A Stakeholder Value Framework for Augmentative and Alternative Communication

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Abstract

End-users of augmentative and alternative communication (AAC) have diverse speech, cognitive, and motor abilities. AAC's heterogeneous user groups and persistent usability issues create a challenging and rich design space. Our work takes a value-sensitive design (VSD) approach to develop a stakeholder value framework that describes stakeholders' multi-dimensional roles and values. Our framework is based on (1) an empirical investigation—a survey and interviews—of AAC users and AAC conversation partners and (2) a conceptual investigation—a systematic literature review—of AAC HCI research. Emergent value themes were ease, fulfillment, acceptance, adaptation, safety, performance, autonomy, justice, design fulfillment, and business fulfillment. These themes inform how AAC end-users engage with AAC and how indirect stakeholders, such as AAC technologists, make choices that ultimately impact AAC users. Our stakeholder value framework and rich descriptions of AAC socio-technical barriers can inform AAC designers in making ethically sound decisions that support, not hinder, stakeholder values.

CCS Concepts

• **Human-centered computing** → **Accessibility theory, concepts and paradigms**; **Empirical studies in accessibility**.

Keywords

communication assistive technology, value sensitive design, stakeholder analysis

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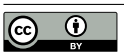

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1 Introduction

Augmentative and alternative communication (AAC) methods and tools are designed to assist communication to increase participation in communities; however, complex usability issues persist in adopting and using AAC. Usability issues include difficulty personalizing the device, high cognitive load for finding appropriate vocabulary, and difficulty incorporating non-verbal communication. Adoption and retention rates are low, especially among people with severe disabilities [6]. AACs need to meet the needs of primary user groups—those with speech disabilities—and secondary users—family, therapists, etc.—involved in researching, acquiring, configuring, teaching, and maintaining AACs. Popular commercially-available speech generating devices—one form of AAC—tend to have a one-size-fits-all default configuration requiring extensive adaptation and learning by primary and secondary users, with secondary users most often customizing AAC apps [56]. In particular, alternative communication devices for single-input modalities (e.g., switch-scanning) used by people with motor disabilities "offer limited versatility and personalization" often requiring "extensive setup and maintenance by a caregiver, frequent recalibrations, and manual interface customizations that burden both caregiver and AAC user" [51, p.2]. Therefore, the design of AAC is complicated by the goals, values, and abilities of the various stakeholders.

Trends in human-computer interaction (HCI) research on AAC have turned from focusing on performance aspects of AAC communication, such as rate of text entry and accuracy, to considering the context in which AAC is used. While acknowledging the importance of performance enhancements (e.g., [16]) and exploring the potential for machine learning language models to make performance strides (e.g., [73, 82]), our work examines the broader AAC design space in response to calls from AAC researchers and designers to consider "the physical environment, social context, and personal characteristics" [79, p.1]. Establishing a holistic view of AAC is a challenging endeavor, requiring designers to account for users with a range of complex communication needs (CCN), ages, intellectual abilities, and access to analog and digital communication tools. The potential user group of CCN communication tools is in the millions—approximately 5 million Americans and 97 million people worldwide [5]. This population of potential and current AAC users is a diverse demographic with varying speech, cognitive,

and motor abilities. Users of AAC include children and adults who are minimally verbal or non-speaking. AACs are speech tools for some people with cerebral palsy, autism, aphasia, Amyotrophic Lateral Sclerosis (ALS), etc., if warranted by their communication capabilities. AACs commonly used today include analog picture exchange communication systems (PECS), signed language, and digital speech-generating devices (SGDs). SGDs, such as Accent 1400 and Proloquo2Go, translate the user's input of images or text into speech using text-to-speech (TTS) technology.

Our work takes up the challenge of considering the context of use of AAC. In the spirit of understanding users as a foundational component of user-centered design (UCD), we inquire into who the stakeholders of AAC are and what they care about. We use the framing of value sensitive design (VSD) [27, 28] to surface the common and unique values of the various stakeholder groups. VSD orients technology design towards values—things of importance to stakeholders that influence their experiences with technology. Through a VSD lens, we ask **what are the values embodied in AAC-facilitated communication?** Specifically, we ask who are the key AAC stakeholders and the values that inform their AAC choices, usage, and satisfaction?

We report on two types of investigations that are part of the VSD framework: empirical and conceptual investigations. Our empirical investigation comprised (1) an online survey of people who rely on AAC to communicate in their daily lives and people who communicate with AAC users and (2) follow-up interviews with AAC users. Our work demonstrates the gathering of primary data from AAC users, of which there are "very few published studies that report the active participation of AAC users" [79, p.1]. We qualitatively coded our empirical data for values, which revealed that AAC users value ease, fulfillment, acceptance, adaptation, and safety. Building upon our empirical investigation, we conducted a VSD conceptual investigation—a literature review of HCI AAC research to extract stakeholders and values. Based on our values codebook, we found alignment in the article corpus with the value themes from our empirical investigation and additional value themes of performance, autonomy, justice, design fulfillment, and business fulfillment. Synthesizing across our investigations, we present a VSD stakeholder analysis comprising stakeholders and values. In summary, this work contributes empirically-based (1) rich descriptions of AAC-facilitated conversation dynamics between stakeholders and (2) a framework of multi-dimensional stakeholders and values. With a deeper understanding of technology stakeholders and the connections between their values[28], our work can inform AAC designers to make more informed design decisions, design to prevent potential harms, and provide more robust socio-technical support to people with CCNs.

2 Background

In this section, we provide a background of the AAC ecosystem—by which we mean a set of communication tools used by people with complex communication needs. The ecosystem has social and technology components comprising diverse stakeholder groups, analog and digital tools, and communication practices [78]. AAC users face many challenges in everyday conversations, including device limitations, imbalance in conversation dynamics, and social stigma [66]. Understanding the background and challenges faced by AAC users is important for understanding the experiences of all stakeholders.

2.1 AAC Usability and Performance

Research on AAC usability and performance tends to focus on short verbal requests and simple responses. Performance is typically measured by throughput, speed, and accuracy. Speech-generating devices can be slow and have limited throughput, which can constrain users' contributions to conversations [39, 57]. Due to non-inclusive social norms, AAC users are often allowed only a short window to respond during in-person conversations [32]. Researchers have explored using affordable smartphones and smart objects to facilitate light-weight communication exchanges. An AAC user may pair their AAC device to their smartphone to communicate in different contexts and take advantage of smartphone capabilities. Lancioni et al. designed smart objects in the form of communication cardboard chips with embedded RFID tags. The user scans the cardboard chip with their smartphone to voice objects and and make requests [41]. These are promising research directions, although usability and performance gains should be weighed against difficulties users can have managing numerous hardware devices and software applications, especially users with multiple impairments, including sensory, intellectual, and motor disabilities.

2.2 AAC Conversation Dynamics

Building on foundational AAC usability and performance improvements, researchers have explored the use of AAC in meeting higher-level communication goals, such as equitable conversational dynamics and maintaining close relationships [20]. Thinking of AACs within the context of conversations (e.g., [75]), perhaps as groupware [23], could facilitate more effective communication by enabling all communicators to work together. Most AACs seek to augment and enhance communication yet have limited support for non-verbal forms of communication like body language and gestures [76]. Non-verbal communication is crucial to facilitate turn-taking and for communication partners to interpret cues when speakers want to contribute to conversations; however, most existing AACs provide limited feedback to indicate the status of the AAC – thinking, typing, or speaking. This gap presents barriers to interpersonal interactions because people find it challenging to convey non-verbal communication, paralinguistic cues, and indications of conversational flow with an SGD [67]. Specifically, to convey emotions, users need to express emotions through words or a limited set of imagery showing facial expressions. As a result, Bircanin et al. call for more scaffolding of user-friendly environments for AAC and personalization of AAC [6]. One research prototype, AACrobat, is a groupware system in which the AAC user and communication partners co-construct communication [23]. Conversational partners can see a real-time view of synchronous messages and the status of the user's actions (calibrating, typing, or speaking) and suggest predictive words. Users can maintain their autonomy by accepting or rejecting their partner's suggestions. Users also have control over who receives their communications by establishing social circles and privacy permissions.

2.3 Societal Factors of AAC

Social stigma and insufficient knowledge can negatively impact the participation of an AAC user in everyday conversations. For example, it is common for people to refrain from directly addressing AAC users in conversations. They usually use conversation partners to converse with individuals [75]. Talking in groups can often be difficult because many non-AAC users do not wait for AAC users to finish typing, making it challenging to make relevant contributions. Furthermore, it can be uncomfortable to rely on caregiver assistance to converse in groups [23]. Conversational partners often guess words incorrectly or correct an individual's speech without permission [36]. Individuals prefer communicating in familiar settings and are usually passive conversation speakers [39]. This can also stem from the conversational partner's limited knowledge of the individual's preferred form of communication. For example, many people with Down syndrome choose to sign rather than use AAC devices[63]. There can also be limited support from speech therapists and caregivers, which can result in decreased use of AACs. Although caregivers have a specific way of supporting users, their actions may sometimes imbalance conversational dynamics and limit the agency of AAC users.

