AAC users' experiences with AAC Peer Support

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. *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 the People Who Use AAC's Identity
3. Guidance in Improving AAC Skills
4. Advocacy for the AAC Community
5. No Need for Peer Support

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 the People Who Use AAC's 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 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.*

The first theme, Mentoring Support to Improve Self-Advocacy, was chosen because it was one of the expressed goals of the project. There was some discussion from members of the Consortium about how peer support could provide mentors and role models that can assist people who use AAC gain self-advocacy skills. Dr. Lateef McLeod's research and other literature support this claim that people who use AAC will increase their self-advocacy with the right peer support. We also see from the survey responses that 28% of respondents were looking for mentoring and improvement of their self-advocacy skills. Responses include, "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." We see from these responses how people who use AAC can be positive role models for other people who use AAC and expand their self-advocacy skills.

The theme of Validation of the People Who Use AAC's Identity 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." Like this quote alludes to, people who use AAC don't want to feel alone and want other people who use AAC to identify with and relate to their experiences using AAC to speak. It is important for people who use AAC to find community with each other.

The third theme, Guidance In Improving AAC Skills, evolved from responses that commented on how peer support specifically improved people's AAC communication skills. Twenty-eight percent of respondents reported that they were looking for support in navigating their AAC system. A quote from one of the respondents is as follows, "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." There were many quotes in the survey like this, where people who use AAC expressed an appreciation for or a need to share different methods of AAC communication. With this sharing of information people who use AAC can assist each other in gaining efficiency 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. An example response from this category is as follows, "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." This quote referred to the corporate and political forces that may impede people who use AAC from gaining access to forms of AAC and also AAC peer support. As a result, a

form of AAC peer support could be to organize as an AAC community and advocate to make sure AAC peer supports are 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. Responses included quotes like this, "I don't think I need any mentorship from other AAC users." We have to recognize that some people who use AAC do not want to collaborate with others like them to achieve their communication and self-advocacy goals and we should respect their decision. What we should do, however, is to make sure that AAC peer support is available to everyone that desires it.

This data shows that most of the respondents desired AAC peer supports and wanted it most in the areas of increasing their self-advocacy and communication and AAC device skills. Future AAC peer support programs can be designed with these goals in mind.