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The Impact of Parent Education With Augmentative and Alternative Communication

Presented in Partial Fulfillment of the Requirements for the Degree of Doctor of Occupational Therapy

Eastern Kentucky University College of Health Sciences Department of Occupational Science and Occupational Therapy

> Kirsta M. von Hellens 2020

## EASTERN KENTUCKY UNIVERSITY COLLEGE OF HEALTH SCIENCES DEPARTMENT OF OCCUPATIONAL SCIENCE AND OCCUPATIONAL THERAPY

This project, written by Kirsta M. von Hellens under direction of Camille Skubik-Peplaski, Faculty Mentor, and approved by members of the project committee, has been presented and accepted in partial fulfillment of requirements for the degree of

## DOCTOR OF OCCUPATIONAL THERAPY

CAPSTONE COMMITTEE

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Committee Member

Date

11/25/2020

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# EASTERN KENTUCKY UNIVERSITY COLLEGE OF HEALTH SCIENCES DEPARTMENT OF OCCUPATIONAL SCIENCE AND OCCUPATIONAL THERAPY

## Certification

We hereby certify that this Capstone project, submitted by Kirsta M. von Hellens, conforms to acceptable standards and is fully adequate in scope and quality to fulfill the project requirement for the Doctor of Occupational Therapy degree.

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## **Executive Summary**

**Background:** Communication is an essential part of who we are, as we participate in our occupational roles, even for those who utilize an augmentative and alternative communication device. Although communication devices are used at school, they rarely went home for the weekend or the summer.

**Purpose:** The purpose of this project was to evaluate the impact of a parental training program, as parents utilized a communication device, in order to increase the number of opportunities for their child to engage with and participate with at home and in the community.

**Theoretical Framework:** The Human Activity Assistive Technology and the Person, Environment, Occupation, and Performance model are used throughout the foundation. The Person, Environment, Occupation, and Performance model was utilized in the intervention and outcomes for this project as well.

**Methods:** A descriptive mixed methods case study with a sequential exploratory design was used in this project. The qualitative aspect utilized a semi-structured interview with the participant. The quantitative aspect utilized a pretest and posttest with the Family Impact of Assistive Technology Scale- Augmentative and Alternative Communication. Participant was a single parent of two children; 8 years-old and 6 years-old respectively. The 8 year-old has been diagnosed with Autism and Attention Deficit Hyperactivity Disorder.

**Results:** The parent provided consent and participated in multiple intervention sessions. Qualitative results indicated parent's initial reluctance, her discovery, and enthusiastic response when she implemented strategies that increased communicative opportunities while engaged in meaningful family activities. Quantitative results indicate that the parent overcame several barriers as she implemented the communication device, and the child factors of communicating face-to-face and social engagement were increased. **Conclusions:** The use of a family-centered parental training created several positive outcomes such as increased family connectedness and sense of belonging as the parent learned and demonstrated implementation strategies. Parent then provided an increased number of communication opportunities for the child. With increased opportunities to communicate, both the parent and child's occupational performance was enhanced.

# Acknowledgements

I'd like to thank Dr. Camille Skubik-Peplaski and Dr. Allen Keener for all their help and encouragement throughout this project.

I'd also like to thank my parents, Nancy and Rolf, being my biggest fans, for believing in me as I complete my doctorate degree and move forward in the next phase in my life.

## EASTERN KENTUCKY UNIVERSITY COLLEGE OF HEALTH SCIENCES DEPARTMENT OF OCCUPATIONAL SCIENCE AND OCCUPATIONAL THERAPY

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 Title of Submission: The Impact of Parent Education With Augmentative and Alternative

 Communication

Certification of Authorship: I hereby certify that I am the author of this document and that any assistance I received in its preparation is fully acknowledged and disclosed in the document. I have also cited all sources from which I obtained data, ideas, or words that are copied directly or paraphrased in the document. Sources are properly credited according to accepted standards for professional publications. I also certify that this paper was prepared by me for this purpose.

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Date of Submission: 11/30/2020

# **Table of Contents**

Nature of the Project and Problem Identification	
Section Two: Literature Review	9
Section Three: Methods	
Results	
Qualitative Results A Mother's Reluctance, Discovery and Adoration Increased Opportunities, Increased Family Identity	
Quantitative Results	
Discussion Qualitative Quantitative Study Outcomes	
Conclusion	
References	
Appendix A: Semi Structured Interview Guide	
Appendix B: Data Collection Tool- FIAT-AAC Worksheet	55
Appendix C: IRB Approved Consent Form	61

# List of Tables

Table 1: Databases and Search Terms Used	9
Table 2: Information in Google Classroom Modules	17
Table 3: Inclusion and Exclusion Criteria	
Table 4: Results of Initial FIATS-AAC Interview	32

# **List of Figures**

Figure 1:	Capstone Project	Timeline	24
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#### Nature of the Project and Problem Identification

Communication is an essential component a person utilizes to engage and participate at home, school, and throughout the community (American Occupational Therapy Association, 2020). Assistive technology (AT) shapes the individual and family identities, making it necessary to understand the AT effects throughout all environments (Ripat & Woodgate, 2011). Parents and teachers observed children's improved self-esteem, increased self-determination and motivation, as benefits to children who used AT (Copley & Ziviani, 2004; Derer et al. 1996; Hutinger et al., 1996; Reed & Kanny, 1993; Swinth & Case-Smith, 1993). Using AT, such as augmentative and alternative communication (AAC) devices, enabled children to participate and socialize with others in schools and in the community (Copley & Ziviani, 2004; Derer et al. 1996; Hutinger et al., 1996; Reed & Kanny, 1993; Swinth & Case-Smith, 1993).

The Individuals with Disabilities Education Act (IDEA, 2004) mandates that schools provide any assistive technology, which includes AAC, to all students with disabilities that are required to participate in school. With this federal law, school districts are responsible for finding and providing AT for the nonverbal students' ages 3-21 years old to be successful in participating and engaging in the educational environment. In schools, Huang et al. (2008) found the support for using AT devices was stronger in the educational setting due to it being encouraged by peers and teachers, while parents were observed to rarely utilize the device at home or in the community (Huang et al., 2009). In fact, Huang (2008) found that parents rarely used assistive technology in the home, as it was inconvenient, and as the children found other ways to get what they wanted. Often, children who use communication devices just at school or only at home have difficulty generalizing the communication skills to other settings (Anderson et al., 2016; Kent-Walsh & McNaughton, 2005).

1

Parental involvement is critical because the more parents learn about AAC, the more they can see the benefits their child receives as the child becomes a competent communicator (Light & McNaughton, 2014; Therrien & Light, 2018). Tegler et al. (2018) found inequalities in the trainings provided to caregivers and teachers. For instance, when the school assistive technology team issues a communication device, the teacher and parent get initial training. However, teachers get additional training as the team is able to work with the child in class, thus providing more hands-on implementation strategies and demonstrations. Furthermore, when there is a lack of training and support for parents, there is a risk of low device usage and even device abandonment (Anderson et al., 2015; Bailey et al., 2006; Stadskleiv, 2017; Tegler et al., 2019). In order to help nonverbal children use AAC, parents need support and intervention strategies beyond handouts, in order to incorporate AT into the home setting (Parette & Huer, 2002) and to influence identity and meaningful interactions (Ripat & Woodgate, 2011).

This investigator has also observed that when students are assessed for communication devices in order to participate in activities used at schools where she is employed; devices rarely go home on weekends or over the summer. As recently as last summer, 60 students utilized a communication device in school and only 6 of those went home when school was not in session. According to IDEA (2004), a child is typically assessed for a communication device when the student is nonverbal for the student to participate in school activities. Once the device has been acquired, training is provided to teachers, staff, parents and the child. The current training, in the school district where the investigator is employed, is done by the Speech and Language Pathologist. The Speech and Language Pathologist focuses on why the system was chosen for the child, how the system is set up, personalizing the device with family members, teachers, favorite foods and toys. Then the pathologist provided resources for parents to search out how to

use the device. The occupational therapist has not been involved in the trainings regarding AAC devices, yet communicating and social engagement are a part of occupations. At this time, there is little to no standard policy or process regarding parent education content in the literature when communication devices are issued from several school districts. Parent education content was identified from personal communication from the following: California (S. Springer, personal communication, October 5, 2020), Kentucky (B. Scheide, personal communication, Oct. 6), Georgia (K. Cobb, personal communication, October 5, 2020), Missouri and South Carolina (K. Myracle, personal communication, January 15, 2020).

Studies have confirmed that children who use AAC need to use it in multiple environments to become competent communicators and participate in all their chosen occupational roles (Copley & Ziviani, 2004; Light & McNaughton, 2014, McNaughton et al., 2008). The problem this project is addressing is when a child is limited to use of device in the school setting, parents are unknowingly limiting the opportunities available for their child to fully utilize the communication device in all environments, both to engage with others and fully develop their identities (Copley & Ziviani, 2004; Kent-Walsh & Light, 2003). There is very little literature found regarding training content for parents. Therefore, the purpose of this project is to evaluate the impact of an occupational therapist led parental training program, wherein parents utilize a communication device. The desired outcome is to increase the number of opportunities for their child to engage and participate at home and in the community.

