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AAC Use by Children With ASD and Their AAC Co-Pilots

by

Kelcy Rolak

Thesis

Submitted to the Department of Special Education

Eastern Michigan University

in partial fulfillment of the requirements

for the degree of

MASTER OF ARTS

in

Communication Sciences and Disorders

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Abstract

Employing a multiple case study approach, this study explored the perspectives of parents of children with autism spectrum disorder (ASD) on their child's use of augmentative and alternative communication (AAC). Deemed "AAC co-pilots" by this study, these parents play a crucial role in their children's daily AAC use, yet their perspective is largely under-explored in existing research that otherwise explores AAC use by individuals with ASD extensively. Semi-structured interviews were conducted with parents of children with ASD who have used AAC for at least one year and whose AAC use is documented in their IEP. Findings indicated the depth and significance of the parental role of co-pilot to their child's AAC use, namely as a co-pilot whose keen observations lend to a deep understanding of their child's communication, a staunch facilitator of device support and navigation, and a crucial conversation partner. The facets of the role, and the many individual efforts and insights that accumulate to form them, converge under the common goal of supporting, encouraging, and promoting successful communication by the pilot, the child AAC user. From the data emerged the vital importance and significance of the co-pilot as a foremost presence in their child's AAC use and the need for this role to be supported, encouraged, and fostered in the implementation of AAC.

Table of Contents

Acknowledgments.....	ii
Abstract.....	iii
Chapter 1: Introduction.....	1
Background Information.....	1
Justification and Significance.....	2
Research Question.....	2
Chapter 2: Review of Literature.....	3
What Is AAC?.....	3
AAC Modalities.....	4
Access Methods.....	6
The Role of Occupational and Physical Therapy.....	8
Optimal User Experience.....	8
Autism Spectrum Disorder and Communication.....	9
Chapter 3: Methods.....	14
Study Design.....	14
Study Participants.....	14
Data Collection.....	15
Data Analysis.....	16
Chapter 4: Results.....	17
Jane and Mary.....	17
Amy and Ben.....	23
Chapter 5: Discussion.....	32

Co-Pilot View From the Cockpit	32
Co-Pilot Navigation	34
Pilot and Co-Pilot Communication.....	36
Chapter 6: Conclusion.....	40
Summary of Findings.....	40
Implications.....	42
Limitations and Delimitations.....	44
Directions for Future Research	45
References.....	46
Appendix A: Expedited Initial Approval Form	52
Appendix B: Informed Consent Form	53
Appendix C: Survey Instrument	58

Chapter 1: Introduction

Background Information

Augmentative and alternative communication (AAC) is a highly utilized method of communication that “supplements and compensates for impairments in speech-language production and/or comprehension, including spoken and written modes of communication” (American Speech-Language-Hearing Association [ASHA], n.d.-b, para. 1). The scope of AAC includes many different forms and modalities, including gestures, drawings, picture and letter boards, and devices that produce speech (ASHA, n.d.-b). Numerous populations of individuals with complex communication needs, including those with autism spectrum disorder (ASD), may utilize AAC due to a wide variety of speech, communication, and language difficulties and/or impairments.

When such difficulties are suspected in individuals with ASD, it is the role of the speech-language pathologist (SLP) to evaluate and, if applicable, provide treatment. Based on the needs of the individual, use of AAC in some form may be implemented. The process involves a great deal of collaboration with various other clinicians and professionals as well as the family of the AAC user. In particular, the parent plays a particularly crucial role. While the SLP may be an expert on language and communication, the parent is the expert on their child.

This study aimed to explore and examine the perspective of parents surrounding use of AAC by their children with ASD. By exploring the experiences and perspectives of parents of children with ASD who are AAC users, this research sought to garner insights into possible patterns and commonalities of AAC use.

Justification and Significance

Though some studies have explored use of AAC from the parent perspective, such as those by Calculator (2013) and Bailey et al. (2006), it is a route to insight that is largely unexplored in existing related research. Additionally, while research has been conducted in exploration of AAC use specifically by individuals with ASD and the many factors that might impact said use, the focus can be further narrowed.

With an instrument as crucial as AAC, the sole purpose of which is to aid and support the inherent communicative abilities of individuals who would benefit from such augmentation, it's necessary to learn as much as possible about the interaction and preferences of those who use such devices. One route to doing so would be to explore this use from the perspectives of those closest to the user and with a front row seat to the daily use of AAC, such as the parent. Every piece of reliable information learned from those directly involved with and impacted by AAC use will allow for further development and improvement of AAC itself, better understanding of how user individuality and preference impacts use, and inform what makes for successful use in the daily lives of such individuals.

Research Question

What are the perspectives of parents on the implementation, use, and overall communication success of augmentative and alternative communication by their child with ASD?

Chapter 2: Review of Literature

What Is AAC?

For many individuals, the ability to communicate verbally may be non-existent or may be limited to a point that inhibits effective and sufficient communication with others. There are a vast number of reasons why an individual's communicative abilities may be so impacted, including developmental disorders such as ASD, acquired disorders such as multiple sclerosis, or neurologically impacting events such as a stroke or traumatic brain injury (Beukelman & Mirenda, 2013). Just as there are a wide variety of causes for such communicative challenges, there are also a wide range of ways in which speech, language, and communication may be impacted as well as extent of said impact.

In working with individuals with complex communication needs, the role of the speech-language pathologist is to assess the present level of ability of the individual and provide subsequent treatment, with the goal of targeting and supporting their highest level of communicative capabilities. If deemed appropriate, that treatment might include employment of AAC, an alternative method of communication for individuals who are unable to communicate verbally or a method of augmentation for the communication of individuals who have complex communication needs.

There are various modalities or types of AAC presently available, organized on a continuum. This continuum categorizes AAC modalities as being low-tech, mid-tech, or high-tech, ranging from paper core boards to tablets enabled to produce speech. Which modality an individual uses is based on various factors, including extent of augmentation needed and the individual's communicative goals. It can also be noted that the AAC modality employed by an

individual can change over time, either in favor of another modality or due to discontinued use of AAC entirely.

There exists an increasing number of options within the realm of AAC, with some modalities incorporating highly advanced technology. With the rise in use of AAC as a communication method, the question should be posed of how individuals with communication impairments employ and interact with these tools. Numerous studies have been conducted on AAC within the many populations that employ the modes of communication encompassed within its scope and which offer further insight into the realm of possibilities offered by AAC utilization (Calculator, 2013; Elsahar, 2019; McNaughton & Light, 2013; Ogletree & Pierce, 2010). Early candidacy models of AAC use that focused on *who* exactly is an eligible candidate for successful AAC use have been phased out in favor of the newer and more inclusive participant model, which instead “provides a systematic process for conducting AAC assessments and designing interventions based on the functional participation requirements of peers without disabilities of the same chronological age as the person with CCN” (Beukelman & Mirenda, 2013, p. 108; Ogletree & Pierce, 2010).

AAC Modalities

Research has been conducted on the many modalities of AAC available as well as how advancements in AAC have impacted the ultimate end goal of communication (Elsahar et al., 2019; McNaughton & Light, 2013). In examining the continuum on which AAC devices are organized, devices at the base level can be either aided or unaided.

Unaided AAC Modalities

Unaided AAC modalities encompass “modes that rely on a user’s body to convey messages” (Baxter et al., 2012, p. 116). This could include communication done by way of

vocalizations, gesture, or body language and is essentially any form of non-verbal communication by an individual that doesn't incorporate an outside device (ASHA, n.d.-c; Beukelman & Mirenda, 2013). It does not include sign language, however, as sign languages, such as American Sign Language, are languages in and of themselves (ASHA, n.d.-a).

Aided AAC Modalities

Aided AAC modalities, on the other hand, do incorporate an outside device in order to support communication, and within the aided categorization there exists the three subgroups of low-tech, mid-tech, or high-tech (Baxter et al., 2012; Desch et al., 2008). Low-technology AAC devices might include systems such as core boards or Picture Exchange Communication Systems (PECS)®, which utilize paper-based visual representations of words that can be gestured to or manipulated in order to communicate (Baxter et al., 2012). Among these low-tech systems are more specific activity-based communication boards and devices, which still employ paper-based formats but are created solely around a single activity and therefore contain words specific to said activity, as opposed to being comprised of more general, sweeping words (AssistiveWare, n.d.-a).

Devices categorized as mid-tech bridge the gap between low-tech and high-tech. As described by Desch et al. (2008), “Mid-tech devices are typically battery-operated portable voice-output storage devices or devices that produce printed text” (p. 1272). GoTalk® devices perfectly exemplify the mid-tech categorization. The plastic shell is battery operated and able to generate vocalizations for a limited, set number of words. However, the words available exist on a paper-based communication board that slides into the side of the mechanism, allowing for interchangeability of the words available on the GoTalk® (Attainment Company, n.d.).

