

# **Analysis of Learning Process of Augmentative and Alternative Communication Devices**

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On my honor as a University Student, I have neither given nor received unauthorized aid on this assignment as defined by the Honor Guidelines for Thesis-Related Assignments

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## ***Introduction***

Augmentative and alternative communication (AAC) devices help their verbally challenged users communicate better to improve the users' quality of life. They are a vital part of the toolkit that allows the users to be more independent and increases the opportunities they are afforded in life. Angelo (2008) shows that of those participating in his study, "more than half of the families acknowledged the importance of gains in educational and social opportunities. Almost half of all families reported more opportunities for higher education, independent living, and employment". (p.45) AAC devices empower verbally challenged users that might have been previously discouraged from employment. The study by Richardson et al. (2018) documents the "successful employment of individuals with ASD who present with complex communication needs and require the use of AAC" (p.215). For devices that have such powerful impacts, it is important to make sure that the user can learn the device and integrate it into their lives as quickly and simply as possible.

Even as users testify to the importance of the devices, there is a lack of unified understanding on how users are meant to learn to use the devices. The process through a user acquires and uses a device is dependent on a network of actors that include family, medical personnel, schools, and more. The actors are not able to properly support the users' learning process due to a lack of productive coordination with each other.

The process of analyzing the users' experience of the learning process is important to being able to improve the system and make the usage of the devices more accessible. Gaining a better understanding of the faults of the system is helpful in designing devices that better answer the needs of the public, doing a better job of presenting and training users on those devices, and boosting patient trust in future devices.

In this paper, I analyze the reactions of users and their families to the process of learning to integrate AAC devices into their lives. Through these reactions, I attempt to construct the current actor network system that facilitates the learning process and find potential areas where it is inefficient.

I argue that the current process of learning to use AAC devices has inefficiencies that make it unnecessarily difficult to be able to use a device. This research falls into the expectations for research that AAC users have. In a study by O’Keefe et al. (2007), they find that AAC users would value further research in “identify[ing] the variables that impact on the lifestyles of persons who are non-speaking, determin[ing] the best and fastest ways for providing AAC services to people who have complex communication needs, design[ing] programs for increasing public awareness, determin[ing] the best teaching methods for developing reading and writing skills in people who use AAC, and design[ing] programs to meet desirable outcomes of AAC intervention” (pg. 94)

### ***Problem Definition***

The process of starting to use an augmentative and alternative communication device is complex. The complexity starts from choosing the device with the right specifications and extends to finding resources to learn how to integrate the device into the users' lives. This process, when put into the framework of a sociotechnical system, turns into a complex network of actors that include the patient, their families, schools, medical professionals, and more. Each actor in this system has their own perspective of the problem, each with their own motivations and blind spots. In much of AAC research, the specific devices and disabilities faced by the users are not individually addressed. Through gaining a device-agnostic understanding of the users' and their families' perspectives, we would be able to find ways to improve the learning process in general.

Currently, researchers and medical professionals are the drivers of the network. As the primary data gatherers, researchers have the vital role of analyzing the situation and communicating any necessary changes to the actors. Because they are actors in such a crucial position, their approach has the potential to be highly problematic. As Stone and Priestly (1996) describe it "the inherent power relationship between researcher and researched is accentuated by the unequal power relationship which exists between disabled people and non-disabled people in the wider world" (p. 700). This imbalance makes it the responsibility of the researcher to be more accountable for the methods and relevance of their research and make their research more vulnerable.

To ensure that the research conducted is relevant and impactful, Stone and Priestly (1996) define a strict direction that the research should follow: "the focus of disability research will have less to do with the ability of disabled people to 'cope with' or 'adapt to' their situation and

more to do with the identification and removal of disabling physical and social barriers.” (p. 702). This implies that rather than just developing machines that help users communicate, researchers must focus on making sure that the machines work towards removing the communication barrier that these users experience.

Like the broader research in disability study, the research into AAC devices has not always been led by the users of the devices. One of the studies that guided the research priorities from the mid-90s to the 2000s was the 1994 National Institute of Deafness and Other Communication Disorders (NIDCD) study on research priorities for augmentative and alternative communication. Instead of working with users of AAC devices and making principles based on their experiences, the participants were individuals with expertise in child language development, literacy, developmental psychology, interactional therapy, and motor speech disorders. While the thoughts of those that study and work with users of AAC devices are still valuable, there are clear differences between the priorities of the “experts” and the users.

