“YOU JUST WANT TO BE ABLE TO COMMUNICATE WITH YOUR CHILD”:
CAREGIVERS’ PERSPECTIVES ON COMMUNICATION AND AAC FOR BEGINNING
COMMUNICATORS ON THE AUTISM SPECTRUM

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by

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ABSTRACT

For young children on the autism spectrum who are beginning communicators, augmentative and alternative communication (AAC) can support various language skills and provide a means of participating in the social interactions that serve as critical contexts for early language learning. To maximize language-learning opportunities for these children, it is important for AAC to be integrated into interactions within the context of daily life. It is particularly important for AAC to be integrated into caregiver-child interactions, as parents and others in similar caregiving roles are some of the most important early communication partners for young children. Research suggests that AAC is more likely to be implemented at home when it fits well with the needs and priorities of the family and when it is able to be supported within the home environment. Understanding parents’ experiences surrounding communication and AAC can provide important insight into the process of implementing AAC within everyday life, including barriers and supports to communication and use of AAC systems. To date, however, little research has investigated the experiences of parents of young children on the autism spectrum who are beginning communicators with respect to communication and AAC. This study addressed the following questions: (a) What are parents’ communication experiences with their children on the autism spectrum who are beginning communicators? What challenges and supports do parents face relative to their child’s communication?; and (b) What are parents’ experiences surrounding use of AAC systems with their children on the autism spectrum who are beginning communicators? What challenges and supports do they face relative to use of AAC systems? The study used a phenomenological qualitative design. Eight parents or caregivers of seven children on the autism spectrum participated in the study. Data were collected via semi-structured interviews, and thematic analysis was used to identify themes within the data. Five main themes and 16 sub-themes emerged from the data, suggesting the following key messages:
1. Young children on the autism spectrum with limited speech have a profound impact on parents and the entire family.

2. Parents often devote enormous amounts of time, energy, and other resources to ensure the best life and outcomes for their child and their family. Often, supporting their child requires them to make substantial sacrifices and to take on roles and responsibilities that go beyond those required of many other parents.

3. Parents often have positive experiences with AAC professionals, but also have to work to seek out additional support, including practical support, emotional support, and information about topics including but not limited to AAC, to enhance quality of life for themselves, their child, and their family. Parents often seek support and information from other parents of children on the autism spectrum.

4. Parents of beginning communicators on the autism spectrum value communication and consider it a priority.

5. Parents consider AAC to be beneficial; however, the practical challenges of obtaining, learning, and implementing AAC can be numerous, and these challenges are often ongoing as child and family needs and skills (and, therefore, the best fit in an AAC system) evolve over time.

6. Every child and every family is different. What works for one family may not work for another. Each child and family’s unique needs are dynamic, changing over time as skills develop and priorities shift.

7. Communication outcomes are impacted by factors external to the child and the family, including the healthcare and education systems.

8. The communication team (child, parents, and professionals) is a system that thrives on mutual respect, communication, and collaboration. Parents must be recognized as experts
in their children and given opportunities to both share their knowledge and to receive training from professionals that meets their specific learning and support needs.

The results affirm the need to think in terms of ecological and family systems when providing AAC services. Additionally, they suggest implications for provision of family-centered AAC services, including implications for (a) provision of support for parents; (b) design of AAC systems; (c) adoption of a personalized intervention approach in AAC, (d) consideration of stakeholder-defined outcomes; (e) provision of AAC provider training in family-centered services, (f) provision of support for building caregiver competencies, and (g) design of AAC service delivery models.

**Keywords:** augmentative and alternative communication, autism spectrum disorder, beginning communicators
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Chapter 1

Interpretive Autobiography

The current study was inspired largely by my experiences as a speech language pathologist working with beginning communicators on the autism spectrum with limited speech, and the data in this study are viewed through the lens of my professional training and experiences. During my time as a clinician, I had the privilege of working extensively with individuals on the autism spectrum in home and community settings. This work primarily involved provision of augmentative and alternative communication (AAC) services. As part of this work, I collaborated regularly with parents to provide training in implementation of AAC supports for their child with limited speech; I met with parents on a regular basis, I provided hands-on instruction and demonstration of AAC tools, and I worked with parents to identify priorities and ensure that AAC supports were meeting the needs of their child.

In addition to working with children and parents at home and in the community, I have also provided services within a school setting, a hospital outpatient clinic, and a private practice. Each of these work settings offered unique insight into the challenges and supports related to AAC implementation from a professional perspective. For instance, my role at the private practice provided experience working with insurance companies to obtain reimbursement for AAC services and funding for AAC systems, and my role at the school provided experience working with a large, interdisciplinary team that included the child, the family, and a number of professionals. It should be noted that I provided services to one of the families that participated in the current study while working as a clinician. The duration of these services was less than one year, and approximately five years have passed since I last worked with them in a clinical capacity.
The lens through which the study data were analyzed was also impacted by my experience as a new parent. My son was born during the data collection process for this study, and this placed me in a new role that influenced my perspective. It is important to note that my child does not have a diagnosis of autism spectrum disorder; thus, while I brought the perspectives of a professional and a parent to the processes of data collection and analysis, I am not a parent of a child known to be on the autism spectrum.