As the name suggests, highly sophisticated forms of technology are utilized for modalities in the high-tech range. Tablets, iPads, and computers are often employed as speech-generating devices (SGDs), for example (Baxter et al., 2012). Using apps specifically designed for AAC purposes, like Proloquo2Go™, individuals can choose words and visual representations within the app that are then spoken aloud by the device (AssistiveWare, n.d.-b). In addition to the ability of electronic voice generation, high-tech devices can also include both dynamic displays that change “with the input so that many levels of symbols, words, or lengthy messages can be stored for quicker retrieval, [and] the capability to have multiple access methods ranging from direct selection on a touch screen to...mouse/joystick controllers” (Desch et al., 2008, p. 1273).

Access Methods

In addition to the range of technologically varied devices existing on the continuum, there also exists a vast number of selection or access methods, which are the ways an individual “selects or identifies items from the selection set” (Beukelman & Mirenda, 2013, p. 84). Beukelman and Mirenda (2013) break these methods down into classifications of direct selection or scanning.

Direct Selection Access Methods

Direct selection methods involve physical contact and depression, pointing without direct physical contact, and speech recognition. Specific examples would include modalities such as touch screens, keyboards, and eye gaze systems, all of which would accompany high-tech devices. While touch screens and keyboards are commonplace in non-AAC technology, Elsahar et al. (2019) describes eye gaze systems as working “using the principle of tracking the eye movements of a user for the determination of the eye gaze direction” (p. 4). Essentially, these systems are able to track the eye movements of the user to determine where they are looking and,

therefore, which selection is desired. It's also stated that many eye gaze AAC systems work "in a multimodal form. This enables the users to use other methods of input, such as switch access, headtracking or touchscreens together with the tracking software to suit their individual needs" (p. 4).

Scanning Access Methods

Per Beukelman and Mirenda (2013), "Some individuals who require AAC technology are unable to choose items directly from the selection set" (p. 88). In these cases, scanning methods can be utilized. This involves the selection options being "displayed either by a facilitator or by electronic technology in a predetermined configuration" and the AAC user waiting for their desired selection, at which point they then "[indicate] in some way that the desired item has been presented" (p. 88). It's further noted that, "typically, those who rely on scanning access involving an AAC device accept the preferred item by activating a switch" (p. 88).

Barriers to Access

In considering the many access methods available, it's necessary to consider accompanying access issues and barriers, including those related to the motor and sensory capabilities of the individual that could influence the decision to use one access method over another. For instance, Elsahar et al. (2019) note that, "in the context of AAC, non-invasive eye tracking methods are better suited to address the daily needs of the users who lack motor abilities" (p. 4). An individual with impaired motor planning or motor control would likely benefit from use of an access method that does not rely on precise, repeated, and controlled movements in making selections.

Similarly, sensory capabilities must be considered when implementing AAC. For example, size of the device itself and of the selections, what visual or pictorial stimuli are

representative of each selection, “spacing and arrangement of items,” and even auditory feedback would all be considerations for an individual with a visual impairment (Beukelman & Mirenda, 2013, p. 82). Per Beukelman and Mirenda (2013), “cognitive, language, sensory, and motor capabilities of the individual who relies on AAC” must all be considered (p. 80).

The Role of Occupational and Physical Therapy

In exploring not only access methods but AAC implementation as a whole, it is crucial to consider the role of professionals such as occupational and physical therapists as well.

Beukelman and Mirenda (2013) highlight the importance of having both professions as part of the AAC team, including during the initial assessment process, stating that “input from occupational and/or physical therapists is critical to determine appropriate seating and positioning to maximize motor performance” (p. 326). This importance is exemplified further by Binger et al. (2012) in the statement that “occupational therapists (OTs) and physical therapists (PTs) are two of the most common collaborators, assisting with seating, positioning, and device access issues” (p. 284). Especially for those with motor and/or sensory impairments or other barriers to access, as noted above, input and involvement from occupational and physical therapists is crucial to not only select and implement an appropriate form of AAC initially but to maintain continued optimal access and therefore success on the part of the user.

Optimal User Experience

With these many technologically advanced modalities in mind, Elsahar et al. (2019) also points out that “the interaction between the user and the assistive technology is still challenged for an optimal user experience centered around the desired activity” (p. 1). These insights are echoed by McNaughton and Light (2013), who caution that, “perhaps the greatest danger in the iPad/mobile technology revolution is that the excitement over these new technologies will result

in an isolated focus on the technology alone, to the neglect of the true end goal—communication” (p. 110). Among these technologically advanced modalities of AAC, accessibility by the user and the meeting of their individualized communicative needs is of the utmost importance. With so many variable factors at play, the focus and end-goal should be selecting an AAC modality whose said variables are considered, customized, and adapted to best fit the unique needs of the individual user.

Beukelman and Mirenda (2013) explore this in their participation model that breaks down an individual’s communicative opportunity and access barriers in order to direct the decision-making process of AAC implementation. In their model, an individual’s AAC system-specific profile is considered in terms of motor, cognitive/linguistic, literacy, and sensory/perceptual factors. Similarly, Light (2003) proposes a conceptual approach to AAC use that suggest “the attainment of communicative competence is influenced not just by linguistic, operational, social, and strategic competencies but also a variety of psychosocial factors (e.g., motivation, attitude, confidence, resilience) as well as barriers and supports in the environment” (as cited in Light & McNaughton, 2014, p. 1).

Autism Spectrum Disorder and Communication

ASD is defined as “a developmental disability that can cause significant social, communication and behavioral challenges,” with a reliable diagnosis able to be made starting around the age of two (Centers for Disease Control and Prevention, n.d., para. 1). Per Beukelman and Mirenda (2013), “The etiology of autism is not known” though “considerable research is being focused on identifying a number of genetic, neurological, and environmental factors that may cause the syndrome” (p. 211). As autism is considered on a spectrum, areas and extent of

impairment vary widely, though a frequently impacted area for individuals with autism is communication and language.

These difficulties can present in “both the means and the forms of language and communication,” both expressive and receptive, though “most striking in individuals with ASD are a number of verbal and nonverbal impairments of social interaction that are apparent early in life” (Beukelman & Mirenda, 2013, p. 212). These include lack of early non-verbal communication behaviors such as gestures and facial expressions and limited or non-existent speech (p. 212). Additionally, the American Speech-Language-Hearing Association offers that “people with autism...often find it hard to have conversations and may not pick up on social cues. Some people with autism may not talk at all, and others may talk very well. But all will have some challenges making friends and communicating socially” (n.d.-d, para. 1). Given these frequently impacted areas for an individual with ASD, AAC may be implemented due to these various language and communication difficulties.

Assessing AAC Use and Performance in ASD

Given the many options available in regard to AAC modalities, many researchers have compared efficacy, acquisition rates, and student preference of these modalities both within the ASD population, and among individuals with developmental delay/disability (Achmadi et al., 2014; Boesch et al., 2013; Ganz et al., 2013; Hill & Flores, 2014; Lorah et al., 2013; Lorah, 2016; McLay et al., 2015; McLay et al., 2016; van der Meer et al., 2012a; van der Meer et al., 2012b). These studies have examined how AAC devices perform in their role of aiding communication and how they compare to one another. Does one device lead to quicker learning (acquisition rates)? Is a certain device more successful than another at allowing the individual the ability to communicate efficiently and effectively (efficacy)? Do the individuals using the

devices on a daily basis seem to consistently prefer using one type over another (student preference)? These questions, and others, are analyzed in an effort to better understand use of AAC and how certain factors can impact the resulting communicative success of a device for an individual.

Common modalities involved in these comparison studies include manual sign, picture exchange (PECS®), and SGDs, such as iPads. In their 2020 systematic review and meta-analysis, Aydin and Diken analyzed 21 studies that compared AAC modalities across the ASD population, with their results indicating that “PECS® and SGD applications...resulted to be equally effective in teaching social communication skills,” and additionally, it seemed that the majority of participants from each study “preferred SGD applications. This is an indication that individuals with ASD are more interested in technologically based applications” (p. 136). Similarly, Van der Meer et al. (2011) reviewed previous studies with a specific focus on preference among individuals with developmental disability. The review indicated that “67% of the participants demonstrated some degree of preference for using a SGD,” with the remaining 33% showing preference for PE (p. 1428).

Contributing Perspectives on AAC in the Research

In assessing AAC use within the ASD population, researchers approached the topic via the direct perspective of and interaction with the individual users of AAC. McLay et al. (2015), for instance, assessed factors such as acquisition and preference in four children with ASD by delivering direct intervention to each child for using a SGD, picture-exchange, and manual sign (MS), with the target being the ability to use the device to request an object. With respect to preference and acquisition specifically, the study resulted in each child showing a preference for

the SGD device, and each child learning to use all devices “to criterion,” except for one unable to “reach criterion with the MS option” (McLay et al., 2015, p. 334).

Bailey et al. (2006), however, approached the topic of AAC use from the family’s perspective. The individuals involved in the study were asked their view point on a number of factors pertinent to their child’s use of an AAC device, with the authors pointing out the great deal of involvement on the part of the family: “Participating in the many activities associated with AAC use means that family members often play a large role in relating important vocabulary and messages, facilitating device use across settings, programming devices, and troubleshooting problems, as well as in the daily maintenance of devices” (p. 51).

