

Participatory Design of Augmentative and Alternative Communication (AAC) Technology with Autistic Adults

Luke Kudryashov

Augmentative and Alternative Communication (AAC) technology has potential to improve wellbeing and communication access for speaking and semi-speaking autistic adults, but most research, design, and provision focuses on non-speaking autistic children. We conducted two virtual participatory design sessions with five autistic adults who have situational or occasional difficulty speaking to elicit their values around communication and AAC design. We found that social stigma is a major barrier to effective communication and can be mitigated through aspects of AAC design that increase users' agency in social situations. Communication difficulties and AAC use held many affective dimensions, including positive emotions such as joy, relief, and calm and challenging emotions associated with stigma and internalized ableism. Privacy and a related preference for dedicated devices and wearables over applications were key priorities identified by participants. We offer a discussion of ways that autistic adults' values around communication can guide the design of communication tools.

1 INTRODUCTION

Autistic¹ people face many barriers to effective communication, including social stigma, others' lack of understanding around their communication styles and needs, and lack of sufficient supports for people whose speech is intermittent or unreliable [43,68,108,112]. Augmentative and Alternative Communication (AAC) tools (Fig 1) have been employed to support the communication of autistic people since the 1980s [43]. However, most AAC research, design, and service provision for autism focuses on nonspeaking autistic children. Many autistic adults who have access to speech experience "intermittent" or situational difficulty speaking or find that their speech is "unreliable" or "insufficient" to "fully meet their communication needs" [112]. Their needs differ significantly from those of children in areas including range of functions, visual design, communication goals, settings of use, and availability of services and financial support [28,72,112] and are not adequately considered in AAC research, design, and provision. A better understanding of situationally nonspeaking autistic adults' needs, values, and priorities around AAC and communication is necessary for the design of more effective and appropriate AAC tools for this population.

¹ We have chosen to use identity first language ("autistic people") rather than person first language ("people with autism") due to research and statements from autistic advocacy organizations indicating a preference for identity first language among the majority of autistic people [11,17,18,51]. Both identity first and person first language were used in recruitment to respect differences in language preferences.

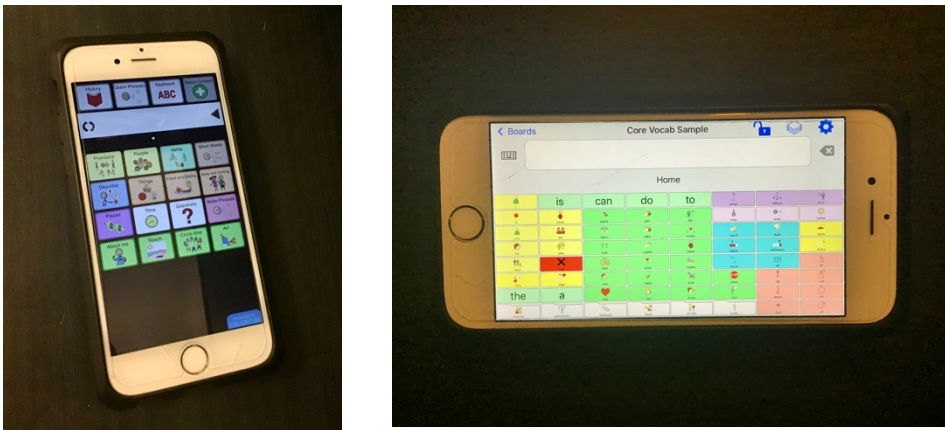


Figure 1: AAC Mobile Applications

To address this gap, we conducted two virtual participatory design (PD) sessions with five autistic adults to elicit their values around communication and AAC design. Our research questions were:

- (1) What do situationally nonspeaking autistic adults value in assistive communication technologies?
- (2) How can participatory design sessions with autistic adults, conducted effectively and accessibly, enable us to design technology with and for situationally nonspeaking autistic adults?

The sessions consisted of discussions, brainstorming, and design activities aimed at “problem setting” (defining the problem, priorities, and values), “envisioning” (generating ideas about possible designs), and “concretising” design ideas through iterative sketching [13]. Following PD traditions that aim for exploration and “future making through design” [13,27], our goals were exploratory with a focus on better understanding the barriers that autistic adults face due to difficulties with speech and lack of appropriate AAC tools, and determining open-ended priorities and opportunities rather than detailed design specifications. We chose PD in order to take a strengths-based approach that viewed autistic people as experts on autism [34,69] and put their perspectives and experiences at the center of the design process.

We found that social stigma was a major barrier to effective communication and AAC use, resulting in a loss of agency. AAC tools for this population should therefore be designed in ways that mitigate social stigma and increase user agency. Next, in contrast to autism research that has focused on difficult and challenging emotions [24,62,85], we find that there are many affective dimensions to speech difficulties and AAC use, including positive emotions such as joy, relief, and calm that are rarely considered in autism research. Finally, when asked about their priorities for AAC features, participants considered privacy a key priority, an area rarely addressed in AAC and other disability-related research and design [5,92,102]. Privacy concerns led participants to prefer dedicated devices and wearables over AAC applications.

This work opens up new directions for developing AAC tools that better align with the needs and priorities of autistic adults who have occasional or situational difficulty speaking. We describe key priorities and design ideas shared by participants during the session and discuss additional areas for future research. We close by offering some methodological reflections around conducting virtual PD with autistic adults

2 BACKGROUND

2.1 Autism

Differences in social interaction, communication, interests, movement, and sensory experiences are key characteristics of autism, a lifelong developmental disability [20,50,74]. In contrast to research that frames autism according to the medical model as deficit to be eliminated, we have instead relied on a social model and neurodiversity framework that focuses on celebrating strengths and differences while ameliorating difficulties and barriers, many of which are socially imposed [20,50,90,106]. While social model and neurodiversity approaches to autism and assistive technology research have historically been underrepresented, recently there has been a groundswell of work in this area [5,20,90,91,105,106,109]. These approaches are a particularly good fit with PD as it is often grounded in socio-technical and strengths-based approaches that place emphasis on the social context of technology use and the strengths and knowledge that intended users of a technology can bring to its design [83]. While PD is not inherently liberatory [39,90] and has limitations, including requiring significant amounts of labor from the participants [6], when done well it has the potential to counter “epistemic violence” [109] by placing disabled people’s perspectives and priorities at the center of technology design [7]. Following the PD tradition of understanding participants as domain experts [83], we view our participants as experts on autism [34,69] and draw on their lived experience to determine priorities for AAC design for speaking and semi-speaking autistic adults.

2.2 Gaps in AAC Design

Augmentative and Alternative Communication (AAC) is a category of assistive technology that supports communication for people with a wide range of speech and communication disabilities. AAC takes many forms, including low-tech tools such as communication cards and boards, high-tech tools such as smartphone and tablet applications or dedicated speech generating devices, and unaided strategies such as signs and gestures [99,112]. AAC has been employed in autism service provision since the 1980s, but, like most autism research and services, has focused largely on autistic children [43]. A building body of evidence suggests that AAC tools can be highly effective in increasing wellbeing and access to social participation, employment, education, and healthcare for autistic adolescents and adults, but much more research and development of AAC technologies that support the unique needs of autistic adults is needed [30,45,66,99,112].

Many autistic adults have complex communication needs, however most autism research and service provision focus on children, leading many autistic adults to not receive communication services and supports [41,43,45,87,99]. It is common for parents, caregivers, and healthcare and service providers to overlook the communication needs and challenges of autistic adults as they age out of AAC and speech pathology services, especially for those adults who can speak and understand speech some or most of the time and for those who are undiagnosed or are diagnosed later in life [43,112]. Levy & Perry [56] estimate that while roughly 20-30% of autistic adolescents and adults have no or very limited speech, the remaining 70-80% still experience some differences and challenges around speech and language. Many autistic people who use speech experience speech that they find to be “intermittent”, “unreliable”, or “insufficient”, particularly during periods of anxiety, illness, stress, sensory overload, meltdowns, co-occurring conditions like migraines and epilepsy, and/or in specific social environments [112]. The focus of AAC research and development on autistic children and non-speaking autistic people thus results in a significant gap for the majority of autistic adults

who can speak some or most of the time but whose ability to speak is not always reliable, especially during periods of crisis or high stress.

There have been many critiques of gaps in AAC research and design, including:

- lack of attention to fit between the user and the AAC technology [16]
- high learning demands [57]
- lack of attention to aesthetic elements [57], “qualities of interaction” [79], nuance and expressivity of AAC voices [77–79], and the “psychological and sociological impact” of the devices on their users [1]
- imposition of external values and priorities of nondisabled designers [79,90] and lack of understanding of what constitutes a successful outcome from the perspective of AAC users [16]
- high cost and structural inequalities based on social class and cultural background [4,112].

While many of these critiques focus on AAC design and provision for children, they become even more relevant when considering AAC use by adults, who are not usually imagined to be the primary users of these technologies. The needs of children and adult AAC users also differ significantly, as children primarily use AAC for making requests while adults use a wider range of functions, including giving information, making comments, and asking questions, which are not necessarily well-supported by existing designs [72]. These gaps in AAC design result in risks of underutilization or abandonment of the technologies and diminish their potential benefits [16]. AAC users and potential users are “rarely involved in decision-making relating to AAC” [16] resulting in AAC technologies reflecting “the conceptual models and priorities of nondisabled adults” [57]. PD with current and potential AAC users can address many of these critiques by placing the needs, experiences, and priorities of the users at the center of the design [10,78,90].

2.3 Participatory Design and Autism

Participatory Design (PD) is an approach in which stakeholders, especially the intended users of a technology, are invited to participate in the design process. PD was developed in Scandinavia in the 1960s and 70s and is rooted in labor and civil rights movements [83]. The goals of PD are thus democratic and emancipatory with an “unshakable commitment to ensuring that those who will use information technologies play a critical role in their design” [83]. PD places an emphasis on mutual learning, trust, and equalizing power relations between participants and designers and takes a socio-technical approach recognizing that “information technology is never neutral.” PD therefore takes an exploratory approach to design, inviting stakeholders to define the problem as well as the solution [83].

PD has been employed for the design of a range of assistive technologies, though it remains underutilized [80]. A PD approach to assistive technologies is useful as it allows for a holistic understanding of user motivations and needs, helps avoid early abandonment, and can rectify the knowledge gap created when nondisabled designers “do not consider [the] voices [of users with disabilities] from the beginning of the design processes” [80]. The field of AAC research and design has been critiqued for settling “into rather conservative ways of approaching communication devices” [77]. While there have been calls to bring person- and user-centered approaches to AAC research [58] and user-centered approaches are becoming more common, many of these have involved the use of personas [95,96], PD with nondisabled peers [59], or involvement of disabled users in evaluation but not initial design [19,38] rather than PD with disabled users. Most of these studies have also centered on AAC technologies for users with motor disabilities, cerebral palsy, and aphasia rather than autistic users. There have been several PD and co-design studies of AAC and

other assistive communication technologies [1–3,19,25,38,54,59,64,82] but none have focused specifically on AAC for autistic adults.