In summary, usability issues, maladaptiveness, and unmet needs of AAC primary and secondary users can often lead to abandonment because they do not reflect individual personalities, limit social acceptance, and do not adapt to the constantly evolving communication needs of all stakeholders [6, 35, 36, 47, 57, 59]. This range of concerns highlights that designing AAC technologies is transdisciplinary, involving linguistics, physiology, and sociology. A unifying theoretical framework can be a tool for creating mutual understanding among researchers, technologists, and stakeholders. Some AAC researchers draw from theories and models from fields including semiology and socio-linguistics [68]. Semiotics provides clarity and precision around AAC terminology, sign use in AAC, and formulating a theory of visual language. Other AAC researchers have contributed theoretical understandings of communication, such as the co-constructed and embodied nature of communication [36]. These models help researchers consider the physical, tangible, and social nature of communication. Our work explores AAC from the framing of values—in essence, the meaning ascribed to AAC by indirect and direct stakeholders. A values framework gives space for the diversity of AAC users in a way that extends beyond their acquisition of signs and interpretation of visual language. Values broaden our lens to consider AAC not only in-the-moment of conversation but also their impact to users' sense of identity, community, and culture. Thus, our work proposes a unifying framework of values as a tool for designers to make more holistic and ethically-aware design decisions.

3 Methodology

VSD is a framework for investigating and designing socio-technical phenomena and interventions. In a foundational article about VSD, Friedman et al. describe VSD as an "approach to the design of technology that accounts for human values in a principled and comprehensive manner" [28, p. 1]. VSD is a tripartite methodology of conceptual, empirical, and technical investigations, which can be undertaken in any order and iterated upon as necessary throughout the design process. Broadly speaking, the purpose of a VSD conceptual investigation is to thoughtfully consider the central questions regarding what values and whose values are at play for a given socio-technical phenomenon. Empirical investigations examine how stakeholders exhibit, experience, and grapple with values as they engage in technology-mediated activities. Technical investigations examine specific technology to explore and assess how it influences, supports, or hinders stakeholders' values. In this paper, we report on our conceptual and empirical investigations; our study design is shown in Figure 1.

Each VSD investigation can be conducted using various research and design methods [27]. In our work, we focused on conducting a stakeholder analysis and creating a framework of values at play in the AAC domain [29]. Researchers and organizations have conducted VSD-oriented stakeholder analyses to identify direct and indirect stakeholders and their values within a given domain (e.g., hospital navigation aids for people with dementia [40], OpenStreetMap [37], and open-source intelligence technologies [61]). Direct stakeholders are individuals or organizations who interact directly with technology. Indirect stakeholders are those who are affected by the use of the system.

VSD calls for researchers and designers to reflect on their positionality in relationship to the phenomenon of focus. We are a team of researchers with different levels of familiarity with AAC from the vantage point of HCI academic researchers, previous employees of the accessible technology field, and undergraduate computer science students conducting AAC research for their senior capstone. We obtained institutional review board approval for this study.

3.1 Empirical Investigation: Survey and Interview Method

Our empirical investigation comprised a survey of AAC users and conversation partners of AAC users, followed by interviews with AAC users.

3.2 Survey

We conducted an online survey of AAC users (n=13) and conversation partners (n=14) to gain insight into the communication patterns and the benefits and challenges of AAC devices. To recruit participants for the online survey, posted to Reddit ('R/SLP'), and Facebook ('AAC & AT Community Chat', 'Out and About: Creating Community Groups for AAC Users'). Additionally, we requested survey distribution via AAC-related organizations such as AAC Institute, AACCESSIBLE, A Voice Discovered, and Communication Matters.

We deployed the survey in November 2023 using Google Forms. The survey description let participants know that its purpose was to learn about AAC-supported conversations and understand the conversation dynamics between AAC users and non-AAC users, along with the fact that this survey is a preliminary phase of our AAC-related research studies and it will help guide our subsequent research stages. We assured respondents of the confidentiality of the survey responses and that the data collected would be used for research purposes only. Following demographic questions, the survey asked 14 questions of AAC users and 18 questions of non-AAC users, some with conditional follow-up questions. Key questions

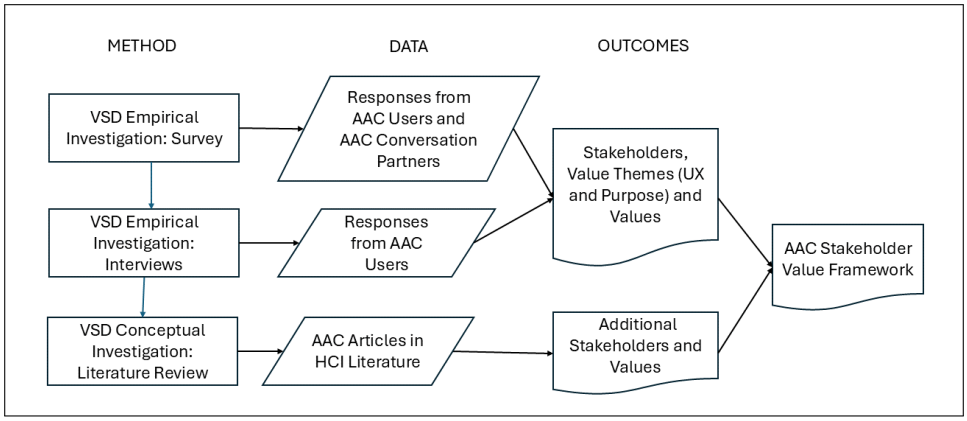

Figure 1: Study Design Flowchart

about AAC use and conversational dynamics were required; however, some secondary and follow-up questions were optional or could be answered with a generic "other" in case some participants felt uncomfortable sharing sensitive information. To improve data validity, we removed four incomplete survey responses in which respondents only answered multiple-choice questions or entered random text for open-ended questions. We received valid responses from participants in Canada, the USA, and the UK, who each received a $10 gift card.

3.3 Participant Demographics

Our "AAC user" participants (n=13, 5 female, 8 male) used AAC in their daily routines. As listed in Table 1, they use AAC for a range of communication needs, which they described as being related to autism, language disorders, movement disorders, aphasia, etc.

Conversation partners of AAC users (n=14, 13 female, 1 non-binary) were parents, teachers, and speech therapists who interact with AAC users, as detailed in 2. Note that there were no known relationships between our "AAC users" and "conversation partners" participants. Our conversation partners engaged with AAC users with various abilities, including a deaf and visually impaired child who relies on AAC for receptive and expressive language and an autistic child with good engagement, joint attention, and imitation skills who is beginning to use verbal speech. Other reported conditions of AAC users included apraxia of speech, selective mutism, hearing loss, and congenital or acquired conditions. The conversation partners noted that AAC users may encounter challenges like clarity and articulation issues, motor impairments, and cognitive difficulties. The AAC-faciliated conversations primarily involved Proloquo, Tobii, and PECS; however, other AACs mentioned were Word Wizard, TouchChat HD, Language Acquisition through Motor Planning (LAMP), and GoTalkNow. In one case, a communication partner made a custom AAC using Microsoft PowerPoint and free voice software that replicated a symbol-based layout from the user's paper AAC setup.

3.4 Interviews

We interviewed AAC users (n=7, 3 female, 4 male) whom we recruited from the survey respondents in February and March 2024. Interview topics were about their experiences choosing AAC, current AAC use, changes in perceptions of AAC use, and tailoring communication. We did not explicitly ask what they valued related to AAC use; rather, questions explored factors making it easier and more challenging to use AAC, social implications, and unique communication needs. We conducted the interviews in an asynchronous, text-based manner. Asynchronous research methods have been used in studying vulnerable groups [46] to engage participants remotely with the convenience of time and location. Conducting asynchronous, text-based interviews allowed AAC users the flexibility and comfort to respond at their own pace, ensuring their perspectives were effectively captured in the qualitative data essential to our formative study. We offered participants both a Discord community (n=1) and Google Forms (n=6) to accommodate their communication preferences. If we wanted to ask a follow-up question or get clarification on a response, we followed up by email. For the participant on Discord, we asked follow-up questions in real-time. These Discord and email exchanges provided the researcher insight into the participant's personality and asynchronous conversation style. Each interviewee received a $50 Amazon card gratuity.

3.5 Empirical Investigation: Data Analysis

We conducted a theoretical thematic analysis of the survey and interview responses to find patterns in the data related to values [13]. We drew from Burmeister et al.'s VSD qualitative analysis [15] to inform our analytic process for determining values, as shown in (Figure 2). This grounded and inductive approach involved (1) searching for value categories, (2) clustering them into themes, (3) refactoring the value themes as necessary, and (4) identifying the key values within each theme.