There are several definitions utilized in this capstone project to provide a common understanding. Assistive technology (AT) is defined by the Assistive Technology Act of 2004, which states that "assistive technology device means any item, piece of equipment, or product system, whether acquired commercially off the shelf, modified, or customized, that is used to increase, maintain, or improve functional capabilities of individuals with disabilities" (29 U.S.C. 3001). For this capstone project, AAC is defined as a high-tech mobile device with a communication app installed. A communication opportunity is defined as a comment or question or choice provided by the parent to the child (Douglas et al., 2017). Occupations are defined as everyday activities (American Occupational Therapy Association, AOTA, 2020). Occupational roles defined by Clark and Larson (1993) view occupation as what we do. For instance, children are siblings, students, peers, and friends, while parents are caregivers, workers, and friends. Occupational identity is who we are (Wilcock, 1999). Occupational competency is our self-fulfillment in proficiency of our tasks and roles (Cole & Tufano, 2020). Occupational performance is the outcome interlinking the person, occupation, and environment (Bass et al., 2017). A parent is defined as the primary caregiver of a child who uses at AAC device.

This capstone project was a parent training program conducted to help the parent learn how to increase communicative opportunities and to be an effective communication partner with their nonverbal child. This education program provided identification of family strengths and limitations when there is a nonverbal child in the family. Adult learning strategies were utilized to teach how to create communication opportunities through role playing and interactive activities for parents to practice using the device. Through this project, parents will learn specifics about the communication applications, modeling, and provide the opportunities for their child to increase AAC device use, which will affect the child's occupational engagement and improve their quality of life.

A needs assessment (von Hellens, 2019) was completed by the primary investigator in July 2019, which indicated the need for parent education and training to support their child who uses a communication device. Literature reviewed to support the needs assessment (von Hellens, 2019) indicated that the most significant finding was the importance of parent support for their child to utilize a communication device throughout all environments (Topia & Hocking, 2012). It is critical for nonverbal students to become competent communicators, so they can participate in any and every occupational role they encounter (Light & McNaughton, 2014).

There are three primary objectives for this project. The first objective is to provide parent education on device use and management to enable the parents to learn about the app and device itself. The second objective is to provide opportunities for parents to practice implementation strategies that they can apply at home and in the community to increase the number of communication opportunities to enhance their child's occupational performance. The third objective is to identify family strengths and impacted dimensions on the child's functional performance outside the school environment. Meeting these objectives will provide the education, practice and support parents need to increase the use of the communication device in all settings, which will allow the child to participate in all their occupational roles.

The foundation of this study utilized the Human Activity Assistive Technology (HAAT) framework originally by Cook and Hussey (2002) and updated by Cook and Polgar (2008). The original framework integrated the person, activity, and assistive technology device throughout the physical, social, and emotional contexts in every environment (Cook & Hussey, 2002; Cook & Polgar, 2008). Cook and Polgar (2008) updated the framework by adding the performance component. These four components created the assistive technology system which impact a person's occupational performance (Cook & Polgar, 2008; Giesbrecht, 2013). The assistive technology system in this study focused on the shared activities between the parent and child. Cook and Polgar (2008, p. 37) describe the activity as a fundamental component which defined "the overall goal of the assistive technology system." In this study, the parents utilized training

modules to learn how to engage their child's communication device with the child in meaningful activities, thus, creating a successful assistive technology system and improved occupational performance for both the parent and child.

This study is also guided by the Person- Environment- Occupation- Performance (PEOP) model by Bass et al. (2017) throughout the assessment, intervention, and outcomes. This model focuses on the role of the person and family, the environment, occupation, and occupational performance in order to enhance social participation (Bass et al., 2017). In this study, the family's narrative was assessed and used throughout the project as parents learned how to use a communication device. The family was the focus in this capstone project with this model. The environment was focused on the home and community. The communication device was incorporated in all occupations for social interaction. All these components influenced the occupational performance for the parent and child (Bass et. al., 2017). The PEOP outcomes were evident as parents participated in social activities with their child as they used AAC, which directly impacted the occupational performance of all the participants.

The PEOP model was also utilized in the assessment of family narratives in this project through the interview guide. Probing questions were also asked throughout the parental training. The Family Impact of Assistive Technology- Augmentative and Alternative Communication Assessment (FIAT-AAC) was used to assess parental perceptions of family strengths and limitations. The FIAT-AAC is a parental questionnaire which looked specifically at the roles and responsibilities that influence the family when a communication device is integrated into the family (Ryan & Renzoni, 2015). The interview guide and the survey were used to identify family narratives as parents learned about strategies to implement the communication device which impacted the family, the child, and their environment. Bass et al. (2017) describe how the person, environment and activities continuously interact and when one area is improved, one gains in occupational performance. Through videos and activities provided in this educational training, parents have the opportunity to practice using the communication device to engage with their child. Utilizing both the HAAT framework (Cook & Polgar, 2008) and PEOP model (Bass et al., 2017), guidance will be provided throughout this study to integrate the assistive technology system into more activities and routines thus providing social engagement between parents and child. Social participation is part of who we are as we are doing, being and becoming (Wilcock, 1999). Therefore, using this framework and model provide all the components necessary for assessment, intervention with evidenced based practices, and outcomes supporting improved occupational performance and social engagement (Goodrich et al., 2016).

This research project is significant because it will identify specific learning strategies to provide opportunities for social engagement for their child and help parents overcome barriers. McNaughton and Light (2013) found that the more communication exchanges that occur, the more competent the child will be with their communication. As a child becomes a more competent communicator, the child's occupational performance and occupational identity will improve (Bass et al., 2017; McNaughton & Light, 2013). The parent training will provide the guidance and modeling for parents to help integrate the AAC device into family routines. Research has shown that providing AAC interventions with just one member of the family will influence the rest of the family (Angelo, 2000; Cardon et al., 2011). Ryan et al. (2015) found that there are significant gaps in understanding the impact of AAC on everyday participation, social engagement, and the quality of lives for the children and their families. The knowledge gained from this study is necessary to help professionals provide effective education and intervention to

assist families in addressing barriers and promoting their child's communication and

participation, and to facilitate building their occupational identity at home and in the community.

#### **Section Two: Literature Review**

A review of the literature identified several studies providing evidence of the need for augmentative and alternative communication devices, the barriers families face when a member is nonverbal, various types of parental trainings, and the effectiveness of using communication devices. Little research was found regarding the content of parental education and training. Both computerized and hand searches were conducted for this project. The hand search for articles consisted of back-tracking through relevant citations and references from relevant articles and systematic reviews. See Table 1 for the databases and search terms. The limitations from the studies most relevant to this research project had small samples, thus decreasing the generalization of the results. However, they all confirmed the need for children who require AAC to use it in multiple environments, so they can become competent communicators able to participate and engage with others in all their occupational roles and environments (Angelo, 2000; Bailey et al., 2006; Biggs et al., 2019; Bruno & Dribbon, 1998; Cardon et al., 2011; Chung & Stoner, 2016; DeCarlo et al., 2019; Kent-Walsh & Light, 2003; Light & McNaughton, 2014; Parette et al., 2000; Therrien & Light, 2018).

Table 1: Databases and Search Terms Use	ed
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Databases Used	Search Terms Used	
Google Scholar	• AAC, participation, occupation, and family	
• Medline	• "Augmentative and Alternative Communication with Families,"	

CINHL Complete	"Families and AAC"	
• EBSCOHost Web	• "Children who use AAC"	
- ·	• "Effectiveness of AAC"	
• Researchgate.net	"Communication partners with AAC"	
• ProQuest	• "AAC and families"	
	• "AAC and Occupation"	
	• "Assistive Technology and Occupation and Participation"	
	• "Assistive Technology and Occupation and Participation"	

There are over 3.5 million Americans who have such significant communication issues that require the use of augmentative and alternative communication to participate throughout most of their occupational roles (Olson & DeRuyter, 2003; Wendt & Lloyd, 2011). Augmentative and alternative communication (AAC) refers to the use of devices or techniques that compensate and/or supplement a person's verbal communication (Johnston et al., 2004; Wendt & Lloyd, 2011). No matter the type of device, there is foundational evidence that a person can learn to make requests to participate in occupations of choice with the use of communication devices (Lancioni et al., 2016).

Children crave a sense of belonging (Frances et al., 2012). For a nonverbal child, it is even more important to utilize the communication device during daily encounters, routine activities, special events and parties which create the sense of belonging and have meaningful interactions (Kantartzis, 2019). Furthermore, Topia and Hocking (2012) reported that AAC devices need to be individualized, usable in all environments, and used with a variety of communication partners. Studies have also found that using assistive technology, such as AAC, facilitates independence and self-determination, thus creating the user's occupational identity (Hutinger et al., 1996; Todis & Walker, 1993). Copley and Ziviani (2004) found that parental involvement is necessary to help integrate the AAC device into home and community activities, thereby creating many opportunities for nonverbal children to successfully engage in those occupational roles. It is vital to strengthen a nonverbal child's occupational performance competency and sense of belonging by using AAC to make interactions meaningful.