In my clinical experiences across various settings and roles, interactions with parents have always been an important part of my work with beginning communicators on the autism spectrum. While school placements, services, IEP team members, and other factors change over time, parents (or guardians/primary caregivers) are often constants in each child’s life. As a professional I typically got to know each child within a single setting, but parents have unique insight into their child’s communication needs and challenges across contexts and communication partners. They are uniquely positioned to help others understand challenges and supports to communication and AAC implementation. In this study, I hope to elevate parent voices. I aim to understand the challenges parents face when interacting with their children and implementing AAC in daily life, as well as supports that can enhance interactions. Ultimately, I hope that understanding parents’ perspectives may lead to potential solutions and future research directions to improve supports and services for beginning communicators on the autism spectrum who may benefit from AAC and their families.
Chapter 2

Introduction and Statement of Topic

Language development is one of the most important achievements of early childhood. It has been argued that language development, like development in other domains, is shaped by the social context in which it occurs (e.g., Hoff, 2006, Tomasello, 2000). This is the case for both children with typical development and children on the autism spectrum (Grandgeorge et al., 2009).

While a number of contextual factors (e.g., cultural values surrounding the nature of parent-child interactions, family socioeconomic status) are related to and may impact language development (Hoff, 2006), the interactions that occur between young children and their communication partners play an especially important role as contexts for early language learning. According to social pragmatic theories of language development\(^1\), language learning is a social activity requiring both exposure to language models and opportunities for practice through interactions with others (Golinkoff et al., 2015; Hoff, 2006; Hollich et al., 2000; Tomasello, 2000). Opportunities for back-and-forth conversation, in which both the child and the communication partner are active participants, are critical for language learning (e.g., Hirsh-Pasek et al., 2015; Hoff, 2006, Romeo et al., 2018; 2021). For young children in particular, these supportive interactions often occur with parents (Granlund et al., 2008).

For children on the autism spectrum\(^2\) who have limited speech, participation in the interactions that support early language learning is complicated. Autism spectrum disorder (ASD) is a developmental disability characterized by deficits in social communication and social interaction (American Psychiatric Association, 2013). Many children on the autism spectrum also have complex communication needs, meaning that they are unable to rely on speech or writing to meet all of their communication needs (Beukelman & Light, 2020; Kasari et al., 2014). Estimates
vary, but studies suggest that approximately 25-30% of children on the autism spectrum demonstrate little or no use of speech by the time they enter kindergarten (Kasari et al., 2014). Without reliable access to speech, young children on the autism spectrum are at risk for missing out on opportunities to participate in the social interactions that are critical contexts for learning language and social skills (Light, 1997).

For young children on the autism spectrum with limited speech who are beginning communicators (i.e., not yet combining words into original phrases and sentences on a regular basis; Tager-Flusberg et al., 2009), augmentative and alternative communication (AAC) can provide a means of participating in social interactions that provide a context for early language learning (e.g., Chapin et al., 2021; Light et al., 2019; Therrien & Light, 2018). According to the American Speech-Language-Hearing Association (ASHA):

Augmentative and alternative communication (AAC) is an area of clinical practice that supplements or compensates for impairments in speech-language production and/or comprehension, including spoken and written modes of communication. AAC falls under the broader umbrella of assistive technology, or the use of any equipment, tool, or strategy to improve functional daily living in individuals with disabilities or limitations. (n.d.a.)

There are a range of AAC systems available to support individuals with complex communication needs, including both aided and unaided systems. Unaided AAC systems do not require any external equipment and include options such as vocalizations, gestures and manual signs. Aided AAC systems require external equipment or technology and include options such as low-tech picture communication boards and mobile devices with apps that offer speech output (Beukelman & Light, 2020). In this study, the term “AAC” refers to the tools used to support communication, including both aided and unaided AAC systems. The term “communication” refers more broadly to the interactions that involve aided and/or unaided AAC systems and strategies used within these interactions.
Studies have demonstrated improvements in various language skills including requesting, protesting, expressive vocabulary, and social interaction for young children on the autism spectrum who are in the early stages of language development following the introduction of AAC (e.g., Ganz, 2015; Light et al., 2019; Kasari et al., 2014). Additionally, several meta-analyses have demonstrated that use of AAC does not limit and may enhance use of speech for some individuals with disabilities including ASD (Ganz, 2015; Millar et al., 2006). It is clear that AAC holds substantial promise for supporting development of language and communication skills for beginning communicators on the autism spectrum in addition to supporting participation within the social interactions that are important contexts for language learning. It is important for AAC to be integrated into interactions within the context of daily routines and activities in order to maximize language learning opportunities for these children (e.g., Granlund et al., 2008).