With a similarly parent-focused approach, Calculator (2013) examined AAC use and preference among individuals with Angelman’s syndrome via parent survey, with 122 parents participating. When asked what their child’s current “most effective way of communicating” is, the top three responses were, in order, electronic devices, gestures, and vocalizations (Calculator, 2013, p. 560). In response to the follow-up question asking what the reasoning was behind the choice of device, the top responses being ease of use and accessibility, with other considerations including portability, durability, and speed (Calculator, 2013, pp. 560-561).

Given the current literature and adjacent studies on the topic of AAC use within the ASD population, further research is warranted. More specifically, blending a focus on factors such as student preference and ease of use with the point of view of parents, as was exhibited by Calculator and Bailey, will allow for AAC use to be observed and analyzed from a crucial parallel perspective of sorts. This importance of the role of the parent in relation to implementation and use of an AAC device cannot be overstated nor underestimated. Rather, the parental role can best be described as that of “AAC co-pilot,” a term coined here in an effort to

adequately summarize the role of parents who often act as integral facilitators, moderators, maintainers, and co-operators of their children's AAC devices.

In gaining the most well-rounded and comprehensive understanding of AAC use by the ASD population as possible through careful consideration of the role of the many factors at play in AAC use, and from every angle and perspective possible, we will be able to further shape AAC use for the most ideal individualized implementation and for maximum communicative efficacy for each individual and their unique communication needs.

Chapter 3: Methods

Study Design

This study employed a qualitative, non-experimental, multiple case study research design in which interviews were conducted with two parents of children with ASD who are or were previously AAC users. The goal of this study was phenomenological, in that the purpose was not to collect hard numerical data but to instead gain further insight into the practical applications and use of AAC, and the direct personal experiences of both users and their co-pilots.

As stated by Bogdan and Biklen (2007), “The qualitative research approach demands that the world be examined with the assumption that nothing is trivial, that everything has the potential of being a clue that might unlock a more comprehensive understanding of what is being studied” (p. 5). This study sought to interview parents in order to further examine AAC use through their unique lens as AAC co-pilots and with the mindset that the perspectives and experiences of the parents involved can lead to before unconsidered insights. By employing a qualitative approach, the resulting outcomes can further inform clinician and professional understanding of the experience of AAC users, and of those directly involved with the daily use and handling of the devices, in terms of operation, preference, and device maintenance, which may then impact further development of AAC use towards increasingly effective communicative outcomes.

Study Participants

The study participants included two parents of children with a diagnosis of ASD who use or have previously used AAC devices. Participants were also included if there was use of AAC for at least one year and specification within the child’s Individualized Education Plan (IEP).

Parents were chosen as interviewees due to their clear and profound role in student AAC use. To again reiterate this concept, as explained by Bailey et al. (2006), this crucial role ranges from daily maintenance and programming to overall facilitation of their child's communication via AAC device. Pseudonyms have been assigned to both parents and children.

Jane and Mary

Jane is the mother of Mary, who was approximately 16 years old at the time of the interview. Mary used AAC until she was approximately 9 years old. She currently still receives speech and language services.

Amy and Ben

Amy is the mother of Ben, who was approximately 9.5 years old at the time of the interview. Ben currently receives speech and language services and has used AAC in some form for approximately 7 years.

Data Collection

Institutional Review Board (IRB) approval for study collection procedures (Appendix A) was granted by the Eastern Michigan University Human Subjects Review Committee (UHSRC). Speech-language pathologists were the direct point of contact in the recruitment processes. Emails were sent to speech-language pathologists across the United States in a wide variety of settings to introduce the study and its purpose, and to request, if interested, that a parent-directed recruitment letter be sent to potential parents who might have been interested in participation in the study.

Upon contact by the potential parent participants via email, meeting of the qualifications needed for participation in the study was confirmed using an in-take document filled out by the potential participant. In addition to the in-take document, participants were required to sign

informed consent documents (Appendix B). Interviews were scheduled after completed documents were returned to the researcher.

Due to the COVID-19 pandemic, interviews were conducted via Zoom video teleconferencing software. A set of pre-determined, semi-structured questions (Appendix C) were used to guide the interview, providing a framework and cohesiveness among answers while also allowing for the full perspective and experience of the participants to be incorporated, including any additional dialogue on the topic (Bogdan & Biklen, 2007; Creswell, 2014).

Data Analysis

Once data was gathered, the interviews were then professionally transcribed, and the process of qualitatively coding and analyzing for common themes was conducted. Each transcript was analyzed in an effort to identify codes, both prevalent and unique, and insights into use of AAC by adolescents with ASD based on the responses from the participants. Themes were developed using an in-depth process that involved combing through the data compiled from the interviews for “regularities and patterns” to develop coding categories, which “are a means of sorting the descriptive data...so that the material bearing on a given topic can be physically separated from other data” (Bogdan & Biklen, 2007, p. 173). These codes and categories were then used to provide a scoping view of the resounding similarities, unique differences, and resulting outcomes from the data, the impacts of which can then be considered in regard to AAC use by individuals with ASD.

Chapter 4: Results

Jane and Mary

Mary, age 16 at the time of the study, lives with her parents, Jane and Dave, as well as her older brother. She was diagnosed with autism around the age of 3 and was primarily non-verbal, unable to “enunciate anything,” though it was clear to her mother Jane that she had the desire to do so. Through enrollment in an early on program, Mary received in-home speech services starting at the age of 2. It was at this time that she was first introduced to picture exchange communication system (PECS)®, which was primarily used at school and in speech therapy. PECS® would occasionally be used at home as well, though other modes of communication were often preferred by Mary in that environment. As put by Jane, “We did some [PECS®] at home. She was really good at kind of communicating with us without the PECS® but she would use PECS® quite a bit when she would go to school...and of course with the speech,” adding that “when she wanted something, she would either initiate; she would go get it or she would take us and point to what she wanted.”

Early Parent Insights and Advocacy

Jane shared, “I had wanted to pursue [a speech generating AAC device] since she was about four because I really at that point had given up. I just didn’t think speech was going to come because she seemed to have the desire to speak but it would just be an utterance.” In trying to get such a device for Mary, they were met with resistance from Mary’s school at the time. Describing a mid-tech device, Jane said,

“We were trying to persuade them that we did want to do this, and they had something at the school that they sent home that was probably older than I am. It was a waste of time.

So, we tried, and she knew what it was, but it was one of those things where you slide the pictures in, and eight pictures was all it was, and she was way ahead of that already.”

She expressed not only a lack of receptivity from the school speech-language pathologist in particular, but also feeling that the school SLP “kind of down-played what she thought Mary’s capabilities were.”

When Mary was approximately 6 years old, a private SLP with whom Mary worked broached the idea of a SGD herself and was “integral” in acquiring a speech-generating device, described as having “spear-headed the idea.” In acquiring a device, the SLP initially borrowed one from a lending library offering short-term use of assistive technology to Michigan public schools. Upon Mary’s quick acclimation and success with the borrowed device, the SLP then moved to get her a permanent one.

Parent Knowledge and Training

Before receiving the device, Jane shared that she and her husband attended a “full-day seminar type thing” by what was assumed to be the device manufacturing company:

“It was really helpful because then you could see how the device worked and also of course, they had some demonstrations with the kids using it and stuff like that. So, I didn’t feel like we were walking to an abyss. We at least had an idea of what it would look like and maybe how it would work. I remember we walked out of there so excited, and we couldn’t wait to actually try it.”

In addition to this excitement, however, Jane also shared feelings of hesitation:

“I guess the only hesitancy that I had before we got it was that I felt like I was giving up on her being able to [verbally communicate]. I was afraid that she would rely on it and

wouldn't want to speak but it was actually completely the opposite. So that was a wonderful surprise for me, and [SLP] tried to tell me, but I was too scared to believe it."

The device Mary would receive was a Language Acquisition through Motor Planning (LAMP™) device from the company PRC-Satillo, described by Jane as "strictly a talker." It featured an on-screen grid of picture selections that could be spoken aloud by the device when chosen. Mary's acclimation to the device was immediate: "She took off with it. Oh my goodness! It was like night and day!" Jane shared, adding, "She knew how to find those things way better than we did, so within a few weeks, she was everywhere on it." Mary's previous experience using PECS® was cited as a contributing factor in her quick inclusion of the device as a frequent mode of communication, as was the fact that the device offered a form of expressive communication previously inaccessible. Per Jane, Mary "didn't have any problem whatsoever with wanting to use it. She did want to use it, especially at first, because that gave her a voice. Up until that time, she really didn't have one. She wanted to; she just couldn't."

