

Key characteristics of organic peer support:

- **Informal:** No formal power hierarchy [though there may be an administrative structure of some kind, if needed, for ensuring practical tasks are accomplished consistently].
- **Natural:** Develops spontaneously among people with relatable or 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.

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?

There was consensus that in general, the mission of all peer support groups for AAC users is to provide peer support that works specifically for AAC user participants. AAC Peer Support groups should determine early on if they wish to establish a unique purpose, such as meeting new people, engaging in an activity, learning a new skill, or testing various SGD systems. Some members felt identifying a clear purpose could help attract potential participants and ensure peers are on the same page. However, others expressed concern that if outcomes are predetermined, an obvious hierarchy would exist. Thus, any anticipated outcomes should be loosely defined, flexible, and open to change over time, based on the needs of participants.

The Consortium members defined AAC Peer Support within their workgroups (see Appendix B3 for workgroup roles and members).

Workgroup 1: “AAC Peer Support is a gathering of people in a safe place to speak their minds, who help and learn from each other. It consists of sharing positive and negative experiences, ideas, activities, and frustrations to manage life difficulties and find validation of all feelings and in all ways to communicate. AAC Peer Support can build trust, friendship, a sense of belonging, pride, and form a shared identity.”

Workgroup 2: “Peer support is a flexible set of actions or activities that involves shared understanding and experiences in reciprocal relationships based on lived experiences.



It aims to provide connections, support, and personal growth through common interests or histories.”

Workgroup 3: “Peer support is grounded in the idea of a safe place to achieve connection, collaboration and reciprocity where mentorship is fluid and authentic which cultivates an atmosphere of interdependence, empowerment and social justice. Peer support empowers AAC users to create a safe space where the foundation of shared lived experiences leads to collaboration. Peer support leads to both greater interdependence and independence. Trust and respect (respecting each other, all communication, different views and experiences, etc.) are critical to a successful peer support group. With trust and respect, group members will share openly. A successful peer support group will foster trust and respect leading to open and honest sharing. Trust and respect are imperative to the success of peer support writ large.”

Workgroup 4: “Peer support at its foundation is built on trust and respect, and some of its key elements include healthy relationships, honest sharing, love, community, empowerment, and the goals the peers have. AAC Peer Support is a state where people who use AAC are connected to others who share lived experience that consists of a variety of meaningful activities, such as group social experiences and one-to-one consultation, and can be more structured or organic in order to create a reciprocally beneficial impact.”

Workgroup 5: “Peer support for AAC users is a community where individuals connected through similar characteristics (and their support staff) come together to deepen connection through a discourse of shared experiences meant to create trust, transparency and reciprocity. Peer support empowers the lived experience of all in the group, regardless of mode, method or expertise of AAC tools used.”

Workgroup 6: “Peer support models leverage the power of reciprocal community support and honest sharing. In peer support, people who have a shared non-professional connection¹ to the area of support mentor and guide each other to reach the goals *they* each have (not goals others think they should have).”

In summary, AAC Peer Support is a community where individuals who use augmentative and alternative communication (AAC) systems come together in a safe space to share their positive and negative experiences. This support system is built on trust and respect, fostering open and honest communication. It involves sharing ideas,

¹ “Professional connections are fine as long as the non-professional connection exists too—people can have multiple relationships to an area.”



activities, and frustrations to manage life's challenges and validate all forms of communication.

AAC Peer Support aims to create an environment of collaboration, mentorship, and social justice, empowering users to achieve personal growth and community integration.

Key elements of AAC Peer Support include:

- **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 participated in two visual exercises to describe AAC Peer Support. A word cloud that was populated by Consortium members lists descriptors of AAC Peer Support (see Appendix D). The environment and elements of AAC Peer Support are illustrated by a tree in Appendix E.

3.2.2. Barriers and facilitators to AAC Peer Support

What are barriers to AAC Peer Support?

This project was funded based on the concern that many, if not most, people who need AAC lack effective access to it. The availability of peer support is a vital piece of alleviating the problem. However, barriers to peer support exist. The Consortium described the circumstances that must be in place before a person who needs AAC can access AAC Peer Support:

1. Use or need access to AAC
2. Know that other people use AAC (some people don't ever meet another AAC user)
3. Have some knowledge of the value of peer support
4. Desire access to peers for support
5. Find out about the peer support group, activity, opportunity, etc., the format of which must be suitable/appealing to the person
6. Have the individualized support needed to access the peer support

Consortium members identified and discussed barriers to AAC Peer Support. These barriers should also be acknowledged as reasons why the majority of people throughout



the U.S. who need AAC do not have access to AAC that enables them to communicate effectively and enjoy meaningful inclusion in their communities.

Organizational barriers

- Lack of access to AAC
- Funding
- Infrastructure
- Inadequate training or access
- Institutional barriers, like logistical support
- Prioritization of professional support over peer support

Structural barriers

- Geographic isolation
- Physical barriers
- Lack of accessible communication platforms
- Lack of transportation
- Lack of trained support

Social barriers

- Stigma, marginalization, and discrimination
- Ableism and internalized ableism
- Behavioral barriers
- Lack of access to medical services/supports
- Unwarranted assumptions and beliefs about disability
- Decisions needlessly controlled by others, not people with disabilities

Technology barriers

- Internet and computer access
- Internet and computer savvy
- Access to AAC systems
- Juggling virtual meeting functions as well as AAC system
- Microphone/speaker feedback issues
- Caregiver technology skills and attitudes

What are solutions and facilitators for AAC Peer Support?

Consortium members proposed solutions and facilitators for AAC Peer Support that address breaking down barriers. Appendix F discusses barriers that specifically impact



multiply marginalized communities and those who lack access to AAC. Below are descriptors to facilitate and improve access to AAC Peer Support activities.

Minimize barriers. An unforeseen outcome of this project that was frequently reported by AAC users was that their engagement in the Consortium itself served as a form of peer support. A key facilitator to this outcome was the core leadership's efforts to foresee and minimize barriers to participation, as well as access flexibility and a continual willingness to adapt as needed. Project core leadership prioritized AAC users' perspectives, frequently sought member input, offered multiple methods for sharing input, and rapidly adjusted and accommodated based on that input.

Consider meeting format. The Consortium met and worked fully virtually, which is crucial for many AAC users who are geographically isolated, have mobility issues, lack access to transportation, need support to travel, or risk damage to their assistive technology during travel. However, virtual peer support is not accessible to or preferred by all AAC users. Offering a variety of options, both in-person and online, enables broader participation. Multiple modes of connection (e.g., one-on-one support, group discussions, recreational activities, asynchronous virtual chat groups) encourage individuals to participate in more than one. However, consistency and predictability in scheduling is also identified by many in the Consortium as key to facilitating engagement in peer support.

Get the word out. Consortium membership grew steadily over the course of the project as participants shared their experience with friends and colleagues and encouraged them to join. To facilitate AAC Peer Support, messages about its value and availability need to be shared broadly and through multiple channels. Examples Consortium members provided include: physicians and other medical professionals, case managers, state and local DD service agencies, social workers, speech therapists, AAC specialists, mental health therapists, professional organizations, service providers, AAC device manufacturers, advocacy and self-advocacy organizations, school districts, universities, UCEDDs, DD Councils, Centers for Independent Living, disability rights organizations, adaptive sports groups, state assistive technology organizations, existing online AAC communities, and broadly through social media.

AAC users need support to access peer support. Consortium members repeatedly stated that people with significant disabilities require adequate support, whether family or paid staff, in order to access peer support in both virtual and in-person settings. Physical barriers to accessing peer support range from the need for transportation to



in-person activities, to the need for support to open or plug in a device or computer and navigate online to access virtual activities. All this comes *after* the discovery of the peer support opportunity. Those supporting AAC users may not understand the value of peer support, or may not have the skills or capacity to research opportunities on behalf of the person they support, again highlighting the importance of broadly spreading the word about both the benefits of peer support and opportunities to access it.

Utilize feedback. We identified many barriers and facilitators through anonymous feedback from Consortium members in post-meeting surveys. Members rated increased satisfaction with meetings following efforts to reduce jargon, acronyms, and initialisms; lengthen meetings; increase presentation and discussion time for AAC users; and adapt discussion topics based on member interest - all adjustments made based on survey responses. Highlights of AAC user feedback below exemplify facilitators to peer support within the Consortium.

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

Social barriers to AAC Peer Support are rooted in ableism and speechism.² AAC users are often seen as needing education and training directed by nondisabled people, with decision-making power withheld from them. Treating AAC users as AAC experts, whether or not they are also researchers or professionals, has been key to continued participation in the project.

Non-AAC users may be present in an AAC Peer Support opportunity, whether their role is support personnel, family member, facilitator, administrative support, or another role. It is crucial that non-AAC users who are involved in AAC Peer Support activities, whatever their role, recognize that AAC users are the experts on their own lives.

“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.”

Positive AAC representation and role models are crucial for positive identity development and can counteract societal and internalized ableism. Solutions include

² Speechism is prejudice and discrimination that occurs when a person or a group is discriminated against, stigmatized, treated unfairly and/or deemed inferior because their language, use of language, and/or means of expression is judged to be unintelligible or inferior (CommunicationFIRST, www.communicationfirst.org/what-is-speechism. December 16, 2022).



positioning or training AAC users as leaders. This project had AAC users in leadership positions from the beginning, providing a model of shared power in action. Further, all participants were paid for their time spent working on the Consortium and workgroup tasks, a form of equity and respect.

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

A firm commitment to accessibility for AAC users is critical for engagement in peer support activities. The Consortium adopted accessibility and discussion guidelines that prioritize AAC user perspectives and respect their communication access needs (Appendix K). AAC users frequently reported that the Consortium’s efforts to adhere to these guidelines enabled them to feel comfortable sharing their thoughts in meetings.

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

It is acknowledged that disability is diverse, and what one person needs to participate might make it harder for someone else to participate. To facilitate participation, AAC Peer Support activities must be adaptable to the access needs among members and promote positive cultural norms around addressing inevitable conflicting access needs. There’s no way to avoid addressing such conflicting needs, nor is there a single answer for any given situation. Instead, there should be as many means of engagement and access as possible. Accessibility must be built based on the best information and input available with a clear willingness to adjust. Consortium members report that “access flexibility,” meaning an “accommodating spirit to adapt,” should work in tandem with any set of guidelines.

“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.”

Consortium members expressed that AAC Peer Support activities should be directed by AAC users and peer-led whenever possible. However, support for organizational and logistical tasks might be required, unless a group member can provide it (e.g., scheduling, emailing, planning). Having a point person who can manage behind-the-scenes arrangements allows AAC users to relax and focus on contributing their lived experiences rather than managing administrative details. Similarly, consistent logistical support enables participants to feel confident in joining the activity knowing



what to expect from the peer support experience, which increases the likelihood of further engagement.

“Laughter is very underrated.”

Consortium members note that laughter, fun, and finding friendship is an important reason they engage in peer support. Participation increases in environments where people can connect with others as they choose, rather than being matched based on diagnosis, age group, or other characteristics.

A Consortium member that leads an AAC Peer Support group reported the value of “fun with a purpose,” such as ice breakers. This member reported that “kidding around and getting to know each other better through games” deepened the relationships of the group members, and increased participation and attendance. This prioritization of fun and social connection is in contrast to AAC Peer Support that is explicitly educational or solely focused on increasing communication or AAC use.

3.3. Completed Schema: An overarching framework that articulates the necessary adaptations to existing peer-support approaches which are needed for the AAC community

3.3.1. Background and rationale

Peer support models offer a promising, person-centered approach to enhancing communication, self-efficacy, and social connectedness for individuals who use AAC. These models are grounded in the theory that reciprocal relationships and shared lived experience provide a mechanism for behavior change (Substance Abuse and Mental Health Services Administration, 2023; Myrick & del Vecchio, 2016). Peer support allows AAC users to draw on shared experiences with communication disabilities to help one another achieve meaningful goals (McLeod, 2024). Activities such as interpersonal sharing, mentoring, mutual self-help, and networking may help reduce feelings of social isolation, improve communication skills, and mitigate barriers to accessing services. To advance peer support intervention development and ensure models are appropriate, acceptable, and effective for individuals who use AAC, a synthesis of the peer support literature in this space is needed. The following review seeks to identify research gaps, inform future studies, and guide the development or adaptation of peer support models tailored to AAC users.



3.3.2. Purpose statement and research questions

The purpose of this scoping review was to explore the characteristics of peer support research for individuals who use or need AAC. Our aims and research questions (RQ) were:

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

- RQ 1.1. What models of peer support (content, structure, formats, delivery) have been implemented for individuals who use AAC?
- RQ 1.2: In what settings are peer support models most frequently implemented?

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

- RQ2.1: What populations (diagnostic groups, age groups) are represented in peer support literature?
- RQ2.1: What is the role of family members, peers, and professionals in AAC Peer Support models?

Aim 3: Summarize reported outcomes and identify research gaps.

- RQ 3.1 What outcomes are commonly reported in AAC Peer Support research (e.g., social connection, communication, speech-language, advocacy)?
- RQ 3.2: Are there gaps in the literature regarding specific age groups, speech-related disabilities or marginalized AAC user populations?

3.3.3. 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., 2025). To be eligible for the review, papers had to (a) focus on individuals who used or needed AAC and (b) described one or more peer support activities, programs or models. In this review, the term “peer” refers to individuals of any age who share a personal experience with a speech or communication-related disability. Interventions that grouped AAC users with age-matched peers without communication-related disabilities were excluded because the use of aged-matched peers who do not share the lived experience of disability in AAC interventions eliminates a significant component of the proposed mechanism of change (Pfieffer et al., 2021, 2024). In the literature, such interventions are frequently labeled “peer mediated AAC interventions,” “communication partner instruction,” or “peer-networked interventions” and have been evaluated in several reviews (e.g., Biggs & Robinson, 2023; O’Donoghue et al., 2021; Therrien et al., 2016). Quantitative, qualitative, and mixed-method studies were included



in order to consider different aspects of evaluating peer support. Broad inclusion criteria were set to account for the natural variation in etiology and differences in language and communication functioning among individuals who use AAC and to obtain a comprehensive sample of peer support activities.

The search strategy included comprehensive database searchers (PubMed, PsycINFO, SCOPUS, and ERIC) using MeSH terms and keywords related to “AAC” and “peer support” followed by backward and forward citation searching of included articles. The initial search was performed in November 2024 and updated in January of 2025, yielding 1,309 articles. The study team created the screening and data extraction tools (available on OSF) and piloted them with five studies prior to selecting sources and extracting data from included studies. Covidence, a web-based software platform for systematic reviews, was used to complete title and abstract screening, full text screening, and data extraction. Each study was screened independently by two reviewers. We resolved disagreements on study selection and data extraction by consensus and discussion with other reviewers if needed. We extracted information from each study to describe the study design; characteristics of participants; content, delivery, and structure of existing programs; AAC community engagement and leadership in the program; reported outcomes; barriers to participation; and accommodations to encourage participation.

3.3.4. Results

Fifteen studies met the eligibility criteria and were included in the scoping review. Most studies used qualitative designs (53%) or quasi-experimental designs (20%) and focused on adults (60%). See Appendix I for study, participant, and outcome characteristics tables.

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

RQ 1.1: What models of peer support (content, structure, formats, delivery) have been implemented for individuals who use AAC?

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 activity types included semi-structured discussions and unstructured conversations (each reported in 47% of studies), followed by education/instruction (40%), mutual self-help (27%), and peer counseling (20%). Fewer studies incorporated role-playing or structured exercises (13%), developing goals or treatment planning (13%), or networking (7%).



Delivery formats were split evenly between online (40%) and in-person (40%), with a smaller proportion using blended approaches (13%). Meeting formats also varied: nearly half (47%) included synchronous activities, while others used asynchronous formats (20%) or a combination of both (20%). The frequency and duration of programs were frequently underreported, with over half of studies not specifying total number of sessions (53%) or total duration (47%).

RQ 1.2: In what settings are peer support models most frequently implemented?

The most common peer support contexts included online forums, Facebook groups, or online simulations (33%), recreational activities (13%), group interventions or therapy (13%), and camps (7%). Other formats such as children's events and classes and e-mentoring programs were also used but reported less frequently. 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.

RQ 2.1: What populations (diagnostic groups, age groups) are represented in peer support literature?

Participants represented a range of communication-related disabilities. 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 with disabilities. This suggests that the current literature on peer-support programs 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.

RQ 2.2: What is the role of family members, peers, and professionals in AAC Peer Support models?

Stakeholder involvement varied across studies. Peer mentors or facilitators were included in 27% of studies, and communication partners (e.g., family, peers, or caregivers) 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%). Community engagement was also documented: 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.

RQ 3.1: What outcomes are commonly reported in AAC Peer Support research?

Outcomes were underreported across studies. Only 27% of included studies specified outcome measures. Among those, the most frequently reported domains were social connectedness (13%), speech-language or communication outcomes (7%), and program fidelity (7%). **No studies reported outcomes related to autonomy, leadership, advocacy, or service access.**

RQ 3.2: What barriers and facilitators are reported for participation in AAC Peer Support programs?

Specific barriers and facilitators were not systematically reported in the table. However, the high prevalence of online and blended delivery formats suggests a response to accessibility needs and flexibility. The limited demographic reporting and underrepresentation of certain disability groups suggest potential barriers related to equity, inclusion, or program fit.

RQ 3.3: Are there gaps in the literature regarding specific age groups, speech-related disabilities, or marginalized AAC user populations?

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 in significant numbers, and only 13% reported



the inclusion of 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.

Within the initial AAC Users' Survey, respondents answered the question, "Please tell us either what kind of support or mentorship from AAC users you have gotten, and/or what kinds of support you would like to have from other AAC users." The survey had 135 entries. As stated above, **this is the largest AAC users survey ever conducted in the U.S.** Data show that 64% of AAC users experienced peer support activities when learning AAC. 94% of these respondents stated they wanted more peer support from other AAC users. Of those who did not experience peer support when learning AAC, 78% stated they would like to receive peer support from other AAC users, or they were unsure.

Five groups or themes were categorized from the 135 survey entries. The five themes are:

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

The percentage of survey entries divided in each theme were as follows: 28% commented on Mentoring Support to Improve Self-Advocacy Skills, 24% addressed Validation of AAC User Identity, 28% expounded upon Guidance in Improving AAC Skills, 3% mentioned Advocacy for the AAC Community, and 23% said they had No Need for Peer Support. From these results we see that **respondents see peer support as a way to improve their capacity for communication and also their ability to direct their own lives.**

The first theme, Mentoring Support to Improve Self-Advocacy, was chosen based on Consortium discussions on the ways in which peer support could provide mentors and role models who can contribute to AAC users' self-advocacy skills. The research of Dr. Lateef McLeod, a member of the Consortium, and other literature supports this claim. We also see that 28% of respondents were looking for mentoring and improvement of



their self-advocacy skills. One respondent said, “I was introduced to AAC through another AAC user. I received encouragement often from other AAC users to acquire the skills I needed for AAC. It became my way to have friends as it was a group that accepted and valued me. I would like more support from other AAC users on how to navigate the college environment, how to explore work possibilities and how to expand my social network.”

The Validation of AAC User Identity theme emerged from the many survey entries by people who use AAC wanting to interact and be in community with other people who use AAC who can relate to their experiences. Twenty-four percent of survey responses were categorized under this theme. To quote one of the respondents, “I met another AAC user during my last year of High School. Mostly it gave me the realization that I wasn’t alone. I went to his AAC camp at UW-Whitewater, and it helped me to accept my communication device as my voice.” As this quote shows, coming together with other AAC users can reduce feelings of isolation, loneliness, and shame, while increasing self-acceptance and confidence.

The third theme, Guidance In Improving AAC Skills, evolved from the twenty-eight percent of respondents who reported that they were looking for or valued peer support in navigating their AAC system. One such respondent said, “Sharing files and screenshots of customized pagesets/vocabularies; troubleshooting app issues; affirmations that there’s no such thing as too /whatever/ to use AAC; creating and moderating AAC-user led spaces; being members of said spaces; providing different perspectives and sharing of all the wonderful ways we communicate; helping me over time to learn about AAC and then slowly realize that I’m an AAC user that AAC is something I can use / that I use; creating and sharing symbols/images to use with symbol-based AAC.” With this sharing of information, people who use AAC can assist each other in gaining skill and even mastery in using their AAC devices.

The fourth theme that emerged from the data was Advocacy for the AAC Community. These are the survey responses that advocated for people who use AAC and their right to have peer supports in the community. This category of responses was 3% of the overall responses. One respondent said, “Corporate community-based placements in Massachusetts do not like individuals using AAC devices. They do not want them communicating their wants and needs. They certainly do not want the responsibility of maintaining devices or teaching individuals to use AAC devices. The most impaired individuals are the least likely to have access to AAC.” Quotes like these indicate awareness of the social and political forces that often impede people who need AAC



from gaining access to the tools, supports, and resources they require for effective communication. As a result, a form of AAC Peer Support could be to organize as a community and advocate to make sure AAC and AAC Peer Support is available to everyone.

The final theme is categorized as No Need For Peer Support, which included responses from people who didn't desire peer support or didn't provide a response for the question. Twenty-three percent of the respondents fit within this category, writing responses such as, "I don't think I need any mentorship from other AAC users." Some people who use AAC do not want or need to collaborate with peers to achieve their communication and self-advocacy goals. AAC Peer Support should be available to everyone that desires it, but not compulsory.

This data shows that most of the respondents desired or felt they had benefited from AAC Peer Supports, particularly in the areas of increasing their skills in self-advocacy, communication, and using AAC. 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. We sought input from a large sample of AAC users to identify relevant program topics, goals and outcomes. Seventeen domains were selected:

<ul style="list-style-type: none"> • Early childhood development • Literacy • Speech, language, communication • Inclusive education • Higher education • Topic specific education • Leisure and recreation • Quality of life • Advocacy and leadership skills 	<ul style="list-style-type: none"> • Community living • Community engagement and participation • Career path/employment • Social connectedness • Relationships/dating • Financial planning • Healthcare delivery • Identity development
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3.4.2. Insights from the scoping review regarding evaluation

Results from the scoping review of AAC Peer Support programs indicated that only 40% of studies reported outcome measures or specified program goals (6 studies). Researchers measured social connectedness (Marshall, 2020), quality of life (Marshall, 2020) speech, language, or communication skills (Mooney et al., 2018; Marshall, 2020) peer mentors' fidelity (Light et al., 2007) and community engagement and participation (Grace et al., 2019).

Findings from the scoping review also highlighted that AAC users were rarely involved in the program evaluation, though four studies (27%) assessed participant or caregiver satisfaction with the peer support activity. Going forward, it is critical that the community of AAC users assess the feasibility, acceptability, and appropriateness of peer support activities.

We identified several promising measures used by researchers evaluating peer support programs (see table below). Future researchers and program administrators can employ these instruments to measure the impact of peer support activities on social connectedness, emotional health and wellbeing, self-efficacy, resilience and mental health.

3.4.3. Table: Promising measures to evaluate the impact of Peer Support activities

Measure	Description
Self-Reported Experiences of Activity Settings ^{a, b}	Self-reported measure designed for individuals who use AAC to evaluate their participation experiences across 5 domains: Personal Growth, Psychological Engagement, Social Belonging, Meaningful Interactions, and Choice and Control
Warwick-Edinburgh Mental Wellbeing Scale	Self-reported measure that assesses wellbeing in the general population and evaluates the intervention effects on mental wellbeing



Social Connectedness Scale—Revised	Self-reported measure of social connectedness
Multidimensional Scale of Perceived Social Support	Self-reported instrument used to measure social support from family, friends, and significant others
NIH Toolbox Emotion Battery: Emotional Support Form	Self-reported measure of emotional support
PROMIS General Self-Efficacy Form	Self-reported measure of an individual's belief in their ability to succeed in different situations and accomplish tasks
Brief Resilience Scale	Self-reported measure of resilience
Generalized Anxiety Disorder 7-Item Scale	Self-reported measure of general anxiety symptoms

Note. ^a Batorwicz et al.,2017. ^b King et al.2014.

3.4.4. Recommendations related to evaluation

To achieve balance between the research and the knowledge gained from lived experience, there must be more dialogue between AAC users and allies. It is immensely important that evaluation efforts recognize that the independent living, self-advocacy, and psychiatric survivor movements are grounded in peer support and the notion that we are the experts on ourselves, and this movement is no different. We can look to other cross-disability peer support experiences to inform our evaluation of AAC Peer Support.

Peer support is complex and dynamic. It does not neatly fit into objective study models without understanding the motives of people who need or use AAC in their daily environments and cultural settings. Any evaluation should be informed by lived experience through participatory action research, as well as, to the extent appropriate, other research (e.g., implementation science, mixed methods, or qualitative).

The following outcomes are recommended as measures for evaluating the effectiveness of AAC Peer Support based on collaboration between AAC users and allies in the Consortium. However, these recommendations for evaluation are preliminary and require a more extensive review that includes input from more individuals with lived



experiences using AAC. When identifying the right outcomes to measure for evaluating peer support effectiveness, we find the following:

3.4.4a. Communication performance is not the only goal

Peer support can help create the reasons and environment that can motivate AAC users to express themselves, be heard, and lead life as they want. Although increased access to and opportunities to communicate with all forms of AAC may be a byproduct of peer support activities in some cases, unless the main purpose of the peer support group is specifically to increase the use of AAC, **outcomes focused on communication performance alone are inadequate and inappropriate for evaluating the impact of peer support.** As such, 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.”

3.4.4b. Participation and engagement

We recommend that metrics of participation and engagement be used to evaluate peer support outcomes. Participation and engagement can indicate that an AAC user enjoys the activity, benefits from it, finds it helpful, or thinks it is important. This measure should be broad and inclusive, honoring and accepting all forms of communication and acknowledging a wide range of indications of engagement, both verbal and nonverbal.

Participation and engagement in peer support can take many forms, such as attending, eagerness to attend, putting events into schedules, and taking initiative to be prepared for events. Nonverbal expressions of engagement that may be observed include facial expressions and body language, such as smiling and nodding during discussions, and personal utterances that indicate positive sentiments. Other ways people participate include contributing to a conversation, or getting what one needs by simply observing others.

It is important to recognize barriers to participation and engagement that people who use AAC may encounter. For example, scheduling conflicts, lack of transportation, or lack of availability of family or paid supporters may block an individual’s involvement in



real-time or in-person peer support. In this scenario, participation may take other innovative forms depending on the AAC user, such as watching recordings outside of the group, and/or reading meeting notes.

3.4.4c. The “I matter” factor

Perhaps one of the most important and least defined evaluation metrics identified by the Consortium is the *I matter* and *we matter* factor. Members agreed that one of the most impactful outcomes from peer support is the sense of feeling valued, that one belongs, and that they matter. In part, a fostering of camaraderie and having a space where one can just *be*—in whatever way that they desire to be—was a theme in conversations around this measure. There should be an iterative and ongoing process to explore the *I matter* factor, as this is an abstract but universal experience that is applicable to outcomes in AAC Peer Support.

We sought input from AAC users in the Consortium about their perceptions around what *I matter* means 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.”

3.4.4d. Measuring effectiveness of AAC Peer Support through self-assessment

One of the Consortium’s key recommendations is that evaluation of AAC Peer Support activities must be conducted from the lens of AAC users. Outcome measures should be determined by the peers; outcomes defined by others are antithetical to peer support. Evaluating from the perspective of AAC users will avoid perpetuating outdated or biased standards of what is considered “normal” communication. Overt effort is needed to avoid reinforcing performative and normative standards.

AAC users proposed that evaluations of peer support utilize self-assessment to examine what impacts the activity has on their sense of self, choice, autonomy, agency,



privacy, trust, camaraderie, well-being, and other subjective quality of life measures. This approach will offer insight into peer support's primary effects and a framework for exploring its more nuanced effects on individuals' opportunities to make effective use of AAC.

Measures focused on subjective quality of life outcomes acknowledge that AAC users should be trusted to express what is important to them, and what is working and not working in terms of meeting their own goals. This may be accomplished by asking what, if any, impact peer support had, both before and after engagement in peer support opportunities to determine if the experience is meeting expectations. Example questions³ aimed at gathering this information might include:

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

Some Consortium members became uneasy at the idea of developing a tool or checklist for assessing effectiveness of AAC Peer Support, as such instruments may be too structured, may not capture a full range of outcomes, or may not provide a complete measure of quality of the experience. Individualized feedback should be solicited and additional rating methods considered to enhance results of any assessment tool. It is important that any tools for assessment be personalized to individual goals and adapted to participant accessibility needs.

This being said, the following self-assessment tool was developed with extensive Consortium member input. It is designed to encourage the participant's reflection on their goals and interests following a peer support experience. Responses from each category can demonstrate the goodness of fit of the peer support experience for an individual, as well as the effectiveness of the peer support model, based on its goals. To allow for flexibility, response options are *I got this*, *I want this but didn't get it*, and *I don't*

³ It is important to note that these questions need to be available in alternative and accessible formats for all individuals.

⁴ 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.



want this from the peer support experience. It should be noted that a participant might take part in peer support for only a few of the reasons on the list.

The statements could be rephrased to establish individual goals prior to accessing the peer support opportunity, and they may also be structured in a survey format that can help establish measurable outcomes. This qualitative approach to data collection can inform scholarly research while maintaining the emphasis on ensuring peer support engagement is person-centered. Additional survey, ethnographic study, and related qualitative methods can be considered in the future, as well.

3.4.4e. Self-assessment tool

Self-assessing goodness of fit and effectiveness in AAC Peer Support activities			
Individual effects: I Matter/We Matter	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			
Individual effects: Connections	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			
Individual effects: Communication	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			
Individual effects: Personal growth	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			
Characteristics of the experience that are likely to increase participation	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			

3.4.4f. Individualized approach to Peer Support and increased autonomy

An individualized approach to peer support is tailored to each individual, and peers should drive their own support. As such, one potential measure of the effectiveness of peer support is increased autonomy and self-advocacy. However, we must recognize that some people may have limited experience with autonomy, restricted access to education, lack of effective AAC, and/or an acquired disability, all of which can impact self-advocacy and planning for one's own support. To ensure that individuals can be the driver of their own peer support opportunities and experience successful outcomes, we must first "meet individuals where they are." This does not mean peer support opportunities should be planned for these individuals. Rather, they need to be provided opportunities to learn how to drive their plans more independently. Neglecting to adapt ways for driving peer support will be more harmful than helpful for this group of individuals.

One example of building these skills in peer support is in photo activities that encourage self-expression and create dialogue about support and individual aspirations. In the participatory research method Photovoice, people take photos and share them with a group, then support each other to write captions or narratives describing why they took the photos. In photo elicitation, a similar research method, this activity is performed one-on-one. This type of adaptation and creative approach to engagement fosters an inclusive and productive community. By sharing experiences, participants understand each other better and find camaraderie, and by working together on a creative project, participants build leadership skills and recognize individual strengths, which enhances self-esteem.



3.4.4g. AAC users define success of Peer Support activities

To examine what constitutes successful AAC Peer Support, the AAC users in the Consortium were asked, “Describe what success in peer support means to you. Try 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.”

3.4.4h. Critical considerations for establishing and evaluating AAC Peer Support

Accessibility is a fundamental human right that should be considered across all communities, platforms, environments, ages, races, genders and disabilities. There are numerous factors related to accessibility that need to be considered when seeking to establish and evaluate peer support, as initial and ongoing access is required to achieve any desired outcome.



A key component of accessibility when it comes to peer support is format. Virtual meeting platforms have allowed people who experience different disabilities to overcome barriers to connect with one another. However, online spaces are not accessible or desired by all. We believe that, to have the farthest reach, peer support should offer access flexibility by accommodating both physical and virtual space preferences and also recognizing that an individual's preferences can change (i.e., meeting in-person is preferred for a time, then later a virtual setting works best). Access flexibility also means continually assessing and resolving accessibility barriers based on individual and group needs. Failing to address participants' accessibility needs undoubtedly affects peer support outcomes.

Identifying the specific focus or aim of the peer support one is seeking to establish (e.g., grief, socializing, education, self-advocacy, relationships) is crucial to establishing and evaluating the model. Seeking out existing peer support models addressing similar aims may offer a springboard for continued improvement of peer support evaluation. Evaluating general support groups may offer insights and opportunities that are not unique to using AAC. That said, we maintain that there is incredible value in AAC-specific peer support opportunities.

It is important to consider the wide variety of ways that people offer and receive peer support (e.g., storytelling, books, videos, art, meetups, social media) and adapt evaluation methods as needed. Similarly, understanding the missions and values of the peer support setting and leaders or facilitators of the opportunity is important as each will have distinct approaches, limitations, and strengths. These factors will impact evaluation efforts.

3.5. A set of actionable recommendations to encourage the use of AAC devices by those who are not currently using them for communication

Children, youth, working age and older persons who use AAC or who lack needed access to it encounter barriers, bias, and discrimination that limit their opportunities in life, including offering, receiving, and benefitting from peer support. Such individuals who are members of unserved and underserved communities tend to be more likely to face these barriers more often. Appendix F lists considerations, as perceived by AAC users, that address barriers and solutions for individuals who have not successfully acquired effective AAC, and those who are from multiply marginalized communities.



3.6. Legal frameworks report with findings and recommendations

Below we discuss 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 sustainable and continue year to year, or multi-year funding for peer support and similar purposes. We believe the federal legal, program, and funding authorities summarized below are sufficiently broad and flexible to permit them to be utilized to advance these purposes and pursuits individually or collectively.

The summary does not identify all sources of federal financial assistance that might support, strengthen, and grow the availability and quality of AAC Peer Support driven by the lives, aspirations, and needs of people of all races, generations, disability types, classes, cultures, and languages. It is also not government-wide in scope. We believe, however, that conducting such a comprehensive review would be beneficial.

We have no firm basis for estimating how much funding might be necessary to initiate, ramp up, and sustain peer support activities at a nationwide, state, or project level. However, we can say generally that permissible uses for federal funding for peer support activities would primarily include those associated with administrative, logistical, training, and related expenses. We believe, therefore, that the total amount of such assistance needed to address this would be modest. Organizations prioritized to receive such funds should include those led by and for AAC users and other people with disabilities, such as national, state, or local peer support, independent living, and self-advocacy organizations. It is anticipated that organizations receiving such funding might choose to create, partner with, or access services from a third-party entity that functions as a fiscal and administrative support intermediary agent and/or provide technical assistance. These entities should collaborate with such peer support groups to find ways to provide them with administrative and logistical support without interfering with their individual or collective autonomy.

Centers for Medicare and Medicaid Services (CMS). The only resource we believe accurately describes a potential source of sustainable funding for peer support offered by and for people with disabilities generally, and AAC users specifically, is funds made available through Medicaid. In recent years, several states have used various authorities or funding streams in Medicaid to fund peer support services and activities for children and adults with disabilities. Most of the peer support activities funded with Medicaid funds have focused on individuals with mental health and substance use



disorders (CMS, 2024). However, Medicaid can also be used to fund peer support for and by people with a range of disabilities, including AAC users, and for a range of purposes. Over 30 states are using Medicaid to fund peer support to improve behavioral services and life outcomes for children and families (MACPAC, 2019). In the nationwide Money Follows the Person Demonstration programs, states used Medicaid to fund various peer support services to leave nursing homes, ICF/IDD, and other institutions and move into their communities. AAC users, most particularly those lacking effective access to it, require ready access to peer support to improve their everyday lives and futures. Medicaid is a vital resource for achieving this aim.

We strongly recommend that ACL work with the Centers on Medicare and Medicaid Services, AAC users, the disability and aging communities, and states to develop and implement practical strategies for accessing Medicaid and other funding streams to expand peer support for AAC users and other people with disabilities regardless of their race, age, gender identity, home language, or socioeconomic status.

The U.S. Department of Education (ED). ED's Office of Special Education Programs (OSEP) is responsible for implementing IDEA. Several of its provisions are or could be used to provide funding for peer support activities. Under Part B and Part D of IDEA, OSEP competes, selects, and awards discretionary grants to institutions of higher education and other non-profit organizations to support research, demonstrations, and technology and personnel development. We recommend that OSEP fund grants to identify, investigate, and improve peer support and other practices to enhance the educational and inclusive lifespan outcomes of infants, toddlers, preschoolers, students, and transition-age young people who need AAC.

Under IDEA, OSEP competes, selects, and funds about one hundred parent training and information centers, community parent resource centers, and technical assistance for parent centers nationwide. We believe there are a variety of ways cross-generational peer support led by and for children and adults who need AAC can improve the lives of such children and youth in their infancy, throughout the school years, transition, and beyond. The Consortium, therefore, recommends that OSEP fund Centers to develop and pilot AAC Peer Support activities to (1) enable children and young people who need AAC to get to know, learn from, and be motivated by others using AAC; (2) provide information, training, and support on AAC, literacy, and opportunity to these young people, their parents, schoolmates, and teachers; and (3) enhance the use of natural and technology-assisted use of AAC by children, youth, and transition age young people who are multiply marginalized or may be inappropriately identified.



IDEA and Section 504 of the Rehabilitation Act require compensatory educational support be provided to help students make up for progress or skills they lost when their special education services were not provided. We, therefore, recommend OSERS (OSEP and RSA), state, and local education authorities develop, and fund peer support activities centered on enabling these youth to receive an equally effective education, including by making up for one they lost out on.

With regard to transition to post-secondary life opportunities, the Consortium recommends that OSEP, state and local school authorities, and federally assisted programs develop and implement strategies to expand the access and quality of peer support available to transition age young people—especially those who need AAC—to learn from, support, navigate barriers, and create better futures together.

Rehabilitation Services Administration (RSA). The Rehabilitation Act programs are administered by the Rehabilitation Services Administration (RSA). The Act funds nationwide comprehensive systems of youth transition, rehabilitation and supported employment to maximize the employment, independence, and integration of individuals with disabilities in their communities. People with significant disabilities have long sought and received the support, advice, experiential knowledge, and encouragement of each other in exploring and working towards post-secondary education, career, and related goals. While some AAC users have benefitted from this type of peer support, most lack access to it.

We recommend, therefore, that RSA partner with individuals using AAC, families, peer support networks, states, localities, foundations, and others to identify and pursue immediate, intermediate, and long-term actions that can be taken to ensure peer support becomes an integral part of the educational and transition process, as well as vocational rehabilitation and supported employment services.

Furthermore, the Consortium recommends that the Office of Career, Technical, and Adult Education (OCTAE) works with its state grantees, individuals who need AAC, advocates, foundations, and others to develop and pursue strategies for enhancing the opportunities of AAC users to access adult education and literacy services, including through peer support.

The Administration on Children and Families (ACF). The Consortium strongly recommends ACF and its grantees partner with people using AAC and others to enhance the lives and futures of people through peer support by providing technical assistance and funding its Head Start, child care, foster care, and other child welfare



grantees to develop and pilot activities to enable children and young people who need AAC to get to know, learn from, and be motivated by others using AAC.

Administration for Community Living (ACL). ACL is already utilizing many authorizing statutes to demonstrate and elevate the crucial roles peer support plays in enabling older adults and people with disabilities of all ages to lead valued lives in community with all others. All of ACL's operating components—the Administration on Aging, Administration on Disabilities, Center for Innovation and Partnerships, and the National Institute on Disability, Independent Living and Rehabilitation Research—invest in a rich range of peer support strategies and approaches (such as ACL's Peer Provider Programs). The Consortium believes that ACL's demonstrated leadership, commitment, and experience provides a strong foundation to build upon.

Furthermore, we believe ACL's statutory purpose and funding authorities should be used to support, strengthen, and grow the availability and quality of peer support driven by the lives, aspirations, and needs of people who need AAC of all races, generations, disability type, classes, cultures, and languages.

With regard to the Assistive Technology Act of 2022, we recommend that ACL partner with AAC users, its grantees, and others to identify and build on the TECH Act network, Centers for Independent Living, and others to expand peer support opportunities for people with disabilities, particularly those who lack effective access to AAC.

With regard to the Older Americans Act, ACL and the aging network are on the leading edge of developing, scaling, and leveraging peer support strategies to remedy and reverse the disproportionate personal and public health consequences of loneliness and social isolation on older people, especially those from underserved communities. This certainly includes AAC users, and many adults who develop acquired disabilities and have never heard of AAC. Based on its strong record of leadership, therefore, we strongly recommend ACL partners with AAC users, the aging and disability community, and others to identify and build on past and current efforts to expand peer support opportunities for older people with disabilities, particularly AAC users and those without effective access to AAC.

Under Title VII of the Rehabilitation Act, ACL provides discretionary grant funding to 350 local Centers for Independent Living (CILs) as well as State Independent Living Councils (SILCs) across the country. Independent living and peer support are synonymous with each other CILs. At least 51 percent of the members of the Board and staff of every CIL and SILC must be people with disabilities. Services provided by CILs are designed, provided, and evaluated by and for individuals with significant disabilities,



and each CIL must offer IL core services in a consumer-directed manner. We recommend that ACL partner with AAC users and the IL network to identify and build on what CILs, SILCs, and others are doing to expand peer support opportunities for AAC users, particularly those who lack effective access to AAC.

State Councils on Developmental Disabilities. DD Councils are federally funded, self-governing organizations charged with identifying the most pressing needs of people with developmental disabilities in their state or territory. There are 56 Councils across the United States and its territories.

Councils design five-year state plans that address new ways of improving service delivery for people with developmental disabilities. To implement their state plans, Councils work with different groups in many ways, including:

- Educating communities to welcome people with developmental disabilities.
- Funding projects to show new ways that people with disabilities can work, play, and learn.
- Seeking information from the public as well as state and national sources.

The next five-year state plan for each Council will cover federal fiscal years 2027 – 2031. Councils are currently (early 2025) in the process of gathering information from people with developmental disabilities and other interested groups. This information will be used to create goals and objectives for their state plan. Each Council will have a different process and timeline for seeking public input and comments on their proposed state plan.

Advocates for peer support models for AAC users should contact the Council in their state or territory and inquire about how to respond to surveys or requests for information about priorities for the 2027–2031 state plan. The reports and recommendations generated by the Peer Supports for AAC Users initiative and information about the needs of AAC users in your state or territory can be used to support the inclusion and funding of peer support activities in your Council's systems change activities.

Additional sources. AAC Peer Support could be justified from many other sources and Acts, such as NIDILRR, the National Paralysis Resource Center (under the Christopher and Dana Reeve Paralysis Act), centers and programs funded under the Traumatic Brain Injury Act, the Health Resource and Services Administration (HRSA), and the Substance Abuse and Mental Health Services Administration (SAMHSA). They all have missions and goals that resonate with the recommendations laid out in this preliminary



final report to improve access to and effective use of AAC by all Americans. Other sources could include foundations and non-governmental funding through philanthropy.

3.7. Initial list of resources and information

The project compiled a list of Peer Support models, projects, approaches and activities that are current within the U.S., provided by Consortium members and their networks. Appendix H details these models.

3.8. AAC key/preferred terms

The Consortium uses augmentative and alternative communication (AAC) to refer to all forms of communication other than speech, like gestures, eye gaze, vocalizations, facial expressions, body positioning, alphabet boards, speech generating devices (SGDs), handwriting, and other tools or supports.

Terminology used to describe AAC users is important because language shapes perceptions, influences attitudes, and reflects respect for individual identities. The words below represent just some of the terms that may be used, but preferences vary widely among individuals. Some AAC users may embrace certain terms, while others may strongly dislike the same terms. Additionally, the choice between identity-first language (e.g., “AAC user”) and person-first language (e.g., “person who uses AAC”) is deeply personal and may be shaped by characteristics of one’s identity. Identity-first language emphasizes AAC as an integral part of who someone is, while person-first language highlights the person before their method of communication. Both approaches are valid. Furthermore, language and terms evolve as societal perspectives shift and as AAC users advocate for terminology that best represents their experiences and identities. The Steering Committee proposed the list below, and the AAC users on the Consortium agreed on the first six terms.

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



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

Terminology is also important when searching for AAC Peer Support. Consortium members considered that a potential barrier to AAC Peer Support might be an individual's ability to locate or find activities. As such, the Steering Committee worked with the AAC users to identify alternate keywords or search terms that could be applied in an internet search for AAC Peer Support. Appendix G lists the alternative search terms that the AAC users in the Consortium agreed upon.

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 during the one-year process of development. It meets the requirements set out in the AUCD-OHSU contract, and establishes nationwide, comprehensive, consensus-based 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 a level of **AAC user-led** training for professionals, mentoring opportunities provided by AAC users for families and AAC users in their natural environments [e.g., schools, homes, employment sites], evaluation of activities by AAC users, and funds to make AAC Peer Support activities sustainable. Below we list 10 actionable, practical recommendations that were discussed by Consortium members.

Recommendation #1: Establish a Center of Excellence for AAC Peer Support. We endorse the establishment of a Center of Excellence for AAC Peer Support built on the recommendations outlined by the Consortium based on the critical insights of AAC



users. This center will serve as a national leader in advancing development, implementation, evaluation and dissemination of AAC Peer Support activities. A dedicated center will enhance collaboration among community organizations, professionals, individuals who use or need AAC, their family members, and networks. The center should focus on the development and effective evaluation of peer support activities; advocacy for policies to improve communication access and the availability of peer support; and strengthening peer-led AAC Peer Support activities for the effective access to, acquisition of, and use of AAC tools and techniques by everyone who needs or uses AAC.

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. Any leadership team should be compensated for their time and contributions.

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 national community mini-grants that sustain existing peer support projects, reduce access barriers, and develop new programs responsive to community needs. A mini-grant is a small award of money given to support a project or initiative. For example, mini-grants might be provided to reduce travel costs or other participation barriers for in-person meetings, or develop extension activities to sustain the relationships built during AAC camp. Additionally, a few Consortium members mentioned that AAC services for adults with intellectual and developmental disabilities in their states (i.e., Colorado) are no longer supported by Medicaid waivers, so peer support activities for adult AAC users with I/DD could be a mini-grant award.

The Center of Excellence for AAC Support should provide technical assistance for writing the mini-grants. The grant review committee should include members who use AAC and their families and should prioritize identifying activities that meet the needs of a local population.

There is a precedent for awarding mini-grants to community organizations. The OHSU UCEDD provides yearly community mini-grants distributed and administered by our Community Partners Council (the UCEDD's consumer advisory council).

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 structured,



consultative model for engaging community members in collaborations by facilitating a balanced discussion between professionals and stakeholders (AAC users and their networks) focused on evaluating specific program components such as the inclusion approaches, survey instruments, instructional materials, and implementation and dissemination strategies (Byrne et al., 2012; Joosten et al., 2015, 2018). The CES goal is to receive rapid feedback and collaborative input from AAC users, family members and their networks to adapt proposals to the AAC community's needs before initiating a project (Coulter et al., 2019; Joosten et al., 2015; Nielson et al., 2020). We emphasize the CES approach because it includes listening sessions, focus groups, and other events that are familiar and open to people who need or use AAC.

CES has been successful in increasing participation from underrepresented groups. Our recommendation is to increase participation from groups that have been underrepresented in AAC Peer Support activities, including people with acquired disabilities, people who use graphic symbols (vs. orthography), preliterate AAC users, potential AAC users with intellectual and developmental disabilities, and people from multiply marginalized communities. The CES approach can identify specific features of successful AAC Peer Support activities to accommodate the unique needs of these specific populations of AAC users.

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 that would be available to anyone who is interested in starting, maintaining, funding or evaluating AAC Peer Support activities. This project has started to compile initial tools and resources to enhance peer support activities (e.g., guidelines for holding online meetings with AAC users), and looked to Peer Support activities outside of the AAC field for their guidelines. The development of a dedicated Implementation Toolkit for AAC Peer Support 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 not only for AAC users, but for families and others who provide support frameworks for AAC users (i.e., paraprofessionals, direct support professionals, nurses). There are models, such as the Family to Family [f2f] Networks, that help individuals with disabilities and their family members define and achieve success for themselves and their loved ones. A family-centered approach to peer support has also been adopted successfully by AAC camps and community organizations with activities designed intentionally for caregivers, siblings, and children of AAC users.



Recommendation #7: Establish a repository for AAC users who are interested in being peer mentors within AAC Peer Support activities. A major feature of AAC Peer Support activities is the availability of experienced AAC users who mentor and model effective AAC use to others. AAC Peer Support took place in Consortium meetings and workgroup meetings where experienced AAC users were present and participating in all discussions. Within a national landscape, there are communities of people who need AAC who have never met or interacted with an AAC user. We recommend the establishment of a repository of AAC users that details their locations, their AAC tools and techniques, and their expertise and availability to meet new users. A visual, interactive map could be created to achieve this goal. There are networking efforts within and outside the AAC community with similar goals, such as:

- The U.S. Society for AAC (USSAAC) has a Speakers Bureau where AAC users can promote their availability to lecture at AAC courses offered in universities or at conferences.
- PRC-Salttillo is an AAC manufacturer that supports an Ambassador Program, where AAC users who rely on their specific speech generating devices can meet with potential users or novice users.