To date, the majority of AAC research, including research involving children on the autism spectrum, has been conducted in didactic, highly structured settings, usually outside of the home (Ganz, 2015; Granlund et al., 2008). However, research is increasingly beginning to investigate use of AAC in more naturalistic contexts and with a variety of communication partners; this research suggests that AAC interventions implemented by varied communication partners, including parents, may be as effective for children on the autism spectrum as those implemented by researchers (Ganz, 2015; Sigafoos et al., 2004; Trottier et al., 2011). Research involving individuals with various disabilities, including autism spectrum disorder, suggests that AAC is more likely to be implemented at home when it fits well with the needs and priorities of the family and when it is able to be supported within the home environment (Anderson et al., 2014; Bailey et al., 2006; Granlund et al., 2008; McNaughton et al., 2008; McCord & Soto, 2004; Parette et al., 2000). Moreover, family involvement in AAC planning and decision-making can help families feel a sense of ownership of AAC intervention and contribute to greater satisfaction with AAC solutions (Crais, 1991; McNaughton et al., 2008; Parette et al., 2000). On the other
hand, lack of attention to family perspectives can result in alienation of families and selection of AAC systems and intervention targets that do not match family priorities or lifestyle, and/or are not able to be supported by family members (Granlund et al., 2008). When AAC systems and goals are not a good fit for the family, AAC may be seen as an extra task that creates new demands and may be perceived as stressful (Granlund et al., 2008). Ultimately, disregard for family perspectives can contribute to AAC rejection and abandonment (Moorcroft et al., 2020; Parette et al., 2000; Parette & Angelo, 1996).

Parents can provide important insight into child and family needs, priorities, challenges, and supports. During the early stages of language development, parents are primary communication partners for most children and the interactions that occur between parents and children shape language development in important ways (Granlund et al., 2008; Hoff, 2006). Parents are experts in their children’s abilities and needs; they are in a position to advocate for AAC solutions that are a good fit for their child as well as for the entire family (Goldbart & Marshall, 2004; O’Neill & Wilkinson, 2020). Moreover, parents typically remain constants in their child’s life while other team members may come and go (Parette et al., 2000). Understanding parents’ experiences can provide important insight into the process of implementing AAC within everyday life, including barriers and supports to communication and use of AAC. It is essential to understand the challenges, supports, and everyday experiences of parents to develop effective intervention services and AAC systems that match child and family needs and priorities.

**Considerations for young beginning communicators on the autism spectrum**

While a number of studies have explored AAC experiences of parents of children with developmental disabilities, few have focused on parents of beginning communicators on the
autism spectrum specifically. These individuals and their families may have unique experiences that impact their perspectives on communication and AAC. More specifically, research suggests that families of beginning communicators on the autism spectrum may have unique experiences related to (a) family life and (b) AAC systems and services. Because of this, the challenges, supports, and priorities of parents of beginning communicators on the autism spectrum with respect to integrating AAC into daily life may differ from those of other parents and should be explored separately.

Family life

Families with a child on the autism spectrum may encounter unique experiences and challenges within daily and family life. These families often report high levels of parental stress and mental health challenges (Cassidy et al., 2008; Estes et al., 2009; Karst & Van Hecke, 2012; Walton & Tiede, 2020), as well as high divorce rates (Karst & Van Hecke, 2012; Walton & Tiede, 2020). Many report experiencing restrictions on social and community activities related to their child on the autism spectrum (e.g., Cassidy et al., 2008). Compared to families of children with other developmental disabilities, families of children on the autism spectrum are more likely to experience financial problems and interruptions in parental employment related to their child, and parents are more likely to experience greater caregiving demands and caregiving-related fatigue (Karst & Van Hecke, 2012; Kogan et al., 2008). Parents often experience complicated emotions related to their child, such as grief following their child’s diagnosis, confusion surrounding the optimal course of treatment, and a reduced sense of parental self-efficacy compared to parents of children with typical development or other developmental disabilities (Karst & Van Hecke, 2012).
On the other hand, parents have also reported increased family closeness as a result of their child (Cassidy et al., 2008). Sibling relationships in these families have been reported to be strong, particularly in early childhood (Karst & Van Hecke, 2012). Families of children on the autism spectrum have been found to demonstrate great resilience (Bayat, 2007), and to effectively apply adaptive coping strategies and social supports to help manage stress (Karst & Van Hecke, 2012).