To describe this in more detail, two researchers searched for value categories by open-coding the first interview and discussed their initial insights and emergent values revealed by the data (Step 1). They clustered the emergent values into an initial codebook (Step 2). The researchers used the codebook as a guide to code the second interview independently. They then discussed and revised the codebook to consolidate and add codes (Step 3). To assess the effectiveness of the codebook on the survey responses, the researchers coded survey responses from one AAC conversation

Table 1: Demographics of AAC Users

ID	Gender	Age	Condition	AAC	Research Studies
AAC01	M	18-25	Autism	PECS, Tobii Dynavox	Survey, interview
AAC02	F	26-35	Non-speaking	PECS	Survey, interview
AAC03	F	18-25	Autism, language disorder, and semi-verbal	Coughdrop	Survey, interview
AAC04	F	26-35	Congenital language disorder	Tobii Dynavox, GoTalk Express 32	Survey, interview
AAC05	M	36-45	Autism and non-verbal	Tobii Dynavox	Survey, interview
AAC06	M	26-35	Movement disorder	GoTalk Express 32, Proloquo2Go	Survey, interview
AAC07	M	15-17	Motor disabilities	PRC Accent 1400	Survey, interview
AAC08	M	26-35	Non-speaking	Tobii Dynavox	Survey
AAC09	M	26-35	Non-speaking	GoTalk Express 32	Survey
AAC10	M	26-35	Aphasia	Proloquo2Go, GoTalk Express 32	Survey
AAC11	F	18-25	Developmental delays	Proloquo2Go, GoTalk Express 32	Survey
AAC12	M	26-35	Stroke-related problems	Proloquo2Go, GoTalk Express 32	Survey
AAC13	F	18-25	Autism and non-speaking	Coughdrop, Proloquo2Go, Tobii Dynavox	Survey

Table 2: Demographics of AAC Conversation Partners

ID	Gender	Age	Relationship to AAC Users	Types of AAC
CP01	F	26 - 35	Mother of autistic minimally verbal child	Proloquo2Go
CP02	F	36 - 45	Mother of two children with apraxia	Proloquo2Go, Word Wizard plus access to TouchChat HD
CP03	F	26 - 35	Speech therapist of clients with autism, selective mutism, hearing loss	Proloquo2Go, LAMP
CP04	F	46 - 55	Interact with autistic and non-verbal early emergent communicators	GoTalk Now (GTN) on an iPad
CP05	F	26 - 35	Speech therapist of clients with autism (or suspected autism; apraxia) or genetic/congenital disorders associated with dysarthria	Tobii Dynavox, novachat
CP06	F	36 - 45	Mother of child with hypotonia and cerebral palsy	AVAZ
CP07	F	36 - 45	Mother of autistic minimally verbal child	Tobii Dynavox
CP08	F	18 - 25	Speech therapist of autistic (non-speaking), deaf and/or blind clients with other disabilities	PECS, Proloquo2Go, Speak for yourself, TouchChat
CP09	F	26 - 35	Speech therapist of clients with autism, intellectual disabilities, and/or severe speech disorders	PECS, Tobii Dynavox, Sign language, Touchchat, switches
CP10	F	36 - 45	Mother of non-verbal autistic child with learning/intellectual disability, severe speech language and CCNs	PECS, custom-made AAC using PowerPoint and free voice software (symbol-based using the same symbols and layout as their PECS).
CP11	F	56 - 64	Speech therapist of clients with congenital and acquired conditions	PECS, Proloquo2Go, Tobii Dynavox, GoTalk Express 32, Supercore, Alphacore, PODD, Vocochat, SymbolTalker
CP12	Non-binary	26 - 35	Parent of profoundly deaf and visually impaired child with low muscle tone in hands	Proloquo2Go, Core Board printout from Proloquo2Go
CP13	F	46 - 55	Special education teacher of children with apraxia and neurodiversity	PECS, Proloquo2Go, Tobii Dynavox, Grid 3
CP14	F	46 - 55	Mother of non-verbal child	Grid for iPad

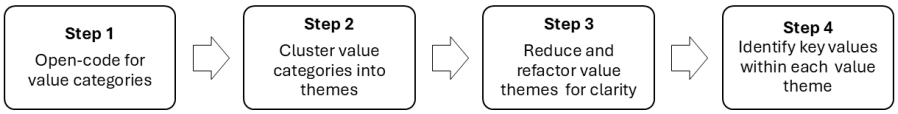

Figure 2: Four-step analytic process for determining values adapted from [15].

partner. The researchers found the codebook needed only a slight edit and finalized the codebook. To finalize coding, each researcher independently coded all remaining data and discussed for consensus. The researchers identified key values based on the code frequency and impact on AAC users in daily communications (Step 4). Table 3 reports our codebook, organized into the final value themes.

3.6 Conceptual Investigation: Systematic Literature Review Method

Equipped with rich descriptions of values from our empirical investigation, we set out to determine if our emergent stakeholder and value framework resonated across recent AAC research in the HCI field. Thus, we conducted a systematic literature review of AAC articles published by the American Computing Machinery (ACM) database between 1990-2024. Note that this systematic literature review had a distinct focus that set it apart from the literature review we conducted as part of planning our study, articulating research questions, and establishing the background for our work as described in the Background section. For our systematic literature review, we searched for articles with titles containing (1) "augmentative and alternative communication" or, (2) with the terms switched, "alternative and augmentative communication," or (3) abbreviated to "AAC" or (4) "complex communication." Our initial search resulted in 103 articles. We excluded 12 articles about technical audio communication and government communication needs. Of the remaining 91 articles, we excluded articles that were not full papers, eliminating introductions to special journal editions, workshop descriptions, and short papers of less than four pages. We eliminated one literature review [18]. Three papers were published in Portuguese with English Abstracts [1, 25, 53]. Towards building representation from non-Western communities—a stated goal of the HCI community—we translated the articles using Microsoft Word Translation. Our final corpus comprised 45 articles (See the Appendix for Table 9.)

We followed a structured process to extract a list of stakeholders and values evident in each article. We used an online literature review tool, Covidence [1], to facilitate having one researcher extract the stakeholders and values and a second researcher review and confirm the extraction. To extract stakeholders, we read the article Abstract, Introduction, and Methods to identify stakeholder groups that the authors emphasized and we noted the stakeholder groups represented in the research method. To extract values, we also read the Discussion. The authors did not explicitly call out values, so our criteria for identifying values was a clear statement about a stakeholder group's goals, beliefs, and high-level needs. We used our codebook for values derived during our empirical investigation (Table 3). It was valuable to conduct our empirical research first because it resulted in rich descriptions of values and a stable code book, which we could then apply to our systemic lit review. The articles do not explicitly name or discuss values, so it would not have been apparent how to code for values without our codebook from the conceptual research. We identified new values described in articles that had not emerged in our conceptual investigation. Any disagreements were captured by the tool and discussed for consensus.

[1]https://www.covidence.org/

4 Results of Empirical Investigation: Survey and Interviews

In our empirical investigation, AAC users and conversation partners valued ease, fulfillment, acceptance, adaptation, and safety. In describing these value themes below, to help differentiate between AAC users and conversation partners, we use AAC## for AAC users and CP## for conversation partners. We preserved the participants' grammar and punctuation in direct quotes to convey their written communication styles.

4.1 Value Theme: Ease

Participants value several factors when adopting and using AACs, like availability (ease of access), convenience (low maintenance), mobility (portability), price (being affordable), quality (more vocabulary and pictures), and familiarity (using a device with a known user interface and user experience). AACs can significantly enhance communication capabilities, empowering individuals to engage in personal and professional conversations confidently. For example, AAC04 talked about AACs easing participation in work and school environments, saying*"in the work environment, AAC equipment helps me to participate in team discussions, share ideas and make suggestions, thus making the most of my professional abilities. In a school setting, AAC devices can support my learning process, helping me participate in class discussions, complete assignments and exams, and improve my academic performance."* By easing and improving communication, AACs can boost confidence; *"It not only improved my communication and expression skills but also enhanced my self-confidence and independence, laying a good foundation for my future study and career development."* (AAC06)

Although AACs can be an effective and convenient tool for communication, participants expressed some drawbacks that caused hindrances in their communication, such as managing devices, the effort required to communicate using technology, and the lack of personalization of AAC. Portable AACs can sometimes be paradoxical because they become less mobile in certain situations. For example, CP12 talked about using AACs outdoors, *"It can be hard to lug 2 devices around while chasing a toddler on the playground."*

Table 3: Codebook of Values of AAC Primary Users and Conversation Partners of AAC Users. Code themes are listed from highest-to-lowest frequency of the codes that comprise the theme (code frequencies in parenthesis).