Parent Observations

Mary's successful use included navigating the selection sets on the device. Jane shared, "It worked really well because she could kind of rearrange things and she knew what to touch to get to another screen, to get to another screen, to find the word she wanted." Mary also enjoyed changing the device's voice output settings—it was always a surprise whether Jane would return home to "Mary Poppins or...some guy who sounds like a radio DJ"—and sentence productions. Jane stated,

"It was real cool because she could kind of push the different pictures and it would put it into order, and then when she'd get done, she'd push the sentence... And sometimes she would do it in the wrong order just to be funny, after she got more used to it...and then

she'd start laughing. She thought that was funny. Like the moo-cow said, and then she'd start laughing.”

For Mary, the SGD also acted as a strong facilitator of her own verbal communication, to the extent that, while Jane felt Mary might have eventually acquired verbal communication, she found the SGD to be “really what helped [Mary] take off.” She wished they had gotten such a device earlier. Jane was passionate and emotional in her retelling of the first instances in which it became evident that Mary’s verbal output was growing with use of the SGD. She described a morning in the kitchen, approximately two weeks after Mary received the device, saying, “She was sitting there at the dining room table, and she was playing with it. It was a Saturday morning, and I was just watching her do what she [was] doing and she started making the sounds. Oh my gosh! I can’t describe the feeling.” She added that she had thought she might be imagining the verbal growth, but others noticed it too, and she “started making more sounds and started trying and things were coming.”

For about two years after getting the device, Mary used it primarily “out and about,” especially at school, where she would frequently use it to “answer questions and to ask questions.” As Jane described it, the device was “heavy enough where you thought about it but it wasn’t so heavy it would have prevented from taking it along.” The device would accompany Mary in the car and would typically stay there once they arrived at their destination. Jane shared that Mary and her SLP would use the SGD during speech sessions as well and that “[Mary] would go where she wanted to go [on the device] instead of where [the SLP] wanted her to go. She knew exactly what [the SLP] wanted but she wanted to go somewhere fun.”

At home, “it would normally sit on the dining room table...by her chair and any time she sat down, then she would ask for things.” Mary would, for instance, be asked what she’d like to

drink and would then turn to her device to select “milk.” As her verbal output began to grow, her response then involved her aiming to vocalize the target herself. “The more that she tried, of course the more we encouraged her to try, and so it just kind of grew from there,” Jane said. She further shared that occasionally, especially in the early days of getting the device, they would steer her to it:

“We would kind of refer her to it. Can you tell me on the talker? And then she would type and out it would come. So just trying to encourage her to get used to it but it didn’t take but a minute. And from then on, with her doing the utterances, we tried to maybe encourage that as much or more. And toward the end there, it got more where if I couldn’t understand her, then I would ask her to tell me on her talker.”

As Mary grew in her use of the device (and in her verbal communicative abilities, for that matter), so did the device. Jane said, “[The device] kind of grew with her and it was set up to do that.” The device underwent adaptations to keep up with that growth, including increases in grid size by the SLP:

“Initially, the size of the little squares were larger because there were lots to choose from and then...within a few weeks, the SLP had taken it from maybe 16 squares up and basically doubled, so then she had all those other options. And every time that you push something, there would be a new set of display and so it was almost endless but things you could view with it.”

“Wishing We Had Better Knowledge”

Mary’s efficient and effective navigation of the device outpaced her parents and sometimes even lead to getting stuck within the depths of the device, requiring the help of either the SLP or a representative from the manufacturing company. “She knew how it worked way

better than any of the rest of us did. And there was a time or two where it kind of got tied up, and we had to call the company and have them walk us through how to back it out,” Jane stated, adding that “that would probably be the only down side that I could think of was that wishing that we had better knowledge of it, and sometimes it really did need a person who that was their thing.” In efforts to better understand not only the SGD but also how their daughter was navigating it, Jane and her husband both aimed to better acquaint themselves with the device.

For Jane, her efforts to explore the device were often thwarted:

“When she did walk away from the table or something like that...I would try to take it and figure out things but then she would come back and want it because it was hers. And I wanted her to take ownership. And of course, she wanted to make it make the sounds and do the cool stuff with it, so I didn’t get nearly as familiar with it as she was.”

Her husband, Dave, who explored the programming aspects of the device and “was hands-on as far as that goes,” aimed to familiarize himself “with how to get to different things and add-in different options and try and do some of the things she did.” Jane shared that,

“After Mary would go to bed...he would sit down and try to learn a little bit more about it, try to figure out how did she get the bear and why this and why that. Or how do we get it back out of that? So that was mostly the time he would look at it because if she was around, it was hers. So she didn’t want anybody on her toys. Unless it got tied up, and then she might be willing to let us look at it.”

Evolving Communication Skills

Between age eight and nine, the device “started to be more of a chore than it was a helper” and “kind of slowed her down and she wanted to keep going.” By that point, Mary’s verbal abilities had grown to the point that “it was almost a hinderance to have to take [the

device] along with her because she was talking so much more, and she would rather talk than to have to the PECS® and whatever,” Jane said, speaking to how Mary had “evolved” in her use of the SGD. Mary ceased her use of the SGD around the age of nine and utilized her preferred mode of verbal communication from then on.

After Mary’s discontinuation of use of the SGD, they donated the device to a nearby school with hopes that another child might benefit, even if just as a trial device. Jane evidenced being a continual strong advocate for such devices. She shared that, at the request of both a representative of the AAC manufacturing company and their private SLP, she and Dave had spoken with a few other interested families about their own experience of using high-tech AAC. “I just can’t say enough good about the use of that technology; whether it’s on an iPad or whatever it is. Giving them a voice! To me, it’s a no-brainer,” she said.

Amy and Ben

Ben, approximately age 9:6 at the time of the study, lives with his parents, Amy and Jim, and his older brother. His parents are his primary communication partners, though his grandfather, and less frequently his brother, were also cited as individuals he might communicate with.

Ben is non-verbal, though will use verbal sounds and “occasionally will do word approximations but it is very limited and very inconsistent.” In addition to AAC, Ben utilizes other modes of communication, including hand-over-hand communication, which Amy exemplified as, “He likes playing with water, so he would lead you over to the hose, taking your hand and guide you over to the hose and put your hand on the hose to say, ‘Hey, I want this.’” Additional modes include biting and noise productions when upset and what Amy refers to as “expectant motion,” described as, “instead of leading you to something, he will go stand by

something and kind of stare at you. He doesn't do any kind of gesture, but he will just kind of go to an area." He will also use eye contact "with people he really is close to and trusts," Amy shared, adding, "He will do eye contact with me all day long but if you are a new person, no." Ben's preferred and primary modes of communication, however, are AAC and hand-over-hand.

Ben first began using AAC in the form of PECS® around age 2-and-a-half, before he had received an official diagnosis of autism spectrum disorder. "I didn't even know that was what they were called at the time," Amy shared. She recalled how during an autism evaluation at the Kennedy Krieger Institute, Ben used a book of PECS® to pick out a snack and the evaluating speech-language pathologist identified them then, saying, "Oh, he can use PECS®."

"I Started Making My Own"

Ben's use of PECS® primarily involved single-word selections for "requesting food and to describe the animals. So, you could show him an animal and ask him what it was, and he would go navigate to 'octopus' or 'bee,' and he really kind of liked to do that." His school had initially provided a "basic starter set of PECS®," which Amy realized wouldn't meet Ben's communicative needs. "Personally, I just dove right in..." she said, "I realized that he needed more than that because there are certain things they might provide, like Cheez-Its® for whatever as a snack option, but there were things like a pastry that he really enjoyed eating but they didn't really have the PEC...so I started making them on my own." She bought her own laminator and began "pumping out the PECS®" to the point of "running out of binders to put all of them in," which were used to organize the PECS® categorically. "We had animal binder, we had food binder, and for him to take that everywhere was just...a challenge," Amy stated, "Carrying around all those binders in his backpack, he looked like a turtle."

This issue of practicality, coupled with Ben’s excelling in his use of the modality—to the point that they “couldn’t keep up with the rate he was using” it at—led to consideration of attaining a new device for Ben. “We talked with his school and because he was excelling so well with the PECS®, they were on-board to move forward with getting him a communication device,” Amy shared. Around the age of 3:6, he acquired a high-tech AAC device in the form of an iPad equipped with the TouchChat® HD with Word Power™ AAC application. Amy stated that, while Ben’s brother has “learned over time” and “doesn’t really mess with it or play with it” anymore, the device “was like a new toy” at first—however, now “it’s just his device.” They “differentiate because he does have his iPad, so we call them the iPad and his communication device. At school, they call it his talker.”

While he’s received some replacement devices in the years since transitioning to a high-tech device, Ben continues to use the TouchChat® app, which features an on-screen grid of selections represented by pictures that, when selected, are spoken aloud by the device. Amy noted that while his classmates use devices equipped with Proloquo2Go™, another AAC application, “because he’s been using his so long, [she’s] not going to switch him. Not when he has his figured out. [She’s] not going to throw a curveball.”