There have been several studies showing how parents want to be involved with various aspects of AAC. For instance, Light & McNaughton (2014) found that parental involvement is critical as parents learn about technology and see the benefits of their child as a competent communicator. Meanwhile, Bailey et al. (2006) reported that parents stated they know their children best and want to be involved in deciding what communication devices should be used. Other studies found that when parents saw the benefits of their child using an AAC device, there was improved communication within the family and the community (Angelo, 2000; Bailey et. al, 2006; Bruno & Dribbon, 1998). Other benefits include, but are not limited to, increased independence of the AAC user, increased communicative competence, and more communication partners (Bailey et al., 2006, Light & McNaughton, 2014). These studies support the need to have parents involved to best support their child's growth in communication in all their occupational roles.

Kinney and Gitlow (2015) found that documented AT outcomes were more successful when therapists focused on the family, environment, and desired occupations. The child's occupational competency and identity are impacted with increased AT usage (Kinney & Gitlow, 2015). Parental involvement is critical as parents learn about technology to aid their child in becoming a competent communicator (Light & McNaughton, 2014; Therrien & Light, 2018). Bailey et al. (2006) and Parette et al (2000) found that when the family voice was not valued, there was a higher incidence of device abandonment. Therefore, it is important to provide training and support for the child and family, as it is necessary to improve the child's occupational roles in a variety of settings.

Results of other relevant studies found that parents want to know how their child's communication device works, but also how to use it to help their child communicate independently. Anderson et al. (2016) found that families who are comfortable with technology, accepted the use of a device more readily than families who rarely use technology. When parents learned how to manage the communication device and use the device to increase communication exchanges, it was easier for them to implement the device at home (Baxter et al., 2012; Bruno & Dribbon, 1998). Parents have reported they also want to know how to customize the vocabulary available for home situations, facilitate device usage across settings, and complete the daily maintenance of the AAC devices (Angelo, 2000, Bailey et al., 2006; Light & McNaughton, 2014; Parette et al., 2000). Therefore, when providing parents trainings on a device, it is important to understand and address parental concerns and family priorities (Moorcroft et al., 2019b). When concerns are adequately addressed, the parents are more likely to follow through with integrating the device to help the child generalize their communication skills in order to fulfill all the child's occupational roles.

Parents face multiple barriers which interfere with implementing communication devices. One barrier parents face is the lack of acceptance of assistive technology (Lorah, 2016). Lorah (2016) found that acceptance from the child and adults working with the child with the AT is necessary in order in increase participation in any occupation. Operational competency and acceptance are critical factors and are barriers when not addressed (Johnson et al., 2006; Kent-Walsh & Light, 2003; Light & McNaughton, 2014; McNaughton et al., 2008). Another barrier for parents is the misconception that using a device to communicate will keep a child from talking (Anderson et al., 2016; Cardon et al., 2011; Romski & Sevcik, 2005). Other barriers that parents face include financial needs, stress, and time barriers of taking care of other family needs (Angelo, 2000; Mandak et al., 2017; Moorcroft et al., 2019a). Another barrier is device abandonment. Hemmingsson et al. (2009) found that assistive technology devices are quickly abandoned when users perceive they are different from others or when the child experiences a negative interaction with peers when using the communication device. Devices were often abandoned when there was a lack of training on how to operate AAC devices and when the family and user had poor support, creating another barrier in the home (Anderson et al., 2016; Johnson et al., 2006; Kent-Walsh et al., 2015; McNaughton et al., 2008).

Parents' interpretation of information about AAC provided to them can make a difference in the impact of using a communication device (Senner et al., 2019). Anderson et al. (2016) found that families who are comfortable with technology, accepted the use of a device more readily than families who rarely use technology. When giving parents training on a device, it is important to understand and address parental barriers. Therrien and Light (2018) found that reducing one or more barriers to interaction can produce a positive effect on social communication, such as the number of initiations and responses with peers. Bruno and Dribbon (1998) found that when parents learned how to manage the communication device and how to use the device to increase communication exchanges, it was easier for them to implement the device at home. Parents want to know about the specifics of working the communication device, as well as implementation strategies to utilize the device at home (Bailey et al., 2006). With thorough training and parent support on using AAC, parents are able to support their child in all occupations and environments.

Utilizing a holistic approach with the Person, Environment, Occupation, and Performance theory (Bass et al., 2017) to assist in understanding the family strengths and barriers, an intervention plan for a training/education and support can be developed. O'Niell et al. (2018) completed a systematic review of AAC interventions and found that interventions are effective when implemented through daily naturally occurring environments. Senner et al. (2019) found that parents learned more when parent trainings were paired with their children, so they could practice the implementation strategies as they were presented. Meanwhile, Anderson et al. (2016) had parents report that complete online learning resources helped with training as they accessed it when they had time.

There are several strategies that can be used when providing training to parents. Strategies, such as modeling AAC communication, can be effective by itself or in combination with other interventions (Finke et al., 2017; O'Niell et al., 2018). However, it's important to note, that AAC interventions need to focus on communication, not just operational competency (DeCarlo et al., 2019; McNaughton & Light, 2013). Interventions have positive gains on the child's comprehension when using partner strategies such as open-ended questions, environment set up, least to most prompting, and modeling (Finke et al., 2017; Tegler et al., 2019; Therrien & Light, 2018). Cress (2004) researched parent perspectives and recommended to keep family priorities as the goal for the AAC intervention and utilize functional interactions for the family to implement the AAC device. Kent-Walsh and McNaughton (2005) and Kent-Walsh et al. (2015) found that communication partners learn to use AAC devices through practice, role modeling, video, and feedback. Parents need to learn AAC implementation strategies to help their child communicate and participate at home and within the community. In addition to those strategies, Schlosser et al. (2000) found other adult learning strategies can help parents overcome barriers and provide an increase in opportunities for participation in any desirable occupational role. Modeling, mand-modeling, and least-to-most prompting are all intervention strategies that can occur to increase communication opportunities (Biggs et al., 2019; Finke et al., 2017; Gevarter & Zamora, 2018; Kent-Walsh et al., 2015; Lynch et al., 2018; Sennott et al., 2016). Modeling occurs when a communication partner uses the device as she/he speaks (Biggs et al., 2019; Gevarter & Zamora, 2018; Tegler et al., 2019; Therrien & Light, 2018). Mand-modeling is described as naturally occurring opportunities when a communication partner sees what the child is interested in, and then uses the AAC device to model making a request or response (Finke et al., 2017; Gevarter & Zamora, 2018; Johnston et al., 2004; Lynch et al., 2018; Sennott et al., 2016; Tegler et al., 2019). Finke et al. (2017) and Tegler et al. (2019) describe least-to-most prompting as when the initial natural cue is given, and then two more levels of cues are given until target skill has been acquired. This is used most often when chaining multiple symbols to make phrases and sentences (Finke et al., 2017).

Another strategy used to create communication opportunities include asking open ended questions as this requires the AAC user to communicate a variety of responses (Tegler et al., 2019; Therrien & Light, 2018). Just using yes/no questions or dominating the conversation prevents children from demonstrating their communication competence and fully participate (Kent-Walsh et al., 2010; Kent-Walsh et al., 2015). Gevarter and Zamora (2018) and Kent-Walsh et al., (2010) reported on several studies that found using natural interventions for all AAC device users increased device use and enhanced the users' communication competency. Parents should have ample opportunities to practice these strategies and receive feedback as they complete interactive activities with their child. Providing a variety of parental training platforms is another useful strategy. Anderson et al. (2015) found parents like face-to-face trainings, but they like online trainings as well. Parents reported that with online training, they were able to access it whenever they had time, whether that was while their child was at school, or in the evening after the child was in bed (Anderson et al., 2015; Douglas et al. 2017). Meanwhile, parents liked in-person training as they were able to hear questions from other parents and get hands on experiences with the AAC devices (Anderson et al., 2015). Douglas et al. (2017) found that online parent communication training increased both the communication opportunities with the child and the number of child's responses. Stockwell et al. (2019) utilized smartphones for parents to video sessions with their own child utilizing communication strategies from a handout. Then parents sent the video to the therapist for video coaching (Stockwell et al., 2019). Parents reported the video coaching helped them focus on their child's communication and provided more communicative opportunities for both prearranged activities and naturally occurring activities (Stockwell et al., 2019).

There are numerous activities that can be used to elicit communication during training and educational opportunities. One example of an activity was when DeCarlo et al. (2019) had parents participate in a challenge where parents had to use the device as a sole source of communication for 30 minutes. This helped the parents learn the device so they would be able to provide better modeling for their child. Another activity example is baiting the environment to elicit responses (like using a coloring activity where the child has to ask for specific colors) or asking open ended questions after reading a story, or requesting motivating items from a storybook (Chung & Stoner, 2016; Gevarter & Zamora, 2018;Therrien & Light, 2018). These types of activities are necessary as parents learn to create opportunities to engage in recreation and leisure time with their child. The most consistent finding that each study indicated was the importance of parent support for their child to utilize a communication device throughout all environments. Also, that it is critical for nonverbal students to become competent communicators (Light & McNaughton, 2014), so they can participate in any and every occupational role they encounter.