AAC systems and services

Young children with complex communication needs who are beginning communicators and their families may experience unique supports, challenges, and barriers related to AAC. As young children undergo substantial social, cognitive, and language development, skills in these areas can impact the ways in which they learn and interact with AAC. For instance, young children may have particular difficulty learning the graphic symbols that are commonly used in traditional AAC systems. There is evidence that individuals with disabilities use their spoken language comprehension skills to support learning of the graphic symbols (Sevcik, 2006); beginning communicators with emerging receptive language may therefore have a more difficult time with this task. Moreover, a number of studies have found that the graphic symbols used in traditional AAC systems are not intuitive for young children and are relatively difficult for children to identify (Light & Drager, 2007; McCarthy et al., 2018; Worah et al., 2015). For example, Light and Drager (2007) reported that when children age 4-7 years with typical development were asked to draw 10 early emerging concepts (all gone, big, come, eat, more, open, up, want, what, and who), the children’s drawings differed substantially from the representations in current AAC symbol sets; the drawings depicted entire scenes (which often included the child) rather than the individual objects/parts of objects and conventional symbols.
(e.g., directional arrows) that tended to characterize commercially available representations. In an extension of this work, McCarthy et al. (2018) asked children on the autism spectrum and children with typical development to draw the same language concepts, then compared the drawings across the two groups. They found no significant differences between the two groups with respect to the main components included in the drawings. This research suggests that, like young children with typical development, young children on the autism spectrum may hold internal representations of language concepts that differ substantially from the representations on most commercially available AAC systems.

Beyond the single symbol level, evidence also suggests that young children have substantial difficulty both understanding and constructing phrases using graphic symbols (Sutton et al., 2010; Trudeau et al., 2010; Trudeau et al., 2014). Comprehension and production of graphic symbol sequences require not only an understanding of the symbols themselves, but also sufficient knowledge of morphosyntax; an understanding that the visual symbols correspond to spoken words; and the cognitive skills to hold individual concepts or full messages in working memory throughout the often slow process of constructing graphic symbol sequences, particularly if a fixed display is not available (Trudeau et al., 2014). Young children undergo substantial changes as they grow and develop, and these changes may impact their experiences using symbols both individually and in combination. This in turn may have implications for the selection of AAC systems as well as instruction. It is possible that young beginning communicators on the autism spectrum and their families have a unique perspective on communication and AAC related to the child’s developmental stage.

Due to these unique considerations with respect to family life and AAC, it is important to understand the experiences and perspectives of parents of beginning communicators on the autism spectrum specifically. To support communication and language development through successful integration of AAC into everyday life, there remains a need to understand
communication and AAC experiences, including challenges, barriers, and supports to communication and use of AAC, from the perspective of these parents. The aim of this study is to understand that unique perspective.
Chapter 3

Theoretical Framework

The theoretical framework has been described as the “blueprint” for a qualitative study (Grant & Osanloo, 2014). It outlines the concepts and ideas that help to guide the research process, including the design of the study, the focus of the literature review, and the data analysis process. In qualitative research, the theoretical framework may be determined at the outset of the study, or it may be determined as the data emerge and can be considered in relation to existing theories and models (Grant & Osanloo, 2014). As Grant and Osanloo state, “allowing theory to arise from qualitative methods may lead to a new conceptualization of the topic, or to the alignment of findings with an existing theory that can be compared and contrasted in the analysis” (p. 21). In the current study, several potential theoretical frameworks were considered; as the data were analyzed and patterns began to emerge, a theoretical approach that provided a useful framework for understanding and exploring these patterns was selected to guide the focus of the paper.

The bioecological model of human development (Bronfenbrenner, 1979) and family systems theory (Minuchin, 1985) provide theoretical frameworks that illustrate the importance of understanding parents’ perspectives relative to communication and AAC for beginning communicators on the autism spectrum. The use of both models in this study draws on prior work by Mandak and colleagues (2017), who proposed a model for AAC services that situates the family system within a broader ecological system and highlights how AAC services can be improved by drawing on concepts from both frameworks. Family systems theory has also been used in previous research as a framework to guide family-focused autism research (Cridland et al., 2014).
According to family systems theory, the family is an interconnected system consisting of multiple individuals and sub-systems (e.g. parent-child sub-system, sibling sub-systems), with varying roles and functions within each sub-system (Turnbull et al., 2015). The family system is governed by the principles of interdependence and wholism, which hold that all family members and sub-systems are integrally linked and can only be understood in relation to one another (i.e., by viewing the family as a whole; Minuchin, 1985). Families must continually adjust in response to the demands of daily life (adaptation); when they do so successfully, they achieve a state of balance, or homeostasis (Minuchin, 1985). To support the family system, AAC services must involve all individuals and sub-systems that are relevant as defined by the family themselves (interdependence/wholism; Mandak et al., 2017). Professionals must be sensitive to a family’s unique needs and to the stressors that they face in daily life (adaptation). Additionally, they must recognize how introduction of AAC impacts the family and ensure that it can be integrated into daily routines without introducing stress or placing any additional burden on the system (homeostasis; Mandak et al., 2017; O’Neill & Wilkinson, 2020).

As Mandak et al. (2017) further argue, families do not exist in isolation. They are part of a larger ecological system that includes contexts both proximal and distant to the family. In the bioecological model of development, Bronfenbrenner (1979) describes these contexts as a set of nested systems with the child at the center. The child is surrounded by increasingly distant systems: the child’s immediate surroundings and the interactions that take place within those surroundings make up the microsystem, the relationships between two or more of the child’s immediate settings (e.g., home and school) make up the mesosystem, settings in which the child does not participate directly but which affect (or are affected by) the child’s immediate surroundings (e.g., a parent’s place of work, parents’ support groups or networks) make up the exosystem, and the belief systems or ideology impacting the culture as a whole (e.g., values,
public policy) make up the macrosystem. The child and the family both influence and are influenced by variables across all levels of the ecological system.