Several PD studies have worked with autistic people, primarily with children and adolescents, mirroring wider trends in autism research [9,20,22,28,31,33,36,37,60,61,63,67,75,94,111]. These studies focus on social skills training, education, wellbeing, or assistive technologies not related to communication or AAC. While some researchers have expressed concerns that PD approaches may not be suitable for working with autistic people [100], several PD studies have found high levels of engagement, valuable contributions, and positive experiences for participants when providing sufficient scaffolding and support [9,111]. Zhu et al. [111] argue that a PD approach to autism research in HCI is valuable as the autistic adolescents they worked with “expect to make design decisions for applications built for them” yet often encounter a poor user experience with technologies that do not take their unique perspectives and experiences into account.

As Spiel et al. [90] note, however, PD approaches are not inherently liberatory and empowering, as half of studies that employed PD methods for designing technologies for autistic children worked with proxies, such as parents, professionals, or nondisabled children, who only have indirect insight into the autistic children’s experiences and perspectives. Even among the studies that worked directly with autistic children, Spiel et al. [90] found that study design decisions often marginalized the participants and allowed them minimal say over the goals and priorities of design. Harrington et al. [39] argue that for PD research with underserved populations to be equitable and empowering, researchers must take into account “the history of their discipline,” some of which will “undoubtedly hold particular traumas for communities that are oppressed.” In the context of HCI research with autistic people, this history includes a focus on “normalizing technologies” [106] that limit users’ agency, increase social stigma, contribute to interventions that have been linked to the development of PTSD, and may increase rates of suicidality [90,106]. A PD approach to AAC design for autistic adults that is rooted in a neurodiversity framework has the potential to bridge the existing gap between AAC researchers, designers, and providers and the current and potential users they are intending to serve.

PD has traditionally been conducted in co-located spaces. Virtual forms of PD are a new area without much published research, though we will likely see at least a temporary shift to virtual PD due to the COVID-19 pandemic. While adapting PD activities to virtual contexts can come with challenges and limitations, it can also offer opportunities for new and creative ways of engaging with participants [52,55], requiring “fresh approaches to traditional methods” [98]. In-person PD approaches have been employed successfully with groups of autistic participants, but virtual PD offers additional accessibility benefits that can reduce several barriers identified in previous studies [9,32,111], including a reduction in sensory stimulation and the discomfort of being in an unfamiliar environment, greater ease of facilitating multimodal communication such as typing as an alternative to speaking, and reduced social anxiety. Virtual approaches to PD can also be useful for working with groups that are geographically dispersed where community building often happens online, such as disabled and LGBTQ people, as well as for recruiting a more heterogeneous group of participants.

3 METHODS

To understand our research questions regarding autistic adults’ needs and values around communication, we conducted two virtual PD sessions with five autistic adults who have occasional or situational difficulty speaking.

3.1 Positionality Statement

I am an autistic researcher who experiences occasional difficulty speaking. The study was motivated by my frustrations with a lack of AAC tools designed for speaking and semi-speaking autistic adults and conversations about this topic with autistic friends and others in online autistic communities. The method of PD was selected due to the heterogeneity and diversity of experiences among autistic adults, the collaborative elements of PD, and the desire to center the ideas and experiences of underrepresented autistic people in research on assistive technologies intended to serve them. Since PD emphasizes mutual learning between participants and designers, building trust, and equalizing power relations [83], I shared my autistic identity and investments in the topic during recruitment and participant onboarding. I also shared several of my own experiences, ideas, and sketches – a modification of Benton et al.'s [9] suggestion of providing example ideas and designs – while making it clear that participants were welcome to disagree with my and each other's ideas.

3.2 Participatory Design Sessions

We conducted two virtual PD sessions over Zoom video conferencing. The sessions were spaced one week apart with each session lasting one hour. Jamboard (Fig 2), a collaborative digital whiteboard platform in the Google Workspace, was used in combination with Zoom because it has a simple, uncluttered interface, is easy and fast to learn, and is similar to other Google Workspace tools that many participants would already be familiar with. Both sessions were first piloted with the research team to refine the activities and approach.

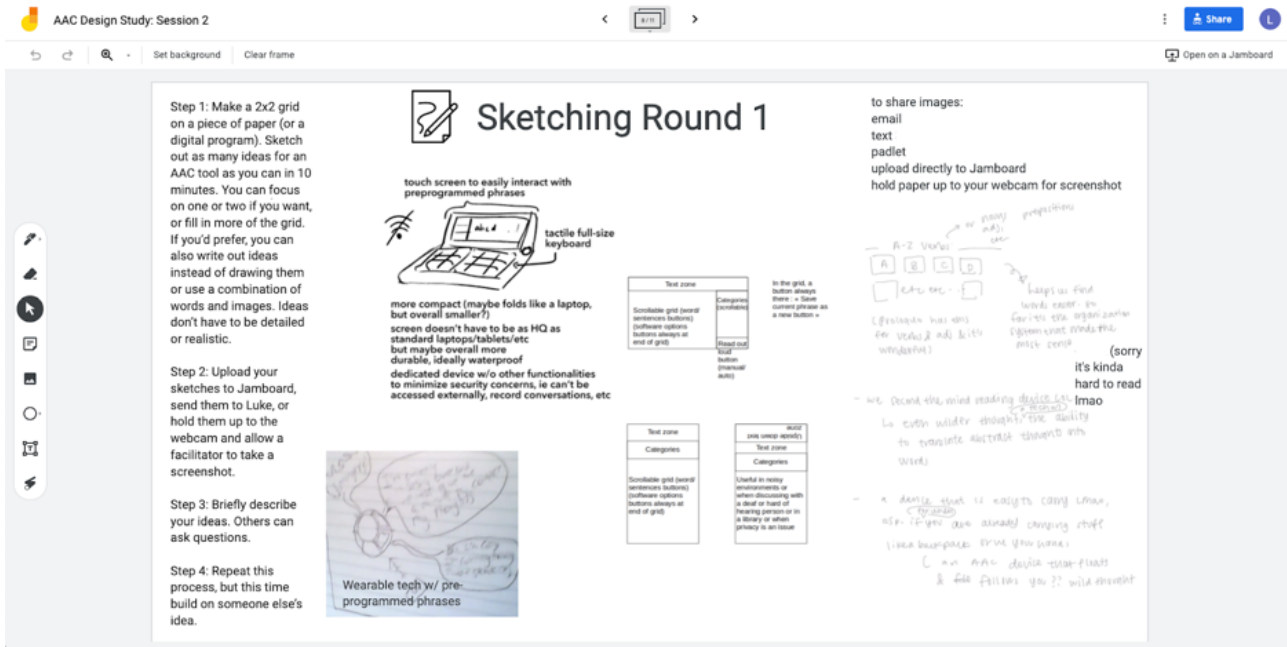


Figure 2: An activity slide on Jamboard (identifying information removed)

The first session focused on “problem setting” (defining the problem and priorities, following the ethos of PD) and “envisioning” (generating ideas about possible designs) [13]. After a warm-up introductory activity,

participants were asked to complete a “pain/gain map” activity, which was modified to focus on the participants’ direct experiences rather than on a hypothetical persona [53]. This activity grounded discussion in participants’ personal experiences and produced an artifact that was referenced in future design activities. This activity drew on the technique of scenarios [13] without requiring participants to disclose more than they were comfortable with or present experiences in a linear format. Taking a strengths-based approach, we focused on identifying strengths, dreams, and goals as well as challenges with communication and AAC use. The final activity in the session asked participants to envision an “AAC Device of the Future” using a speculative brainstorming approach. This activity focused on determining values and priorities around AAC technologies rather than on implementation and produced another artifact that was referred to in later design activities.

The second session focused on “concretising” through sketching. As Bratteteig et al. [13] recommend, we used sketching activities “for exploring and mutual learning rather than for specification of a solution”. We first presented several images of existing AAC devices (Fig 3), including applications, dedicated devices, a watch, and low-tech tools such as communication boards, as probes for discussion [13]. The initial discussion was followed by two rounds of individual sketching, the second inviting participants to build on another participant’s design. Some participants chose to sketch digitally and others sketched their designs on papers and uploaded photos of the sketches. This approach provided time for participants to gather their thoughts before being asked to share and encouraged collaboration without requiring breakout rooms, which pose accessibility barriers and can be difficult to monitor. Sketching activities were based on the 6-8-5 activity [53], with timing modified based on feedback from a pilot session, which included two autistic people. To reduce time pressure and account for technology lag, the number of sketches requested was lowered to 1-4 from 6-8 and the time allotted for each round was increased to 9-10 minutes from 5. The session concluded with an activity asking each participant to share three things they liked and three questions they had about other participants’ sketches.



Figure 3: Jamboard slide with images of existing AAC tools presented prior to the “concretising” through sketching phase

We used existing guidelines for engaging with autistic participants [23,71] and facilitating virtual workshops [52,98] to inform the structure and interactions in the PD sessions. For example, we encouraged multiple modes of participation, including speaking, chat, typing on Jamboard, and sketching. We shared the agendas ahead of time, split activities into two shorter sessions to reduce potential for fatigue and sensory overload, provided examples and probes for each design activity, and provided live captioning through CART. We aimed to create an environment that was accessible, welcoming, and affirming by sharing accessibility information from the outset, checking in about access needs at multiple points throughout the process, and sharing the lead facilitator’s personal experiences and investments around the topic.

Table 1: Design Session Activities

Activity	Prompt	Purpose	Phase
Session 1			
Pain-Gain Map	Think about a recent time you had difficulty speaking. Write down or draw a few “pains” related to this experience (thoughts or emotions, issues, or barriers). Now write or draw a few “gains” (things that went well, strategies or tools, goals and desires, or things that would have been helpful).	Understand the experience of communication difficulties. Identify strengths, dreams, goals, challenges, and barriers around communication and AAC use. Produce an artifact to refer to in future design activities.	Problem Setting
AAC Device of the Future	If you could create an AAC device of the future, what are things it MUST have? What would be NICE to have? What should it definitely NOT have? If you could only have 3 things on this list, what would they be?	Determine values and priorities around AAC technologies. Produce an artifact to refer to in future design activities.	Envisioning
Session 2			
Existing AAC Tools Discussion	The Jamboard has a few images of existing AAC tools as a starting point for discussion. Is there anything you like or dislike about any of these? How well do they fit the priorities we determined?	Warm up. Build an understanding of what does and does not work in existing AAC technologies.	
Sketching Round 1	Sketch out 1-4 ideas for an AAC tool in 10 minutes. If you'd prefer, you can also write out ideas instead of drawing them or use a combination of words and images. Ideas don't have to be detailed or realistic.	Concretize and build on ideas through sketching. Explore ways that values and priorities can be expressed through designs.	Concretising
Sketching Round 2	Repeat the process above, but this time build on someone else's idea.	Further develop ideas through iteration and collaboration.	Concretising
Comments and Questions	Take a few minutes to think of ~3 things you liked most about other people's ideas and ~3 questions that you have.	Determine priorities, confusing elements, and further directions to explore. Deepen understanding of motivations and feelings.	Concretising

3.3 Recruitment

We recruited participants through email listservs of support and advocacy groups for autistic adults and social media (Twitter, Reddit, Tumblr, and Facebook). Through these sources, 87 people responded to the screening survey. There were three eligibility criteria: identifying as autistic, having autism, or being on the autism spectrum; being 18 years of age or older; and experiencing occasional or situational difficulty speaking.