In O’Keefe’s et al. (2007) assessment, he found that the researchers tended towards quantitative measures of AAC success. They wanted to see improvement in terms of an increase in vocabulary or a faster rate of response. The scientists valued investigating how the device impacted the communication skills of the user, how the users’ individual traits influenced their experience of the device, how to best measure communication competence, and how to encourage further research. While all these priorities would improve a user’s experience, the user priorities were more functional and personal.

The users and their facilitators tended to measure success by functional indicators. When looking at a larger population, O’Keefe et al. (2007) found that users generally seemed to measure their success through “(a) the ability to communicate successfully in specific situations,

(b) the willingness of others to communicate with them, and (c) the attainment of respect through communication” (p.90). While most users and facilitators agreed with the priorities determined by the researchers, they valued improvements to the performance of the devices, the accessibility of the devices, the teaching methods, and public awareness. Rather than improving the education of PhD-level researchers, the users wanted to educate all people that are close to AAC users. They also wanted to improve the reading and writing skills of the AAC users. The priorities expressed by the users were directed more closely towards holistically building up the user and their support system rather than just better quantitative data and improved opportunities for research.

There was also a clear difference in how each group expressed the research priorities. The scientists defined their priorities as ways “to study” or “to investigate” the impact and efficiency of AAC technologies. The users and their facilitators used more direct language such as “determine”, “design”, and “identify”. This falls in line with the difference in background with researchers approaching the problem from a more impersonal knowledge-gathering perspective while the users and facilitators want direct improvements to their experiences.

The users’ main interest is in how the device improves their daily life. Rackensperger et al. (2005) observes that the skills that users desired fell into three categories: linguistic, operational, and social competence. Users wanted the ability to have conversations in which they were able to clearly convey their thoughts. This meant having the appropriate words and phrases pre-programmed into the devices to respond quickly. This usually was a product of a cycle of using the device, identifying frequently used vocabulary, and storing it for later use. They also had insights into their physical ability to use the devices. They found that sometimes devices had been designed only to be used while sitting in the customized wheelchair. It was a struggle at

times to be able to communicate in more casual settings. Device malfunctions made the users unsure of their ability to be in public. Their caregivers were very important in helping them debug issues with the devices and calling help lines. The manufacturer's support personnel were also found to be very helpful in fixing their issues. Users also wanted to feel normal when using their device in public. They found that gaining other people's attention, explaining the device, and communicating their needs to be difficult when the public was not aware of the situation. People would talk to the machine rather than the person.

To support their competency goals, users engaged in a variety of training methods. These included using text and technological support, exploring the device on their own, learning from professionals, structured practice, learning from peers, and functional use. The users then rated their experiences with each activity. Figure 1 depicts their ratings:

Resource	Activity	Used			Did not use		
		Very Helpful	Moderately or a little helpful	Not helpful	Want to	Don't want to	No response
Text and technological supports	Interactive computer program				4	2	1
	On-board software programs (e.g., Icon Tutor)	3	1		1	1	2
	Manuals (print)	3	2	1			1
	Manuals on CD-ROM				6	1	
	Manuals on Internet				7		
	On-line classes				7		
Individual exploration		6	1				
Learning from Professionals	Attending workshops	2	2		2		1
	Demos by reps	2	3				2
	Training by a SLP	2		2	2	1	
Structured practice	Drill and practice	2	1	1	1	2	2
Learning from peers	Watching other individuals who use AAC		2		4	1	
	Advice from individuals who use AAC on listservs	5	1		1		
Functional use	Conversation with familiar partners	6				1	
	Conversation with unfamiliar partners	5	2				

Figure 1: Each activity has the number of users that found it very helpful, moderately helpful, or not helpful. Users that did not have the opportunity to use the tool rated how much they wanted to use it. Reprinted [or adapted] from ““When I First Got It, I Wanted to Throw It Off a Cliff”: The Challenges and Benefits of Learning AAC Technologies as Described by Adults who use



AAC,” by T. Rackensperger, C. Krezman, D. Mcnaughton, M.B. Williams, K. D’Silva 2005, *Augmentative and Alternative Communication*, 21(3), 173. Copyright [2005] by International Society for Augmentative and Alternative Communication

Users in general seemed to feel better about their learning process and usage of the device when they were actively involved by using the device and exploring on their own. They felt that they knew their needs the best and were the most qualified to accept or reject a device. Some felt that having a SLP in the process clouded their judgement. Ultimately the usage, practice, and care required falls upon the user and their caregivers.