The bioecological model and family systems theory highlight the importance of understanding family experiences and perspectives, including supports and barriers to communication and use of AAC within daily life. These models suggest a need to consider not only child communication, as is typical in most AAC research with beginning communicators on the autism spectrum (e.g., Ganz, 2015), but also communication between and among all members of the family system and the potential impact of AAC on communication and family functioning. Moreover, they highlight the need to recognize and consider factors external to the family system (e.g., societal structures and values) that may impact communication and AAC implementation. Throughout this study, these theories provide a framework within which to situate parents’ experiences.

Additionally, family systems theory and the bioecological model provide a framework for understanding the importance of integrating parents’ perspectives within the field of AAC. AAC services that are truly family-centered (a) respond to child and family priorities; (b) build partnerships with families and collaborate in individualized ways; and (c) aim to produce optimal child, parent, and family outcomes (Dunst, 2002; Turnbull et al., 2007). Family-centered services have been shown to result in a number of benefits for both children and their families, including increased family well-being, greater family satisfaction with services, stronger family feelings of self-efficacy, and improved child functioning (Dunst et al., 2007). Despite the established benefits of centering the needs and experiences of families, AAC services for school-aged children are traditionally driven by professionals who determine goals and provide instruction within didactic, highly structured settings (e.g., Granlund et al., 2008). Although AAC professionals often believe they are providing family-centered services, parents do not always perceive this to be the case (Mandak & Light, 2018). Thus, AAC professionals/professional services and families represent
separate microsystems within the bioecological model, and there may be a breakdown in the connection and communication between these systems (the mesosystem). This breakdown highlights the need for professionals to better understand family priorities to improve both family and child outcomes.
Chapter 4

Review of the Literature

A literature review was conducted to understand what is currently known about the experiences of parents of beginning communicators on the autism spectrum. To date, little research has focused specifically on the AAC experiences of parents of children on the autism spectrum. Therefore, the following discussion begins by reviewing the research on the AAC experiences of parents of children with developmental disabilities generally. It then reviews the research on experiences of parents of children on the autism spectrum, focusing on communication generally as well as specifically on AAC-related experiences.

Experiences of parents of children with developmental disabilities

Previous research has investigated the AAC experiences of parents of children with disabilities such as cerebral palsy or intellectual and developmental disabilities. Some of this research has included parents of children on the autism spectrum (e.g., Anderson et al., 2014; Anderson et al., 2015; Anderson et al., 2016; Angelo, 2000; Crisp et al. 2014; Meder & Wegner, 2015), though the experiences of those parents are embedded within themes and patterns that emerged from the larger group and cannot be understood independently.

Role, value, and impact of AAC

In these studies, parents of children with complex communication needs frequently expressed favorable attitudes toward AAC. Parents considered AAC to be a valuable tool for
supporting their child’s communication (Goldbart & Marshall, 2004; Marshall & Goldbart, 2008; McCord & Soto, 2004; Schladant & Dowling, 2020). Many reported that AAC had had a positive impact on their child, citing increases in independence, communication skills, educational and social opportunities, and quality of life as a result of using AAC (Angelo, 2000; Bailey et al., 2006; Schladant & Dowling, 2020). In some cases, parents reported positive effects of AAC on their interactions with their child. For instance, many parents surveyed by Angelo (2000) reported enhanced relationships with their child and reduced stress surrounding communication with their child because of AAC. In recognizing the value of AAC, parents have also acknowledged that their children are often skilled multimodal communicators who make use of both aided and unaided means, including non-symbolic means (e.g., behaviors), depending on the communication context (Bailey et al., 2006; Marshall & Goldbart, 2008; McCord & Soto, 2004; O’Neill & Wilkinson, 2020). For instance, aided AAC may not play a crucial role in the home environment for all children, but may still be valuable at school and in the community (e.g., McCord & Soto, 2004). Similarly, some high tech AAC (e.g., devices that are accessed via eye gaze technology and must be mounted to a wheelchair) may not be practical or accessible in all contexts, but children may be able to use unaided or low tech alternatives instead in these situations (O’Neill & Wilkinson, 2020).