3.4 Participants

We selected five participants from the screening survey. Since autistic people of color, women, and nonbinary people are often underrepresented in autism research [35,47,48,70,86,88,90,93,97,103], respondents from these groups were prioritized. Participants were between 18-43 years old. One was female, one male, and three nonbinary. All participants had at least one additional disability, including ADHD, mental health conditions, chronic illnesses, chronic pain, dyspraxia, sensory processing disorder, and speech disorder. The frequency with which they experienced difficulty speaking varied from several times a month to about once a day. Three participants have had previous experience with AAC tools but did not use AAC tools the majority of the time they had difficulty speaking.

Table 2: Participant Table

Pseudonym	Age	Gender	Race/ Ethnicity	Frequency of Speech Difficulty	Prior AAC Use
Wei	23	Nonbinary	Asian	About once a day	Yes
Frank	18	Nonbinary	Asian	Almost always	Yes
Catherine	43	Female	Caucasian	Several times a month to several times a week	Yes
Rullo	21	Nonbinary	Latine, mixed race	Several times a week	No
Sean	28	Male	Black, biracial	Several times a week	No

3.5 Analysis

We analyzed the data (transcripts of recorded audio, chat transcripts, and PDF downloads of the Jamboard slides) using reflexive thematic analysis (TA) [15]. We selected the TA approach because the sample was relatively heterogeneous and we aimed to capture diversity and identify themes across the dataset. TA also enabled us to focus on “actionable outcomes” and “clear implications” for the practice of AAC research and design, with an interest in “how personal experiences are located within wider socio-cultural contexts” [14]. I coded all data was coded iteratively in Dedoose. I developed three themes inductively based on patterns observed in the codes through discussions with the thesis advisor. The codes fell into nine main categories: Barrier (from difficulty speaking or to AAC use), Cause/ Contributor to Difficulty Speaking, Emotion and Sensation, Feature of AAC Technology (negative or positive), Goal/ Desire, Mitigator, Situation, Social Attitudes, Tool. These codes will be described in more detail in the findings as they relate to the three themes: (1) stigma and loss of agency (Barrier, Cause/ Contributor, Situation, and Social Attitudes codes); (2) affective dimensions of AAC (Emotion and Sensation, Barrier, and Mitigator codes); and (3) priorities for AAC features (Feature, Goal/Desire, and Tool codes).

4 RESULTS

We found that stigma, agency, and affective dimensions are key factors that should be considered in the design of AAC tools for this population. Privacy and a related preference for dedicated devices and wearables over applications were the main priorities identified by participants.

4.1 Stigma and Loss of Agency

Throughout the design sessions, participants shared criticisms about specific features of AAC tools, from visually overwhelming design, to difficulty setting the technology up, to confusing and ambiguous images. However, when asked directly about the biggest barriers and issues that they faced when they had difficulty speaking, nearly all participants focused on the impact of stigma and societal attitudes. Reflecting on a recent incident when she had difficulty speaking, Catherine wrote, *“I was afraid that the people would call an ambulance and I would be tied again. I didn’t had my tablet [...] and was doing a lot of stereotypies which seemed to afraid people. [...] But was also discouraged [...], people will talk to me like I’m a child on a nonverbal day. Even professionals will talk [...] like I’m not in the room.”*² Catherine’s fear of stigma was based on her prior experience of being restrained in an ambulance when someone called emergency services when she was having difficulty speaking. While not having the tablet with Catherine’s AAC app posed an additional barrier to communication, her main concerns were around the violence she has faced due to other people’s fear and lack of understanding of her difficulty with speaking and the way she moved. This indicates an important difference between the ways adults and children use AAC that must be taken into account when designing AAC tools for autistic adults, as children likely have an adult with them while adults often may not. Catherine’s fear was heightened during the incident when she did not have access to her AAC tool, but she also connected this fear to a broader sense of discouragement, since even when she has had access to AAC, other people, including professionals, do not treat her seriously because she cannot speak.

Frank also expressed fear around the general societal stigma of using AAC, writing that they were *“afraid that other people will judge us if we use AAC apps because people treat speaking as the superior form of communication & we look ‘obviously disabled’ & be a target of ableism.”* Wei shared concerns about stigma and perception of AAC users in relation to opportunities for employment and economic mobility, a key concern for autistic adults as 50-85% of autistic adults in the US are estimated to be unemployed [21,66,84]. Wei wrote that he was *“worried about a potential job interview; I am incredibly bad at speaking in interviews but also obviously concerned that AAC use will weigh against me.”* Fear that employers would perceive AAC use to be unprofessional or indicative of lower competence poses a barrier in a high stress situation of a job interview where AAC might be particularly helpful. Rullo shared an experience in which another person’s lack of patience and understanding resulted in an increase in stress during an already distressing situation: *“I had a hard time communicating an emergency after a person was violent and the person supposed to help only triggered a meltdown by not being patient and waiting for me to talk”*. Ableist assumptions that AAC use indicates a lack of competence present a major barrier to AAC use even when a person has access to an AAC tool. Some, like Wei, are forced to choose between using a less accessible mode of communication or appearing unprofessional if they use AAC in high stakes settings like a job interview. Others, like Catherine, Frank, and Rullo, were unable to receive the support they needed due to other people not understanding their communication needs.

A thread that connects participants’ experiences of stigma and social bias against people with communication differences is a loss of agency, heightened by the fact that participants often had the most difficulty speaking in situations in which they were already feeling vulnerable, such as in emergencies, periods of high stress, and high stakes events such as job interviews. This loss of agency variably took the form of physical restraint, infantilization, and assumptions of incompetence and intensified the challenges and

² Spelling and punctuation have been edited in some quotes for clarity.

communication barriers that participants faced. AAC tools that, as Williams & Gilbert [106] and Spiel et al. [90] recommend, focus on increasing their users' agency can help users to mitigate the stigma and more effectively navigate inaccessible social environments. Following Spiel et al., Williams & Gilbert, Ibrahim et al., and Valencia et al. [46,90,101,106], we understand "agency" as user control over aspects such as when and how to use a technology, when to communicate, what to say, whom to address, and how to influence the ways that conversational partners respond in order to "further an individual's objective in the face of outside structure or constraints" [101].

The participants in the PD sessions shared several potential design strategies for mitigating stigmatizing perceptions of AAC devices. Sean shared, "*I feel there would be less stigma towards AAC if things weren't all cheerfully colored little doodles? [...] we might get taken more seriously if it quote looks professional.*" Sean's comment echoes Catherine's observation that she was treated "like a child" by others, including professionals, when she used AAC. While a visual design that is aimed at adults rather than children would not eliminate ableism, it could help reduce some of the stigma in situations where autistic adults are already fighting an uphill battle against infantilization. Participants also discussed several features that would provide them with a greater degree of control over aspects such as mode and voice than existing AAC tools they have used currently allow. Design decisions around volume, tone, and other aspects of voice can provide users with a greater degree of agency, allowing users to choose when and how to draw attention to what they have to say or to blend in, depending on their goals and the environment that they are in. For example, many participants expressed a strong desire for a tool that would allow them to switch between visually displaying text and reading the text out loud. Being able to visually display the text is beneficial in settings where there is a need for privacy or quiet, such as a library or a professional setting, when in a very loud environment, or when communicating with someone who is D/deaf or hard of hearing. In other situations, the conspicuousness of the speech can be a major advantage. Catherine noted, for example, that "*The 'voice' of the AAC software kind of forces [people] to 'listen' to what I have to say,*" whereas when she was only typing on her tablet, many people refused to look at the screen. Wei, on the other hand, shared that "*using my [AAC] app [during Zoom class] feels disruptive because suddenly everyone will be noticing me since the robotic voice is distinctive,*" indicating that a less conspicuous voice would help to reduce the stigma and unwanted attention in that context. Other related requested features included the ability to express emotions through tone, a voice that mimics the user's voice, loud speakers for noisy environments, and the ability to play animal sounds as an alternative for self-expression.

The AAC technology by itself also will not increase levels of social understanding of autism and communication needs and access, but it can provide its users with tools to help bridge gaps of understanding. For example, Sean proposed an "emergency mode" – a button that can be clicked when the user is feeling overwhelmed that will say "quiet please, thinking" to indicate to others that the user needs space to express what they want to say. Catherine said that she wished she "had at least cards with a few sentences explaining I'm autistic" during the situation when she did not have her tablet and was not able to communicate. She later suggested that an AAC tool could have "*phrases and even longer saved texts (for example 'who I am' type of stuff)*" to be able to quickly explain to others why the person is using AAC technology. Although an AAC device or disclosure cards can draw attention to a disability that may otherwise be "invisible" and result in stigma, in Catherine's experience, lack of access to AAC resulted in a greater degree of stigma and risk, due to others perceiving her difficulty speaking and repetitive movements as a threat or medical emergency.

Assistive tools such as AAC and disclosure cards can allow a person to have a greater degree of control over how they are perceived and communicate and legitimize their needs [29]. While some of the features desired by participants, such as a more professional appearance and less robotic voices, correspond with Shinohara and Wobbrock's [89] "design for social acceptance" approach, others, such as a loud or conspicuous voice, switching between speaking and visual display, range of emotional expressions, emergency mode, or animal noises, point instead to a more complex interplay between visibility and invisibility described by Faucett et al. [29]. To navigate complex and dynamic issues of visibility, stigma, and perception, participants expressed desire for features that would afford greater agency and control by allowing users to better adapt the technology to a specific situation.

4.2 Affective Dimensions of AAC

Despite misconceptions that autistic people do not feel, understand, or express emotions, participants shared many emotions, both pleasant and difficult, surrounding AAC use. Many of these emotions related directly to experiences of internalized ableism, or the internalization of negative societal norms around disability [49]. Much of the research and literature on autism and AAC focus on the difficulties, pain, and barriers that autistic people experience. Participants in this study did describe significant barriers and difficult emotions associated with having difficulty speaking, especially when facing ableist attitudes and coping with internalized ableism. However, many participants also expressed joy, relief, calm, and gratitude associated with AAC use, finding other effective communication methods, and receiving support and understanding from others.

The participants who had used AAC found it largely positive and helpful, despite many design limitations. However, most had only recently begun using it due to factors including internalized ableism and not realizing that these tools existed or could benefit them. Others were still trying to get access to AAC tools or had not considered that such tools were an option. Wei said, "*I only really discovered AAC in the last year or so but it's felt like a huge life changing thing,*" confirming both that AAC can be highly beneficial to speaking and semi-speaking autistic adults and that the lack of services and focus on AAC for autistic adults presents a major barrier to AAC use. Frank similarly wrote, "*just!! the autistic joy!! of using AAC!!! !! after working thru internalized ableism*" and explained that "*by using text- or picture-to-speech, we are more able to calm ourselves and think about what we want to communicate instead of letting our body autopilot through the conversation & say what we don't mean to say.*" Frank's comments suggest that in addition to benefits for communication in areas such as employment, education, social relationships, and healthcare, AAC can also help autistic adults work through and release feelings of internalized ableism and feel more secure, proud, and joyful in their autistic identity.