The families of the users also play a crucial role in using the AAC device, especially when the user is young. However, the socio-economic status of the user’s family has a strong impact on how well the user uses their device. Lower-income and minority families have difficulties dealing with prejudice and discrimination in the learning process. Kemp finds that “stereotypes exist among many European American professionals that children from minority backgrounds have, for example, lower social and academic capabilities” (Kemp and Parette, 2000, p. 385) which makes it difficult for them to work with and understand their patients. Parents with limited English proficiency (LEP) have difficulties communicating with professionals and advocating for their child’s needs. Professionals that are insensitive to specific ethnic and family issues are also problematic. Parette specifies an example when “the color black may be used to denote ‘wrong’ or ‘bad’”( Parette, Brotherson, and Huer 2000, p. 185). Improved communication between the various support structures that AAC device users have is crucial for a more efficient learning process.

### ***Research Approach***

This research paper characterizes the process of learning how to use an AAC as a technical process supported by a network of actors such as users, families, medical professionals, and more. This is done through the analysis of the discourse of the actors to gain a better understanding of how users and families perceive the professionals they work with and how they feel they are perceived by the professionals. The analysis relies on the support of the social model of disability that describes the relationship of disabled people with society in general.

There are several models of disability that can be used for this purpose. Since this research is based on individuals with some form of medical condition that does not allow them to communicate typically, the medical model of disability seems relevant. The medical model views disability as a set of physical or mental deficiencies that can be corrected or mitigated with medicine. While it may be intuitive for abled people to think in its terms, this model tends to have a binary view of people, marking them as able and disabled due to some conditions.

In Grue's analysis he finds that the medical model "reduces every aspect of disability to bodily impairment, prescribes only medical treatment and normalization as appropriate interventions, and denies agency to disabled people while reserving power for medical profession" (Grue, p.540, 2011). This leads to positivist research that places emphasis on curing an individual's condition. Researchers fall into a power imbalance, deeming themselves as "experts" in the subject. Disabled people become treated like passive subjects rather than active participants.

In contrast to this, the social model of disability helps mitigate some of the problems in the medical model. The social model of disability characterizes disability as "a form of economic

and political oppression enacted on people” (Grue, p.538, 2011) created by a disabling environment and disabling attitudes” (Stone & Priestly, 1996, p. 701). Instead of using a medical condition to decide that a person is disabled, the social model of disability questions what systemic issues and circumstances would cause a person to be considered disabled. Critics of the social model point out that it does not consider medical phenomenon in explaining disability. While this is a fair critique, for the purpose of this research the evaluation of the social context around disability fits very closely with the discourse analysis that this research aims to conduct.

As disability research evolves, the research tends to fall closer towards the framework of the social model of disability by having the disabled individuals and their families be more active participants in the research process. Following this trend, there is a fair body of evidence that consists of direct accounts users of AAC devices and their families expressing their thoughts on their experiences. These accounts provide a clear picture of how the users perceived the network of support that they had in learning to use their devices. The accounts also provide an idea of how the user felt they were perceived by the actors in that network. In each one, they define an actor in the network and assign that actor an evaluation. By compiling the experiences across many users, it is possible to construct an actor network that depicts the perceptions of the users. Figure 2 depicts the steps taken to analyze the accounts:

<b>Steps</b>	<b>Goal</b>
1	Gather discourse from users and their families about their experiences learning to navigate the environment of AAC devices
2	Categorize the discourse as it relates to different actors in the network
3	Analyze how the interactions with each actor in the network affect the user and their families understanding of the network and the process of learning

Figure 2: Steps taken to gain a better understanding of the process of learning to use an AAC device

## **Results**

Through the process of analyzing accounts of users and their families, we gain a better understanding of how the users perceive the actors in the network as well as how they feel they are perceived by the actors. In the accounts provided, users and their families express their perspectives on how they learned to use their AAC device. The main actors identified are schools, manufacturers, the users and their families, and medical personnel. The accounts provided by the users have been placed into categories of the actors they are most pertinent to. By grouping and analyzing these accounts we find the proficiencies and deficiencies in the contributions of each actor and how the actors relate to each other.