Value Theme	Key Values	Definition
Ease	Ease of communication (75)	Communicating with low effort and without obstacles
Ease	Ease of adoption (24)	Reasons people choose particular AAC
Fulfillment	Full engagement with others (66)	Being fully understood; free flow exchange of ideas and feelings
Fulfillment	Learning (25)	Desire to learn and improve skills
Acceptance	Social acceptance (49)	Respectful communication style
Acceptance	Self-acceptance (12)	Sense of self and identity, accepting AAC use
Adaptation	Flexible communication (56)	Choice of form factors and modes of communication
Safety	Safety of self and others (20)	Reliable and efficient communication in emergency situations.
Safety	Privacy (2)	Secure communications and data privacy

Besides mobility, distraction can be another challenge when using AAC applications on the iPad. Ownership of the device can create hurdles in the use of AACs. Children often get attached to their devices and often self-imposed barriers by preventing caregivers from modeling and teaching them about the device. CP09 said that *"children are overly possessive of the device, to the point that they don't want others to touch it, even for teaching purposes."* Some children might face difficulty focusing while using their devices because *"there's a learning curve, especially for children. They need to understand that the iPad is for communication purposes, not for playing."* (CP09)

The effort involved in finding words and the delay in communication often cause frustration, *"Her frustration with the slow speed and inability to use the exact words she wants"* (CP06). The effort of browsing through the AAC-provided vocabulary often multiplies as the conversations get deeper and more complex. *"Complex conversations may involve more word choices, language structure, and logical thinking, which requires more thought and effort on my part to communicate"* (AAC06). The mechanized voice of AACs can also make conversations feel less natural. AAC users feel a lack of identity expression: *"Although existing AAC devices provide speech synthesis capabilities, sometimes the speech output still appears mechanized and unnatural, and there is a certain gap compared to the expression of human language."* (AAC06) Existing AACs have limited ways for users to convey expressions and feelings, which are critical to conversations, as described by AAC04, *"While existing devices can help me express some basic emotions, I wish they could more accurately understand and express complex emotions, such as humor, sarcasm, or teasing. This way, I can express my feelings and emotions more freely"*. This participant further echoed the need for personalization in AACs, *"personalization allows AAC devices to better meet my unique communication needs, allowing me to communicate more freely and fluently with others."*

4.2 Value Theme: Adaptation

Context often determined how AAC users adapted their mode of communication. For example, AAC06 preferred using AAC in formal, professional settings, like work environments, because of its ability to use different language-specific constructs. AAC06 said, *"AAC devices offer a wider range of customization options and specific features designed for communication, allowing me to express complex concepts and ideas more clearly and effectively. In addition, the professionalism and reliability of the AAC device makes it a better choice when I need to communicate for a long time or include specific language structures in my communication."* On the other hand, AAC06 uses smartphones for informal settings, like conversing with friends and family, saying *"smartphones enable me to quickly send text messages and use social media, which are easy ways to stay in touch with those close to me."* Likewise, AAC07 prefers using AAC for in-person and online conversation while using mobile phones connected to the AAC for sending text messages, *"I don't use my phone to communicate. I like talking to people in person and Zoom. I use my talker, which is an Accent 1400. I connect my phone to my AAC via Bluetooth sometimes to send texts."*

Adaptive form factors can enable constant communication, as noted by AAC07 who said, *"I think that each person needs different devices - waterproof, wearable, mobile, desktop - so that they could always communicate."* Some users complemented their devices with computers because it helped them find information otherwise not available on their devices, *"if the word I want to use is not in my talker, I can type with my Accent qwerty keyboard. Yes, I use a computer connected to my talker"* (AAC07). Portability was another reason why users completed their AACs with other devices, like smartphones, *"when I am out and about, the smartphone has become my preferred communication tool due to its portability. It allows me to communicate anytime, anywhere, regardless of the environment"* (AAC06). These insights reveal the often hidden work of AAC users to learn, manage, and access various technology devices and software. Adaptation is related to the value of ease of adoption, but the work involved is not just about obtaining and learning a new tool; it includes adapting in the moment to the social context and AAC capabilities.

4.3 Value Theme: Fulfillment

Participants expressed experiencing a sense of fulfillment through full engagements with others and through pursuing learning of topics of interest and about their AAC. Fully engaging with others was demonstrated by being able to exchange their ideas and feelings and *"a true sense of communication"* (AAC04). In terms of conversational dynamics, some AAC users expressed that they tended to lead conversations and other AAC users tended to follow

in conversations. Of importance was being given time and opportunities to express their ideas and feelings. Their descriptions of being fully engaged with others sometimes highlighted physical, embodied communication.

Conversation partners described ways that they gain an understanding of the AAC users' engagement with the interaction. They observe physical cues such as eye contact and behaviors that align with the conversations (e.g., responses to instructions). Sign language was noted as important for communication and a source of learning for several participants (AAC01, AAC02, CP09) and can take the form of standardized sign language and/or homemade, personalized gestures [2].

AAC users valued learning for personal growth in terms of pursuing opportunities to obtain knowledge and skills. Learning opportunities were avenues for participants to pursue topics they were *"passionate about"* (AAC04) and to share their interests with others by, for example, *"using my AAC device, I began to recount my learning experience, including the projects I completed and the new skills I learned"* (AAC04). Sharing about learning leads to exchanging ideas, making AAC04 *"feel like I'm an integral part of the conversation and that my thoughts and experiences are worth sharing and celebrating."* This sentiment was echoed by AAC06, who shared, *"once, I took part in a panel discussion with several friends about a social issue. During this discussion, I used AAC equipment to communicate with others and felt particularly satisfied and positive."* Feeling valued and respected by friends and more public groups was elemental in AAC users feeling encouraged to express their ideas and *"more willing to participate in the discussion"* (AAC06) and future social activities.

AAC tools themselves were a source of learning valued by AAC users. They valued gaining a level of *"familiarity"* with AAC capabilities to increase their *"confidence and engagement in conversations"* (AAC06). Through AAC use, users gained communication skills, including learning how to pronounce words (AAC01, AAC03) and the phonetic spelling of words to help them *"voice pronounce things"* (AAC03). AAC06 used his AAC to *"take notes, make reports and presentations, and enhance my learning and expression skills."* He summarized his AAC-faciliated learning saying, *"using AAC equipment allows me to be more exposed to and learn new vocabulary, phrases, and sentence patterns. By communicating with others and practicing with AAC equipment, my language skills have been continuously improved and enriched. I began to express my thoughts and feelings more fluently, using more accurate and appropriate words."*

AAC users noted that conversations were more challenging when they were not comfortable using the device interface, features, and vocabulary. As described by AAC04, *"learning how to operate new technology or equipment is often one of the biggest challenges. For AAC devices, this includes understanding what the device does, how it navigates, and how to choose and use the right communication symbols or words."* AAC03 described difficulty learning the AAC interface as *"the hardest was most definitely figuring out where everything was located. I custom made my AAC board and I still have the hardest time remembering where anything is. I think the thing I learnt the fastest was the customizing part. The longest part is both the customizing and the learning where everything is."*

Emergent communicators learn to use the AAC using speech strategies and AAC learning strategies including *"modeling by adults and attributing meaning to buttons they press"* (CP04). CP12 described how she uses the same AAC, Proloquo2Go, on a separate device as her 3-year-old son to *"to speak to him "in his own language" and for aided language stimulation consistently throughout the day."* Both mother and son used joint movements to coordinate AAC work. CP12 said, *"if I'm modeling a new word/phrase that he wants to practice the motor plan for, he will take my finger and put it near where he thinks the motor plan starts (the initial button from the home page)."* A key frustration with modeling AAC was the *"time it takes to find specific vocabulary when modeling"* (CP05).

Whether using the AAC as a source of learning and storing information or learning through modeled AAC conversations, AAC users demonstrated a sense of confidence and autonomy as they gained AAC skills and modified their AAC use to their needs.

4.4 Value Theme: Acceptance

Our participants who used AAC expressed that they valued self and social acceptance, which they felt internally and observed in others' behaviors. Self and social acceptance were connected to being able to *"communicate effectively with others, express my thoughts and feelings, participate in social activities, and advocate for my needs"*, as expressed by AAC05.