In addition to individual feelings towards AAC use, several participants also expressed positive emotions regarding support from others, in particular an appreciation for people who were patient and understanding about participants' need for AAC. For example, Catherine shared that during the situation when she could not speak and did not have her tablet, understanding from a stranger helped her navigate the situation more safely and feel less afraid. She wrote, "*A man stood close to me and told other people he will take care of me and to move on – that was very lucky the guy was familiar with autism.*" Wei also shared that "*I appreciate when classmates see stuff in the chat and read it out for me.*" Although the professor not checking the chat caused frustration and a less accessible learning environment, other classmates showing support and ensuring that Wei's communication would be recognized helped to reduce the barriers.

While Frank had found AAC helpful in working through internalized ableism, other participants focused more on the barriers and difficult emotions internalized ableism continued to present both for them and others close to them. Sean discussed internalized ableism as presenting a barrier to AAC use and communication more generally. He wrote, *“The more overwhelmed I am, the more difficult it is for me to speak up, and express my needs, and the harder it is for me to get out of my own head. That triggers a lot of internalized ableism, and a whole ‘my needs aren’t important’ spiral.”* This negative spiral of shame and internalized ableism resulted in difficulties communicating his needs for more processing time to his spouse when he was feeling stressed and had difficulty speaking after coming home from a long day at work. For Rullo, internalized ableism came up in their interactions with an autistic cousin who *“has a lot of internalized ableism. I would like to share more with him without having this communication issue that he wants me to speak when I don’t or I want him to write when he wants to talk.”* These comments suggest that AAC has the potential to be beneficial in family relationships, including in communication between autistic people, but internalized ableism poses a significant barrier.

4.3 Priorities for AAC Features

Participants identified 27 features that were important to them in an AAC tool, with ten features rated as one of the top three priorities by at least one participant. Although AAC design often focuses on functional communication, participants were in unanimous agreement that privacy was a top priority in an AAC tool. Anytime communication is mediated by digital technology, privacy concerns can arise, but with AAC these concerns are particularly salient because AAC users often do not have other more secure means of communication and, especially for adults, AAC may be necessary in settings where high levels of security are required, such as for people employed in areas including law, healthcare, social services. Three other features were identified as a priority by more than one participant: the ability to save specific phrases, options to switch between multiple languages, and a more intuitive organization system (for example, alphabetical ordering or scrolling instead of a grid layout that fits to the screen). Six features were rated as a priority by one participant: ability to type, not requiring wifi, expressing emotions through tone, more advanced vocabulary (e.g. more relevant to adults, words to talk about abuse), predictive text, emergency mode (e.g. “Quiet please, thinking”).

Several participants pointed to the need for privacy in professional settings in particular. Wei, a law student, wrote, “my ideal device needs to be designed to protect against [the possibilities of surveillance and subpoenas] and privacy issues could jeopardize my ability to even have a job.” He added, “I’m just extremely alarmed by the idea of being recorded.” Wei had never heard of a lawyer using AAC where he lived, so his use of AAC in a professional setting would be especially scrutinized. Participants expressed concerns over privacy breaches in existing AAC tools, such as hearing about developers of an AAC app releasing a word cloud of users’ phrases. Multiple participants also emphasized that control over privacy and tracking should always be with the AAC user, not parents, guardians, or professionals such as a Speech Language Pathologist.

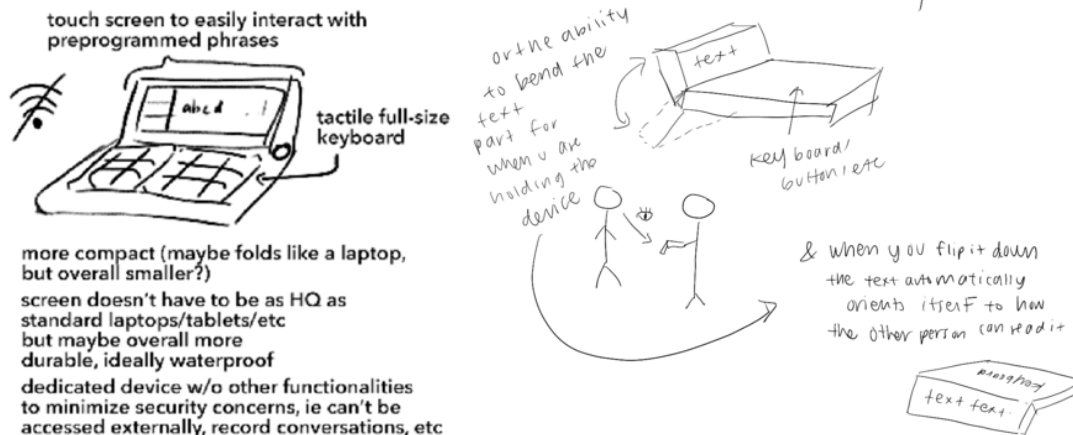


Figure 4: Wei (left) and Frank's (right) sketches of dedicated devices

Through the sketching PD activity, concerns over privacy manifested in a strong preference for dedicated devices and wearables rather than phone, tablet, or computer applications. For instance, Wei described his sketch (Fig 4) as a “dedicated device w/o other functionalities to minimize security concerns, ie can't be accessed externally, record conversations, etc.” Most other participants (all participants in the second round of sketching) also designed dedicated devices or wearables. When asked about this preference over a phone or tablet application, privacy was named as a major factor. Wei shared, “I just don't like that phones are always listening to you on some level. like I can't fully control my phone or laptop 100%.” Sean echoed, “Apps have a lot of privacy concerns.” Participants therefore expressed a higher degree of trust in the privacy and security of dedicated devices and wearables over applications.

Participants identified several other benefits to dedicated devices, including: ease of use of a tactile keyboard or buttons over a touchscreen only, the ability to “separate communication & entertainment” (Frank), the ability to use the phone for other purposes such as stimming or calming down, more durable and waterproof hardware, and a longer battery life. Many participants have had negative experiences with their phone or tablet running out of battery or being unable to access an AAC application due to lack of wifi, so dedicated devices were perceived as being more reliable. For example, Sean said, “I'm worried [apps] wouldn't work when necessary,” expressing a concern that a phone or tablet might not work or be available in a situation such as an emergency when he might need to use AAC. Participants saw dedicated devices as fulfilling the need for a tactile keyboard, while being more portable than a laptop and more sturdy and less complicated to use than laptops, tablets, and phones. Catherine explained that “Screen definition could be lower than tablets/pc displays and that would allow maybe more robust device and better battery life too.” Wei added that “for me having a tactile keyboard is preferred over like, screens or symbols but also laptops are big and clumsy and easy to break and have a bunch of other functionalities.” A major focus in the design of dedicated devices was portability when compared to an AAC program on a laptop, with folding designs being particularly favored (Fig 4). Another advantage of a folding design that several participants highlighted is an

easier way to share text visually with another person by flipping the display screen without having to hold out a phone or rotate a laptop (Fig 4, right).

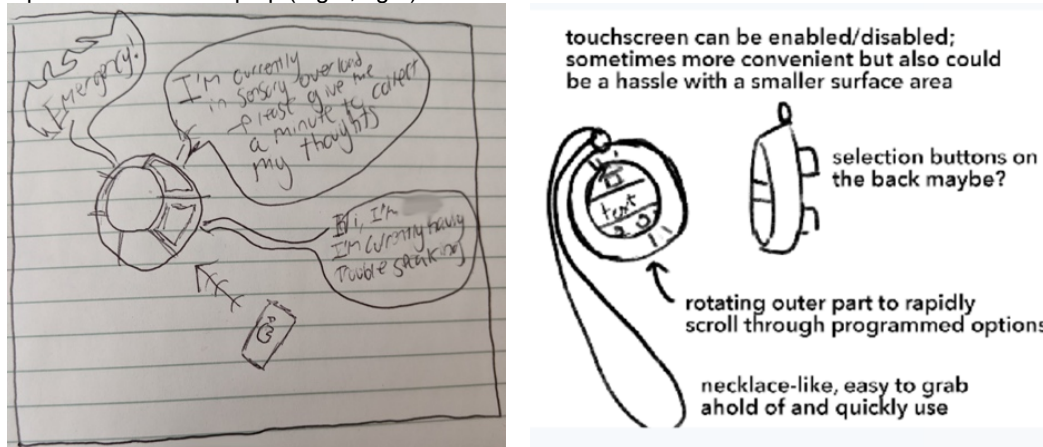


Figure 5: Sean's sketch of a wearable bracelet (left) and Wei's sketch of a wearable necklace (right)

Wearables, such as bracelets and necklaces, also had additional advantages of being highly portable and convenient to access quickly in an emergency. Participants recognized that the functionality of a wearable device would be limited due to the small screen size but felt that there were situations in which such a device would be highly useful. Sean described his bracelet design (Fig 5, left) as “a wearable with preprogrammed phrases, maybe a bracelet, different panels along the side that activate preset phrases [...], basically like an emergency, you're in the middle of talking and BAM, you're out of it.” He explained that it could also have an emergency setting that could call a trusted person or a fire station and could be connected to a phone app to edit phrases. Wei similarly described his necklace design (Fig 5, right) as “easy to grab ahold of and quickly use.” Catherine added, “A necklace design is interesting for when you don't want to carry a heavy/large device!” and said that “a very portable device” would be useful for “outdoor sports, hiking, etc. I use low tech for these occasions but a necklace would be great!” These comments and designs confirm Williams and Gilbert's [106] finding that AAC is a promising but underexplored area in research on wearable technologies for autistic people.

In addition, features that were discussed but were not rated as a priority by any participant fall into four main categories: hardware, visual design, voice, and functionality and usability. Hardware-related features focused on durability, portability, and integration and included: heavy duty hardware, long battery life, compact, tactile keyboard and/or buttons, loud speakers, mouse support, and broadcasting sound to video and phone calls. Features related to visual design included: professional aesthetics, ability to toggle between displaying words only and words with images, and customizability of display (e.g. different colors, dark mode, adjustable brightness). Features related to voice included: mimicking the user's voice and the option for animal sounds. Features related to functionality and usability included: the ability to toggle between speech

and visual display, software that is easy to set up and start using, customizability of the vocabulary and organization, optional autocorrect, and ability to copy-paste into another program.

5 DISCUSSION

Using our findings, we return to our initial research questions. We first asked about what situationally nonspeaking autistic adults valued in assistive communication technologies. Although prior work on autism and assistive technology has rarely addressed privacy and agency [26,65,81,90,106], we found that participants highly valued privacy and agency in assistive communication technologies. Next, we asked how PD can be used to design technology with and for autistic adults. We observed how PD allowed us to elicit values and priorities around communication through a combination of verbal responses and visual sketches. In this section, we expand on autistic adults' values around assistive communication technologies and PD methods.