The accounts covered the user and family difficulties in interacting with the schools. When families lack the guidance of dedicated medical professionals, the next place they look to for guidance is the school system. This, however, was not always helpful. The schools sometimes did not even have enough information to even recommend the use of an AAC device.

**Fred:** Unfortunately, even though my child was making NO progress at verbal speech, an AAC option was NEVER mentioned by the school nor any professionals . . . I found an advertisement for a Blackhawk . . . in Exceptional Parent Magazine and ordered it (without school testing, funding, approval, etc.) . . . For now, it [selection of device] was 100% our choice. The school offered nothing and NO information . . .

Schools did not provide the kind of individual focused guidance and assistance that was required by some of the users. Teachers were not given proper guidance on how to integrate the devices into lessons with the students. This meant that students were extremely limited in terms of being able to get used to everyday conversations with their devices.

**Rosie:** Unfortunately, no one helped him [son] learn signs but me, and he had little support in this until about sixth grade when they hired a classroom aide that knew sign language. To have AAC not be integrated into a child's life until middle school is sad and [makes it] very difficult for them to adjust.

**Barbara:** When my son went to school so many opportunities were missed . . . The teachers knew nothing of the AAC, and wanted to know nothing. There is no acceptable reason that he was not expected, encouraged, or allowed to use the device in school. So many missed opportunities.

Only a few teachers were able to make clear lesson plans to help the student consistently improve at using the device.

**Billy:** When I entered high school, I needed to take a foreign language. So my speech teacher and me asked the school if I could get Word Strategy as my foreign language and they let me. That's how I really learned a lot of Minspeak. During each week, my speech teacher gave me 10 words that she thought I would use to learn for the week, then she would test me every Friday. Then when final exams came I had a final exam on all of the words that she had tested me on.

It becomes apparent that the schools that the students rely on to learn do not have access to the appropriate information to facilitate their education.

The users and their families expressed mixed feelings with their device manufacturers.

Many times, the devices were designed to be used in a wheelchair, limiting the users' flexibility in where and what situations they could use their device.

**Carla:** "Naturally, the more time you have access to the device, the more you learn and the more proficient you become". However, many of the individuals could only use their device when seated in an electric wheelchair, and many of the desired environments (relative's homes, parks) were not wheelchair accessible.

While using the devices, users experienced frequent breakdowns. These breakdowns discouraged the user from practicing using the device and being able to communicate with their families.

**Carla:** With her previous device, it would freeze up dozens of times a day. We put a note on it telling how to 'reset' it. The reset button was in such an awkward place you had to practically be a contortionist to reset it while mounted on the chair . . .

**Julie:** The scanning was accomplished by a head switch, and was about as slow as chiseling on stone with a toothpick. This problem was further complicated by the computer's hard drive crashing about once a week. Needless to say, desire to communicate plummeted.

In addition to this, the breakdowns made the users unsure of using their devices in public due to fear of spontaneously losing the ability to communicate.

**Dan:** “I am going to be blunt here. I am pretty much screwed if my Pathfinder locks and I am alone or with somebody that doesn’t know how to reset it.”

When learning to use the device, users found the physical manual books to be difficult to use and parse through. However, they felt like the alternative forms of manuals (CDs) and customer support representatives were very helpful. Overall, the users were able to access information from the manufacturers on how to use the devices. They continued to have issues with understanding that information and operating the devices efficiently.

Given the state of their support systems, the users and their families had to take a great deal of responsibility for their learning process. As stated before, each user has a unique set of abilities and restrictions. The user’s experience of using an AAC device was greatly improved when they were able to be involved in every step of the process to tailor their tools to their needs. The user and their family being able to choose the correct device set them on the correct path for smooth learning.

**Sally:** Every time I needed a new AAC device, I told the SLP what I thought I needed and they agreed with me. I know my needs best.

With the absence of support from the SLP and school system, users relied on their families to help them learn to use the devices. Families broke down the dense documentation into manageable chunks that the users could incrementally learn.

**Julie:** I had my mom take a couple of sections at a time out of the thick Unity binder and put them into a thinner binder so it wasn’t too mind boggling for me. Then I would study the sequences and description . . . I did most of my practicing (or) memorizing sitting on the family room floor with my Liberator perched on a chair in front of me along with a few sections of the Unity program (manual) in front of me. I did pretty good with motivating myself to keep on studying on a regular basis three or four times a week for two hours at a time . . . It took about two years to learn the entire vocabulary really well.

