Peer Support Models, Projects, Approaches, and Activities 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 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 l*eadership 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 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.

List of Peer Support Models, Projects, Approaches, and Activities submitted by the AAC Peer Support Consortium

AAC Camp - Communicare, LLC. https://www.facebook.com/AACcommunicare; https://www.aaccommunicare.com/
AAC Peer Support Project https://www.ohsu.edu/university-center-excellence-development-disability/augmentative-and-alternative-communication-aac
AAC Research Learning Communities AAC Social Portland State University
AAC peer groups (preschool groups, school aged groups) AAC peer support for young adults https://www.aac-therapy.com/
AAPD Summer Internship Program (American Association of People with Disabilities) https://www.aapd.com/summer-internship-program/
ACES Program Temple University https://disabilities.temple.edu/news/2025/01/aces-communication-program-ramps-2025
ALS (1: support group, 2: Lectures, seminars, presentations) https://alsofmichigan.org/
Alanon/Nar-Anon https://www.nar-anon.org/find-a-meeting
Aphasia Community Center AAC group chat https://www.aphasiasarasota.org/
Aphasia Support groups www.aphasia.org
Ask Me, I'm an AAC User https://www.facebook.com/groups/456220758119314
AssistiveWare AAC zoom chats [private event in the AssistiveWare's Adult AAC users community]
AssistiveWare AAC Users Community facebook group https://www.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 https://autisticadvocacy.org/aci/
Bridge School- self determination program https://selfdetermined.bridgeschool.org/
Bridging Communities Through Alternative Communication (BCTAC) https://www.bridgeschool.org/outreach/bctac/
Camp ALEC https://www.campalec.com/home

Camp Chatterbox https://www.facebook.com/p/Camp-Chatterbox-100064405853508/
Camp ImpAACt-Ellis Center https://www.elliscenter.org/camp-impaact
Camp McYack https://www.jcisd.org/special-education3/camp-mcyack
Camp SPEAK AAC (1: children 2: parents of children) https://www.campspeak.org/
Camp TALK www.camptalk.org
Cancer Support Community Greater Philadelphia https://www.cancersupportcommunity.org/
Children's Hospital Colorado First Steps Camp www.childrenscolorado.org/doctors-and-departments/departments/audiology-speech-learning/first-steps-camp/
Children's Hospital Colorado Talking with Technology Camp www.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 www.phillyautismproject.org/community-autism-peer-specialist-caps-hub/
Community Vision (1: AAC Social Group, 2: AAC Play Group ages 0-5) https://cv-atlab.org/
Conversations with Caregivers (ALS of Michigan) https://alsofmichigan.org/mec-category/support-groups/
Family to Family Health Information Centers https://mchb.hrsa.gov/programs-impact/programs/f2f-health-information-centers
ImpAACT Voices (1: Virtual Hangouts, 2: In-person events) https://www.impaactvoices.org/
ISAAC online chats https://isaac-online.org/english/news/pwuaac-online-chats/
Let's Talk Communication Access Initiative www.letstalkinitiative.org
Ohio University Sparkles Cheerleading https://www.facebook.com/OHIOSparkles/; https://ohio.campuslabs.com/engage/organization/ohio-university-sparkles
Oregon Family Support Network https://ofsn.org/
Parent to Parent https://www.p2pusa.org/
Peer-Mediated Learning https://vkc.vumc.org/assets/files/resources/psiPeermedstrategies.pdf

PRC-Saltillo employment https://www.prc-saltillo.com/careers
PRC-Saltillo Toastmasters AAC Club https://www.prc-saltillo.com/articles/AAC-Toastmasters?mode=view
Rainbow Kids https://familyconnectionscc.org/rainbow-kids/#:~:text=Rainbow%20Kids%20provides%20peer%20support,%2C%20incarceration%2C%20abandonment%20or%20deployment.
SHARE Cancer support https://www.sharecancersupport.org/
Sharing our Strength Bereavement Support Group (ALS of Michigan) https://alsofmichigan.org/events/sharing-our-strength-bereavement-support-group/
SHIBA - Senior Health Insurance Benefits Assistance https://shiba.oregon.gov/Pages/index.aspx
Support for Patients and Family (ALS) https://alsofmichigan.org/mec-category/support-groups/
Tele-STELLA https://www.ohsu.edu/oregon-center-for-aging-and-technology/stella-family-studies
Traditional Healthcare Workers - Peer Support Specialists https://www.oregon.gov/oha/ei/pages/about-traditional-health-workers.aspx
USSAAC awareness committee https://ussaac.org/about-us/committees/
USSAAC Speaker Connection https://speaker.ussaac.org/