5.1 Social Contexts and AAC Design

The PD sessions demonstrate that in the design, research, training, and evaluation of AAC technologies, it is necessary to focus on a broad scope of interaction that takes into account not only the AAC user and the technology but also other people who the user is interacting with. Since the technology will always be used to communicate with other people, others' perception of the AAC technology, and by extension of the person using it, is just as if not more important than the users' own perception and feelings towards elements of the design such as the visual aesthetics. Social attitudes are much more difficult to influence through the design of technology than technical aspects, such as weight, size, colors, word banks, and organization. Since the purpose of AAC is communication, the broader social contexts and interactions in which these technologies will be used must be at the center of AAC design if it is to live up to its full potential. Ableist attitudes can not be fixed through technology design, but creative designs that are aware of the ableist environments users will likely be facing can help users more effectively navigate inaccessible environments and can begin to shift attitudes. PD allows researchers and designers to work with users to develop these creative solutions that, as Yergeau [107] urges, hack bigotry rather than disabled bodies.

5.2 Designing for Connected AAC

The findings of this study indicate that a single AAC tool is unlikely to meet the needs of all semi-speaking or situationally nonspeaking autistic adults or even of a single user in different contexts. There is a need for an ecosystem of multiple tools that are specialized for different purposes. While a larger dedicated device would be useful for professional settings or other situations that require more robust functionality and extended communication, a wearable device would be useful for a much smaller set of pre-programmed phrases or words that are likely to be needed in an emergency situation when it might not be practical or possible to take out a larger device. Having a wearable readily accessible around a user's neck or wrist could help in particular with the issue of motor difficulties and information processing that often accompany difficulty speaking for several of the participants, since wearables would require less movement to access and have a simpler interface with a reduced amount of information. Other communication tools, including low-tech options such as business cards that disclose a person's disability and communication needs, can also be part of this ecosystem. A variety of tools that can optionally be integrated or used on their own would provide a greater

degree of flexibility and fit based on the user's needs, preferences, abilities, and contexts of use. Given that people with disabilities engage in complex strategies around (in)visibility and management of perceptions when using assistive technologies [29,76,89], multiple tools would also allow for more nuanced and dynamic negotiations of disclosure, with a wearable device likely being less obtrusive and easier to conceal.

5.3 Privacy in AAC for Adults

It is clear from the discussion and design activities that there is a pressing need for attention to privacy in AAC. Although some researchers, professionals, and AAC users have argued that privacy and security should be important considerations in AAC, especially with the growth of internet-connected and more personalized forms of AAC, it is an aspect that remains frequently overlooked in AAC research, design, and service provision [10,26,40,42,44,65,73,81,104,110]. Lack of attention and communication around privacy leads to mistrust and reluctance to use AAC tools among autistic adults. While the participants in this study strongly favored dedicated devices and wearables, more research is necessary to determine whether this trend is representative of the needs and preferences of autistic adults. Despite the disadvantages identified by participants, phone and tablet applications carry several important advantages including affordability, convenience, and easier access for users who already own phones and tablets. The extensive concerns that participants had over the privacy of AAC phone and tablet applications indicate that developers of such applications in particular would benefit from better consideration and communication around privacy, such as accessible privacy notices, robust privacy controls, and transparent data flows. Additionally, while academic discussions of privacy in AAC have focused more on the needs and perceptions of users who are adolescents or adults when age is mentioned as a factor [65], more research should be done around perceptions and feelings around privacy among children users of AAC as well as adult users who began to use AAC as children. The emphasis of several of the autistic adult participants that control over privacy and tracking should lie with the user not the parent or professional suggests that lack of or uncertainty over privacy may also be an issue of concern to children or may become a more pressing issue as children grow up. Building on past work on privacy and disability [5,12,92,102], we affirm that research into privacy in assistive communication technologies should adopt a critical lens that fosters transparency and user agency. Follow-up steps that researchers, designers, and providers can take to address privacy concerns and build user trust include:

- Developing a deeper understanding of the expectations and requirements that children and adult users have around privacy in assistive communication technologies in a range of settings, including social, educational, employment, and healthcare, and how current tools and practices in AAC fall short of those expectations and requirements.
- Increasing the transparency and clarity of information about the privacy and security of existing tools, through means such as accessible plain-language privacy notices and transparent data flows.
- Introducing a greater degree of user control over privacy settings, including the option to not log or share any data, and ensuring that the AAC user (not only the provider, parent, guardian, or aide) is always given the permissions to modify these settings.
- Developing tools and devices that can be entirely disconnected from the internet for use in settings with heightened security concerns, such as law practice.

- Considering how other advances in information privacy and security, such as encryption, accessible authentication, and distortion of training datasets [12,102], can be integrated into or used to inform AAC design.

5.4 Reflecting on PD for AAC Design

Participants' discussions of emotions relating to AAC use and of the desire for more emotionally expressive AAC tools indicate that there is a strong need to pay attention to the affective dimensions of AAC use in the design and implementation of AAC technologies. If AAC tools were designed and promoted towards speaking and semi-speaking autistic adults, they could have a major positive impact in many people's lives. Potential and beginner AAC users can also benefit from support around working through internalized ableism, which can be a barrier to AAC use and accessible and fulfilling communication. Spiel et al [90] critique AAC technologies for "imply[ing] that neurotypically oriented communication is a desired norm," being "conceptually tied to a notion of failure," and limiting the range of communication to the "needs of an outside world" rather than the AAC users. Our study suggests that if AAC design and provision is approached from a strengths-based perspective and is shaped by AAC users, AAC has the potential to be empowering and emancipatory by expanding options for communication and encouraging users to gain acceptance, confidence, and pride in their autistic identity. Users and potential users of assistive technology such as AAC hold many valuable perspectives, experiences, and creative ideas that can inform more effective, inclusive, and relevant research and design of these technologies. PD offers a way for researchers and designers to incorporate users' values and priorities from the start of the design process rather than solely at the evaluation stage.

5.5 Accessibility and Virtual PD

Virtual PD carries the potential for significant accessibility benefits for autistic participants by easily allowing multimodal participation, including speaking, typing in the Zoom chat, typing on Jamboard, and sharing digital or hand-drawn images on Jamboard. Throughout the sessions, participants switched seamlessly between the Zoom chat and the Jamboard and often responded to one another by using symbols such as "^" and "+" to indicate agreement or reference a specific comment, responding in chat while someone else was speaking, and referencing other participants' ideas when typing their own. These kinds of engagements would be more difficult and more constrained in an in-person environment, especially for participants with communication-related disabilities who are not regular or highly experienced users of AAC. Additional accessibility benefits afforded by virtual PD include: greater control over the display and format of the CART transcript, familiarity with the environment as virtual PD sessions can be attended from the participants' homes, individualized control over sensory aspects such as noise levels and brightness, ease of splitting sessions into shorter segments since there are no travel requirements, and visibility of name and pronouns next to the video of each participant. Notably, the recommendations for accessible research with autistic participants shared significant overlap with general guidelines for effective and engaging virtual workshops, including smaller groups, shorter sessions, clear and consistent agendas, reducing clutter and number of technologies used, clear and concise communication, and multimodal engagement [23,52,55,71,98]. Echoing Benton and Johnson's [8] finding that approaches to PD developed for autistic children can have benefits for conducting PD with a broader population of non-autistic children, this overlap suggests that approaches that increase the

accessibility of virtual PD for autistic participants can also improve the experience and engagement of PD for non-autistic participants.

However, the accessibility benefits of virtual PD are realized only if accessibility is consciously integrated into multiple stages of the study design. Several participants shared that they were surprised about how accessible and welcoming the sessions felt compared to other Zoom events they had participated in, such as meetings and university courses, and discussed frustrations around professors and classmates demanding spoken participation or not monitoring the chat. These comments point to the need for intentionally cultivating access, regardless of the specific format or medium of the sessions. While the video call and digital whiteboard format worked well for the participants in this study, there is also a need to explore alternatives to synchronous video calls, as several screening survey respondents indicated that they were not comfortable with video calls. It is likely that autistic people who find video calls inaccessible would have different values, perspectives, and needs around communication and AAC. Because video calls require relatively high bandwidth and familiarity with computer use, alternative forms of participation could also make PD more accessible to people with fewer resources or computer knowledge.

6 CONCLUSION

This study identified several priority areas, including social stigma, agency, and privacy, that can make the design and service provision of AAC tools more useful and relevant for speaking and semi-speaking autistic adults. It also demonstrated the efficacy and benefits of virtual PD methods for working with this population. AAC tools designed with a focus on and in collaboration with autistic adults have considerable potential to improve wellbeing and communication access.

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REFERENCES

- [1] Jonathon Allen. 2005. Designing desirability in an augmentative and alternative communication device. *Univ Access Inf Soc* 4, 2 (December 2005), 135–145. DOI:<https://doi.org/10.1007/s10209-005-0117-2>
- [2] Meghan Allen, Joanna McGrenere, and Barbara Purves. 2007. The design and field evaluation of PhotoTalk: a digital image communication application for people. In *Proceedings of the 9th international ACM SIGACCESS conference on Computers and accessibility - Assets '07*, ACM Press, Tempe, Arizona, USA, 187. DOI:<https://doi.org/10.1145/1296843.1296876>
- [3] Meghan Allen, Joanna McGrenere, and Barbara Purves. 2008. The Field Evaluation of a Mobile Digital Image Communication Application Designed for People with Aphasia. *ACM Trans. Access. Comput.* 1, 1 (May 2008), 1–26. DOI:<https://doi.org/10.1145/1361203.1361208>
- [4] Meryl Alper. 2017. *Giving voice: mobile communication, disability, and inequality*. MIT Press, Cambridge, MA.
- [5] Cynthia L. Bennett and Os Keyes. 2019. What is the Point of Fairness? Disability, AI and The Complexity of Justice. *arXiv:1908.01024 [cs]* (August 2019). Retrieved April 13, 2021 from <http://arxiv.org/abs/1908.01024>