An AAC Peer Support repository could be impactful in multiply marginalized communities where no one currently uses AAC, and experienced AAC peers could address questions on topics such as access to multilingual AAC devices or devices that present non-English orthography for selections.

Recommendation #8: Create an AAC Peer Support hub to increase means to locate and find peer support activities that support a diverse array of options to meet the interests of people who need or use AAC. A virtual hub should be created that lists contact information for current peer support activities. The Commit to Connect Champions (committoconnect.org) and Patient Connect (polygonhealth.app) platforms may be used as examples of how to promote peer support activities and enable peers to connect.

The hub should also expand on the range of AAC Peer Support activities so that a wide variety of options are available. Consortium members identified a few of the most impactful peer support activities, demonstrating that a range of support activities must be available. The peer support experiences that AAC users shared ranged greatly. Many attended AAC camps (mainly sleepover camps for children who are learning AAC paired with mentors who use AAC, some with families present). Others rely on internet



communities on Facebook, Discord, or Twitter (X), or online technical assistance. These experiences should all be explained and available on the hub.

Recommendation #9: Host a bi-annual conference about AAC Peer Support. Over this past year, AAC users, family members, and professionals have collaborated to investigate peer support approaches for individuals who need or use AAC. Consortium members indicate that in-person networking is one critical path towards successful implementation and monitoring of AAC Peer Support activities. In this regard, an online or hybrid conference (with flexible and adaptable access considerations) could be convened with three goals: (1) offer training and consultation services to AAC users and their networks who are considering developing specific AAC Peer Support activities, as well as influencing their healthcare providers, educators, and community self-advocacy organizations; (2) provide networking opportunities to disseminate best practices; and (3) set new implementation and dissemination, advocacy, and policy priorities regarding AAC Peer Support.

Recommendation #10: Implement a rigorous evaluation framework to assess the effectiveness and the appropriateness of programs and interventions, using outcome measures that are specified by the AAC community. Evaluation of AAC Peer Support activities must be conducted from the lens of AAC users. Peer support can help create an environment that motivates and empowers people who use AAC to express themselves, be heard, and lead life as they want. Although increased access to and opportunities to communicate with AAC may be a byproduct of peer support activities, unless the main purpose of the peer support group is specifically to increase the use of AAC, outcomes focused on communication performance alone are inadequate for evaluating the impact of peer support. However, measuring a variety of indicators of participation or engagement can indicate that an AAC user enjoys the activity, benefits from it, or thinks it is important. This measure should honor and accept all forms of communication. Participation may be showing up to an event, adding a meeting to one's schedule, answering a survey, responding by email, watching recordings, and reading notes between meetings.

Consortium members indicated that a “goodness of fit” indicator rather than an outcome measure might be more impactful for AAC users. Evaluating goodness of fit from the perspective of AAC users will minimize the risk of reinforcing historical indicators of non-normative communication performance. To determine goodness of fit, it will be particularly helpful to ask AAC users about their goals specific to peer support and how they prioritize progress.



Further notes on the effective evaluation of AAC Peer Supports are detailed within section 3.4.4 of this report.

4.2. Outcomes and outputs

In addition to recommendations, Consortium members discussed the value of this project, the outcomes, and the outputs that occurred because of AoD/ACL funding. Appendix L provides many outputs that resulted from this project, and a few exceptional outputs are highlighted below.

Unprecedented collaboration. It is vital to acknowledge that the AAC Peer Support Project was considered pivotal, positive, and far reaching to many Consortium members, especially AAC users. There has been a very significant engagement of the national AAC community with energizing actions by AAC users, clinicians and service providers, families and social networks, and researchers. We saw considerable collaboration that bridged gaps between academicians and community members. **This is the greatest collaboration that has been witnessed in the AAC field to date**, and Consortium members spoke loudly about how the AAC Peer Support Project created a paradigm shift in the AAC field. Appendix J includes many comments from Consortium members, demonstrating the value of this work and their inclusion in the process and products.

Guidelines to establish communication equity. One critical outcome that affects the entire AAC community is the development of discussion guidelines and accessibility guidelines so that there are equal contributions by AAC users and people who only rely on speech for expression. It is well documented that AAC users are not often equal partners in conversations with people who use natural speech. Collaborating with the steering committee, this project acknowledged that barrier and put into place, early in the year, guidelines in an attempt to equalize participation. For example, participants were instructed to be patient and comfortable with silence as AAC users generate a message during the meeting. As one AAC user stated, *“We (AAC users) are typically afraid to give our opinions during a live session because often we [feel] that we are interrupting the flow of meetings.”* People tend to fill in moments of what is perceived as awkward silence. This often results in AAC users responding or reacting later via e-mail or prepared messages after the conversational moment has passed or at the next meeting, which doesn’t facilitate productive and deep conversation. The practice of pausing the conversation gave some AAC users the time they needed to respond, but



also allowed for all members to thoughtfully process the information. As one AAC user stated, *“being comfortable in silence is not about being quiet, it is about incorporating the message being said.”*

In another example, both AAC users and people who rely on natural speech were instructed to use the chat feature in the Zoom recording, or to raise their hands to be recognized before making a contribution to the discussion. All chat entries were read aloud by a moderator. The moderator also recognized participants with raised hands. This equalized contributions significantly.

These guidelines will be shared in many venues (i.e., the International AAC journal; reports from the AAC Special Interest Group at the American Speech-Language-Hearing Association; the newsletter for the International Society for AAC; the webinar for the Assistive Technology Industry Association). The guidelines can be found in Appendix K.

Finally, Consortium members spoke loudly about how the AAC Peer Support Project created paradigm shifts in the AAC field:

Creating an AAC identity. A number of AAC users clearly stated that their participation in this project helped them with self-advocacy and the creation of their AAC identity. Many stated that the workgroup and Consortium meetings were a form of AAC Peer Support that empowered them to be contributing members of the groups.

AAC agency. Personal agency refers to the sense of control over one’s own thoughts, behaviors, and actions, and the ability to see oneself as the source of these actions, ultimately leading to a sense of self-advocacy, empowerment and self-efficacy. A number of AAC users stated that this project created AAC agency, where their opinions, expertise, and turns in a conversation were acknowledged as powerful and valued. They discussed the difference between using AAC and being an AAC user, and said that this project flipped the usual communication power dynamic, making the AAC user the expert and the person to be listened to. For many, this was one of the only times when this power dynamic existed, creating a new sense of AAC agency.

Valuing the messages of AAC users. With this project, the thoughts shared by AAC users were the most valued contributions of each meeting and interaction. Many AAC users expressed that their typical experiences when interacting with people who relied on speech were unsatisfying, and they felt like the creation of messages interfered with or created a barrier to the flow of conversation. The culture created in this project was



just the opposite: the messages shared in ways other than speech were the most important component of the conversation. According to Consortium members, these experiences created confidence and empowerment with communication, leading to meaningful participation and actions.

Moving forward. Future activities for this project are being discussed. Options include identifying future funding opportunities from ACL/AoD to support the proposed recommendations, moving to a volunteer-based USSAAC project, and using WITH Foundation or PCORI funds to elevate AAC users. Consortium members self-identified whether they would like to continue participating and implementing the proposed recommendations (Appendix B4).



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Appendix A: Consortium Membership Roles and Expectations

Consortium Membership
Roles and Expectations
AAC Peer Support Project
June, 2024

We invite you to participate on the **AAC Peer Support Consortium**, a national group of AAC users, representatives from disability organizations, underrepresented communities, private-practice service providers to self-advocacy and other independent living organizations, from law centers and AAC manufacturers to university programs. We take this opportunity to present different roles and expectations so that you understand the commitment that you are making to join the Consortium.

1. This project is funded from February to October, 2024.
2. We expect about 50 people/organizations to participate.
3. Members may join until July 1, 2024, at which time we plan to close entry.
4. The Consortium will meet virtually, every month, for 1-2 hours, from March through October.
5. Workgroups will meet from May through September, 2024 to complete tasks.
6. Everyone will get paid for their participation- we will send you, via email, a digital Amazon card for \$50/meeting. Compensation for your participation is voluntary.
7. You will be acknowledged for your participation in the final report and in any document that you have contributed significantly to during the project, unless you want your participation to remain anonymous.
8. You may choose a representative from your organization to accompany you or replace you, as needed.

ROLES with expected timeline and potential time commitments per month:

Consortium Role	Description	Expected timeline	Expected time commitment
Receive Consortium updates only	Receive monthly updates on activities and accomplishments [Note: This role does not include participant gift cards]	about 10 minutes/month	March through October
Consortium observer	Attend the monthly discussions and peer support model presentations only	about 1 hour/month	March through October

Consortium reviewer	Join the Consortium for the review of the final recommendations for a national plan of AAC Peer Support	about 2 hours/month	September-October
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Consortium workgroup member	Participate in one or more of the 5 workgroups. Work plan will be formed by the members who participate [Note: compensation for additional work done outside of meetings also]	about 4-6 hours/month	March through October
Consortium workgroup leader	Along with a steering committee member, you will take the lead of convening the workgroup, setting schedules and goals, and implementing tasks to meet a specified timeline [Note: compensation for additional work done outside of meetings also]	about 5-7 hours/month	March through October

WORKGROUPS and Expected Outcomes:

Workgroup Description	Outcome
(1) Identify peer support models within the AAC field	List and description of current or past AAC peer support models
(2) Identify peer support models outside the AAC field	List and description of current or past peer support models outside AAC field
(3) What are we evaluating? Determine characteristics of peer support models that we will evaluate and include in our recommendations for a national AAC peer support model	List and description of variables we should use to evaluate peer support models
(4) Present your peer support model, activities, strategies to the Consortium	Presentation to group during meetings

(5) Develop strategies for inclusion of diversity and underrepresented communities in models and recommendations	List of strategies to ensure and increase inclusion of diversity and underrepresented communities in models and recommendations
(6) Systematic review	Literature search for peers support models within and outside AAC

EXPECTATIONS FOR WORKGROUPS:

1. A person from the core leadership group will be a member of each workgroup
2. Each workgroup will include between 4-8 people
2. There will be different ways to contribute, based on the group goals, your expertise, experience, and skills
3. 70% attendance at workgroup meetings
4. Completion of assignments based on a timeline
5. Timely communication with core leadership team (including steering committee) as well as workgroup members
6. Compensation for your work with \$50 Amazon digital cards at each meeting, or at the discretion of the project coordinator, if you so chose.

Any questions? Please email Sarah Fjeldstad, Project Coordinator at fjeldsta@ohsu.edu

We look forward to making an impact with you!

Appendix B1: National Partnership Consortium Roster

The AAC Peer Support Project Established a Partnership Consortium With Significant Representation of:

People who use AAC

- **Bob Williams** (CommunicationFIRST)
- **enderver* corbin**
- **Jan Staehely** (Community Research Liaison, OHSU)
- **Jordyn Zimmerman, M.Ed, MB** (CommunicationFIRST)
- **Lateef McLeod** (CommunicationFIRST; ISAAC; OHSU UCEDD)
- **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)

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, AT Lab (Community Vision AT Lab)

Bold = Core Leadership

Bold & Italicized = Steering Committee

- 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, AT Lab (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)

Bold = Core Leadership

Bold & Italicized = Steering Committee

- 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) friedm@ohsu.edu
- **Emily Quinn, Ph.D.** (OHSU) quinnem@ohsu.edu
- 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) friedm@ohsu.edu
- **Emily Quinn, Ph.D.** (OHSU) quinnem@ohsu.edu
- **Tracy Rackensperger, Ph.D.** (Public Service Faculty, Institute on Human Development and Disability, University of Georgia) trackens@uga.edu
- 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)

Bold = Core Leadership

Bold & Italicized = Steering Committee

- 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)

Bold = Core Leadership

Bold & Italicized = Steering Committee

Appendix B2: Consortium Members Who Use AAC

- Bob Williams (CommunicationFIRST)
- endeavor* corbin
- Jan Staehely (Community Research Liaison, OHSU)
- Jordyn Zimmerman, M.Ed, MB (CommunicationFIRST)
- Lateef McLeod (CommunicationFIRST; ISAAC; OHSU UCEDD)
- 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)

Appendix B3: Consortium Member Roles

<u>Steering Committee</u>

- Lateef McLeod
- Jordyn Zimmerman
- Tracy Rackensperger

<u>Workgroups</u>

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

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 Jacob
 - Samuel Sennott
 - Thanh My Diep
-

Workgroup 4: Presentations to the Consortium

Leadership/steering committee co-leader: endeavor* 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

<u>Observers</u>

-
- Chloe Rothschild
 - Esther Klang
 - jorja harper t schall
 - Sophie Korpics
 - Tawara Goode
 - Teresa Moore
 - Tyson Renze

<u>Monthly Updates Only</u>

- Allison Cohen Hall
- Chris Klein
- David Niemeijer
- Robert Groenendaal
- Tori Gilbert
- Vicki Casella

<u>Reviewer</u>

- Chris Klein
- Darrius Frazier
- Donnie Denome
- Grant Blasko
- Jill Tullman
- Kirk Behnke
- Mary Sowers
- Michael Fondacaro
- Morgan Whitlatch
- Noelle Birky
- Rachel Acevedo
- Tamara Bakewell
- Tracy Rackensperger
- Vicki Casella

Appendix B4: Future Partners in Implementation

Consortium members self-identified that they would like to continue participating and implementing the proposed recommendations.

Adrianna Noyes
Alyssa Zisk
Amy Goldman
Amy Hanreddy
Amy Szarkowski
Bob Williams
Darrius Frazier
Gloria Soto
Jan Staehely
Jenn Seale
Jill Tullman
Jordyn Zimmerman
jorja t harper schall
Kevin Williams
Kirk Behnke
Lateef McLeod
Linda Akagi
Lisa Bardach
Mateo Moreno
Maura Silverman
Michael Fondacaro
Morgan Whitlatch
Otto Lana
Patrick Regan
Rachel Acevedo
Sam Sennott
Terri Wofford
Thanh My Diep
Tina Moreno
Tori Gilbert
Tracy Rackensperger

Appendix C1: Schedule of Consortium and Steering Committee meetings

Consortium Meetings:

April 5, 2024

May 22, 2024

June 26, 2024

July 24, 2024

August 28, 2024

September 25, 2024

November 13, 2024

December 11, 2024

January 8, 2025

February 12, 2025

March 12, 2025

Steering Committee Meetings:

March 25, 2024

June 28, 2024

- ❖ After June 2024, the Steering Committee worked together asynchronously through email. On the dates below, the Steering Committee convened AAC User meetings to discuss and come to consensus on topics raised in the project.

July 15, 2024

July 23, 2024

August 21, 2024

January 14, 2025

January 22, 2025

February 26, 2025

Appendix C2: Slide Presentations for Consortium meetings

Consortium Orientation Meeting
April 5, 2024
AGENDA

Topic	Description
Log in	Log in time and getting settled; please check if anyone needs help, especially with meeting accessibility
Welcome	Thanks for joining us!
Project summary	What is this project about? Funder, goals. We have a short work period (9 months) which we view as a beginning to a multi-year and impactful project
AAC definitions	What is AAC? Who is an AAC user? Who needs AAC?
Peer supports definitions	Different ways that peer support has been thought of
Core team introductions	Introducing Tauna Szymanski, Bob Williams, Melanie Fried-Oken, Janice Staehely, Rachel Benson, Larissa Yoshino, Jordyn Zimmerman, Lateef McLeod, Holly Hohmeister and endever* corbin
Consortium introductions	Who is present? Please state your name and organization.
Work group expectations	Introducing the 7 workgroups for the AAC Peer Support Project: our expectations and your suggestions; timeline. Payment: You will receive a digital Amazon card through email for each meeting.
Additional members to join?	Who else should join the Consortium? We will be sending an email to get your suggestions.
Next steps	Our success so far and where we are going.
Closing	This is just our first meeting- an orientation meeting to share who we are and what the project is. Expect emails from us. Thank you, we are looking forward to working together.

A national partnership to develop an approach and plan to advance peer-support models for people who use or need augmentative and alternative communication (AAC)

Consortium Orientation Meeting
April 5, 2024



Settling In

If you need help,

- Email Larissa at yoshino@ohsu.edu
- Or use the CHAT window

Accessibility considerations

- For information about meeting controls, please reference the Zoom document emailed ahead of this meeting
- We will be reading the CHAT aloud for the recording, please let us know in your chat message if you **do not** want it read out loud
- Let us know anytime during the meeting if you have any access needs
- ASL translation is available in real time

WELCOME
Thanks for joining us!

Project summary

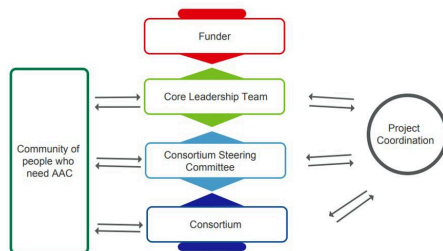
Our goal: To advance the use of peer support models for people who use or need Augmentative and Alternative Communication (AAC) through the creation of a nationwide, comprehensive, consensus-based approach. We hope to answer:

1. What peer supports exist for AAC users now?
2. What peer support models exist outside the field of AAC that may be applicable to AAC?
3. Can we create a nationwide resource for developing peer support models for people who use or need AAC?

Partnerships

- Our federal funder: Administration for Community Living (ACL)
- Our contractual partner: The Association for University Centers on Disabilities (AUCD)
- Our community partners: YOU

Governance Structure Flow Chart



What will we do in this 9-month contract?

1. Conduct a survey of AAC users and peer supports
2. Present different peer support models and discuss their outcomes
3. Conduct a systematic literature review
4. Identify barriers and opportunities, with attention to multiply marginalized communities
5. Adapt models, approaches and activities for AAC advancement
6. Build consensus on initial findings and recommendations
7. Draft a final report on our findings and recommendations for a national plan

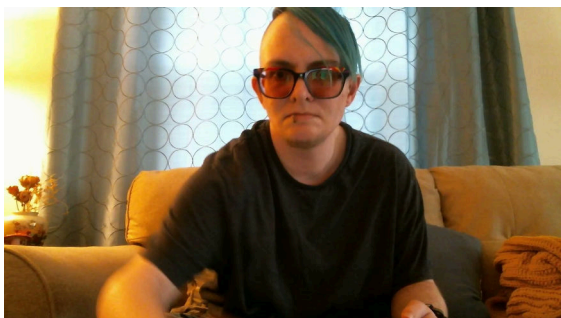
Start with definitions

- What is AAC?
- Who is an AAC user?
- Who needs AAC?

- What are peer supports?
- What are the different ways that peer supports have been thought of?

Introducing the Core Leadership Team

- CommunicationFIRST
- The OHSU UCEDD
- AUCD
- The Steering Committee



The Consortium

- Who is present?
- Please state your name and organization
- We will be sending you an email asking for your experience with peer supports soon

Workgroups

- (1) Identify peer support models within the AAC field;
- (2) Identify peer support models outside the AAC field;
- (3) Examine outcomes and reactions from people who had peer support;
- (4) What are we evaluating? Determine characteristics of peer support models that we will evaluate and include in our recommendations for a national AAC peer support model;
- (5) Conduct a systematic review of the literature around peer supports;
- (6) Present your peer support model, activities, strategies to the Consortium;
- (7) Develop strategies for inclusion of diversity and underrepresented communities in models and recommendations

Who should join the Consortium?

- You wrote letters of support for our proposal or expressed interest once we were awarded the contract.
- We want to add others, especially multiply marginalized AAC users, who can contribute significantly to the creation of the nationwide resource for developing peer support models for people who use or need AAC.
- We will send out an email asking for your recommendations that will include Consortium expectations, our timeline and payment options.

Next Steps

1. Continue to collect data from AAC and peer supports survey until July 1.
2. Work with Consortium members to
 - a. Understand your expectations for participation
 - b. Develop workgroups and goals
 - c. Invite additional people to the Consortium
 - d. Establish easy digital payment method
3. Share our timeline and work plan
4. Schedule monthly Consortium meetings

Thank you

- For joining the Consortium Orientation meeting
- Sharing your expectations and recommendations in an upcoming email
- Completing a poll about workgroup membership and your role in this project
- Recommending peers for future meetings and workgroups
- Hanging in there with us as we develop a national plan for AAC peer supports.

Consortium Meeting

May 22, 2024

AGENDA

[LINK](#) to slides

WHO	Topic	Text	Minutes
LARISSA	Log in	Login time and getting settled; please check if anyone needs help, especially with accessibility issues	5
MFO	Welcome to all	Thanks for joining us	1
e*c	Welcome new Consortium members	We have had one Consortium meeting so far. Let's welcome our new members who have joined since the last meeting. <ul style="list-style-type: none"> - Would new members like to introduce yourselves (name, pronouns, affiliation)? 	10
mfo	Goals today	<ul style="list-style-type: none"> - A review of the project and goals for those who could not join us for our first meeting - Review the workgroup assignments and tasks - A presentation of a peer support model from a Consortium member - An overview of what you can expect next 	4
mfo	Review of the project	<ul style="list-style-type: none"> - Review of project summary - Review of project goals 	2
Rachel	Survey preview	<ul style="list-style-type: none"> - 100+ responses to our survey to learn about experiences with peer support; have until July 1 	4
mfo	Workgroup and roles, tasks and timelines	<ul style="list-style-type: none"> - Review of Consortium Membership Roles and Expectations - Review of the workgroup assignments, including co-leaders - If you have not selected a workgroup and want to join one, please email Sarah Fjeldstad (fjeldsta@ohsu.edu) - The workgroups will work together on their assigned tasks, led by the co-leaders, now through September 2024. 	8
Kevin Williams	Peer Support presentation	Presentation on an AAC peer support model: Kevin Williams	15
MFO	Next steps	<ul style="list-style-type: none"> - An email thread was started with each workgroup. We will provide a framework with potential outcomes to each group. - Your workgroup will need to decide when to meet, what tasks to complete, by whom. - Co-leaders should start planning their work and schedule their first meeting by June 1. Co-leaders, please follow up with your workgroup. - Please be sure to include Sarah Fjeldstad in your workgroup's email communications so we can track progress and ensure you're compensated for your work. - If you/your workgroup needs any assistance contact Sarah 	2
JAN	Who else needs to join?	<ul style="list-style-type: none"> - Who else should join and contribute to the Consortium? This is our final call for new members. We'll give you a month to respond. We are closing membership on July 1. - We are still running a survey and inviting emailed descriptions of current and past Peer Support experiences until July 1 to help us learn what AAC users have experienced with peer supports. 	2

		<ul style="list-style-type: none"> - Please continue sharing the survey links and information emailed previously, we will send them out again after this meeting. 	
SF	What you can expect	<ul style="list-style-type: none"> - You'll continue receiving emails from me now - A recording of this meeting will be sent out with information and links to the surveys you can share - The monthly full Consortium meetings will be held the fourth wednesday of the month from 12p-1pm (west coast) 3pm-4pm (east coast). - Compensation for your participation will be provided as you requested in the Consortium Roles and Workgroup survey you completed. If you need to change how you receive your gift card or email communications, or if you did not complete the survey and want to be compensated, please email Sarah Fjeldstad 	2
SF	Closing	<p>Thank you</p> <ul style="list-style-type: none"> ● For joining the Consortium meeting ● Sharing your input and expertise ● Recommending peers for meetings and workgroups ● Joining as we develop a national plan for AAC peer supports 	1

Settling In

If you need help,

- Email Project Coordinator Sarah at fieldsta@ohsu.edu
- Or use the CHAT window

Accessibility considerations

- For information about meeting controls, please refer to the Zoom document emailed before this meeting and instructions linked in the chat
- We will be reading the chat aloud for the recording, please let us know in your chat message if you **do not** want it read out loud
- Let us know anytime during the meeting if you have any access needs
- ASL translation and closed captions are available

AAC Peer Support Project:

A national partnership to develop an approach and plan to advance peer-support models for people who use or need augmentative and alternative communication (AAC)



Consortium Meeting
May 22, 2024



WELCOME

Thanks for joining us!

This is our second meeting. Welcome to Consortium members who joined since our last meeting!

- Would new members like to introduce yourself to the group?
 - Please share your name, pronouns, affiliation

Goals of this meeting:

1. Review project summary and goals for those who could not join us for our first meeting
2. Summary of AAC user survey results
3. Workgroup assignments and tasks
4. Presentation of a peer support model from a Consortium member
5. What to expect next

AAC Peer Support Project summary

Our goal: To advance the use of peer support models for people who use or need Augmentative and Alternative Communication (AAC) through the creation of a nationwide, comprehensive, consensus-based approach. We hope to answer:

1. What peer supports exist for AAC users now?
2. What peer support models exist outside the field of AAC that may be applicable to AAC?
3. Can we create a nationwide resource for developing peer support models for people who use or need AAC?

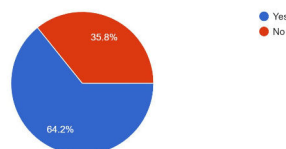
What will we do?

1. Conduct a survey of AAC users and peer supports
2. Present different peer support models and discuss their outcomes
3. Conduct a systematic literature review
4. Identify barriers and opportunities, with attention to multiply marginalized communities
5. Adapt models, approaches and activities for AAC advancement
6. Build consensus on initial findings and recommendations
7. Draft a final report on our findings and recommendations for a national plan

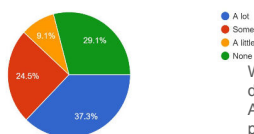
What we have accomplished so far:

- 100+ survey responses to learn about AAC users' peer support experiences

1. Have other AAC users helped you develop AAC skills?
120 responses



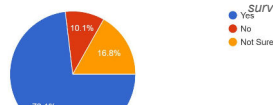
2. If so, how much have other AAC users helped you use or develop your skills in using AAC?
110 responses



We received over 100 written descriptions about what kind of AAC support and mentorship people have received, and what kind of support they want.

We still welcome more responses, the survey link will be shared again

3. Would you like more mentoring from other AAC users?
119 responses



Consortium Membership
Roles and Expectations
AAC Peer Support Project
April, 2024

We invite you to participate on the **AAC Peer Support Consortium**, a national group of AAC users, representatives from disability organizations, underrepresented communities, private-practice service providers to self-advocacy and other independent living organizations, from law centers and AAC manufacturers to university programs. We take this opportunity to present different roles and expectations so that you understand the commitment that you are making to join the Consortium.

1. This project is funded from February to October, 2024.
2. We expect about 50 people/organizations to participate.
3. Members may join until July 1, 2024, at which time we plan to close entry.
4. The Consortium will meet virtually, every month, for 1-2 hours, from March through October.
5. Workgroups will meet from May through September, 2024 to complete tasks.
6. Everyone will get paid for their participation- we will send you, via email, a digital Amazon card for \$50/meeting. Compensation for your participation is voluntary.
7. You will be acknowledged for your participation in the final report and in any document that you have contributed significantly to during the project, unless you want your participation to remain anonymous.
8. You may choose a representative from your organization to accompany you or replace you, as needed.

ROLES with expected timeline and potential time commitments per month:

Consortium Role	Description	Expected time commitment	Expected timeline
Receive Consortium updates only	Receive monthly updates on activities and accomplishments [Note: This role does not include participant gift cards]	about 10 minutes/month	March through October
Consortium observer	Attend the monthly discussions and peer support model presentations only	about 1 hour/month	March through October
Consortium reviewer	Join the Consortium for the review of the final recommendations for a national plan of AAC Peer Support	about 2 hours/month	September-October
Consortium workgroup member	Participate in one or more of the 5 workgroups. Work plan will be formed by the members who participate [Note: compensation for additional work done outside of meetings also]	about 4-6 hours/month	March through October
Consortium workgroup leader	Along with a steering committee member, you will take the lead of convening the workgroup, setting schedules and goals, and implementing tasks to meet a specified timeline [Note: compensation for additional work done outside of meetings also]	about 5-7 hours/month	March through October

WORKGROUPS and Expected Outcomes:

Workgroup Description	Outcome
(1) Identify peer support models within the AAC field	List and description of current or past AAC peer support models
(2) Identify peer support models outside the AAC field	List and description of current or past peer support models outside AAC field
(3) What are we evaluating? Determine characteristics of peer support models that we will evaluate and include in our recommendations for a national AAC peer support model	List and description of variables we should use to evaluate peer support models
(4) Present your peer support model, activities, strategies to the Consortium	Presentation to group during meetings
(5) Develop strategies for inclusion of diversity and underrepresented communities in models and recommendations	List of strategies to ensure and increase inclusion of diversity and underrepresented communities in models and recommendations

EXPECTATIONS FOR WORKGROUPS:

1. A person from the core leadership group will be a member of each workgroup
2. Each workgroup will include between 4-8 people
3. There will be different ways to contribute, based on the group goals, your expertise, experience, and skills
4. 70% attendance at workgroup meetings
5. Completion of assignments based on a timeline
6. Timely communication with core leadership team (including steering committee) as well as workgroup members
7. Compensation for your work with \$50 Amazon digital cards at each meeting, or at the discretion of the project coordinator, if you so chose.

Workgroup assignments

1. **Identify peer support models within the AAC field**
 - **Co-leaders:** Lateef McLeod, Melanie Fried-Oken
 - **Members:** Jill Tullman, Becky Reese, Rick Reese, Tina Moreno, Mateo Moreno, Terri Wofford, Michael Fondacaro, Jan Staehely
2. **Identify peer support models outside the AAC field**
 - **Co-leaders:** Jordyn Zimmerman, Amy Goldman
 - **Members:** Maura Silverman, Allie Tasche, Samuel Sennott
3. **What are we evaluating? Determine characteristics of peer support models that we will evaluate and include in our recommendations**
 - **Co-leaders:** Bob Williams, Bre Mercier, Jennifer Seale
 - **Members:** Tracy Rackensperger, Lewis Golinker, Otto Lana, Noelle Birky, Samuel Sennott, Rachel Jacob, Lisa Bardach, Morgan Whitlatch, Grant Blasko, Patrick Regan

Workgroup assignments

4. **Present peer support model, activities, strategies to the Consortium:**
 - **Co-leaders:** endeavor* corbin, Jill Tullman
 - **Members:** Kirk Behnke, Lewis Golinker, Tamara Bakewell, Patrick Regan, Samuel Sennott
6. **Develop strategies for inclusion of diversity and underrepresented communities in models and recommendations**
 - **Co-leaders:** tbd
 - **Members:** Tracy Rackensperger, Otto Lana, Kevin Williams, Gloria Soto, Anastasia Wilson, Morgan Whitlatch, Grant Blasko

- The workgroups will work together on their assigned tasks, led by the co-leaders, now through September 2024.
- If you have not selected a workgroup and want to join one, please email Sarah Fjeldstad (fjeldsta@ohsu.edu)

Presentation: by Kevin Williams ISAAC PWUAAC Chat



Next Steps:

- An email thread was started with each workgroup. We will provide a framework to each group.
- Your workgroup needs to decide when to meet, what tasks to complete, by whom. Co-leaders should start planning their work and schedule their first workgroup meeting by June 1st.
- Include Sarah Fjeldstad in your workgroup's email communications so we can track progress and ensure you're compensated.
- If you/your workgroup needs any help - literature search, document creation, meeting set up, translation services - contact Sarah

Who else needs to join?

- Final call to add new members to the Consortium. We will close membership on July 1.
- Survey and email descriptions of experiences with peer support until July 1
- Please share the links and information emailed previously, and email Sarah Fjeldstad (fjeldsta@ohsu.edu) if any help is needed

What you can expect:

- You'll continue receiving emails from Project Coordinator Sarah Fjeldstad, please email fjeldsta@ohsu.edu with any questions.
- A recording of this meeting will be shared with Consortium members
- The monthly full Consortium Meetings will be the **4th Wednesday of each month from 12pm-1pm (west coast) 3pm-4pm (east coast)**
- Compensation will be provided as you requested in the Consortium Roles and Workgroup survey. If you need to change this, or you haven't completed the survey, please email Sarah.

Thank you!

- For joining the Consortium meeting
- Sharing your input and expertise
- Recommending peers for meetings and workgroups
- Joining as we develop a national plan to advance AAC peer supports.

AAC Peer Support Project - National Partnership Consortium Meeting AGENDA

June 26, 2024

[LINK](#) to meeting slides
[LINK](#) to Zoom meeting participant guide

WHO	Topic	Text	Minutes
LARISSA	Log in	Login time and getting settled; please check if anyone needs help, especially with accessibility issues	5
Jan	Welcome,	This is our third meeting. Welcome to Consortium members who have joined since our last meeting!	1
SF	what will we do today?	<ul style="list-style-type: none"> • Hear from each Workgroup about what they have accomplished and discussed so far • Learn from a presentation on peer supports from Consortium workgroup members • Share AAC user survey results and plans to share with others • Review next steps and what you can expect 	1
MFO	GROUP EFFORT AND SHARING: Workgroup updates	<p>Each group will discuss what they have been working on so far (2-5 mins each)</p> <ul style="list-style-type: none"> - Workgroup 1: Kirk Benhke - Workgroup 2: Amy Goldman - Workgroup 3: Jennifer Seale - Workgroup 4: Sarah Fjeldstad - Workgroup 5: Sarah Fjeldstad - Workgroup 6: Emily Quinn 	15
Workgroup 4	Peer Support presentation	<p>As we enter summer, let's hear about AAC summer camp peer experiences</p> <ul style="list-style-type: none"> • Jill Tullman and endever* corbin - introductions • Patrick Regan - share workgroup discussion • Kirk Behnke- show the models template, review Camp Chatterbox and introduce the video 	15
Rachel	Survey preview	We ran a survey to learn about experiences with peer support; presenting results	4
LARISSA	AUCD conference	<p>We submitted 2 abstracts to AUCD based on data from the initial AAC peer support survey (closing 7/1)</p> <p>AUGMENTATIVE AND ALTERNATIVE COMMUNICATION (AAC) USERS REPORT ON THE PEER SUPPORT EXPERIENCES THAT HELPED THEM LEARN AAC</p> <p>AUGMENTATIVE AND ALTERNATIVE COMMUNICATION (AAC) USERS REPORT ON TOOLS AND TECHNIQUES THEY RELY ON FOR COMMUNICATION</p>	1
JS	Last call	The Consortium will close to new members on July 1st.	1

		<p>The survey about AAC Peer Support experiences will also close July 1st. If you haven't filled it out yet, please do. If you know someone who should fill it out, please share the link: https://forms.gle/aD4h4wtKBDfmy6fA7 shared in the chat</p> <p>Please feel free to share information about the project that was emailed to you previously. Email Sarah Fjeldstad (fjeldsta@ohsu.edu) if any help is needed</p>	
Sarah	Next steps	<ul style="list-style-type: none"> - Workgroups will continue to meet through October 2024 - Include Sarah in your communications and meetings so we can track progress and ensure you are compensated - Email Sarah if you need any assistance or have ideas, questions, etc 	2
SF	What you can expect next	<ul style="list-style-type: none"> - A recording of this meeting will be shared with Consortium members in their shared folders. - The monthly full Consortium Meetings will continue to be the 4th Wednesday of each month from 12pm-1pm (west coast) 3pm-4pm (east coast). A recurring google calendar invitation was sent. The zoom link we are on today will be the same for all Consortium meetings. - Compensation will be provided as you requested in the Consortium Roles and Workgroup survey. If you need to change this, or you haven't completed the survey, please email Sarah. - There will be an anonymous survey at the end of this meeting. 	2
mfo	Closing	<p>Sharing USSAAC article https://ussaac.org/speakup/articles/aac-peer-support-models/</p> <p>THANK YOU</p> <ul style="list-style-type: none"> - For joining the Consortium meeting - Sharing your input and expertise with your workgroups and the full Consortium - Joining as we develop a national plan to advance AAC peer supports. 	1

Settling In

If you need help,

- Email Project Coordinator Sarah at fieldsta@ohsu.edu
- Or use the CHAT window

Accessibility considerations

- ASL translation, captions, and live transcription are available.
- For information about meeting controls, please refer to the Zoom meeting participant guide emailed before this meeting and instructions in the chat.
- We will be reading the chat aloud for the recording, please let us know in your chat message if you **do not** want it read out loud
- Let us know anytime during the meeting if you have any access needs

AAC Peer Support Project:

A national partnership to develop an approach and plan to advance peer-support models for people who use or need augmentative and alternative communication (AAC)



Consortium Meeting
June 26, 2024



WELCOME

Thank you for joining us!

Recording of
Jan Staehely

Goals of this meeting:

1. Hear from each Workgroup about what they have accomplished and discussed so far
2. Learn from a presentation on peer supports from Consortium workgroup members
3. Share AAC user survey results and plans to share with others
4. Review next steps and what you can expect

Workgroups: Share what you have worked on so far

Workgroup 1: Identify peer support models within the AAC field

- Kirk Behnke

- Learning from Lateef McLeod's dissertation presentation on AAC Peer Supports
- **Workgroup goal:** Recording AAC Peer Support models, activities, approaches, strategies (see *next slide*)

Workgroup 1

MODELS TEMPLATE For Workgroup 1: Peer support models, approaches, strategies inside the AAC field			
Name of model	Camp AAC	Who are the peers?	Children who have AAC needs, parents/guardians who use AAC, teachers, paraprofessionals, and family members
Reference and/or name of group member	Parents' input	Implementation location	Online, CO (remotely) and in-person (locally) at home
What is the context/setting?	COOP: recreation and education	How is it funded? Is funding sustainable?	Funding: Parents' input, grants, and donations. COOP: a fee for service, but the fee is waived for families who are unable to pay.
What is the activity?	Parents' input: meeting format (online + in-person) + campers spend 10 days in therapy activities and 10 days in traditional summer camp activities. The camp format provides structure and support.		
What is the context/setting?	An environment where learning takes place in a safe space, where potential is promoted and campers feel encouraged and supported during their time.		
What is the expected outcome?	Increased independence, functional, improved literacy, educational outcomes, fun.		
How are barriers and opportunities addressed? (What are the challenges or barriers? What are the opportunities or strengths? What are the recommendations?)			
Name of model	Camp Challenge	Who are the peers?	Campers, parents, siblings, care providers, teachers, therapists, SLPs and parents
Reference and/or name of group member	Dr. Katherine Tappin-Vanderka	Implementation location	Both in-person and online
What is the context/setting?	COOP: all levels, all ages, all abilities. Focuses on campers' input, support groups for siblings, and community of parents.	How is it funded? Is funding sustainable?	
What is the activity?	Facilitation: peer talks, parent/care provider educational sessions, recreational activities, free time, lunch announcements, and activities announcements.		
What is the context/setting?	A place where AAC users are not talked to, but encouraged to speak.		
What is the expected outcome?	Building friends, providing use of their communication systems and related with other children and adults, fun.		
How are barriers and opportunities addressed? (What are the challenges or barriers? What are the opportunities or strengths? What are the recommendations?)			

Workgroups: Share what you have worked on so far

Workgroup 2: Identify peer support models outside the AAC field

- Amy Goldman

Workgroups: Share what you have worked on so far

Workgroup 3: What are we evaluating? Determine characteristics of peer support models that we will evaluate and include in our recommendations

- Jennifer Seale

Workgroups: Share what you have worked on so far

Workgroup 4: Present peer support model, activities, strategies to the Consortium

- This workgroup will introduce themselves and their work later on in this meeting and share a presentation

Workgroups: Share what you have worked on so far

Workgroup 5: Develop strategies for inclusion of diversity and underrepresented communities

- Get ready Workgroup 5 members! This group first meeting is tomorrow 6/27/2024. Their work will be vital to ensure inclusion and diversity in the work of the other workgroups and in the final recommendations

Workgroups: Share what you have worked on so far

Workgroup 6: Systematic Review/Meta-Analysis

- Initial Search Strategy Created : [Search Strategy](#)
- Operational Definitions: [Spreadsheet](#)
- Inclusion/ Exclusion Criteria Drafted: [Eligibility Criteria](#)
- Data Collection Form : [Participant Characteristics](#)
- Data Collection Form: [Program Characteristics](#)
- Meeting with other groups to get feedback on drafts.

Workgroup 4: Presentations

- Jill Tullman & endeavor* corbin: Introducing the workgroup and goals
- Patrick Regan: Sharing work done so far, discussions, and plans for future work
- Kirk Benhke: Share the models template and video (next slides)

Workgroup 4: Presentation - Models Template									
Name of model	Reference and/or name of group member	Location	Who are the peers? Include as many characteristics as applicable	What is the format? Include the frequency it takes place.	How is it funded? Is funding assistance available?	What is the context/ environment/ setting?	What is the activity?	What is the expected outcome?	Are there any barriers to participation? Are there opportunities to increase participation?
Camp Chatterbox	Kirk Behnke Katherine Tappin Verdessa	Northern NJ	Campers, parents, siblings, care providers, mentors, counselors, SLPs and guests	CAMP one week, overnight, recreation, therapy sessions for campers, support groups for siblings, and workshops for parents		A place where AAC users are not rushed to talk, but encouraged to speak	Socialization, peer talks, parents/ care providers educational sessions, recreational activities, free time, lunch announcement is, night activity showcasing what the campers did that day	Making friends, promote use of their communication systems and interact with other children and adults, fun	



AAC Peer Support Experiences

We ran a survey to learn about AAC users' peer support experiences and what forms of AAC they use. We received more than 130 responses, here are some results

4. Please tell us either what kind of support or mentorship from AAC users you have gotten, and/or what kinds of support you would like to have from other AAC users.

Some responses:

- To let me know I am doing well and they also struggle at times; to show me what is possible as my skills improve.
- There is a very helpful discussion group on Facebook I follow where there are discussions about devices, scenarios, and real-life situations people deal with that are very helpful for processing, practicing, and learning how to manage some situations of my own.
- Not much at all and all through school I wanted to be in an AAC group but no one communicated me like
- Advice on pre-programmed/pre-written phrases and what phrases to include to express needs
- I have received every day practical information from AAC users like how to navigate relationships with doctors or loved ones, and also I received a sense of normalcy that I'm not struggling to do things by myself. Sharing information to support each other, as mentorship is never a one way street, gives encouragement that the methods used to augment my communication doesn't define the capability of the individual.

AUCD conference

November 3, 2024 - Wednesday, November 6, 2024 in Washington DC

AUCD = Association of University Centers on Disabilities

We submitted 2 abstracts to AUCD based on data from the AAC peer support survey:

- AUGMENTATIVE AND ALTERNATIVE COMMUNICATION (AAC) USERS REPORT ON THE PEER SUPPORT EXPERIENCES THAT HELPED THEM LEARN AAC
- AUGMENTATIVE AND ALTERNATIVE COMMUNICATION (AAC) USERS REPORT ON TOOLS AND TECHNIQUES THEY RELY ON FOR COMMUNICATION

Last Call

Jan Staehely

- The Consortium will close to new members on July 1st
- AAC Peer Support Survey also closes on July 1st (link in chat)
- Please share the project information and email Sarah (fjeldsta@ohsu.edu) if any help is needed

Next Steps:

- Workgroups will continue to work together through October 2024 to meet the goals for your workgroup
 - Workgroup co-leaders were given access to all workgroup folders, and can share with their groups and support each other
- Include Sarah in your workgroup's email communications so we can track progress and ensure you're compensated.
- If you/your workgroup needs any help - literature search, document creation, meeting set up, translation services, issues with google - contact Sarah

What you can expect next:

- A recording of this meeting will be shared with Consortium members in their shared folders
- The monthly full Consortium Meetings will continue to be the **4th Wednesday of each month from 12pm-1pm (west coast) 3pm-4pm (east coast)**.
The zoom link we are on today will be the same for all Consortium meetings
- Compensation will be provided as you requested in the Consortium Roles and Workgroup survey. If you need to change this, or you haven't completed the survey, please email Sarah.
- There will be an anonymous survey at the end of this meeting.

USSAAC SpeakUp article

Fresh off the press just today!

AAC Peer Support Models

You can view it from this link :

<https://ussaac.org/speakup/articles/aac-peer-support-models/>



Thank you!

- For joining the Consortium meeting
- Sharing your input and expertise with your workgroups and the full Consortium
- Joining as we develop a national plan to advance AAC peer supports.

AAC Peer Support Project - National Partnership Consortium Meeting AGENDA

July 24, 2024

12pm-1:30 (Pacific) / 3pm-4:30 (Eastern) (1 ½ hours)

Zoom meeting link: <https://us06web.zoom.us/j/81047697493>

- [LINK](#) to meeting slides
- [LINK](#) to Zoom meeting participant guide
- [LINK](#) to meeting survey

WHO	Topic	Text	Minutes	
LY	Log in (slide 1)	Login time; check in if anyone needs help, especially with accessibility issues	5	30 minutes 12-12:30pm
JS	Welcome! (slide 2)	Welcome to the 4th Consortium meeting of the AAC Peer Support project.	1	
JS	What will we do today? (slide 3)	<p>Consortium meetings are not intended to be working meetings. We hope to use this time to learn and report back on our progress and plans with the full Consortium</p> <p>In this meeting we will:</p> <ol style="list-style-type: none"> 1. Review the project goals, timeline, and progress so far 2. Hear a report from the project Steering Committee 3. Hear reports from the project Workgroups 4. Learn from a presentation on peer support 5. Review next steps in the project 	1	
MFO	Review of project goals, timeline, and progress so far (slide 4) (slide 5 & 6) (slide 7)	<p>Our goal: To advance peer support models for people who use or need AAC. We are exploring:</p> <ol style="list-style-type: none"> 1. What peer supports exist for AAC users now? 2. What peer supports exist outside of the AAC field that may apply to AAC users? 3. Can we create a nationwide resource for developing peer support models for people who use or need AAC? <ul style="list-style-type: none"> • Review of forms for recording peer support models • Please note: August 16 is soft stop for adding to Models form. Core leadership is happy to meet 1:1 to fill out the form with committee members. <p>Review of timeline, funder, leadership, consortium membership, workgroup, and steering committee tasks</p>	5	

BW	Steering Committee update (slide 8-11)	<p>We're honored to have Jordyn Zimmerman, Lateef McLeod, and Tracy Rackensperger serve as our steering committee</p> <p>The role of the Steering Committee is:</p> <ol style="list-style-type: none"> 1. To ensure that AAC users are integrally involved in the work this project is doing. 2. To review the products and deliverables from each workgroup and the national plan. <p>The Steering Committee will share a report about their work</p>	15	
TS	<p>Workgroup updates</p> <p>Slide 12</p> <p>Slide 13</p> <p>Slide 14-17</p> <p>Slide 18</p> <p>Slide 19</p> <p>Slide 20</p>	<p>Each group will report what they have been working on so far, discussions they want to share, or questions they have. (2-5 mins each) If you are comfortable, please also share how long it took to prepare your presentation.</p> <ul style="list-style-type: none"> • Workgroup 6 (Systematic Review / Metanalysis): Amy Hanreddy (3:44-3:48) • Workgroup 1 (Existing Peer Support Models Within the AAC Field): Michael Fondacaro (3:57-3:58) • Workgroup 2 (Existing Peer Support Models Outside the AAC Field): Sam Sennott (3:58-4:03) • Workgroup 3 (What Are We Evaluating?): Bob Williams and Jenn Seale (4:03-4:07) • Workgroup 4 (Present Your Own Models, Activities, Strategies): Jill Tullman (4:08-4:10) • Workgroup 5 (Strategies for Inclusion of Underrepresented Communities): Kevin Williams and Bob Williams (4:10-4:12) 	30	<p>30 minutes</p> <p>12:30 -1pm</p>
SF	<p>Peer Support presentation</p> <p>(slide 21)</p> <p>(slide 22)</p>	<ul style="list-style-type: none"> • Workgroup 4 <ul style="list-style-type: none"> ○ Patrick Regan: Bridging Communities Through Alternative Communication (BCTAC) **** held until August meeting **** ○ Lateef McLeod recorded presentation 	25	
SF	<p>Next steps, what you can expect</p> <p>(slide 23)</p> <p>(slide 24)</p>	<ul style="list-style-type: none"> • Workgroups will continue to meet to accomplish their goals through the end of September 2024. • We ask that the forms are filled out with your peer support models by August 16th. Core leadership will be in contact to assist members to fill it out. • If you need any help, email Project Coordinator Sarah Fjeldstad fjeldsta@ohsu.edu google form 	2	<p>30 minutes</p> <p>1 -1:30pm</p>

		<ul style="list-style-type: none"> • Consortium meetings will continue to be the 4th Wednesday of the month. Meetings will now be 1 ½ hours to allow for more input. Agendas will be broken into 30 minute sections as much as possible. • There will be an anonymous survey at the end of this meeting. Please share your feedback so we can improve our meetings. 		
JS	Closing (slide 26)	<p>THANK YOU</p> <ul style="list-style-type: none"> • For joining the Consortium meeting • Sharing your input and expertise with your workgroups and the full Consortium • Joining as we develop a national plan to advance AAC peer support. 	1	

Let's review the project goals, timeline, and progress so far

- This is a 9 month project.
- The project is funded through the Administration for Community Living (ACL) and Association for University Centers on Disabilities (AUCD)
- The University Center for Excellence in Developmental Disabilities at Oregon Health and Science University (OHSU UCEDD) and CommunicationFIRST are the project leadership team.
- We expect to have final recommendations for a national plan to advance AAC peer support in December 2024.
- We have formed a Consortium of 50+ experts in peer supports and AAC from across the country. 38% of Consortium members are AAC users.
- Consortium members have formed 6 workgroups that have specific tasks. They'll work together through October 2024 to contribute to the final plan. Workgroups are co-led by an AAC user and either a member of the core leadership or Steering Committee.