Parents described ways in which AAC impacts all aspects of their lives. Many have discussed the substantial demands of supporting AAC use for their child, often describing a wide variety of parent roles and responsibilities related to AAC. In fact, more than half of the participants surveyed by Angelo (2000) reported that their roles, responsibilities, and demands on their time had increased as a result of their child’s AAC system, and parents interviewed by Goldbart and Marshall (2004) believed that they faced demands above and beyond those faced by other parents. Among these roles and responsibilities, parents have reported the following: (a) taking initiative to seek out information about AAC and learn new skills such as signing
(Anderson et al., 2014; Angelo, 2000; Goldbart & Marshall, 2004; McNaughton et al., 2008), (b) working to facilitate learning and device use at home (e.g., by creating motivating activities for the child, providing opportunities for practice with family members, and programming devices; Anderson et al., 2014; Goldbart & Marshall, 2004; Marshall & Goldbart, 2008; McNaughton et al., 2008; O’Neill & Wilkinson, 2020), (c) educating others about AAC (Marshall & Goldbart, 2008; McNaughton et al., 2008; O’Neill & Wilkinson, 2020), and (d) being an advocate who “fights for” the child (Angelo, 2000; Goldbart & Marshall, 2004; O’Neill & Wilkinson, 2020).

While many parents recognize the value of AAC, they have also reported that communication with their child who uses AAC can be effortful and fatiguing (Goldbart & Marshall, 2004). Some parents have reported feelings of social isolation due to lack of support (Goldbart & Marshall, 2004; Marshall & Goldbart, 2008). Parents have expressed both hope and uncertainty about the future (O’Neill & Wilkinson, 2020). Parents have expressed the desire for professionals to have increased understanding and sensitivity to the complexity of each family’s life, the demands that the family faces on a daily basis, and the specific, unique needs of the family (Goldbart & Marshall, 2004; Marshall & Goldbart, 2008; McNaughton et al., 2008).

**Challenges and barriers related to AAC implementation**

Parents have discussed challenges with AAC implementation as well as specific factors that hinder the use of AAC. Some discussed the challenge of providing ongoing support for the child’s use of AAC. For instance, parents reported challenges related to the amount of time, equipment, and finances necessary to support AAC use (e.g., Crisp, 2014; Goldbart & Marshall, 2004; Marshall & Goldbart, 2008). They have also described their own lack of knowledge as a challenge, with some parents feeling that they did not possess the technical skills to support an
AAC system or adequate knowledge about how to help their child use the system and learn new language skills (McCord & Soto, 2004).

Parents also identified challenges and barriers related to professional services and teaming such as limited provider knowledge and experience (Anderson et al., 2014; Crisp et al., 2014; Goldbart & Marshall, 2004; Marshall & Goldbart, 2008; O’Neill & Wilkinson, 2020; Schladant & Dawling, 2020), lack of training and support for parents (Anderson et al., 2014; O’Neill & Wilkinson, 2020), and ineffective team coordination and communication (Anderson et al., 2014). In some cases, lack of adequate training and support for parents led to abandonment of the AAC system (Anderson et al., 2014). A recurrent theme was that AAC implementation suffered when parents were not treated as valued members of the team (Anderson et al., 2014; Bailey et al., 2006; McNaughton et al., 2008). Specifically, parents found it problematic that decisions regarding AAC device selection and goals were sometimes made by professionals without adequate input from parents, resulting in AAC systems and goals that did not reflect family values, needs, and priorities (Anderson et al., 2014; Bailey et al., 2006; McNaughton et al., 2008).

Many parents described barriers related to the AAC system itself. Parents expressed that AAC devices were often difficult to learn, time consuming to program, and cumbersome and impractical to use in daily life (O’Neill & Wilkinson, 2020; Schladant & Dowling, 2015). They described barriers related to the use of technology during outdoor and physical activities (e.g., swimming) or in certain weather conditions (e.g., rain, sunshine; O’Neill & Wilkinson, 2020). Many expressed that the features of the AAC device or system were insufficient to support communication or a poor fit for the child’s abilities and needs (Angelo, 2000; McCord & Soto, 2004; O’Neill & Wilkinson, 2020; Schladant & Dowling, 2015). For instance, vocabulary was often insufficient to support more than basic interactions, or the available concepts were not practical for the child; families who did not speak English at home were often unable to access
their preferred language on the AAC system (McCord & Soto, 2004); and AAC system organization was sometimes a poor fit for the child (O’Neill & Wilkinson, 2020). Some parents expressed frustration related to the lack of reliability of AAC technologies and the frequent need for maintenance, which often took a long time and left the child without a device while it was away for repairs (Schladant & Dowling, 2015). Some parents discussed ways in which the device interfered with their child’s interactions. For instance, they described interactions involving the device as inefficient (McCord & Soto, 2004) and effortful (Marshall & Goldbart, 2008; O’Neill & Wilkinson, 2020), and this sometimes reduced the likelihood that the device would be embraced (McCord & Soto, 2004). In some cases, the AAC device was felt to create a physical barrier that could make interactions feel impersonal or disengaged (McCord & Soto, 2004; O’Neill & Wilkinson, 2020).

Parents have described challenges and barriers related to societal beliefs and systems. These include difficulty accessing AAC services (e.g., due to lack of availability or restrictive eligibility requirements; Anderson et al., 2014; Crisp et al., 2014; Goldbart & Marshall, 2004), lack of understanding and support for AAC in the community (Crisp et al., 2014) and among professionals (O’Neill & Wilkinson, 2020), and the prohibitive cost and lack of funding for AAC devices (Crisp et al., 2014; Marshall & Goldbart, 2008).

