Adapting Design Workshops for Autistic Adults

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Abstract

Autism is a neurodevelopmental disability that impacts one's social communication and interaction. When left unsupported, this can increase the amount of loneliness felt by autistic people. Communication technology, such as AAC, can be helpful in supporting social communication, especially when co-designed with autistic people. We conducted a series of design workshops to co-design a new AAC system specifically supporting social communication. In this paper, we focus on the accessibility issues that were identified when running our workshops and provide recommendations on how to improve the process. We found that it is critical to build support for information processing time into the workshops, include a variety of AAC stakeholders, and create a shared vocabulary between the workshop participants to make design workshops more accessible to autistic adults.

CCS Concepts

• **Human-centered computing** → **Empirical studies in accessibility**.

Keywords

autism, co-design, design workshops, augmentative and alternative communication (AAC)

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1 Introduction and Background

Autism is a neurodevelopmental disability that impacts, in part, social communication and interaction [2]. With approximately 1 in 36 children receiving an autism diagnosis [16], it is necessary that supports for social communication and interaction are developed and implemented. However, as autistic people age into adulthood, the amount of research and support diminishes [8, 23, 27]. This lack of social support can limit interpersonal connections, leading to greater amounts of loneliness [9, 21]. Autism advocates like Zisk and Dalton [30] call for more research into supporting the communication needs of autistic adults to help address this phenomenon.

In an attempt to appear more neurotypical to other people, some autistic people will mask. Masking is when autistic people make efforts, such as copying the way others communicate, to "pass" as neurotypical [15, 18]. Masking is often done to increase access to social opportunities [1] and make friends [1, 15], but it is an exhausting undertaking that can negatively impact an autistic individual's health and well-being [1, 18]. Some autistic people will share their identity with trusted people to foster more genuine connections that are not based on masking [10], but remain cautious about who they disclose to.

Augmentative and Alternative Communication (AAC) can be a useful tool for supporting social communication. AAC is a set of practices, tools, and supports designed to address the needs of those with speech and communication disabilities [4]. Current research on AAC and autism has found that assistive technology can be an effective means of supporting communication [11], there is a lack of AAC research that includes autistic adults [13], and the support needs of speaking adults have been overlooked [30]. Martin and Nagalakshmi [17] show that autistic adults have their own set of communication needs for AAC systems to address, including: being tailored for adult communication over child communication, accommodating dynamic communication needs, and accommodating different communication tasks.

When researching and designing new technology, especially technology for autistic people, it is critical to include autistic people in the research [19]. This can be done by implementing participatory design methods in the research. Participatory design is the philosophy that users should be involved in designing the tools they will use [20, 24]. The lived experiences of these users are a critical component of designing technology that is usable by the target audience [24]. Participatory design can range from ethnographic observation [5] to interviewing users in the places they use the technology [12] to bringing users into the design process and co-designing the technology [6, 22]. However, it is important to ensure that participatory design methods are accessible to people with a communication disability [3, 26].

Co-design has been used to create AAC systems for autistic people [14, 28, 29]. However, these examples all focus on creating AAC for autistic children, not adults. Additionally, Zhu et al. [29] is the only study that provides an analysis of the participant experience during co-design workshops. Research shows that using technology for communication, not limited to AAC, can be a frustrating experience for autistic adults [7, 31]. This shows that there is a need for a participatory design approach to creating communication technology, including AAC, specifically targeted for autistic adults.

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Additionally, there is a need to explore the accessibility of co-design methods with autistic participants.

This study reports on how design workshops are being used in a larger study co-designing and evaluating an AAC system for autistic adults. We are conducting a series of five design workshops that are held via Zoom. The design team consists of the first author, three autistic adults, and two interventionists. Through these workshops, the design team is developing the idea for a new AAC system, sketching interface designs, and crafting and evaluating both a low-fidelity paper prototype and a high-fidelity mobile application implementation of the interface design. The design team participants are also given a series of three surveys to collect feedback on the workshop experience: one before the workshops begin, one after creating the paper prototype, and one after the workshops have ended. To date, the first three workshops have been conducted, the paper prototype created, and the first two surveys administered. This study reports the results of the surveys and the workshop experience of the participants thus far.

2 Methods

Participants used both the video and chat features of Zoom to take part in the workshops. For each workshop, the participants receive an email before the workshop outlining the plan for the workshop and another email after the workshop summarizing what occurred during the session. A breakdown of the topics and activities covered by each workshop can be found in Table 1. The participants in this work do not take part in the usability testing or software development processes.

Additionally, we are administering surveys at regular intervals to gather feedback on the participants' experience during the workshops. To date, two surveys out of three have been administered; the final survey will be administered after all workshops have been completed. These surveys ask questions about how important participants believe their contributions are, what the strengths of the design workshops are, and what the weaknesses of the design workshops are. The questions used in the initial and midterm surveys can be found in Appendix A. These surveys are anonymous to allow participants to share their true feedback while still actively participating in the design workshops. For the Likert data, we use a five-point scale and report the average value of participants' responses. The anchors used with each scale can be found in Appendix A.