Users also found that they learned well when they simply played with their devices.

**Dan:** I found the best way for me to learn anything is to just jump in and use the technology or whatever. This forces me to learn fast and be highly motivated. My rationale was the more I use Word Strategy or Unity the more I will learn. With this technique I learned Word Strategy in about three months, and Unity in about a month.

In the absence of authoritative sources of information on device usage, the users and families found good results in trying to be self-sufficient.

Intuitively it may seem that medical personnel like speech-language pathologists (SLPs) are usually the first people outside of the family that have an impact on the process of learning to use an AAC device. However, SLPs seemed to be disliked in general. In the initial stages of choosing an AAC device, they should provide important guidance. After acquiring the device, they should help teach the user how to operate the machine and act as an interface between the user and the other actors in the system. The users and their families feel that SLPs are not up to the standard in their duties.

When working with an SLP, users and their families felt that the SLP assumed too much of a decision-making position. Each user has unique abilities and needs to which the machines they use must fit. Ideally a user would be able to test out different types of devices and make well-informed decisions. The SLPs tended to either pick out a device for the user or give them a limited selection of devices to choose from rather than finding machines that best match the user's situation.

**Katrina:** They [evaluation team] said it [the device recommended by evaluation team] was the most sophisticated on the market and that she was a good candidate for it. We really didn't have anything to compare it to, so we went along with their decision . . . right away my daughter was having trouble using her head wand trying to hit the keys

without constantly hitting the ‘erase’ button that was right next to the ‘enter’ button. Not to mention the device was ugly and not friendly looking.

The SLPs had issues communicating when helping the user learn the device as well.

SLPs had an initial issue not knowing how to fully use the devices themselves. Learning to use the devices would mean parsing through dense documentation and being able to convert that information into usable advice for the user.

**Julie:** My Mom and I had a hard time finding a SLP who was willing to learn the Minspeak Application Program. They didn’t understand its importance and value. They didn’t want to take on the challenge of understanding and memorizing the vocabulary, and they broke out in a sweat when we showed them the thick Unity three ring binder.

Their unwillingness to do this meant that the onus was now on the user and their families to decode the instructions. After learning to use the device, the SLP would formulate a plan on how to teach the device to the user. This plan was not communicated to the user or their families.

Families found SLPs unwilling to change their plans even when they expressed that the plan did not match the user.

**Barbara:** She [SLP] did not help to show teachers how to incorporate the AAC into the rest of his day . . . She did not visit his classes and they did not request it. She [SLP] often wasted his time. She did not have strong goals or a plan; if they felt like walking the corridors that’s what they did. There should have been much more accomplished.

**Katrina:** My daughter did not receive help from an SLP to learn her device. We looked for two years before settling for a speech therapy student. I felt like we were pulling her [speech therapy student] along in baby steps. Her baby steps. She wasn’t looking at my daughter’s age or abilities when it came to assignments and programming phrases. Repeatedly, I tried to tell her [SLP student] my daughter’s vocabulary was much more advanced than the three or four word commands and sentences she wanted my daughter to program and use . . . It came to be that her [SLP student’s] supervisor did not like Minspeak. My daughter wanted to give it a try. The [SLP] student said we would have to part ways. GLADLY. I couldn’t figure out why there was reluctance to this encoding method and gave up trying to find someone willing to work with my daughter with it.

SLP’s are generally trained to work with patients with verbal communication issues. They are not typically trained to work with AAC devices. Due to this, SLPs also were not up to the



standard when communicating these plans to the users' schools and teachers to create a more holistic learning environment.