This capstone project focused on children who use AAC devices and their families. This parent training provided the guidance on the operations of the device, modeling with the AAC device, feedback through role playing, and support for parents to help integrate the AAC device into family routines through an extensive module system developed presented in a Google Classroom. Through this capstone project, parents learned how to implement interventions to help their child communicate with anyone they encounter throughout all their occupational roles. See Table 2 for the contents in each module.

Table 2: Information in Google Classroom Modules

Module	Contents		
Introduction	Basic Navigation within the Google Classroom		
	Goals and Objectives		
Mechanics of the iPad	Diagram of iPad		
	• Troubleshooting tips for the iPad		
Implementation	• Video on Myths and Realities of AAC		
	• Video on how to be a good communication partner		
	• Video on modeling with an AAC device		
	• Video on implementation strategies		

	<ul> <li>Video on how to make a conversation using AAC</li> <li>Video on activities and how to use AAC within an activity</li> </ul>
Low Tech AAC Boards	Low tech communication boards for Avaz, LAMP,
	Proloquo2go, and TouchChat with WordPower
Other Resources	Emergency Go Bag for Communication
	Activities by Assistiveware
	• Activities by Talk To Me Technologies
	• Full study on Myths and Realities by Romski & Sevcik
	(2005)

#### **Section Three: Methods**

This capstone project utilized a descriptive mixed methods case study with a sequential exploratory design. A case study was chosen in order to describe the client's response to a new intervention (Nelson et al., 2017). A semi-structured interview was utilized to explore the parental perceptions gained from the educational training. Stanley (2014) described descriptive studies as a valuable way to gain the occupational perspective of the need for social engagement and creating the sense of belonging. A pretest and posttest were utilized to see if there was a change due to the intervention, according to the 13 factors on the Family Impact of Assistive Technology Scale for Augmentative and Alternative Communication (FIATS-AAC; Ryan & Renzoni, 2015).

The population for this study was a cluster of parents who have nonverbal children that use a communication device at school. These parents were a convenience sample due to the change in timeline of the capstone project as COVID-19 pandemic shut schools down in March

2020 until the end of the school year. Additionally, the start of the 2020-2021 school year was delayed for safety and health concerns for the public. The pandemic and mandated isolation made contact with parents difficult. Multiple parents were recruited for this project from PA, TN, KY, GA, and SC.

Data was collected by the primary investigator via telephone interview and face-toface interventions. For qualitative data, the primary investigator used a semi-structured interview, observations and documentation. The second and third sessions were audio recorded with parent permission and transcribed verbatim by the investigator.

19

There were several outcomes from this project. A semi-structured interview (See Appendix A for the interview guided questions) was utilized during the initial and final interview. These questions consisted of demographics of the family and the child who uses AAC, previous experience with AAC, previous trainings, meaningful activities for the child, and parental outcomes that the parent would like to see occur. As interventions occurred, other questions were asked, such as was the device used this weekend and if so, how? Answers to all the questions, provided the parent perspective and ensured concerns were addressed.

To increase the rigor of the study, the investigator utilized several strategies. One strategy was to increase the pool for the convenience sample, therefore the investigator reached out to multiple states and settings. The primary investigator also used an audit trail and reflexive thinking to enhance the rigor (Stanley, 2014).

For the quantitative data, the pretest and posttest in this capstone project utilized the Family Impact of Assistive Technology Scale for Augmentative and Alternative Communication Systems (FIATS-AAC), located in Appendix B. The FIATS-AAC was chosen for the outcome

measures of occupational performance through thirteen designated dimensions regarding the use of AAC devices (Ryan & Renzoni, 2015; Ryan et al., 2018). The FIATS-AAC identified strengths and barriers on the impact of family roles and responsibilities through 13 factors: seven child related factors and six family related factors (Ryan & Renzoni, 2015). The child related factors include behavior, communication, contentment, doing activities, education, self-reliance and social versatility. The family related factors include caregiver relief, energy, family roles, finances, security, and supervision. Each factor has 6-7 statements, where parents assign a rating from 1-7. The numbers corresponded to the following: strongly disagree, disagree, somewhat disagree, neutral, somewhat agree, agree and strongly agree (Kron et al., 2018; Ryan & Renzoni, 2015; Ryan et al., 2018). The initial FIAT-AAC results from the initial interview was used direct the intervention while the results from the final interview were used to determine what changes occurred since the initial interview and intervention were provided.

The reliability of the FIATS-AAC has been established, with a high internal consistency at 0.91 overall (Delarosa et al., 2012; Kron et al., 2018). Content validity was established as results indicated that the subscales and domains the inventory covered are important areas which influence the use of AAC devices in the home (Ryan et al., 2006). The test/re-test reliability was established with 95% confidence interval with varying scores of 0.86-0.97 in all the factors of FIATS-AAC (Delarosa et al., 2012; Kron et al., 2018). The sensitivity analysis indicated that the FIATS-AAC demonstrated statistically significant sensitivity to changes (Ryan & Renzoni, 2015; Ryan et al., 2018).

Descriptive data analysis occurred by the primary investigator on the data obtained by the semi-structured interview along with the FIATS-AAC. Qualitative data analysis consisted of the transcribed data that was coded and categorized by the primary investigator. Thematic analysis

was used to identify themes and utilize participant's words to keep the richness of the participant's perspectives (Stanley, 2014). Quantitative data analysis consisted of the means, standard deviations and range of scores (Creswell & Creswell, 2018) in each of the 13 factors of the FIATS-AAC to determine whether there was a significant change in that particular factor (Kron et al., 2018; Ryan & Renzoni, 2015). Ryan and Renzoni (2015) provided a worksheet that accompanies the FIATS-AAC. This worksheet provided two tables for data analysis. Any factor with more than 2 standard deviations from the before and after scores indicate there was a significant change within that factor utilizing an 80% confidence level for a single participant (Ryan & Renzoni, 2015). The confidence level can be changed by the investigator from 70%- 99% on the worksheet as it determines that changes that are detected are not explained by measurement of error alone (Ryan, & Renzoni, 2015). With higher confidence interval indicates the range in which results are true (Taylor, 2017).

This capstone project was initiated with the signing of consent (See Appendix C for the approved Consent Form). Then, one parent per household participated in the following: An initial pretest completed by telephone interview, 2 interactive training sessions, and the posttest to be completed by telephone interview at the parent's convenience. The telephone interview for the pretest and posttest took approximately 20-40 minutes at a convenient time for the parents. Once the pretest interview was completed, each participant received an emailed invitation to join a Google classroom titled AAC Training for Parents.

In the Google classroom (See Table 2), a link to the virtual sessions was provided, as well as six educational videos and supporting resources. The six videos covered the following topics: myths and realities of using AAC, strategies on how to be a good communication partner, instructions on how to model with the device, implementation strategies, how to make a

conversation and activities that can be used with the AAC device. Parents were directed to watch the first three videos prior to the first virtual session and the remaining three videos by the second session. This strategy provided parents with information before the actual interventions in order to give the parents needed information prior to an interactive session where the information was applied. Each interactive session was planned to last approximately an hour. The initial interview occurred prior to the intervention sessions while the final interview occurred six weeks after the initial interview.

Overall, participants were typically healthy groups of people. The lists below provide the specific criteria for participants in this study. See Table 3 for inclusion and exclusion criteria.

Table 3: Inclusion and Exclusion Criteria	Table 3	: Inci	lusion	and	Excl	lusion	Crit	teria
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Inclusion Criteria	Exclusion Criteria
• English speaking families as 1 <sup>st</sup>	Non-English speaking families
language	• Parents of a child who uses only a low
• At least one parent/guardian of a child	tech communication AAC device
who uses an AAC device	

There were several steps taken to ensure an ethical capstone project. These steps include the following: Approval #2985 was granted from the institutional review board (IRB) from Eastern Kentucky University on February 10, 2020, recruited participants were fully informed about the purpose of the study and the option to stop participation at any time, parents signed the consent form, participant names were masked on the data recording forms, and all data was stored in a locked location for participant protection. Parents were provided with a copy of the

report once it was completed. All documents, such as the consent, were created at a low-level readability, and the investigator strictly adhered to the Occupational Therapy Code of Ethics by the American Occupational Therapy Association (2020) to guide all aspects of the study. All participants faced minimal risk throughout the study and experienced a reward as they helped others participate in various occupational roles, and gained knowledge on how their child's AAC can and should be used.

See Figure 1 for this capstone project timeline.

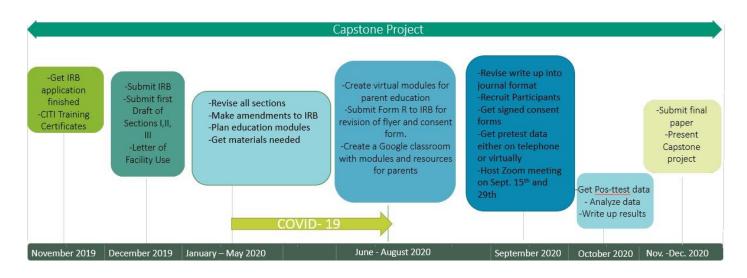


Figure 1: Capstone Project Timeline

#### **Section Four: Results and Discussion**

#### Results

Participants were recruited through emails, texts, and social media in various locations, such as California, Kentucky, Georgia, Tennessee, Pennsylvania, and South Carolina. One parent responded to the flyer, provided consent, and participated in the project. For participant protection, the parent will be addressed as Laura for this project.