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Steering Committee

Tracy Rackensperger, Lateef McLeod, and Jordyn Zimmerman

The role of the Steering Committee is:

To ensure that AAC users are integrally involved in the work this project is doing.

To review the products and deliverables from each workgroup and the national plan.

8

Work of the Committee

We met with AAC users to find out:

- What's going well?
- What's not working?
- What's confusing or needs clarified?
- How are the working group meetings going? Are the meetings long enough or are they too long?
- Do we understand peer support or do we need to create a universal definition? (I'm personally seeing some confusion / overlap with mentorship, so curious if others are too)
- What do people need from us?
- Is everyone clear with the goals of the consortium?
- Are there qualities of AAC peer support we are missing in our evaluation?

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Feedback

Positives:

- Good meetings
- User participation
- Virtual verses in-person meetings make things more accessible

Barriers / Things Needing Improving:

- Academic jargon
- Focus on scholarly research verses lived experience
- Practical outcomes verses another academic funded project
- Peer support definition is vague
- Information-sharing

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How Can We (the Consortium) Address Issues?

How can we better balance the emphasis on scholarly research with the inclusion and value of lived experiences of AAC users in our project?

What specific steps can we take to simplify our language and reduce the use of academic jargon to make our meetings and materials more accessible to all participants? Maybe plain language handouts?

In what ways can we ensure that the outcomes of our project are practical and directly beneficial to AAC users, rather than just academic exercises?

How can we develop a clear and universally understood definition of peer support within the context of our consortium to eliminate confusion and overlap with mentorship?

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Workgroups: Share what you have worked on so far

Workgroup 6: Systematic Review/Meta-Analysis of literature and peer support models

- Amy Hanreddy

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Workgroups: Share what you have worked on so far

Workgroup 1: Identify peer support models within the AAC field

- Michael Fondacaro

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Workgroup 2: Identify Peer Support Models, Projects, Approaches, and Activities **outside** the AAC Field

The goals of this workgroup are to:

1. Identify current peer-to-peer **models, projects, approaches, activities**, outside the AAC field
2. Identify **barriers and opportunities** within the models/approaches or activities that should be considered for national recommendations.
3. Identify whether peer support models for AAC device users can be developed, and, **if those peer support models will help more people use AAC devices**

Contribute to a list of resources and information to inform and develop a proposed approach and plan to advance AAC Peer Support



Product (October)

A list of Peer Support **models, projects, approaches, activities** outside the AAC field, with recommendations for which features to include in the national plan to advance AAC peer support.

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Subset of sources **outside** of AAC

Areas to Consider	Example	Insights
Rehabilitation (Stroke)	Aphasia support groups	Amazing read here.
Cancer	SEND IT Foundation	Support from people with lived experience.
Education	Peer tutoring	
Parenting	Birth classes, La Leche League, Parent support groups	
LGBTQ+	PDX Queer Resource Center + Q Center	Q Center Groups

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Subset of sources **outside** of AAC

Areas to Consider	Example	Insights
Addiction	AA	https://www.aa.org/what-is-aa
PTSD	Veterans and Peer Support	Nice read from the VA.
Parent-to-Parent Programs	Oregon Family-to-Family Health Information Center	To speak to an OR F2F HIC Parent Partner Call...
Autism	Autistic Self Advocacy Network (ASAN)	Check out the affiliate groups.
Independent Living Centers	Local PDX Peer Support Groups	Bob Williams has been sharing about this.

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Members

Sarah Fjeldstad	Project Coordinator	OHSU
Jordyn Zimmerman	Co-Lead	Communication First
Amy Goldman	Co-Lead	USSAAC
Tamara Bakewell	Member	Oregon Family to Family Health Information Center
Maura Silverman	Member	National Aphasia Association
Sam Sennott	Member	Portland State Universal Design Lab
Allie Tasche	Member	Autism Society of America
Jill Jacobs	Member	National Association of Councils on Developmental Disabilities

17

Workgroups: Share what you have worked on so far

Workgroup 3: What are we evaluating? Determine characteristics of peer support models that we will evaluate and include in our recommendations

- Bob Williams and Jenn Seale

18

Workgroups: Share what you have worked on so far

Workgroup 4: Present peer support model, activities, strategies to the Consortium

- Jill Tullman

19

Workgroups: Share what you have worked on so far

Workgroup 5: Develop strategies for inclusion of diversity and underrepresented communities

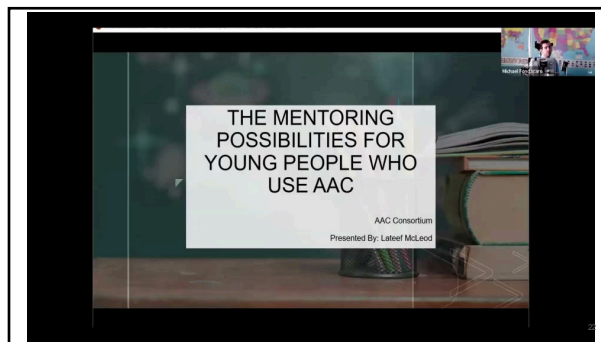
- Bob Williams and Kevin Williams

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Workgroup 4: Presentation of a Peer Support model

- Patrick Regan, Bridging Communities Through Alternative Communication (BCTAC)

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Next Steps for workgroups:

- Workgroups will continue to work together through September 2024 to meet the goals for your workgroup
 - Workgroup co-leaders were given access to all workgroup shared google folders, and can share with their groups and support each other
 - We ask that the forms are filled out with your peer support models by August 16th. Core leadership will be in contact to assist members to fill it out.
- If you or your workgroup needs any help - literature search, document creation, meeting set up, translation services, issues with google - contact Sarah

23

What you can expect next

- Consortium meetings will continue to be the **4th Wednesday of the month**. Meetings will now be **1 ½ hours** to allow for more input. Agendas will be broken into 30 minute sections as much as possible.
- A recording of this meeting will be shared with Consortium members in their shared google folders
- There will be an anonymous survey at the end of this meeting

24

Summary of today's meeting

- We reviewed the project goals and timeline
- We learned how the Steering Committee will ensure AAC users are integral to the project
- We learned what workgroups have discussed, what they have accomplished, and their plans for next steps
- We learned about a peer support model
- We reviewed the next steps for workgroups

25

Thank you!

- For joining the Consortium meeting
- Sharing your input and expertise with your workgroups and the full Consortium
- Joining as we develop a national plan to advance AAC peer supports.

26

AAC Peer Support Project - National Partnership Consortium Meeting AGENDA

August 28, 2024

12pm-1:30 (Pacific) / 3pm-4:30 (Eastern) (1 ½ hours)

Zoom meeting link: <https://us06web.zoom.us/j/81047697493>

- [LINK](#) to meeting slides
- [LINK](#) to Zoom meeting participant guide
- [LINK](#) to the meeting survey - tell us how this meeting went for you!

WHO	Topic	Text	Minutes	
RB	Log in <i>Slide 1</i>	Login time.	5	30 minutes 12-12:30p m
JS	Welcome! What will we do today? <i>Slide 2, 3</i>	Welcome to the 5th Consortium meeting of the AAC Peer Support project. In this meeting we will: <ul style="list-style-type: none"> 1. Learn from a report on the survey about AAC user experiences with peer support 2. Learn from a report on the peer support models shared by the consortium 3. Learn from a presentation on organic peer support 4. Have a group discussion about defining peer support with a Word Cloud activity 	1	
EQ	AAC user survey report <i>Slide 4, 5</i>	Report on a survey about AAC user experiences with peer support Share your feedback with Emily: quinnem@ohsu.edu	2	
SF	Peer Support models <i>Slide 6, 7</i>	The consortium described peer support models in a google survey; here is what we learned so far Please continue adding at this link: https://forms.gle/ZJg1GKdr6yjWAvjE8	2	
SF intro- ducing	Peer Support presentation <i>Slide 8 to introduce only</i>	Workgroup 4 co-leader Patrick Regan, with Tyson Renze and Thanh My Diep: Bridging Communities Through Alternative Communication (BCTAC) <ul style="list-style-type: none"> • Questions from the Consortium 	20	
MFO & BW	Defining peer support	Following up on the questions posed by the Steering Committee at the July Consortium meeting, we need to define peer support . <ul style="list-style-type: none"> • Introduction from Bob Williams - <i>Slide 9</i> • W List of basic values for peer supports.docx - <i>Slide 10</i> • Peer Support Tree - <i>Slide 11</i> • Word Cloud activity. Link to add keywords for peer support: www.menti.com/ala5az57k286 - <i>Slide 12 and Menti presentation</i> • Group discussion - <i>Slide 13 to introduce the prompts only</i> 	60	1 hour 12:30-1:30

JS	Closing Slide 14	<p>THANK YOU</p> <ul style="list-style-type: none"> • For joining the Consortium meeting • Sharing your input and expertise with your workgroups and the full Consortium • Joining as we develop a national plan to advance AAC peer supports. • See you in September! 	1	
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WELCOME

Thank you for joining us!

If you need help at any time in the meeting, email Project Coordinator Sarah at fjeldsta@ohsu.edu or use the CHAT window

- ASL interpretation video, captions, and live transcription are available using the controls on your Zoom meeting screen
- There is a Zoom meeting participant guide linked in the google meeting invitation. This will also be shared in the chat.
- The agenda will be shared in the chat.
- We will be reading the chat aloud for the recording, please let us know in your chat message if you **do not** want it read out loud.

1

AAC Peer Support Project:

A national partnership to develop an approach and plan to advance peer-support models for people who use or need augmentative and alternative communication (AAC)



Consortium Meeting
August 28th, 2024



2

Today we will:

1. Learn from a report on the survey about AAC user experiences with peer support
2. Learn from a report on the peer support models shared by the consortium
3. Learn from a presentation on organic peer support
4. Have a group discussion about defining peer support with a Word Cloud activity

3

Survey about AAC user experiences with peer support

Question 4: Please tell us either what kind of support or mentorship from AAC users you have gotten, and/or what kinds of support you would like to have from other AAC users.

4

Discussion Topics / Focus Areas for Peer Support

Gaining skills with AAC or Information about AAC	"Guidance on using symbol based apps, navigating cost barriers, decided on which app is most helpful to purchase."
Acquiring and training direct support staff	"How to train staff as communication support and how to find funding for that staff."
Navigating college	"I would like more support from other AAC users on how to navigate the college environment, how to explore work possibilities and how to expand my social network."
Transportation and Mobility	"I am no longer able to get to library bc I began using a power wheelchair 10 months ago. Too heavy and large to transport in cars. I need AT now more than ever..."
Practicing Real World Skills	"How to use devices successfully in various settings out in the community."

5

You recorded 59 Peer Support Models!

There are a wide variety of programs and activities, with many different activities.

Who do the peer support models support?

Focused on AAC users: 36	Not focused on AAC users: 23
Focused on adults: 41	Focused on children/young adults: 22

6

Where Does Peer Support Take Place?

Online - 26

regional: 8

national: 15

international: 3

In person - 35

East coast: 9

South: 6

Midwest: 5

West coast: 10

various locations nationwide: 5

7

Workgroup 4: Presentation of a Peer Support model

- Patrick Regan, Bridging Communities Through Alternative Communication (BCTAC)

8

Defining Peer Support

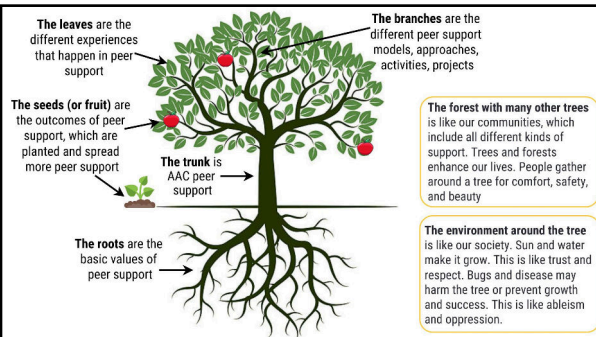
Introduction by Bob Williams

9

Peer Support: Basic values

- 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, our community, spelling it out, and taking action

10



Peer Support WordCloud - 235 keywords entered so far

How to add words to the Word Cloud:

- You can add new words or the same words to make them bigger.
- Unmute yourself and say them
- Type into the meeting chat, or send a private chat to Sarah
- Email Sarah: fjeldsta@ohsu.edu
- Type into the WordCloud: www.menti.com/ala5az57k286

A web page will open that asks "When you think of peer support, what keywords come to mind?" There is a box that says "Enter a word" and you can type up to 25 letters. Then, click the blue button that says "Submit."

After you click "Submit," the text box will be empty and you can type in more words.

⇒ [LINK to open the word cloud presentation](#)

12

Discussion

1. What are the key characteristics that we should include in our definition of Peer Support?
2. What are some outcomes that we should consider in our definition?
3. What are the most important points that should define an AAC Peer Support model?

13

Thank you!

- For joining the Consortium meeting
- Sharing your input and expertise with your workgroups and the full Consortium
- Joining as we develop a national plan to advance AAC peer supports.
- *See you in September!*

14


AAC Peer Support Project - National Partnership Consortium Meeting AGENDA

September 25, 2024

12pm-1:30 (Pacific) / 3pm-4:30 (Eastern) (1 ½ hours)

Zoom meeting link: <https://us06web.zoom.us/j/81047697493>

- [LINK](#) to meeting slides
- [LINK](#) to Zoom meeting participant guide
- [LINK](#) to the meeting survey - tell us how this meeting went for you!

WHO	Topic	Text	Minutes
LY	Log in	Login time.	5
JS	Welcome! What will we do today?	<ul style="list-style-type: none"> • Hear about future plans for the Consortium and project • Hear from each workgroup about their progress • Learn from a presentation on how we know a peer support model is successful • Review and discuss definitions of peer support 	2
MFO	Where do we go from here?	<ul style="list-style-type: none"> • Please join us at AUCD, ATIA, and ISAAC conferences • Sharing future plans for the Consortium and project 	30
TS	Workgroup progress	<ul style="list-style-type: none"> • Report from each workgroup on what they have done so far (1-2 minutes each) <ul style="list-style-type: none"> ○ Workgroup 1: Michael Fondacaro ○ Workgroup 2: Sam Sennott ○ Workgroup 3: Bob Williams ○ Workgroup 4: Jill Tullman ○ Workgroup 5: Kevin Williams ○ Workgroup 6: Emily Quinn 	10-15
Jill Tullman	Workgroup 4 Presentation	<ul style="list-style-type: none"> • Defining <i>success</i> in a peer support model. 	20
LMc MFO	Discussion	<ul style="list-style-type: none"> • We've been working as a consortium to define Peer Support, using last meeting's word cloud results, the list of core values, and the peer support tree  Defining Peer Support <ul style="list-style-type: none"> ○ Presenting definitions of peer support written by each workgroup ○ Discussion: Where are we going? What comes next? What do Consortium members want this project to do in the next year? 	30

JS	Closing	<p>THANK YOU</p> <ul style="list-style-type: none">● For joining the Consortium meeting● Sharing your input and expertise with your workgroups and the full Consortium● Joining as we develop a national plan to advance AAC peer supports	1
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Doc 30

WELCOME

Thank you for joining us!

If you need help at any time in the meeting, email Rachel Benson bensonra@ohsu.edu or use the CHAT window

- ASL interpretation video, captions, and live transcription are available using the controls on your Zoom meeting screen
- There is a Zoom meeting participant guide linked in the google meeting invitation. This will also be shared in the chat.
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1

AAC Peer Support Project:

A national partnership to develop an approach and plan to advance peer-support models for people who use or need augmentative and alternative communication (AAC)



Consortium Meeting
September 25th, 2024



2

What will we do today?

- Hear about future plans for the Consortium and project
- Hear from each workgroup about their progress
- Learn from a presentation on how we know a peer support model is successful
- Review and discuss definitions of peer support

3

Join us at these conferences - links for more info in chat

- **AUCD** - Association of University Centers on Disabilities
 - November 3-6 2024 - Washington, D.C. (2 posters on Monday afternoon, November 4.
 - **ISAAC** - International Society for Augmentative and Alternative Communication
 - October 29-30 2024 - Virtual
 - **ATIA** - Assistive Technology Industry Association
 - January 30, 2025 (3-4:30pm) - Orlando, FL
- Lateef McLeod and Tracy Rackensperger will present at ATIA. If you can attend, Kirk Behnke will take a Consortium photo of all of us!

4

Workgroups: Share what you have accomplished so far

Workgroup 1: Identify peer support models within the AAC field

- Michael Fondacaro

5

Workgroups: Share what you have accomplished so far

Workgroup 2: Identify peer support models outside the AAC field

- Sam Sennott

6

Workgroups: Share what you have accomplished so far

Workgroup 3: Determine characteristics of peer support models that we will evaluate and include in our recommendations

- Bob Williams

7

Workgroups: Share what you have accomplished so far

Workgroup 4: Present peer support model, activities, strategies to the Consortium

- Jill Tullman

8

Workgroups: Share what you have accomplished so far

Workgroup 5: Develop strategies for inclusion of diversity and underrepresented communities

- Kevin Williams

9

Workgroups: Share what you have accomplished so far

Workgroup 6: Systematic Review/Meta-Analysis

- Emily Quinn

10

Workgroup 4 Presentation

How do we define success in a peer support model?

We sent out a survey to the consortium and asked this:

A peer support experience is successful when...

11

Respondents who have multiple roles to AAC

- Two respondents use AAC and are researchers
- One respondent uses AAC and mentors a child who uses AAC
- One respondent uses AAC, is a researcher and a service provider or professional
- One respondent uses AAC, is a family member/supporter of AAC, a researcher and a service provider or professional

Individuals who use AAC

- 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.
- There's mutual respect, shared experience, and growth.
- My peer support is huge because I totally need my friends who 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.
- Outcomes and measurable goals are met.

Individuals who use AAC continued

- 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.

Individuals who use AAC continued

- Everyone is on the same page.
- 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.
- They are competent.
- 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.

Family members or supporters of AAC

- The members are engaged with each other, supporting each other in communicating and continue to attend sessions, groups or meetings.
- Members feel a belongingness, heard and understood.
- You feel you were heard.
- The person who initiated the peer support comes away feeling like "that was a great use of my time!". Our Family to Family Health Information Center in Oregon has a 'look back' form to help us gauge whether or not our peer support was successful. It reads: "Look back after each call you have with another parent. Do they: 1) have new information or ideas? 2) have a new resource to try? 3) have increased confidence around the problem or reason they called? 4) feel better by just connecting with you? and 5) your contact information and an invitation to call back anytime?"

Researchers

- Both partners benefit and are able to make progress towards their goals for the experience.
- You feel part of a group where you can share and not be judged, listen and learn from others, and form lasting relationships that matter.
- Outcomes and measurable goals are met.
- Everyone is on the same page.
- 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.

Service Providers or Professionals

- Members feel a belongingness, heard and understood.
- Everyone is on the same page.
- There is continued desire to participate.
- People who use AAC get connected with someone who shares their lived experience, and develops an ongoing trusted relationship.
- You feel you were heard.

Service Providers or Professionals continued

- Outcomes and measurable goals are met.
- Success means creating a space where individuals using AAC feel empowered, heard, and supported by those who share similar experiences. It involves fostering a community where AAC users can express themselves freely, exchange knowledge, and build confidence in their communication methods. Successful peer support allows for collaboration, reciprocity, mutual emotional support, resource sharing, shared advocacy and open non judgmental communication. A peer support experience is successful when all involved feel empowered, valued, and supported in expressing themselves, learning from each other, and building meaningful connections that enhance their communication abilities, personal well-being and ability to engage with their chosen communities.

Mentor children who use AAC

- Is so amazing important and I need that support!!!

Family peer support professional

- Our Family to Family Health Information Center in Oregon has a 'look back' form to help us gauge whether or not our peer support was successful. It reads: "Look back after each call you have with another parent. Do they: 1) have new information or ideas? 2) have a new resource to try? 3) have increased confidence around the problem or reason they called? 4) feel better by just connecting with you? and 5) your contact information and an invitation to call back anytime?"

How did we share existing successful peer support models

- List of peer support models
- Presentations in Consortium meetings; Patrick Regan and BCTAC, Camp Chatterbox, Lateef's dissertation, Kevin's ISAAC PWUAAC
- Survey responses and quotes from consortium members

22

How do we define Peer Support?

Let's review definitions written by each workgroup

Workgroup 1:

AAC Peer support is a gathering of people in a safe place to speak their mind, who help and learn from each other. It consists of sharing positive and negative experiences, ideas, activities, and frustrations in order to manage difficulties in life, and find validation of all feelings and in all ways to communicate. AAC peer support can build trust, friendship, a sense of belonging, pride, and forming of a shared identity.

23

How do we define Peer Support?

Workgroup 2:

- Jordyn: Peer support is shared understanding and experience that consists of some type of reciprocity in order to grow
- Amy: Peer support is a flexible set of actions or activities that consist of reciprocal relationships based on lived experience, in order to provide connections, support, and growth
- Jill: Peer support is an invaluable part of life that consists of interactions with others that have some sort of common interest or common history in order to progress in our personal experience
- Sam: Peer support is fun and meaningful activities in order to set the stage for making friends and connections

24

How do we define Peer Support?

Workgroup 3:

Peer support is grounded in the idea of a safe place to achieve connection, collaboration and reciprocity where mentorship is fluid and authentic which cultivates an atmosphere of interdependence, empowerment and social justice. Peer support empowers AAC users to create a safe space where the foundation of shared lived experiences leads to collaboration. Peer support leads to both greater interdependence and independence.

Trust and respect (respecting each other, all communication, different views and experiences, etc.) are critical to a successful peer support group. With trust and respect, group members will share openly. A successful peer support group will foster trust and respect leading to open and honest sharing. Trust and respect are imperative to the success of peer support writ large.

25

How do we define Peer Support?

Workgroup 4:

Peer support at its foundation is built on trust and respect, and some of its key elements include healthy relationships, honest sharing, love, community, empowerment, and the goals the peers have.

Sam: AAC peer support is a state where people who use AAC are connected to others who share lived experience that consists of a variety of meaningful activities, such as group social experiences, one-to-one consultation and can be more structured or organic in order to create a reciprocally beneficial impact.

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How do we define Peer Support?

Workgroup 5:

Peer support for AAC users is a community where individuals connected through similar characteristics (and their support staff) come together to deepen connection through a discourse of shared experiences meant to create trust, transparency and reciprocity. *Peer support empowers the lived experience of all in the group, regardless of mode, method or expertise of AAC tools used.*

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How do we define Peer Support?

Workgroup 6:

Peer support models leverage the power of reciprocal community support and honest sharing. In peer support, people who have a shared non-professional connection* to the area of support mentor and guide each other to reach the goals *they* each have (not the ones other people maybe think they should have.)

*Professional connections are fine as long as the non-professional connection exists too -- people can have multiple relationships to an area.

28

Discussion

- Defining peer support: were we successful?
- What have you learned in this project so far?

We will continue these discussions in our workgroup meetings and full consortium meetings

29

Plans for the AAC Peer Support Project and Consortium

- Where are we going? What comes next?

Discussion:

- What do Consortium members want this project to do in the next year?

30

Thank you!

- For joining the Consortium meeting
- Sharing your input and expertise with your workgroups and the full Consortium
- Joining as we develop a national plan to advance AAC peer supports
- See you next month!

31

AAC Peer Support Project - National Partnership Consortium Meeting AGENDA

November 13, 2024

12pm-1:30 (Pacific) / 3pm-4:30 (Eastern) (1 ½ hours)

Zoom meeting link: <https://us06web.zoom.us/j/81047697493>

- Link to the [Meeting Slides](#).
- Link to the [Zoom Meeting Participant Guide](#).
- Link to the [Meeting Survey](#) - tell us how this meeting went for you!

WHO	Topic	Text	Minutes/Time (PT)
LY	Log in	Login time.	5 minutes 12-12:05
JS	Welcome!	What will we do today? <ul style="list-style-type: none"> • Provide an update on the project • Report back on how we are sharing the work of the consortium • Share feedback from Consortium member • Learn from a presentation about organic peer support activities and discuss them as a group. • Our next meeting will be on Wednesday, December 11 before this coming holiday season. Workgroup 5 will lead a discussion on DEIA. 	3 minutes 12:05-12:08
mfo	Project update	Where we are now, and what comes next	5 minutes 12:08-12:13
SF TR LY	Sharing our work	We're presenting the project at conferences and events.	10 minutes 12:13-12:23
SF	Survey results	Consortium and Workgroup members respond to surveys after meetings. We'll review some of their feedback and how we responded.	10 minutes 12:23-12:33
ec JT LMc PR	Presentation	Organic peer support Group discussion, opportunities for feedback and participation	12:33-1:30
JS	Closing	THANK YOU <ul style="list-style-type: none"> • For joining the Consortium meeting • Sharing your input and expertise with your workgroups and the full Consortium • Joining as we develop a national plan to advance AAC peer supports • Please remember to complete the short survey after this meeting • We will see you on Wednesday December 11 	1 minute

WELCOME

Thank you for joining us!

If you need help at any time in the meeting, email Sarah Fjeldstad fjeldsta@ohsu.edu or use the CHAT window

- ASL interpretation video, captions, and transcription are available using the controls on your Zoom meeting screen
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1

AAC Peer Support Project:

A national partnership to develop an approach and plan to advance peer-support models for people who use or need augmentative and alternative communication (AAC)



Consortium Meeting
November 13, 2024



2

What will we do today?

- Provide an update on the project.
- Report back on how we are sharing the work of the consortium.
- Share feedback from Consortium members.
- Learn from a presentation about organic peer support. We will have a group discussion.

3

What have we done, and what comes next with the AAC Peer Support project?

The project received a six month extension through March 31st, 2025. We will continue meeting in workgroups and as a consortium.

We're sharing our work at conferences and will soon have webpages.

We take your feedback to improve the project and our meetings. We will continue to learn and grow as we work together toward our goal.

4

Update on AAC Peer Support Survey

We ran a survey on two topics:

- 1) What kind of peer support AAC users had experienced, and what kind of peer support they wanted
- 2) The tools and methods they use to communicate

We're presenting the results of the survey and the whole project at conferences.

5

Project background - How we got started

The University Center for Excellence in Developmental Disabilities (UCEDD) at OHsu, in partnership with Communication FIRST, was awarded a contract from AAC to develop recommendations for a national plan for Augmentative and Alternative Communication (AAC) Peer Support.

A survey was sent to AAC users to gather data about their personal peer support experiences. These data, not often sought from AAC users, will inform future recommendations.

This is the largest national survey to gather data about AAC peer support experiences. The results formed the foundation for the AAC Peer Support Consortium, a national group of AAC users, disability organizations, providers, and researchers who meet monthly to develop the recommendations for a national plan.

Survey process - What we did

The AAC Peer Support survey was distributed nationally through social media, disability organizations, providers, and AAC manufacturers.

It was made available to users in many formats, including a Google survey form, Microsoft Word form, or individual assistance from Peer Support Project team members.

The survey asked four questions:

1. How often did you use peer support to develop AAC skills?
2. How often did you use peer support to learn more about AAC?
3. What kind of support or mentorship from other AAC users have you gotten?
4. What kind of support would you like to have from other AAC users?

Survey results - What we learned

What kind of support or mentorship from AAC users have you gotten?

Gaining information about AAC
"I've been reading a lot of books and articles, watching YouTube videos, and I've found which app is most helpful to purchase."

Acquiring and training direct support staff
"How to train staff as communication support is the most helpful to me."

Navigating college
"I would like more support from the AAC community on how to navigate the college requirements, how to register work, and how to find the right school network."

Transportation and mobility
"I am no longer able to get to therapy because I have a car accident which is 22 months ago. They have a target to target to get me out of my car more."

Practicing real world skills
"How to use a decision-making tool in the community."

Community learning
"How to get support from AAC users in my area? I have the car made to be used on just in general, but I have a lot of resources about to get to it. I have a lot of resources about to get to it. I have a lot of resources about to get to it."

Data show that 66% of AAC users experienced peer support when learning AAC. 46% of those respondents stated they would more peer support from other AAC users.

Of those who did not experience peer support when learning AAC, over 70% stated they would like to receive peer support from other AAC users, or they were unsure.

The peer support experiences that AAC users shared ranged greatly. Many discussed AAC causes. Others said they learned communities on Facebook, Discord, Twitter, or online technical assistance.

Respondents reported that AAC peer supports reduce isolation, normalize their communication, and validate the process, while also preventing troubleshooting of technical challenges on speech generating devices. These data will be presented as part of the recommendations for a national plan.

Conclusion - Why this matters

Most AAC users want peer support. Their support experiences help AAC users in many different ways and takes many different forms. It offers social, emotional, and technical support. This is only a sample of AAC users who could request.

Contact info - Where to learn more

To sign up for email updates about this work, and to view written descriptions of the image, go to our site: www.aacpeer.org

Or use the QR code:

Project background - How we got started

The University Center for Excellence in Developmental Disabilities (UCEDD) at OHSU, in partnership with CommunicationFIRST, was awarded a contract from AACUD to develop a national plan for Assistive and Alternative Communication (AAC) First Supports.

A survey was sent out to identify the tools and techniques that AAC users rely on for expression. This survey did not focus on disability type or health conditions, but rather the functional skills of communication.

This is the first survey to report on a large AAC user base about the tools and techniques that they use.

Survey process - What we did

The AAC First Support survey was distributed nationally through social media, disability organizations, providers, and AAC manufacturers.

It was made available to users in many formats, including a Google survey form, Microsoft Word form, or assistance from Individual/Peer Support Project team members.

Survey respondents answered one question: **Please identify every AAC technique or tool that you use to express yourself. Please check all boxes or type out your response in the OTHER box at the bottom of the list.**

There were 19 options provided in the checklist.

Survey results - What we learned

AAC Users Report the Tools and Techniques They Use to Communicate

AAC Users Rely on Multiple Forms of Communication

Over 120 AAC users completed the survey. The data shows that each person relies on multiple forms of expression.

Conclusion - Why this matters

A multi-modal model of communication is supported by these data, indicating that no one can just use one way to express themselves.

Contact info - Where to learn more

To sign up for email updates about this work, and to see written descriptions of the data, go to our site: <https://www.consortiumoffirst.org>

Or scan the QR code

Email: qa@consortiumoffirst.org or info@consortiumoffirst.org

This work was supported by a subgrant from AACUD, funded by the Administration for Community Living.

Presentations at conferences

- **AUCD** - Association of University Centers on Disabilities
 - November 3-6 2024 - Washington, D.C.
- **ISAAC** - International Society for Augmentative and Alternative Communication
 - October 29-30 2024 - Virtual
- **ATIA** - Assistive Technology Industry Association
 - January 30, 2025 - Orlando, FL

Lateef McLeod and Tracy Rackensperger will present at ATIA. If you can attend, Kirk Behnke will take a Consortium photo of all of us!

8

Feedback on Consortium meetings

"I'm hoping we create more space for more individuals using AAC to drive the discussions." "[The meeting should be] longer. Allow time for discussion"

- We extended the meetings to 1.5 hours and planned more time for discussion. We worked to prioritize speaking time for AAC users.

"There is a lot of AAC jargon and acronyms being used."

- We worked to use plain language and explain the words and acronyms we are using.

"I am not sure if/how I can be actively participating or if just listening is okay." Others asked for clarity about the agenda and any action steps.

- We state the purpose of the meeting, send the meeting agenda in advance, attached to invitations, shared in chat, and reviewed at the start of meetings.

9

Quotes from our survey after workgroup meetings:

- "So happy to move this agenda forward, taking back our power, we are fully AAC-tivated!"
- "Thank you so much for this platform to share my lived experiences."
- "Great meeting! I like it whenever we work together. As an AAC user, I am gaining many skills in preparing my device with quick, easy-to-access comments that will help me add to the conversation."
- "I look forward to this meeting every week. I learn from my peers, especially those who use AAC. I never lose my excitement for the project when we are together. I hope we can keep this group going after the grant ends."

10

More quotes from workgroup members:

- "This meeting was superb! I love how things evolve through discussion and collaboration. Every time, we make the project better."
- "LOVE having this particular conversation led by AAC users almost exclusively rather than having mostly speakies doing the talking :)"
- "It feels like we have gotten a lot done, and also this is just the beginning of a movement across the U.S. and probably further to open doors for AAC users to get more than language supports."
- "Each week we uncover more layers to the complexity of AAC and AAC users. So blessed to be part of this committee."

11

Feedback from the Consortium

We want your feedback! Please keep filling out the surveys.

The survey will open on your screen, Or
you can use the QR code,
Or you can follow the link: s.zoom.us/j/8ZgtFMjv



If the survey is not accessible or if you prefer, you can email feedback to:

Project Coordinator: fieldsta@ohsu.edu
Steering Committee: trackens@uga.edu

12

November Consortium share-out and conversation

Workgroup 4

Agenda for our presentation/discussion

- Share accessibility reminders
- Discuss the working definition for Organic Peer Support
- Invite feedback and dialogue

Accessibility reminders

- “Lean in” to wait time between comments
 - Look out for individual signals of adding to the conversation
 - Ask if anyone has more thoughts before moving on to the next topic
 - Bring up additional access needs as they arise
- ...what else?

Working definition

Organic peer support refers to informal, naturally occurring support networks 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 formal structure or external organization.

Working definition continued

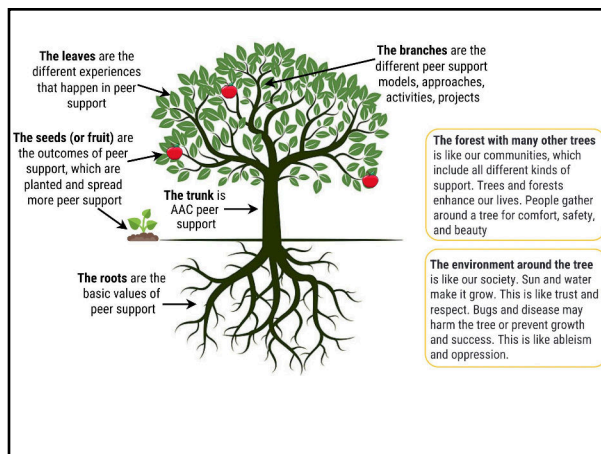
With **organic peer support**, individuals connect with others who share similar experiences, fostering empathy, understanding, trust, self-expression, and mutual aid. This type of support often emerges within communities, social groups, or online forums, where people share common interests, conditions, or life experiences.

Key characteristics of organic peer support

1. **Informal:** No formal power hierarchy [though there may be an administrative structure of some kind, if needed, for ensuring practical tasks are accomplished].
2. **Natural:** Develops spontaneously among people with relateable or shared experiences.
3. **Mutual:** Support is reciprocal, with each person helping one another.
4. **Non-professional:** Support is not provided by trained professionals, but by peers with similar experiences.

How much do you agree with this definition?

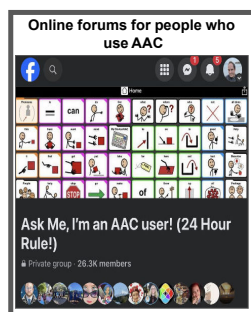
- 1 = Yay, I approve!
- 2 = Meh, I'm not thrilled, but I'll approve.
- 3 = I am not sure, I need more information or discussion.
- 4 = I don't like it, I won't approve it, but I can live with it.
- 5 = I hate this so much that I can't live with it.



Basic values of Peer Support...

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

Examples we have discussed



Related terms

Natural supports
Self-determination
Agency

We want your feedback! Let's have a dialogue.

What is your **main takeaway** about **organic peer supports**?

What **questions** do you have?

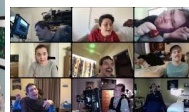
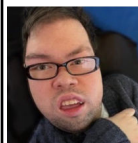
Can you share other examples of **organic peer supports**?

Has this discussion helped improve the consortium definition of Organic Peer Support?

- 1 = Yay, I approve!
- 2 = Meh, I'm not thrilled, but I'll approve.
- 3 = I am not sure, I need more information or discussion.
- 4 = I don't like it, I won't approve it, but I can live with it.
- 5 = I hate this so much that I can't live with it.

example, presented at August full consortium meeting

Patrick Regan, Bridging Communities Through Alternative Communication (BCTAC)



Web meeting

2015 BCTAC Spring Retreat

Examples of organic peer supports

- Online forums for people who use AAC
- Support groups for family members of AAC users (e.g. very local parent groups, or sibling groups)
- Social media groups for people who have the same speech-generating device and/or vocabulary (e.g. Accent with Unity)
- Informal friendships or friend groups based (partially or fully) around shared communication traits

We want your feedback! Let's have a dialogue about *organic peer supports*.

- What is your main takeaway about organic peer support?
- What questions do you have?
- Can you share other examples of organic peer supports?

Thank you!

- For participating in the Consortium meeting
- For sharing your input and expertise with your workgroups and the full Consortium
- For joining as we develop a national plan to advance AAC peer support
- See you next month - December 11th

Please answer our survey about this meeting.

A page will open after you leave the meeting,

You can use the QR code,

Or you can follow this link: s.zoom.us/j/bZlgtFMJv



AAC Peer Support Project - National Partnership Consortium Meeting

AGENDA

December 11, 2024

12pm-1:30 (Pacific) / 3pm-4:30 (Eastern) (1 ½ hours)

Zoom meeting link: <https://us06web.zoom.us/j/81047697493>

- Link to the [Meeting Slides](#) - these will be shown on screen during the meeting
- Link to the [Zoom Meeting Participant Guide](#) - learn how to use the Zoom features
- Link to the [Meeting Survey](#) - tell us how this meeting went for you

WHO	Topic	Text	Minutes/Time (PT)
LY	Log in	Login time.	5 minutes 12:00-12:05
JS	Welcome!	What will we do today? <ul style="list-style-type: none"> • Review accessibility reminders and discussion ground rules that prioritize the voices of AAC users • Present our new web page • Hear from each workgroup about their progress and next steps • Learn about and discuss diversity, equity, inclusion, and accessibility (DEIA) in AAC Peer Support 	2 minutes 12:05-12:07
e*	Review of discussion guidelines	<p>Accessibility Reminders:</p> <ul style="list-style-type: none"> • Lean into pauses to offer the wait time often needed by AAC users to contribute to the conversation. • Pause to ask whether anyone has additional thoughts before switching to new topics. • Look for individual signs that a person might want to contribute to the conversation. • Please let us know about additional access needs as they arise. <p>Discussion ground rules:</p> <ul style="list-style-type: none"> • Fully speaking people will raise their hands and wait to speak until called on by the discussion moderator. • If a discussion goes off topic, or if a speaking person is taking up too much time, the moderator will notify them first by private chat, then verbally. <p>You can let us know how these guidelines work for you in the survey after the meeting. Or you can email Sarah Fjeldstad fjeldsta@ohsu.edu during or after this meeting.</p>	3 minutes 12:07-12:10

SF		<p>Report back from each workgroup on recent progress and next steps. 1-2 minutes each.</p> <ul style="list-style-type: none"> • WG 1: Michael Fondacaro • WG 2: Jordyn Zimmerman • WG 3: <i>We'll hear from workgroup 3 at the January consortium meeting</i> • WG 4: Jill Tullman <ul style="list-style-type: none"> ◦ Preview of planned presentations for January and February consortium meetings: Barriers to organic peer support, and possible solutions to those barriers • WG 5: <i>We'll learn about workgroup 5's progress in today's presentation</i> • WG 6: Emily Quinn; <ul style="list-style-type: none"> ◦ 762 Titles and Abstracts screened by at least 2 participants. ◦ Next Steps: 234 Reports for Full Text Screen (This Week and Next) <ul style="list-style-type: none"> ■ Older adults (General Population) ■ Individuals with Dementia ■ Individuals with Aphasia ■ Individuals with ALS ■ Qualitative Interviews ■ Peer-support, Peer Network, and Peer-Mediated Interventions ◦ Ask follow-up questions (via email) to those who filled out Google Form and the leaders for greater detail on some program components (ex: average participant age, demographics; discussion topics) • Interested in analyzing the results from the Peer Support Survey. Join us: quinnem@ohsu.edu 	<p>10 minutes</p> <p>12:10-12:20</p>
WG 5 BW, BM, OL	Presentation	<ol style="list-style-type: none"> 1. Presentation of definitions of diversity, equity, inclusion, and accessibility (DEIA). 15 minutes (12:30-12:45). Consortium members are invited to add suggestions to this document: WG5'S DEIA Definitions 2. Presentation on barriers and opportunities to DEIA. 15 minutes (12:45-1:00). 3. Consortium discussion on these questions: 30 minutes (1:00-1:30). <ul style="list-style-type: none"> • What should be our next steps? • What is missing from our definitions? • How can we make it more specific to people who need AAC? • Any place where you'd like to see forward movement? 	<p>1 hour</p> <p>12:20-1:20</p>

		<ul style="list-style-type: none"> Do your workgroups have additions to make? <p>We will discuss as a group, and also schedule a follow up listening session in January.</p> <p>You can also share your answers to What are barriers to DEIA in AAC peer support? in a Word Cloud. Link: www.menti.com/alvcx5hkwcj2</p>	
mfo	Web page	<p>We now have a web page, please share it! RAN OUT OF TIME! WE'LL SHARE IN JANUARY</p> <p>www.ohsu.edu/university-center-excellence-development-disability/augmentative-and-alternative-communication-aac</p> <p>bit.ly/AAC_PeerSupportProject</p>	<p>5 minutes</p> <p>1:20-1:25</p>
JS	Closing	<p>THANK YOU</p> <ul style="list-style-type: none"> For joining the Consortium meeting and joining as we develop a national plan to advance AAC peer supports Sharing your input and expertise with your workgroups and the full Consortium We will see you at our next consortium meeting on Wednesday January 8th Please complete the short survey after this meeting 	<p>2 minutes</p> <p>1:25-1:27</p>

WELCOME

Thank you for joining us!

If you need help at any time in the meeting, email Sarah Fjeldstad fjeldsta@ohsu.edu or send a Zoom chat

- ASL interpretation video, captions, and transcription are available using the controls on your Zoom meeting screen
- There is a Zoom meeting participant guide linked in the google meeting invitation. This will also be shared in the chat.
- The agenda will be shared in the chat.
- We will be reading the chat aloud for the recording. If you **do not** want it read out loud, please say so in your chat message.

1

AAC Peer Support Project:

A national partnership to develop an approach and plan to advance peer-support models for people who use or need augmentative and alternative communication (AAC)



Consortium Meeting
December 11, 2024



2

What will we do today?

- Review accessibility reminders and discussion ground rules that prioritize the voices of AAC users
- Present our new web page
- Hear from each workgroup about their progress and next steps
- Learn about and discuss diversity, equity, inclusion, and accessibility (DEIA) in AAC Peer Support

3

Accessibility Reminders:

- Lean into pauses to offer the wait time often needed by AAC users to contribute to the conversation.
- Pause to ask whether anyone has additional thoughts before switching to new topics.
- Look for individual signs that a person might want to contribute to the conversation.
- Please let us know other additional access needs as they arise.

4

Discussion ground rules:

- Fully speaking people will raise their hands and wait to speak until called on by the discussion moderator - Emily Quinn.
- If a discussion goes off topic, or if a speaking person is taking up too much time, the moderator will notify them first by private chat, then aloud.

5

Is there anything we should add or change to these guidelines?

You can tell us how these guidelines work for you in the survey after the meeting.

Or you can send a zoom chat or email to Sarah Fjeldstad fjeldsta@ohsu.edu during or after this meeting.

6

Workgroup 1: Peer support models within the AAC field

- Michael Fondacaro

7

Workgroup 2: Peer support models outside the AAC field

- Jordyn Zimmerman

8

Workgroup 3: Evaluation (Determine characteristics of peer support models we should evaluate)

- We'll learn about their work at the January Consortium meeting

9

Workgroup 4: Presentations of peer support models to the consortium

- Jill Tullman
 - We have expanded and more AAC users have joined
 - Thanks to consortium members who have sent us or the steering committee feedback following our November presentation to the consortium
 - We continues to discuss organic peer support—barriers and solutions
 - Our ongoing dialogue is being shared directly to the leadership team where it is discussed
 - We are working on our January 6th presentation about barriers to organic peer support

10

Workgroup 5: Strategies for inclusion of diversity, equity, inclusion, accessibility (DEIA) in our recommendations for peer support models

- We'll learn about workgroup 5's progress in the next presentation

11

Workgroup 6: Literature review and analysis of peer support models

- Emily Quinn

If you are interested in helping to analyze the survey results, email fjeldsta@ohsu.edu

12

Workgroup 5: Diversity, equity, inclusion, accessibility (DEIA)

Introduction to [Workgroup 5 DEIA Definitions](#)

13

DIVERSITY

Diversity is recognizing the intersectionality between the many seen and unseen characteristics that makes an individual unique. Intersectionality recognizes that a person holds multiple identities, forming an intersectional one that faces unique opportunities and challenges where identities combine.

For example, a multilingual AAC user faces challenges that neither a monolingual AAC user nor a fully speaking multilingual person encounters.

In peer support activities, diversity is used to learn and grow together in order to have a better understanding of the world from perspectives that differ from our own.

14

EQUITY

Equity is the quality of ensuring fair access to opportunities and resources, while taking into consideration circumstances and needs of individuals and the group as a whole.

Assuring equity requires the acknowledgment of the need to make adjustments through thoughtful considerations rather than a general mandate of equality for everyone. This is important as different groups of individuals need different resources and opportunities allocated to them in order to thrive.

Equity also requires honesty and transparency among all members to achieve a feeling of full access. Equity only exists when a real feeling of access is present and not before. In peer support activities, equity enables people to view a situation from a different point of view and create solidarity with people from different circumstances.

15

INCLUSION

Inclusion is a platform for collaborative problem solving and decision making; it fosters empowered participation, respectful treatment, and engaged listening by all members of a conversation.

Inclusion is the actions taken to understand, embrace, and leverage the authentic voice of each individual, which is central to peer support activities.

16

ACCESSIBILITY (part 1)

Accessibility is the process and strategies for identifying and removing the barriers that create disparities in access to resources based on characteristics like disabilities, race, ethnicity, language, gender identity, and socio-economic status.

Technical measures work in tandem with policies to ensure that accessibility includes digital/virtual and face-to-face environments. People often think about the physicality of accessibility like curb cuts and enlarged bathroom stalls. People don't readily think of virtual platforms like Zoom when in-person meetings are not possible for whatever reason. In both digital/virtual and face-to-face environments, the community at large is responsible for environmental access. The environmental aspect of accessibility includes social facilitation efforts from communication-privileged people. Communicating is a shared responsibility, never the sole responsibility of AAC users. Communication is never done completely independently of others because by definition, it is an exchange of ideas between at least two people in an interdependent relationship. Otherwise, so-called "communication" would be a monologue into the void.

17

ACCESSIBILITY (part 2)

Environmental accessibility, while an equally necessary part of accessibility, is not sufficient on its own. Communication accessibility for people who need AAC ensures that people understand what is said or written and can communicate what they want to convey.

When considering accessibility, another thing that people don't readily think of is trained support staff to assist individuals who have higher support needs in order to communicate. Availability of trained support is an accessibility issue since many AAC users need support to access our devices or voice over our messages. Agencies do not think accessibility is their issue to tackle, but the cultural shift toward inclusion necessitates accessibility.

Accessibility is essential in peer support activities.

18

Barriers and opportunities to DEIA

- Otto Lana

19

What are barriers to DEIA?

Share your thoughts in this word cloud:

www.menti.com/alvcx5hkwcj2

Or

Email fjeldsta@ohsu.edu



20

Let's continue this discussion:

- What should be our next steps?
- What is missing from our definitions?
- How can we make it more specific to people who need AAC?
- Any place where you'd like to see forward movement?
- Do your workgroups have additions to make?
- And are there any additional terms we may want to define?

Link to the [DEIA Definitions](#) document

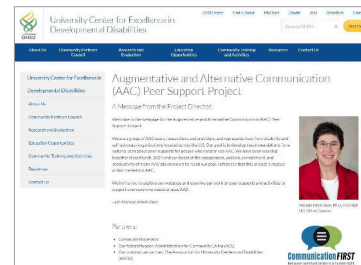
21

The AAC Peer Support Project has a webpage

bit.ly/AAC_PeerSupportProject

The link is added in the chat

Please share it!



22

Thank you!