For AAC users, being a user of AAC was a component of their identity, regardless of when they began using AAC. AAC users who started using AACs as teens or adults described going through a period of adjusting to using communication technology. They described that their sense of self was strengthened by their acceptance of needing to use AAC. For example, AAC06 began relying more on their AAC during the COVID-19 pandemic, during which they attended school in-person with reduced class sizes due to the pandemic safety protocols. AAC03 said that during this period, she was *"able to come to terms with needing to use AAC, [which was] much easier because while I was in person for school, there were a lot fewer people and thus [I] felt safer. Though, of course, even then I was still greatly upset and extremely depressed about it but by now it's just an everyday part of life and thus sort of neutral."* For AAC03, communicating more often with an AAC *"helped me accept the fact that my abilities (and especially my ability to speak) were getting worse."*

Self and social acceptance were strengthened through positive interactions with their peers, communication-related activities that built confidence, and connecting with other AAC users. Positive interactions with others gave them a sense of pride and confidence. AAC06 shared that they experience a sense of pride in setting a good example as an AAC-communicator, saying, *"by demonstrating my positive attitude and confidence, I will set a good example and show others that I can fully participate in various social, academic or professional activities and communicate effectively with them. This will make others more respectful and understanding of my communication preferences and needs."* AAC users shared that they experienced growth in *"independence"* and *"self-confidence"* (AAC04, AAC05). For example, AAC07 said that giving a class presentation *"is hard, but it helps."* They appreciated being able to connect with online or in-person AAC users because it provided access to *"a community of people who understood and can help me because they've experienced that as well"* (AAC03). AAC07 expressed the importance

of the AAC community, saying *"I love to talk with other kids who use SGD because i don't have to worry that they will be impatient or think that i am not smart because i talk so slowly."*

The quality of relationships contributed to social acceptance for AAC users and conversation partners. To AAC users, meaningful relationships were demonstrated by *"their deep understanding and patience with my communication style, which made me feel very satisfied and accepted...My family gave me plenty of time, patiently waiting for me to type my words and speak through my device"* (AAC04). Deep conversations were those in which *"they not only encouraged me to continue sharing, but also actively asked questions and expressed interest in my learning and achievements"* (AAC04). Conversation partners valued these meaningful exchanges. They placed importance on developing meaningful relationships with people who use AAC. As stated by CP12, *"being a communication partner is a privilege as you get to know the person really well."*

AAC users face limitations placed on them by other people and social norms of the pace, style, and content of conversations. AAC users noted a lack of patience in others. AAC07 said, *" I have to sit to use my SGD. Also it is very slow to type out all my words but I prefer using the keyboard to the icons. It is impossible to have a quick interaction and most people are not patient enough to talk with me."* A mother of an AAC user, CP10, expressed the value of communication and overcoming perceived limitations, sharing that *"our communication is more than just 'what do you want?' - he helps to plan journeys and events, discuss art/craft (at a basic level), negate, and express preferences as well as to request. It's not bad as his intellectual disability was meant to stop him from using AAC at all. (We live in UK and really were told that, for the record.)"*

In addition to barriers placed by speech professionals, AAC users noted occasions when they felt excluded by others in conversations and social activities. Some AAC users noted that being identified as an AAC user was stigmatizing. AAC03 relayed that *"two girls behind me start talking about me, calling me an "iPad kid"* in reference to their AAC device. AAC01 shared that *"the challenges I had was trying to convince people to accept it that it is part of me. Many people thought it was a joke for me."* AAC07 expressed that, *"most people have no experience with aac users. in my presentation, i tell them that my disabilities are motor based, that my receptive language is fine, that I want to be friends, and that I need them to be patient when I talk because it is so slow. most people seem to understand but only a few actually are good partners - but that is better than none."* In sharing about their experience and communication needs with non-AAC users, AAC07 highlights the importance of awareness of communication differences and sharing of communication best practices to non-AAC users.

Overall, we observed that AAC users felt a sense of social acceptance connected to their AAC use because the AAC enhanced their ability to *"express opinions clearly and accurately and communicate effectively"*, and in conjunction be fully *"heard and respected"* (AAC06). This increased their *"confidence"* and *"willingness to actively participate"* in future exchanges and social activities (AAC04, AAC06).

4.5 Value Theme: Safety

Participants' safety concerns encompassed information security and physical safety. Regarding the former, some participants expressed concerns about the security of their AAC devices and software. For example, AAC01 expected to be able to keep their AAC secure via facial lock *"because I always want my AAC device private."* Influenced by their use of smartphones, they considered both AAC and smartphones essential everyday technology and desired similar security user experiences.

Physical safety was centered around concerns about AAC reliability, accuracy, and communication with family and friends during emergency situations (AAC01, AAC02, AAC04, AAC05, AAC06). AAC users expressed concerns about the stress and physical health issues they face during an emergency and the impacts on communication, especially given the AAC usability issues already present in non-emergency situations. For example, AAC06 talked about how it can be demanding to use an AAC during an emergency, saying *"although AAC equipment provides valuable help in some emergency situations, it can also face some difficulties. For example, if I am in a high-pressure situation in an emergency situation, it may affect my thinking and operating ability, making it difficult for me to communicate quickly and accurately using AAC equipment."* Besides the delay, network and technical issues can also make communicating difficult. AAC06 anticipated technical issues they may face, saying, *"I may experience network connection problems or device failures, which may affect my communication effectiveness. So, while AAC devices provide an important communication tool, in an emergency, I may also need to rely on the support and assistance of others to ensure a timely and efficient resolution of the problem."* AAC06 raised the importance of interdependent, mutual aid among people during an emergency situation.

Although our data for safety was based on AAC users' responses, we extend this value to communication partners as well since they will also be concerned about the AAC users' safety and may be involved in emergency situations. Everyone involved, including emergency workers, would value clearly conveyed information, instructions, and confirmation of the state of affairs.

5 Results of Conceptual Investigation: Systematic Literature Review

We found 45 AAC-related articles published by the ACM between 1990-2024. In this section, we summarize the corpus in terms of stakeholders and value themes. For a detailed list of the articles' stakeholders of interest, research participants, and evident value themes, see Table 9 in the Appendix.

5.1 Stakeholders

The majority of articles stated that their research focused on AAC end-users—individuals with CCN who are non-verbal or have limited verbal skills [18]. The prominent end-user groups were individuals with motor and communication impairments (36 articles) and individuals with intellectual and developmental disabilities (IDD) (8 articles), which includes autism. AAC users can be independent communicators, context-dependent communicators, or emergent communicators. Depending on their level of communication ability, they might use different types of AACs. For example, independent

communicators often have similar literacy and communication skills as their peers and use text-based AACs that can help them generate complete, spontaneous messages. Context-dependent communicators primarily use symbolic communication, relying heavily on their communication partners to facilitate AAC use [43]. Similarly, emergent communicators primarily use body language and gestures, rely on communication partners to interpret communication context, and often use static or single-button communication boards with common symbols and limited vocabulary.

The second largest group of stakeholders studied were conversation partners, such as family, aids, educators, therapists, and medical providers. Their AAC use cases include modeling AAC use and configuring AAC. The third largest group of stakeholders in AAC research was proxies for people with CCN. Researchers sometimes state that their AAC is designed for a direct stakeholder, yet their research is conducted with a proxy group. This occurred in 12 of the 34 articles. Reasons given include designing for inclusive communication particles in which conversation partners are familiar with and use AAC [53], as well as gathering early design input from AAC educators, technologists, and designers (e.g., [31], [25]).

Influential, but often obscured groups of indirect stakeholders, are HCI designers (8 articles), AAC manufacturers and suppliers (1 article), funders (9 articles), and public policymakers (1 article). In an analysis of U.K. and U.S. public policy issues regarding AAC, Waller describes the public policy landscape that governs the assessment, procurement, and support of AAC. AAC designers should be aware of stakeholders' roles and the policies that affect the design, adoption, and deployment of AAC [78]. For example, the definition of speech-generating device (SGD) AAC, as defined by Medicaid dictates that the SGD is "a dedicated speech device used solely by the individual who has a severe speech impairment" [10] as cited by [78, p. 7]. Thus, the design choices of form factor and dedicated versus multi-use devices, such as an iPad, impact the funding sources for some SGD users.

5.2 Value Themes

We found that many of the articles explored value themes we had identified in our empirical investigation. As shown in Table 4, the values of Fulfillment and Ease were most prominent. Values were exhibited in a variety of ways in the articles. Some values were evident in how the researchers expressed the research goals; other values were embedded in the researchers' discussion about design implications. Our assessment of value themes was based on our reading of the article; thus, we recognize the limitation that the researchers' intentions may extend to a different set of values if asked explicitly about their work.

Our article corpus surfaced **six new values themes: performance, autonomy, justice, design fulfillment, and business fulfillment.** We also identified **four new values that we placed within existing value themes: personalization and embodied communication (both within adaptation), usability (within ease), and cultural communication (within acceptance).** These additions emphasized different aspects of AAC user experiences, and, more broadly, the role and purpose of AAC in stakeholders' lives. (See the Appendix for the mapping of values to each article.)

Performance was a consistent thread in AAC research, which focuses on improving the ability to predict and save words and make the process of communicating words faster. Studying ways to optimize AAC performance is along the same vein as HCI research on text entry performance through different input methods, such as alternative keyboards.

Participants described AAC's role in their sense of self and social connections. These experiences extend beyond the immediate interactions with the AAC and point to the purpose of AAC in their identity, relationships, and communities. **Autonomy** was based on increasing the agency of all stakeholders by respecting their communication style, facilitating the co-creation of conversations, indicating communication status, and increasing privacy by restricting the sharing of communication data.