- [6] Cynthia L. Bennett, Burren Peil, and Daniela K. Rosner. 2019. Biographical Prototypes: Reimagining Recognition and Disability in Design. In *Proceedings of the 2019 on Designing Interactive Systems Conference*, ACM, San Diego CA USA, 35–47. DOI:<https://doi.org/10.1145/3322276.3322376>
- [7] Cynthia L. Bennett and Daniela K. Rosner. 2019. The Promise of Empathy: Design, Disability, and Knowing the “Other.” In *Proceedings of the 2019 CHI Conference on Human Factors in Computing Systems*, ACM, Glasgow Scotland Uk, 1–13. DOI:<https://doi.org/10.1145/3290605.3300528>
- [8] Laura Benton and Hilary Johnson. 2014. Structured approaches to participatory design for children: can targeting the needs of children with autism provide benefits for a broader child population? *Instr Sci* 42, 1 (January 2014), 47–65. DOI:<https://doi.org/10.1007/s11251-013-9297-y>
- [9] Laura Benton, Hilary Johnson, Emma Ashwin, Mark Brosnan, and Beate Grawemeyer. 2012. Developing IDEAS: supporting children with autism within a participatory design team. In *Proceedings of the 2012 ACM annual conference on Human Factors in Computing Systems - CHI '12*, ACM Press, Austin, Texas, USA, 2599. DOI:<https://doi.org/10.1145/2207676.2208650>
- [10] Sarah W. Blackstone, Michael B. Williams, and David P. Wilkins. 2007. Key principles underlying research and practice in AAC. *Augmentative and Alternative Communication* 23, 3 (January 2007), 191–203. DOI:<https://doi.org/10.1080/07434610701553684>
- [11] Kristen Bottema-Beutel, Steven K. Kapp, Jessica Nina Lester, Noah J. Sasson, and Brittany N. Hand. 2021. Avoiding Ableist Language: Suggestions for Autism Researchers. *Autism in Adulthood* 3, 1 (March 2021), 18–29. DOI:<https://doi.org/10.1089/aut.2020.0014>
- [12] Danielle Bragg, Oscar Koller, Naomi Caselli, and William Thies. 2020. Exploring Collection of Sign Language Datasets: Privacy, Participation, and Model Performance. In *The 22nd International ACM SIGACCESS Conference on Computers and Accessibility*, ACM, Virtual Event Greece, 1–14. DOI:<https://doi.org/10.1145/3373625.3417024>
- [13] Tone Bratteteig, Keld Bødker, Yvonne Dittrich, Preben Holst Mogensen, and Jesper Simonsen. 2013. Methods: organising principles and general guidelines for Participatory Design projects. In *Routledge International Handbook of Participatory Design* (1st Edition). Routledge, London, 117–144.
- [14] Virginia Braun and Victoria Clarke. 2020. Can I use TA? Should I use TA? Should I *not* use TA? Comparing reflexive thematic analysis and other pattern-based qualitative analytic approaches. *Couns Psychother Res* (October 2020), capr.12360. DOI:<https://doi.org/10.1002/capr.12360>
- [15] Virginia Braun, Victoria Clarke, Nikki Hayfield, and Gareth Terry. 2019. Thematic Analysis. In *Handbook of Research Methods in Health Social Sciences*, Pranee Liamputtong (ed.). Springer Singapore, Singapore, 843–860. DOI:https://doi.org/10.1007/978-981-10-5251-4_103
- [16] Katherine Broomfield, Deborah Harrop, Simon Judge, Georgina Jones, and Karen Sage. 2019. Appraising the quality of tools used to record patient-reported outcomes in users of augmentative and alternative communication (AAC): a systematic review. *Qual Life Res* 28, 10 (October 2019), 2669–2683. DOI:<https://doi.org/10.1007/s11136-019-02228-3>
- [17] Lydia Brown. Identity-First Language | Autistic Self Advocacy Network. *Autistic Self-Advocacy Network*. Retrieved April 13, 2021 from <https://autisticadvocacy.org/about-asan/identity-first-language/>
- [18] Simon M. Bury, Rachel Jellett, Jennifer R. Spoor, and Darren Hedley. 2020. “It Defines Who I Am” or “It’s Something I Have”: What Language Do [Autistic] Australian Adults [on the Autism Spectrum] Prefer? *J Autism Dev Disord* (February 2020). DOI:<https://doi.org/10.1007/s10803-020-04425-3>
- [19] Andrei Carniel, Carla Diacui Medeiros Berkenbrock, Gian Ricardo Berkenbrock, Simone Erbs da Costa, and Aliciene Fusca Machado Cordeiro. 2019. Supporting the Dialog of People With Intellectual Disabilities Through Augmentative and Alternative Communication. *IEEE R. Iberoamericana Tecnologias Aprendizaje* 14, 1 (February 2019), 3–10. DOI:<https://doi.org/10.1109/RITA.2019.2909715>
- [20] M. Ariel Cascio, Florian Grond, Rossio Motta-Ochoa, Tamar Tembeck, Dan Ten Veen, and Stefanie Blain-Moraes. 2020. Working Together: Ethnographic Observations on Participatory Design Involving Adults with Autism. *Human Organization* 79, 1 (March 2020), 1–12. DOI:<https://doi.org/10.17730/0018-7259.79.1.1>
- [21] Robert Evert Cimera, Paul Wehman, Michael West, and Sloane Burgess. 2012. Do sheltered workshops enhance employment outcomes for adults with autism spectrum disorder? *Autism* 16, 1 (January 2012), 87–94. DOI:<https://doi.org/10.1177/1362361311408129>
- [22] Aurora Constantin, Hilary Johnson, Elizabeth Smith, Denise Lengyel, and Mark Brosnan. 2017. Designing computer-based rewards with and for children with Autism Spectrum Disorder and/or Intellectual Disability. *Computers in Human Behavior* 75, (October 2017), 404–414. DOI:<https://doi.org/10.1016/j.chb.2017.05.030>
- [23] Cooperative Research Centre for Living with Autism. 2016. *Inclusive Research Practice Guides and Checklists for Autism Research: Version 2*. Autism CRC Ltd., Brisbane, Queensland.
- [24] Andraia P. Costa, Georges Steffgen, and Andrea C. Samson. 2017. Expressive Incoherence and Alexithymia in Autism Spectrum Disorder. *J Autism Dev Disord* 47, 6 (June 2017), 1659–1672. DOI:<https://doi.org/10.1007/s10803-017-3073-9>
- [25] Rhian Davies, Skip Marcella, Joanna McGrenere, and Barbara Purves. 2004. The ethnographically informed participatory design of a PD application to support communication. In *Proceedings of the ACM SIGACCESS conference on Computers and accessibility - ASSETS '04*, ACM Press, Atlanta, GA, USA, 153. DOI:<https://doi.org/10.1145/1028630.1028658>
- [26] Frank Deruyter, David McNaughton, Kevin Caves, Diane Nelson Bryen, and Michael B. Williams. 2007. Enhancing AAC connections with the world. *Augmentative and Alternative Communication* 23, 3 (January 2007), 258–270. DOI:<https://doi.org/10.1080/07434610701553387>

- [27] Pelle Ehn. 2014. *Making Futures*. The MIT Press. Retrieved April 13, 2021 from <http://www.myilibrary.com?id=660682>
- [28] Marc Fabri and Penny C.S. Andrews. 2016. Human-Centered Design with Autistic University Students: Interface, Interaction and Information Preferences. In *Design, User Experience, and Usability: Novel User Experiences*, Springer International Publishing, Cham, 157–166.
- [29] Heather A. Faucett, Kate E. Ringland, Amanda L. L. Cullen, and Gillian R. Hayes. 2017. (In)Visibility in Disability and Assistive Technology. *ACM Trans. Access. Comput.* 10, 4 (October 2017), 1–17. DOI:<https://doi.org/10.1145/3132040>
- [30] Erinn H. Finke, David B. McNaughton, and Kathryn D. R. Drager. 2009. “All Children Can and Should Have the Opportunity to Learn”: General Education Teachers’ Perspectives on Including Children with Autism Spectrum Disorder who Require AAC. *Augmentative and Alternative Communication* 25, 2 (January 2009), 110–122. DOI:<https://doi.org/10.1080/07434610902886206>
- [31] Christopher Frauenberger, Judith Good, and Wendy Keay-Bright. 2011. Designing technology for children with special needs: bridging perspectives through participatory design. *CoDesign* 7, 1 (March 2011), 1–28. DOI:<https://doi.org/10.1080/15710882.2011.587013>
- [32] Christopher Frauenberger, Julia Makhaeva, and Katta Spiel. 2017. Blending Methods: Developing Participatory Design Sessions for Autistic Children. In *Proceedings of the 2017 Conference on Interaction Design and Children*, ACM, Stanford California USA, 39–49. DOI:<https://doi.org/10.1145/3078072.3079727>
- [33] Katie Gaudion, Ashley Hall, Jeremy Myerson, and Liz Pellicano. 2015. A designer’s approach: how can autistic adults with learning disabilities be involved in the design process? *CoDesign* 11, 1 (January 2015), 49–69. DOI:<https://doi.org/10.1080/15710882.2014.997829>
- [34] Kristen Gillespie-Lynch, Steven K. Kapp, Patricia J. Brooks, Jonathan Pickens, and Ben Schwartzman. 2017. Whose Expertise Is It? Evidence for Autistic Adults as Critical Autism Experts. *Front. Psychol.* 8, (March 2017). DOI:<https://doi.org/10.3389/fpsyg.2017.00438>
- [35] Judith Gould. 2017. Towards understanding the under-recognition of girls and women on the autism spectrum. *Autism* 21, 6 (August 2017), 703–705. DOI:<https://doi.org/10.1177/1362361317706174>
- [36] Florian Grond, M. Ariel Cascio, Rossio Motta-Ochoa, Tamar Tembeck, Dan Ten Veen, and Stefanie Blain-Moraes. 2019. Participatory design of biomusic with users on the autism spectrum. In *2019 8th International Conference on Affective Computing and Intelligent Interaction (ACII)*, IEEE, Cambridge, United Kingdom, 1–7. DOI:<https://doi.org/10.1109/ACII.2019.8925484>
- [37] Florian Grond, Rossio Motta-Ochoa, Natalie Miyake, Tamar Tembeck, Melissa Park, and Stefanie Blain-Moraes. 2019. Participatory Design of Affective Technology: Interfacing Biomusic and Autism. *IEEE Trans. Affective Comput.* (2019), 1–1. DOI:<https://doi.org/10.1109/TAFFC.2019.2922911>
- [38] Foad Hamidi, Melanie Baljko, Toni Kunic, and Ray Feraday. 2015. TalkBox: a DIY communication board case study. *Jnl of Assistive Technologies* 9, 4 (December 2015), 187–198. DOI:<https://doi.org/10.1108/JAT-10-2014-0027>
- [39] Christina Harrington, Sheena Erete, and Anne Marie Piper. 2019. Deconstructing Community-Based Collaborative Design: Towards More Equitable Participatory Design Engagements. *Proc. ACM Hum.-Comput. Interact.* 3, CSCW (November 2019), 1–25. DOI:<https://doi.org/10.1145/3359318>
- [40] Jeff Higginbotham and AAC RERC partner. 2000. Problems and Solutions in Data Logging. *Alternatively Speaking* 5, 4–5.
- [41] Alyssa Hillary. 2019. Am I the curriculum? *Curriculum Inquiry* 49, 4 (August 2019), 373–386. DOI:<https://doi.org/10.1080/03626784.2019.1664255>
- [42] Alyssa Hillary. Respecting privacy in AAC. *AssistiveWare*. Retrieved April 13, 2021 from <https://www.assistiveware.com/blog/respecting-privacy-in-aac>
- [43] Monique Hines, Susan Balandin, and Leanne Togher. 2011. Communication and AAC in the Lives of Adults with Autism: The Stories of Their Older Parents. *Augmentative and Alternative Communication* 27, 4 (December 2011), 256–266. DOI:<https://doi.org/10.3109/07434618.2011.587830>
- [44] Rick Hohn. 2000. Securing Confidentiality in DynaVox and DynaMyte. *Alternatively Speaking* 5, 3.
- [45] Christine Holyfield, Kathryn D. R. Drager, Jennifer M. D. Kremkow, and Janice Light. 2017. Systematic review of AAC intervention research for adolescents and adults with autism spectrum disorder. *Augmentative and Alternative Communication* 33, 4 (October 2017), 201–212. DOI:<https://doi.org/10.1080/07434618.2017.1370495>
- [46] Seray B. Ibrahim, Asimina Vasalou, and Michael Clarke. 2018. Design Opportunities for AAC and Children with Severe Speech and Physical Impairments. In *Proceedings of the 2018 CHI Conference on Human Factors in Computing Systems - CHI '18*, ACM Press, Montreal QC, Canada, 1–13. DOI:<https://doi.org/10.1145/3173574.3173801>
- [47] Desiree R Jones and David S Mandell. 2020. To address racial disparities in autism research, we must think globally, act locally. *Autism* 24, 7 (October 2020), 1587–1589. DOI:<https://doi.org/10.1177/1362361320948313>
- [48] Desiree R. Jones, Christina Nicolaidis, Lisa J. Ellwood, Arianne Garcia, Khalilah R. Johnson, Kristina Lopez, and Tc Waisman. 2020. An Expert Discussion on Structural Racism in Autism Research and Practice. *Autism in Adulthood* 2, 4 (December 2020), 273–281. DOI:<https://doi.org/10.1089/aut.2020.29015.drj>
- [49] Heesoon Jun. 2018. Disablism/Ableism. In *Social Justice, Multicultural Counseling, and Practice*. Springer International Publishing, Cham, 243–271. DOI:https://doi.org/10.1007/978-3-319-72514-7_9
- [50] Steven K. Kapp, Kristen Gillespie-Lynch, Lauren E. Sherman, and Ted Hutman. 2013. Deficit, difference, or both? Autism and neurodiversity. *Developmental Psychology* 49, 1 (2013), 59–71. DOI:<https://doi.org/10.1037/a0028353>
- [51] Lorcan Kenny, Caroline Hattersley, Bonnie Molins, Carole Buckley, Carol Povey, and Elizabeth Pellicano. 2016. Which terms should be used to describe autism? Perspectives from the UK autism community. *Autism* 20, 4 (May 2016), 442–462.