**Factors that support AAC implementation**

Parents of children with complex communication needs have also described specific factors that support implementation of AAC. Parents in several studies discussed professional services as a positive source of help, information, and support for implementation of AAC (e.g., Anderson et al., 2015; Crisp et al., 2014; Jones et al., 1998; McNaughton et al., 2008; Meder & Wegner, 2015; O’Neill & Wilkinson, 2020). Some reported that the opinions of professionals
played a vital role in the AAC selection process (Meder & Wegner, 2015). Many found it helpful to receive training and guidance to learn and use AAC with their child, and expressed support for less traditional forms of training such as telehealth and video-based trainings (Anderson et al., 2015; Crisp et al., 2014).

Beyond simply receiving information and training from professionals, parents have also stressed the role of team dynamics and the critical importance of parent involvement. Parents expressed a desire to be integrated as key members of the AAC team (McCord & Soto, 2004; Parette et al., 2000). They felt that AAC implementation was enhanced by treating parents as respected and knowledgeable team members, by recognizing parents as experts in their children, and by considering parent priorities throughout the AAC decision-making process (McNaughton et al., 2008; Parette et al., 2000).

Some parents discussed the value of receiving support to learn about and implement AAC from individuals who are not professionals, such as extended family (e.g., Jones et al., 1998), other parents (e.g., Anderson et al., 2015; Marshall & Goldbart, 2008; O’Neill & Wilkinson, 2020), other individuals who use AAC (e.g., McNaughton et al., 2008), and online communities (Anderson et al., 2015; O’Neill & Wilkinson, 2020).

Many parents discussed ways in which features of the AAC system itself could support implementation. Positive features of AAC systems include intuitive design and ease of use (Bailey et al., 2006; Crisp et al., 2014; Meder & Wegner, 2015; O’Neill & Wilkinson, 2020); and inclusion of multiple features to support learning, communication, and environmental access (e.g., icon prediction, internet access, environmental controls, social media; McNaughton et al., 2008; O’Neill & Wilkinson, 2020). Features that enhanced the appeal of the AAC system and motivated the child to use it, such as access to games and music, have also been identified as a support (O’Neill & Wilkinson, 2020).
Parents of children on the autism spectrum have reported experiences relative to communication and AAC that are similar in many ways to those reported by parents of children with developmental disabilities. They have also reported experiences that are unique. The next section summarizes research on communication and AAC experiences of parents of children on the autism spectrum.

Experiences of parents of children on the autism spectrum

As discussed above, families with a child on the autism spectrum may encounter different experiences and challenges than families of children with other developmental disabilities (e.g., Cassidy et al., 2008). Therefore, to inform more family-centered services for individuals on the autism spectrum, it is necessary to consider the communication and AAC experiences within their families specifically.