Laura completed the pretest via telephone interview. During this initial call, Laura also answered several questions from the semi-structured interview guide (See Appendix C). Laura reported basic demographics: Laura is working on finishing her bachelor's degree. She is a single parent of two children. Laura's children consist of an 8 year-old female who is nonverbal, and one younger male who is 6 years old and verbal. Laura reported her oldest child (who was addressed as Tammy for this project), was diagnosed with Autism and Attention Deficit Hyperactivity Disorder. Laura estimated that Tammy's language comprehension was that of a six-year-old, and Tammy's expressive language was that of a two-year-old. Tammy attends a self-contained classroom at a local elementary school.

Laura did not have access to a computer after work hours, therefore, she participated in the first training education by telephone and then the remaining 3 trainings took place face-to- face during her lunch break, each lasting approximately a half hour. Material from the Google Classroom was scaffolded, graded and presented. During the first educational training, only modeling with the communication device and some myths/realities were covered due to limitations of the telephone. In the second training, modeling was reviewed, demonstrated, and practiced. Role playing was also addressed. In the third training, strategies for being a good communication partner were covered along with the Emergency Go bag, and the importance of having a backup communication system. The fourth training utilized a meaningful activity to practice using the communication device.

The posttest interview was completed face-to-face during Laura's lunch break, six weeks after the initial pretest. The remaining questions from the interview guide (See Appendix C) were also covered during this visit. To increase the trustworthiness of the study, a reflexive

journal was kept. Lastly, the investigator used peer debriefing and triangulation of data with the literature.

#### **Qualitative Results**

The semi-structured interview took place throughout the capstone project. The formal question guide (See Appendix C) was used during the initial interview and the final interview. Meanwhile, the investigator asked probing questions like "Did you use the communication device this past week?" and "How did it go?" during each intervention. Investigator noted observations and documentation through reflexive notes and an audit trail. Two interventions were audio recorded and transcribed verbatim by the investigator. Transcriptions were saved digitally on a password protected flash drive and stored in a locked location.

The investigator utilized reflexive notes and transcripts of descriptive

sessions to code, categorize, and find the themes that emerged through the parental parent training. Fourteen codes were analyzed, and the following three categories emerged: Family history of device use, family learns to use the AAC, and meaningful activities used to incorporate AAC. Two themes then emerged from the data. The first theme was a mother's reluctance, discovery and adoration. The second theme was increased opportunities and increased family identity.

### A Mother's Reluctance, Discovery and Adoration

Although Laura was interested in the educational training, as evidenced by her consent to participate, she was reluctant to participate. After the initial interview, the investigator sent multiple emails with information to join the Google Classroom and Laura always replied that she got the email and she could get into the Google classroom. At the scheduled time for the first interactive session, Laura still had not logged into the site. Five minutes after the virtual session was to have started, Laura called the investigator to reschedule the session. Upon Laura's request, three days later the investigator was online in the virtual session only to see Laura had yet to join the Google classroom therefore, Laura was not able to have seen any of the videos or resources provided. At the newly appointed time, Laura called the investigator instead of joining virtually. During this half hour conversation, the investigator explained modeling and the importance of everyone in the family using the device as it makes it a more normal way to communicate. The parent exclaimed, "I'd never thought of it like that before!" Laura reported that learning to have everyone in the family use the device was a turning point for her. However, it took two more weeks before the device was

implemented.

Laura excitedly started off the third meeting, as she discovered how she was able to use the AAC device and Tammy's reaction to it. Laura used the device for the first time as she typed out the message, "Tammy, clean up." Laura then demonstrated how Tammy's eyes opened wide with surprise, and then she [Tammy] laughed. Laura was astonished when Tammy was able to show her where everything was on the device, "I'm like, can she handle this? And she showed me where everything was. I said where's the keyboard, Tammy? And she knew exactly what I was talking about too." Then Laura laughed.

By the end of six weeks, Laura demonstrated her trust in the investigator as she successfully implemented strategies and saw the successful results. Laura sought out the investigator's opinion on how to deal with Tammy's behaviors regarding the use of the device. For instance, when Tammy initially received the device, she would repeatedly hit a message button over and over again. The investigator provided Laura with researched evidence of the importance to acknowledge the communicative intent and then model a response. Once Laura started using the device, along with other family members, Tammy ceased playing with the

device. Laura was stunned as she said, "She doesn't think it's a toy anymore...now, she's fine with it." Laura took the educational training personally and took the time to put the strategies into practice. After seeing the success, Laura requested more educational sessions beyond the capstone project in order to continue to increase communication and engagement among the family members, as she adored the family's newfound sense of connectedness. Near the end of the study, Laura further requested advice regarding educational programming as she advocated for her daughter.

### Increased Opportunities, Increased Family Identity

As Laura and her family used the communication device, not only did communication increase, but interactions were more meaningful to every family member. For example, Laura shared one anecdote that occurred after Laura and her family started using the communication device. One afternoon, Tammy and her younger brother wanted to watch tv. The brother used the device to make the request, "I watch tv." Tammy got her mother's phone and set the timer for 15 minutes. Once the timer went off, Tammy used the device to say "My turn" and changed the tv program. When the timer went off again, the brother used the device to say, "my turn" and changed it to his tv program. Sibling interactions were more meaningful as they engaged one another with the increased communication.

Another example of the changed family dynamics came as the investigator orchestrated a modified version of Hedbanz. In this game, each player put a card on their headband without looking at it. Then, the player had to use the communication device to ask questions in order to figure out what was on the card. The game was used to learn where items of food, animals, colors, and transportation were located on the device. Each player asked questions using the device to ask questions like "Am I a food? Am I a fruit? Am I red?" Once the player decided

what the card must be, the AAC device was used to say, "I am an apple." Questions

using the device were asked until the item on the card was discovered. When it was Tammy's turn, she took her card down, looked at it, and then typed "I am a frog" and handed the device to her mom. Watching Tammy, Laura's eyes got big as she said, "You see Tammy, she's a cheater. I loved it." For the first time, this family engaged in a leisure activity filled with giggles and laughter as they interacted with one another. Each family member used the AAC device to ask questions until the item on the card was discovered. Laura commented later that she enjoyed seeing everyone participate and seeing "everyone's personality come out." Laura exclaimed, "I loved it!" It was inspiring for Laura to see her children interacting and sharing in the same leisure activity.

Once Laura implemented some of the strategies she learned, such as modeling and waiting for a response from the educational training, Laura appeared amazed as she watched her children interact in a meaningful activity. Family games provided a fun way to functionally interact and increase communicative opportunities with the AAC device. Laura appeared excited as she saw the benefits of utilizing the device which increased everyone's occupational engagement. As she explained, "We can all use it. It don't make Tammy singled out. It is normal. That was big to me. Loved it." The family dynamics changed for the better as each family member was included, socially engaged, and accepted, creating improved occupational identity and performance for all. These were just a few examples of how the family's identity increased when there were more communication opportunities provided to utilize the communication device.

### **Quantitative Results**

Results from the initial Family Impact of Assistive Technology Scale-Augmentative and Alternative Communication (FIATS-AAC) questionnaire provided data regarding family strengths and barriers (Table 4). The results of the pretest data (indicated in the Before column) enabled the primary investigator to individualize and design interventions to maximize the family strengths and address Laura's concerns and goals.

After six weeks of intervention and educational trainings, the final interview utilized the FIATS-AAC questionnaire once again. The results are indicated in the After column on Table 4. Four factors were identified has having a significant change. The data indicated a significant change in security (highlighted in Purple on Table 4) and caregiver relief (highlighted in blue on Table 4) for the parent. Laura reported having more security about the child's safety when she received a low-tech back-up communication board to use in emergencies (this factor is highlighted in purple), while managing caregiving responsibilities was more of a concern after the intervention than before it (this factor is highlighted in blue), due to Applied Behavior Analysis services being reduced. Other significant changes occurred with increases within the child related factors of face-to-face communication and social versatility (these are highlighted in green). This is observed as Tammy used her communication device with more people (face to face communication) and took part in more activities (social versatility).

FIATS-AAC Summary				
*Level of C	onfidence for	Change (%)	95	
	Before	After	Difference	*Change?
Total FIATS-AAC	49.9	52.2	2.3	No
Behaviour	4.5	4.3	-0.2	No
Caregiver Relief	4.6	3.3	-1.2	Yes
Contentment	4.9	5.4	0.6	No
Doing Activities	6.4	6.4	0.0	No
Education	5.1	5.6	0.4	No
Energy	4.2	4.2	0.0	No
F2F Communication	2.0	3.5	1.5	Yes
Family Roles	3.0	2.9	-0.1	No
Finances	3.0	1.6	-1.4	No
Security	2.3	3.4	1.1	Yes
Self Reliance	4.9	5.3	0.4	No
Social Versatility	2.3	3.9	1.6	Yes
Supervision	2.9	2.4	-0.4	No

*Note*. Table of FIATS-AAC Results by Ryan and Renzoni (2015)

The FIATS-AAC statistical data was analyzed using the worksheet that accompanied the protocol. After consultation with the author and a statistical counselor, it was determined that Table 4 provided the most appropriate data with a single participant. There was no statistical flexibility in this protocol. Although a confidence level of 80% was suggested in the FIATS- AAC protocol, most studies utilized 95% confidence intervals to ensure valid results (Taylor, 2017). Table 4 demonstrates the results at 95% confidence level. Any data between .5 to -.5 indicate that the change within the factor may be explained by measurement error rather than real change. These results indicate that true significant changes occurred in the family factors of caregiver relief, finances, security and the child factors of face to face communication and social versatility.