Turbulence with AAC

Ben “uses his communication device a lot for labeling and requesting,” prefers single word selections over sentence strips, and “his vocabulary is always expanding.” However, a significant characteristic of Ben’s AAC use that was frequently expressed was a persistent difficulty in transferring his thoughts and communicative intentions to the device. This challenge appeared to be based on how Ben perceives and processes information.

“The way he processes the information and puts into his device is sometimes a little...I would say challenging to understand because he is doing it from his perspective,” Amy shared. For example, when trying to convey something unfamiliar using his device, Ben’s “go-to descriptor” is color: “If he doesn’t know the word for garden hose and where it’s located at in his device, he will just say, ‘play green, play green.’” Amy explained that Ben will also use alternative words:

“Occasionally, he’ll ask for something...he would ask for the word ‘laugh’ like laughter and the word for ‘lamp’ like light. And I have no idea still what exactly he is asking for...so sometimes you don’t necessarily know exactly what it is that he is picturing in his mind, but those two words are the ones that he selects.”

As Amy noted, “Sometimes it’s less about what it really is and more about just whatever association he is making in his head. Because I think he thinks in images. I don’t think he thinks in terms.” Despite the use of image representations for selections on the device, challenges persist in this interrelation between user and device: “Because they all have images on them, he knows it’s not the image of what he wants”; however, “some of the images don’t necessarily make sense for him.” The term “basement” was given as an example. Whereas the basement at Ben’s house—the one he would be familiar with—is a finished basement, the device features pictures of unfinished basements: “So, I don’t know if he would associate that image with that location. Unless you specifically teach that this button/this picture represents this over here... and sometimes that’s the case.”

In considering Ben’s inputs and navigation of the device, Amy stated, “Some of the way it’s laid out isn’t necessarily intuitive for him in the way that he is thinking about things.” For example, the first page of descriptive selections on the device is colors:

“That’s all that’s on it is just colors. And then you have to click the next page button to get to more descriptors and they have opposite words like soft/hard, warm/cool, broke/fixed, and that kind of thing. And you can click through a couple of those but...I don’t think when he is thinking about things he thinks about [them] in terms of opposites. So, I don’t necessarily think he thinks soft and hard should be right next to each other.”

Such challenges result in subsequent behavioral adaptations by Ben, such as deferring to another mode of communication entirely. While he is able to navigate quickly to familiar selections, “if it’s too complicated basically for him to search something out, or if it’s significantly easier for him to just lead you to what he wants, then he’ll do that,” Amy stated, “He kind of takes the path of least resistance sometimes.” In considering the device page featuring feelings as another example, the first page contains “dominant feelings like happy, sad, frustrated, angry...but to get to some of the different ones like silly, you have to go to next page. And if it’s on the next page, unless he is really familiar with that page, he just won’t go to the next page until he kind of learns...either he really wants something that is one of those pages.” Essentially, “unless it’s like a strong draw, dialing down into multiple other pages” isn’t easy for Ben.

Parent Preference

Expressing a preference for modeling over prompting, Amy stated, “I don’t really do prompting to make him do it; I just kind of show him where it’s at and if you do that enough times, they kind of figure it out usually, unless they are not really interested in it.” She further added, “I try not to tell him what he wants; I try to ask him what he wants, so instead of, ‘You’re frowning; you must be sad,’ I would say, ‘Oh, you’re frowning. Are you sad?’ Not saying this must be what he is feeling because that could be completely different than what he is feeling.”

As for modeling, she shared, “I feel like I model more than anybody else, but his dad does use it and ask him what he wants to eat, and kind of pushes it towards him kind of thing. And he has an ABA therapist right now; she does kind of the same.”

Amy additionally stated, “I’ll model things that are existing in there or I’ll model things that I add in there.” She spoke specifically of adding in the garden hose after Ben requested “play green, play green,” saying,

“Like with the hose...where would garden hose be on his device? I don’t know. Is there a gardening section on there? I don’t really see one but under tools they had a rake and some other things, so I just shoved it there. So, I went in and created a button and I placed it with ‘hose,’ and I showed him where it was, and then the next time he asked for ‘green,’ I would ask if he wants hose and then he will go in and yes, that is what he wants. That’s normally how I do that.”

Parent Knowledge and Frustrations

Similar to Ben’s initial use of PECS®, Amy found the selections available on the SGD to be lacking. “When we moved into AAC, I realized there were certain things on there that he might need or might need to utilize so I got permission from the school so that I could edit his device in any way that I wanted,” she stated, offering, for example, that when Ben went through a phase of being interested in construction equipment, she added in “an excavator and a cement mixer and things like that that weren’t on the page to begin with.”

Amy experienced difficulties in adding and maintaining vocabulary in Ben’s device, specifically when it came to button sets. On some high-tech aided AAC devices such as Ben’s, button sets are a way to link and maintain a selection button throughout the device, across multiple pages that the button may be included on due to relevancy: “The problem is if you

accidentally edited a button that looks like a button but is actually a button set, then you are changing it across all the things. So, you will accidentally go into hygiene and then...why is there a rainbow where shower should be?”

Other frustrations that have arisen over the years of Ben’s use of high-tech AAC include accidental device edits. Instead of erasing the current selections in the sentence strip at the top of the SGD screen by “hitting the clear button,” Amy shared that,

“He likes to backspace through every single word, but the problem is there is a little button right underneath that which is for editing or changing pronunciations and things like that. He will accidentally hit that and mess things up. So, I wish there was a way to change it so that it wouldn’t open that up and mess him up and then mess buttons up, because occasionally buttons just get messed up and I don’t know why. They make no sense how one thing appeared where it was, and I think it might be just because he is accidentally hitting buttons to try to get out of that.”

Variation in voice output between devices though the same AAC application and settings are being employed and inadequate pronunciations were also noted as frustrations by Amy:

“The only other thing that is I feel like annoying to me is the pronunciation. He likes the show *Pokoyo*. So if you type in “*Pokoyo*,” it doesn’t pronounce it “*Pokoyo*,” it pronounces it completely different. But instead of having where you go in to change the pronunciation, instead of having more phonetic letter based or something like that, you just have to kind of type it in a couple different ways until it sounds like you want it to sound...You have to fiddle with it until it says what you want it to say.”

Amy herself exhibited a real familiarity with Ben’s device, sharing, “I’m pretty good at navigating finding things and if it doesn’t exist, creating it and putting it some place that I think

is the logical place for it or kind of maneuvering things around.” She likened understanding the organization aspect of the device to having “a filing cabinet system brain” in which

“You have to go to somebody else’s computer and find a document and all they have on their desktop is folders with different names on them...some people have a really easy time of narrowing down exactly where it might be in a folder and searching those particular folders to try to figure it out.”

In regard to difficulties that may present themselves, Amy expressed a sense of determination, declaring, “Okay, we’ll figure this out and if I can’t figure it out, I’ll ask somebody who can figure it out for me.” Further demonstrated, too, was a sense of responsibility to really understand her son’s device: “I have to feel like as the parent learn his device so I can model for him...Unless you have a really inquisitive kid who is just going to poke around, that’s not going to happen. So, we are pretty good about trying to model things for him.”

Communication Partners

Although Ben’s primary communication partners are his parents, it was also shared that “he recognizes that if he wants something, he is more likely to get it from an adult,” as opposed to his brother, for example,

“So, he’ll take his device to an adult, or he’ll go to an adult and do hand-over-hand to try to get what he wants or what he’s interested in; and he’ll do that with adults he is close to like grandfather and that sort of thing but if it’s an adult that he’s not really close to, he just kind of doesn’t interact with them at all, even if they try to engage him.”

Who his communication partner was exhibited to be more influential over use than setting, with Amy sharing that “he’ll use it in other places, but with other people, [she’s] not really sure” though “he’s rarely without a familiar individual.”

Amy stated that although “he’s less likely to use it in a busy setting...just because there is a lot of distractors,” Ben’s use of his device in the community largely resembles his home use. In addition to use at school, where he also uses it to request food, he’ll use it in other settings: “If we go to the park and I’ve packed a small picnic lunch, and I’ve put his device on the picnic table, he’ll use it the same way he does at home. ‘I want watermelon’ or ‘I want this thing over here.’” Use at the museum or zoo was also offered as a situational example, in that “he would tell [his parents] what each of the animals were that he could identify, and that’s on his device. Sometimes that is prompted, like ‘Oh, what’s that?’ rather than prompting like ‘press that button.’”

Chapter 5: Discussion

As the participants described both their children's interactions with AAC devices and their own experiences, the extent of the parental role as co-pilot became increasingly apparent. The perspectives and knowledge shared, efforts exhibited, and commitments made that were demonstrated by the parent participants separately inform the resultant themes below and cumulatively converge to forge the overarching role of co-pilot in their child's AAC use. These themes include co-pilot view from the cockpit, co-pilot navigation, and pilot and co-pilot communication. The culmination of these themes results in the co-pilot as a foremost support in their child's successful piloting.