The previously described value themes were aspects of the lived experiences of the direct stakeholders; however, justice, design fulfillment, and business fulfillment encompassed what the AAC designers, researchers, and product owners expressed as important to them as well. **Justice** focused on understanding funding and adoption policies of AAC provision and managing ethical challenges of research (consent, confidentiality, and respect) while ensuring fair participation. **Design Fulfillment** entails a sense of purpose, prestige, and professional development. **Business Fulfillment** involves meeting market demands and achieving profitability and strategic goals. For policymakers, this includes meeting organizational or governmental goals, such as supporting citizens' rights to communication and access to resources.

Regarding the values that we placed within existing value themes, the adaptation value theme was enriched with the addition of **personalization** and **embodied communication**. Personalization entailed simplifying the use of AACs through multiple modalities (e.g., gestures and pictures) or supporting context-based vocabularies. **Embodied Communication** involved using alternative modes of communication depending on the context, communication partner, task, and intention to communicate persuasively through expression.

Another new value, usability, was grouped within the theme of ease. **Usability** entails user satisfaction and ease of use with AAC. Usability included using heuristics to identify areas of improvement for AAC interactions and interfaces. The final new value, **cultural connection**, was placed within the acceptance theme to emphasize that people's geography and culture influence their language and communication social norms. AAC users and their communication partners desire culturally-situated interactions [54, 62]. However, AACs have generally been designed by Western countries [81], and thus, are designed from the linguistic frame of English. Although the vocabulary can be translated to specific languages, this does not account for different linguistic dynamics and grammar construction [6].

6 AAC Stakeholder Value Framework

This section consolidates the results from our conceptual and empirical investigations to present a holistic AAC stakeholder value framework. We provide this as an easy-to-access reference for future AAC researchers and designers, as well as researchers conducting value-sensitive design in other domains.

Table 4: Literature Review Articles with Values Aligned with Empirical Investigation

Value Theme	Number of Articles	Articles Citation
Ease	7	[1, 19, 31, 39, 57, 74, 78]
Fulfillment	11	[6, 9, 12, 16, 24, 36, 39, 42, 44, 57, 67]
Acceptance	4	[19, 39, 53, 58]
Adaptation	4	[6, 24, 38, 63]
Safety	2	[23, 60]

6.1 Stakeholder Groups

As listed in Table 5, AAC stakeholder groups include people with CNN, conversation partners, assistive technology (AT) industry members, academics, funders, and policy makers. Our list of stakeholders is aligned with a summary of AAC research participants provided by Curtis et al.'s recent AAC literature review [18]. However, our work expands that knowledge by (1) framing them as direct or indirect stakeholders of AAC, (2) expanding the list to include AT vendors, funders of AT purchases [30], and AT research funders, and (3) articulating stakeholder dimensions that impact AAC use.

The list of stakeholders is extensible and could include additional dimensions to highlight functional needs (such as cognitive supports) and information about the social context. For example, someone with selective mutism may select which AAC to use, or whether to use an AAC at all, depending on whether they are with family or strangers. We identify additional dimensions of AAC users in Table 6. These are attributes of stakeholders that could help designers to better articulate and meet user needs.

Our work highlights the dual roles communication partners can take as both direct users of AAC and indirect stakeholders who engage in conversations with AAC users. The last row of Table 6 captures the role of conversation partners as AAC users when they are interacting with the AAC to configure or model its use to AAC users with CCNs. Some people are strictly only communication partners and do not directly use the AAC. See Table 7 further categorizes communication partners by dimensions of family relationship, type of educators, type of therapist, and type of researcher. The knowledge of people who shift between direct and indirect AAC users is different from that of people who strictly remain indirect users. Most prior work considers communication partners as indirect users. Exceptions are research on the configuration of AAC for communication partners (e.g., [6, 65]) and expanding the design of AAC by considering AAC as groupware [23]. Considering these various and shifting roles can illuminate different use cases and communication abilities and needs when designing for AAC.

6.2 Stakeholder Values

The consolidated list of value themes includes ease, fulfillment, acceptance, adaptation, safety, performance, autonomy, justice, design fulfillment, and business fulfillment. Table 8 represents this holistic view of values at play in the design and research of AAC. Value themes in bold were found in our literature review, not in our empirical investigation.

Although we list the values in a table, we do not imply any hierarchy of values. The organization, priority, and relationship between the values are highly personal and contextual. Also, the values in reality are not self-contained but rather entwined. Usability and performance are examples of entwined values since the efficiency of communicating via AAC influences the user's satisfaction. These values are also related to social acceptance because the AAC user communicates under the pressure of social norms for conversational pace and styles. Another example is embodied communication and ease, which are closely related since people with CCN's movements, gestures, and faces are also communicative moves and can be a means of sense-making and sensory processing.

7 Discussion

Our AAC stakeholder value framework is rooted in the unifying value of the right to communication [78]. The right to communicate stems from the United Nations Article 19, which states, "Everyone has the right to freedom of opinion and expression; this right includes freedom to hold opinions without interference and to seek, receive and impart information and ideas through any media and regardless of frontiers" [55]. This right is echoed by disability advocacy organizations, such as Washington D.C.-based TASH. Their 2016 resolution on the right to communicate advocates that, "the right to communicate is both a basic human right and the means by which all other rights are realized. All people communicate and are presumed to have an active interest in communicating their decisions and choices" [69]. Grounding explorations of AAC in person-centered values such as those reflected in the 2016 TASH resolution can generate meaningful and evidence-based advancements [50].

Our work sharpens our understanding of the AAC socio-technical ecosystem, comprising not only AAC hardware and software but, importantly, the direct end-users, indirect stakeholders, and their entwined values. By identifying stakeholders and analyzing their experiences, roles, and expectations of AAC use, we further legitimize the stakeholder groups, especially vulnerable populations [72]. Our framework suggests connections and potential value tensions that warrant further investigation, such as between (1) autonomy and acceptance, (2) ease of communication and flexibility, and (3) performance and both embodied communication and adaptation. To expand on the latter, the performance of AAC communication output may not be optimized as a person dynamically expresses themselves and adapts to AAC capabilities. The AAC-facilitated communication may not produce communication output at a pace that matches societal norms. Considering these factors, designers can consider how the concept of performance can be matched to the person's cognitive style and the receptive capabilities of the conversation partner, who may also be using an AAC. We believe

Table 5: AAC Stakeholder Groups

Stakeholder Group	Description	Direct stakeholder use case	Indirect stakeholder use case
People with CCN	Primary users of AAC	Using AAC to communicate	Observing others using AAC (e.g., peers using AAC; parents modeling AAC use)
Conversation partners	Family, aides, educators, therapists, medical providers	Modeling AAC use; configuring AAC	Interacting with AAC user
AT industry members	AT evaluators, AAC vendors	Configuring and modeling	Designing, building, deploying AAC
Academics	AAC researchers and educators	Interacting with AAC users	Configuring, learning, or modelling AAC
Funders and Policy Makers	Organizations and government agencies funding and governing the provisioning of AAC or AAC research		Reviewing AAC research progress

Table 6: AAC Stakeholders - Additional Dimensions of Stakeholder Group: People with CNNs

Dimension	Examples of Categories
Age	Young child, youth, teen, young adult, elderly
Developmental condition	autism, Downs syndrome, cerebral palsy
Cognitive abilities	intellectual disability
Acquired or progressive condition	aphasia, Parkinson's
Communication levels	emergent communicators, non-speaking, minimally speaking, selective mutism, independent communicators
Literacy level	pre-literature
Interaction techniques [18]	eye gaze, switches, mechanical pointing devices, keyboards, gestures, contextual input from smart environments, etc.
Cultural language	English (the dominant linguistic frame for AAC, non-English)
Context of use [18]	Setting, informal vs formal communication, etc
Role	Rely on AAC for communication due to CCN, Conversation partners who configure, maintain, and model AAC

Table 7: AAC Stakeholders - Additional Dimensions of Stakeholder Group: Conversation Partners

Dimension	Examples of Categories
Family relationship	Parents, siblings, spouse
Type of educator	Special educator, mainstream teacher
Type of therapist	speech, occupational, art
Type of medical clinician	Pediatrician, primary care provider
Type of researchers	HCI, rehabilitation

AAC should support naturalistic, embodied communication and see design opportunities for interdependent communication to be more adaptive to diverse communication styles. These are not hierarchical values but rather intertwined values. Future work could probe these values and relationships.

Our work highlights that stakeholders can shift between roles, from AAC users to designers, for example, or from communication partners to users of AAC as they model AAC use. Understanding these dynamic roles can help designers gain a broader view of AAC use cases to examine the co-creation and interdependency [4] inherent in communication. This perspective can point designers to consider new use cases and approaches to AAC design. For example, to support an AAC user's learning goals, the AAC could optimize

Table 8: Values of Direct and Indirect AAC Stakeholders. Bolded values surfaced in our literature review, not our empirical investigation.