The participants (n=5) in this work are all stakeholders in the AAC process. Three of our participants are autistic adults, one is a speech-language pathologist (SLP), and one is a board-certified behavior analyst (BCBA)[1]. We chose to include the two interventionists in an effort to include a broad perspective of the needs of autistic adults. All three autistic adults use speech as their primary means of communication, and two have some prior AAC experience but do not use it regularly. They also expressed a desire during the recruitment phase to increase their AAC use, which is part of their motivation for joining the study.

[1]We recognize that Applied Behavior Analysis as a field has a harmful history with the autistic population. This BCBA was recommended by autistic individuals and autism support organizations. We sought the approval of the autistic participants before having a BCBA on the design team.

Table 1: A breakdown of the workshops and the topics and activities covered by each. The workshops in bold and marked with an asterisk (*) have already been conducted.

Workshop	Topics and Activities
***Workshop 1**	**Present research already conducted.** **Identify potential contexts and features for the new AAC system based on the research.**
***Workshop 2**	**Choose the context to support.** **Vote on features of new AAC system.** **Sketch designs implementing chosen features.**
***Workshop 3**	**Refine features based on the sketches.** **Create a user flow for the AAC system.** **Begin crafting a paper prototype based on the user flow.**
Interlude 1	Research team finishes paper prototype. Usability testing on paper prototype.
Workshop 4	Analyze the usability testing results. Refactor the AAC interface as needed.
Interlude 2	Research team creates a mobile app implementation of the interface. Conduct usability testing on mobile app.
Workshop 5	Analyze the usability testing results. Refactor AAC interface as needed.

3 Results

To date, the first three workshops have been completed, the paper prototype has been created, and the research team is conducting the usability testing on the paper prototype. All participants completed the initial survey and the midterm survey. This paper is focused on the design of the workshops and survey results. Artifacts of the design process will be presented and discussed in future work once the co-design process has completed.

3.1 Workshop Observations

In addition to the surveys, some participants have provided direct feedback during the workshops by self-advocating. For example, some participants found verbal discussions to be too overwhelming and chose to communicate and engage primarily through the Zoom chat feature. The research team responded to this by having the chat window open during the entire workshop and reading the messages aloud to ensure everyone's input was heard by all participants.

During Workshop 2, where the design team discussed and sketched features, there was much discussion about what the AAC system might do. The participants used language to describe what they were envisioning that did not match how the research team used the same terms. For example, several participants used the term "dashboard" as a label for a feature they believed necessary

and cast their votes for it during the dot voting[2] process. The dashboard feature was voted the most critical feature, which led the first author to ask follow-up questions about the information that might be summarized in the dashboard. It became clear there was a disconnect in language when the participants did not want data summarization. To address this, the first author then asked the participants to sketch out what they envisioned as a dashboard. These sketches revealed that the participants were using "dashboard" to describe the ability to create, edit, and delete content in the new AAC system, whereas the research team members were using "dashboard" to describe a data overview page [25] (e.g., amount of content or content organization scheme). After identifying this discrepancy, some participants asked to review more features with sketching and change their votes.

We found that having the two interventionists on the team helped as we hoped. They both contributed insights based on their extensive experience with people across the autism spectrum. Their input during discussions helped the other team members envision designs outside their direct experiences or needs.

3.2 Survey Results

In the initial survey, participants responded that they feel it was very important to include AAC stakeholders in the design process (average rating of 4.8). Participants explained their rating with statements such as: "You can't design something that's meant to help someone without including the people who are doing to use it in the process if you want your product to actually be as helpful as it can be", "[The users] have an extremely important perspective", and "If you are trying to make something to better a group you need to talk with people in the field using the tools...to problem solve what is happening and how effective it is". Despite this, the participants were not confident in their ability to create a new AAC system (average rating of 2.6), saying "I have no experience with software design and struggle with technology beyond communication devices" and "My confidence is pretty low because I don't quite understand what I can bring to the table yet". They had slightly more confidence in their contributions (average rating of 3.4).

By the midterm survey, the participants who responded had more confidence in their contributions (average of 3.8). Some continued to worry about the participation, sharing thoughts like "Sometimes my brain struggles to keep up with the process so I worry I'm not contributing very well". Despite this, the participants reported having a positive experience so far (average rating of 4.8). They shared positive aspects of the workshops, such as "Knowing that I am helping to design a tool to help people like me" and "Seeing things from different perspectives and brainstorming what could help all of us the most, remaining broad without losing its focus, has been a very satisfying experience".