- For participating in the Consortium meeting and joining as we develop a national plan to advance AAC peer support
- For sharing your input and expertise with your workgroups and the full Consortium
- We'll see you at our next consortium meeting on January 8th

A survey will open after the meeting ends, or you can follow this link: s.zoom.us/j/6P1Wcg2pn

If the survey isn't accessible or you'd rather send an email:

Sarah Fjeldstad, Project Coordinator: fjeldsta@ohsu.edu

Steering Committee: trackens@uga.edu (all links in the chat)

23

AAC Peer Support Project - National Partnership Consortium Meeting

AGENDA


January 8, 2025

12pm-1:30 (Pacific) / 3pm-4:30 (Eastern) (1 ½ hours)

Zoom meeting link: <https://us06web.zoom/j/81047697493>

- Link to the [Meeting Slides](#) - these will be shown on screen during the meeting
- Tell us how this meeting went for you in our [Meeting Survey](#)
- How to use the Zoom functions: [Zoom Meeting Participant Guide](#)

WHO	Topic	Text	Minutes/Time (PT)
LY	Log in	Login time.	5 minutes 12:00-12:05
JS	Welcome!	<p>What will we do today?</p> <ul style="list-style-type: none"> • Review accessibility reminders and discussion ground rules that prioritize the voices of AAC users • Present our new web page • Learn about recommendations for how to evaluate peer support • Learn about and discuss barriers to organic peer support • We welcome Pam O'Brien, our project officer from ACL to the consortium meeting. 	2 minutes 12:05-12:07
e*	Review of discussion guidelines	<p>Accessibility Reminders:</p> <ul style="list-style-type: none"> • Lean into pauses to offer the wait time often needed by AAC users to contribute to the conversation. • Pause to ask whether anyone has additional thoughts before switching to new topics. • Look for individual signs that a person might want to contribute to the conversation. • Please let us know other additional access needs as they arise. <p>Discussion ground rules:</p> <ul style="list-style-type: none"> • We prioritize the voices of AAC users. We will seek AAC user input first. • A 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 them first by private chat, then aloud. We can put these topics in a “parking lot.” 	3 minutes 12:07-12:10

		You can tell us how these guidelines work for you in the survey after the meeting. Or you can email Sarah Fjeldstad fjeldsta@ohsu.edu .	
mfo	Web page	<p>We now have a web page, please share it!</p> <p>Full link: www.ohsu.edu/university-center-excellence-development-disability/augmentative-and-alternative-communication-aac</p> <p>Short URL for social media: bit.ly/AAC_PeerSupportProject</p> <p>Please answer the survey to Give feedback about the webpage (also linked on the page)</p>	<p>5 minutes</p> <p>12:10-12:15</p>
SF	WG 3	Report on progress toward finalizing recommendations for evaluating the effectiveness of peer support.	<p>5 mins</p> <p>12:15-12:20</p>
SF	WG 4 Presentation	<ol style="list-style-type: none"> 1. Review the  Working definition of Organic Peer Support 5 mins 2. Present findings on barriers to organic peer support 3 mins 3. Panel discussion: Barriers to organic peer support 20 mins <ul style="list-style-type: none"> o Attitudinal Barriers: Kevin Williams o Structural Barriers: Michael Fondacaro o Social Barriers: Lateef McLeod o Organizational Barriers: endever* corbin o Technology Barriers: Linda Akagi 4. Consortium group discussion 30 mins <ul style="list-style-type: none"> o Has organic peer support been available to you? o What are barriers to organic peer support? o What gets in the way of getting or giving organic peer support? 5. Next steps: 1 min <ul style="list-style-type: none"> o At the next Consortium meeting on February 12, we will have a group discussion on opportunities to overcome barriers to organic peer support. o We will also send a survey for your input. Link: forms.gle/kyjeYi92y9DXmnr1A or email fjeldsta@ohsu.edu 	<p>1+ hour</p> <p>12:20-1:30</p>
JS	ng	<p>THANK YOU</p> <ul style="list-style-type: none"> • For joining the Consortium meeting and joining as we develop a national plan to advance AAC peer supports • Sharing your input and expertise with your workgroups and the full Consortium • We will see you at our next consortium meeting • Please complete the short survey after this meeting 	<p>1 minute</p> <p>1:30</p>

WELCOME

AAC Peer Support Project

A national partnership to develop an approach and plan to advance peer-support models for people who use or need augmentative and alternative communication (AAC)



AAC Peer Support Consortium Meeting

January 8, 2025

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2

What will we do today?

- Review accessibility reminders and discussion guidelines that prioritize the voices of AAC users
- Present our new web page
- Learn about recommendations for how to evaluate peer support
- Learn about and discuss barriers to organic peer support
- Welcome Pam O'Brien, our project officer from Administration for Community Living (ACL).

3

Accessibility Reminders:

- Lean into pauses to offer the wait time AAC users often need to contribute to the conversation.
- Look for individual signs that a person might want to contribute to the conversation.
- Pause to ask whether anyone has additional thoughts before switching to new topics.
- We will read all chat messages aloud. If you do **not** want yours read out loud, please say so, for example "Don't ROL."
- Please let us know any additional access needs as they arise.

4

Discussion guidelines:

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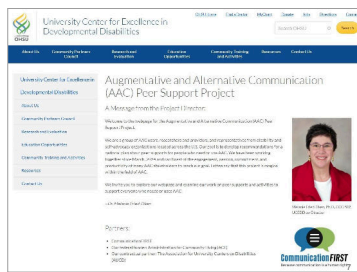
6

The AAC Peer Support Project has a webpage

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The link is in the chat

Please share it!



Evaluating Peer Support

Workgroup 3

Evaluating “Goodness of Fit”

Ask people about their goals...and the degree of importance they place on making progress toward achieving them via peer support.

Questions around goodness of fit could include:

- “How does peer support affect your...”
 - Sense of well-being and/or mental health
 - Friendships
 - Sense of loneliness
 - Sense of increased agency and resilience
 - Sense of belonging
 - Sense of satisfaction
 - Sense of confidence
 - Sense of control
 - Sense of safety
 - Sense of privacy

What we need your help with...

We have identified the “I feel valued factor” (e.g., being understood and respected) as an important outcome that should be measured. Not just “I feel valued,” but likewise “We feel valued.” We are asking for your input about both.

- What are things that make you feel like you have been understood and respected?
- Can you share times when you felt like you were understood and respected as a result of peer support, or in group settings?

Why is giving and receiving peer support from others who need AAC a part of what makes you feel valued?

Our next steps...

We are seeking your help, but first:

1. What is missing?
2. **How can we make recommendations more specific to people who use AAC?**
3. Are there any places you'd like to see more movement or hope that we focus more on?
4. Do you have any suggestions or additions to make?

Next steps continued...

We will be offering multiple ways to give input, including:

- Listening Session
 - Stay tuned for a poll where you can vote on a date when we may meet.
- Survey
 - In the near future, we will also send out a survey on another one of the topics we're discussing: definitions of “peer” and “peer support.”
 - We'll report back to the Consortium in February.

Workgroup 4: Consortium presentations

1. Review of the definition of organic peer support
2. Present identified barriers to organic peer support
3. Panel discussion: Barriers to organic peer support
4. Group discussion: What are barriers to organic peer support?

13

Organic Peer Support

Organic peer support refers to informal, naturally occurring support networks 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 formal structure or external organization.

In organic peer support, individuals connect with others who share similar experiences, fostering empathy, understanding, trust, self-expression, and mutual aid. This type of support often emerges within communities, social groups, or online forums, where people share common interests, conditions, or life experiences.

Organic peer support can branch off from and complement formal support services, providing an additional layer of connection, confidentiality, and understanding.

14

Key characteristics of organic peer support:

1. Informal: No formal power hierarchy [there may be an administrative structure of some kind, if needed, for ensuring practical tasks are accomplished consistently].
2. Natural: Develops spontaneously among people with relateable or shared experiences.
3. Mutual: Support is reciprocal, with each person helping one another.
4. Non-professional: Support is not provided by trained professionals, but by peers with similar experiences.

Examples of organic AAC peer supports include:

- Online forums for people who use AAC
- Support groups for family members of AAC users (e.g. very local parent groups, or sibling groups)
- Social media groups for people who have the same speech-generating device and/or vocabulary (e.g. Accent with Unity)
- Informal friendships or friend groups based (partially or fully) around shared communication traits

15

Barriers to organic peer support

Attitudinal Barriers

- Assumptions and beliefs about disability
- Decisions controlled by people in power

Social Barriers

- Stigma/marginalization
- Communication barriers (methods, styles, etc.)
- Unequal opportunities (employment, income, education, etc.)
- Internalized ableism
- Behavioral barriers
- Lack of access to medical services/supports

Structural Barriers

- Geographic isolation
- Physical barriers
- Lack of accessible communication platforms
- Lack of transportation
- Lack of direct support

Organizational Barriers

- Funding
- Infrastructure
- Inadequate training or access
- Institutional barriers, like logistical support
- Prioritization of professional support over peer support

Technology Barriers

- Internet and computer access
- Internet and computer savvy
- Access to AAC systems
- Juggling virtual meeting functions as well as AAC system
- Sound/microphone/feedback issues
- Caregiver tech skills and attitudes

16

Panel discussion: Barriers to Organic Peer Support

- Attitudinal Barriers: Kevin Williams
- Structural Barriers: Michael Fondacaro
- Social Barriers: Lateef McLeod
- Organizational Barriers: endever* corbin
- Technology Barriers: Linda Akagi

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Attitudinal Barriers to Organic Peer Support

- Expression of the struggle with confidence and investment among key stakeholders
- Feelings individuals have towards a particular subject that limits growth or impact of activities and projects that support it
- For peer support in AAC, individuals with feelings are the key stakeholders in this space
- Key stakeholders of peer support are participants, support partners, community resource managers

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Structural Barriers to Organic Peer Support

- Geographical location
- Accessibility
 - Mobility issues can affect transport accessibility
 - Public transportation
 - Lack of accessible platforms
 - Virtual platforms are not accessible to everyone
 - Example: Not everyone can read/use chat
 - Lack of accessibility on virtual platforms

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Social Barriers to Organic Peer Support

- Roots of social barriers
 - Ableism
 - Internalized ableism
 - Speechism

20

Ableism

- Shows up if people who use AAC have families or people supporting them who do not value AAC peer support and having people who use AAC mentor each other
 - People may not value the importance of the disability community and how we need to support each other

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Developing Internalized Ableism

- People with disabilities observe ableism, may develop internalized ableism, and may not want to associate with other people with disabilities
 - This can cause another barrier for AAC peer support

22

Speechism

- People discriminate against people who use AAC because their communication mode deviates from the norm
 - Family members, specialists, support people might dissuade use of AAC and instead encourage oral speech or other forms of normalized communication

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Combating Barriers

- Promote more the importance of AAC peer support
- Create space for disabled people to be in community with each other, especially for people who use AAC

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Organizational Barriers to Organic Peer Support

- Can relate to funding, infrastructure, logistical support
- Will describe an imaginary summer camp for people who need/use AAC to illustrate
- All comes down to **ableism**, **speechism** specifically and often intersecting oppressions

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Imaginary prototypical summer camp

- Self-describes as offering peer support
- Directed by professionals and caregivers, NOT AAC users
- May be primarily educational in nature
- May be designed for children only
- Camp's policies and procedures may inadvertently prohibit people who use AAC from building more natural support networks
- Professionals or caregivers may interfere with authentic relationships
 - May try to coach the interactions

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Details of this imaginary summer camp:

- Do NOT match our working definition of organic peer support
- Yet these types of opportunities receive funding, infrastructure, logistical support, and practical resources

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Burdens for Organic peer support

- Ableism
 - Everyone except those who need or use AAC seen as more "reliable narrators"
 - AAC users seen in need of education and training directed by nondisabled people
 - Decision making power withheld from disabled people, especially disabled youth
 - Peer interactions often micromanaged

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Oppressions Shape More Practical Roadblocks

- Resources need to be reallocated to all kinds of peer supports
- Policy changes need to address organizational barriers
- **We NEED these things NOW**

29

Technology Barriers to Organic Peer Support

- AAC device accessibility: charging, mounting, overall access
- Internet access: home internet access, mobile internet access
- Computer access: for meetings and also organizing calendars and communications

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Technology Barriers to Organic Peer Support

- Caregivers' technology skills and attitudes
- Zoom or web meeting integration with AAC systems
- AAC systems' sound integrations with phone and web meetings

31

Technology Barriers to Organic Peer Support

- Managing "Zoom" functions during meetings (i.e., juggling the chat, captions, reactions)
- Sound issues with microphones and feedback
- Communication timing issues and keeping up with the flow of conversations

32

Time to discuss as a group

- Has organic peer support been available to you?
- What are barriers to organic peer support?
- What gets in the way of getting or giving organic peer support?

33

Next Steps:

- February 12 Consortium Meeting group discussion about solutions and opportunities to overcome the barriers we discussed today.
- We will send a survey for your input:
forms.gle/kyjeYi92y9DXmnr1A
Or email fjeldsta@ohsu.edu

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Thank you!

- For participating in the Consortium meeting
- For sharing your expertise with the Consortium
- We'll see you at our next consortium meeting on February 12

A survey will open after the meeting ends, or you can follow this link: s.zoom.us/j/6PIWcg2pn

If the survey isn't accessible or you'd rather send an email:

Sarah Fjeldstad, Project Coordinator: fjeldsta@ohsu.edu

Steering Committee: trackens@uga.edu (all links in the chat)

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AAC Peer Support Project - National Partnership Consortium Meeting

AGENDA

February 12, 2025

12pm-1:30 (Pacific) / 3pm-4:30 (Eastern) (1 ½ hours)

Zoom meeting link: <https://us06web.zoom.us/j/81047697493>

- Link to the [Meeting Slides](#) - these will be shown on screen during the meeting
- Tell us how this meeting went for you in our [Meeting Survey](#)
- How to use Zoom functions: [Zoom Meeting Participant Guide](#)

WHO	Topic	Text	Minutes/Time (PT)
LY	Log in	Login time.	5 minutes 12:00-12:05
LY	Welcome!	What will we do today? <ul style="list-style-type: none"> • Hear a report from the steering committee • Review the preliminary report recommendations • Presentation on ways to overcome barriers to AAC peer support • Group discussion on overcoming barriers • Thanks to Bre Mercier and endever* corbin who will be leaving the Core Leadership in February 	2 minutes 12:05-12:07
e*c	Review of discussion guidelines	Accessibility Reminders: <ul style="list-style-type: none"> • Lean into pauses to offer the wait time often needed by AAC users to contribute to the conversation. • Pause to ask whether anyone has additional thoughts before switching to new topics. • Look for individual signs that a person might want to contribute to the conversation. • We will read all chat messages aloud. If you do not want your message read out loud, please say so, for example “Don’t ROL.” • Please let us know other additional access needs as they arise. Discussion ground rules: <ul style="list-style-type: none"> • We prioritize the perspectives of AAC users. We will seek AAC user input first. • A moderator will be selected. Speaking people will raise their hands (physically or using the Zoom feature) and wait to speak until called on. 	3 minutes 12:07-12:10

		<ul style="list-style-type: none"> If a discussion goes off topic, or if a speaking person is taking up too much time, the moderator will notify them first by private chat, then aloud. <p>Tell us how these guidelines work for you in the survey after the meeting (link) . Or you can email Sarah Fjeldstad fjeldsta@ohsu.edu.</p>	
SF	Steering Committee	<p>Steering Committee report, recommendations, and feedback from AAC users</p> <p>Jordyn Zimmerman, Lateef McLeod, Tracy Rackensperger</p>	<p>10 minutes</p> <p>12:10-12:20</p>
MFO	Preliminary final report	<p>Sharing our preliminary recommendations for AAC peer support. Final report to be shared at the March 12 Consortium meeting.</p> <p>Winding down the workgroups</p>	<p>10 minutes</p> <p>12:20-12:30</p>
SF	WG 4 Presentation	<p>Topic: How can we get past barriers to organic AAC peer support?</p> <p>Opening remarks: Jill Tullman</p> <p><u>Panel discussion</u> (2-3 mins each):</p> <ul style="list-style-type: none"> Kevin Williams: Attitudinal Barriers Michael Fondacaro: Structural Barriers Lateef McLeod: Social Barriers endevery corbin: Organizational Barriers Linda Akagi: Technology Barriers Lisa Bardach: Support for Technology Jordyn Zimmerman: Big picture/overarching issues <p><u>Group Discussion</u></p> <ul style="list-style-type: none"> How has this consortium overcome some of the barriers to AAC peer support? What would more solutions look like? 	<p>1 hour</p> <p>12:30-1:30</p>
e*c	Closing	<p>THANK YOU!</p> <ul style="list-style-type: none"> Thanks to Bre Mercier. Best wishes! To all for joining the Consortium meeting and working together to develop a national plan to advance AAC peer support Sharing your input and expertise with your workgroups and the full Consortium <p>Note:</p> <ul style="list-style-type: none"> March 12 will be our final Consortium meeting Please complete the short survey after this meeting: LINK 	<p>1 minute</p> <p>1:30</p>

WELCOME

AAC Peer Support Project

A national partnership to develop an approach and plan to advance peer-support models for people who use or need augmentative and alternative communication (AAC)



AAC Peer Support Consortium Meeting

February 12, 2025

- ASL interpretation video, captions, and transcription are available using the controls on your Zoom meeting screen.
- The agenda and a Zoom meeting participant guide are linked in the google meeting invitation and shared in the chat.
- If you need help during the meeting, email Project Coordinator Sarah Fjeldstad fjeldsta@ohsu.edu or send a Zoom chat

What will we do today?

- Hear a report from the steering committee
- Review the preliminary final report
- Panel presentation: overcoming barriers to AAC peer support
- Group discussion on overcoming barriers to AAC peer support
- Thanks to Bre Mercier and endeavor* corbin who will be leaving the Core Leadership in February

Accessibility Reminders:

- Lean into pauses to offer the wait time AAC users often need to contribute to the conversation.
- Pause to ask whether anyone has additional thoughts before switching to new topics.
- Look for individual signs that a person might want to contribute to the conversation.
- We will read all chat messages aloud. If you do **not** want yours read out loud, please say so, for example "Don't ROL."
- Please let us know any additional access needs as they arise.

Discussion guidelines:

- Fully speaking people will raise their hands and wait to speak until called on by the discussion moderator - Emily Quinn.
- If a discussion goes off topic, or if a speaking person is taking up too much time, the moderator will notify them first by private chat, then aloud.

Is there anything we should add or change to these guidelines?

You can tell us how these guidelines work for you in the survey after the meeting.

Or you can send a zoom chat or email to Sarah Fjeldstad fjeldsta@ohsu.edu.

Report from the Steering Committee

Jordyn Zimmerman, Lateef McLeod, Tracy Rackensperger

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Preliminary final report to ACL for 2/18/2025

Background

- What is AAC?
- Who uses or needs AAC?
- What is peer support?
- What is AAC peer support?
- What are barriers and facilitators to successful AAC peer supports?
- How should we evaluate outcomes for AAC Peer Support activities?

Recommendations

- Create a mechanism to provide community mini-grants that sustain peer support activities or reduce individual barriers.
- Increase representation of AAC users with acquired disabilities.
- Create self-supporting activities.
- Create lifespan peer support activities
- Increase means to locate and find peer support activities.
- Examples of successful AAC peer support activities from the scoping review
- Sustainable funding recommendations

8

Summary gleaned from an AI-generated definition based on six definitions of AAC Peer Support

AAC Peer Support is a community where individuals who use Augmentative and Alternative Communication (AAC) systems come together in a safe space to share their experiences, both positive and negative. This support system is built on trust and respect, fostering open and honest communication. It involves sharing ideas, activities, and frustrations to manage life's challenges and validate all forms of communication.

AAC peer support aims to create an environment of collaboration, mentorship, and social justice, empowering users to achieve personal growth and community integration.

Key elements of AAC peer support include:

- **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

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Self-assessment checklist of successful AAC Peer Support

Individual outcomes: Connections

- ☐ 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

Individual outcomes: Communication

- ☐ I am a good listener when others speak
- ☐ I respect other people's communication method, style, and skill
- ☐ I understand myself (I know how I feel and I know what I like and don't like)
- ☐ I can express myself better than before
- ☐ I learned how to use my AAC device
- ☐ I got better at using my AAC device

Individual outcomes: Personal growth

- ☐ 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

Activity/group outcomes: That increase participation

- ☐ There is a good structure and organization
- ☐ I know what to expect from the meeting
- ☐ We meet or communicate often (at least once a month)
- ☐ We are comfortable expressing ourselves
- ☐ We meet consistently at the same time and day
- ☐ I'm getting what I want out of the experience

What do AAC Users consider successful peer support?

"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."

"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."

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What do AAC Users consider successful peer support?

"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."

"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 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."

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Thank you Workgroups!

But the project is coming to a close

It is time to start winding down the workgroups

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Workgroup 4: Overcoming Barriers to organic AAC Peer Support

Opening remarks from Workgroup co-leader Jill Tullman

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Organic peer support refers to informal, naturally occurring support networks among people who relate to one another through experiences, strengths, challenges, or backgrounds, fostering empathy, understanding, trust, self-expression, and mutual aid. The term "organic" emphasizes that these support systems develop naturally, with limited formal structure or external organization. This type of support often emerges within communities, social groups, or online forums, where people share common interests, conditions, or life experiences.

Key characteristics of organic peer support:

- Informal: No formal power hierarchy [though there may be an administrative structure of some kind, if needed, for ensuring practical tasks are accomplished consistently].
- Natural: Develops spontaneously among people with relateable or 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.

Organic peer support can branch off from and complement formal support services, providing an additional layer of connection, confidentiality, and understanding.

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Question for later group discussion:

- How has this consortium overcome some of the barriers to AAC peer support
- What would more solutions look like?

You'll have a chance to respond after the panel discussion

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Overcoming Attitudinal Barriers

Panelist: Kevin Williams

- Assumptions and beliefs about disability
- Decisions controlled by people in power

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Overcoming Structural Barriers

Panelist: Michael Fondacaro

- Geographic isolation
- Physical barriers
- Lack of accessible communication platforms
- Lack of transportation
- Lack of direct support

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Overcoming Social Barriers

Panelist: Lateef McLeod

- Stigma/Marginalization
- Communication barriers (methods, styles, etc.)
- Unequal opportunities (employment, income, education, etc.)
- Ableism and internalized ableism
- Behavioral barriers
- Lack of access to medical services/supports

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Overcoming Social Barriers

- Any solution to a social barrier must be initiated or heavily influenced by the perspectives of people who use AAC.
- Families, caregivers, and schools should be educated on the importance of the disability community especially to people who use AAC.
- For AAC peer support to succeed the community has to be involved.

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Overcoming Organizational Barriers

Panelist: endeavor* corbin

- Funding
- Infrastructure
- Inadequate training or access
- Institutional barriers, like logistical support
- Prioritization of professional support over peer support

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Overcoming Technology Barriers

Panelist: Linda Akagi

- Internet and computer access
- Internet and computer savvy
- Access to AAC systems
- Juggling virtual meeting functions as well as AAC system
- Sound/microphone/feedback issues
- Caregiver tech skills and attitudes

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Tech Support for Overcoming Technology Barriers

Panelist: Lisa Bardach

- Person-first Solutions
- Solutions are a Toolkit
- Examples of Solutions within the Consortium
- Finding Someone with the Necessary Tech Skills

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Big picture

Panelist: Jordyn Zimmerman

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Time to discuss as a group

- How has this consortium overcome some of the barriers to AAC peer support?
- What would more solutions look like?

26

Thank you!

- For participating in the Consortium meeting
- For sharing your expertise with the Consortium
- March 12 will be our **final meeting**

A survey will open after the meeting ends, or you can follow this link:
s.zoom.us/j/6PvxAXS4p

Or email Sarah Fjeldstad, Project Coordinator: fjeldsta@ohsu.edu

Or the Steering Committee: trackens@uga.edu

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AAC Peer Support Project - National Partnership Consortium Meeting AGENDA

March 12, 2025

12pm-1:30 (Pacific) / 3pm-4:30 (Eastern) (1 ½ hours)

Zoom meeting link: <https://us06web.zoom.j/81047697493>

- Link to the [Meeting Slides](#)
- Tell us how you want to stay involved in this work: [Meeting Survey](#)
- How to use Zoom functions: [Zoom Meeting Participant Guide](#)

Who	Topic	Details	Minutes/Time (PT)
RB	Log in	Login time.	3 minutes 12:00-12:03
RB	Welcome!	Today's agenda: <ul style="list-style-type: none"> • Final summary reports from the workgroups • How we will share our work • Summary of AAC peer support survey results • Final report from the Steering Committee • What comes next for this project and how you can be involved • Group discussion on your future vision for the project 	2 minutes 12:03-12:05
SF	Review of discussion guidelines	Accessibility Reminders: <ul style="list-style-type: none"> • Lean into pauses to offer the wait time often needed by AAC users to contribute to the conversation. • Pause to ask whether anyone has additional thoughts before switching to new topics. • Look for individual signs that a person might want to contribute to the conversation. • We will read all chat messages aloud. Tell us if you do not want your message read out loud, for example "Don't ROL." • Please let us know other additional access needs as they arise. Discussion ground rules: <ul style="list-style-type: none"> • We prioritize the perspectives of AAC users. We will seek AAC user input first. • A 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 them first by private chat, then aloud. 	2 minutes 12:05-12:07

Who	Topic	Details	Minutes/Time (PT)
SF	Final reports from workgroups (2-3 minutes each)	<ul style="list-style-type: none"> • Workgroup 1 (Peer Support in AAC): Jan Staehely • Workgroup 2 (Peer Support outside AAC): Sam Sennott • Workgroup 3 (Evaluation): Jenn Seale • Workgroup 4 (Presentations): Patrick Regan • Workgroup 5 (DEIA): Otto Lana 	15 minutes 12:07-12:22
EDQ	Workgroup 6 final report and next steps	<ul style="list-style-type: none"> • Sharing our findings and continued work • Sharing Results of Scoping Review <ul style="list-style-type: none"> ○ Goal: Pre-print report posted to Open Science Framework June 2025 <ul style="list-style-type: none"> ■ Pre-print is an early version of a paper before it is submitted/ peer reviewed to enable rapid dissemination of findings. ○ Goal: Report submitted to the Augmentative and Alternative Communication Journal for peer review August 2025 • Sharing Results of AAC User Survey 	15 minutes 12:22-12:37
SF	AAC Peer Support Survey results	<ul style="list-style-type: none"> • Lateef McLeod: What peer support experiences were reported by AAC users 	10 minutes 12:37-12:47
SF	Steering Committee	<ul style="list-style-type: none"> • Tracy Rackensperger, Lateef McLeod, Jordyn Zimmerman <ul style="list-style-type: none"> ○ Final report ○ Preferred terms 	10 minutes 12:47-12:57
MFO	Review the project final report	<ul style="list-style-type: none"> • Consensus building for the final report occurred during the year. Thank you....Just a few more emails to put the icing on the cake! From MFO as PI. • Survey after meeting: Really important to complete PLEASE • Who would like to be acknowledged in the final report? Respond with your name, title, affiliation. • Do you want a copy of the final report? • To those who respond YES: <ul style="list-style-type: none"> ○ Who would like to help create a plain language version of the report? ○ Who would like to be named as a future partner in implementation if we can proceed? • Would you like to collaborate on submissions to national conferences, such as ASHA 2025? Send interest to Sarah: fjeldsta@ohsu.edu 	5 minutes 12:57-1:02

Who	Topic	Details	Minutes/Time (PT)
JT	Group discussion	Future vision for the project	25 minutes 1:02-1:30
MFO	Closing	THANK YOU! <ul style="list-style-type: none"> • To all for joining the Consortium meeting and working together to develop national recommendations to advance AAC peer support • Look out for an invitation to an optional follow up meeting in June to share our report and discuss what comes next. • Please answer the survey after the meeting: s.zoom.us/m/bPvzWxMXD • Check out and share our webpage: bit.ly/AACPeerSupportProject 	1 minute 1:30

WELCOME

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A national partnership to develop an approach and plan to advance peer-support models for people who use or need augmentative and alternative communication (AAC)



AAC Peer Support Consortium Meeting

March 12, 2025

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2

What will we do today?

- Final summary reports from the workgroups
- How we will share our work
- Summary of AAC peer support survey results
- Final report from the Steering Committee
- What comes next for this project and how you can be involved
- Group discussion on your future vision for the project

3

Accessibility Reminders:

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- Offer the wait time AAC users often need to contribute to the conversation.
- Pause to ask if anyone has additional thoughts before switching to new topics.
- Look for individual signs that a person might want to add something to the conversation.
- Please let us know any additional access needs as they arise.

4

We have a full agenda!

We won't pause for comments or questions until the full group discussion later in the meeting

5

Group Discussion guidelines:

- Fully speaking people will raise their hands and wait to speak until called on by the discussion moderator.
- If a discussion goes off topic, or if a speaking person is taking up too much time, the moderator will notify them first by private chat, then aloud.

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Final reports from workgroups

Workgroup 1: Peer Support in AAC

- Jan Staehely

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Final reports from workgroups

Workgroup 2: Peer Support Outside AAC

- Sam Sennott

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Final reports from workgroups

Workgroup 3: Evaluation of AAC Peer Support

- Jennifer Seale

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Recommendations for PS Evaluation

- One-size-fits-all approach?—**it's not that simple.**
- Must be AAC user led
 - SO, if we're talking about research, it must be led by AAC users.
- Person receiving PS must be the driver and evaluator.
- Be mindful of tensions re: medical and social models of disability
- Participation, Engagement & I/We Matter Factor
 - Communication performance & AAC use NOT RECOMMENDED

Critical Considerations for PS Evaluation

- PS needs specific to AAC use & needs not unique to using AAC
- Who is a peer? Who is leading PS?—
 - Peer mediated intervention is not PS
 - Peer led? Professional/instructor led, co-facilitated?
- **Access flexibility**—accommodate both physical and virtual space
- AVOID checklists and cookie cutter approaches

Preliminary Metrics for Evaluating: “Goodness of Fit” (should not be standardized)

Sample Questions to ask (before, during and after) PS:

- What do/did you hope to get out of, and what are your goals ...? Was this what you expected? (Why/Why not?)
- Are you able to attend [peer support] opportunities regularly?
 - What motivates you to attend regularly? What prevents you from wanting to attend regularly?
- How does peer support affect your...
 - sense of loneliness or belonging | sense of increased agency and resilience
 - sense of encouragement | personal satisfaction and confidence

Final reports from workgroups

Workgroup 4: Consortium Meeting Presentations

- Patrick Regan

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Final reports from workgroups

Workgroup 5: Diversity, Equity, Inclusion, Accessibility in AAC Peer Support

- Otto Lana

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Final reports from workgroups

Workgroup 6: Scoping Review and Analysis of Peer Support Models

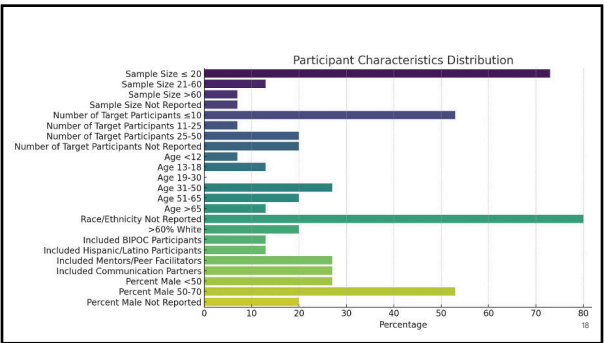
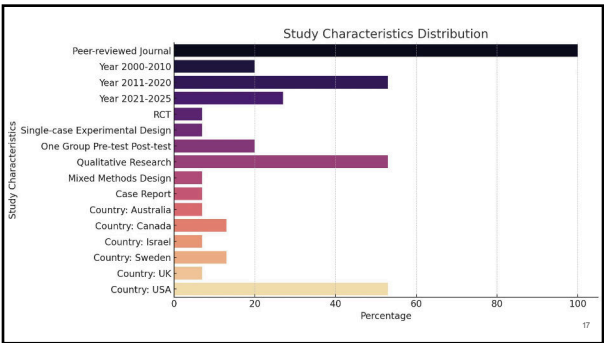
- Emily Quinn

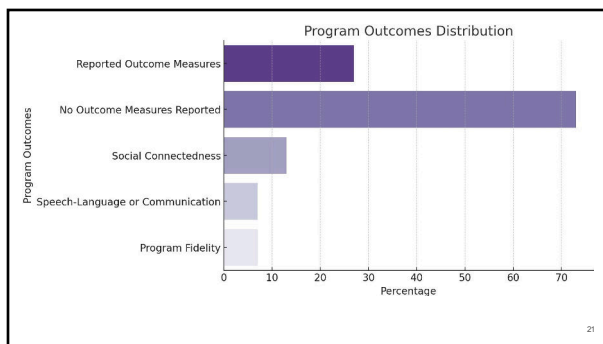
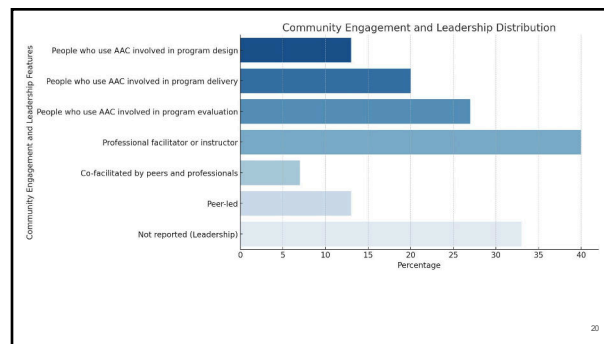
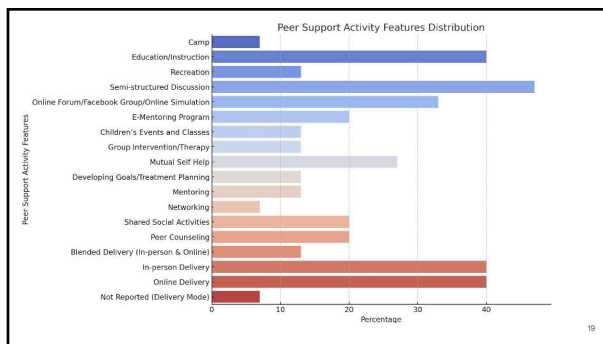
15

Scoping Review

- Established Inclusion and Exclusion Criteria
- Developed a Systematic Search Strategy:
- Iteratively developed data extraction tools
- Completed Title and Abstract and Full-Text Screening
- Extracted information from 15 reports
- Table 1 Summarizes the Characteristics of Included Studies [LINK](#)

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Studies Included in the Scoping Review

Ratnowicz, B., McDougall, S., & Shepherd, T. A. (2006). AAC and community partnerships: The participation path to community inclusion. *AAC: Augmentative and Alternative Communication*, 22(3), 178-195. <https://doi.org/10.1080/07434840500046498>

Beauchamp, J. E. S., Wang, M., Leon-Nowell, L. G., Cox, C., Meyer, T., Fagundes, C., Savitz, S. I., Shariet, A., Dohman, D., & Johnson, C. (2024). Feasibility and user-experience of a virtual environment for social connection and education after stroke: A pilot study. *Journal of Stroke and Cerebrovascular Diseases*, 33(2). <https://doi.org/10.1097/JSC.000000000000107516>

Caron, J., & Light, J. (2015). "My world has expanded even though I'm stuck at home": Experiences of individuals with amyotrophic lateral sclerosis who use augmentative and alternative communication and social media. *American Journal of Speech-Language Pathology*, 24(4), 680-695. https://doi.org/10.1044/2015_AJSLP.15-0010

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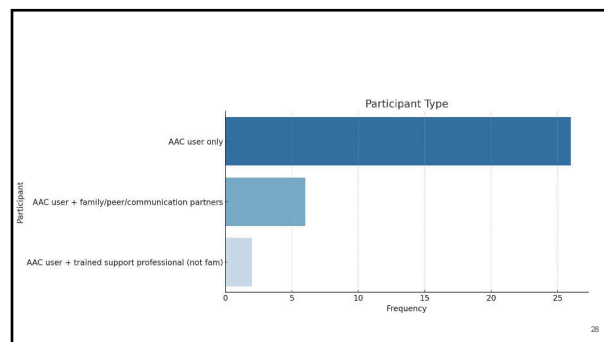
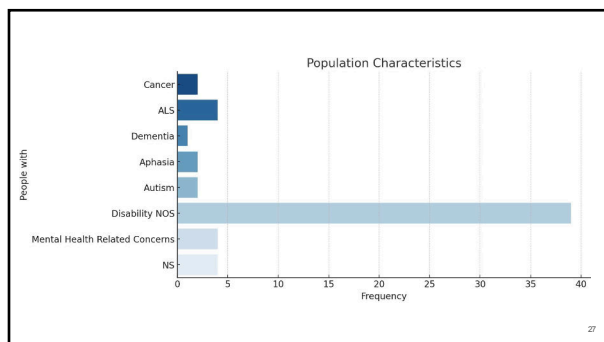
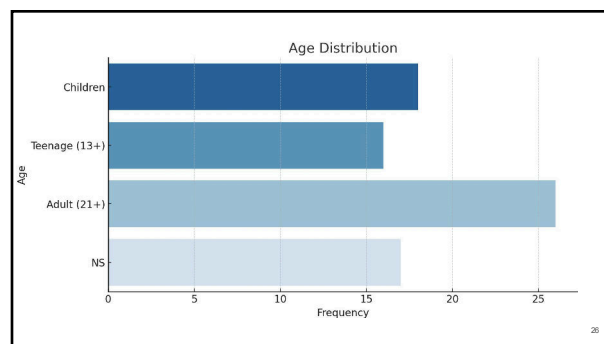
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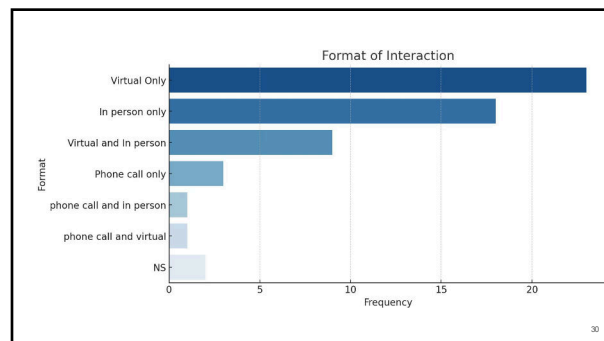
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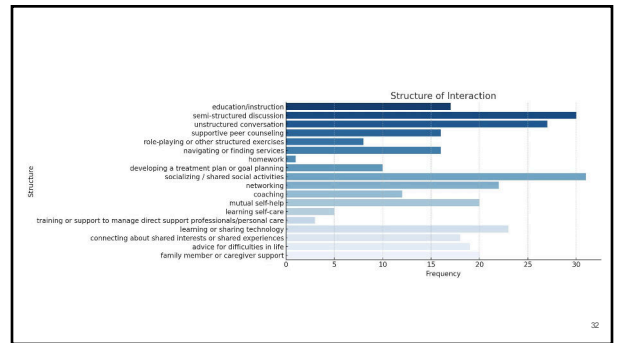
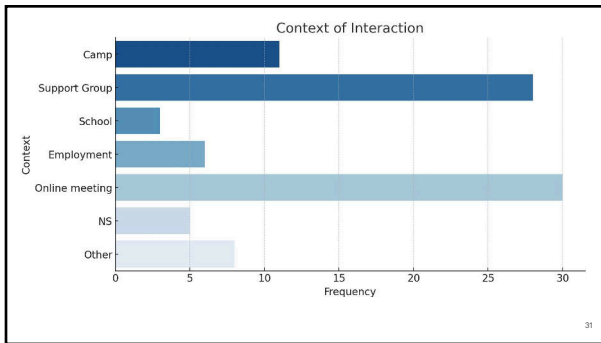
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Peer Support Activity Features

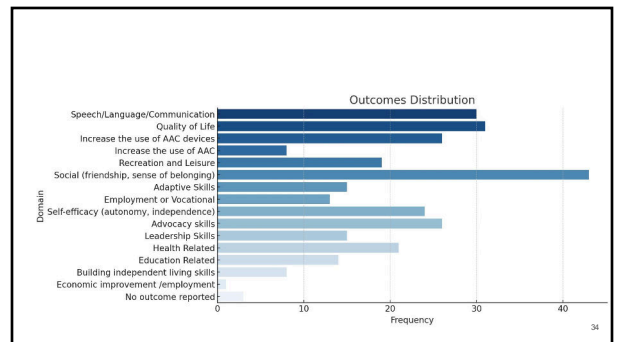
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Peer Support Activity Outcomes

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Sharing our findings and continuing our work

- Results of Scoping Review
 - Goal: Pre-print report posted to Open Science Framework June 2025
 - Goal: Report submitted to the *Augmentative and Alternative Communication Journal* for peer review August 2025
 - Goal: Plain language summary posted to OHSU UCEDD Website in August 2025.
- Results of AAC User Survey
 - Goal: Plain language summary posted to OHSU UCEDD Website October 2025.

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AAC Peer Support Project Survey Results

By Dr. Lateef McLeod

Survey Question

“Please tell us either what kind of support or mentorship from AAC users you have gotten, and/or what kinds of support you would like to have from other AAC users?”

Themes

- Mentoring Support to Improve Self-Advocacy Skills (28%)
- Validation of the People Who Use AAC's Identity (24%)
- Guidance in Improving AAC Skills (28%)
- Advocacy for the AAC Community (3%)
- No Need for Peer Support (23%)

Thesis Statement

From these percentages we see that most respondents were interested in both Mentoring Support to Improve Self-Advocacy Skills and Guidance in Improving AAC illustrating that respondents see peer support as a great way to improve their capacity for communication and also their ability to direct their own lives. AAC peer support could be seen as a great way people who use AAC can increase their skills in these areas and should be provided for anyone who wants to achieve those goals.

Mentoring Support to Improve Self-Advocacy Skills

“I was introduced to AAC through another AAC user. I received encouragement often from other AAC users to acquire the skills I needed for AAC. It became my way to have friends as it was a group that accepted and valued me. I would like more support from other AAC users on how to navigate the college environment, how to explore work possibilities and how to expand my social network.”

Validation of the People Who Use AAC's Identity

“I met another AAC user during my last year of High School. Mostly gave me the realization that I wasn't lone. I went to his AAC camp in Wisconsin, and it helped me to accept my communication device as my voice.”

Guidance in Improving AAC Skills

“Sharing files and screenshots of customized pagesets/vocabularies; troubleshooting app issues; affirmations that there's no such thing as too /whatever/ to use AAC; creating and moderating AAC-user led spaces; being members of said spaces; providing different perspectives and sharing of all the wonderful ways we communicate; helping me over time to learn about AAC and then slowly realize that I'm an AAC user that AAC is something I can use /that I use; creating and sharing symbols/images to use with symbol-based AAC.”

Advocacy for the AAC Community

“Corporate community-based placements in Massachusetts do not like individuals using AAC devices. They do not want them communicating their wants and needs. They certainly do not want the responsibility of maintaining devices or teaching individuals to use AAC devices. The most impaired individuals are the least likely to have access to AAC.”

No Need For Peer Support

“I don’t think I need any mentorship from other AAC users.”

Conclusion

People Who Use AAC desire peer support:

- To increase self-advocacy skills
- To increase communication skills

Any questions? Email mcleodl@ohsu.edu

Steering Committee Final Report

Tracy Rackensperger, Lateef McLeod, and Jordyn Zimmerman

AAC Users Meeting

AAC users meeting on February 26th.

Discussed terminology and endorsing the final report.

Terminology

Complexities of terminology within the AAC community.
Language is constantly evolving; individual preferences vary widely.

Takeaways

Terminology is deeply personal, often carrying emotional significance for AAC users.
There may not be all-encompassing terms that work for everyone.
Language naturally evolves to reflect the changing needs and preferences of a community, reinforcing the importance of adaptability.
Rather than focusing on what people cannot do, it might be more inclusive to describe individuals in terms of what they need to be understood in different settings and across various communities.

Conclusions

Importance of using flexible language while acknowledging that no set of terms can fully capture the diversity of AAC users.

We can't have universal phrases that would best reflect the experiences of those who use AAC.

AAC users identify with multiple terms, suggesting that it would be most effective to recognize and validate different ways people describe themselves.

Language should prioritize individual agency and self-identification, allowing people to define their own communication experiences in ways that feel authentic to them.

Document Created: [Preferred Terms](#)

The Consortium uses augmentative and alternative communication (AAC) to refer to all forms of communication other than speech, like gestures, eye gaze, vocalizations, facial expressions, and body positioning.

Terminology used to describe AAC users is important because language shapes perceptions, influences attitudes, and reflects respect for individual identities. The words below represent just some of the terms that may be used, but preferences vary widely among individuals. Some AAC users may embrace certain terms, while others may strongly dislike the same terms. Additionally, the choice between identity-first language (e.g., "AAC user") and person-first language (e.g., "person who uses AAC") is deeply personal and may be shaped by characteristics of one's identity. Identity-first language emphasizes AAC as an integral part of who someone is, while person-first language highlights the person before their method of communication. Both approaches are valid. Furthermore, language and terms evolve as societal perspectives shift and as AAC users advocate for terminology that best represents their experiences and identities.

Calling someone by their given or preferred name.	AAC communicators
AAC users	Augmented communicators
People who need or use AAC	Augmentative communication users
People who cannot rely on speech	Alternative communication users
People with communication access needs	Speech device users
People using AAC	Assistive technology users
Individuals who use AAC	Individuals using AAC
Individuals who utilize AAC	Users of assistive communication devices
Individuals using AAC	

Endorsing the Final Report

We discussed endorsing the final report, emphasizing the importance of AAC users' endorsement before its official presentation.

We highlighted the ongoing consensus-building process and the role of AAC users in shaping the report's recommendations.

We explored strategies to facilitate endorsement, ensuring full representation of AAC users and addressing any barriers to participation.

Please answer the post-meeting survey:

1. Do you want to be listed as a contributor in the final report?
 - Respond with your name, title, and affiliation.
2. Do you want a copy of the final report?

To those who respond YES:

 - Can you help write a plain language version of the report?
 - Do you want to be a future partner in implementation if we can proceed?
3. Would you like to collaborate on submissions to national conferences, such as ASHA 2025?



Recommendations in the final report

1. Establish a Center of Excellence for AAC Support.
2. Form a main leadership team that includes AAC users, their families, and professionals.
3. Offer small community grants to support peer activities or help remove personal obstacles.
4. Increase inclusion of people who need AAC in multiply marginalized communities through community engagement studios.
5. Create a toolkit to help implement AAC peer support.
6. Develop peer support activities that focus on families.
7. Set up a database for AAC users who want to be peer mentors.
8. Establish a central hub to make it easier to find peer support activities.
9. Organize an online conference about AAC peer support every two years.
10. Use a thorough evaluation system to measure how effective and suitable the programs are, based on feedback from the AAC community.

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Time to discuss as a group:

- What should come next for this project?
- How can we keep our work going?
- What would you like to see happen as a result of this project?
- Tell us about your future vision for AAC Peer Support

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Thank you!

For all you have done as a member of the AAC Peer Support Consortium!

Look out for an invitation to a follow up meeting in June.

Please answer the survey:

[s.zoom.us/m/bPvzWxMXD](https://s.zoom.us/j/6PvzWxMXD)



Share our webpage: bit.ly/AACPeerSupportProject

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Appendix C3: Monthly Progress Reports

Subaward 01-8843-24

A national partnership to develop an approach and plan to advance peer-support models for augmentative and alternative communication (AAC) device users

May 2024 Work Plan Report

Statement of Work –

In this planning phase, the purpose of this project is to advance the use of peer support models for Augmentative and Alternative Communication (AAC) users through the creation of a nationwide, comprehensive, consensus-based approach. This approach will identify meaningful ways for potential and current AAC users to communicate so that they may fully participate in community living and pursue educational and vocational goals.

The outcomes will include addressing the research areas of:

1. An exploration of the question of whether peer support models for AAC device users can be developed, and, if those peer support models will help more people use AAC devices, while acknowledging the broader framework of all people who need and use AAC.
2. A set of actionable recommendations for the creation of a nationwide resource for developing peer support models to encourage the use of AAC devices by those who are not currently using them for communication.