DOI:<https://doi.org/10.1177/1362361315588200>

- [52] E. Kuhn, D.L. Starks, and E.L. Aurbach. 2020. Facilitation Guide: Participatory Sessions in a Virtual Environment (Beta Version). Retrieved from <https://docs.google.com/document/d/1yDD-RTmM55dRbk83bzBB7pdEgU6qgZIsFOkix5W-ch4/edit?usp=sharing>
- [53] Jim Lamiell, Al Ming, Priya Ollapally, Josh Turk, and Christine Yom. 2015. Product Discovery Activity Guide. Retrieved from <https://www.slideshare.net/almingwork/nyt-product-discovery-activity-guide>
- [54] Antonio Lanzotti, Massimo Martorelli, Stefano Papa, Gennaro Sicignano, Alessandro Pepino, Salvatore Orrei, Stefano Ciarabella, Domenico Maria Del Giudice, Antonio Gloria, and Salvatore Gerbino. 2018. Participatory Design of a Personalized Device for a Student with Spastic Quadriplegia at Federico II. 7, (2018), 339–349. DOI:<https://doi.org/10.3233/978-1-61499-898-3-339>
- [55] Kung Jin Lee, Wendy Roldan, Tian Qi Zhu, Harkiran Kaur Saluja, Sungmin Na, Britnie Chin, Yilin Zeng, Jin Ha Lee, and Jason Yip. 2021. The Show Must Go On: A conceptual model of conducting synchronous participatory design with children online. *Proceedings of the 2021 CHI Conference on Human Factors in Computing Systems* (2021). Retrieved from Preprint at http://bigyipper.com/wp-content/uploads/2021/01/The-show-must-go-on_preprint_Final.pdf
- [56] Alissa Levy and Adrienne Perry. 2011. Outcomes in adolescents and adults with autism: A review of the literature. *Research in Autism Spectrum Disorders* 5, 4 (October 2011), 1271–1282. DOI:<https://doi.org/10.1016/j.rasd.2011.01.023>
- [57] Janice Light and Kathryn Drager. 2007. AAC technologies for young children with complex communication needs: State of the science and future research directions. *Augmentative and Alternative Communication* 23, 3 (January 2007), 204–216. DOI:<https://doi.org/10.1080/07434610701553635>
- [58] Janice Light and David McNaughton. 2013. Putting People First: Re-Thinking the Role of Technology in Augmentative and Alternative Communication Intervention. *Augmentative and Alternative Communication* 29, 4 (December 2013), 299–309. DOI:<https://doi.org/10.3109/07434618.2013.848935>
- [59] Janice Light, Rebecca Page, Jennifer Curran, and Laura Pitkin. 2007. Children's ideas for the design of AAC assistive technologies for young children with complex communication needs. *Augmentative and Alternative Communication* 23, 4 (January 2007), 274–287. DOI:<https://doi.org/10.1080/07434610701390475>
- [60] Laura Malinverni, Joan Mora-Guiard, Vanesa Padillo, Lilia Valero, Amaia Hervás, and Narcis Pares. 2017. An inclusive design approach for developing video games for children with Autism Spectrum Disorder. *Computers in Human Behavior* 71, (June 2017), 535–549. DOI:<https://doi.org/10.1016/j.chb.2016.01.018>
- [61] Laura Malinverni, Joan Mora-Guiard, and Narcis Pares. 2016. Towards methods for evaluating and communicating participatory design: A multimodal approach. *International Journal of Human-Computer Studies* 94, (October 2016), 53–63. DOI:<https://doi.org/10.1016/j.ijhcs.2016.03.004>
- [62] Carla A. Mazefsky, John Herrington, Matthew Siegel, Angela Scarpa, Brenna B. Maddox, Lawrence Scahill, and Susan W. White. 2013. The Role of Emotion Regulation in Autism Spectrum Disorder. *Journal of the American Academy of Child & Adolescent Psychiatry* 52, 7 (July 2013), 679–688. DOI:<https://doi.org/10.1016/j.jaac.2013.05.006>
- [63] Keith McAllister and Sean Sloan. 2016. Designed by the pupils, for the pupils: an autism-friendly school. *British Journal of Special Education* 43, 4 (December 2016), 330–357. DOI:<https://doi.org/10.1111/1467-8578.12160>
- [64] Joanna McGrenere, Rhian Davies, Leah Findlater, Peter Graf, Maria Klawe, Karyn Moffatt, Barbara Purves, and Sarah Yang. 2003. Insights from the aphasia project: designing technology for and with people who have aphasia. In *Proceedings of the 2003 conference on Universal usability - UUU '03*, ACM Press, Vancouver, British Columbia, Canada, 112. DOI:<https://doi.org/10.1145/957205.957225>
- [65] David McNaughton and Diane Nelson Bryen. 2007. AAC technologies to enhance participation and access to meaningful societal roles for adolescents and adults with developmental disabilities who require AAC. *Augmentative and Alternative Communication* 23, 3 (January 2007), 217–229. DOI:<https://doi.org/10.1080/07434610701573856>
- [66] David McNaughton and Laura Richardson. 2013. Supporting Positive Employment Outcomes for Individuals With Autism Who Use AAC. *Perspect Augment Altern Commun* 22, 3 (October 2013), 164–172. DOI:<https://doi.org/10.1044/aac22.3.164>
- [67] Sevi Merter and Deniz Hasirci. 2018. A participatory product design process with children with autism spectrum disorder. *CoDesign* 14, 3 (July 2018), 170–187. DOI:<https://doi.org/10.1080/15710882.2016.1263669>
- [68] Damian E.M. Milton. 2012. On the ontological status of autism: the 'double empathy problem.' *Disability & Society* 27, 6 (October 2012), 883–887. DOI:<https://doi.org/10.1080/09687599.2012.710008>
- [69] Damian EM Milton. 2014. Autistic expertise: A critical reflection on the production of knowledge in autism studies. *Autism* 18, 7 (October 2014), 794–802. DOI:<https://doi.org/10.1177/1362361314525281>
- [70] Rachel L. Moseley, Tanya Druce, and Julie M. Turner-Cobb. 2020. Autism research is 'all about the blokes and the kids': Autistic women breaking the silence on menopause. *Br J Health Psychol* (September 2020), bjh.p.12477. DOI:<https://doi.org/10.1111/bjhp.12477>
- [71] Christina Nicolaidis, Dora Raymaker, Steven K Kapp, Amelia Baggs, E Ashkenazy, Katherine McDonald, Michael Weiner, Joelle Maslak, Morrigan Hunter, and Andrea Joyce. 2019. The AASPIRE practice-based guidelines for the inclusion of autistic adults in research as co-researchers and study participants. *Autism* 23, 8 (April 2019), 2007–2019. DOI:<https://doi.org/10.1177/1362361319830523>
- [72] David Niemeijer. AAC in English-speaking countries: Survey Results - AssistiveWare. *AssistiveWare*. Retrieved June 3, 2020 from <https://www.assistiveware.com/blog/survey-aac-in-english-speaking-countries>
- [73] David Niemeijer. AAC data collection and privacy. *AssistiveWare*. Retrieved April 13, 2021 from