### Discussion

This capstone project focused on individualizing parent training designed to target parental goals for their nonverbal child who uses an AAC device. The parental goal was to increase the child's social participation that impacted the child's occupational identity and occupational performance. This goal was successfully addressed as Laura watched her children engage and participate in meaningful activities. Research has found that parental involvement is necessary to help integrate a communication device to create more opportunities for social engagement and interactions (Copley & Ziviani, 2004).

# Qualitative

Two important themes emerged from this study. In the first theme, A Mother's Reluctance, Discovery, and Adoration, Laura learned to trust the investigator. The trust was earned as the investigator utilized Laura's narrative and addressed only her questions and concerns. Once Laura was heard, she was able to learn about AAC device, operational competency, and achieved buy-in of using the communication device. The buy-in was crucial for Laura, as it wasn't until the investigator informed her that when other members of the family used the AAC device, that way of communicating becomes normal. That resonated with Laura, when she saw the power of using the communication device with Tammy as they had several meaningful exchanges. Multiple studies have found that buy-in is necessary (Lorah, 2016) and can become a constraint if not addressed (Johnson et al., 2006; Kent-Walsh & Light, 2003; Light & McNaughton, 2014; McNaughton et al., 2008). The second theme uncovered was increased opportunities to communicate increased the family identity. Meaningful activities with others is important as it creates a sense of belonging and connectedness (Kantartzis, 2019; Stanley, 2014). Laura learned how to use the device during

meaningful activities, which allowed her to see her child's personality come out which enhanced both Laura's and Tammy's occupational identity. Copley and Ziviani (2004) found parental involvement was necessary to help integrate the AAC device by creating communicative opportunities to engage in various occupational roles. Through meaningful activities, the family was able to participate and connect like never before. People need to engage with others in occupations as it creates a sense of connectedness to one another (Stanley, 2014). Laura's family used meaningful activity that allowed them to socially connect with each other which enhanced their occupational performance.

### Quantitative

The results of FIATS-AAC indicated five significant changes after a shortterm use of the communication device. Three family factors changed considerably as security increased, while caregiver relief and finances became significant barriers. Laura reported she was more stressed about caregiver relief within the past six weeks due to the current health pandemic as Applied Behavior Analysis services were decreased. Laura also reported more financial stress as the school increased virtual school days, thus, forcing Laura to miss work due to lack of outside childcare. Laura may have become more confident when she received a low-tech back-up communication device and instructions to establish an Emergency Go bag in case of emergencies. These results validate, Therrien and Light (2018) and Moorcroft et al. (2019b) studies, that parent barriers and family priorities must be addressed, as reducing even one barrier has a positive effect on social communication.

Significant changes in the child factors indicated gains associated with the use of the communication device and the training (Ryan & Renzoni, 2015) as the child successfully increased face-to-face communication and social interactions. The occupational identity wasimpacted for Tammy and the rest of the family as they each used the AAC device in purposeful and meaningful activities. The results of the child factors substantiate Kantartzis (2019) and Frances et al. (2012) as they both found that meaningful interactions help create that sense of belonging and improve the occupational identity.

### **Study Outcomes**

Although Laura sought out getting a communication device before Tammy started school, it was quickly abandoned due to minimal training. Device abandonment occurs when there is a lack of training or when the family is not supported (Anderson et al., 2016; Bailey et al., 2006; Parette et al., 2000). The family abandoned the AAC device until the current school- based team evaluated the child. Once Laura notified the school-based team that Tammy already had an AAC device, she was able to get training on device management that she and her family needed to get started implementing the AAC device.

Bailey et al. (2006) found parents want to know about the specifics of working the communication device, as well as implementation strategies to utilize the device at home. Therefore, trainings from the assistive technology team evolved from device management to implementing the device in various activities making the training more meaningful and engaging. This capstone project looked at the effectiveness of using a family-centered approach as a way to improve school-based trainings. Parent education was needed to increase the number of communication opportunities for Tammy, as she increased social engagement and improved occupational performance. The parent/family narrative and the initial FIATS-AAC assessment results provided an individualized intervention. Laura not only learned about the device, but she learned how to be a competent communication partner and to use various strategies to promote socialization and engagement through activities (Bailey et al., 2006; Light & McNaughton, 2014).

This capstone project was guided by the Person, Environment, Occupation, and Performance model (Bass et al., 2017) and the Human Activity Assistive Technology framework (Cook & Polgar, 2008) as the educational training provided an increase in the parent's occupational identity, performance and participation. The parent narrative and assessment allowed the intervention to utilize family strengths, as barriers were decreased, and communicative opportunities were increased. Specific occupations were used to guide interactions that facilitated communication. For instance, for the first time, siblings were able to engage in reciprocal communication throughout a meaningful activity. The occupational performance improved for every member of the family. The interventions included meaningful activities which increased the number of communicative opportunities thus enhanced both the parent and child's occupational performance and the communicative competence (Goodrich et al., 2016). It also included adult learning strategies as the parent learned how to become a better communication partner (Gevarter & Zamora, 2018; Light & McNaughton, 2014; Therrien & Light, 2018). The outcomes provided improved occupational identity, occupational performance and participation for both the parent, child and the sibling.

This case study reflected changes as family strengths increased and barriers were overcome. Romski and Sevcik (2005) studied six myths and realities about using communication devices. One myth was that using a communication device prevented a child from talking, yet actually, an AAC device provides a model of language and literacy (Romski & Sevcik, 2005).

Another myth was that communication devices be used as a last resort. However, Romski and Sevcik (2005) found that AAC devices need to be used sooner rather than later with nonverbal

children to help learn language skills and prevent children from experiencing failure with communication. These myths, misconceptions, and barriers are reduced when intervention is provided not only to the individual who uses AAC but to the communication partners (Light & McNaughton, 2014). Results of this case study found that barriers, such as decreased face to face communication and social versatility were overcome as communication opportunities increase and social engagement improved. The mother's reluctance to use the communication device was overcome as she saw her children interact and connect with each other, thus, strengthening the family's identity. There were a few limitations throughout this capstone project. One limitation was the lack of parent access to a computer after work hours, making it impossible for the parent to access the virtual training so the investigator modified materials to make it accessible for the parent. Therefore, the study was adapted for the parent as they completed the first intervention via telephone call and the following interventions were face-to-face. Another limitation was COVID-19, as the pandemic made contacting and recruiting parents difficult especially while isolation was encouraged, and group gatherings were limited to no more than three people.

Therefore, emails, texts, and social media were used in KY, GA, TN, PA, CA, and SC to recruit participants. In addition, the fall school start was delayed, coinciding with the beginning of the study start. The investigator shifted focus to see one parent to provide the education. Selection bias was possible. Single case study results need to be generalized with caution.

The following are clinical implications from this study: Good communication is necessary between community-based therapies, school-based therapies, and families to help prevent device abandonment and help keep goals family centered. Another implication includes utilizing best practice with the client's narrative and goals. Therapists will see an increase in client buy in and increased implementation of the AAC device after working alongside the client and following their narrative. Lastly, this project provided evidence that an individualized, family-centered approach to intervention improved occupational performance for both the parent and the child. Plus, it improved the parent and child's occupational identity and created a sense of belonging for the child. Therapists should listen to the family goals and strive to design the intervention with those goals as the outcome.

Future research is needed, beginning with a need to look at the effectiveness of implementation of AAC using occupational performance as a measure with a larger sample for a longer length of time than the six weeks allotted in this project. Another area of focus would be utilizing parent-led trainings as an alternative strategy for parents, rather than no observed training at all. Lastly, further research should be done on policy and procedures regarding parental education that is needed to support evidence-based practice.

The results of this capstone project provided the importance of focusing on familycentered practice utilizing the client/family narratives for goals, intervention and outcomes. It also demonstrated the importance of communication between the community-based therapies, school-based therapies and the family. This capstone project provided a positive step in expanding the knowledge base regarding the use of the People-Environment-Occupation-Performance model with adult learning strategies in trainings for parents to improve occupational therapy practice.

### Conclusion

This capstone project was developed to look at the effectiveness of parental training and education to support nonverbal children utilizing AAC in order to enhance participation and social engagement across environments. The parent training program using an extensive module system was designed for virtual access. For this case study, the modules were scaffolded and graded for maximum parental participation. This educational training provided family-centered focus and parent driven goals and outcomes. Family strengths and barriers were identified and addressed in the educational training. Results indicated the training reduced some barriers for parents, as they learned strategies to increase implementation of an AAC device and become a competent communication partner. Through effective parental training, parents learn to become competent communicators with their nonverbal child utilizing AAC, thus improving the family's identity and occupational performance across all settings.