The Subrecipient is expected to achieve the outcomes listed in this Scope of Work, organizing the activities around the following tasks:

Objective 1 – Establish Partnership Group			
	Responsible Party	Timeline	Update
Partner with AUCD to establish partnership consortium with significant representation of people who use AAC, potential users of AAC, nonprofit community-based service provider organizations, direct support professionals, self-advocacy organizations, youth and adults with ID/DD, families, related service providers, educators, others in their support system, and people from multiply marginalized communities.	Core leadership	March, 2024	Partnership plan established and agreed upon. AUCD attends weekly project meetings, contributes to agenda and reports to both project core leadership and ACL. Completed

Identify members of Steering Committee of the National Partnership Consortium.	Core leadership	March-April, 2024	Two members of steering committee have been identified and agreed to participate. We will look for one additional AAC user to serve. -Another AAC user will be invited to join the Steering Committee in May 2024
Partner with AUCD to develop equitable and inclusive governance structure for Consortium.	Core leadership	March-April, 2024	Governance structure established. Completed.
Deliverable - A full roster of confirmed National Partnership Consortium and Steering Committee members, along with their affiliations, roles, and contact information.	Core leadership	March-April 2024	On 4/15/24, the roster as of 4.5.24 was submitted to AUCD with names, email addresses and affiliations -An updated roster was submitted on 5/2/2024 and will continue monthly updates

Objective 2 – Develop Governance and Management Plan			
	Responsible Party	Timeline	Update
Partner with AUCD to draft partnership management plan with shared decision-making model.	MFO, AUCD	March-April, 2024	Completed
Partner with AUCD to plan for and facilitate monthly meetings of partnership consortium.	Core leadership + AUCD	March-April, 2024	We held our first consortium meeting on 4/5/2024 with 40 participants present virtually. AUCD worked to invite consortium members and make sure ACL was present at meeting. -May 2024: The second partnership consortium meeting is scheduled for 5/22/2024. -The leadership team agreed to a plan for monthly meetings; they will be held virtually on the 4th Wednesday of the month, 12pm-1pm (west coast).
Establish a schedule of monthly meetings with AUCD and AoD to monitor progress of activities and discuss any concerns.	Core leadership + AUCD	March-April, 2024	AUCD attends weekly core leadership meetings.
Deliverables			
A schedule of National Partnership Consortium and Steering Committee meetings with locations (virtual or in-person).	Core leadership	March-April, 2024	All consortium and steering committee meetings will be virtual. -The leadership team agreed to a plan for monthly meetings; they will be held virtually on the 4th Wednesday of the month, 12pm-1pm (west coast). -Steering Committee meetings will be held

Minutes/notes from any National Partnership Consortium and Steering Committee meetings held.	MFO	ongoing	Weekly minutes available from consortium and steering committee meetings in Google Drive -agendas and other documentation continues to be made available on the leadership team's shared google drive
Written monthly reports of project activities using Progress Report Template.	MFO	Ongoing	Progress Report Template sent from AUCD to MFO. Completion of first progress report 4/15/2024. -Second progress report submitted 5/17/2024

<p>Objective 3 – Conduct Comprehensive Review and Analysis</p> <p>The comprehensive review and analysis of peer support models, projects, approaches and activities within and outside the field of AAC will be accomplished by the Consortium, with input from the greater community of people who use or need AAC, guided by the Steering Committee, and managed by the leadership team. The Subrecipient will:</p>			
	Responsible Party	Timeline	Update
Engage AUCD, the Consortium and AoD in the development of a plan for the comprehensive review and analysis (CRA) of peer-to-peer models for people who use AAC with specific focus on models, projects, approaches, and activities with strong potential for positive life changes at the individual level.	Core leadership + Consortium workgroup	May-October	- We have engaged a national consortium
Conduct a survey of AAC users in coordination with of identified advocacy and AAC provider organizations.	Core leadership	March-June	100 AAC users have responded to the on-line survey. A list of AAC and advocacy organizations who have added the survey link to their social media or emails is in the weekly partner minutes. -As of 5/6/2024, 119 responses have been collected. The survey continues to be distributed with invitations to respond through June 2024.
Identify current peer-to-peer <u>models</u> , including any that support the use of AAC.	Core leadership + Consortium workgroup	May-September	-Consortium workgroups are established as of 5/17/2024, with co-leaders assigned from the core leadership and steering committee teams. Two workgroups are specifically tasked to "Identify peer support models within the AAC field" and "Identify peer support models outside the AAC field." -Another workgroup is tasked to "Present your own peer support model, activities, strategies to the Consortium;" we hope to learn from a presentation at each monthly meeting. The 5/22/2024 Consortium meeting will include a presentation of an AAC Peer Support model from an AAC user.

Identify current peer-to-peer projects, including any that support the use of AAC.	Core leadership + Consortium workgroup	May-September	<ul style="list-style-type: none"> -Consortium workgroups are established as of 5/17/2024, with co-leaders assigned from the core leadership and steering committee teams. Workgroups are specifically tasked to "Identify peer support models within the AAC field" and "Identify peer support models outside the AAC field."
Identify current peer-to-peer approaches including any that support the use of AAC.	Core leadership + Consortium workgroup	May-September	<ul style="list-style-type: none"> -Consortium workgroups are established as of 5/17/2024, with co-leaders assigned from the core leadership and steering committee teams. Two workgroups are specifically tasked to "Identify peer support models within the AAC field" and "Identify peer support models outside the AAC field."
Identify current peer-to-peer activities, including any that support the use of AAC.	Core leadership + Consortium workgroup	May-September	<ul style="list-style-type: none"> -Consortium workgroups are established as of 5/17/2024, with co-leaders assigned from the core leadership and steering committee teams. Two workgroups are specifically tasked to "Identify peer support models within the AAC field" and "Identify peer support models outside the AAC field." -The leadership team has solicited and received descriptions of Peer Support activities members of the Consortium have participated in. -The leadership team has solicited and received descriptions of Peer Support activities AAC users have participated in. These include online communities and resources, peer groups, conferences, and camps. We continue to invite descriptions of experiences through June 2024.
Develop a protocol for review and analysis of peer support models, projects, approaches and activities within and outside of the AAC field that are organized, at minimum, around three descriptors: person characteristics (who is included), program characteristics (what is done), program outcomes (why).	Core leadership + Consortium workgroup	May-September	<ul style="list-style-type: none"> - A workgroup has been established, which will focus on: "What are we evaluating? Determine characteristics of peer support models that we will evaluate and include in our recommendations for a national AAC peer support mode." The goal of this workgroup is to meet this outcome.
Identify existing partnerships/organizations that use peer-to-peer models to support AAC use with the goal of positive impact on activities of daily living for the individual. Barriers and opportunities within the model/approach or activity that should be considered for national recommendations will also be identified.	Core leadership + Consortium workgroup	May-September	<ul style="list-style-type: none"> - The leadership team has focused on soliciting consortium membership by individuals and organizations that support AAC use with the goal of positive impact on activities of daily living. - The leadership team has solicited and received descriptions of Peer Support activities members of the Consortium have participated in.

Develop a schema (an overarching framework that articulates the necessary adaptations to existing peer-support approaches which are needed for the AAC community) to be reviewed by the Consortium.	Core leadership + Consortium workgroup	May-September	- A workgroup for systematic review is being formed that will develop a schema.
Address the research question of whether peer support models for AAC device users can be developed, and, if those peer support models will help more people use AAC devices, while acknowledging the broader framework of all people who need and use AAC.	Core leadership + Consortium workgroup	May-September	-
Identify, Analyze, and consider legal frameworks and funding support systems and include any findings and recommendations included in the Comprehensive Review and Analysis.	Core leadership + Consortium workgroup	May-September	-
Identify barriers and action steps to address these barriers, particularly those faced by people from multiply marginalized communities and include any barriers and action steps included in final Comprehensive Review and Analysis.	Core leadership + Consortium workgroup	May-September	- A workgroup has been established to “Develop strategies for inclusion of diversity and underrepresented communities in models and recommendations.” This workgroup will be key in identifying barriers and action steps to address those barriers.
Identify themes, promising approaches and practices, and areas of need to develop the plan, working alongside the partnership consortium to ensure attention to Diversity, Equity, and Inclusion.	Core leadership + Consortium workgroup	May-September	- A workgroup has been established to “Develop strategies for inclusion of diversity and underrepresented communities in models and recommendations.” This workgroup will be key in developing the final recommendations. Consortium members in other workgroups have expressed personal interest in contributing to this topic.
Partner with AUCD, consortium, and AoD to develop an initial list of resources and information to inform and develop a proposed approach and plan.	Core leadership + Consortium workgroup	May-September	-
Deliverables:			

Results of the survey of AAC users and their peer support preferences.	Core leadership	ongoing	As of 4/15/2024, results from 100 AAC users was sent to AUCD. We continue this survey until June 2024. An abstract has been submitted to ISAAC for a 2-hour presentation, including data on AAC users and their peer support preferences. - As of 5/6/2024, 119 responses have been collected. The survey continues to be distributed with invitations to respond through June 2024.
An analysis of the existing activities and approaches that could be applied to an AAC support model.	Core leadership + Consortium workgroup	May-September	-
Completed Schema (an overarching framework that articulates the necessary adaptations to existing peer-support approaches which are needed for the AAC community).	Core leadership + Consortium workgroup	May-September	-
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.	Core leadership + Consortium workgroup	May-September	-
A set of actionable recommendations for the creation of a nationwide resource for developing peer support models to encourage the use of AAC devices by those who are not currently using them for communication.	Core leadership + Consortium workgroup	May-September	-
Legal frameworks report with findings and recommendations.	Core leadership + Consortium workgroup	May-September	-
Initial list of resources and information.	Core leadership + Consortium workgroup	May-September	-

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

	Responsible Party	Timeline	Update
Produce, Share and discuss the report with the Consortium.	Core leadership + Consortium	September-December	
Collaborate with AUCD and the Consortium to develop recommendations and action steps that include special consideration for those that would advance Equity, Diversity, and Inclusion.	Core leadership + Consortium workgroup	September-December	
Develop report with the Consortium and use criteria for adopting final recommendations.	Core leadership + Consortium workgroup	September-December	
Partner with AUCD and the partnership consortium to deliver to AoD and all stakeholders a comprehensive recommended plan and proposed approach for establishing a nationwide resource for developing peer-to-peer models that will promote and enhance the use of AAC devices as well as the overall quality of life of people who use AAC.	Core leadership	September-December	
Develop external reports for the members of the Consortium and for health systems, universities, and education entities, and public service agencies. This includes an online accessible plan that will be available on OHSU UCEDD and CommunicationFIRST websites. Additional formats that will be available online include a plain language version, an audio version, and a symbol-based version.	Core leadership + Consortium	September-December	

Deliverables			
Completed plan with recommendations.		December	
Completed external reports.		December	

June 2024 Work Plan Report

Objective 1 – Establish Partnership Group			
	Responsible Party	Timeline	Update
Partner with AUCD to establish partnership consortium with significant representation of people who use AAC, potential users of AAC, nonprofit community-based service provider organizations, direct support professionals, self-advocacy organizations, youth and adults with ID/DD, families, related service providers, educators, others in their support system, and people from multiply marginalized communities.	Core leadership	March, 2024	Partnership plan established and agreed upon. AUCD attends weekly project meetings, contributes to agenda and reports to both project core leadership and ACL. Completed -The Core Leadership and Consortium has continued inviting and accepting new members. The Consortium will close to new members on July 1st. AAC users make up 40% of active consortium members, which includes core leadership, workgroup members, co-leaders, steering committee, observers, and reviewers. Note: those who elected to receive monthly updates only are not included as they have not self-identified their AAC use status and are unknown. -Consortium representation is detailed on the Consortium roster, last updated on 6/17/2024. LINK -Consortium roster was updated on 7/9/2024 LINK
Identify members of Steering Committee of the National Partnership Consortium.	Core leadership	March-April, 2024	Two members of steering committee have been identified and agreed to participate. We will look for one additional AAC user to serve. -Another AAC user will be invited to join the Steering Committee in May 2024 -Tracy Rackensperger, an AAC user who is faculty at the GA UCEDD is the third member of the Steering Committee. Completed.
Partner with AUCD to develop equitable and inclusive governance structure for Consortium.	Core leadership	March-April, 2024	Governance structure established. Completed

Deliverable - A full roster of confirmed National Partnership Consortium and Steering Committee members, along with their affiliations, roles, and contact information.	Core leadership	March-April 2024	On 4/15/24, the roster as of 4.5.24 was submitted to AUCD with names, email addresses and affiliations. Completed -An updated roster was submitted on 5/2/2024 and will continue monthly updates -The roster was updated on 6/17/2024 to add additional members who had recently joined, and identify all Steering Committee members. LINK -Consortium roster was updated on 7/9/2024 to add new members LINK
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Objective 2 – Develop Governance and Management Plan			
	Responsible	Timeline	Update
Partner with AUCD to draft partnership management plan with shared decision-making model.	MFO, AUCD	March-April, 2024	Completed
Partner with AUCD to plan for and facilitate monthly meetings of partnership consortium.	Core leadership + AUCD	March-April, 2024	We held our first consortium meeting on 4/5/2024 with 40 participants present virtually. AUCD worked to invite consortium members and make sure ACL was present at meeting. - May 2024: The second partnership consortium meeting is scheduled for 5/22/2024. - The leadership team agreed to a plan for monthly meetings; they will be held virtually on the 4th Wednesday of the month, 12pm-1pm (west coast). - Completed (agreed on 5/20/2024) LINK
Establish a schedule of monthly meetings with AUCD and AoD to monitor progress of activities and discuss any concerns.	Core leadership + AUCD	March-April, 2024	AUCD, represented by Holly Hohmeister, attends weekly core leadership meetings. Completed
Deliverables			

<p>A schedule of National Partnership Consortium and Steering Committee meetings with locations (virtual or in-person).</p>	<p>Core leadership</p>	<p>March-April, 2024</p>	<p>All consortium and steering committee meetings will be virtual.</p> <ul style="list-style-type: none"> -The leadership team agreed to a plan for monthly meetings; they will be held virtually on the 4th Wednesday of the month, 12pm-1pm (west coast). -The meeting schedule was announced at the 5/22/2024 Consortium Meeting, with 36 participants present. LINK LINK LINK LINK -Consortium members who joined in the month of May and beyond receive an introductory email informing them of this schedule, as well as the zoom link that is used for all Consortium meetings. Link to sample email -Individuals who were invited by consortium members, and who registered for the 5/22/2024 consortium meeting were provided the zoom link via email, which also included the meeting agenda noting the recurring meeting schedule. LINK -A document detailing the meeting schedule and recurring zoom meeting link was placed in each workgroup's google folder, which is shared with each member of their workgroup. (example provided). LINK -The Steering Committee has held one meeting so far, and has not established a meeting schedule going forward. The committee will collaborate and determine a meeting schedule once the workgroups begin to produce work output. -A post-meeting participant survey was established for the June Consortium meeting. The results indicated a need to extend the length of Consortium meetings and change the structure of meetings LINK -Steering Committee met on June 28th. They decided to hold AAC user-only meetings on 7/15 and 7/22/24.
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Minutes/notes from any National Partnership Consortium and Steering Committee meetings held.	MFO	ongoing	<p>Weekly minutes available from consortium and steering committee meetings in Google Drive</p> <ul style="list-style-type: none"> -agendas and other documentation continues to be made available on the leadership team's shared google drive -Consortium meeting agendas and slides are stored in the project's shared google drive. Copies of Consortium meeting agendas, slides, zoom meeting recordings (audio, video, in-meeting chat, and transcripts) are all saved to each workgroup's shared google folder within the project's shared drive. LINK -Copies of these same items, as well as other pertinent project documents (Consortium Member Roles and Responsibilities; language to used to invite new consortium members or invite survey respondents) are saved to a separate shared folder created for Consortium members who joined at the "Observer" or "Monthly Updates Only" level. The link to this shared folder was provided via email to those members sharing the monthly updates from May. Each monthly update email will include that information. LINK -The Steering Committee has held one meeting so far. The meeting agenda is available on the project shared google drive. Future meeting agendas will be saved to the project shared drive. -Steering Committee meeting agendas are available on the project shared drive. The link to the 6/28/2024 meeting: LINK
Written monthly reports of project activities using Progress Report Template.	MFO	Ongoing	<p>Progress Report Template sent from AUCD to MFO. Completion of first progress report 4/15/2024.</p> <ul style="list-style-type: none"> -Second progress report submitted 5/17/2024 -Third progress report submitted 6/17/2024 -Fourth progress report submitted 7/15/2024

Objective 3 – Conduct Comprehensive Review and Analysis

The comprehensive review and analysis of peer support models, projects, approaches and activities within and outside the field of AAC will be accomplished by the Consortium, with input from the greater community of people who use or need AAC, guided by the Steering Committee, and managed by the leadership team. The Subrecipient will:

	Responsible Party	Timeline	Update
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Engage AUCD, the Consortium and AoD in the development of a plan for the comprehensive review and analysis (CRA) of peer-to-peer models for people who use AAC with specific focus on models, projects, approaches, and activities with strong potential for positive life changes at the individual level.	Core leadership + Consortium workshop	May-October	<ul style="list-style-type: none"> -We have engaged a national consortium -The Consortium workshops were assigned in May 2024. Workshop co-leaders were chosen and are directing the work of their workshop members to meet those goals. Workshops are divided as follows: <ul style="list-style-type: none"> -Workgroup 1: Identify peer support models within the AAC field -Workgroup 2: Identify peer support models outside the AAC field -Workgroup 3: What are we evaluating? Determine characteristics of peer support models that we will evaluate and include in our recommendations for a national AAC peer support model -Workgroup 4: Present peer support model, activities, strategies to the Consortium -Workgroup 5: Develop strategies for inclusion of diversity and underrepresented communities in models and recommendations -Workgroup 6: Systematic review/ metaanalysis of peer support literature -Each workshop was provided a shared google folder containing a "Goals and Progress Notes" document that details the goals of the workshop in the project. The contents of the workshop's shared folders, including the Goals and Progress Notes document were described via email, with direct links to the folder: LINK LINK -Each workshop continues to work toward their goals and to report out at the monthly consortium meetings.
Conduct a survey of AAC users in coordination with identified advocacy and AAC provider organizations.	Core leadership	March-June	<ul style="list-style-type: none"> 100 AAC users have responded to the on-line survey. A list of AAC and advocacy organizations who have added the survey link to their social media or emails is in the weekly partner minutes. -As of 5/6/2024, 119 responses have been collected. The survey continues to be distributed with invitations to respond through June 2024. -As of 6/13/2024, 132 responses have been collected. Results of the following survey questions: <ul style="list-style-type: none"> -Have other AAC users helped you develop AAC skills? -How much have other AAC users helped you develop your skills in using AAC? -Would you like more mentoring? were shared at the 5/22/2024 Consortium meeting (see meeting recordings previously linked). Additional survey results will be shared at the 6/26/2024 Consortium meeting. -Data about AAC peer support activities reported in the survey are undergoing a thematic analysis.

Identify current peer-to-peer models, including any that support the use of AAC.	Core leadership + Consortium workgroup	May-September	<ul style="list-style-type: none"> -Consortium workgroups are established as of 5/17/2024, with co-leaders assigned from the core leadership and steering committee teams. Two workgroups are specifically tasked to "Identify peer support models within the AAC field" and "Identify peer support models outside the AAC field." -Another workgroup is tasked to "Present your own peer support model, activities, strategies to the Consortium;" we hope to learn from a presentation at each monthly meeting. The 5/22/2024 Consortium meeting will include a presentation of an AAC Peer Support model from an AAC user. -Workgroups were provided a document titled "Models Template" in each of their workgroup folders. Workgroups will record peer support models they have identified on this document. LINK -The first peer support model presentation occurred at the 5/22/2024 Consortium meeting (see meeting recordings previously linked). -The models template is being updated by each workgroup. Templates are located in each shared workgroup folder.
Identify current peer-to-peer projects, including any that support the use of AAC.	Core leadership + Consortium workgroup	May-September	<ul style="list-style-type: none"> -Consortium workgroups are established as of 5/17/2024, with co-leaders assigned from the core leadership and steering committee teams. Workgroups are specifically tasked to "Identify peer support models within the AAC field" and "Identify peer support models outside the AAC field." -Workgroups were provided a document titled "Models Template" in each of their workgroup folders. Workgroups will record peer support projects they have identified on this document. LINK -The models template is being updated by each workgroup. Templates are located in each shared workgroup folder.
Identify current peer-to-peer approaches including any that support the use of AAC.	Core leadership + Consortium workgroup	May-September	<ul style="list-style-type: none"> -Consortium workgroups are established as of 5/17/2024, with co-leaders assigned from the core leadership and steering committee teams. Two workgroups are specifically tasked to "Identify peer support models within the AAC field" and "Identify peer support models outside the AAC field." -Workgroups were provided a document titled "Models Template" in each of their workgroup folders. Workgroups will record peer support approaches they have identified on this document. -Workgroup 3 has begun to document their exploration and define the characteristics of peer support on a shared google document in their project folder. LINK -The models template is being updated by each workgroup. Templates are located in each shared workgroup folder.

Identify current peer-to-peer activities, including any that support the use of AAC.	Core leadership + Consortium workgroup	May-September	<p>-Consortium workgroups are established as of 5/17/2024, with co-leaders assigned from the core leadership and steering committee teams. Two workgroups are specifically tasked to "Identify peer support models within the AAC field" (Workgroup 1) and "Identify peer support models outside the AAC field" (Workgroup 2).</p> <p>-The leadership team has solicited and received descriptions of Peer Support activities members of the Consortium have participated in.</p> <p>-The leadership team has solicited and received descriptions of Peer Support activities AAC users have participated in. These include online communities and resources, peer groups, conferences, and camps. We continue to invite descriptions of experiences through June 2024.</p> <p>-Workgroup 6 has begun evaluating the data collected in the survey question 4: "Please tell us either what kind of support or mentorship from AAC users you have gotten, and/or what kinds of support you would like to have from other AAC users" and has begun defining categories of peer support activities, for example:</p> <ul style="list-style-type: none"> -Individual Mentoring (1 on 1 mentoring) -Group Mentoring ("Group Chats", "AAC Group") -Camp -Social Networks (Discord, Twitter) LINK <p>-The models template is being updated by each workgroup. Templates are located in each shared workgroup folder.</p>
Develop a protocol for review and analysis of peer support models, projects, approaches and activities within and outside of the AAC field that are organized, at minimum, around three descriptors: person characteristics (who is included), program characteristics (what is done), program outcomes (why).	Core leadership + Consortium workgroup	May-September	<p>-A workgroup has been established, which will focus on: "What are we evaluating? Determine characteristics of peer support models that we will evaluate and include in our recommendations for a national AAC peer support mode." The goal of this workgroup is to meet this outcome.</p> <p>-Workgroup 3 has begun to document their exploration and define the characteristics of peer support on a shared google document. LINK In their shared workgroup folder, the Goals and Progress Notes document details this task as their workgroup goal, with the expected outcome to "Create a list and description of variables we should use to evaluate peer support models." LINK</p> <p>-Workgroup 6 has created the protocol for review. COMPLETED DataExtractionInterventionDesc.pdf, DataExtractionParticipantDescr.pdf</p>

Identify existing partnerships/organizations that use peer-to-peer models to support AAC use with the goal of positive impact on activities of daily living for the individual. Barriers and opportunities within the model/approach or activity that should be considered for national recommendations will also be identified.	Core leadership + Consortium workgroup	May-September	<ul style="list-style-type: none"> -The leadership team has focused on soliciting consortium membership by individuals and organizations that support AAC use with the goal of positive impact on activities of daily living. -The leadership team has solicited and received descriptions of Peer Support activities members of the Consortium have participated in. -Workgroups are tasked with identifying peer support models, projects, activities, and approaches. -The AAC user survey is collecting data on AAC users' experiences with peer support. The data appears to be revealing barriers and opportunities AAC users have faced in various settings. The survey will close on July 1st. The data will be evaluated by Workgroup 6. LINK -The tasks of Workgroups 1, 2 LINK, and 5 include identifying "barriers and opportunities within Peer Support models/approaches or activities that should be considered by the Consortium" in their final work output. This is detailed in each workgroup's Goals and Progress Notes document, which is stored in the workgroup's shared google folder. This was introduced in the introductory emails to the workgroup leaders. LINK -Workgroup members are identifying models on the Models Template. Barriers is an included field on the template.
Develop a schema (an overarching framework that articulates the necessary adaptations to existing peer-support approaches which are needed for the AAC community) to be reviewed by the Consortium.	Core leadership + Consortium workgroup	May-September	<ul style="list-style-type: none"> -A workgroup for systematic review is being formed that will develop a schema. -Workgroup 6 has formed and is tasked with developing a schema to be reviewed by the Consortium. This is noted on the workgroup's Goals and Progress Notes document. LINK -Workgroup has developed a schema. COMPLETED DataExtractionParticipantDescr.pdf, DataExtractionInterventionDescr.pdf
Address the research question of whether peer support models for AAC device users can be developed, and, if those peer support models will help more people use AAC devices, while acknowledging the broader framework of all people who need and use AAC.	Core leadership + Consortium workgroup	May-September	<ul style="list-style-type: none"> -The Consortium workgroups are each analyzing peer support models, many of which are for AAC users. The question of whether models can be developed that will help more people use AAC devices is being formally considered by Workgroup 1. This goal is noted on the Goals and Progress Notes document. LINK -Workgroups continue to evaluate this question.

Identify, Analyze, and consider legal frameworks and funding support systems and include any findings and recommendations included in the Comprehensive Review and Analysis.	Core leadership + Consortium workshop	May-September	<p>-Workgroups 1, 2, and 4 are compiling information about peer support models in and outside of the AAC field on their workgroup's Models Template documents. The Models template form includes a section on how the model or activity is funded. LINK</p> <p>-Workgroups continue to evaluate this question.</p>
Identify barriers and action steps to address these barriers, particularly those faced by people from multiply marginalized communities and include any barriers and action steps included in final Comprehensive Review and Analysis.	Core leadership + Consortium workshop	May-September	<p>-A workgroup has been established to "Develop strategies for inclusion of diversity and underrepresented communities in models and recommendations." This workgroup will be key in identifying barriers and action steps to address those barriers.</p> <p>-Workgroup 5 has faced barriers to progress in this step, as there have been no volunteers from the Consortium to co-lead alongside one of our leadership/steering committee members. The person initially recruited to co-lead this workgroup has not responded to multiple messages from the Core Leadership and has not engaged in any Consortium activities despite frequent invitations from multiple Core Leadership team members. We have worked to recruit a co-leader from among our Consortium members who represents multiply marginalized communities; several qualified members have declined due to conflicting schedules and responsibilities. A new member has recently joined that we plan to recruit to co-lead this group.</p> <p>-Workgroups 1, 2, and 4 have begun compiling information about peer support models in their Models Template documents, which includes a section prompting to consider: "Are there any barriers to participation? Are there opportunities to increase participation?" LINK</p> <p>-Workgroups continue to evaluate this question.</p>
Identify themes, promising approaches and practices, and areas of need to develop the plan, working alongside the partnership consortium to ensure attention to Diversity, Equity, and Inclusion.	Core leadership + Consortium workshop	May-September	<p>-A workgroup has been established to "Develop strategies for inclusion of diversity and underrepresented communities in models and recommendations." This workgroup will be key in developing the final recommendations. Consortium members in other workgroups have expressed personal interest in contributing to this topic.</p> <p>-Workgroup 5 has significant representation and continues to meet to address this topic. Meeting notes can be found in the shared workgroup folder.</p>
Partner with AUCD, consortium, and AoD to develop an initial list of resources and information to inform and develop a proposed approach and plan.	Core leadership + Consortium workshop	May-September	<p>-The Models Template documents are being used by Workgroup members, and will be utilized in the initial list of resources and information.</p> <p>-Workgroups continue to add to the Models Templates.</p>

Deliverables:				
Results of the survey of AAC users and their peer support preferences.	Core leadership	ongoing	<p>As of 4/15/2024, results from 100 AAC users was sent to AUCD. We continue this survey until June 2024. An abstract has been submitted to ISAAC for a 2-hour presentation, including data on AAC users and their peer support preferences.</p> <p>-As of 5/6/2024, 119 responses have been collected. The survey continues to be distributed with invitations to respond through June 2024.</p> <p>-As of 6/17/2024, the survey has received 133 responses. The survey will close on July 1st, 2024. Workgroup 6 has begun the process of analyzing the results. LINK</p> <p>-Some of the survey data was shared at the 5/22/2024 and 6/28/2024 Consortium meetings.</p>	
An analysis of the existing activities and approaches that could be applied to an AAC support model.	Core leadership + Consortium workgroup	May-September	<p>-The finalization of the Consortium and formation of workgroups was delayed. The Core leadership will begin work on this deliverable once there is work output from the workgroups. The workgroups have begun compiling information in their shared workgroup folders that will be analyzed by the core leadership.</p> <p>-A thematic analysis is in process.</p>	
Completed Schema (an overarching framework that articulates the necessary adaptations to existing peer-support approaches which are needed for the AAC community).	Core leadership + Consortium workgroup	May-September	<p>-The Core leadership will begin work on this deliverable as the workgroups produce work output. Workgroups 3 and 6 in particular are associated with this task.</p> <p>-A systematic review is in process.</p>	
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.	Core leadership + Consortium workgroup	May-September	<p>-The Core leadership will begin work on this deliverable as the workgroups produce work output.</p>	
A set of actionable recommendations for the creation of a nationwide resource for developing peer support models to encourage the use of AAC devices by those who are not currently using them for communication.	Core leadership + Consortium workgroup	May-September	<p>-The Core leadership will begin work on this deliverable as the workgroups produce work output</p>	

Legal frameworks report with findings and recommendations.	Core leadership + Consortium workgroup	May-September	-The Core leadership will begin work on this deliverable as the workgroups produce work output
Initial list of resources and information.	Core leadership + Consortium workgroup	May-September	-The Core leadership will begin work on this deliverable as the workgroups produce work output

Objective 4 – Endorse a Nationwide Comprehensive, Consensus-Based Peer Support Model for Advancing AAC.			
	Responsible Party	Timeline	Update
Produce, Share and discuss the report with the Consortium.	Core leadership + Consortium	September-December	
Collaborate with AUCD and the Consortium to develop recommendations and action steps that include special consideration for those that would advance Equity, Diversity, and Inclusion.	Core leadership + Consortium workgroup	September-December	
Develop report with the Consortium and use criteria for adopting final recommendations.	Core leadership + Consortium workgroup	September-December	
Partner with AUCD and the partnership consortium to deliver to AoD and all stakeholders a comprehensive recommended plan and proposed approach for establishing a nationwide resource for developing peer-to-peer models that will promote and enhance the use of AAC devices as well as the overall quality of life of people who use AAC.	Core leadership	September-December	

Develop external reports for the members of the Consortium and for health systems, universities, and education entities, and public service agencies. This includes an online accessible plan that will be available on OHSU UCEDD and CommunicationFIRST websites. Additional formats that will be available online include a plain language version, an audio version, and a symbol-based version.	Core leadership + Consortium	September-December	
Deliverables			
Completed plan with recommendations.		December	
Completed external reports.		December	

July Work Plan Report

Objective 1 – Establish Partnership Group			
	Responsible Party	Timeline	Update
Partner with AUCD to establish partnership consortium with significant representation of people who use AAC, potential users of AAC, nonprofit community-based service provider organizations, direct support professionals, self-advocacy organizations, youth and adults with ID/DD, families, related service providers, educators, others in their support system, and people from multiply marginalized communities.	Core leadership	March, 2024	Partnership plan established and agreed upon. AUCD attends weekly project meetings, contributes to agenda and reports to both project core leadership and ACL. Completed -The Core Leadership and Consortium has continued inviting and accepting new members. The Consortium will close to new members on July 1st. AAC users make up 40% of active consortium members, which includes core leadership, workgroup members, co-leaders, steering committee, observers, and reviewers. <i>Note:</i> those who elected to receive monthly updates only are not included as they have not self-identified their AAC use status and are unknown. -Consortium representation is detailed on the Consortium roster, last updated on 6/17/2024. LINK -Consortium roster was updated on 7/9/2024 LINK

Identify members of Steering Committee of the National Partnership Consortium.	Core leadership	March-April, 2024	Two members of steering committee have been identified and agreed to participate. We will look for one additional AAC user to serve. -Another AAC user will be invited to join the Steering Committee in May 2024 -Tracy Rackensperger, an AAC user who is faculty at the Georgia UCEDD is the third member of the Steering Committee. Completed.
Partner with AUCD to develop equitable and inclusive governance structure for Consortium.	Core leadership	March-April, 2024	Governance structure established. Completed
Deliverable - A full roster of confirmed National Partnership Consortium and Steering Committee members, along with their affiliations, roles, and contact information.	Core leadership	March-April 2024	On 4/15/24, the roster as of 4.5.24 was submitted to AUCD with names, email addresses and affiliations. Completed -An updated roster was submitted on 5/2/2024 and will continue monthly updates -The roster was updated on 6/17/2024 to add additional members who had recently joined, and identify all Steering Committee members. LINK -Consortium roster was updated on 7/9/2024 to add new members LINK
Objective 2 – Develop Governance and Management Plan			
	Responsible Party	Timeline	Update
Partner with AUCD to draft partnership management plan with shared decision-making model.	MFO, AUCD	March-April, 2024	Completed
Partner with AUCD to plan for and facilitate monthly meetings of partnership consortium.	Core leadership + AUCD	March-April, 2024	We held our first consortium meeting on 4/5/2024 with 40 participants present virtually. AUCD worked to invite consortium members and make sure ACL was present at meeting. -May 2024: The second partnership consortium meeting is scheduled for 5/22/2024. -The leadership team agreed to a plan for monthly meetings; they will be held virtually on the 4th Wednesday of the month, 12pm-1pm (west coast). - Completed (agreed on 5/20/2024) LINK
Establish a schedule of monthly meetings with AUCD and AoD to monitor progress of activities and discuss any concerns.	Core leadership + AUCD	March-April, 2024	AUCD, represented by Holly Hohmeister, attends weekly core leadership meetings. Completed
Deliverables			

<p>A schedule of National Partnership Consortium and Steering Committee meetings with locations (virtual or in-person).</p>	<p>Core leadership</p>	<p>March-April, 2024</p>	<p>All consortium and steering committee meetings will be virtual.</p> <ul style="list-style-type: none"> -The leadership team agreed to a plan for monthly meetings; they will be held virtually on the 4th Wednesday of the month, 12pm-1pm (west coast). -The meeting schedule was announced at the 5/22/2024 Consortium Meeting, with 36 participants present. LINK LINK LINK LINK -Consortium members who joined in the month of May and beyond receive an introductory email informing them of this schedule, as well as the zoom link that is used for all Consortium meetings. Link to sample email -Individuals who were invited by consortium members, and who registered for the 5/22/2024 consortium meeting were provided the zoom link via email, which also included the meeting agenda noting the recurring meeting schedule. LINK -A document detailing the meeting schedule and recurring zoom meeting link was placed in each workgroup's google folder, which is shared with each member of their workgroup. (example provided). LINK -The Steering Committee has held one meeting so far, and has not established a meeting schedule going forward. The committee will collaborate and determine a meeting schedule once the workgroups begin to produce work output. -A post-meeting participant survey was established for the June Consortium meeting. The results indicated a need to extend the length of Consortium meetings and change the structure of meetings LINK -Steering Committee met on June 28th. They decided to hold AAC user-only meetings on 7/15 and 7/22/24. -Steering Committee has been holding meetings with the AAC users on the Consortium, reporting at the Consortium and attending core leadership meetings. Very active group.
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Minutes/notes from any National Partnership Consortium and Steering Committee meetings held.	MFO	ongoing	<p>Weekly minutes available from consortium and steering committee meetings in Google Drive</p> <p>-agendas and other documentation continues to be made available on the leadership team's shared google drive</p> <p>-Consortium meeting agendas and slides are stored in the project's shared google drive. Copies of Consortium meeting agendas, slides, zoom meeting recordings (audio, video, in-meeting chat, and transcripts) are all saved to each workgroup's shared google folder within the project's shared drive. LINK</p> <p>-Copies of these same items, as well as other pertinent project documents (Consortium Member Roles and Responsibilities; language to used to invite new consortium members or invite survey respondents) are saved to a separate shared folder created for Consortium members who joined at the "Observer" or "Monthly Updates Only" level. The link to this shared folder was provided via email to those members sharing the monthly updates from May. Each monthly update email will include that information. LINK</p> <p>-The Steering Committee has held one meeting so far. The meeting agenda is available on the project shared google drive. Future meeting agendas will be saved to the project shared drive.</p> <p>-Steering Committee meeting agendas are available on the project shared drive. The link to the 6/28/2024 meeting: LINK</p> <p>-Minutes available in google folder for weekly core leadership, weekly workgroups, steering committee and consortium meetings.</p>
Written monthly reports of project activities using Progress Report Template.	MFO	Ongoing	<p>Progress Report Template sent from AUCD to MFO. Completion of first progress report 4/15/2024.</p> <ul style="list-style-type: none"> - Second progress report submitted 5/17/2024 - Third progress report submitted 6/17/2024 - Fourth progress report submitted 7/15/2024 - July progress report submitted 8/15/2024

<p>Objective 3 – Conduct Comprehensive Review and Analysis</p> <p>The comprehensive review and analysis of peer support models, projects, approaches and activities within and outside the field of AAC will be accomplished by the Consortium, with input from the greater community of people who use or need AAC, guided by the Steering Committee, and managed by the leadership team. The Subrecipient will:</p>			
	Responsible Party	Timeline	Update

Engage AUCD, the Consortium and AoD in the development of a plan for the comprehensive review and analysis (CRA) of peer-to-peer models for people who use AAC with specific focus on models, projects, approaches, and activities with strong potential for positive life changes at the individual level.	Core leadership + Consortium workshop	May-October	<ul style="list-style-type: none"> -We have engaged a national consortium -The Consortium workgroups were assigned in May 2024. Workgroup co-leaders were chosen and are directing the work of their workgroup members to meet those goals. Workgroups are divided as follows: <ul style="list-style-type: none"> -Workgroup 1: Identify peer support models within the AAC field -Workgroup 2: Identify peer support models outside the AAC field -Workgroup 3: What are we evaluating? -Workgroup 4: Present peer support model, activities, strategies to the Consortium -Workgroup 5: Develop strategies for inclusion of diversity and underrepresented communities in models and recommendations -Workgroup 6: Systematic review/ metanalysis of peer support literature -Each workgroup was provided a shared google folder containing a "Goals and Progress Notes" document that details the goals of the workgroup in the project. The contents of the workgroup's shared folders, including the Goals and Progress Notes document were described via email, with direct links to the folder. LINK -Each workgroup continues to work toward their goals and to report out at the monthly consortium meetings. -Each workgroup continues to work toward their goals and to report out at the monthly consortium meetings.
Conduct a survey of AAC users in coordination with of identified advocacy and AAC provider organizations.	Core leadership	March-June	<p>100 AAC users have responded to the on-line survey. A list of AAC and advocacy organizations who have added the survey link to their social media or emails is in the weekly partner minutes.</p> <ul style="list-style-type: none"> -As of 5/6/2024, 119 responses have been collected. The survey continues to be distributed with invitations to respond through June 2024. -As of 6/13/2024, 132 responses have been collected. Results of the following survey questions: <ul style="list-style-type: none"> -Have other AAC users helped you develop AAC skills? -How much have other AAC users helped you develop your skills in using AAC? -Would you like more mentoring? <p>were shared at the 5/22/2024 Consortium meeting (see meeting recordings previously linked). Additional survey results will be shared at the 6/26/2024 Consortium meeting.</p> <ul style="list-style-type: none"> -Data about AAC peer support activities reported in the survey are undergoing a thematic analysis. -Thematic analysis completed and will be shared with core leadership on 8/20/2024 from workgroup 6.

Identify current peer-to-peer models, including any that support the use of AAC.	Core leadership + Consortium workgroup	May-September	<ul style="list-style-type: none"> -Consortium workgroups are established as of 5/17/2024, with co-leaders assigned from the core leadership and steering committee teams. Two workgroups are specifically tasked to “Identify peer support models within the AAC field” and “Identify peer support models outside the AAC field.” -Another workgroup is tasked to “Present your own peer support model, activities, strategies to the Consortium,” we hope to learn from a presentation at each monthly meeting. The 5/22/2024 Consortium meeting will include a presentation of an AAC Peer Support model from an AAC user. -Workgroups were provided a document titled “Models Template” in each of their workgroup folders. Workgroups will record peer support models they have identified on this document. LINK -The first peer support model presentation occurred at the 5/22/2024 Consortium meeting (see meeting recordings previously linked). -The models template is being updated by each workgroup. Templates are located in each shared workgroup folder. -Google survey designed for use of and accessibility and sent out to Consortium to complete. -To date, we have 56 models described. (Most of the models from the proposal are included as well as many models/activities that were not in the proposal.)
Identify current peer-to-peer projects, including any that support the use of AAC.	Core leadership + Consortium workgroup	May-September	<ul style="list-style-type: none"> -Consortium workgroups are established as of 5/17/2024, with co-leaders assigned from the core leadership and steering committee teams. Workgroups are specifically tasked to “Identify peer support models within the AAC field” and “Identify peer support models outside the AAC field.” -Workgroups were provided a document titled “Models Template” in each of their workgroup folders. Workgroups will record peer support projects they have identified on this document. LINK -The models template is being updated by each workgroup. Templates are located in each shared workgroup folder. -To date, we have 56 projects described in Google survey.

Identify current peer-to-peer approaches including any that support the use of AAC.	Core leadership + Consortium workgroup	May-September	<ul style="list-style-type: none"> -Consortium workgroups are established as of 5/17/2024, with co-leaders assigned from the core leadership and steering committee teams. Two workgroups are specifically tasked to "Identify peer support models within the AAC field" and "Identify peer support models outside the AAC field." -Workgroups were provided a document titled "Models Template" in each of their workgroup folders. Workgroups will record peer support approaches they have identified on this document. -Workgroup 3 has begun to document their exploration and define the characteristics of peer support on a shared google document in their project folder. LINK -The models template is being updated by each workgroup. Templates are located in each shared workgroup folder. -To date, we have 56 projects described in Google survey.
Identify current peer-to-peer activities, including any that support the use of AAC.	Core leadership + Consortium workgroup	May-September	<ul style="list-style-type: none"> -Consortium workgroups are established as of 5/17/2024, with co-leaders assigned from the core leadership and steering committee teams. Two workgroups are specifically tasked to "Identify peer support models within the AAC field" (Workgroup 1) and "Identify peer support models outside the AAC field" (Workgroup 2). -The leadership team has solicited and received descriptions of Peer Support activities members of the Consortium have participated in. -The leadership team has solicited and received descriptions of Peer Support activities AAC users have participated in. These include online communities and resources, peer groups, conferences, and camps. We continue to invite descriptions of experiences through June 2024. -Workgroup 6 has begun evaluating the data collected in the survey question 4: "Please tell us either what kind of support or mentorship from AAC users you have gotten, and/or what kinds of support you would like to have from other AAC users" and has begun defining categories of peer support activities, for example: <ul style="list-style-type: none"> -Individual Mentoring (1 on 1 mentoring) -Group Mentoring ("Group Chats", "AAC Group") -Camp -Social Networks (Discord, Twitter) LINK -The models template is being updated by each workgroup. Templates are located in each shared workgroup folder. -To date, we have 56 activities described in Google survey.

Develop a protocol for review and analysis of peer support models, projects, approaches and activities within and outside of the AAC field that are organized, at minimum, around three descriptors: person characteristics (who is included), program characteristics (what is done), program outcomes (why).	Core leadership + Consortium workshop	May-September	<p>-A workgroup has been established, which will focus on: “What are we evaluating? Determine characteristics of peer support models that we will evaluate and include in our recommendations for a national AAC peer support mode.” The goal of this workgroup is to meet this outcome.</p> <p>-Workgroup 3 has begun to document their exploration and define the characteristics of peer support on a shared google document. LINK In their shared workgroup folder, the Goals and Progress Notes document details this task as their workgroup goal, with the expected outcome to “Create a list and description of variables we should use to evaluate peer support models.” LINK</p> <p>-Workgroup 6 has created the protocol for review. COMPLETEDDataExtractionInterventionDesc.pdf, DataExtractionParticipantDescr.pdf</p> <p>-Dr. Emily Quinn, responsible faculty for systematic review, is increasing her FTE for this project to make sure that the review is completed on time.</p>
Identify existing partnerships/organizations that use peer-to-peer models to support AAC use with the goal of positive impact on activities of daily living for the individual. Barriers and opportunities within the model/approach or activity that should be considered for national recommendations will also be identified.	Core leadership + Consortium workshop	May-September	<p>-The leadership team has focused on soliciting consortium membership by individuals and organizations that support AAC use with the goal of positive impact on activities of daily living.</p> <p>-The leadership team has solicited and received descriptions of Peer Support activities members of the Consortium have participated in.</p> <p>-Workgroups are tasked with identifying peer support models, projects, activities, and approaches.</p> <p>-The AAC user survey is collecting data on AAC users’ experiences with peer support. The data appears to be revealing barriers and opportunities AAC users have faced in various settings. The survey will close on July 1st. The data will be evaluated by Workgroup 6. LINK</p> <p>-The tasks of Workgroups 1, 2 LINK, and 5 include identifying “barriers and opportunities within Peer Support models/approaches or activities that should be considered by the Consortium” in their final work output. This is detailed in each workgroup’s Goals and Progress Notes document, which is stored in the workgroup’s shared google folder. This was introduced in the introductory emails to the workgroup leaders. LINK</p> <p>-Workgroup members are identifying models on the Models Template. Barriers is an included field on the template.</p> <p>-Meeting set up 8/29/24 with PA DD system to discuss barriers, finances and policies they identify for peer supports.</p>

Develop a schema (an overarching framework that articulates the necessary adaptations to existing peer-support approaches which are needed for the AAC community) to be reviewed by the Consortium.	Core leadership + Consortium workgroup	May-September	<ul style="list-style-type: none"> -A workgroup for systematic review is being formed that will develop a schema. -Workgroup 6 has formed and is tasked with developing a schema to be reviewed by the Consortium. This is noted on the workgroup's Goals and Progress Notes document. LINK -Workgroup has developed a schema. -Work continues.
Address the research question of whether peer support models for AAC device users can be developed, and, if those peer support models will help more people use AAC devices, while acknowledging the broader framework of all people who need and use AAC.	Core leadership + Consortium workgroup	May-September	<ul style="list-style-type: none"> -The Consortium workgroups are each analyzing peer support models, many of which are for AAC users. The question of whether models can be developed that will help more people use AAC devices is being formally considered by Workgroup 1. This goal is noted on the Goals and Progress Notes document. LINK -Workgroups continue to evaluate this question. -Work continues.
Identify, Analyze, and consider legal frameworks and funding support systems and include any findings and recommendations included in the Comprehensive Review and Analysis.	Core leadership + Consortium workgroup	May-September	<ul style="list-style-type: none"> -Workgroups 1, 2, and 4 are compiling information about peer support models in and outside of the AAC field on their workgroup's Models Template documents. The Models template form includes a section on how the model or activity is funded. LINK -Workgroups continue to evaluate this question. -Work continues. Meeting set up 8/29/24 with PA DD system to discuss barriers, finances and policies they identify for peer supports.