Co-Pilot View From the Cockpit

In sharing their stories and experiences, each participant consistently demonstrated extensive observations of—and keen perceptions into—their child's AAC use and their communication as a whole. It can be noted that in the sharing of such observations and resulting insights, the participants did so distinctly from the perspective of observer or witness. Their children's preferences, patterns, habits of use, moments of success or lack thereof, etc., were not questioned nor challenged, but simply recognized. As the observer—a co-pilot—the participants relayed their parallel point of view; they described their perspectives of their children's communicative tendencies and preferences and aspects of the devices they observed to potentially impact communicative success, all with the same underlying, unspoken goal—to better understand their child. Or, put more comprehensively, to better understand the many facets of their child's communication, how their child relates to his or her device, and how they could best help them succeed.

These observations ranged from how communication and AAC use varied based on where they were and who they were communicating with, to why and how they were communicating. Jane recognized that Mary's device was used more "when she was out and about" as opposed to at home, and that there, with family, she was "really good" at—and appeared to prefer—communicating using unaided methods such as gesture. Amy perceived that Ben would be deterred from AAC use in some community settings due to the many "distractors," but that in less crowded situations he would employ AAC "the same way he does at home." She too observed *who* the communication partner is to be crucial in that Ben "doesn't interact" with unfamiliar individuals. This includes when the unfamiliar individuals initiate the interaction themselves.

Participants noticed changes in how their children used the devices over time and circumstance. Jane saw Mary's initially high level of motivation for device use eventually decrease as verbal output became her preferred mode and the device became more of a "hinderance." Amy discerned that searching through multiple device pages for an unfamiliar selection wasn't easy or inherent for Ben, and that in those cases, he'd rather just use a different, simpler method to communicate his wants.

These keen observations by the co-pilots also fueled their ability to advocate for their children. By understanding their children's communicative patterns and needs, they were better equipped to champion what would most benefit their child. Jane recalled having to "persuade" Mary's school to get on board with the idea of a SGD for her and how she wanted Mary to take "ownership" of the device—because she witnessed how the device "gave her a voice." Amy doesn't *tell* Ben, but instead, she tries "to ask him what he wants," because her assumption "could be completely different than what he is feeling."

“Co-Pilot View” Connections to the Literature

The insights resulting from the co-pilots’ observations echo factors explored in previous AAC research, offering a pattern of consistent considerations. Though exploring AAC use by individuals with Angelman’s syndrome, parents in Calculator’s (2013) study were asked to identify factors impacting their child’s “most effective” methods of communication (p. 560). Their responses mirror the aspects of device use recognized by Jane and Amy as being either helpful or hindering, such as ease of use, which both Ben and Mary grappled with in their own ways.

Existing research examining modality preference highlights a majority preference for speech-generating devices by individuals with ASD (McLay et al., 2015; McLay et al., 2016; van der Meer et al., 2012b). Mary’s preference for the SGD was recognized by Jane, due to its allowing for verbal expression in a way previously unavailable. However, Mary’s primary modality was also reported to change based on her environment, such as school versus home. For Ben, an explicit preference for a SGD was never stated. His use of the device as a primary modality was rather evidenced as being based on its efficient practicality as compared to other aided modalities. Ben’s modality of choice appeared to fluctuate based on context as well.

Co-Pilot Navigation

The ways in which co-pilots offered direct device-related support were extensive and comprehensive. Such efforts included adapting the device to best suit the child’s needs, making sure the device was readily available, and modeling and prompting to expand the child’s knowledge and create communicative opportunities. Additionally, just as effective co-pilots require adequate knowledge and familiarity of the airplane, the participants indicated efforts to

expand their own knowledge surrounding AAC, as well as a longstanding commitment to their role.

Noticing that the existing selections for both PECS® and the SGD were inadequate for Ben, Amy “just dove right in.” She became proficient in not only creating more relevant vocabulary, but also in maneuvering selections around the device and “doing almost everything.” Her familiarity was enough to have frustrations with device technicalities she wished could be changed for more suitable use—such as pronunciation of Ben’s favorite show, *Pokoyo*—as well as to develop a preference for modeling over prompting. With modeling, she’s found that if she shows Ben enough times where a word is, he’ll learn it—if he’s interested enough. And while she’s partial to the former, when prompting is utilized, Amy frames it as a direct question—such as, “What’s that?”—as opposed to a directive, namely, “press that button.”

Jane too aimed to create opportunities for device use by referring Mary to the device, especially in the early days after acquiring the SGD. This commitment to encouraging communicative opportunities persisted as Mary’s use evolved, shifting focus over time from device use to verbal output as she grew to prefer the latter. Even then, however, Jane would refer Mary back to the device in instances when she couldn’t quite understand Mary’s speech.

Both participants conveyed a responsibility on their part to ensure the device was on hand and available. In sharing how Mary’s device would always be in the car but would typically be left there when going into places, Jane determined, “I probably didn’t take it with us as much.” Amy similarly put the onus on herself when speaking of Ben’s device use at the park, saying when “I’ve put his device on the picnic table, he’ll use it the same way he does at home.”

Fortifying co-pilot’s efforts to provide device support is a foundational knowledge—and pursuit of continued learning—and commitment. Both are found in Dave’s “hands-on” efforts to

familiarize himself with Mary's device, using the time after she went to bed to understand its innerworkings, and "why this and why that." This same dedication was initially demonstrated in Jane and Dave's attendance of a device seminar, which they left feeling "excited" and as though they weren't "walking into an abyss." And when recalling instances when Mary got "so into the system" that outside assistance was required, Jane placed the onus of such challenges on their own lack of proficiency and expressed "wishing we had better knowledge of it." Amy expressed a keen understanding of the device, likening it to a "filing cabinet system brain," though too noted a resolve for instances in which her knowledge or familiarity may be lacking, stating, "We'll figure this out," and if not, "I'll ask somebody who can."

"Co-Pilot Navigation" Connections to the Literature

The ways in which the co-pilots offered device support resonates with responsibilities outlined similarly by Bailey et al. (2006), who highlighted the family role in "relating important vocabulary and messages, facilitating device use across settings, programming devices, and troubleshooting problems, as well as in the daily maintenance of devices" (p. 51). Foundational knowledge was illustrated as being a key component of the co-pilots' ability to offer successful device support, aligning further with Angelo et al.'s (1995) reporting of the need of families "for more information and training about AAC devices" (as cited in Bailey et al., 2006, p. 51). It can be noted that the participants in this study demonstrated self-initiation to fulfill this requirement, taking it upon themselves to familiarize themselves with the devices, attend training seminars, etc.

Pilot and Co-Pilot Communication

The lengths gone to by the co-pilots culminate in a resultant strengthening of an inherent aspect of their role as co-pilot—that of crucial conversation partner for their children. The

success of this role is bolstered by the efforts, knowledge, and commitments of the co-pilots to understand *and* actionably support both their children as communicators and their devices as aids to that communication.

Though participants inadvertently demonstrated themselves to be a primary and foremost communication partner for their children, the crux of the crucial conversation partner is that it is a position appointed by the child—by the pilot themselves. This is perhaps the defining component that distinguishes the parent as co-pilot, and thus puts them in such a position to integrate their own self-driven understandings and efforts to be that foremost support for their child. This communicational connection spans across modalities and is displayed not only in the subtext of the experiences shared by the participants, but directly as well. Ben’s use of eye contact is limited to only those he is closest to—with Amy, he’ll make eye contact “all day long.” In addition to a frequent shift in primary modality when Mary was at home with her co-pilots, they would be who she—though protective of her device—would turn to for troubleshooting when the device “got tied up.”

Augmenting this crucial communication role appointed by the pilot are then the skills and knowledge honed within the other facets of the co-pilot role—their expansive understanding of their child’s communication and insight into what lends to their communicative success, their foundational knowledge and familiarity with AAC, and their commitment to continued growth of that knowledge and continued support of their child. This knowledge, skill, and commitment—this expertise—converges to directly strengthen, fortify, and support the co-pilot in their part of “pilot and co-pilot communication.” Essentially, the pilot’s chosen communication partner is also the most informed on how they communicate, what impacts their ability to effectively do so, and has perhaps the best insights into how to support said communication as well.

In recognizing that not only was Mary’s verbal output increasing, but that she was beginning to favor it as her preferred modality as well, Jane adapted her support accordingly. Mary’s use of speech was thus encouraged “as much or more” than the SGD, until the latter was referred to only when Mary couldn’t quite be understood. In this, Jane incorporated her resulting co-pilot knowledge into her approach to supporting Mary’s communication, subsequently facilitating continued communicative growth as well as further strengthening of the communicative connection between pilot and co-pilot.

Similarly, Amy relayed the difficulties she observes Ben to have in inputting his thoughts into the device because he’s “doing it from his perspective,” and his use of color as a “go-to descriptor.” In doing so, she demonstrated not only her own awareness and recognition of various impacts on Ben’s ability to effectively utilize his device, but also the ability to determine exactly where the breakdown is occurring and what strategies Ben uses to compensate for such difficulties. In turn, this knowledge then further informs both her support of Ben’s communication and device use—such as her addition of ‘garden hose’ into his device after realizing that was his intention in saying “play green, play green”—and her ability to engage in successful communicative interactions with him. After adding “hose” to the device, Amy showed Ben where it was located, and upon his next request for “green,” she would “ask if he wants hose, and then he will go in and, yes, that is what he wants”—an interaction that is the culmination of initial co-pilot understanding, knowledge-based deciphering, and device navigation to support effective communication use, incorporated into action by the co-pilot in her conversing with the pilot as his crucial and foremost communication partner.