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### **Appendix A: Semi Structured Interview Guide**

- 1. What's the parent's educational background?
- 2. What's your child's formal diagnosis?
- 3. What age is your child? Siblings?
- 4. What's the age equivalent of your child's comprehension?
- 5. What's the age equivalent of your child's expressive language?
- 6. What's your child's most common educational setting?
- 7. What's your experience with augmentative and alternative communication?
- 8. How often is the communication device used at home?
- 9. What functional outcomes would you like to see with the communication device?
- 10. What routines or activities does your child use the device for?
- 11. What kind of training have you received in the past?
- 12. When did your child first receive her AAC device?
- 13. What are some of your child's favorite activities?
- 14. How do you think your child's life routines will change?
- 15. What do you think of this training experience?

Holland Bloorview Kids Rehabilitation Hospital

A CHILD USES A.A.C.

WHEN

OF FAMILY

IMPORTANCE

Family Impact of Assistive Technology Scale for AAC (FIATS-AAC) (Ryan & Renzoni, 2015)

with this statement because your child always needs help from others when communicating, circle '7'. If you strongly disagree because your child never needs help, then circle '1'. Circle one of the other numbers if you agree or disagree to PLEASE READ: This questionnaire will help us to learn a bit about you, your child, and your family life as it relates to your statement. For instance, the first item says: 'My child needs help from others when communicating.' If you strongly agree child's face-to-face communication. Please complete the questionnaire by saying how much you agree with each a lesser amount. Please circle only one rating for each statement.

1My child needs help from others when76543212My child needs help from others when76543212My child test me know if something is76543213I need more support from family members76543214I find it easy to play with my child.76543215My child needs a lot of help to be76543216Being independent improves my child's self-76543217My child has a lough time starting a76543218My child has a lough time starting a765432110Others share the caregiving responsibilities765432111My child tells me about her/his day.765432111My child tells me about her/his day.765432112My child tells me about her/his day.765432113My child tells me ubout her/his day.765432114My child tells me ubout her/his day.7654321 <tr< th=""><th>- 1</th><th></th><th>Strongly Agree</th><th>Agree</th><th>Somewhat Agree</th><th>Neither Ågree nor Disagree</th><th>Somewhat Disagree</th><th>Disagree</th><th>Strongly Disagree</th></tr<>	- 1		Strongly Agree	Agree	Somewhat Agree	Neither Ågree nor Disagree	Somewhat Disagree	Disagree	Strongly Disagree
My child lets me know if something is765437I need more support from family members785438I need more support from family members785438I find it easy to play with my child.765438My child needs a lot of help to be765438My child reads a lot of help to be765438My child tells me what she/he wants.765438My child tells me what she/he wants.765438My child tells me what she/he could ask765438My child tells me atough time starting a765438My child tells me atough time starting a765<		My child needs help from others when communicating.	7	9	ю	4	ю	2	+
I need more support from family members765438I find it easy to play with my child.765438My child needs a lot of help to be understood.765438My child needs a lot of help to be understood.765438My child needs a lot of help to be understood.765438My child relis me what she/he wants.765438My child tells me what she/he wants.765438My child tells me what she/he wants.765438My child tells me what she/he could ask for my child got lost, she/he could ask for my child tells me about her/his day.765438My child tells me about her/his day.7654388	1200	My child lets me know if something is wrong.	7	9	ω	4	0	2	-
I find it easy to play with my child.765435My child needs a lot of help to be understood.765435Being independent improves my child's self- esteem.765435My child has a tough time starting a conversation with people.765435My child has a tough time starting a conversation with people.765435If my child delis me what she/he could ask for working go lost, she/he could ask for my child.765435My child tells me about her/his day.765435435My child tells me about her/his day.765435435	10000	I need more support from family members when caring for my child.	7	9	Q	4	8	2	-
My child needs a lot of help to be765433Being independent improves my child's self- esteem.765433My child tells me what she/he wants.765433My child has a tough time starting a conversation with people.765433If my child optiost, she/he could ask for my child7654335Others share the caregiving responsibilities 		I find it easy to play with my child.	7	9	5	4	3	2	-
Being independent improves my child's self-765433My child tells me what she/he wants.765433My child has a tough time starting a conversation with people.765433If my child got lost, she/he could ask someone for directions.765433Others share the caregiving responsibilities765435My child tells me about her/his day.765435	120	My child needs a lot of help to be understood.	7	9	2	4	3	2	-
My child tells me what she/he wants.       7       6       5       4       3         My child has a tough time starting a conversation with people.       7       6       5       4       3         If my child got lost, she/he could ask someone for directions.       7       6       5       4       3         Others share the caregiving responsibilities       7       6       5       4       3       5         My child tells me about her/his day.       7       6       5       4       3       5	Property 11	Being Independent improves my child's self- esteem.	7	9	5	4	з	2	-
My child has a tough time starting a conversation with people.     7     6     5     4     3       conversation with people.     7     6     5     4     3       If my child got lost, she/he could ask someone for directions.     7     6     5     4     3       Cothers share the caregiving responsibilities     7     6     5     4     3       My child tells me about her/his day.     7     6     5     4     3		My child tells me what she/he wants.	7	9	Ş	4	e	2	-
If my child got lost, she/he could ask 7 6 5 4 3 3 someone for directions. 7 6 5 4 3 3 Others share the caregiving responsibilities 7 6 5 4 3 for my child. My child tells me about her/his day. 7 6 5 4 3	1	My child has a tough time starting a conversation with people.	7	9	Q	4	e	2	-
Others share the caregiving responsibilities         7         6         5         4         3           for my child.         My child tells me about her/his day.         7         6         5         4         3		If my child got lost, she/he could ask someone for directions.	7	9	2	4	0	2	*
My child tells me about her/his day. 7 6 5 4 3	- I		7	9	5	4	0	2	-
			7	9	5	4	6	2	

# **Appendix B: Data Collection Tool- FIAT-AAC Worksheet**

Page 1 of 6

1		Dalac		aaifw	Disagree	Disagree	R	Disagree
12	My child's communication disability affects my ability to work outside the home.	7	9	Q	4	e	8	÷
13	It is hard for me to get anything else done when my child is at home.	7	9	ß	4	e	2	۴
4	My child likes to be independent.	7	9	2	4	ю	13	+
15	My child can phone for help in an emergency.	2	9	ß	4	ю	2	*
18	I need help from professionals to care for my child.	7	ø	ß	4	e	2	+
11	More than one person is required to help my child communicate.	7	60	ъ	4	0	2	-
18	My child knows how to take turns during conversations.	2	9	S	4	9	2	-
18	My child is learning to communicate independently.	T	9	Q	4	ø	2	٠
20	My family needs to give up many other luxuries so my child can have the devices she/he needs.	7	9	vo	4	ю	N	*
21	My child communicates with other people on the phone.	7	9	5	4	3	2	+
52	All family members take turns supporting my child when going out into the neighbourhood.	7	9	5	4	3	N	1
23	My child is very sociable.	7	9	ŝ	4	n	5	۰
24	My child communicates with family members.	7	9	S	4	ю	2	-
25	I feel my child is safe if I leave her/him with another babysitter/caregiver.	7	9	Q	4	e	2	÷
26	My child communicates with people with whom she/he is less familiar.	7	9	Q	4	в	2	-

Induced Illustration

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2		Strongly Agree	Agree	Somewhat Agree	Agree nor Disagree	Somewhat Disagree	Disagree	Strongly Disagree
27	I find it tiring to help my child communicate.	7	G	£	4	ო	2	T
28	My child's communication disability affects family finances.	7	9	5	4	3	2	-
29	I do most of the caregiving for my child at home.	7	g	Q	4	e	2	-
30	We watch our finances because of my child's communication disability.	7	9	ю	4	e	2	-
31	Other people understand my child.	7	9	a	4	0	2	-
32	It is very demanding saying what my child wants to others.	7	9	a	4	8	2	-
33	My child knows how to keep a conversation going.	7	9	Q	4	ო	2	-
34	Everyone in my family knows how to communicate with my child.	7	9	ŝ	4	ы	2	-
35	My child plays with friends.	7	9	5	4	e	2	-
36	Communication devices for my child make it difficult for my family to afford anything else.	7	9	5	4	3	2	-
37	My child tells me when she/he is afraid.	7	9	2	4	3	2	-
38	My child's independence is increasing.	7	9	5	4	ę	2	-
39	My child communicates her/his ideas.	7	9	5	4	ო	2	-
40	Much of my time during the day is spent helping my child to communicate.	7	9	ø	4	e	2	<b>N</b> .
41	My child participates in community activities.	7	9	2	4	9	2	-
42	My child tells me when she/he feels sick.	7	9	2	4	e	2	-