Identify barriers and action steps to address these barriers, particularly those faced by people from multiply marginalized communities and included any barriers and action steps included in final Comprehensive Review and Analysis.	Core leadership + Consortium workgroup	May-September	<p>-A workgroup has been established to “Develop strategies for inclusion of diversity and underrepresented communities in models and recommendations.” This workgroup will be key in identifying barriers and action steps to address those barriers.</p> <p>-Workgroup 5 has faced barriers to progress in this step, as there have been no volunteers from the Consortium to co-lead alongside one of our leadership/steering committee members. The person initially recruited to co-lead this workgroup has not responded to multiple messages from the Core Leadership and has not engaged in any Consortium activities despite frequent invitations from multiple Core Leadership team members. We have worked to recruit a co-leader from among our Consortium members who represents multiply marginalized communities; several qualified members have declined due to conflicting schedules and responsibilities. A new member has recently joined that we plan to recruit to co-lead this group.</p> <p>-Workgroups 1, 2, and 4 have begun compiling information about peer support models in their Models Template documents, which includes a section prompting to consider: “Are there any barriers to participation? Are there opportunities to increase participation?” LINK</p> <p>-Workgroups continue to evaluate this question.</p> <p>-Workgroup 5 (DEIA group) is writing their recommendations to address these issues.</p>
Identify themes, promising approaches and practices, and areas of need to develop the plan, working alongside the partnership consortium to ensure attention to Diversity, Equity, and Inclusion.	Core leadership + Consortium workgroup	May-September	<p>-A workgroup has been established to “Develop strategies for inclusion of diversity and underrepresented communities in models and recommendations.” This workgroup will be key in developing the final recommendations.</p> <p>Consortium members in other workgroups have expressed personal interest in contributing to this topic.</p> <p>-Workgroup 5 has significant representation and continues to meet to address this topic. Meeting notes can be found in the shared workgroup folder.</p> <p>-Workgroup 5 (DEIA group) is writing their recommendations to address these issues.</p>
Partner with AUCD, consortium, and AoD to develop an initial list of resources and information to inform and develop a proposed approach and plan.	Core leadership + Consortium workgroup	May-September	<p>-The Models Template documents are being used by Workgroup members, and will be utilized in the initial list of resources and information.</p> <p>-Workgroups continue to add to the Models Templates.</p> <p>-Google survey designed for use and accessibility and sent out to Consortium to complete.</p> <p>-To date, we have 56 models described. (Most of the models from the proposal are included as well as many models/activities that were not in the proposal.)</p>
Deliverables:			

Results of the survey of AAC users and their peer support preferences.	Core leadership	ongoing	<p>As of 4/15/2024, results from 100 AAC users was sent to AUCD. We continue this survey until June 2024. An abstract has been submitted to ISAAC for a 2-hour presentation, including data on AAC users and their peer support preferences.</p> <p>-As of 5/6/2024, 119 responses have been collected. The survey continues to be distributed with invitations to respond through June 2024.</p> <p>-As of 6/17/2024, the survey has received 133 responses. The survey will close on July 1st, 2024. Workgroup 6 has begun the process of analyzing the results. LINK</p> <p>-Some of the survey data was shared at the 5/22/2024 and 6/28/2024 Consortium meetings.</p> <p>-Thematic analysis completed and will be shared with core leadership on 8/20/2024.</p>
An analysis of the existing activities and approaches that could be applied to an AAC support model.	Core leadership + Consortium workgroup	May-September	<p>-The finalization of the Consortium and formation of workgroups was delayed. The Core leadership will begin work on this deliverable once there is work output from the workgroups. The workgroups have begun compiling information in their shared workgroup folders that will be analyzed by the core leadership.</p> <p>-A thematic analysis is in process.</p> <p>-Thematic analysis completed and will be shared with core leadership on 8/20/2024.</p>
Completed Schema (an overarching framework that articulates the necessary adaptations to existing peer-support approaches which are needed for the AAC community).	Core leadership + Consortium workgroup	May-September	<p>-The Core leadership will begin work on this deliverable as the workgroups produce work output. Workgroups 3 and 6 in particular are associated with this task.</p> <p>-A systematic review is in process.</p> <p>-Workgroup 6 is in the middle of the systematic review to date.</p>
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.	Core leadership + Consortium workgroup	May-September	<p>-The Core leadership will begin work on this deliverable as the workgroups produce work output.</p>
A set of actionable recommendations for the creation of a nationwide resource for developing peer support models to encourage the use of AAC devices by those who are not currently using them for communication.	Core leadership + Consortium workgroup	May-September	<p>-The Core leadership will begin work on this deliverable as the workgroups produce work output</p>

Legal frameworks report with findings and recommendations.	Core leadership + Consortium workgroup	May-September	-The Core leadership will begin work on this deliverable as the workgroups produce work output
Initial list of resources and information.	Core leadership + Consortium workgroup	May-September	-The Core leadership will begin work on this deliverable as the workgroups produce work output

Objective 4 – Endorse a Nationwide Comprehensive, Consensus-Based Peer Support Model for Advancing AAC.			
	Responsible Party	Timeline	Update
Produce, Share and discuss the report with the Consortium.	Core leadership + Consortium	September-December	
Collaborate with AUCD and the Consortium to develop recommendations and action steps that include special consideration for those that would advance Equity, Diversity, and Inclusion.	Core leadership + Consortium workgroup	September-December	
Develop report with the Consortium and use criteria for adopting final recommendations.	Core leadership + Consortium workgroup	September-December	
Partner with AUCD and the partnership consortium to deliver to AoD and all stakeholders a comprehensive recommended plan and proposed approach for establishing a nationwide resource for developing peer-to-peer models that will promote and enhance the use of AAC devices as well as the overall quality of life of people who use AAC.	Core leadership	September-December	

Develop external reports for the members of the Consortium and for health systems, universities, and education entities, and public service agencies. This includes an online accessible plan that will be available on OHSU UCEDD and CommunicationFIRST websites. Additional formats that will be available online include a plain language version, an audio version, and a symbol-based version.	Core leadership + Consortium	September-December	
Deliverables			
Completed plan with recommendations.		December	
Completed external reports.		December	

August Work Plan Report

Objective 1 – Establish Partnership Group			
	Responsible Party	Timeline	Update
Partner with AUCD to establish partnership consortium with significant representation of people who use AAC, potential users of AAC, nonprofit community-based service provider organizations, direct support professionals, self-advocacy organizations, youth and adults with ID/DD, families, related service providers, educators, others in their support system, and people from multiply marginalized communities.	Core leadership	March, 2024	Completed
Identify members of Steering Committee of the National Partnership Consortium.	Core leadership	March-April, 2024	Completed

Partner with AUCD to develop equitable and inclusive governance structure for Consortium.	Core leadership	March-April, 2024	Completed
Deliverable - A full roster of confirmed National Partnership Consortium and Steering Committee members, along with their affiliations, roles, and contact information.	Core leadership	March-April 2024	Completed
Objective 2 – Develop Governance and Management Plan			
	Responsible Party	Timeline	Update
Partner with AUCD to draft partnership management plan with shared decision-making model.	MFO, AUCD	March-April, 2024	Completed
Partner with AUCD to plan for and facilitate monthly meetings of partnership consortium.	Core leadership + AUCD	March-April, 2024	Completed
Establish a schedule of monthly meetings with AUCD and AoD to monitor progress of activities and discuss any concerns.	Core leadership + AUCD	March-April, 2024	Completed
Deliverables			
A schedule of National Partnership Consortium and Steering Committee meetings with locations (virtual or in-person).	Core leadership	March-April, 2024	Completed

Minutes/notes from any National Partnership Consortium and Steering Committee meetings held.	MFO	ongoing	<p>Weekly minutes available from consortium and steering committee meetings in Google Drive</p> <ul style="list-style-type: none"> -agendas and other documentation continues to be made available on the leadership team's shared google drive -Consortium meeting agendas and slides are stored in the project's shared google drive. Copies of Consortium meeting agendas, slides, zoom meeting recordings (audio, video, in-meeting chat, and transcripts) are all saved to each workgroup's shared google folder within the project's shared drive. LINK -Copies of these same items, as well as other pertinent project documents (Consortium Member Roles and Responsibilities; language to used to invite new consortium members or invite survey respondents) are saved to a separate shared folder created for Consortium members who joined at the "Observer" or "Monthly Updates Only" level. The link to this shared folder was provided via email to those members sharing the monthly updates from May. Each monthly update email will include that information. LINK -The Steering Committee has held one meeting so far. The meeting agenda is available on the project shared google drive. Future meeting agendas will be saved to the project shared drive. -Steering Committee meeting agendas are available on the project shared drive. The link to the 6/28/2024 meeting: LINK -Minutes available in google folder for weekly core leadership, weekly workgroups, steering committee and consortium meetings. -All meetings are recorded via zoom video, audio, along with chat and transcript files. These files along with all meeting agendas, notes, and documents shared between Consortium members are stored in corresponding folders in the project google drive.
Written monthly reports of project activities using Progress Report Template.	MFO	Ongoing	<p>Progress Report Template sent from AUCD to MFO. Completion of first progress report 4/15/2024.</p> <ul style="list-style-type: none"> - Second progress report submitted 5/17/2024 - Third progress report submitted 6/17/2024 - Fourth progress report submitted 7/15/2024 - July progress report submitted 8/15/2024 - August progress report submitted 9/13/2024

<p>Objective 3 – Conduct Comprehensive Review and Analysis The comprehensive review and analysis of peer support models, projects, approaches and activities within and outside the field of AAC will be accomplished by the Consortium, with input from the greater community of people who use or need AAC, guided by the Steering Committee, and managed by the leadership team. The Subrecipient will:</p>			
	Responsible Party	Timeline	Update
Engage AUCD, the Consortium and AoD in the development of a plan for the comprehensive review and analysis (CRA) of peer-to-peer models for people who use AAC with specific focus on models, projects, approaches, and activities with strong potential for positive life changes at the individual level.	Core leadership + Consortium workgroup	May-October	<ul style="list-style-type: none"> -We have engaged a national consortium -The Consortium workgroups were assigned in May 2024. Workgroup co-leaders were chosen and are directing the work of their workgroup members to meet those goals. Workgroups are divided as follows: <ul style="list-style-type: none"> -Workgroup 1: Identify peer support models within the AAC field -Workgroup 2: Identify peer support models outside the AAC field -Workgroup 3: What are we evaluating? Determine characteristics of peer support models that we will evaluate and include in our recommendations for a national AAC peer support model -Workgroup 4: Present peer support model, activities, strategies to the Consortium -Workgroup 5: Develop strategies for inclusion of diversity and underrepresented communities in models and recommendations -Workgroup 6: Systematic review/ metaanalysis of peer support literature -Each workgroup was provided a shared google folder containing a “Goals and Progress Notes” document that details the goals of the workgroup in the project. The contents of the workgroup’s shared folders, including the Goals and Progress Notes document were described via email, with direct links to the folder: LINK LINK -Each workgroup continues to work toward their goals and to report out at the monthly consortium meetings. -Each workgroup continues to work toward their goals and to report on their progress at the monthly consortium meetings.

Conduct a survey of AAC users in coordination with of identified advocacy and AAC provider organizations.	Core leadership	March-June	<p>100 AAC users have responded to the on-line survey. A list of AAC and advocacy organizations who have added the survey link to their social media or emails is in the weekly partner minutes.</p> <p>-As of 5/6/2024, 119 responses have been collected. The survey continues to be distributed with invitations to respond through June 2024.</p> <p>-As of 6/13/2024, 132 responses have been collected. Results of the following survey questions:</p> <ul style="list-style-type: none"> -Have other AAC users helped you develop AAC skills? -How much have other AAC users helped you develop your skills in using AAC? -Would you like more mentoring? <p>were shared at the 5/22/2024 Consortium meeting (see meeting recordings previously linked). Additional survey results will be shared at the 6/26/2024 Consortium meeting.</p> <ul style="list-style-type: none"> -Data about AAC peer support activities reported in the survey are undergoing a thematic analysis. -Thematic analysis completed and will be shared with core leadership on 8/20/2024 from workgroup 6. -The thematic analysis will be an appendix in the final report.
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Identify current peer-to-peer models, including any that support the use of AAC.	Core leadership + Consortium workshop	May-September	<ul style="list-style-type: none"> -Consortium workgroups are established as of 5/17/2024, with co-leaders assigned from the core leadership and steering committee teams. Two workgroups are specifically tasked to “Identify peer support models within the AAC field” and “Identify peer support models outside the AAC field.” -Another workgroup is tasked to “Present your own peer support model, activities, strategies to the Consortium,” we hope to learn from a presentation at each monthly meeting. The 5/22/2024 Consortium meeting will include a presentation of an AAC Peer Support model from an AAC user. -Workgroups were provided a document titled “Models Template” in each of their workgroup folders. Workgroups will record peer support models they have identified on this document. LINK -The first peer support model presentation occurred at the 5/22/2024 Consortium meeting (see meeting recordings previously linked). -The models template is being updated by each workgroup. Templates are located in each shared workgroup folder. -Google survey designed for use of and accessibility and sent out to Consortium. -To date, we have 56 models described. (Most of the models from the proposal are included as well as many models/activities that were not in the proposal.) -There were 63 models recorded using the models template and google survey, but several models were duplicated. Duplicate responses were combined for a total of 58 models. The results of this survey were summarized and reviewed at the 9/9/2024 Core Leadership meeting. This will be in the final report.
Identify current peer-to-peer projects, including any that support the use of AAC.	Core leadership + Consortium workshop	May-September	<ul style="list-style-type: none"> -Consortium workgroups are established as of 5/17/2024, with co-leaders assigned from the core leadership and steering committee teams. Workgroups are specifically tasked to “Identify peer support models within the AAC field” and “Identify peer support models outside the AAC field.” -Workgroups were provided a document titled “Models Template” in each of their workgroup folders. Workgroups will record peer support projects they have identified on this document. LINK -The models template is being updated by each workgroup. Templates are located in each shared workgroup folder. -To date, we have 56 projects described in Google survey. -There were 58 peer support models recorded, some of which are projects.

Identify current peer-to-peer approaches including any that support the use of AAC.	Core leadership + Consortium workgroup	May-September	<ul style="list-style-type: none"> -Consortium workgroups are established as of 5/17/2024, with co-leaders assigned from the core leadership and steering committee teams. Two workgroups are specifically tasked to “Identify peer support models within the AAC field” and “Identify peer support models outside the AAC field.” -Workgroups were provided a document titled “Models Template” in each of their workgroup folders. Workgroups will record peer support approaches they have identified on this document. -Workgroup 3 has begun to document their exploration and define the characteristics of peer support on a shared google document in their project folder: LINK -The models template is being updated by each workgroup. Templates are located in each shared workgroup folder. -To date, we have 56 projects described in Google survey. -There were 58 peer support models recorded, detailing varying approaches.
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Identify current peer-to-peer activities, including any that support the use of AAC.	Core leadership + Consortium workgroup	May-September	<p>-Consortium workgroups are established as of 5/17/2024, with co-leaders assigned from the core leadership and steering committee teams. Two workgroups are specifically tasked to “Identify peer support models within the AAC field” (Workgroup 1) and “Identify peer support models outside the AAC field” (Workgroup 2).</p> <p>-The leadership team has solicited and received descriptions of Peer Support activities members of the Consortium have participated in.</p> <p>-The leadership team has solicited and received descriptions of Peer Support activities AAC users have participated in. These include online communities and resources, peer groups, conferences, and camps. We continue to invite descriptions of experiences through June 2024.</p> <p>-Workgroup 6 has begun evaluating the data collected in the survey question 4: “Please tell us either what kind of support or mentorship from AAC users you have gotten, and/or what kinds of support you would like to have from other AAC users” and has begun defining categories of peer support activities, for example: Individual Mentoring, Group Mentoring, Camp, Social Networks (Discord, Twitter) LINK</p> <p>-The models template is being updated by each workgroup. Templates are located in each shared workgroup folder.</p> <p>-To date, we have 56 activities described in Google survey.</p> <p>-There were 58 peer support models recorded using our models survey. The survey gave a number of multiple choice options for the peer support activity that took place:</p> <ul style="list-style-type: none"> -structured instruction (i.e. formal curriculum or planned lecture) -semi-structured presentation or discussion -unstructured conversation -supportive peer counseling -role-playing or other structured exercises -navigating or finding services -homework (like an assignment to prepare for the next activity or class) -developing a treatment plan or goal planning -socializing / shared social activities -networking -coaching -mutual self-help -learning self-care -training or support to manage direct support professionals/personal care -learning or sharing technology -connecting about shared interests or shared experiences -advice for difficulties in life
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Develop a protocol for review and analysis of peer support models, projects, approaches and activities within and outside of the AAC field that are organized, at minimum, around three descriptors: person characteristics (who is included), program characteristics (what is done), program outcomes (why).	Core leadership + Consortium workgroup	May-September		

Identify existing partnerships/organizations that use peer-to-peer models to support AAC use with the goal of positive impact on activities of daily living for the individual. Barriers and opportunities within the model/approach or activity that should be considered for national recommendations will also be identified.	Core leadership + Consortium workshop	May-September	<ul style="list-style-type: none"> -The leadership team has focused on soliciting consortium membership by individuals and organizations that support AAC use with the goal of positive impact on activities of daily living. -The leadership team has solicited and received descriptions of Peer Support activities members of the Consortium have participated in. -Workgroups are tasked with identifying peer support models, projects, activities, and approaches. -The AAC user survey is collecting data on AAC users' experiences with peer support. The data appears to be revealing barriers and opportunities AAC users have faced in various settings. The survey will close on July 1st. The data will be evaluated by Workgroup 6. LINK -The tasks of Workgroups 1, 2 LINK, and 5 include identifying "barriers and opportunities within Peer Support models/approaches or activities that should be considered by the Consortium" in their final work output. This is detailed in each workgroup's Goals and Progress Notes document, which is stored in the workgroup's shared google folder. This was introduced in the introductory emails to the workgroup leaders. LINK -Workgroup members are identifying models on the Models Template. Barriers is an included field on the template. -Meeting set up 8/29/24 with PA DD system to discuss barriers, finances and policies they identify for peer supports. -The peer support models survey identified barriers and facilitators to participation in those models. The results of this survey were summarized and reviewed at the 9/9/2024 Core Leadership meeting.
Develop a schema (an overarching framework that articulates the necessary adaptations to existing peer-support approaches which are needed for the AAC community) to be reviewed by the Consortium.	Core leadership + Consortium workshop	May-September	<ul style="list-style-type: none"> -A workgroup for systematic review is being formed that will develop a schema. -Workgroup 6 has formed and is tasked with developing a schema to be reviewed by the Consortium. This is noted on the workgroup's Goals and Progress Notes document. LINK -Workgroup has developed a schema. DataExtractionParticipantDescr.pdf, DataExtractionInterventionDesc.pdf -Work continues. -Work continues.

Address the research question of whether peer support models for AAC device users can be developed, and, if those peer support models will help more people use AAC devices, while acknowledging the broader framework of all people who need and use AAC.	Core leadership + Consortium workshop	May-September	<p>-The Consortium workgroups are each analyzing peer support models, many of which are for AAC users. The question of whether models can be developed that will help more people use AAC devices is being formally considered by Workgroup 1. This goal is noted on the Goals and Progress Notes document. LINK</p> <p>-Workgroups continue to evaluate this question.</p> <p>-Work continues.</p> <p>-Work continues.</p>
Identify, Analyze, and consider legal frameworks and funding support systems and include any findings and recommendations included in the Comprehensive Review and Analysis.	Core leadership + Consortium workshop	May-September	<p>-Workgroups 1, 2, and 4 are compiling information about peer support models in and outside of the AAC field on their workgroup's Models Template documents. The Models template form includes a section on how the model or activity is funded. LINK</p> <p>-Workgroups continue to evaluate this question.</p> <p>-Work continues. Meeting set up 8/29/24 with PA DD system to discuss barriers, finances and policies they identify for peer supports.</p> <p>-Members of the core leadership met with the PA CAPS group to identify their sustainability plan for paid peer support specialists.</p>
Identify barriers and action steps to address these barriers, particularly those faced by people from multiply marginalized communities and include any barriers and action steps included in final Comprehensive Review and Analysis.	Core leadership + Consortium workshop	May-September	<p>-A workgroup has been established to "Develop strategies for inclusion of diversity and underrepresented communities in models and recommendations." This workgroup will be key in identifying barriers and action steps to address those barriers.</p> <p>-Workgroup 5 has faced barriers to progress in this step, as there have been no volunteers from the Consortium to co-lead alongside one of our leadership/steering committee members. The person initially recruited to co-lead this workgroup has not responded to multiple messages from the Core Leadership and has not engaged in any Consortium activities despite frequent invitations from multiple Core Leadership team members. We have worked to recruit a co-leader from among our Consortium members who represents multiply marginalized communities; several qualified members have declined due to conflicting schedules and responsibilities. A new member has recently joined that we plan to recruit to co-lead this group.</p> <p>-Workgroups 1, 2, and 4 have begun compiling information about peer support models in their Models Template documents, which includes a section prompting to consider: "Are there any barriers to participation? Are there opportunities to increase participation?" LINK</p> <p>-Workgroups continue to evaluate this question.</p> <p>-Workgroup 5 (DEIA group) is writing their recommendations to address these issues.</p> <p>-Members of the core leadership met with the PA CAPS group to identify their sustainability plan for paid peer support specialists.</p> <p>-Workgroup 5 continues to identify barriers and opportunities and write recommendations.</p>

Identify themes, promising approaches and practices, and areas of need to develop the plan, working alongside the partnership consortium to ensure attention to Diversity, Equity, and Inclusion.	Core leadership + Consortium workgroup	May-September	<p>-A workgroup has been established to “Develop strategies for inclusion of diversity and underrepresented communities in models and recommendations.” This workgroup will be key in developing the final recommendations. Consortium members in other workgroups have expressed personal interest in contributing to this topic.</p> <p>-Workgroup 5 has significant representation and continues to meet to address this topic. Meeting notes can be found in the shared workgroup folder.</p> <p>-Workgroup 5 (DEIA group) is writing their recommendations to address these issues.</p> <p>-Work continues as described.</p> <ul style="list-style-type: none"> - The Models Template documents are being used by Workgroup members, and will be utilized in the initial list of resources and information. - Workgroups continue to add to the Models Templates. - Google survey designed for use and accessibility and sent out to Consortium to complete. - To date, we have 56 models described. (Most of the models from the proposal are included as well as many models/activities that were not in the proposal.) - 58 peer support models were described in detail.
Partner with AUCD, consortium, and AoD to develop an initial list of resources and information to inform and develop a proposed approach and plan.	Core leadership + Consortium workgroup	May-September	
Deliverables:			
Results of the survey of AAC users and their peer support preferences.	Core leadership	ongoing	<p>As of 4/15/2024, results from 100 AAC users was sent to AUCD. We continue this survey until June 2024. An abstract has been submitted to ISAAC for a 2-hour presentation, including data on AAC users and their peer support preferences.</p> <p>-As of 5/6/2024, 119 responses have been collected. The survey continues to be distributed with invitations to respond through June 2024.</p> <p>-As of 6/17/2024, the survey has received 133 responses. The survey will close on July 1st, 2024. Workgroup 6 has begun the process of analyzing the results. LINK</p> <p>-Some of the survey data was shared at the 5/22/2024 and 6/28/2024 Consortium meetings.</p> <p>-Thematic analysis completed and will be shared with core leadership on 8/19/2024.</p> <p>-The thematic analysis will be an appendix in the final report.</p>
An analysis of the existing activities and approaches that could be applied to an AAC support model.	Core leadership + Consortium workgroup	May-September	<p>-The finalization of the Consortium and formation of workgroups was delayed. The Core leadership will begin work on this deliverable once there is work output from the workgroups. The workgroups have begun compiling information in their shared workgroup folders that will be analyzed by the core leadership.</p> <p>-A thematic analysis is in process.</p> <p>-Thematic analysis completed and will be shared with core leadership on 8/20/2024.</p> <p>-The thematic analysis will be an appendix in the final report.</p>

Completed Schema (an overarching framework that articulates the necessary adaptations to existing peer-support approaches which are needed for the AAC community).	Core leadership + Consortium workgroup	May-September	<ul style="list-style-type: none"> -The Core leadership will begin work on this deliverable as the workgroups produce work output. Workgroups 3 and 6 in particular are associated with this task. -A systematic review is in process. -Workgroup 6 is in the middle of the systematic review to date. -Work continues as described.
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.	Core leadership + Consortium workgroup	May-September	<ul style="list-style-type: none"> -The Core leadership will begin work on this deliverable as the workgroups produce work output. -Work continues as described.
A set of actionable recommendations for the creation of a nationwide resource for developing peer support models to encourage the use of AAC devices by those who are not currently using them for communication.	Core leadership + Consortium workgroup	May-September	<ul style="list-style-type: none"> -The Core leadership will begin work on this deliverable as the workgroups produce work output -Work continues as described.
Legal frameworks report with findings and recommendations.	Core leadership + Consortium workgroup	May-September	<ul style="list-style-type: none"> -The Core leadership will begin work on this deliverable as the workgroups produce work output -Work continues as described.
Initial list of resources and information.	Core leadership + Consortium workgroup	May-September	<ul style="list-style-type: none"> -The Core leadership will begin work on this deliverable as the workgroups produce work output -Work continues as described.

Objective 4 – Endorse a Nationwide Comprehensive, Consensus-Based Peer Support Model for Advancing AAC.			
	Responsible Party	Timeline	Update
Produce, Share and discuss the report with the Consortium.	Core leadership + Consortium	September-December	
Collaborate with AUCD and the Consortium to develop recommendations and action steps that include special consideration for those that would advance Equity, Diversity, and Inclusion.	Core leadership + Consortium workgroup	September-December	

Develop report with the Consortium and use criteria for adopting final recommendations.	Core leadership + Consortium workgroup	September-December	
Partner with AUCD and the partnership consortium to deliver to AoD and all stakeholders a comprehensive recommended plan and proposed approach for establishing a nationwide resource for developing peer-to-peer models that will promote and enhance the use of AAC devices as well as the overall quality of life of people who use AAC.	Core leadership	September-December	
Develop external reports for the members of the Consortium and for health systems, universities, and education entities, and public service agencies. This includes an online accessible plan that will be available on OHSU UCEDD and CommunicationFIRST websites. Additional formats that will be available online include a plain language version, an audio version, and a symbol-based version.	Core leadership + Consortium	September-December	We are developing two posters for presentation at the AUCD conference. The posters will report on the findings of our initial AAC user survey. A poster will be presented at the 2025 Assistive Technology Industry Association (ATIA) conference with two Steering Committee members as co-speakers. A webinar will be produced with ATIA.
Deliverables			
Completed plan with recommendations.		December	
Completed external reports.		December	

Appendix C4: Monthly Email Updates

AAC Peer Support Project - Monthly Update - May

Sarah Fjeldstad <fjeldsta@ohsu.edu>

Thu 5/23/2024 5:19 PM

Greetings from the AAC Peer Support Project! As a reminder, the University Center for Excellence in Developmental Disabilities Education, Research, and Service at Oregon Health & Science University (the OHSU UCEDD), in partnership with CommunicationFIRST, was awarded a 9-month contract from AUCD to create a **national plan to develop and advance peer-support models for augmentative and alternative communication (AAC) users**. This project uses a nationwide, comprehensive, consensus-based approach to identify meaningful ways for potential and current AAC users to communicate so that they may fully participate in community living and pursue educational and vocational goals.

I am the Project Coordinator for this project and I'm emailing today because you expressed interest in receiving **monthly updates** on progress in this project. We held our second meeting with a full Consortium on May 22nd, 2024. This meeting featured our first presentation of a Peer Support model by a Consortium member. I have created a Google Drive folder where you may access the recorded meeting video, audio, closed captions, and chat. Each month I will add the meeting recordings to this folder, and will send the link via email with any other updates. Click this link to view the files:

https://drive.google.com/drive/folders/1e5hZndHmxlFXlYG09ExAb56OlvgzyOZg?usp=drive_link

If you no longer wish to receive these emails, or if you would like to be invited to the next Consortium meeting, please email me.

There are currently 25 Consortium members from across the country who have joined workgroups, which are co-led by a member of the leadership team and a consortium member, one co-leader is an AAC user and one is not. We have established six workgroups who are tasked with the following:

- Identify peer support models within the AAC field
- Identify peer support models outside the AAC field
- What are we evaluating? Determine characteristics of peer support models that we will evaluate and include in our recommendations for a national AAC peer support model
- Present your own peer support model, activities, strategies to the Consortium
- Develop strategies for inclusion of diversity and underrepresented communities in models and recommendations
- Conduct a systematic review/ metanalysis of peer support literature

They begin their work on specific tasks this month. We will continue **recruiting Consortium members through June 30th**. If there is someone you would like to recommend, please email me (fjeldsta@ohsu.edu).

We are gathering input about peer support experiences that will greatly contribute to this project. Please share the information and links below with your networks, and particularly with AAC users.

- The project is grounded in the lived experiences of children and adults who need or use AAC and their networks. If you are an AAC user, please consider completing this 5-question **survey to help us learn what AAC users have experienced** with Peer Supports. Please click this link to complete this survey:
<https://docs.google.com/forms/d/e/1FAIpQLSfU57vbzxsM56i8yQ7F5O7V7OhFoiUtTlhjga-Xppntbt1E2Q/viewform>
- We also welcome written descriptions of your experiences with Peer Support, **both within and outside AAC**. These may be emailed to fjeldsta@ohsu.edu.

We've received over 125 survey responses so far, and will continue collecting responses **through June 30th**.

Thank you for your interest in this important project. Please feel free to email me if you have any questions or need assistance with anything.

Sarah Fjeldstad, MSW
AAC Peer Support Project Coordinator
OHSU UCEDD
she/her

AAC Peer Support Project - Monthly Update - June

Sarah Fjeldstad <fjeldsta@ohsu.edu>

Fri 6/28/2024 3:11 PM

Greetings from the **AAC Peer Support Project**! As a reminder, the University Center for Excellence in Developmental Disabilities at Oregon Health & Science University (the OHSU UCEDD), and CommunicationFIRST were awarded a 9-month contract from AUCD to create a **national plan to develop and advance peer-support models for augmentative and alternative communication (AAC) users**. To achieve this aim, we have built a nationwide Consortium of experts on these topics, representing many groups. Consortium members have formed into workgroups that will focus on specific tasks as we work together toward our project goal. I'm emailing today because you expressed interest in receiving **monthly updates** on progress in this project.

If you no longer wish to receive these emails, or if you would like to be invited to the next Consortium meeting, please email me.

Here is the latest news from the project:

- **Consortium meeting**: We held our third meeting with a full Consortium on June 26th, 2024. A Google Drive folder has been set up so you may access the meeting recordings (video, audio, transcript, chat and meeting agenda). Each month I will add the meeting recordings to this folder. [Click this link to view the files.](#)

This month's Consortium meeting featured 1: a report back from each workgroup on their accomplishments so far, 2: a presentation of a Peer Support model from one of the workgroups, 3: further insights from the nationwide survey we ran on AAC users' experiences with peer support, and 4: our plans to share that data with others.

We ran a post-meeting satisfaction survey to ask participants if their accessibility needs were met and how they experienced the meeting. We received a resounding message that participants "learned from the meeting" and/or "enjoyed the meeting" but some respondents did note the meeting was "complicated or confusing." Nearly half of respondents provided written feedback that will guide the project core leadership team in continually improving our meetings.

- **Workgroup meetings**: The workgroups are meeting virtually on a regular basis to discuss their goals and expected outcomes, and the discussions, questions, and insights shared between members have been absolutely fascinating so far. I invite you to view the workgroup meeting recordings and written materials to learn more about our progress. Each workgroup has a shared Google folder contained within a main shared folder, [LINKED here.](#)

- **Survey:** At the consortium meeting, we also shared a **LAST CALL** to complete the 5-question **survey about AAC user Peer Support experiences**. The project is grounded in the lived experiences of children and adults who need or use AAC and their networks. We've received over 130 responses to this survey so far, and it will **close on July 1st**. If you know someone who should fill it out, please share the link: <https://forms.gle/aD4h4wtKBDfmy6fA7>. We also welcome written descriptions of your experiences with Peer Support, both within and outside AAC. These may be emailed to directly to fjeldsta@ohsu.edu.
- **Steering Committee:** A key feature of the project is the Steering Committee, which is made up of AAC users. The goals of the steering committee are to:
 1. Ensure that AAC users are integrally involved in the work this project is doing.
 2. Review the products and deliverables from each workgroup and the national plan.

The Steering Committee has met to discuss plans and strategies to meet the project goals. They agreed to holding a meeting led by and solely attended by AAC users. All Consortium members who use AAC will be invited to join and share their feedback and experiences in the project so far.

Thank you for your interest in this important project. Please feel free to email me if you have any questions or need assistance with anything,

Sarah Fjeldstad, MSW

AAC Peer Support Project Coordinator

Oregon Health and Science University

University Center for Excellence in Developmental Disabilities (OHSU UCEDD)

she/her

AAC Peer Support Project Monthly Update - July 2024

Sarah Fjeldstad <fjeldsta@ohsu.edu>

Thu 7/25/2024 9:46 AM

Greetings from the **AAC Peer Support Project**! As a reminder, the University Center for Excellence in Developmental Disabilities at Oregon Health & Science University (the OHSU UCEDD) and CommunicationFIRST were awarded a 9-month contract to create a **national plan to develop and advance peer-support models for augmentative and alternative communication (AAC) users**. We have built a nationwide Consortium of 50+ experts on these topics, who have formed into workgroups that are focused on specific tasks toward our project goals. I'm emailing today because you expressed interest in receiving **monthly updates** on progress in this project.

If you no longer wish to receive these emails, or if you have any questions or comments, please reply to this email.

Here is the latest news from the project:

- ♦ **Consortium meeting**: We held our fourth meeting with a full Consortium on July 24th, 2024. You may access the meeting recordings (video, audio, transcript, chat, slides, and meeting agenda) by [following this link](#). Each month I add the meeting recordings to this shared google folder.

This month's Consortium meeting featured 1: A review of the project goals, timeline, and progress so far; 2: A report from the project Steering Committee; 3: Reports from each of the project Workgroups; 4: A presentation of Lateef McLeod's dissertation on AAC peer supports. Powerful conversations and insights were shared, as well as real-time examples of peer support.

- ♦ **Steering Committee**: A key feature of this project is the Steering Committee, which is made up of AAC users. The goals of the steering committee are to:
 1. Ensure that AAC users are integrally involved in the work this project is doing.
 2. Review the products and deliverables from each workgroup and the national plan.

As reported last month, the Steering Committee held two meetings led and solely attended by AAC users in the Consortium, who were asked to share their feedback and experiences in the project so far. This critical information was shared at the Consortium meeting. Plans for next steps include 1: collaboration between the Steering Committee and the core leadership team to integrate this feedback, and 2: key questions raised by the Steering Committee will be reviewed and discussed by each workgroup.

- ♦ **Post meeting survey** We adjusted some aspects of our meetings following results of a post-meeting survey initiated at the June Consortium meeting. We then expanded the survey questions to gain even more insight into participants' experiences. Early results indicate that a

majority of July Consortium meeting participants "learned from the meeting" and/or "enjoyed the meeting," and found the meeting accessible. Respondents provided feedback that the meetings should be "longer" and "allow time for discussion," which speaks to the dedication and enthusiasm Consortium members bring to the project.

- **Workgroup meetings:** The workgroups meet virtually, and the discussions, questions, and insights shared between members continue to be rich and productive. I invite you to view the workgroup meeting recordings and written materials to learn more about our progress. Each workgroup has a shared Google folder contained within a main shared folder, [LINKED here](#).
- **IMPORTANT ASK:** One of the project's expected outcomes is to develop a list of **peer-to-peer models, projects, approaches, activities**, both within and outside the AAC field. We invite your input!

We've launched a google survey form to collect information on peer supports. **Please click this link to record a peer support model** you are familiar with:

<https://forms.gle/HQTL7cssnTVBcu5KA>.

Clicking "submit" at the bottom of the page will send your responses to your email address, even if you haven't completed all questions. This allows you to edit or add to your responses at a later time if needed. Please share the survey link with others who have peer support models to contribute. **If you need any assistance to fill out this form**, please don't hesitate to email me.

Thank you for your interest in this important project.

Sarah Fjeldstad, MSW

AAC Peer Support Project Coordinator

Oregon Health and Science University

University Center for Excellence in Developmental Disabilities (OHSU UCEDD)

she/her

Sarah Fjeldstad <fjeldsta@ohsu.edu>

Thu 8/29/2024 3:20 PM

Greetings, I am pleased to provide the August monthly update on the AAC Peer Support Project, a partnership between OHSU and CommunicationFIRST that is developing a national plan to advance peer-support models for augmentative and alternative communication (AAC) users.

If you no longer wish to receive these emails, or if you have any questions or comments, please reply to this email.

Here is the latest news from the project:

- **Consortium meeting**: We held our fifth full Consortium meeting on August 28, 2024. This month's meeting featured:
 1. Brief updates on what we have learned from our survey on AAC users' peer support experiences and our growing list of peer support models from across the country.
 2. A presentation by workgroup 4 co-leader Patrick Regan and colleagues on their experiences in a successful "organic" peer support group.
 3. A vibrant and profound discussion on defining peer support. Below, I've pasted a Word Cloud generated by the Consortium.

You may access the Consortium meeting recordings by [following this link](#). I encourage you to view them to witness the dedication and brilliance of our Consortium members.

- **Workgroup meetings**: The 50+ Consortium members are formed into six distinct workgroups that meet frequently, and their rich and productive [discussions](#) continue to move the project forward. You may access the workgroup meeting recordings and written materials to learn more about our progress, available at [this link](#).
- **Recommendations** The project leadership is beginning to develop the written recommendations for expanding and strengthening peer support among AAC users nationwide. We are drawing insight from a variety of organizations and individual experiences to identify what works while staying true to the project's core values.

One of the project's expected outcomes is to develop a list of peer-to-peer models, projects, approaches, activities, both within and outside the AAC field. We've launched a google survey form to collect information on peer supports. **Please click this link to record a peer support model** you are familiar with: <https://forms.gle/HQTL7cssnTVBcu5KA> and feel free to share the link with others.

Don't hesitate to email me with any questions or feedback. Thank you for your interest in this important project.

Sarah Fjeldstad, MSW

AAC Peer Support Project

Coordinator Oregon Health and

Science University

University Center for Excellence in Developmental Disabilities (OHSU UCEDD)

she/her

What words come to mind when you think of peer support?

452 responses





AAC Peer Support Project Monthly Update - September 2024

From Sarah Fjeldstad <fjeldsta@ohsu.edu>

Date Tue 10/1/2024 3:32 PM

Greetings, I am pleased to share the September monthly update of the **AAC Peer Support Project**, a partnership between OHSU and CommunicationFIRST that is developing a national plan to advance peer-support models for augmentative and alternative communication (AAC) users.

If you no longer wish to receive these emails, or if you have any questions or comments, please reply to this email.

Here is the latest news from the project:

- ◆ **October is AAC Month!** We're joining this international celebration by honoring AAC and all the different ways people communicate.

International AAC Awareness Month was established by the International Society for Augmentative and Alternative Communication (ISAAC) LEAD Project Committee in October 2007. Thirteen countries participated in the first Awareness Month and events have been increasing in number and scope ever since. This month, ISAAC is hosting a two-day virtual event with many of our colleagues. Find more information and register [at this link](#).

- ◆ **Consortium meeting:** We held our sixth full Consortium meeting on September 25th. This month's meeting featured:
 1. An update on future plans for the Consortium and the project, including how we will share our work with others. We will be represented at these upcoming conferences and we are planning for more:
 - a. International Society for Augmentative and Alternative Communication (ISAAC), October 29-30 2024 - Virtual
 - b. Association of University Centers on Disabilities (AUCD), November 3-6 2024 - Washington, D.C.
 - c. Assistive Technology Industry Association (ATIA) January 30, 2025 (3-4:30pm) - Orlando, FL and virtual

2. A report from each of the six workgroups on their progress
3. A presentation on how we can know that a peer support model is successful
4. A robust group discussion about defining peer support

You may access all the Consortium meeting recordings by [following this link](#).

- ◆ **Workgroup meetings**: The 50+ Consortium members continue to meet frequently in their workgroups to focus on different facets of this project. Each meeting delivers profound insights from our dedicated members, which inform the project's final recommendations. In addition to defining terms like *peer support* and *diversity, equity, inclusion, and accessibility*, questions the workgroups are tackling include:
 - **How do people find each other?** How do people find out about and connect to peer support?
 - Messages about available peer support must be shared broadly across many networks. **How do we make sure there is consistency in our messages about peer support?**
 - Peer support comes in many forms, but some sort of structure and someone to facilitate or coordinate it is necessary. **How do we make sure peer support is sustainable?**

You may access the meeting recordings and written materials at [this link](#) to learn more about their work.

Don't hesitate to email me with any questions or feedback. Thank you for your interest in this important project.

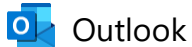
Sarah Fjeldstad, MSW

AAC Peer Support Project Coordinator

Oregon Health and Science University (OHSU)

University Center for Excellence in Developmental Disabilities (UCEDD)

she/her



AAC Peer Support Project Monthly Update - October 2024

From Sarah Fjeldstad <fjeldsta@ohsu.edu>

Date Wed 10/30/2024 2:08 PM

Greetings, I am pleased to share the October monthly update of the **AAC Peer Support Project**, a partnership between OHSU and CommunicationFIRST that is developing a national plan to advance peer support models for augmentative and alternative communication (AAC) users.

If you no longer wish to receive these emails, or if you have any questions or comments, please reply to this email.

Here is the latest news from the project:

- ◆ **Project update:** The AAC Peer Support project had a 9-month contract with AUCD that was due to end on September 30th. However, we are thrilled to announce that AUCD granted a six-month extension through March 31st so that we can continue to expand and deepen our work. In the words of one of our dedicated Consortium members:

"It feels like we have gotten a lot done, and also this is just the beginning of a movement across the U.S. that will further open doors for AAC users."

- ◆ **Sharing our work:** Many of the incredible members of the Consortium, including the Steering Committee and Core Leadership teams, have been presenting at AAC and disability-related conferences. Here is a brief selection of recent and upcoming events:
 - OSHA - Oregon Speech-Language-Hearing Association Fall Conference, October 11, Salem, OR
 - OSHA awarded this project's Principal Investigator, Melanie Fried-Oken, PhD with a Lifetime Achievement award to honor her decades of experience advancing AAC
 - ISAAC - International Society for Augmentative and Alternative Communication, October 29-30 2024, Virtual
 - AUCD - Association of University Centers on Disabilities, November 3-6 2024, Washington, D.C.
 - NW Conference on Disability Services, October 22-24, 2024, Portland, OR
 - Closing the Gap Conference, October 22-24, 2024, Minneapolis, MN

- ATIA - Assistive Technology Industry Association, January 30, 2025, Orlando, FL

We are also developing AAC Peer Support Project webpages for the OHSU UCEDD and CommunicationFIRST websites. These will enable all to learn more about AAC peer support, access the materials and products we have developed, and keep track of what comes next. I will share links and more information as soon as it is available.

- ◆ **Consortium meeting:** Because our Consortium members are so busy presenting at conferences recently, we decided to postpone the October Consortium meeting to November 13th. To accommodate the upcoming holiday season, we will hold Consortium meetings on the second Wednesday of each month going forward.

You may access all the Consortium meeting recordings, agendas, and slides [at this link](#).

- ◆ **Workgroup meetings:** The 50+ Consortium members continue to meet frequently in their workgroups to focus on different facets of this project. Each meeting delivers profound insights from our members, which inform the project's final recommendations. Recent topics include identifying barriers to AAC peer support as well as solutions to those barriers. Other workgroups are grappling with defining the key terms we use to describe AAC. All discussions are led by AAC users and prioritize their perspectives.

You may access meeting recordings and written materials [at this link](#) to learn more about the work of the Consortium.

Don't hesitate to email me with any questions or feedback. Thank you for your interest in this important project.

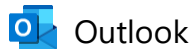
Sarah Fjeldstad, MSW

AAC Peer Support Project Coordinator

Oregon Health and Science University (OHSU)

University Center for Excellence in Developmental Disabilities (UCEDD)

she/her



AAC Peer Support Project Monthly Update - November 2024

From Sarah Fjeldstad <fjeldsta@ohsu.edu>

Date Wed 11/27/2024 1:38 PM

Greetings from the AAC Peer Support Project!

A consortium of 50+ individuals and organizations nationwide have formed into six workgroups that focus on different facets of the project, which will develop a national plan to advance AAC peer support. We continue our work through March 31, 2025. I am pleased to share an update for the month of November.

If you no longer wish to receive these emails, or if you have any questions or comments, please reply to this email.

Here is the latest news from the project:

Consortium Meeting

Each month, the full AAC Peer Support consortium meets to:

- Hear updates from the project leadership team
- Report back on workgroup progress
- Learn from a presentation on peer support.

The topic of the November meeting's presentation was **organic peer support**, which refers to informal, naturally occurring support networks that have minimal or no formal structure or external organization. The presentation sparked a powerful group discussion, and you are invited to [watch the recordings](#).

Enhancing Accessibility

In a recent [presentation on AAC research](#), Dr. Lateef McLeod, a member of our Steering Committee, emphasized, "People who use AAC should be at the decision table regarding everything that involves us as a community." We wholeheartedly agree and strive to prioritize the voices of AAC users in our work.

An important starting point is planning for meaningful inclusion and participation in meetings. We have incorporated the [guidance for improving meeting access for AAC users](#) developed by CommunicationFIRST. We are also trialing assigned moderators in meetings, who will call on fully-speaking people who wish to add to a discussion, and will intervene if a speaking person dominates a discussion.

These approaches aim to ensure AAC users lead the way as we develop our recommendations for a national plan to advance AAC peer support.

Consortium Member Feedback

We run post-meeting surveys inviting anonymous feedback from our members. This feedback has provided the core leadership team with both recommendations for needed changes in the project and glowingly positive reviews of the project's impact. We are often struck by statements that **the consortium itself has become a form of peer support** for members. Here are a few recent comments:

- "I always feel empowered to make big changes in society after I meet with this dynamic group!!"
- "I love how we all work together! I want our group to go on after the grant wraps up. We're just starting our work, and there is more to do."
- "Each week we uncover more layers to the complexity of AAC and AAC users. So blessed to be part of this committee."
- "As an AAC user, I am gaining many skills in preparing my device with quick, easy-to-access comments that will help me add to the conversation."

I hope these quotes contribute to a sense of joy and excitement as you head into the fall and winter holiday seasons. Please don't hesitate to email me with any questions or feedback you may have. Thank you for your interest in this important project.

Sarah Fjeldstad, M.S.W.

AAC Peer Support Project Coordinator

University Center for Excellence in Developmental Disabilities

Oregon Health and Science University (OHSU)

she/her



AAC Peer Support Project Monthly Update - December 2024

From Sarah Fjeldstad <fjeldsta@ohsu.edu>

Date Fri 12/27/2024 4:03 PM

Greetings from the AAC Peer Support Project. Our consortium of over 50 passionate individuals and organizations is developing a national plan to advance AAC peer support, and we're making great strides as we continue our efforts through March 31, 2025. Here's a look at what we've been up to in December:

Consortium Meeting Highlights

Every month, the full AAC Peer Support consortium gathers to:

- Hear updates from the project leadership team
- Report back on workgroup progress
- Learn from a presentation on peer support

In December, we delved into the topic of diversity, equity, inclusion, and accessibility (DEIA) in AAC peer support. Workgroup 5 led an enlightening session, exploring these concepts and their real-world applications for AAC users. The full consortium was invited to contribute to a collaborative document, and we had a vibrant group discussion - you are invited to [watch the recordings](#).

New Web Page Launched

We're excited to announce our new [project page on the OHSU UCEDD website](#)! It details much of our work to date and will be updated with even more in the near future. Please check it out, share with your networks, and let us know what you think through the [feedback form](#) linked on the page.

Share this link with your friends and colleagues: <https://bit.ly/AACPeerSupportProject>

Systematic Review of Peer Support Models

Workgroup 6 is tasked with reviewing the academic and gray literature related to AAC peer support, along with the detailed descriptions of peer support models, projects, and activities that have been collected by the consortium. They've screened more than 700 titles and abstracts and are evaluating nearly 250 full-text articles. This work, along with their thematic analysis of the peer support models, is vital to shaping our final recommendations for national AAC Peer Support models. We're incredibly grateful for the brilliance and dedication of our consortium members who are driving this important work forward.

If you have any questions, comments, or feedback, please don't hesitate to reach out. Enjoy the winter holidays!

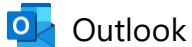
Sarah Fjeldstad, M.S.W.

AAC Peer Support Project Coordinator

University Center for Excellence in Developmental Disabilities (UCEDD)

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she/her



AAC Peer Support Project Monthly Update - January 2025

From Sarah Fjeldstad <fjeldsta@ohsu.edu>

Date Wed 1/29/2025 10:58 AM

Greetings from the AAC Peer Support Project. Our consortium of over 50 passionate individuals and organizations is developing a national plan to advance AAC peer support, and we're making great strides as we continue our efforts through March 31, 2025. Here's a look at our progress this month:

Consortium Meeting Highlights

Every month, the full AAC Peer Support consortium gathers to:

- Hear updates from the project leadership team
- Report back on workgroup progress
- Learn from a presentation on peer support

In January, the consortium explored barriers to AAC peer support, including attitudinal, structural, social, and organizational barriers. Recordings can be viewed at this [link](#). A key point made by the presenters was:

“These barriers can be combated if we promote the importance of AAC peer support, and also create spaces for disabled people to be in community with each other, especially for people who use AAC.”

The consortium will further explore and envision solutions to overcoming these barriers at the February 12 consortium meeting.

Recommendations for AAC Peer Support

Work is underway by the project's Core Leadership team to develop written recommendations for nationwide AAC peer support models. Each consortium work group has a crucial role in this process. The group tasked with identifying ways to evaluate the effectiveness of AAC peer support, has developed an adaptable set of questions to explore “goodness of fit” with participants of a peer support activity. This group has firmly concluded that:

“...Peer support can help create the reasons and environment that can motivate people to express themselves, be heard, and lead life as we [individuals using AAC] want.”

Web Page

We recently launched a web page that details much of our work to date. Please check it out and share the link with your friends and colleagues: bit.ly/AACPeerSupportProject

Thank you for your interest in this important work. Please don't hesitate to reach out with any questions, comments, or feedback.

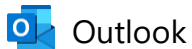
Sarah Fjeldstad, M.S.W.

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AAC Peer Support Project Monthly Update - February 2025

From Sarah Fjeldstad <fjeldsta@ohsu.edu>

Date Fri 2/28/2025 4:51 PM

Greetings from the AAC Peer Support Project. Our consortium of over 50 passionate individuals and organizations has collaborated to develop a national plan to advance AAC peer support. This work is winding down as the final recommendations are currently being developed. Here's a look at our progress this month:

Consortium Meeting Highlights

Every month, the full AAC Peer Support consortium gathers to share:

- Updates from the project leadership team
- Workgroup progress reports
- A presentation on peer support

In February, portions of the preliminary final report were shared with the consortium. All six workgroups contributed significantly to the report's findings and recommendations.

The consortium then discussed ways to overcome barriers to AAC peer support and shared examples of how these barriers were addressed in practice. On the subject of accessibility, one consortium member shared:

"I can honestly say that this consortium has been the most accessible meeting I have attended, and it is not even close."

Meeting recordings can be viewed [here](#).