Value Themes	Value Aspects	Description
1. Acceptance	Self and social acceptance	Sense of self and identity, accepting AAC use; respectful communication style; **culturally-situated communication**
2. Fulfillment	Full engagement with others; learning	Being fully understood; free flow exchange of ideas and feelings; desire to learn and improve skills
3. Adaptation	Flexible communication; **personalization; embodied communication**	Choice of form factors and modes of communication
4. Ease	**Usability**, ease of adoption; ease of communication	Reasons people choose particular AAC; communicating with low effort and without obstacles; usable tools
5. Safety	Safety of self and others; secure communications; privacy	Reliable and efficient communication in emergency situations; data privacy
6. **Performance**	Speed, accuracy	Enable smooth communication by making word prediction and generation faster and more accurate
7. **Autonomy**	Increase agency; deconstruct hierarchies	Increase independence by loosening communication constraints
8. **Justice**	Funding and adoption policies for providing and navigating ethical challenges in consent and confidentiality y	Ethical challenges for HCI researchers and designers and enabling fair participation
9. **Design Fulfillment**	Purpose; prestige; professional development	Motivators for HCI researchers and AAC designers
10. **Business goals**	Meeting market demands; profitability; strategic goals of an organization	Values of AT evaluators, AT vendors, funders, policymakers

ways to locate, store, retrieve, and share information related to an AAC's learning goals.

Our framework includes values related to designers and organizations in the AAC field. VSD calls for designers and researchers to reflect on their positionality and values as designers. This was a notable area missing from our targeted literature review. Although a few papers included HCI designers as research participants, their values were not considered. Mirenda examined the values of AAC researchers and practitioners as they explored AAC innovations via the research-to-practice route or the practice-to-research route, respectively [50]. Mirenda emphasized that both researchers and practitioners are motivated by a set of values and beliefs that inform their process of identifying unmet communication needs and hypothesizing a solution. Researchers then evaluate their prototypes and generate empirical-based insights, whereas practitioners tend to have less rigor in assessing AAC innovations. Both routes are essential, and by examining the values of those engaged in AAC research and practice, we can be more aware of how their disciplinary expectations and roles influence them.

7.1 Insights into Potential Benefits and Harms of AAC

Potential benefits of AAC use include enhanced communication and quality of life, which emerges from self and social acceptance and fulfillment. Our work demonstrates ways that AAC users use various personal, social, and technical resources to negotiate communication. AAC users use their devices to engage in informal and formal communication, enhance expressive skills, practice language, and support learning goals. AAC users dynamically adapt their AAC use and use resources such as Google to source images for memes and learning. Connecting an AAC to the internet or having more speech-to-text integration between mainstream and AAC tools could open new avenues for information finding and usage for AAC-supported conversations. AACs are resources for verbal interactions and a source and storage of information. This insight could lead to design opportunities to consider AAC scenarios of usage that emphasize communication as the social construction and sharing of ideas, thoughts, emotional experiences, and information rather than limiting AAC design to linear communication models [18]. These potential benefits of AAC use could be realized with the design of holistic support for contextual informational retrieval, co-constructed (perhaps visible) communication spaces, and shared meanings.

Users expressed frustration with the usability of AAC and social barriers, which aligns with prior work highlighting device limitations, imbalance in conversation dynamics, and social exclusion (e.g., [39, 57, 73]). Our work demonstrates ways some users work around device limitations by customizing their AAC board, creating custom AAC, personalizing the synthesized voice, optimizing input techniques, and choosing a particular AAC depending on social and physical context. However, despite their creativity and dedication, these workarounds can still result in unsatisfactory user experiences due to difficulties finding desired vocabulary at the moment and barriers to expressing personal identities.

Societal stigma against AT impacts self-perception and AT adoption [66]. Our work demonstrates ways AAC users experience social exclusion. Stigma may also arise from internalized ableism and myths, such as limited verbal language due to AAC use, within the CCN community. In advice to the CCN community, a speech therapy clinic, Small Talk, states that "there has been a stigma attached to AAC for some time that using it will stop the development of verbal communication and children won't 'talk'. In fact, studies have shown the opposite to be true, with most studies showing an increase in speech production after using AAC" [70] citing, for example, research on people with aphasia [34]. AAC positively affects speech because it provides access to vocabulary, phrases, and sentence patterns, enables the production of longer messages, and reduces physical demands [49]. In our work, AAC users describe ways that inclusive communication practices (e.g., patience) and awareness of AAC can mitigate stigma. There is an opportunity for AAC research to use technology to support strategies such as these and explore other ways technology can counteract social biases [11].

7.2 Limitations and Future Work

Our research was conducted with a small number of participants. However, our sample size is consistent with related AAC research and includes direct input from AAC users, a persistent research challenge and opportunity [3, 79]. Also, our survey generated some survey responses that we removed from the data due to incomplete or incoherent text. Although scrubbing the data is a recommended survey practice, it raised the team's awareness of how people with CCN's written responses may differ in tone, style, and content from those without CCNs. People with CCNs may rely on preconstructed phrases or perhaps AI-based tools to construct written responses. Future work could examine ways to make survey content and terminology accessible to those with CCNs and ways for researchers to assess the validity of responses from people with CCNs. In our work, we followed up with survey respondents who indicated interest in future research and engaged with them during our interview process, further validating their data.

Future work could examine the connections between AAC-related values and other domains. Research on AT for dementia surfacing values including autonomy, consent, quality of life, etc. [14]. Insights on AAC-related values could contribute often unheard perspectives to the broader field of technology ethics. Although the VSD framework does not define a set of universal values at play when designing information technology, ethics researchers have proposed curating a set of universal values, such as human well-being, human dignity, justice, welfare, and human rights [15]. Examining the information and communication technology (ICT) user experiences of disabled, neurodivergent, and aging populations can be a productive source of identifying additional universal values or context-specific values. For example, Burmeister's research on seniors in Australia defined relevant values as equality, respect, and a proposed new universal value: freedom [14]. Future work could examine whether making connections and distinctions between communication-specific and universal values is productive.

7.3 Conclusion

Our work contributes to an understanding of the values of AAC stakeholders as evidenced through empirical and conceptual investigations following value sensitive design principles. Our work identified and examined stakeholder values to deepen our collective understanding of how AACs are used. Our work highlights that AAC are used as methods and tools individually, but importantly, within a communication group. AAC users, through informal and formal communication, and communication partners contribute to mutual understanding and respect within the larger society. Our work suggests that the designers can be better attuned to value-based needs centered around ease, adaptability, safety, fulfillment, acceptance, performance, personalization, embodied communication, and cultural support. Further research and understanding of how these values become supported or compromised by the design of AAC can enhance the quality of life and social inclusion for AAC stakeholders.

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8 Appendix - Descriptive Table of Article Corpus from Systematic Literature Review

Table 9 lists the 45 articles identified from our systematic literature review, based on our process described in the Methodology section. The research team identified the stakeholders and research participants described in each article. We identified value themes that were most prominent in each article, recognizing that the research may have other values at play that were not as evident to the reader.

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Table 9: Descriptive Analysis of the Studies

Article	AAC users	Caregivers and communication partners	Acceptance	Fulfillment	Ease	Adaptation	Safety	Other values or capabilities the paper focuses on
At times avuncular and cantankerous, with the reflexes of a mongoose": Understanding Self-Expression through Augmentative and Alternative Communication Devices [39]	People with Amyotrophic Lateral Sclerosis (ALS); Eye gaze input	Parents; Families (parents + siblings); caregiver	Social acceptance	Fully engage with others	Ease of adoption			
A Multimodal Vocabulary for Augmentative and Alternative Communication from Sound/Image Label Datasets [45]	People with language impairment							Clear vocabulary (disambiguated multimodal vocabulary); Efficiency
A System for Multimodal Assistive Domotics and Augmentative and Alternative Communication [7]	People with motor disabilities							Speed of communication; Accuracy of communication; Gesture input; Eye gaze input
AAC with Automated Vocabulary from Photographs: Insights from School and Speech-Language Therapy Settings [24]	Autism; severe sensory dysregulation, apraxia, down syndrome, etc.	Speech Language Pathologist (SPL), assistive technology evaluator		Learning		Flexible communication		Accuracy of communication; Personalization
AACrobat: Using Mobile Devices to Lower Communication Barriers and Provide Autonomy with Gaze-Based AAC [23]	People with neuromuscular diseases; Amyotrophic Lateral Sclerosis (ALS); Eye gaze input	Parents; Families (parents + siblings); Peers (friends, coworkers); spouses, caregivers					Privacy	Design guidelines/goals: Engagement of communication partners, autonomy, privacy and control

Article	AAC users	Caregivers and communication partners	Acceptance	Fulfillment	Ease	Adaptation	Safety	Other values or capabilities the paper focuses on
Ability-based Keyboards for Augmentative and Alternative Communication: Understanding How Individualsâ€™ Movement Patterns Translate to More Efficient Keyboards: Methods to Generate Keyboards Tailored to User-specific Motor Abilities [51]	Individuals with speech and motor impairments; Cerebral Palsy; Parkinson's disease, etc.	Any communication partner						Speed of communication
Applying prediction techniques to phoneme-based AAC systems [71]	People with severe speech and physical impairments (SSPI); Intellectual disability (ID)							Speed of communication; Accuracy of communication
Automatic generation of conversational utterances and narrative for augmentative and alternative communication: a prototype system [22]	Cerebral Palsy; Dysarthria							Speed of communication; Accuracy of communication; Leverage NLP
Challenges and opportunities in using augmentative and alternative communication (AAC) technologies: Design considerations for adults with severe disabilities [6]	Adults with Intellectual disability (ID)	Families (parents + siblings)		Learning		Flexible communication		Personalization; Cultural support for AAC use, Modelling AAC, Scaffolding AAC user-friendly environments.