Given the information gathered by this research, there is a clear lack of cohesion and communication between the actors that should be supporting the users. The schools have a tough time being able to balance the specialized needs of their students that use AAC devices with the rest. One of the reasons for this is that they do not have the right information on how to incorporate learning of these devices into the curriculum. Manufacturers have a difficult time being able to design their products to match the exact needs of their users. Users and their families lack the required knowledge to self-design a good learning plan for the devices. They have difficulty incorporating the devices into real-life use. If the communication channels were ideal, the flow would look similar to Figure 3:

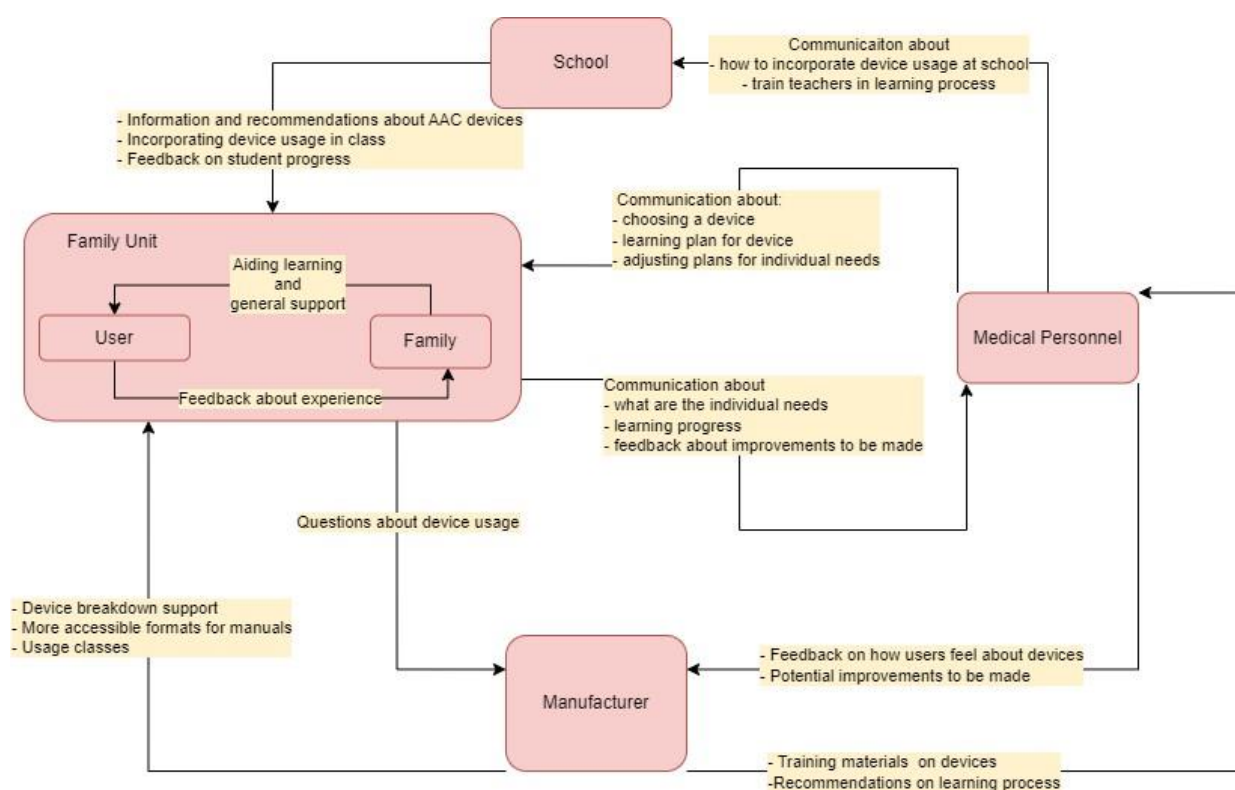


Figure 3: A flowchart depicting ideal communication channels between the actors of the network

## *Conclusion*

Learning to use an AAC device is a complex process. Due to the interactions between the contributors to the process and the users of the devices, the process lends itself to being characterized by the social model of disability. In this model, rather than viewing disability as just a individual's medical condition, it is viewed as a system where social structures are built in a way that promotes inequality to those with disabilities. Through using the social model of disability, it becomes easy to model the process using actor network theory. Through these models we find that the reason for disability is that the inefficiencies and lack of information flow in the network prevent users of AAC devices from having a better level of communication.

Many of the actors in the network have a lack of guidance that makes it difficult to properly educate the users and their families. Medical personnel and schools are the actors with which families interact with the most. These actors are not able to provide structured learning that integrates with the user's daily life and is directed towards real-world use-cases. Both actors have priorities other than the user with schools needing to look after the rest of their students and medical personnel like speech-language pathologists being more specialized in patients that need help verbally rather than with machines. The system exhibits a deep lack of communication between the actors with no central sources of information. This research starts down the path of making the system more efficient, ultimately to help make the learning and usage process of AAC devices much easier for the users and their families.

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