Steering Committee

The project steering committee is composed entirely of AAC users. Their role is to:

- Provide additional guidance and direction to the project's work
- Provide leadership and peer support opportunities for diverse AAC users and others

Throughout the project, the steering committee has convened meetings exclusively attended by the AAC users on the consortium to ensure their perspectives are heard and their goals are being met. This month, the group met to discuss preferred terminology related to AAC, and to affirm their support for the project preliminary report. The steering committee will share their report at the final Consortium Meeting on March 12.

Web Page

Our web page details much of our work to date. Please check it out and share the link with your friends and colleagues: [bit.ly /AACPeerSupportProject](https://bit.ly/AACPeerSupportProject)

Thank you for your interest in this important work. Please don't hesitate to reach out with any questions, comments, or feedback.

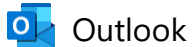
Sarah Fjeldstad, M.S.W.

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AAC Peer Support Project Monthly Update - March 2025

From Sarah Fjeldstad <fjeldsta@ohsu.edu>

Date Thu 3/27/2025 10:25 AM

Greetings from the AAC Peer Support Project. Our consortium of more than 50 passionate individuals and organizations worked together from March 2024 to March 2025 to develop a national plan to advance peer supports for AAC users. As this project wraps up, this is the final monthly update.

Final Report and Recommendations

The project leadership team is finalizing the plan and recommendations. The dedicated steering committee will review the draft this week, and the final report will be available on our webpage by April 28. Check it out and share: bit.ly/AACPeerSupportProject.

Consortium Meeting Highlights

Our final meeting on March 12 was as thought provoking as ever. This month featured:

- Closing summaries from each of ~~the six workgroups and the steering committee~~
- New insights from Dr. Lateef McLeod's analysis of our survey on AAC peer support experiences
- Consensus on preferred terminology related to AAC and peer support
- Envisioning for the future of the AAC peer support project

This important information is incorporated into the project's final report. Meeting recordings can be viewed [here](#).

Next Steps

As a consortium member who has received our monthly updates over the past year, we'd like to understand your interest in future involvement. Please complete this [brief survey](#) or respond by email if you prefer:

- Do you want a copy of the final report?
- Do you want to be a future partner in implementation if we can proceed with this work?
- Do you want to collaborate on submissions to national conferences?

Thank you for your interest in this important work. Feel free to reach out with any questions or feedback.

Sarah Fjeldstad, M.S.W.

AAC Peer Support Project Coordinator

University Center for Excellence in Developmental Disabilities (UCEDD)

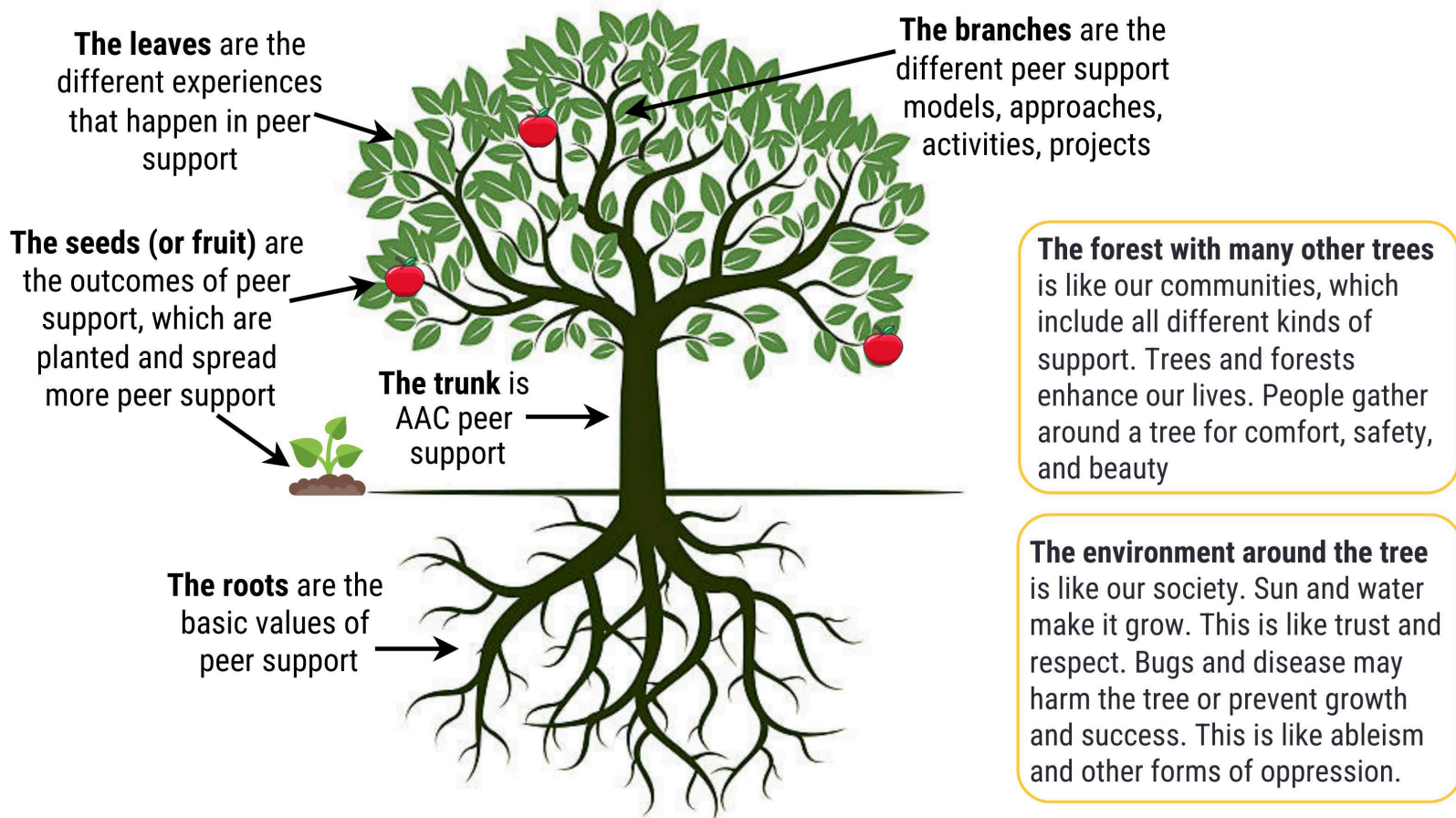
Oregon Health and Science University (OHSU)

she/her

What words come to mind when you think of peer support?

[illegible]

Appendix E: AAC Peer Support Tree Illustration



Appendix F1: Barriers Experienced by Multiply Marginalized Communities

AAC Peer Support: Barriers, Opportunities, and Impacts

Children, youth, working age and older persons who use AAC or who lack necessary access to it encounter barriers, bias, and discrimination that limit their opportunities in life, including offering, receiving, and benefitting from peer support. Such individuals who are members of unserved and underserved communities tend to be more likely to face these barriers more often. Congress has directed that attention and resources be focused on identifying and reducing such barriers through programs authorized by the Developmental Disabilities Act, Older Americans Act, and other federal programs administered by ACL. The AAC Peer Support Consortium strongly recommends advancing these aims in all future peer support activities.

Some of our most important findings identified the needs of and barriers faced by persons in unserved and underserved communities who cannot rely on speech alone to be heard and understood. Addressing their needs and eliminating the barriers in their way is possible by prioritizing diversity, equity, inclusion, and accessibility in AAC peer support models for those who need and use AAC. Such models will support those who do not have effective means of communication to explore AAC systems. It will help these individuals as well as current AAC users to live fuller, more interdependent lives and experience a greater sense of connection to the community.

AAC peer support models must recognize, celebrate, and elevate all unique traits, strengths, and challenges, including the range of linguistic abilities and communication modalities. It also requires a close examination of barriers and opportunities for achieving AAC peer support. Congress has authorized the DD Act, Older Americans Act, Rehabilitation Act, and other laws to increase the valuing, fair treatment, interdependence, productivity, integration, inclusion, and self-determination of all people with disabilities. To achieve these national goals, a deep understanding of and commitment to the concepts of Diversity, Equity, Inclusion, and Accessibility in AAC Peer Support are essential.

The following significance statements were developed by the AAC Peer Support Consortium:

Diversity in AAC Peer Support

Diversity is recognizing the intersectionality between the many noticeable and non-obvious characteristics that make an individual unique. One's identity is shaped by traits like race, disability, who we love, and more. These traits affect how we see ourselves, how others see us, and the barriers we face. For example, a multilingual

AAC user faces challenges that neither a monolingual AAC user nor a fully speaking multilingual person encounters.

In peer support activities, diversity is used to learn and grow together, allowing us to better understand the world from perspectives that differ from our own.

Equity in AAC Peer Support

Unlike *equality*, which means that everyone gets the same thing, *equity* refers to ensuring fair access to opportunities and resources, while considering how the circumstances and needs of individuals and groups affect their access. Assuring equity in peer support activities requires making adjustments through thoughtful considerations as well as honesty and transparency among members. True equity only exists when a genuine feeling of access is present, and not before.

In peer support activities, equity enables people to understand the experiences of others and creates solidarity among people from different backgrounds.

Inclusion in AAC Peer Support

Inclusion provides a foundation for meaningful collaboration, where every participant has a voice in problem-solving and decision-making. It encourages active participation, mutual respect, and attentive listening from all involved. True inclusion happens when we make intentional efforts to understand, value, and uplift each person's individual perspective, which is an essential part of effective peer support.

Accessibility in AAC Peer Support

Accessibility is about the design of AAC peer support activities. It seeks processes and strategies for identifying and removing barriers that create disparities. Accessibility for people who need AAC ensures that people understand what is said or written and can communicate what they want to convey. The cultural shift toward inclusion necessitates accessibility.

Accessibility includes social facilitation efforts by individuals who are communication-privileged, i.e. can rely on speech. It's also imperative to understand the importance of trained, skilled support staff, whose support is necessary for many individuals to communicate (e.g. to access devices or voice messages), to access their communities, along with many other needs. The accessibility of peer support is often dependent on access to paid or unpaid support.

Barriers and Opportunities Among People Who Use and Need AAC:

The consortium collaborated to develop a list of keywords that represent barriers to diversity, equity, inclusion, and accessibility in AAC peer support. The words most frequently offered by consortium members were *funding*, *ignorance*, *transportation*, and

ableism. All the words contributed by members were represented by a word cloud (Appendix F2) and then grouped into themes:

Economic	Constraints	General public awareness
Socioeconomic barriers	Rural	Understanding
	Transportation	Information
Disability	Time	Training
Medical conditions	Technology	Experience
Affordability	Access	Advocacy
Funding	Fear	Unmet support needs
	Self esteem	Lack of support
Cultural histories	Attitudes	Lack of support at school
Cultural	Beliefs	Lack of AAC
	Bias	Lack of know-how
English-only	Implicit or explicit bias	Lack of resources
Languages	Personal bias	Lack of vocabulary in AAC
Monolingual	Ableism	Missing vocabulary
	Speechism	
Rules	Racism	Underestimating AAC users
Hierarchy	Oralism	Not knowing AAC users
		Relationships
Therapists		
SLPs	Ignorance	
Professionals	Misinformation	
	Wrong IQ labels	

Some AAC users report that peer support groups have operated with the assumption that these barriers do not exist or have been overcome. In reality, success and sustainability of peer support activities hinges on addressing these barriers. AAC users contend that it is important not to continue doing the same things.

What follows are paraphrased comments made by Consortium members, primarily AAC users, that describe barriers that drive communication inequities.

- Finances are a major barrier. The communication needs of a loved one often go unaddressed by families that are struggling financially.
- Even with access to an AAC system, without close training and support, many families struggle to integrate AAC into their lives and support their loved one to learn to use it, leaving the individual without full access.
- In many U.S. states, even finding access to information on speech therapists, and where to obtain communication devices is extremely challenging.

- There is a lack of funding for AAC devices in many school districts and a shortage of trained classroom support. Further, there are not nearly enough SLPs with knowledge of AAC. These circumstances form nearly insurmountable barriers to access communication.
- School-aged children should have access to training and support to expand their communication access. However, they are often denied access to AAC because they supposedly do not show competency or capacity to use the device effectively. We should presume competence; communication is a human right.
- If a person is never granted access and support to communicate in their early life, they will often grow to find silence an acceptable life. The consequences of this continue to be felt throughout the lifespan.
- In many U.S. states, there are no programs available for access and support to communicate outside of school settings. For example, in California, even programs through the Department of Rehabilitation that can supply a device and software offer no training or support and have very long waiting lists.
- People are not taught to independently choose AAC systems as new technology becomes available. This is due to lack of awareness among families, caregivers, SLPs, and other professionals, because people who can rely on speech don't need to adjust or upgrade their communication method as AAC users do. AAC users need continual access to and training on the array of AAC systems to meet their communication access needs.
- People, organizations, and institutions seem to think accessibility is not their issue to tackle. However, accessibility is a human right across all communities, platforms, environments, ages, races, genders, and disabilities, etc.
- Environmental accessibility is not sufficient on its own. Curb cuts and enlarged bathroom stalls are critical, but barriers to access can include virtual platforms, internet access, computer skills training, etc. are also barriers to access.
- We should foster the concept of *interdependence in communication*. Communication is never done completely independently of others because it is an exchange of ideas between at least two people. Communication should be considered a shared responsibility, never the sole burden of AAC users.

Appendix F2: Barriers to AAC Peer Support Word Cloud

What are barriers to participation in AAC peer support?

69 responses



Appendix G: Alternate Keywords and Search Terms for AAC Peer Support

Workgroups and leadership discussed the terms *peer* and *peer support* and found the general public may not be familiar with these terms. Webpages and other communications regarding AAC peer support should consider including other commonly used keywords to increase the likelihood that people can find the information. This list of alternative search terms was developed with input from the consortium, in response to these questions:

- What are alternative keywords for what we refer to as *AAC Peer Support* or *peer*?
- What questions or phrases would someone search when they want to become an AAC user or learn about AAC?
- If you want to talk to someone who uses AAC, what would you type into google?

Questions and Phrases

- | | |
|---|--|
| ● Can't talk | ● How many different types of AAC are there? |
| ● Help with AAC | ● What are the types of AAC? |
| ● How to get started with AAC | ● What is the best AAC device? |
| ● How to learn about AAC | ● What kinds of AAC are there? |
| ● How to talk without your voice | ● What methods of selection are there? |
| ● How to use AAC | |
| ● iPad speech generator | ● How can I meet AAC users? |
| ● Talking computer | ● Where can I find people who use AAC? |
| ● Technology for can't talk | |
| | ● Who can help me learn AAC? |
| ● What does AAC mean? | ● Why do I need AAC? |
| ● What does AAC stand for? | ● How to learn about AAC? |
| ● What is AAC? | ● What is AAC and autism? |
| | |
| ● Can anyone learn AAC? | ● Can I get help paying for an AAC device? |
| ● How do you use AAC? | ● Does insurance cover AAC? |
| ● How old do you have to be to use AAC? | ● Does Medicare cover speech generating devices? |
| ● Who can use AAC? | ● How much is AAC? |
| ● Who uses AAC? | ● What companies sell AAC? |

Search Terms

- | | | |
|---------------------|------------------------|-------------------|
| ● Chat room | ● AAC activities | ● Peer advice |
| ● Community | ● AAC advice | ● Peer advisor |
| ● Community support | ● AAC discussion group | ● Peer counseling |

Search Terms		
--------------	--	--

- | | | |
|--|---|---|
| <ul style="list-style-type: none"> • Conversation • Meet up • Social group • Support group • Table talk | <ul style="list-style-type: none"> • AAC friends • AAC help • AAC information • AAC mentor or mentoring • AAC networking • AAC practice • AAC resources • AAC user to AAC user • Meet other AAC users • Talk with AAC | <ul style="list-style-type: none"> • Peer mentoring • Peer to peer • Activities • Advice • Chat • Consultation • Conversation • Friends • Group • Guidance • Mentor • Network |
| <ul style="list-style-type: none"> • Disability community • Disability rights • Disability support group • Communication disability • Self-advocacy | | |

Search terms could be paired with diagnoses such as aphasia, brain injury, cerebral palsy, etc. and/or AAC system if relevant to the peer support model

Appendix H1: Peer Support Models, Projects, Approaches, and Activities

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

Camp Chatterbox facebook.com/p/Camp-Chatterbox-100064405853508/
Camp Communicare, LLC. facebook.com/AACcommunicare ; aaccommunicare.com
Camp ImpAACT-Ellis Center elliscenter.org/camp-impaaact
Camp McYack jcisd.org/special-education3/camp-mcyack
Camp SPEAK AAC (1: children 2: parents of children) campspeak.org/
Camp TALK camptalk.org
Cancer Support Community Greater Philadelphia cancersupportcommunity.org/
Children's Hospital Colorado (1: First Steps Camp, 2: Talking with Technology Camp) childrenscolorado.org/doctors-and-departments/departments/audiology-speech-learning/first-steps-camp childrenscolorado.org/doctors-and-departments/departments/audiology-speech-learning/camp
Communication Access Connect disabilityvoicesunited.org/interchange/communication/communication-access-connect
Community Autism Peer Specialist (CAPS) Program phillyautismproject.org/community-autism-peer-specialist-caps-hub/
Community Vision (1: AAC Social Group, 2: AAC Play Group ages 0-5) cv-atlab.org
Family to Family Health Information Centers mchb.hrsa.gov/programs-impact/programs/f2f-health-information-centers
ImpAACT Voices (1: Virtual Hangouts, 2: In-person events) impaactvoices.org
ISAAC online chats isaac-online.org/english/news/pwuaac-online-chats/
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 vkc.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 familyconnectionsc.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 H2: Peer Support Models Survey Results

The AAC Peer Support Project Survey distributed a survey between July and August 2024 to collect descriptions of peer support models. Respondents recorded 59 peer support models.

- 37 models focused on AAC users
- 23 models focused on other populations
- 41 models focused on adults
- 22 focused on children and/or young adults
- 11 models were camps
- 3 models were school based
- 28 models were support groups
- 6 models were focused on employment
- 26 models were virtual (online)
 - 8 models were available to participants in a particular region
 - 15 models were available to participants nationwide
 - 3 models were available to participants internationally
- 5 models provided phone calls as an option for connecting
- 18 models were in person only
- 35 models were available to participants in-person in the U.S.
 - 9 models were based on the east coast
 - 6 models were based in the south
 - 5 models were based in the midwest
 - 10 models were based on the west coast
 - 5 models operate from various locations nationwide

Peer support focus:

The recorded peer support models covered a broad range of health challenges and diagnosis.

- 2 models were focused on cancer
- 4 models focused on Amyotrophic Lateral Sclerosis (ALS)
- 1 model focused on dementia
- 2 models focused on aphasia
- 2 models focused on autism
- 4 models focused on mental health-related concerns
- 5 models did not specify their focus on any specific health concern, condition, or diagnosis
- 39 models focused on disability, but not specific to any one disability group.

This breakdown highlights the diverse focus of the peer support models. The largest group, which addresses unspecified disabilities, indicates that many models are designed to open to the broader disability community.

Peer support activities:

Models with *structured instruction* (formal curriculum or lecture) tend to be geared toward younger people, mostly children within a “special” (segregated) setting like camp or school. Parents/caregivers also receive *structured instruction* related to caregiving. *Structured instruction* is always noted alongside other activities such as *unstructured* or *semi-structured conversation*, *socializing*, *networking*, and *advice for difficulties in life*, except for those that take place specifically in a school setting.

Socializing is the most commonly noted activity among all peer support models (30) while the next most frequent activities, *semi-structured conversation* and *learning and sharing technology*, each took place in 22 models. *Advice for difficulties in life* was noted in 19 models, and *family member or caregiver support* appeared in 20, further highlighting the importance of shared experiences and mutual aid. *Supportive peer counseling* and *navigating or finding services* both had strong support, with 16 responses each. Other activities like *coaching* (12) and *learning self-care* (5) were also noted, though they were less common.

Outcomes:

The most frequent expected outcome of the peer support models was *social (friendship, sense of belonging)* (43). Following closely, *quality of life* was a key outcome in 31 models. *Speech, language, and communication improvements* were also noted in 30 models. *Recreation and leisure activities* also played a significant outcome in 19 models. In addition, *self-efficacy* was reported in 24 models. Outcomes related to skills development were also significant, with *adaptive skills* and *leadership skills* both appearing in 15 models. *Employment or vocational improvements* were reported in 13 models, while *health-related outcomes*, encompassing both physical and mental health, appeared in 21 models. Education-related outcomes were reported in 14 models and building independent living skills in 8 models. However, there were some areas with less frequent outcomes, such as *economic improvement/employment* (1) and *no outcome reported* (3). The low number of *economic improvement/employment* responses could be due to a survey flaw of having a very similar response of *employment or vocational improvement*. Three models did not report an outcome. Many models reported multiple outcomes, highlighting the broad impact of peer support across various domains.

Most models that are geared toward AAC users have the expected outcome of *increased AAC/AAC device use*. Those that don't specifically note *increased AAC/AAC device use* as an outcome did note *speech/language/communication* as an expected outcome. This may be due to flaws in the survey questions.

Development and leadership:

Most of the peer support models surveyed were *started by professionals for peers* (33), with fewer created by *peers*, *peers who are also professionals*, and/or by *professionals and peers working together* (23). Five models were noted as created solely by *peers*. In models where peers were involved in developing the model, most are *co-led* by peers and non-peer

professionals (18), fewer are solely *peer-led* (4) and none were led solely by a professional who is not a peer.

Models that were created by *peers*, *peers who are also professionals*, and/or by *professionals and peers working together* all support adults 17+ except for one, which welcomes all ages. Those started by non-peer professionals tend to support specific age groups.

Frequency, consistency:

One of Lateef McLeod's recommendations for AAC peer support is solid structure and organization, including a consistent schedule. Kevin Williams noted in his May 2024 Consortium presentation on USSAAC PWUAAC that consistent meeting times not only increased participation but created participants' "sense of normalcy and a chance to be themselves." Online groups with a set schedule of "hangouts," "meetups," or "chats" meet at least once a month at consistent times. Relatedly, the least frequently selected characteristic of peer support models that increased participation was *flexible session time* was (1).

Barriers and facilitators to participation

Peer support models that operate virtually noted that the online platform may have increased participation, and this was the most frequently noted facilitator among the models. Those that had virtual access and did not note *virtual platforms* as enabling participation were all hybrid models, offering both virtual and in-person options. We initially thought *virtual platforms* could be both a facilitator and a barrier to participation (due to technology issues), but only 6 out of 28 online models noted this.

Peer leaders or mentors being paid or employees is the second-most common factor (16) that increases participation in the model.

Peer supports that require payment from participants tend to be in formal, segregated settings (most often schools and camps, and one conference) where there is an imbalanced power dynamic (teacher/expert/professional/adult and student/child/learner) as opposed to mutual/reciprocal peer support models. However, peer support may occur organically in, or grow out of those settings.

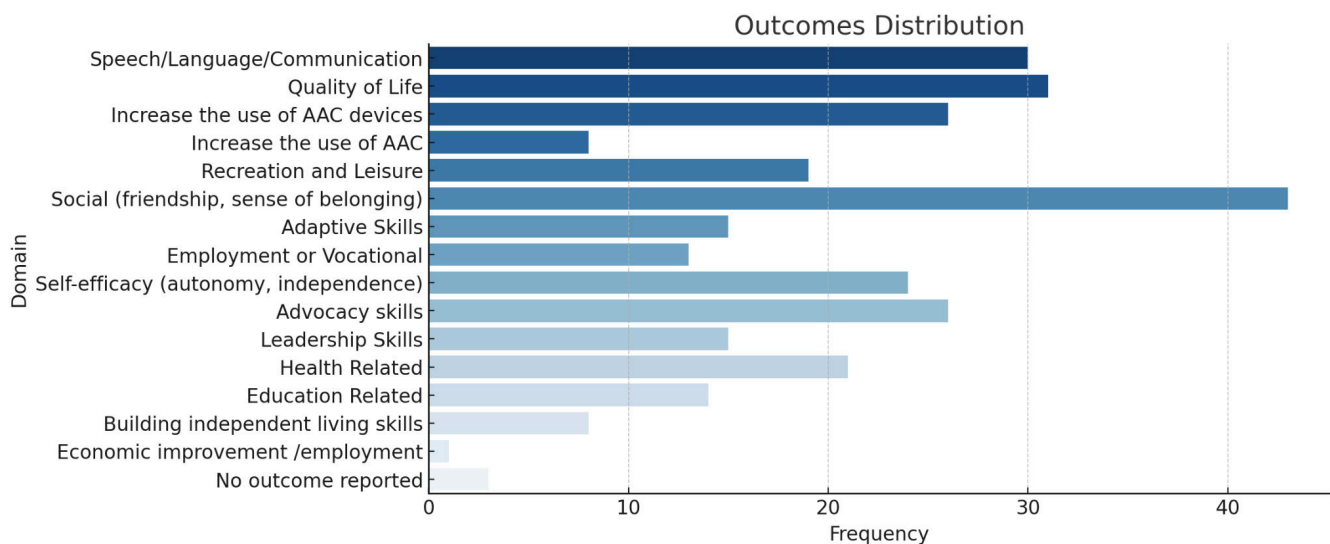
Accessibility was noted as a barrier to participation in three diverse programs: a virtual AAC community (ImpAACT Voices); on an on-campus University program (ACES); and a formalized peer support specialist training program (CAPS).

Survey respondents recording camps as a peer support model acknowledge that *cost* is a barrier, as do membership-based organizations.

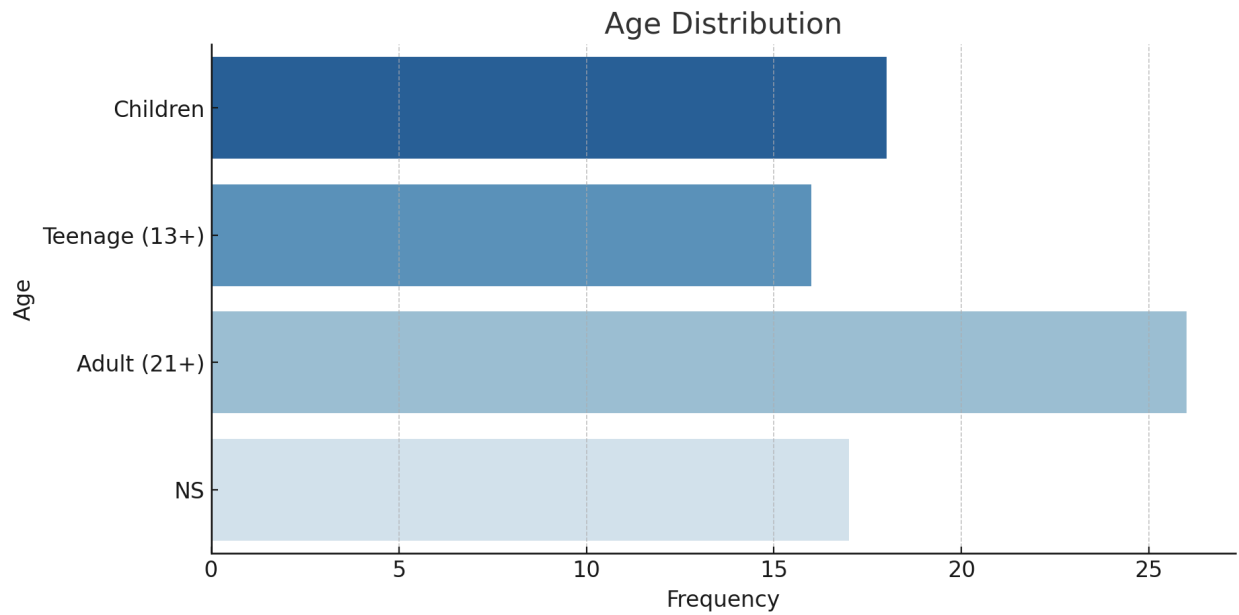
Several AAC-focused peer support models noted that peers may not *recognize the value of the model* or may not find out about the model. Likewise, peer support models that are not specifically geared toward AAC users may indeed benefit them, but they don't advertise as such. This highlights the importance of advancing AAC peer support and raising awareness.

Appendix H3: Peer Support Models Tables

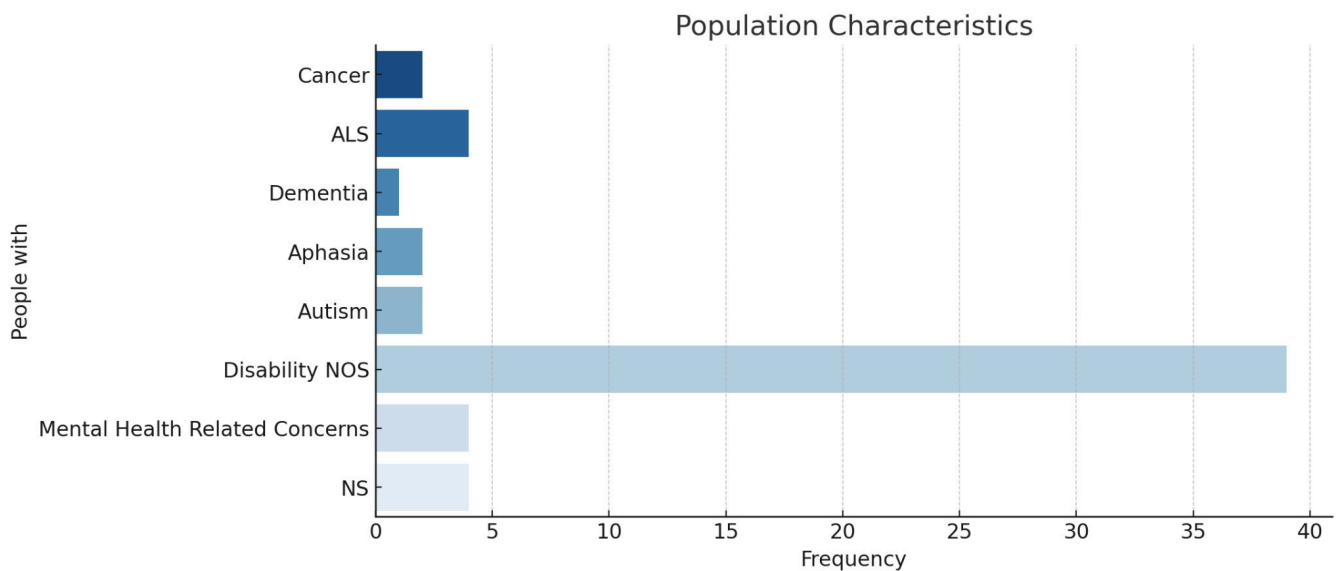
Outcomes Distribution	Frequency	%
Speech/Language/Communication	30	10
Quality of Life	31	10
Increase the Use of AAC Devices	26	9
Increase the Use of AAC	8	3
Recreation and Leisure	19	6
Social (Friendship, Sense of Belonging)	43	14
Adaptive Skills	15	5
Employment or Vocational	13	4
Self-Efficacy (Autonomy, Independence)	24	8
Advocacy Skills	26	9
Leadership Skills	15	5
Health Related (Includes Physical and Mental Health, Emotional Well-Being)	21	7
Education Related	14	5
Building Independent Living Skills	8	3
Economic Improvement /Employment	1	0
No Outcome Reported	3	1
Total Outcomes Reported For Column: 297		



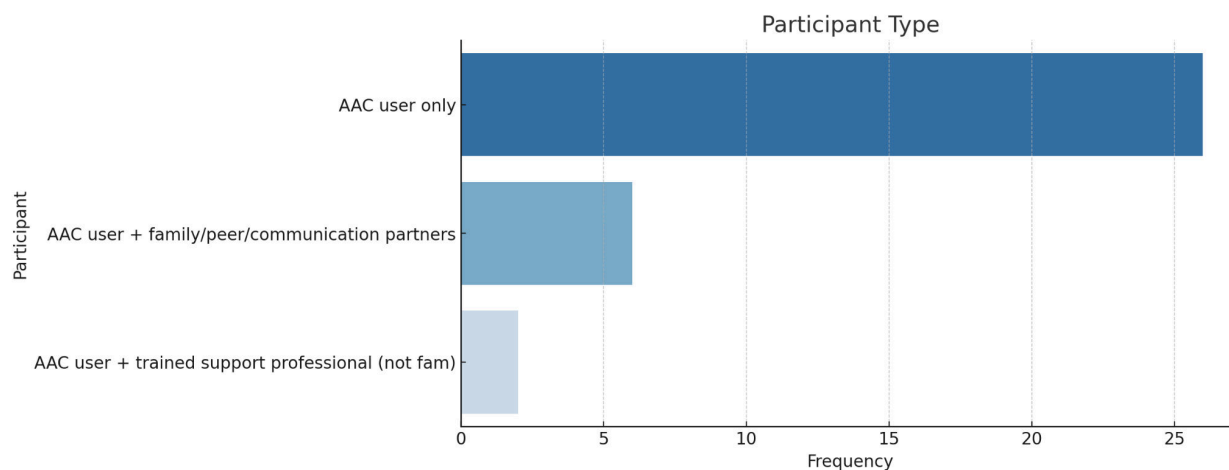
Age Distribution	Frequency	%
Children	18	23
Teenage (13+)	16	21
Adult (21+)	26	34
NS	17	22
Total: 77		



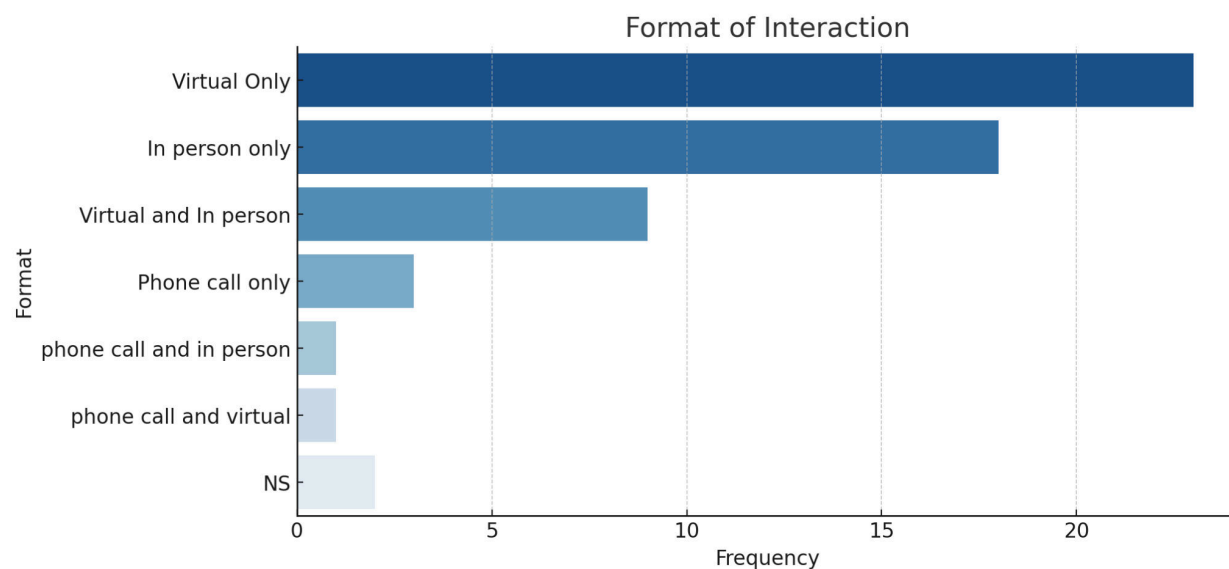
Population Characteristics	Frequency	%
Cancer	2	3
ALS	4	7
Dementia	1	2
Aphasia	2	3
Autism	2	3
Disability NOS	39	67
Mental Health Related Concerns	4	7
NS	5	7
Total: 59		



Participant Type	Frequency	%
AAC User Only	26	76
AAC User + Family/Peer/Communication Partners	6	18
Aac User + Trained Support Professional (Not Family)	2	6
Total: 34		

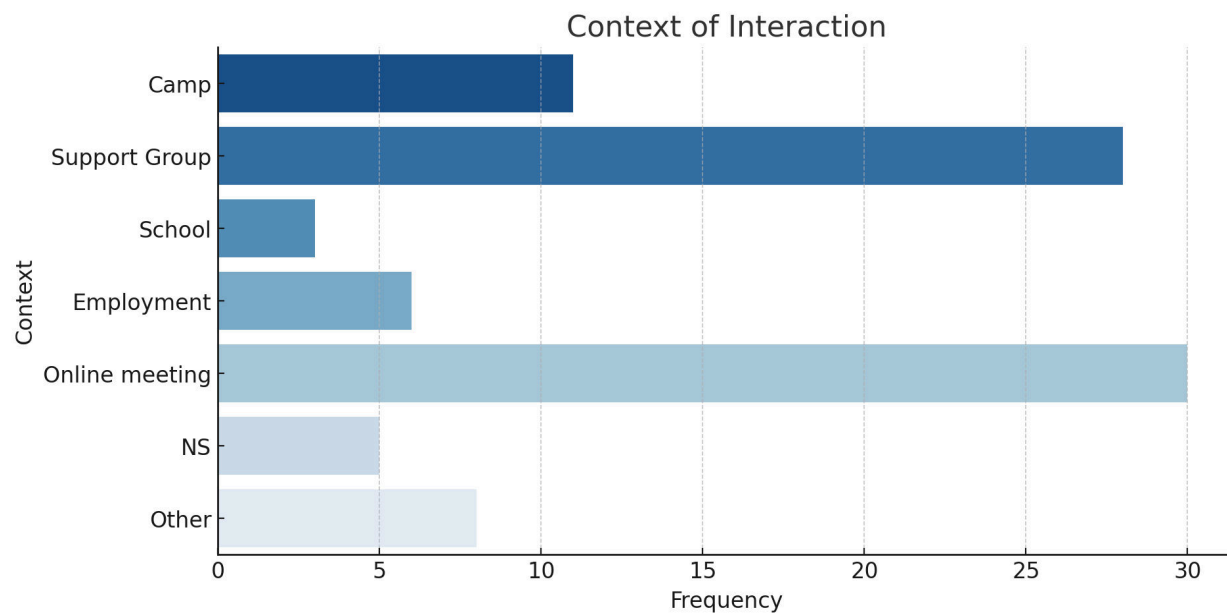


Format of Interaction	Frequency	Percent
Virtual Only	23	40
In Person Only	18	32
Virtual And In Person	9	16
Phone Call Only	3	5
Phone Call and In Person	1	2
Phone Call and Virtual	1	2
Ns	2	4
Total: 57		

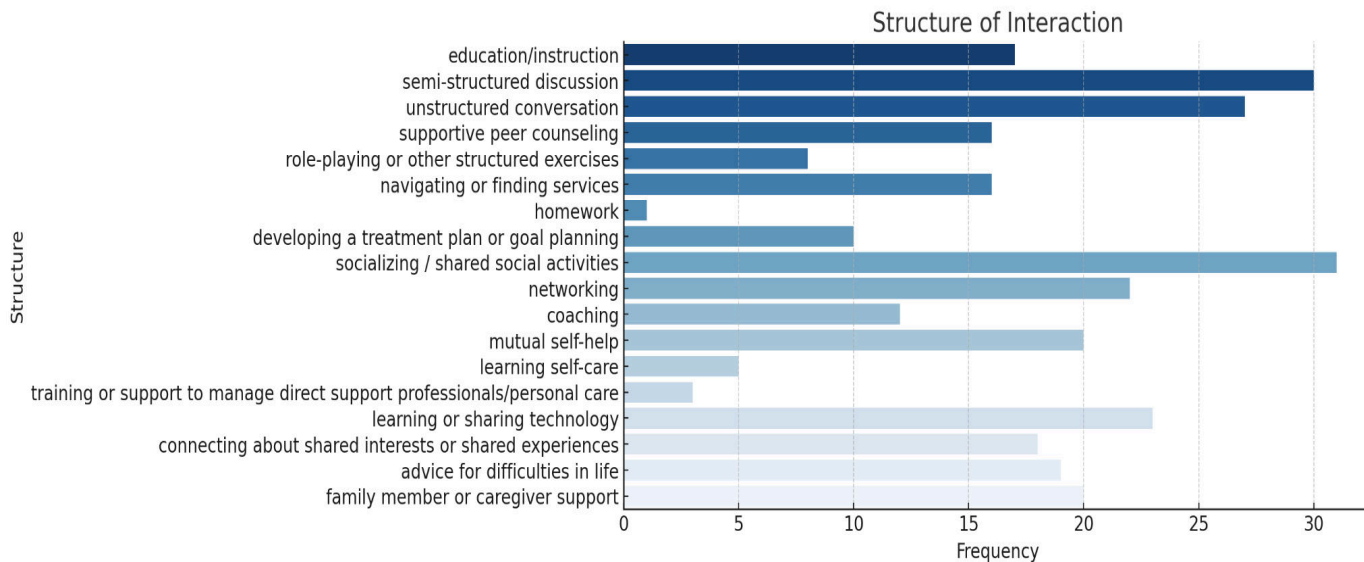


Context of Interaction	Frequency	Percent
Camp	11	12
Support Group	28	31
School	3	3
Employment	6	7
Online Meeting	30	33
NS	5	5
Other	8	9
Total: 91		

Examples Of Other: Community Theatre, Conference



Structure of Interaction	Frequency	Percent
Education/Instruction	17	6
Semi-Structured Discussion	30	10
Unstructured Conversation	27	9
Supportive Peer Counseling	16	5
Role-Playing or Other Structured Exercises	8	3
Navigating or Finding Services	16	5
Homework	1	0
Developing a Treatment Plan or Goal Planning	10	3
Socializing / Shared Social Activities	31	10
Networking	22	7
Coaching	12	4
Mutual Self-Help	20	7
Learning Self-Care	5	2
Training or Support to Manage Direct Support Professionals/Personal Care	3	1
Learning or Sharing Technology	23	8
Connecting About Shared Interests or Shared Experiences	18	6
Advice for Difficulties in Life	19	6
Family Member or Caregiver Support	20	7
Total: 298		



Appendix I: Tables for Scoping Review

Characteristics of Included Studies k = 15

Characteristics	k	%	Characteristics	k	%
Study Characteristics					
Publication type			Year of publication		
Peer-reviewed Journal	15	100	2000- 2010	3	20
Country			2011- 2020	8	53
Australia	1	7	2021- 2025	4	27
Canada	2	13	Design		
Israel	1	7	Randomized control trial	1	7
Sweden	2	13	Single-case experimental design	1	7
United Kingdom	1	7	One group pre-test post-test design	3	20
United States of America	8	53	Qualitative research design	8	53
			Mixed methods design	1	7
			Case report	1	7
Participant Characteristics					
Sample size			Population		
≤ 20	11	73	Amyotrophic lateral sclerosis	2	13
21 - 60	2	13	Aphasia	4	27
>60	1	7	Primary progressive aphasia	2	13
Not reported	1	7	Autism	2	13
Number of target participants			Cerebral palsy	6	40
≤10	8	53	Dementia	1	7
11- 25	1	7	Down syndrome	2	13
25 - 50	3	20	Deaf/ hearing impairment	1	7
Not reported	3	20	Intellectual and developmental disability	2	13
Average target participant age (years)			Speech and language delay	2	13
<12	1	7	Traumatic brain injury	2	13
13-18	2	13	Race/Ethnicity		
31-50	4	27	Not reported	12	80
51-65	3	20	>60% White	3	20
>65	2	13	Included participants who are	2	13
Not reported	3	20	Black, Indigenous, and people of color		
			Included Participants who are Hispanic	2	13
			or Latino/a/x		

Included mentors or peer facilitators	4	27	Percent Male		
Included communication partners	4	27	<50	4	27
Communication modalities used			50 - 70	8	53
Oral speech/ mouth words	7	47	Not reported	3	20
Facial expressions	3	20	Social determinants of health		
Gestures	4	27	Included multiply marginalized	2	13
Graphic symbols	6	40	people with disabilities		
ASL/ manual signs	3	20	Reported on participant income or	1	7
Communication board	9	60	socioeconomic status		
Speech generating device/	3	20			
Voice output communication aid					
Pen/paper	5	33			
Not reported					

Peer Support Program or Activity Features

Activity Type			Program Features		
Camp	1	7	Education/ instruction	6	40
Recreation	2	13	Semi-structured discussion	7	47
Online forum, Facebook group, or online simulation	5	33	Unstructured conversation	7	47
E-mentoring program	3	20	Role playing or structured exercises	2	13
Children's events and classes	2	13	Peer counseling	3	20
Group intervention/ therapy	2	13	Mutual self help	4	27
Program Delivery			Developing goals/ treatment planning	2	13
Blended (In-person and online)	2	13	Mentoring	2	13
In-person	6	40	Networking	1	7
Online	6	40	Shared social activities	3	20
Not reported	1	7	Not reported	3	20
Meeting Type			Group Size		
Both synchronous and asynchronous	4	20	Dyads (peers were paired)	2	13
Asynchronous	3	20	3- 5 participants	1	7
Synchronous	7	47	5 – 20 participants	3	20
Not reported	1	7	Combination of various groups (small and large group activities)	1	7
Total Number of Meetings/Sessions			Not reported	8	53
5- 15	5	33	Activity or Program Frequency		
> 15	1	7	Weekly or biweekly	4	27
Not reported	8	53	Varies	2	13
Total Duration			Not reported	7	47
< 1 – 12 weeks	6	40			
13 – 24 weeks	1	7			
Not reported	8	53			

Community Engagement and Leadership

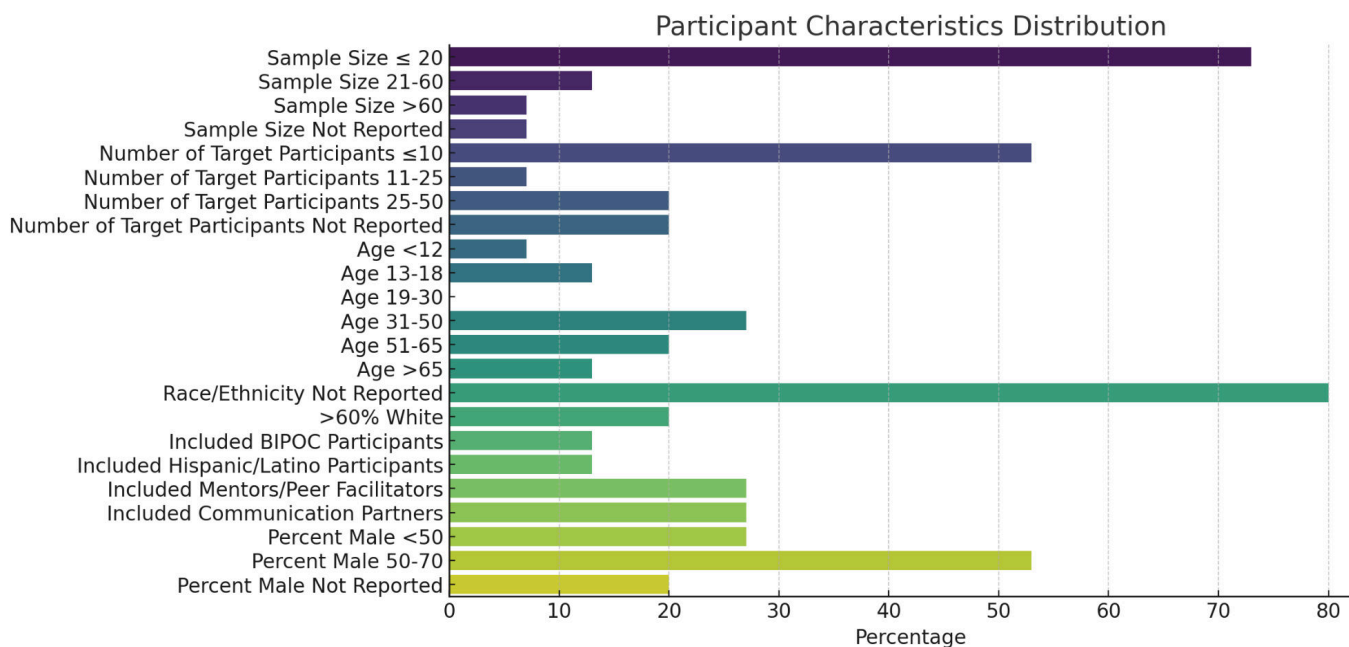
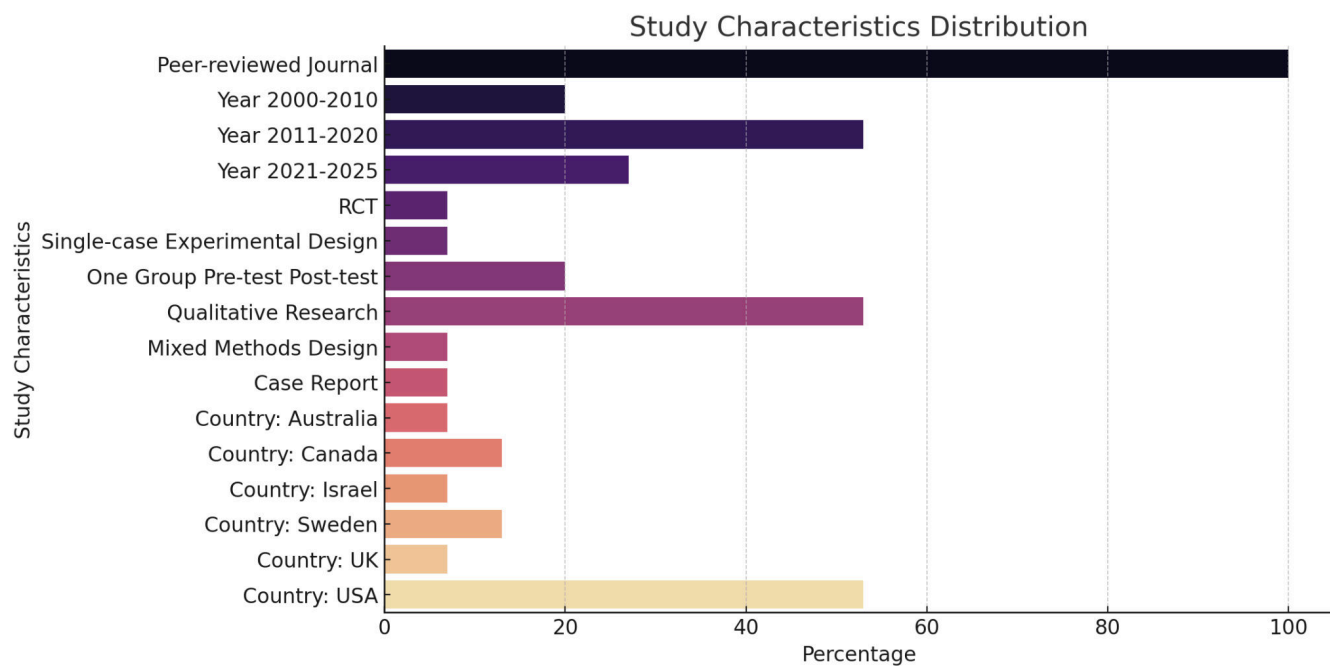
Community Engagement