“Pilot and Co-Pilot Communication” Connections to the Literature

The critical importance of this aspect of the co-pilot role is substantiated in considering the social implications of the persistent language and communication difficulties of individuals with autism. Stated by Beukelman and Mirenda (2013) as “verbal and nonverbal impairments of social interaction” and by ASHA (n.d.-d) as “challenges making friends and communicating socially,” the significant impact on social engagement and communication with others is clear (p. 212, para. 1). In successfully embodying the crucial conversation partner, the co-pilots directly engage with—and in their cumulative efforts, aim to support and ameliorate—a facet of their child’s communication that is one of, if not the most, challenging for their child to navigate. Angelo et al. (1995) further substantiates this idea in stating that the role of the family can include “sharing or fully assuming responsibilities for promoting the operational, linguistic, social, and strategic experiences for AAC users” (as cited in Bailey et al., 2006, p. 51).

Chapter 6: Conclusion

Summary of Findings

This research sought to explore the parent perspective on AAC use by their children with ASD in regard to implementation, use, and overall communicative success. What emerged was a direct insight into the prominent and crucial role played by these parents—that of co-pilot to their child’s use of AAC. In examining both their child’s AAC use and their own experiences and perspectives on the matter, the co-pilots demonstrated the comprehensive ways in which they acted to support their child’s communicative success—or rather, to aid in the takeoff and flight of their child’s communication.

These supportive efforts emerged categorically as three distinct themes: co-pilot view from the cockpit, co-pilot navigation, and pilot and co-pilot communication. In their view from the cockpit, the co-pilots shared observations that resulted in unmatched understanding and insight into their children as communicators, including preferences, needs, and evolving abilities. These understandings further inform and bolster not only their abilities to adequately advocate for their children, but also relate directly to both their acting as a crucial conversation partner and providing device support and navigation, the second theme. The ways in which the co-pilots aim to support device use are many, including both direct involvement, such as adapting the device, modeling, and creating opportunities for communication, as well as the more conceptual efforts of expanding their own knowledge and understanding, and demonstrating continual commitment to these efforts and to their role.

Pilot and co-pilot communication is in essence an active amalgamation of the co-pilot’s knowledge, insights, supportive efforts, and role as their child’s trusted second-in-command in communication. In this, the co-pilots emerge as a foremost communication influence, able to

directly engage in a manner inherently challenging for their child and in a position to see their communicative abilities soar to new heights. A defining feature of the co-pilot as a crucial conversation partner, and subsequently informing the overarching role of co-pilot as well, is that the child themselves grants this position, demonstrated both directly and indirectly in the communicative behaviors and interactions relayed by the participants. In this foremost role, the co-pilots then draw directly from the wealth of knowledge and skills gained in the coinciding facets of their role as co-pilot to maximize their communicative support, and to fortify their crucial communication with their children, the pilots.

The resulting data from this research both support the existing literature and expand current understanding of the role of the parent in their child's AAC use. The device characteristics and modality preferences observed by Amy and Jane as having impacted their child's use of AAC are similarly noted in existing literature (Calculator, 2013; McLay et al., 2015; McLay et al., 2016; van der Meer et al., 2012b). Newly emergent, however, is the depth of co-pilots observations and the scope of their resultant understandings, leading to such insights as preferences and aiding characteristics.

Similarly, the participants in this study corroborated the familial responsibilities often involved in AAC use and the need for such families to have adequate knowledge of AAC, both put forth by Bailey et al. (2006) and Angelo et al. (1995, as cited by Bailey et al., 2006). Further, the co-pilots demonstrated not only the necessity of a foundational understanding of AAC and devices, but also displayed a self-initiated seeking of further knowledge, speaking to a crucial commitment had by co-pilots to best understand in order to best support—to become knowledgeable about the plane in order to assist in flying the plane, in essence.

Lastly, relating not only to the embodying theme of pilot and co-pilot communication but also to the entirety of the co-pilot role is the acknowledgement by the literature of the prevalent communicative and social difficulties experienced by many individuals with ASD (ASHA, n.d.-d.; Bailey et al., 2006; Beukelman & Mirenda, 2013). This research offered direct insights into the communicative fronts afforded to co-pilots within this persistently challenging realm of their child's experience. Within this role, co-pilots are the principal partner for precisely what their child potentially experiences the most difficulty with—communication. Cumulatively, the data from this study sheds light not only on the unique significance of the co-pilot role and its facets, but also on the many possible positive implications of being the pilot's right-hand for such a flight.

Implications

While the importance of parents and families of individuals receiving speech and language services in general has been both established and emphasized within the field of speech-language pathology, the perspectives of the co-pilots in this study illustrated both the extent and depth of the potential impact of these individuals on children using AAC. These expanded insights have widespread potential impacts for the field, both at large and for the subset working specifically with AAC.

In highlighting the role of the parent as co-pilot and delineating the efforts that lend to the influence and effectiveness of the role, the findings of this study reinforce just how crucial the parent can be in targeting AAC—and communication as a whole—with the children we serve. Further suggested by these findings is the importance and potential positive outcomes of successful collaboration between parents and speech-language pathologists. While the cruciality of the SLP cannot be ignored, neither can that of the parent. To collaborate efficiently, fully

honoring the role of co-pilot and the position they hold, will allow for maximized applicability and effectiveness of intervention, and therefore outcomes, assumedly. For instance, such a partnership might involve not only the SLP gaining further insight into the child based on parental knowledge shared, but also the ability of the SLP to offer parent education to further complement their duties as co-pilot.

As outlined in the theme of co-pilot view from the cockpit, the point of view of the co-pilot and the insights they are afforded due to their position are unmatched, and such information can be directly applied to treatment. To understand what aspects of a device prove challenging for a user, or what modalities they employ where, with whom, and under what circumstances allows for interventions targeting potentially turbulent aspects of device use and/or areas of growth that would prove most impactful for the pilot. Furthermore, the defining component of the pilot and co-pilot communication theme is that the AAC user themselves—the pilot—has designated their co-pilot as their foremost communication partner, thus putting them in an inherently imperative position when it comes to targeting communication. This unique communicative connection can, and perhaps should, be incorporated directly into service delivery when possible. Including the parent co-pilot would not only allow for learning on the SLPs part about the child’s interactions with their most prominent communication partner but could also offer potential generalization of skills being targeted across environments.

Co-pilot navigation can be particularly supported in not only offering continued education regarding the innerworkings of the device or maintenance, but also for strategies such as modeling, prompting, and creating more opportunities for communication for their child—all things they are shown to be doing on their own already. While we as SLPs may have precise and exacting knowledge of AAC, the co-pilot is on duty the vast majority of the time. Augmenting

and supporting their knowledge, their expertise, and their comfort level with the device would reinforce and strengthen each facet of the co-pilot role and, potentially, also lead to increased and more consistent use by the pilot themselves.

It is of vital importance for the SLP to support and encourage the role of co-pilot. This research demonstrates both the distinction and significance of this role. The knowledge and insights of the co-pilot are distinctive to them and to the role—not just anyone is allowed into the cockpit. To have the fullest picture of the individuals we work with will only aid in our efforts to best provide services, and co-pilots are an essential component of our most comprehensive understanding and to implementation of the most individualized and effective treatment possible.

Limitations and Delimitations

Limitations of this study include the small number of participants, which led to the multiple case study approach taken. Both study participants were female-identifying and hailed from the Midwest, despite widespread recruitment efforts. Both participants noted that their children continued to receive speech and language services and one participant noted applied behavioral analysis (ABA) services as well. Experiences and outcomes ensuing from such interventions have the potential to influence communicative behaviors and perspectives as examined by this study. A final limitation can be found in the primary use by both AAC users involved in the study of high-tech speech-generating AAC devices, resulting in a significant portion of the qualitative explorations of participant experiences and perspectives revolving primarily around this modality.

Delimitations of this study include the concentration solely on children and adolescents with autism spectrum disorder, thereby eliminating involvement of other populations who employ AAC, as well as older individuals with ASD. Qualification for the study required that the

child's IEP specified AAC use, resulting in participation by individuals who had perhaps engaged in more targeted, structured use of AAC and whose speech and language interventions may have specifically involved such targeted use.

Directions for Future Research

This study analyzed facets of AAC use currently underexplored in existing research, including not only the role of the parent at large, but also the myriad of ways in which they directly support and impact their child's communication. Emergent in this research were insights into the emotional impacts on parents as co-pilots, as well as more conceptual considerations at play, such as commitment. While perhaps unsurprising, these emotional and conceptual components can be further explored to better grasp not only the position and perspective of parents but also to inform further understanding surrounding the impact of this process on parents and how such influences drive their dedication to AAC implementation.