When asked about challenges in the workshops, participants shared "understanding the research parts and pieces and the process/vocabulary to develop and app" and "The real-time video calls can be overwhelming, and it can be hard because if I'm not feeling well or communicating clearly, it's a bigger struggle. But having my voice included even on bad days has meant the world to me." The participants also shared the benefit of the planning and summary emails, sharing "[They] help get my mind focused and moving in the right direction before we sit down on the call, and I feel prepared." However, some participants would still like more time to process information, writing "[The workshop] can feel rushed and/or overwhelming with lots of information to unpack at one time" and offering a solution of "having times before or during the workshop to review and reflect on ideas individually before sharing."

[2]Participants were told they had five dots to use during voting and to place their dots on the feature(s) they would like to see. They could allocate more than one dot to a feature to indicate its relative importance.

4 Discussion

Design work is a dynamic, interactive, and sometimes messy process. Some participants shared that this can be overwhelming for them, which impacts their ability to participate in the design workshops. It is critical for design workshops to take this information processing disability into account when including autistic participants. Conducting our workshops virtually, providing written references before and after the workshops, and making use of Zoom's chat feature helped make the workshops more accessible.

There was also a disconnect between the design participants' vocabulary and the vocabulary of the research team members participating in the design workshops. The research team members have prior training and experience in design work, which biases their vocabulary towards design jargon that may not be familiar to people without design training or experience. This occurred in Workshop 2, as discussed previously, when the participants used design jargon in a different way than the research team would.

Despite these barriers, the participants report feeling good about participating in design work. Being a part of the design process for tools they ultimately want to use can have a positive effect on the participants, helping them feel like they are helping the larger autism community. While there was an increase in their contribution confidence, the participants still reported some concern at the midterm survey.

4.1 Recommendations for Future Design Workshops

When including autistic participants in design workshops, it is critical to account for the different information processing and communication needs of the participants. Some autistic people will struggle to process live conversation without breaks. Building in breaks, checking in with participants at regular intervals, and adding wait time after asking questions are strategies that can help provide the processing time needed for participants not to get overwhelmed. Some autistic people will also prefer to use non-speaking forms of communication. Hosting workshops online allows chat features to be used. When hosting design workshops in person, using a chat tool (e.g., Slack, Discord, Teams, etc.) can provide a way for in-person participants to communicate.

It is also beneficial to include participants who are AAC interventionists. Including interventionists who work with AAC users affords access to their experiences working with many different people, which complements the lived experiences of the autistic participants. This can be useful when discussing design features, as

the interventionists' experiences can help provide a broader context for whether a feature will be usable by a wider range of people.

Not all participants will have a design or research background. This means that they will not have the same vocabulary as trained researchers and designers. It may be a good idea to add a workshop to help participants become familiar with design and research vocabulary. This will also help the research team to become familiar with the vocabulary of the participants used by autistic people to describe their lived experiences and lay a common foundation for the design workshops.

5 Conclusion and Future Work

This study showcases the need to include AAC stakeholders, especially AAC users, in the design process when developing a new AAC system. We found that it was important to: 1) provide support for information processing when conducting design workshops with autistic participants, 2) include other AAC stakeholders (e.g., interventionists) in the design process, and 3) build a shared vocabulary between design team members and research team members. Future work in the design study will be to run the remaining workshops and develop the AAC system. The AAC systems developed will be co-designed with AAC stakeholders from the initial idea to design sketches to a final, tested prototype. We will administer a final survey to the workshop participants that will ask them about their experiences throughout the process, how their attitudes changed by the end, and other reflective questions. The survey responses will then be used to guide how to make design workshops more accessible to autistic adults.

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A Survey Questions

All questions marked with an asterisk (*) are required questions.

- Initial Survey:
  - *How important do you think it is to include AAC stakeholders in the design process? (5-point Likert, 1="not important" to 5="very important")
  - Please explain your rating.
  - *How confident do you feel about creating a new AAC system that better supports social communication and community engagement? (5-point Likert, 1="not confident" to 5="very confident")
  - Please explain your rating.
  - *What do you think the process will be like?
  - *How important do you think your contributions to this design process will be? (5-point Likert, 1="not important at all" to 5="very important")
  - Please explain your rating.
  - *What, if any, design background (e.g., graphic design, drawing or other art forms, making websites, etc.) do you have?
- Midterm Survey:
  - *How important do you think your contributions to the design process so far are? (5-point Likert, 1="not important at all" to 5="very important")
  - Please explain your rating
  - *How would you rate your overall experience so far? (5-point Likert, 1="negative" to 5="positive")
  - *What has been the best part of your experience so far?
  - *What has been the hardest part of your experience so far?
  - *If you could change one thing for the upcoming workshops, what would it be and why?
  - *If you could keep one thing the same for the upcoming workshops, what would it be and why?