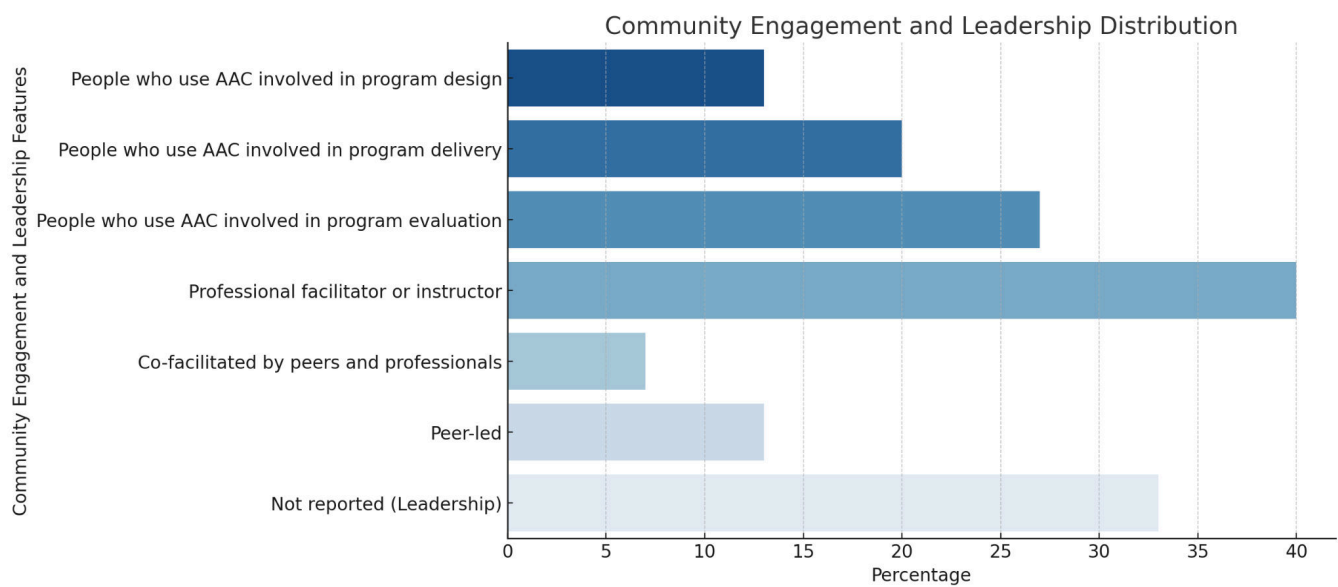
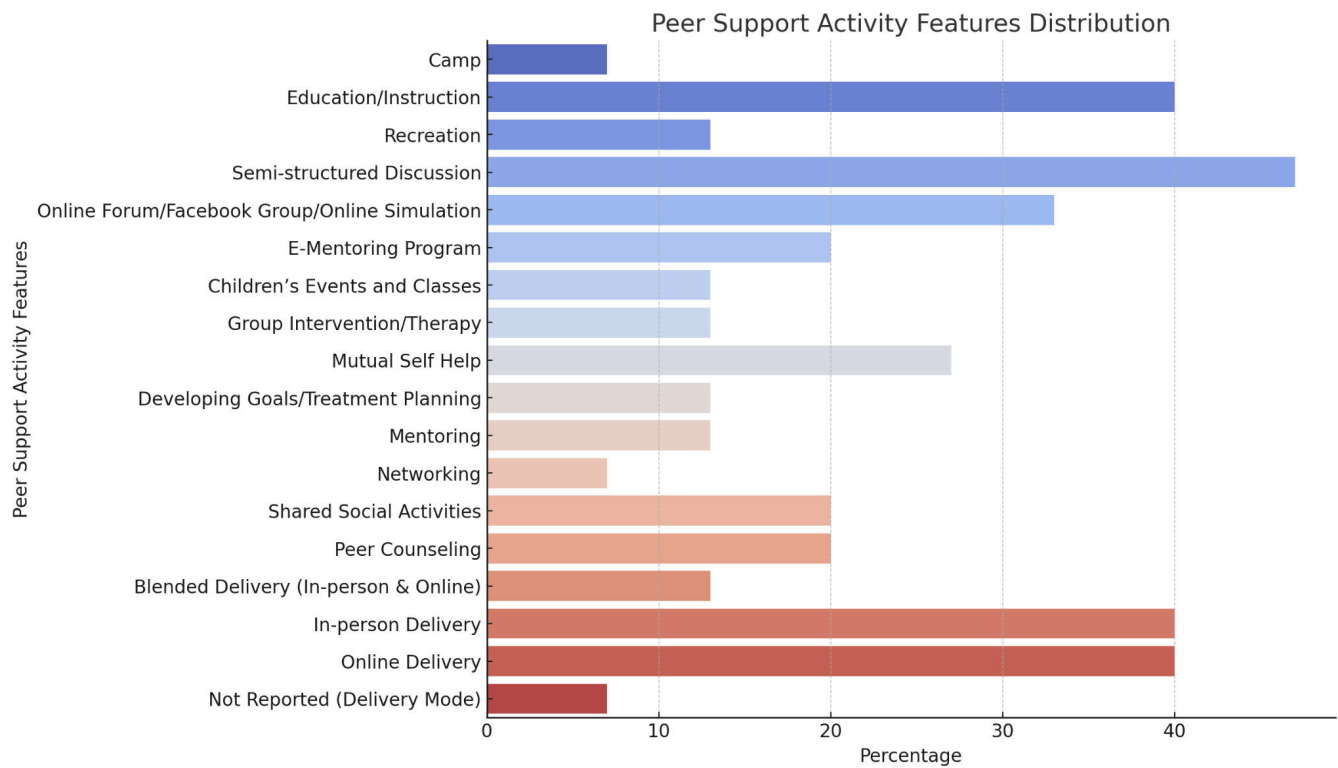
Program leadership

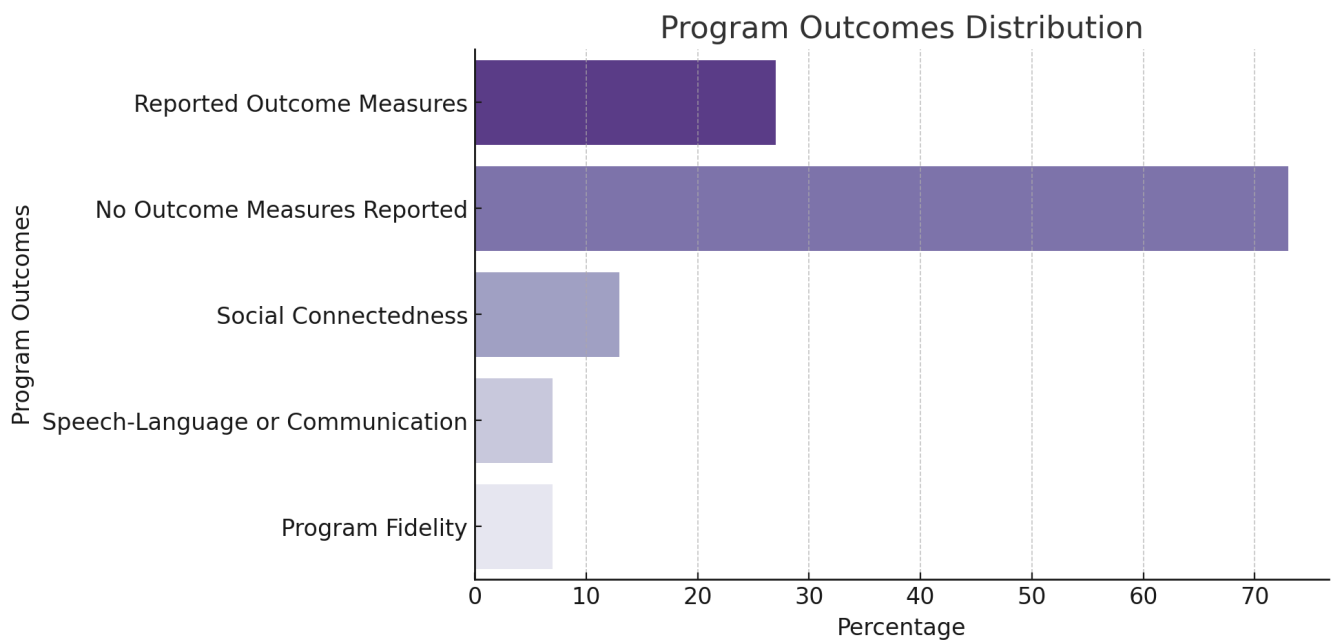
People who use AAC were involved in the design of the program	2	13	Professional facilitator or instructor	6	40
People who use AAC were involved in the delivery of the program	3	20	Co-facilitated by peers and professionals	1	7
People who use AAC were involved in the evaluation of the program	4	27	Peer-led	2	13
			Not reported	5	33

Outcomes

Reported outcome measures	4	27	Outcome Domains		
No outcome measures reported	11	73	Social connectedness	2	13
			Speech-language or communication	1	7
			Program fidelity	1	7







Studies Included in the Scoping Review

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Beauchamp, J. E. S., Wang, M., Leon Novelo, L. G., Cox, C., Meyer, T., Fagundes, C., Savitz, S. I., Sharrief, A., Dishman, D., & Johnson, C. (2024). Feasibility and user-experience of a virtual environment for social connection and education after stroke: A pilot study. *Journal of Stroke and Cerebrovascular Diseases*, 33(2). <https://doi.org/10.1016/j.jstrokecerebrovasdis.2023.107515>

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Eghdam, A., Hamidi, U., Bartfai, A., & Koch, S. (2018). Facebook as communication support for persons with potential mild acquired cognitive impairment: A content and social network analysis study. *PLoS ONE*, 13(1). <https://doi.org/10.1371/journal.pone.0191878>

Grace, E., Raghavendra, P., McMillan, J. M., & Gunson, J. S. (2019). Exploring participation experiences of youth who use AAC in social media settings: Impact of an e-mentoring intervention. *AAC: Augmentative and Alternative Communication*, 35(2), 132–141. <https://doi.org/10.1080/07434618.2018.1557250>

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Hajjar, D. J., & McCarthy, J. W. (2022). Individuals Who Use Augmentative and Alternative Communication and Participate in Active Recreation: Perspectives From Adults With Developmental Disabilities and Acquired Conditions. *Am J Speech Lang Pathol*, 31(1), 375–389. https://doi.org/10.1044/2021_ajslp-21-00179

Ho, H. J., Kamenopoulou, L., & Pinto, C. (2024). Are you fun, funny and laughing? The friendships and social relationships of students with complex communication needs in and outside of special school settings. *Journal of Research in Special Educational Needs*. <https://doi.org/10.1111/1471-3802.12696>

Kim, E. S., Figeys, M., Hubbard, H. I., & Wilson, C. (2018). The Impact of Aphasia Camp Participation on Quality of Life: A Primary Progressive Aphasia Perspective. *Seminars in Speech and Language*, 39(3), 270–283. <https://doi.org/10.1055/s-0038-1660785>

Kramer, J. M., Ryan, C. T., Moore, R., & Schwartz, A. (2018). Feasibility of electronic peer mentoring for transition-age youth and young adults with intellectual and developmental

disabilities: Project Teens making Environment and Activity Modifications. *Journal of Applied Research in Intellectual Disabilities*, 31(1), e118–e129. <https://doi.org/10.1111/jar.12346>

Light, J., McNaughton, D., Krezman, C., Williams, M., Gulens, M., Galskoy, A., & Umpleby, M. (2007). The AAC Mentor Project: Web-based instruction in sociorelational skills and collaborative problem solving for adults who use augmentative and alternative communication. *AAC: Augmentative and Alternative Communication*, 23(1), 56–75. <https://doi.org/10.1080/07434610600924499>

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Appendix J: Consortium Member Feedback

The project was AAC peer support in action

- Great meeting! I like it whenever we work together. As an AAC user, I am gaining many skills in preparing my device with quick, easy-to-access comments that will help me add to the conversation.
- Having a place to meet and talk and share ideas is priceless.
- Having some light-hearted chatting was so nice (peer support!!), and we spun it into something productive in the end!
- I am learning something every time this workgroup meets. Either it is realizing my preferred way of using my voice output system or feeling comfortable sharing ideas.
- I am not around many AAC users, and I feel this experience with meeting you all has helped me grow a lot.
- I look forward to this meeting every week. I learn from my peers, especially those who use AAC. I never lose my excitement for the project when we are together. I hope we can keep this group going after the grant ends.
- It is important work and I have grown personally just by participating... It's empowering to see all of you in action. So many of my social circle only uses letter boards and DSPs to revoice... Seeing you all use your dynamic display devices has given (me) the courage to try again, to type directly on the dynamic display of the iPad instead of always opting for or the separate Bluetooth keyboard. So I just want to thank you for that.
- I think AAC peer support is an untapped resource I didn't even know I needed until I joined this group.
- I think that these meetings are very good, almost therapeutic for some of us AAC users
- Thank you so much for this platform to share my lived experiences.

The project empowered AAC users

- empowering...nuclear fusion level power
- I also feel empowered, ready to take over the world after these meetings.
- As an AAC user, I appreciate people's patience while forming my comments and input.
- It's great to feel like an integral part of something like this. I have felt both seen and heard in this consortium.
- AAC users need to be the leaders and the guides
- I always feel empowered to make big changes in society after I meet with this dynamic group!!
- So happy to move this agenda forward, taking back our power, we are fully AAC-tivated!

This project represents a paradigm shift

- For providers and researchers, this has changed our entire paradigm for 'supporting' AAC users. Really it's about AAC users supporting the field. The power dynamic has changed and really shifted over time, especially in meetings and in the Consortium.
- It feels like we have gotten a lot done, and also this is just the beginning of a movement across the U.S. and probably further to open doors for AAC users to get more than just language supports.
- I continue to appreciate all the AAC users who share ideas and perspectives. Being part of this consortium has enabled me to grow in ways I never anticipated.
- I feel like it blew my thoughts week one.
- I think this project has taught us the value of waiting and watching. Many of us have learned so much.
- I have learned so much from this group and my ideas around evaluating what AAC does for people has shifted significantly because of this work.
- The impact of this consortium extends far beyond these meetings, and I look forward to seeing how our collective efforts continue to shape the AAC landscape moving forward.

This project equalized power and communication

- LOVE having this particular conversation led by AAC users almost exclusively rather than having mostly speakies doing the talking :)
- I think that these are great meetings. 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. Great meetings. Great people.
- really appreciate fully speaking people asking if it's okay to comment while I'm still typing, I am not always assertive enough to say no even if I wanted to but this feels much more welcoming than folks just jumping in with the assumption it's okay
- So glad for AAC users "sticking up for themselves" (when still typing on previous topics for example and need more time), and other folks respecting that!
- So proud to attend a meeting that was about the experiences and opinions of AAC users rather than talkies. Moved the power where it should be for the final product.
- SOO uplifting and wonderful and everyone has a voice, is heard
- This group continues to do a great job at considering, adjusting, and prioritizing accessibility.

The project advanced knowledge

- I continue to be in AWE of ALL this group is doing and accomplishing--GROUNDBREAKING AND MUCH NEEDED WORK

- I loved our deep and insightful discussion today. It is awesome to look back over the year and see how much growth has happened within this Consortium\community!
- I think it's an organic process, and each meeting, our thoughts bloom bigger.
- the meetings have been wonderful, insightful and very productive
- This meeting was superb! I love how things evolve through discussion and collaboration. Every time, we make the project better.
- What another amazing meeting! I feel honored to hear the stories, opinions and thoughtful reflections of the AAC users
- Each week we uncover more layers to the complexity of AAC and AAC users. So blessed to be part of this committee.
- The discussions help fill out and flesh out what people are trying to say. It feels like every word counts.
- I really enjoyed learning how this many people can work together collectively and collaboratively, staying on topic and getting the mission complete. Team work makes the dream work
- This meeting was superb! I love how things evolve through discussion and collaboration. Every time, we make the project better.

The project was a career highlight

- I am beyond appreciative to be part of this project--look forward to every meeting and the workgroup meetings continue to be a highlight of my week AND my career
- for me, this was the most pivotal meeting I've participated in
- I'm going to say thank you to every single person on this consortium for making me a better, more well educated person, a better practitioner, and a better human being in general.
- I always learn from hearing what AAC users think, feel, experience, and their opinions. Best meetings of my week by far, and best meetings of many of my years as a provider.
- such an incredible group of people! So grateful to be part of this project, which impacts my thinking every day.
- There are times when it feels like I lucked out and was in the right place at the right time. I feel like that with this consortium. I feel very honored and humbled to have had the experience to work with all of you, and of course I feel so lucky to have had the opportunity to meet and work with Bob right before he began retiring. I am in awe.
- This has been one of the most powerful experiences of my life and career.

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

Guidelines for the Prioritization of AAC Users in Group Discussions Developed for the 2024-2025 AAC Peer Support Project Virtual Consortium Meetings

- 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 them first by private chat, then aloud. We can put these topics in a “parking lot.”

Accessibility Guidelines for AAC Peer Support Meetings

Accessibility guidelines represent a joint understanding and should aid the process of continual learning and improving together. Accessibility solutions should be treated as a tool kit we draw from, not a checklist or one-size-fits-all fix.

- Planning in advance to maximize accessibility is helpful, but **access flexibility** is key. Access flexibility refers to an accommodating spirit and willingness to adapt to the needs of the group members as they arise. Accessibility measures for one person can be insurmountable barriers to others. Groups should prepare for these inevitable tensions and be willing to adjust as much as possible
- **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.

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.

Appendix L: Appendix L: Outputs from the AAC Peer Support Project

1. The AAC Peer Support Project webpage
2. An article written about the project in the June 2024 newsletter of the International Society for Augmentative and Alternative Communication (ISAAC)
3. An article written about the project, highlighting Bob Williams and Lateef McLeod in the US Society for AAC (USSAAC) on-line magazine, SpeakUp!
4. Two-hour webinar for the October, 2024 virtual conference for ISAAC
5. Two posters for the AUCD conference held November, 2024 in Washington, D.C.
6. Two posters for the Assistive Technology Industry Association (ATIA) conference held January, 2025 in Orlando, FL.
7. Proposed international webinar to be held through the Assistive Technology Industry Association (ATIA)
8. 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 L1: OHSU UCEDD webpage

Link: www.ohsu.edu/university-center-excellence-development-disability/augmentative-and-alternative-communication-aac

Screenshot of the top of the page, March 2025:



University Center for Excellence in Developmental Disabilities

[OHSU Home](#) [Find a Doctor](#) [MyChart](#) [Donate](#) [Jobs](#) [Directions](#) [Contact](#)

[Search](#)

[About Us](#) [Community Partners Council](#) [Research and Evaluation](#) [Education Opportunities](#) [Community Training and Activities](#) [Resources](#)

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[Education Opportunities](#)
[Community Training and Activities](#)
[Resources](#)

Augmentative and Alternative Communication (AAC) Peer Support Project



A screenshot from the February 2025 AAC User Meeting on Zoom. Pictured from left to right: Patrick Regan, Tracy Rackensperger, Jordyn Zimmerman, Michale Fondacaro, Alyssa Zisk, Jan Staehely, Kevin Williams, Lateef McLeod, Grant Blasko, Mateo Moreno.

Who we are



The AAC Peer Support Project is a group of AAC users, researchers, providers, and representatives from disability and self-advocacy organizations located across the U.S. Our goal is to develop recommendations for a national plan about peer supports for people who need or use AAC.

Jump to ["Who is involved?"](#)

Members of the AAC Peer Support Project Steering Committee and Consortium met at the Assistive Technology Industry Association (ATIA) event on January 30, 2025, to present our work on AAC peer support models. Pictured from left to right: Kirk Behnke, Tracy Rackensperger, Yonit Hagoel-Karnieli, Jill Tullman, Lateef McLeod, Amy Goldman.

Appendix L2: Article in the June 2024 newsletter of the International Society for Augmentative and Alternative Communication (ISAAC)

Link: isaac-online.org/wp-content/uploads/The-ISAAC-Communicator-June-2024-June-28.pdf




News

... continued



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



Contract awarded to OHSU UCEDD and CommunicationFIRST by AUCD, February 2024

The University Center for Excellence in Developmental Disabilities Education, Research, and Service (UCEDD) at Oregon Health & Science University ([the OHSU UCEDD](#)), in partnership with [CommunicationFIRST](#), was awarded a 9-month contract from AUCD to create a national plan to develop and advance peer-support models for augmentative and alternative communication (AAC).

The project is grounded in the concepts of (1) peer support; (2) self-advocacy and self-determination; (3) the AAC participation framework; (4) communication equity; (5) diversity, equity, and inclusion, including cultural and linguistic competence; and (6)

a community-based participatory research (CBPR) model.

The leadership team includes Dr. Melanie Fried-Oken (PI), Dr. Emily Quinn, endever* corbin, and Janice Staehely from the OHSU UCEDD, and Tauna Szymanski and Bob Williams from CommunicationFIRST. The team's first task is to establish a national consortium and steering committee composed of people who have experience with a full range of AAC peer support activities in diverse settings, from private-practice service providers to self-advocacy and other disability organizations, from law centers and AAC manufacturers to university programs. It is expected that the consortium and steering committee will include about 50 people and be comprised of AAC users as well as other representatives from agencies and organizations. Members of the consortium, and project staff, will help achieve the project's five goals:

- (1) conduct a national survey about currently used peer supports in the AAC community;
- (2) develop a protocol for review and analysis of peer support models, projects, approaches and activities within and outside the AAC field that are organized, at minimum, around 3 descriptors: person characteristics (who

...continued on page 15

June 2024

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News

... continued

is included), program characteristics (what is done), program outcomes (why); (3) review and analyze AAC models/approaches/activities with the protocol and determine their best fit or contribution for a national AAC Peer Support model; (4) review and analyze related disciplines models/approaches/activities with the protocol and determine their best fit or contribution for a national AAC Peer Support model; and (5) generate initial findings, recommendations and a final report.

International Communication Rights Alliance

ICRA

International Communication Rights Alliance

The International Communication Rights Alliance ([ICRA](#)) was formed in 2020 from the initiative of ISAAC to operationalise the United Nations Convention on the Rights of Persons with Disability (UNCRPD), specifically for people who use AAC. ICRA comprises people with communication difficulties, parents, service providers, researchers, and advocates.



The ICRA has given two presentations to the UNCRPD committee calling for more action regarding communication rights. ICRA will be giving a presentation to the CRPD Committee in August this year to share the findings of a study undertaken to look at what extent AAC is mentioned by the CRPD committee in their responses to reports of signatory countries. We found that AAC was only mentioned in about a quarter of the statements and that the definition of AAC needs to be made clearer in these statements.

We are currently calling for ISAAC members, particularly those who use AAC to join the ICRA committee and continue our work to raise awareness of, increase and improve policies, standards and practices to uphold communication rights. If you represent a State or National peak body or group advocating on communication rights, we would love to hear from you. If you are interested, please contact meredith.prain@ableaustralia.org.au

ISAAC-India


ISAAC
INDIA CHAPTER

ISAAC India Chapter was founded in April 2008 at Ali Yaver Jung National Institute for the Speech and Hearing Disabilities, Mumbai.

...continued on page 16

Appendix L3: Article in the June, 2024 United States Society for Augmentative and Alternative Communication (USSAAC) online magazine, SpeakUp!

Link: <https://ussaac.org/speakup/articles/aac-peer-support-models/>




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AAC Peer Support Models

Posted on June 26, 2024

Introduction

by Bob Williams

There is credible evidence that people who are denied effective access to AAC, especially language-based tools, experience high rates of segregation, illiteracy, institutionalization, extreme isolation, dismal health care, violence, social death, and euthanasia. Some research exists on these matters. But far more comprehensive, rigorous, and participatory action research and development efforts are critically needed. We need to gauge and document both the magnitude and the real life toll such widespread cruel injustice has on individuals, families, communities, and the American people writ large.

To move toward communication equity and justice, we need research grounded in ethnographic, oral history, video storytelling, and similar research methods that chronicles the lives, dreams, aptitudes, and fears of both those who are caught up in the cycle, as well as those of us who have escaped it. For we, possess much of the knowledge, insight, and urgency, that is pivotal to freeing others like us.

As I look back over the decades, it is clear that I am extremely fortunate to know, love, learn from, and emboldened by, other people who need AAC. Richly diverse, in their race, disabilities, so called intelligence quotients, languages, age, gender identity, culture, and life station. External and internal, oppression. Gnaws away, at one's spirit, when we know we are completely alone. Misunderstood. Dismissed as someone, or something, who we know we are not. When there is no one we can turn to who has lived, felt, and experienced, our truth. Someone or better yet, several some, ones, around us who have lived lives that if not the same, are vastly similar to our own. People who we can mutually support, learn with dream, and grieve with, and co create a more just world with. It is called peer support, among other things. And many of us freely offer and receive it every day without thought. It is essential and ubiquitous to us personally and for throwing off oppression of all degrees.

We at CommunicationFIRST believe greater justice will only come when people who need AAC bring it about together for all of us. This is why we are proud to be partnering with the Association of University Centers on Disabilities, and the Oregon Institute on Developmental Disabilities on a project funded by Administration for Community Living. The goal of this project is to explore ways in which people who need AAC are currently engaged in peer support as well as how such efforts can be made more universally available

Interview

by Lateef McLeod

SpeakUp Menu

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- [Guest Author Form](#)
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SpeakUp Topics

- [AAC Strategies & Resources \(28\)](#)
- [Advocacy & Funding \(7\)](#)
- [Firsthand AAC Perspectives \(27\)](#)
- [Research-in-AAC \(4\)](#)
- [Uncategorized \(6\)](#)
- [USSAAC AAC Legends \(4\)](#)

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[SUBMIT](#)

Interview

by Lateef McLeod

SUBMIT

As a person who uses AAC, please describe your earliest experiences meeting peers who also used AAC for communication.

My earliest memories of having peers who use AAC is when my friend Brent transferred to my elementary school, Springhill Elementary School. He was in the second grade and I was in the fourth. We were the only two students who use AAC at that school. The other experience I have is attending a camp put on by The Bridge School where I was able to meet and interact with other children who use AAC.

How did meeting peers who also used AAC influence your life?

Meeting other people who use AAC at an early age helped me understand that my method of communication was used by other people who were successfully navigating through life. Since I saw other people communicate with AAC successfully, it made me come to believe that there was nothing wrong with me or with the way that I communicate and if I met with resistance from other people because of the way that I communicate the problem is with them.

Have you previously been involved in peer support, either providing or receiving peer support? Please describe how that worked.

When I was the VP for people who use AAC at ISAAC I briefly set up an AAC mentoring program that had an international scope. Even though the mentoring program didn't go exactly as planned, because it was hard to keep the mentoring program together throughout the months with people from around the world. But the project peaked my interest and I researched and studied AAC mentoring programs in my dissertation for my dissertation and saw how effective they were in teaching self-advocacy and leadership to people in these mentoring programs.

What do you hope this project will achieve?

I hope this project will achieve a better understanding of how peer supports currently work for people who use AAC and how we can improve of these peer supports for the future.

How can USSAAC help support this initiative?

I think USSAAC are already actively supporting this initiative by being active members of our AAC Consortium and that is a tremendous help. I also think if Speak Up or the AAC Journal could publish our findings after we finish the project that will be a tremendous help too.

Appendix L4: Two-hour Webinar at the October, 2024 ISAAC Virtual Conference

A advance peer-support models for people who use or need augmentative and alternative communication (AAC)

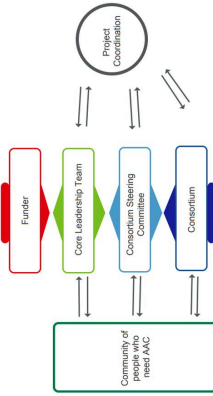
ISAAC Vibes of AAC
October, 2024

Melanie Fried-Oken



Because communication is a human right.

Governance Structure Flow Chart



Project summary

Our goal: To advance the use of peer support models for people who use or need Augmentative and Alternative Communication (AAC) through the creation of a nationwide, comprehensive, consensus-based approach. We hope to answer:

1. What peer supports exist for AAC users now?
2. What peer support models exist outside the field of AAC that may be applicable to AAC?
3. Can we create a nationwide resource for developing peer support models for people who use or need AAC?

Partnerships

- The University Center for Excellence in Developmental Disabilities (UCEDD) at Oregon Health & Science University (the UCEDD at OHsu)
- CommunicationFIRST
- Our federal funder: Administration for Community Living (ACL)
- Our contractual partner: The Association for University Centers on Disabilities (AUCD)

What are we doing in this 9-month contract?

1. Conduct a survey of AAC users and peer supports
2. Identify and present different peer support models and discuss their outcomes
3. Conduct a systematic literature review
4. Identify barriers and opportunities, with attention to multiply marginalized communities
5. Examine models, approaches and activities for AAC advancement
6. Build consensus on initial findings and recommendations
7. Draft a final report on our findings and recommendations for a national plan

The AAC Peer Support Consortium

- A national group of AAC users, AAC service providers, researchers and representatives from
- disability organizations,
- underrepresented communities,
- self-advocacy and other independent living organizations
- law centers
- AAC manufacturers
- university programs

Organizations represented in the AAC Peer Support Consortium

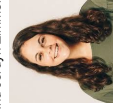
ALS of Michigan
 Aphasia Community Center, Inc.
 Asstake, Inc an AAC User
 Autism Speaks
 AssistiveWare
 AT Lab, Community Vision
 Autism Society of America
 Beyond the Chair
 Beyond the Chair
 Bridge School
 Bridge School's Bridging Communities Through Alternative
 Communication
 Co-founder of CampAEEC
 CommunicationFIRST
 Center on Youth Voice, Youth Choice, CA State Ambassador
 National Association of Councils on Developmental Disabilities
 National Alliance for Direct Support Professionals
 National Aphasia Association
 National Association of Councils on Developmental Disabilities
 National Family to Family Health Information Center
 Oregon Family to Family Health Information Center
 Portland State University University Health Design Lab
 PRC-Sallio ambassador and training program
 SAE
 San Francisco State University
 Supported Decision-Making Initiatives, Center for Public Representation
 The Arc Ohio
 The Arc Ohio
 USAAC
 Waitema Center, University of Wisconsin UCEDD
 HDO Georgia UCEDD
 ImpAACI Voices
 Wyoming Institute for Disabilities and WY AT Resource

Workgroups

1. Identify peer support models within the AAC field
2. Identify peer support models outside the AAC field
3. What are we evaluating? Determine characteristics of peer support models that we will evaluate and include in our recommendations
4. Present peer support models, activities, strategies to the Consortium
5. Develop strategies for inclusion of diversity and underrepresented communities in our recommendations
6. Conduct a systematic review of the literature around peer supports.

Steering Committee

Tracy Rackensperger, Lateef McLeod, and Jordyn Zimmerman



The role of the Steering Committee is:

- To ensure that AAC users are integrally involved in the work this project is doing
- To review the products and deliverables from each workgroup and the national plan

Work of the Steering Committee

We met with AAC users to find out:

- What's going well?
- What's not working?
- What's confusing or needs clarified?
- How are the workgroup meetings going? Are they long enough or too long?
- Do we understand peer support or do we need to create a universal definition?
- What to people need from us?
- Is everyone clear with the goals of the consortium?
- Are there qualities of AAC peer support we are missing in our evaluation?

Feedback from AAC users was integrated into the project and next steps by the Core Leadership team

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What are AAC Peer Supports?

AAC Peer Support Consortium August 28, 2024

Bob Williams

USSAAC SpeakUp article

AAC Peer Support Models

You can view it from this link :

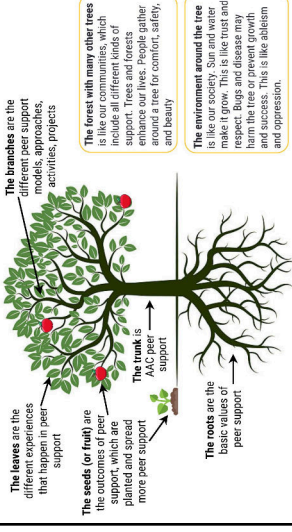
<https://ussaac.org/speakup/articles/aac-peer-support-models/>



AAC Peer Support Consortium

July 24, 2024

Lateef McLeod



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Peer Support: Basic values

- 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, our community, spelling it out, and taking action

How do we define Peer Support?

Let's review definitions written by each workgroup

Workgroup 1:

AAC Peer support is a gathering of people in a safe place to speak their mind, who help and learn from each other. It consists of sharing positive and negative experiences, ideas, activities, and frustrations in order to manage difficulties in life, and find validation of all feelings and in all ways to communicate. AAC peer support can build trust, friendship, a sense of belonging, pride, and forming of a shared identity.

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How do we define Peer Support?

Workgroup 2:

- Peer support is shared understanding and experience that consists of some type of reciprocity in order to grow
- Peer support is a flexible set of actions or activities that consist of reciprocal relationships based on lived experience, in order to provide connections, support, and growth
- Peer support is an invaluable part of life that consists of interactions with others that have some sort of common interest or common history in order to progress in our personal experience
- Peer support is fun and meaningful activities in order to set the stage for making friends and connections

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How do we define Peer Support?

Workgroup 3:

Peer support is grounded in the idea of a safe place to achieve connection, collaboration and reciprocity where mentorship is fluid and authentic and which cultivates an atmosphere of interdependence, empowerment and social justice. Peer support empowers AAC users to create a safe space where the foundation of shared lived experiences leads to collaboration. Peer support leads to both greater interdependence and independence.

Trust and respect (respecting each other, all communication, different views and experiences, etc.) are critical to a successful peer support group. With trust and respect, group members will share openly. A successful peer support group will foster trust and respect leading to open and honest sharing. Trust and respect are imperative to the success of peer support writ large.

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How do we define Peer Support?

Workgroup 4:

Peer support at its foundation is built on trust and respect, and some of its key elements include healthy relationships, honest sharing, love, community, empowerment, and the goals the peers have.

AAC peer support is a state where people who use AAC are connected to others who share lived experience that consists of a variety of meaningful activities, such as group social experiences, one-to-one consultation and can be more structured or organic in order to create a reciprocally beneficial impact.

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How do we define Peer Support?

Workgroup 5:

Peer support for AAC users is a community where individuals connected through similar characteristics (and their support staff) come together to deepen connection through a discourse of shared experiences meant to create trust, transparency and reciprocity. Peer support empowers the lived experience of all in the group, regardless of mode, method or expertise of AAC tools used.

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How do we define Peer Support?

Workgroup 6:

Peer support models leverage the power of reciprocal community support and honest sharing. In peer support, people who have a shared non-professional connection* to the area of support mentor and guide each other to reach the goals *they* each have (not the ones other people maybe think they should have.)

*Professional connections are fine as long as the non-professional connection exists too -- people can have multiple relationships to an area.

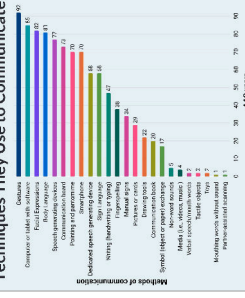
2

Our Two National Surveys

1. To AAC Users within the U.S.:
 - a. What tools and techniques do you rely on for expression?
 - b. What are your experiences with peer supports?
2. To the national community:
 - a. Please add peer support models/activities that you have experience with, inside and outside the AAC field.

Survey about tools and techniques used to communicate

AAC Users Report the Tools and Techniques They Use to Communicate

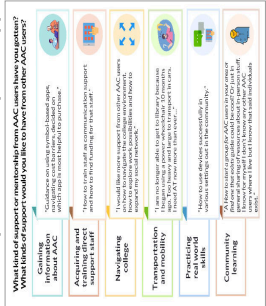


Most people reported using both natural techniques and aids. 129 respondents reported using Aided AAC. 19 people who use aided AAC report they do not use any natural AAC.

110 respondents report using Natural AAC. All 110 who report using unaided AAC also report using aided AAC.

Survey about AAC users experiences with peer support

Most AAC users want peer support. Peer support experiences help AAC users in many different ways and takes many different forms. It offers social, emotional, and technical support.



Survey about AAC users experiences with peer support

- 64% experienced peer supports when learning AAC 94% of these respondents stated they wanted more peer support.
- Of those who did not experience peer support when learning AAC, over 78% stated they would like to receive peer support, or they were unsure.
- Peer support experiences ranged greatly. Many attended AAC camps. Others rely on internet communities or online technical assistance.
- AAC peer supports reduce isolation, normalize their communication, and validate the process, while also presenting troubleshooting of technical challenges on speech generating devices.

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What are Peer Support Models/Activities?

We received models/activities divided into four categories:

1. Camp (9)
2. Online/Virtual/hangouts (21)
3. In-Person (14)
4. Formal (12)

Survey data collected from each model/activity

Responses are in a drop down menu with additional write-in boxes:

- What is the activity?
- Who are the peers?
- Where does the activity occur?
- How is the activity funded?
- What is the context/environment/setting?
- Who leads the activity?
- Who created the model/activity?
- What is the expected outcome?
- What is provided to enable people to participate in this activity?
- What are some barriers that may prevent people from participating?

Where Does Peer Support Take Place?

Online - 26	In person - 35
regional: 8	East coast: 9
national: 15	South: 6
international: 3	Midwest: 5
	West coast: 10
	various locations nationwide: 5

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Who Uses the Peer Support Activities/Models?

Focused on AAC users: 36	Not focused on AAC users: 23
Focused on adults: 41	Focused on children/young adults: 22

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In-Person Peer Support Groups

AAC-alphasia group chak-FL	Aphasia Support Groups- national
AAC social hour at Community Vision- OR	Peer-mediated learning- TENN public schools
AAC play group (0-5 yrs) at Community Vision-OR	Rainbow Kids- Shelbygan, WI grief groups
AAC preschool group- Denver, CO	ALANON/ANON nationwide
AAC school age group- Denver, CO	Ohio University Sparkles Cheerleading
AAC peer support for young adults group- Denver, CO	
AAC Social- AAC Research Learning Communities at Portland State U	
ImpAAC! Voices biennial conference	
Augmentative and Alternative Improvisation (in a number of states)	

How you can participate in this project

Visit the webpage

Join the Consortium

We will have future surveys. If you would like to receive them, please email Sarah Fieldstad, Project Coordinator, at sfieldsta@ohsu.edu

AAC Peer Support Consortium Meeting
August 28, 2024
Patrick Regan
Bridging Communities Through
Alternative Communication (BCTAC)

**Appendix L5 & L6: Two Posters Presented at the 2024
Association of University Centers on Disabilities (AUCD)
Conference and the 2025 Assistive Technology Industry
Association (ATIA) Conference**



Augmentative and Alternative Communication (AAC) Users Report on the Peer Support Experiences that Helped Them Learn AAC



OHSU: Melanie Fried-Oken, Ph.D., Emily Quinn, Ph.D., Sarah Fjeldstad, M.S.W., and Larissa Yoshino, M.P.H.
CommunicationFIRST: Bob Williams, B.A., Tauna Szymanski, J.D., M.P.A., and Bre Mercier, B.S.

Project background – How we got started

The University Center for Excellence in Developmental Disabilities (UCEDD) at OHSU, in partnership with CommunicationFIRST, was awarded a contract from AUCD to develop recommendations for a national plan for Augmentative and Alternative Communication (AAC) Peer Supports.

A survey was sent to AAC users to gather data about their personal peer support experiences. These data, not often sought from AAC users, will inform future recommendations.

This is the largest national survey to gather data about AAC peer support experiences. The results formed the foundation for the AAC Peer Support Consortium, a national group of AAC users, disability organizations, providers, and researchers who meet monthly to develop the recommendations for a national plan.

Survey process – What we did

The AAC Peer Support survey was distributed nationally through social media, disability organizations, providers, and AAC manufacturers.

It was made available to users in many formats, including a Google survey form, Microsoft Word form, or individual assistance from Peer Support Project team members.

The survey asked four questions:

1. Have other AAC users helped you develop AAC skills? If so, how much?
2. Would you like more mentoring from other AAC users?
3. What kind of support or mentorship from AAC users have you gotten?
4. What kinds of support would you like to have from other AAC users?

Survey results – What we learned

**What kind of support or mentorship from AAC users have you gotten?
What kinds of support would you like to have from other AAC users?**

Gaining information about AAC



"Guidance on using symbol-based apps, navigating cost barriers, decided on which app is most helpful to purchase."

Acquiring and training direct support staff



"How to train staff as communication support and how to find funding for that staff."

Navigating college



"I would like more support from other AAC users on how to navigate the college environment, how to explore work possibilities and how to expand my social network."

Transportation and mobility



"I am no longer able to get to library because I began using a power wheelchair 10 months ago. Too heavy and large to transport in cars. I need AT now more than ever..."

Practicing real world skills



"How to use devices successfully in various settings out in the community."

Community learning



"A How to start a group for AAC users in your area or find one that exists guide could be cool? Or just in general sharing of resources about in-person stuff. I know for myself I don't know any other AAC users where I live but I know that said individuals exist."

Data show that 64% of AAC users experienced peer supports when learning AAC. 94% of these respondents stated they wanted more peer support from other AAC users.

Of those who did not experience peer support when learning AAC, over 78% stated they would like to receive peer support from other AAC users, or they were unsure.

The peer support experiences that AAC users shared ranged greatly. Many attended AAC camps. Others rely on internet communities on Facebook, Discord, Twitter (X) or online technical assistance.

Respondents reported that AAC peer supports reduce isolation, normalize their communication, and validate the process, while also presenting troubleshooting of technical challenges on speech generating devices. These data will be presented as part of the recommendations for a national plan.

Conclusion – Why this matters

Most AAC users want peer support. Peer support experiences help AAC users in many different ways and take many different forms. It offers social, emotional, and technical support. Note: this is only a sample of AAC users who could respond.

Contact info – Where to learn more

To sign up for email updates about this work, and to view written descriptions of the image, go to our site:

sites.google.com/view/aac-peer-experiences

Or scan the QR code:



Email ucedd@ohsu.org or info@communicationFIRST.org

This work was supported by a subcontract from AUCD, funded by the Administration for Community Living.



Augmentative and Alternative Communication (AAC) Users Report on Tools and Techniques They Rely on for Communication



OHSU: Melanie Fried-Oken, Ph.D., Emily Quinn Ph.D., Sarah Fjeldstad, M.S.W., and Larissa Yoshino, M.P.H.
CommunicationFIRST: Bob Williams, B.A., Tauna Szymanski, J.D., M.P.A., and Bre Mercier, B.S.

Project background – How we got started

The University Center for Excellence in Developmental Disabilities (UCEDD) at OHSU, in partnership with CommunicationFIRST, was awarded a contract from AUCD to develop a national plan for Augmentative and Alternative Communication (AAC) Peer Supports.

A survey was sent out to identify the tools and techniques that AAC users rely on for expression. The survey did not focus on disability type or health condition, but rather the functional skills of communication.

This is the first survey to report on a large AAC user base about the tools and techniques that they use.

Survey process – What we did

The AAC Peer Support survey was distributed nationally through social media, disability organizations, providers, and AAC manufacturers.

It was made available to users in many formats, including a Google survey form, Microsoft Word form, or assistance from individual Peer Support Project team members.

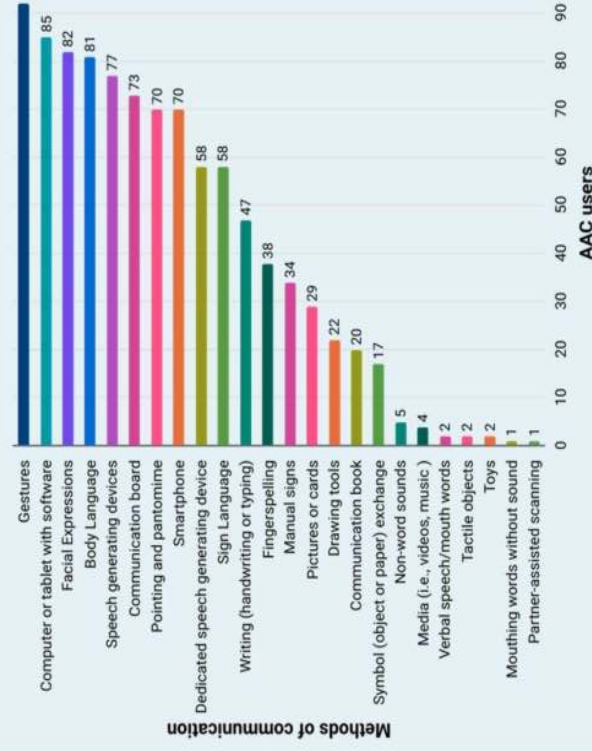
Survey respondents answered one question:

Please identify every AAC technique or tool that you use to express yourself. Please check off boxes or type out your response in the OTHER line at the bottom of the list.

There were 19 options provided in the checklist.

Survey results – What we learned

AAC Users Report the Tools and Techniques They Use to Communicate



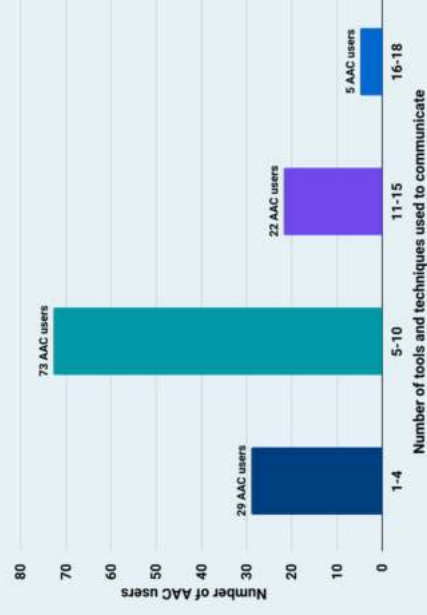
Most people reported using both natural techniques and aids. Commonly selected techniques included gestures (N=92), computer or tablet with communication software (N=85), facial expressions (N=82), body language (N=81), and speech generating devices (N=77).

129 respondents report using Aided AAC: external tools and devices to enhance communication, such as communication boards with symbols or pictures, speech-generating devices, and mobile applications. 19 people who use aided AAC report they do not use any natural AAC.

110 respondents report using Natural AAC: nonverbal methods such as gestures, facial expressions, and body language. All 110 who report using unaided AAC also report using aided AAC.

AAC Users Rely on Multiple Forms of Communication

AAC users selected the tools and techniques they use to communicate. Most use 5-10 methods to communicate.



Over 130 AAC users completed the survey. The data show that each person relies on multiple forms of expression.

Conclusion – Why this matters

A multi-modal model of communication is supported by these data, indicating that no one uses just one way to express themselves.

Contact info – Where to learn more

To sign up for email updates about this work, and to view written descriptions of the data, go to our site:

sites.google.com/view/aactoolsandtechniques

Or scan the QR code:



Email ucedd@ohsu.org or info@communicationFIRST.org

This work was supported by a subcontract from AUCD, funded by the Administration for Community Living.

Appendix L7: International AAC Peer Support Webinar hosted by Assistive Technology Industry Association (ATIA) in June, 2025

Appendix L8: Two Poster and Presentation Abstracts Submitted to the November, 2025 American Speech-Language-Hearing Association (ASHA) Convention