The influence of interdisciplinary professionals involved in the AAC process was also noted by participants in the present study. Research exclusively exploring such collaborations on AAC use between parents and professionals, and factors impacting success in such relationships, would resultingly allow for positive partnerships, increasingly individualized interventions on behalf of the child, and continued overall success of AAC interventions.

Lastly, research exploring similar concepts among larger participant numbers and utilizing various research methodologies/approaches, and across various populations, would allow for expanded and heightened insights and understanding into the use of AAC in its many forms as well as increased generalizability of findings.

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APPENDICES

Appendix A: Expedited Initial Approval Form



University Human Subjects Review Committee

Apr 20, 2021 9:53:29 AM EDT

Kelcy Rolak
Eastern Michigan University, Special Education

Re: Exempt - Initial - UHSRC-FY20-21-207 AAC Use by Adolescents with ASD and their AAC Co-Pilots

Dear Kelcy Rolak:

The Eastern Michigan University Human Subjects Review Committee has rendered the decision below for AAC Use by Adolescents with ASD and their AAC ~~Co-Pilots~~. You may begin your research.

Decision: Exempt - Limited IRB

Selected Category: Category 2(iii). Research that only includes interactions involving educational tests (cognitive, diagnostic, aptitude, achievement), survey procedures, interview procedures, or observation of public behavior (including visual or auditory recording) if at least one of the following criteria is met: The information obtained is recorded by the investigator in such a manner that the identity of the human subjects can readily be ascertained, directly or through identifiers linked to the subjects, and an IRB conducts a limited IRB review to make the determination required by §46.111(a)(7).

Renewals: Exempt studies do not need to be renewed. When the project is completed, please contact human.subjects@emich.edu.

Modifications: Any plan to alter the study design or any study documents must be reviewed to determine if the Exempt decision changes. You must submit a modification request application in [Cayuse IRB](#) and await a decision prior to implementation.

Problems: Any deviations from the study protocol, unanticipated problems, adverse events, subject complaints, or other problems that may affect the risk to human subjects must be reported to the UHSRC. Complete an incident report in [Cayuse IRB](#).

Follow-up: Please contact the [UHSRC](#) when your project is complete.

Please contact human.subjects@emich.edu with any questions or concerns.

Sincerely,

Eastern Michigan University Human Subjects Review Committee

Appendix B: Informed Consent Form

RESEARCH @ EMU

Informed Consent Form

Project Title: *AAC Use by Adolescents with ASD and their AAC Co-Pilots, a Master's Thesis*

Principal Investigator: **Kelcy Rolak, Eastern Michigan University**

Faculty Advisor: **Dr. Sarah Ginsberg, Eastern Michigan University**

Invitation to participate in research

You are invited to participate in a research study. In order to participate, you must be a parent of a child with autism spectrum disorder (ASD) whom has been a user of augmentative and alternative communication (AAC) for at least one year. Use of AAC device must be part of the student's IEP. Participation in research is voluntary. Please feel free to ask any questions you have about participation in this study.

Important information about this study

- The purpose of the study is to gain a better understanding of the experiences and perspectives of children with ASD and their parents regarding use of AAC.
- Participation in this study involves an interview over Zoom teleconferencing software, lasting approximately one hour, that consists of a conversation surrounding the participant and their child's experiences with AAC. There will be a possibility for a brief follow-up interview if needed after the initial interview has taken place.
- Participant interview responses will be transcribed and analyzed in an effort to more fully understand the multifaceted perspectives of parents as their child's AAC co-pilot, as well as the child's experiences as the direct AAC user.
- Risks of this study include the sharing of personal experiences and perspectives relating to AAC use.
- The investigator will protect your confidentiality by keeping all study data and materials logged and locked in a document within a password-protected file on a password-protected computer, and never using identifiable information in the collection or keeping of data, nor in the subsequent thesis paper and possible professional presentation and/or article to follow.

- Participation in this research is voluntary. You do not have to participate, and if you decide to participate, you can stop at any time.

What is this study about?

This study aims to examine what factors impact and contribute to successful AAC use among students with ASD by looking at parent perspectives of their child's AAC use. By exploring the experiences and perspectives of parents of children with ASD who are AAC users, this research will allow for insights into possible patterns and commonalities of use and interactivity of AAC devices.

What will happen if I participate in this study?

Participation in this study involves:

- Participants will be asked questions surrounding their children's use of AAC devices as well as their own personal experiences with and perspectives of AAC.
- A one-hour (approximately) interview conducted over Zoom.
- Possibility of a brief follow-up interview if needed.

We would like to audio record you for this study. If you are recorded, it will be possible to identify you through your voice. If you do not agree to be audio recorded, you may not be eligible to participate in this study.

What types of data will be collected?

Data collected for this study will consist of participant interview responses.

What are the expected risks for participation?

There are no expected physical or psychological risks to participation.

The primary risk of participation in this study is a potential loss of confidentiality.

Some of the interview questions are personal and may make you feel uncomfortable. You do not have to answer any questions that make you uncomfortable or that you do not want to answer. If you are upset, please inform the investigator immediately.

Are there any benefits to participating?

You will not directly benefit from participating in this research.

Benefits to society include further understanding of individual experiences of AAC use, namely the underexplored parent perspective.

How will my information be kept confidential?

We plan to publish the results of this study. We will not publish any information that can identify you.

We will keep your information confidential by using a code to label data with the code linked to identifiable information in a key stored separately from data. Your information will be stored in a password-protected file on a password-protected computer. We will store your information for at least five years after this project ends, but we may store your information indefinitely.

We will make every effort to keep your information confidential, however, we cannot guarantee confidentiality. The principal investigator and the research team will have access to the information you provide for research purposes only. Other groups may have access to your research information for quality control or safety purposes. These groups include the University Human Subjects Review Committee, the Office of Research Development, the sponsor of the research, or federal and state agencies that oversee the review of research, including the Office for Human Research Protections and the Food and Drug Administration. The University Human Subjects Review Committee reviews research for the safety and protection of people who participate in research studies.

If, during your participation in this study, we have reason to believe that elder abuse or child abuse is occurring, or if we have reason to believe that you are at risk for being suicidal or otherwise harming yourself or others, we must report this to authorities as required by law. We will make every effort to keep your research information confidential. However, it may be required by law that we have to release your research information. If this were to occur, we would not be able to protect your confidentiality.

Storing study information for future use

We will not store your information to study in the future. Your information will be labeled with a code and not your name. Your information will be stored in a password-protected or locked file and will be stored indefinitely.

We may share your information with other researchers without asking for your permission, but the shared information will never contain information that could identify you. We will send your de-identified information by email and only upon request.

What are the alternatives to participation?

The alternative is not to participate.

Are there any costs to participation?

Participation will not cost you anything.

Will I be paid for participation?

You will not be paid to participate in this research study.

Study contact information

If you have any questions about the research, you can contact the Principal Investigator, Kelcy Rolak, at krolak@emich.edu or by phone at 734-637-0220. You can also contact Kelcy Rolak's adviser, Dr. Sarah Ginsberg, at sginsberg@emich.edu.

For questions about your rights as a research subject, contact the Eastern Michigan University Human Subjects Review Committee at human.subjects@emich.edu or by phone at 734-487-3090.

Voluntary participation

Participation in this research study is your choice. You may refuse to participate at any time, even after signing this form, without repercussion. You may choose to leave the study at any time without repercussion. If you leave the study, the information you provided will be kept confidential. You may request, in writing, that your identifiable information be destroyed. However, we cannot destroy any information that has already been published.

Statement of Consent

I have read this form. I have had an opportunity to ask questions and am satisfied with the answers I received. I give my consent to participate in this research study.

Signatures

Name of Subject

Signature of Subject

Date

Consent to Audio Recording

I give my consent to be audio recorded for this research study.

Signatures

Name of Subject

Signature of Subject

Date

I have explained the research to the subject and answered all their questions. I will give a copy of the signed consent form to the subject.

Name of Person Obtaining Consent

Signature of Person Obtaining Consent

Date

Appendix C: Survey Instrument

Interview Questions:

1. Tell me about your child's everyday communication. (Follow-up as needed)
2. Can you give an overview of your child's AAC use? (Follow-up as needed)
 - a. What was used first?
 - b. What went into the decision of what to use and what not to use?
 - c. What other items/methods are used for communication (schedules, paper, gestures, etc.)
3. What has been your own personal experience in handling and working with AAC?
(Follow-up as needed)
4. What aspects of the device work and what aspects don't work? (Follow-up as needed)
 - a. Voice, battery, vocabulary, symbols or pictures, portability/weight of the device, etc.
5. How do members of the family view the communication device? (Grandparents, siblings, etc.; follow-up as needed)
 - a. How does your child communicate with everyone in the house and those they are familiar with?
 - b. How does your child communicate within the community?