Article	AAC users	Caregivers and communication partners	Acceptance	Fulfillment	Ease	Adaptation	Safety	Other values or capabilities the paper focuses on
Co-designing Socially Assistive Sidekicks for Motion-based AAC [74]	Individuals with speech and motor disabilities	Motion experts (professional puppeteers)			Accuracy and precision; conversational dynamics			
Conversational Agency in Augmentative and Alternative Communication [75]	Cerebral Palsy; people using pointing-based picture boards	Parents; paid aide conversation partners						Conversational agency
Customizing Usability Heuristics for Augmentative and Alternative Communication Systems [25]	Individuals with severe communicative expression disorders							Usability heuristics
Design Opportunities for AAC and Children with Severe Speech and Physical Impairments [36]	Children with severe speech and physical impairments (SSPIs)	School teachers; special needs assistant, researcher		Fully engage with others				Embodied/ material communication
Designing AACs for People with Aphasia Dining in Restaurants [58]	People with Aphasia	Speech therapists; social partners	Social acceptance					
Discourse-Based Modeling for AAC [52]	People with speech disorders	Any communication partner						Efficiency - predicting responses; keystroke savings
Envisioning the (In)Visibility of Discreet and Wearable AAC Devices [19]	People with Aphasia	Speech therapists	Social acceptance		Ease of adoption			
Establishing Context: AAC Device Adoption and Support in a Special-Education Setting [57]	Children with CCN	Parents; Special education professionals; School teachers; Speech therapists; learning and care assistants		Learning	Ease of adoption			Gesture input; usability

Article	AAC users	Caregivers and communication partners	Acceptance	Fulfillment	Ease	Adaptation	Safety	Other values or capabilities the paper focuses on
Evaluating an iPad Game to Address Overselectivity in Preliterate AAC Users with Minimal Verbal Behavior [12]	Children with Intellectual disability (ID); Autism; minimally-verbal, preliterate	Parents; Special education professionals		Learning				Learning communication skill: Multiple Cue Responding (MCR)
Evaluation of the acceptability and usability of Augmentative and Alternative Communication (ACC) tools: the example of Pictogram grid communication systems with voice output. [17]	Speakers with speech and language impairment							Speed of communication; Efficiency
Experiencing and Delineating a Vocabulary for a Tangible Environment to Support Alternative and Augmentative Communication [53]	Children							Communication fluency
Expert-based Assessment of an Augmentative and Alternative Communication Tool [31]		Experts who are university educators with advanced skills and years of experience in accessibility and autism spectrum disorder			Ease of communication			
Exploring the Design Space of AAC Awareness Displays [67]	Amyotrophic Lateral Sclerosis (ALS)			Fully engage with others				

Article	AAC users	Caregivers and communication partners	Acceptance	Fulfillment	Ease	Adaptation	Safety	Other values or capabilities the paper focuses on
Imperfect Surrogate Users: Understanding Performance Implications of Augmentative and Alternative Communication Systems through Bounded Rationality, Human Error, and Interruption Modeling [83]	Nonspeaking individuals with motor disabilities ; Aphasia; Eye gaze and touch-screen input							Speed of communication; Accuracy of communication
Implications of pragmatic and cognitive theories on the design of utterance-based AAC systems [48]	People with disabilities who cannot effectively use speech to communicate	Any communication partner						Speed of communication; Accuracy of communication
KWickChat: A Multi-Turn Dialogue System for AAC Using Context-Aware Sentence Generation by Bag-of-Keywords [64]	Motor impairments; Cerebral Palsy; Amyotrophic lateral sclerosis (ALS)							Speed of communication; Accuracy of communication
Making as Expression: Informing Design with People with Complex Communication Needs through Art Therapy [42]	People with CCN	Art therapist		Fully engage with others				Agency
Methodology based on Computer Vision and Machine Learning to guide the Design of Augmentative and Alternative Communication Systems using Personalized Gestural Interaction [2]	Motor impairments; Speech difficulties	Special education professionals (as a bucket term)						Gesture input; Personalization
Non-Syntactic Word Prediction for AACP [80]	Individuals with limited or emerging literacy skills							Speed of communication; Accuracy of communication

Article	AAC users	Caregivers and communication partners	Acceptance	Fulfillment	Ease	Adaptation	Safety	Other values or capabilities the paper focuses on
ParlaConMe: an AAC software designed for Italian language [62]	CCN users of Italian AAC	Communication mediators						Accuracy of communication; cultural
Perceived Communication Experiences of Children and Young People with Down Syndrome: The Impact of People, Places, and AAC Methods [63]	Children with Down syndrome	Families (parents + siblings); Speech therapists				Flexible communication		Independence
Public policy issues in augmentative and alternative communication technologies a comparison of the U.K. and the U.S. [78]	People with communication disorders				Ease of adoption			Justice and rights
Robot-based augmentative and alternative communication for nonverbal children with communication disorders [38]	Children with Autism; pervasive developmental disorder	Speech therapists				Flexible communication		
SpeakFaster Observer: Long-Term Instrumentation of Eye-Gaze Typing for Measuring AAC Communication [16]	People with severe motor and speech imapriments; ALS; eye gaze input			Fully engage with others				Speed of communication; temporal dynamics of conversation turn-taking in gaze-based communication
Supporting Personal Narrative for Children with Complex Communication Needs [9]	Children with CCN	Parents; Speech therapists		Fully engage with others	Ease of communication			Location sensors provide context for narratives
TalkingBoogie: Collaborative Mobile AAC System for Non-verbal Children with Developmental Disabilities and Their Caregivers [65]	Non-verbal children; Autism; Cerebral Palsy	Parents; School teachers; Speech therapists; Medical clinicians						Caregiver support and knowledge

Article	AAC users	Caregivers and communication partners	Acceptance	Fulfillment	Ease	Adaptation	Safety	Other values or capabilities the paper focuses on
TalkingTiles: Supporting Personalization and Customization in an AAC App for Individuals with Aphasia [33]	Adults with Aphasia	Spouse, caregiver						Personalization; simplicity
The application of spatialization and spatial metaphor to augmentative and alternative communication [21]	People with severe physical disabilities and are unable to speak or use manual communication methods such as Sign Language	Medical clinicians						Basic functionality
The Effect of Voice Output on AAC-Supported Conversations of Persons with Alzheimerâ€™s Disease [26]	Adults with Alzheimer's disease	Trained research assistants						Performance
The imagination of crowds: conversational AAC language modeling using crowdsourcing and large data sources [77]	People with communication disabilities							Speed of communication; Accuracy of communication
The less I type, the better: How AI Language Models can Enhance or Impede Communication for AAC Users [73]	Autism; Cerebral Palsy; Aphasia; Eye gaze input	Families (parents + siblings); Speech therapists			Physical and cognitive effort			Speed of communication; agency

Article	AAC users	Caregivers and communication partners	Acceptance	Fulfillment	Ease	Adaptation	Safety	Other values or capabilities the paper focuses on
The Study of Augmentative and Alternative Communication Software Development for Children with Complex Communication Needs [44]	Children with CCN; Rett's syndrome	Parents; Families (parents + siblings); Special education professionals; Speech therapists; academics with a background in communication disorders or assistive technology		Learning				Communication ability
Towards a Methodology to Support Augmentative and Alternative Communication by means of Personalized Gestural Interaction [1]	Speech impairments; associated motor impairments				Ease of adoption			Gesture input; Personalization
Trap hunting: finding personal data management issues in next generation AAC devices [60]	Individuals with severe speech impairment	Families (parents + siblings); School teachers; care staffs					Privacy	
Using lexical and corpus resources for augmenting the AAC lexicon [54]	Users of Swedish AAC with severe communication disorders	Any communication Partner						Cultural context
Using NLG and sensors to support personal narrative for children with complex communication needs [8]	Any AAC user (nothing specified other than has speech difficulty; "Complex communication needs"); Children		Conversational narratives for social engagement					