Radiand Biorview

57

. 1		Strongly Agree	Agree	Somewhat Agree	Agree nor Disagree	Somewhat Disagree	Disagree	Strongly Disagree
43	My child needs my help to communicate with others.	7	9	S	4	3	2	÷
4	My child converses well with friends.	7	9	5	4	3	2	-
45	It is hard work helping my child with homework.	7	9	5	4	е	5	τ
46	My child could never go out in the neighbourhood on her/his own.	7	9	S	4	е	2	-
47	My child prefers to communicate with me rather than other family members.	7	9	S	4	e	3	-
48	My child socializes with others at meattime.	7	9	ß	4	Э	2	۲
49	My child's teacher is satisfied with my child's performance in school.	7	9	ω	4	9	2	-
20	Other family members need to help me care for my child.	7	9	ŝ	4	ю	2	-
27	My child must be with others to be content.	7	9	S	4	9	. 2	T
52	I have difficulty managing my child's behaviour.	7	9	Q	4	9	2	۴
53	My child can spend a long time doing one activity.	7	9	ŝ	4	9	2	-
\$	My child can communicate with others.	7	9	22	4	9	2	-
22	My child enjoys school.	7	9	ъ	4	ę	2	*
28	I need longer breaks from watching my child.	7	9	£	4	3	2	5
22	My child gets frustrated easily.	7	9	ŝ	4	9	2	r.
58	I have little time to get chores done around the house.	7	9	Ω	4	e	2	-

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		Strongly Agree	Agree	Somewhat Ågree	Agree nor Disagree	Somewhat Disagree	Disagree	Strongly Disagree
59	My child behaves well around me.	7	9	5	4	e	2	-
60	I have trouble coping with the demands of caring for my child.	7	9	5	4	3	2	-
61	My child participates in the classroom.	7	9	5	4	3	2	-
62	My child likes to explore her/his surroundings.	7	9	S	4	3	2	-
63	My child acts appropriately towards other family members.	7	8	5	4	3	2	-
64	My child wants to be with me when I leave the room.	7	9	5	4	3	2	-
65	I would like to get more breaks from caring for my child.	7	9	5	4	3	2	-
88	My child is performing well in school.	7	9	ŝ	4	3	2	-
67	I would like to spend more time with my other family members.	7	9	3	4	3	2	-
88	My child gets bored easily.	7	9	S	4	ę	2	-
69	My child can play games.	7	9	5	4	e	2	-
22	My child is well behaved at school.	7	9	w	4	6	2	-
71	I must take my child with me when I go from one room to another.	7	9	5	4	e	2	-
72	I need to get more things done around the house.	7	9	2	4	e	2	-
73	My child can be happy when I am not holding her/him.	7	9	ŝ	4	e	2	-
74	I am concerned about my child's safety when she/he is left alone.	7	9	Q	4	0	2	٣

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75	Mv child participates in extra-curricular	Strongly Agree	Agree	Somewhat Agree	Neither Agree nor Disagree	Somewhat Disagree	Disagree	0
0	my critic participates in extra-curricular activities at school.	7	9	5	4	3	2	
76	My child can use her/his hands to play.	7	9	ŵ	4	9	2	
11	I need help to take care of my child.	7	8	5	4	ъ	2	
78	I am satisfied with my child's achievement of personal goals at school.	7	9	2	4	ю	2	
79	My child feels self-confident.	7	9	2	4	3	2	
80	A family member needs to be near my child during the day.	7	9	2	4	e	2	
81	I wish my child could give me a few minutes to myself each day.	7	9	5	4	3	2	
82	I am concerned about the way my child behaves.	7	9	2	4	3	2	
83	My child can control toys without help.	7	9	2	4	9	2	
84	My child is proud of her/his schoolwork.	7	9	5	4	3	2	
85	My child can be happy when left alone to play.	7	9	5	4	е	8	
88	My child needs me nearby to do many activities.	7	9	S	4	в	2	
87	My child disrupts her/his classmates.	7	9	5	4	9	2	
88	I can manage my child on my own.	7	9	5	4	e	2	
88	My child likes to be near me.	7	9	5	4	8	2	

FIATS-AAC (June 2015) Page 6 of 6

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### **Appendix C: IRB Approved Consent Form**

## Consent to Participate in a Research Study

## The Importance of Family When A Child Uses AAC

Institutional Review Board Protocol Number 2985 Approval Valid 9/4/20-12/4/20

### **Key Information**

You are being invited to participate in a research study. This document includes important information you should know about the study. Before providing your consent to participate, please read this entire document and ask any questions you have.

#### Do I have to participate?

If you decide to take part in the study, it should be because you really want to volunteer. You will not lose any benefits or rights you would normally have if you choose not to volunteer. You can stop at any time during the study and still keep the benefits and rights you had before volunteering. If you decide to participate, you will be one of about 5 people in the study.

#### What is the purpose of the study?

The purpose of the study is to learn more about families who have a child who uses a communication device at school. I want to hear your views on what it's like to use a communication device for you and your family. You are invited to participate in this research study because you are a parent/caregiver for a child who currently uses a communication device.

#### Where is the study going to take place and how long will it last?

The research procedures will be conducted virtually online and/or face to face at Westview Primary School. Prior to the sessions, there will be a telephone interview lasting approximately 20-40 minutes. Next, you will receive a Google Classroom code to join the class to access the training material. There will be two sessions approximately a half hour to go over materials and questions. A final interview lasting approximately 20-40 minutes will be completed 6 weeks after the initial interview. The total amount of time you will be asked to volunteer for this study is for no more than 3 hours in September 2020.

#### What will I be asked to do?

You are being asked to participate in the following activities: Provide signed consent to participate, take part in a telephone interview before and after the 2 sessions of camp either virtual or face to face for the training. The two virtual meetings on Sept. 15<sup>th</sup> and 29<sup>th</sup> will be recorded for data purposes only.

#### Are there reasons why I should not take part in this study?

There are no reasons why you should not be able to take part in this study.

#### What are the possible risks and discomforts?

To the best of our knowledge, the things you will be doing have no more risk of harm than you would experience in everyday life. You may, however, experience a previously unknown risk or side effect.

#### What are the benefits of taking part in this study?

You are not likely to get any personal benefit from taking part in this study. Your participation is expected to provide benefits to others by helping others.

#### If I don't take part in this study, are there other choices?

If you do not want to be in the study, there are no other choices except to not take part in the study.

Page 1 of 3

Now that you have some key information about the study, please continue reading if you are interested in participating. Other important details about the study are provided below.

# **Other Important Details**

#### Who is doing the study?

The person in charge of this study is Kirsta von Hellens, a licensed occupational therapy who also works for Berkeley County School District and is a student at Eastern Kentucky University. She is being guided in this research by Camille Skubik-Peplaski. There may be other people on the research team assisting at different times during the study.

#### What will it cost me to participate?

Participants may have to pay for the cost of getting to and from the study site.

#### Will I receive any payment or rewards for taking part in the study?

You will not receive any payment or reward for taking part in this study.

#### Who will see the information I give?

Your information will be combined with information from other people taking part in the study. When we write up the study to share it with other researchers, we will write about this combined information. You will not be identified in these written materials.

We will make every effort to prevent anyone who is not on the research team from knowing that you gave us information, or what that information is. Include the following statement if the data will not be recorded with identifying information: For example, your name will be kept separate from the information you give, and these two things will be stored in different places under lock and key.

However, there are some circumstances in which we may have to show your information to other people. For example, the law may require us to show your information to a court. Also, we may be required to show information that identifies you for audit purposes.

#### Can my taking part in the study end early?

If you decide to take part in the study, you still have the right to decide at any time that you no longer want to participate. You will not be treated differently if you decide to stop taking part in the study.

The individuals conducting the study may need to end your participation in the study. They may do this if you are not able to follow the directions they give you, if they find that your being in the study is more risk than benefit to you, or if the University or agency funding the study decides to stop the study early for a variety of reasons.

#### What happens if I get hurt or sick during the study?

If you believe you are hurt or get sick because of something that is done during the study, you should call Kirsta von Hellens at 843.637.5490 immediately. It is important for you to understand that Berkeley County Schools and Eastern Kentucky University will not pay for the cost of any care or treatment that might be necessary because you get hurt or sick while taking part in this study. Also, Berkeley County Schools and Eastern Kentucky University will not pay for any wages you may lose if you are harmed by this study. These costs will be your responsibility.

Usually, medical costs that result from research-related harm cannot be included as regular medical costs. Therefore, the costs related to your care and treatment because of something that is done during the study will be your responsibility. You should ask your insurer if you have any questions about your insurer's willingness to pay under these circumstances.

#### What else do I need to know?

You will be told if any new information is learned which may affect your condition or influence your willingness to continue taking part in this study.

We will give you a copy of this consent form to take with you.

Page Z of 3

# Consent

Before you decide whether to accept this invitation to take part in the study, please ask any questions that come to mind now. Later, if you have questions about the study, you can contact the investigator, Kirsta von Hellens at 843.637.5490 or email vonhellensk@bcsdschools.net. If you have any questions about your rights as a research volunteer, you can contact the staff in the Division of Sponsored Programs at Eastern Kentucky University at 859-622-3636.

If you would like to participate, please read the statement below, sign, and print your name.

I am at least 18 years of age, have thoroughly read this document, understand its contents, have been given an opportunity to have my questions answered, and voluntarily agree to participate in this research study.

Signature of person agreeing to take part in the study

Date

Printed name of person taking part in the study

Name of person providing information to subject