<https://www.assistiveware.com/blog/aac-data-collection-and-privacy>

- [74] Jason Nolan and Melanie McBride. 2015. Embodied Semiosis: Autistic ‘Stimming’ as Sensory Praxis. In *International Handbook of Semiotics*, Peter Pericles Trifonas (ed.). Springer Netherlands, Dordrecht, 1069–1078. DOI:https://doi.org/10.1007/978-94-017-9404-6_48
- [75] Sarah Parsons, Laura Millen, Sara Garib-Penna, and Sue Cobb. 2011. Participatory design in the development of innovative technologies for children and young people on the autism spectrum: the COSPATIAL project. *Jnl of Assistive Technologies* 5, 1 (March 2011), 29–34. DOI:<https://doi.org/10.5042/jat.2011.0099>
- [76] Halley Profita, Reem Albaghli, Leah Findlater, Paul Jaeger, and Shaun K. Kane. 2016. The AT Effect: How Disability Affects the Perceived Social Acceptability of Head-Mounted Display Use. In *Proceedings of the 2016 CHI Conference on Human Factors in Computing Systems*, ACM, San Jose California USA, 4884–4895. DOI:<https://doi.org/10.1145/2858036.2858130>
- [77] Graham Pullin. 2009. *Design meets disability*. MIT Press, Cambridge, Mass.
- [78] Graham Pullin and Shannon Hennig. 2015. 17 Ways to Say Yes: Toward Nuanced Tone of Voice in AAC and Speech Technology. *Augmentative and Alternative Communication* 31, 2 (April 2015), 170–180. DOI:<https://doi.org/10.3109/07434618.2015.1037930>
- [79] Graham Pullin, Jutta Treviranus, Rupal Patel, and Jeff Higginbotham. 2017. Designing interaction, voice, and inclusion in AAC research. *Augmentative and Alternative Communication* 33, 3 (July 2017), 139–148. DOI:<https://doi.org/10.1080/07434618.2017.1342690>
- [80] Christian Quintero. 2020. A review: accessible technology through participatory design. *Disability and Rehabilitation: Assistive Technology* (July 2020), 1–7. DOI:<https://doi.org/10.1080/17483107.2020.1785564>
- [81] Joseph Reddington and Lizzie Coles-Kemp. 2011. Trap hunting: finding personal data management issues in next generation AAC devices. *SLPAT '11: Proceedings of the Second Workshop on Speech and Language Processing for Assistive Technologies* (2011), 32–42. DOI:<https://dl.acm.org/doi/10.5555/2140499.2140505>
- [82] Norah Richards and Laura Crane. 2020. The Development and Feasibility Study of a Multimodal ‘Talking Wall’ to Facilitate the Voice of Young People with Autism and Complex Needs: A Case Study in a Specialist Residential School. *Journal of Autism and Developmental Disorders* (April 2020). DOI:<https://doi.org/10.1007/s10803-020-04476-6>
- [83] Toni Robertson and Jesper Simonsen. 2013. Participatory Design: an introduction. In *Routledge International Handbook of Participatory Design* (1st Edition). Routledge, London, 1–17.
- [84] Anne M. Roux, Paul T Shattuck, Jessica E. Rast, and Kristy A. Anderson. 2017. *National Autism Indicators Report: Developmental Disability Services and Outcomes in Adulthood*. Life Course Outcomes Research Program, A.J. Drexel Autism Institute, Drexel University, Philadelphia, PA. Retrieved from <https://drexel.edu/autismoutcomes/publications-and-reports/publications/National-Autism-Indicators-Report-Developmental-Disability-Services-and-Outcomes-in-Adulthood/>
- [85] Andrea C. Samson, Antonio Y. Hardan, Ihno A. Lee, Jennifer M. Phillips, and James J. Gross. 2015. Maladaptive Behavior in Autism Spectrum Disorder: The Role of Emotion Experience and Emotion Regulation. *J Autism Dev Disord* 45, 11 (November 2015), 3424–3432. DOI:<https://doi.org/10.1007/s10803-015-2388-7>
- [86] Wendy E. Shaia, Helen M. Nichols, Sarah Dababnah, Karen Champion, and Nicole Garbarino. 2020. Brief Report: Participation of Black and African-American Families in Autism Research. *J Autism Dev Disord* 50, 5 (May 2020), 1841–1846. DOI:<https://doi.org/10.1007/s10803-019-03926-0>
- [87] Paul T Shattuck, Anne M Roux, Laura E Hudson, Julie Lounds Taylor, Matthew J Maenner, and Jean-Francois Trani. 2012. Services for Adults with an Autism Spectrum Disorder. *Can J Psychiatry* 57, 5 (May 2012), 284–291. DOI:<https://doi.org/10.1177/070674371205700503>
- [88] Allison Shefcyk. 2015. Count us in: Addressing gender disparities in autism research. *Autism* 19, 2 (February 2015), 131–132. DOI:<https://doi.org/10.1177/1362361314566585>
- [89] Kristen Shinohara and Jacob O. Wobbrock. 2011. In the shadow of misperception: assistive technology use and social interactions. In *Proceedings of the 2011 annual conference on Human factors in computing systems - CHI '11*, ACM Press, Vancouver, BC, Canada, 705. DOI:<https://doi.org/10.1145/1978942.1979044>
- [90] Katta Spiel, Christopher Frauenberger, Os Keyes, and Geraldine Fitzpatrick. 2019. Agency of Autistic Children in Technology Research—A Critical Literature Review. *ACM Trans. Comput.-Hum. Interact.* 26, 6 (December 2019), 1–40. DOI:<https://doi.org/10.1145/3344919>
- [91] Katta Spiel, Kathrin Gerling, Cynthia L. Bennett, Emeline Brulé, Rua M. Williams, Jennifer Rode, and Jennifer Mankoff. 2020. Nothing About Us Without Us: Investigating the Role of Critical Disability Studies in HCI. In *Extended Abstracts of the 2020 CHI Conference on Human Factors in Computing Systems*, ACM, Honolulu HI USA, 1–8. DOI:<https://doi.org/10.1145/3334480.3375150>
- [92] Abigale Stangl, Kristina Shiroma, Bo Xie, Kenneth R. Fleischmann, and Danna Gurari. 2020. Visual Content Considered Private by People Who are Blind. In *The 22nd International ACM SIGACCESS Conference on Computers and Accessibility*, ACM, Virtual Event Greece, 1–12. DOI:<https://doi.org/10.1145/3373625.3417014>
- [93] John F Strang, Anna IR van der Miesen, Reid Caplan, Cat Hughes, Sharon daVanport, and Meng-Chuan Lai. 2020. Both sex- and gender-related factors should be considered in autism research and clinical practice. *Autism* 24, 3 (April 2020), 539–543. DOI:<https://doi.org/10.1177/1362361320913192>
- [94] Deborah Sturm, Michael Kholodovsky, Rayan Arab, David Shane Smith, Pavel Asanov, and Kristen Gillespie-Lynch. 2019. Participatory Design of a Hybrid Kinect Game to Promote Collaboration between Autistic Players and Their Peers. *International Journal of Human-Computer Interaction* 35, 8 (May 2019), 706–723. DOI:<https://doi.org/10.1080/10447318.2018.1550180>

- [95] Neeraja Subrahmaniyan. 2014. Development of personas to support Augmentative Alternative Communication device design and clinical decision making.
- [96] Neeraja Subrahmaniyan, D. Jeffery Higginbotham, and Ann M. Bisantz. 2018. Using Personas to Support Augmentative Alternative Communication Device Design: A Validation and Evaluation Study. *International Journal of Human-Computer Interaction* 34, 1 (January 2018), 84–97. DOI:<https://doi.org/10.1080/10447318.2017.1330802>
- [97] Julie Lounds Taylor and Leann Smith DaWalt. 2020. Working toward a better understanding of the life experiences of women on the autism spectrum. *Autism* 24, 5 (July 2020), 1027–1030. DOI:<https://doi.org/10.1177/1362361320913754>
- [98] Mark Tippin, Jim Kalbach, and David Chin. 2018. *The Definitive Guide to Facilitating Remote Workshops*. Mural. Retrieved from <https://engage.mural.co/rs/480-LFM-113/images/The%20Definitive%20Guide%20To%20Facilitating%20Remote%20Workshops%20%28V1.5%29.pdf?>
- [99] David Trembath, Teresa Iacono, Katie Lyon, Denise West, and Hilary Johnson. 2013. Augmentative and alternative communication supports for adults with autism spectrum disorders. *Autism* 18, 8 (October 2013), 891–902. DOI:<https://doi.org/10.1177/1362361313486204>
- [100] Anna Urbanowicz, Christina Nicolaidis, Jacqueline den Houting, Stephen M. Shore, Katie Gaudion, Sonya Girdler, and Ralph James Savarese. 2019. An Expert Discussion on Strengths-Based Approaches in Autism. *Autism in Adulthood* 1, 2 (April 2019), 82–89. DOI:<https://doi.org/10.1089/aut.2019.29002.aju>
- [101] Stephanie Valencia, Amy Pavel, Jared Santa Maria, Seunga (Gloria) Yu, Jeffrey P. Bigham, and Henny Admoni. 2020. Conversational Agency in Augmentative and Alternative Communication. In *Proceedings of the 2020 CHI Conference on Human Factors in Computing Systems*, ACM, Honolulu HI USA, 1–12. DOI:<https://doi.org/10.1145/3313831.3376376>
- [102] Yang Wang. 2017. The Third Wave?: Inclusive Privacy and Security. In *Proceedings of the 2017 New Security Paradigms Workshop*, ACM, Santa Cruz CA USA, 122–130. DOI:<https://doi.org/10.1145/3171533.3171538>
- [103] Elizabeth A. West, Jason C. Travers, Talya D. Kemper, Lisa M. Liberty, Debra L. Cote, Meaghan M. McCollow, and L. Lynn Stansberry Brusnahan. 2016. Racial and Ethnic Diversity of Participants in Research Supporting Evidence-Based Practices for Learners With Autism Spectrum Disorder. *J Spec Educ* 50, 3 (November 2016), 151–163. DOI:<https://doi.org/10.1177/0022466916632495>
- [104] Michael B. Williams, Carole Krezman, and David McNaughton. 2008. “Reach for the Stars”: Five Principles for the Next 25 Years of AAC. *Augmentative and Alternative Communication* 24, 3 (January 2008), 194–206. DOI:<https://doi.org/10.1080/08990220802387851>
- [105] Rua M. Williams and Juan E. Gilbert. 2019. Cyborg Perspectives on Computing Research Reform. In *Extended Abstracts of the 2019 CHI Conference on Human Factors in Computing Systems*, ACM, Glasgow Scotland Uk, 1–11. DOI:<https://doi.org/10.1145/3290607.3310421>
- [106] Rua M. Williams and Juan E. Gilbert. 2020. Perseverations of the academy: A survey of wearable technologies applied to autism intervention. *International Journal of Human-Computer Studies* 143, (November 2020), 102485. DOI:<https://doi.org/10.1016/j.ijhcs.2020.102485>
- [107] M. Remi Yergeau. 2014. Disability Hacktivism in Hacking the Classroom: Eight Perspectives. *Computers and Composition Online* (2014). Retrieved from <http://www2.bgsu.edu/departments/english/cconline/hacking/#yergeau>
- [108] M. Remi Yergeau. 2018. *Authoring autism: on rhetoric and neurological queerness*. Duke University Press, Durham.
- [109] Anon Ymous, Katta Spiel, Os Keyes, Rua M. Williams, Judith Good, Eva Hornecker, and Cynthia L. Bennett. 2020. “I Am Just Terrified of My Future” — Epistemic Violence in Disability Related Technology Research. In *Extended Abstracts of the 2020 CHI Conference on Human Factors in Computing Systems* (CHI EA '20), Association for Computing Machinery, New York, NY, USA, 1–16. DOI:<https://doi.org/10.1145/3334480.3381828>
- [110] Carole Zangari. 2017. Privacy and AAC: A Few Reflections. *PrAACtical AAC*. Retrieved April 13, 2021 from <https://praacticalaac.org/praactical/privacy-and-aac-a-few-reflections/>
- [111] Randy Zhu, Dianna Hardy, and Trina Myers. 2018. Building Applications that Matter: Co-designing with Adolescents with Autism Spectrum Disorder. In *Health Information Science*, Siuly Siuly, Ickjai Lee, Zhisheng Huang, Rui Zhou, Hua Wang and Wei Xiang (eds.). Springer International Publishing, Cham, 167–174. DOI:https://doi.org/10.1007/978-3-030-01078-2_15
- [112] Alyssa Hillary Zisk and Elizabeth Dalton. 2019. Augmentative and Alternative Communication for Speaking Autistic Adults: Overview and Recommendations. *Autism in Adulthood* 1, 2 (June 2019), 93–100. DOI:<https://doi.org/10.1089/aut.2018.0007>