A search was conducted to identify relevant studies for review. To be included, the goal of the study must have been to understand everyday communication and/or AAC experiences of parents of children on the autism spectrum, including challenges, barriers, and supports related to communication and AAC. Additionally, studies were peer reviewed and published in English. Synthesis papers and meta-analyses were excluded. Table 4-1 summarizes the studies that met these criteria; the results are synthesized in the discussion that follows.
<table>
<thead>
<tr>
<th>Author(s) and Method</th>
<th>Aim</th>
<th>Participants</th>
<th>Key Findings</th>
</tr>
</thead>
</table>
| Alli et al. (2015)  | To describe the communication experiences and challenges of parents with a child on the autism spectrum in South Africa. | 10 parents of 10 children on the autism spectrum in South Africa (average child age of 11.8 years, language abilities not specified) | - Communication challenges impacted family functioning and participation in community life.  
- Professional services were difficult to access and carryover of recommended strategies to the home environment was limited. |
| Doak (2021)         | To understand the communication practices of children on the autism spectrum in the home environment and barriers to carryover of AAC strategies used at school into the home. | 5 parents of 5 children on the autism spectrum in the UK (child ages ranged from 6-8 years old, all children described as minimally verbal) | - AAC used at school was rarely carried over into the home environment. Barriers included parent doubts about usefulness; child preference for other forms of communication or lack of understanding about how to use AAC at home; and parent difficulty supporting AAC at home.  
- At home, children relied on gestures, vocalizations, facial expressions, and context, among other modalities, to communicate. Often, their messages needed to be interpreted by parents. Parents noted limitations to this approach.  
- Parents faced demands and challenges related to caring for their child above and beyond the usual demands faced by families.  
- Parents’ emotions about communication were intertwined with their hopes and fears about their child’s future, their self-concept as parents, and the desire to have close relationships. |
<table>
<thead>
<tr>
<th>Study</th>
<th>Purpose</th>
<th>Participants</th>
<th>Findings</th>
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| Hines et al. (2011) Interview | To investigate the communication and AAC experiences of older parents with an adult child on the autism spectrum. | 16 parents of 13 grown children on the autism spectrum in Australia (child ages ranged from 31-44 years, language abilities not specified) | • Parents experienced a lack of meaningful interaction with their adult child.  
• The majority of parents did not see a role for communication services or AAC. |
| Hoppe (2005) Interview | To determine parents’ perspectives regarding their child’s instructional needs. | 3 mothers of 3 children on the autism spectrum (child ages ranged from 9-22 years, language abilities not specified) | • Communication, behavior, and social interaction were high priority instructional needs.  
• Communication difficulties made it difficult for children to accomplish their goals and often led to frustration and related behaviors. |
| Jaswal et al. (2020) Interview | To understand how parents of nonspeaking children on the autism spectrum experience social connection with their children. | 13 mothers of 13 children on the autism spectrum (child ages ranged from 5-14 years, all were described as having limited speech) | • A range of child behaviors elicited parents’ feelings of connection with their child (e.g., physical contact, invitation for the parent to join an activity). Use of speech was one of these behaviors.  
• Challenging behaviors were framed as being due to external forces as opposed to reflecting a lack of connection between the child and the parent.  
• Convictions that may have helped parents maintain a sense of connection with their child included attributing personality to their child (e.g., funny, sassy, social), presuming competence, and accepting their child’s autism rather than trying to change their child. |
| Serpentine et al. (2011) Interview | To examine the decision-making process of parents of children on the autism spectrum surrounding communication and AAC in Hungary. | 10 parents (child ages ranged from 6-14 years, language abilities not specified) | • Parents sought information about communication interventions from professionals, other parents, and public information sources (e.g., internet, newspaper, tv).  
• Parents used a variety of different communication interventions and methods with their child (e.g., natural speech, computers, sign language, PECS).  
• Interventions were discontinued due to lack of progress, cost, and poor fit for the child. |
<table>
<thead>
<tr>
<th>Study</th>
<th>Method</th>
<th>Description</th>
<th>Participants</th>
<th>Findings</th>
</tr>
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<tbody>
<tr>
<td>Utami et al. (2018)</td>
<td>Interview</td>
<td>To understand maternal role in supporting child social communication in families of children on the autism spectrum in Indonesia.</td>
<td>5 parents (age and language abilities of children not reported)</td>
<td>- Parents played multiple roles in support of their child’s general well-being and communication development. These included roles related to caregiving, teaching general and communication skills, identifying areas of need, and coordinating support services.</td>
</tr>
</tbody>
</table>
| Wilson et al. (2021) | Focus groups  | To understand the experiences of parents of adults on the autism spectrum regarding supports and services for social communication. | 17 parents of 17 grown children with ASD (children were 18+ years old, most had language described as age-appropriate) | - There were barriers to accessing social communication supports and services related to funding, availability, accessibility, and public education/awareness of social communication challenges.  
  - Parents desired social communication supports that better fit their child’s learning style and day-to-day needs (e.g., online learning opportunities, one-to-one supports in the community), more robust training and public awareness efforts, and better access to information about available supports. |

*Note. SLP = speech language pathologist; AAC = augmentative and alternative communication; PECS = Picture Exchange Communication System (Bondy & Frost, 1994; 1998).*
Experiences with communication and AAC in everyday life

In the studies that explored communication generally (Alli et al., 2015, Jaswal et al., 2020, Hoppe, 2005) as well as one study that specifically explored use of AAC (Hines et al., 2011), parents discussed their experiences communicating and connecting with their children. Some parents described communication with their child as a challenge, citing their child’s difficulties with both comprehension and expression (Alli et al., 2015), frequent communication breakdowns (Hines et al., 2011), child frustration and challenging behaviors that resulted from communication difficulties (Hoppe, 2005), and an overall lack of meaningful interactions with their child (Hines et al., 2011). However, parents interviewed by Jaswal et al. (2020) discussed child behaviors that elicited feelings of connection in the face of communication difficulties and limited speech, including physical contact/proximity, child indication that they enjoyed being together with their parent (e.g., smiling, leaning in), and child invitation to join an activity.

In studies that explored AAC experiences specifically, opinions of and experiences with AAC varied. Many parents described using multiple modes of communication with their child, including aided and unaided AAC (Hines et al., 2011; Alli et al., 2015 Serpentine et al., 2011; Doak, 2021). Sometimes children were able to use non-symbolic forms of communication effectively to meet their needs and seemed to prefer this approach, particularly in the home environment; however, parents acknowledged limitations with respect to the amount and complexity of information that could be conveyed through non-symbolic means (Doak, 2021). In one study involving parents of adults on the autism spectrum who had primarily received AAC services when the field was in its infancy, most parents did not see a role for AAC despite describing many challenges related to their child’s communication (Hines et al., 2011).

Parents discussed the ways in which their child’s communication and communication challenges impacted their personal and family lives. They described adjusting their daily schedule
and activities as a result of their child on the autism spectrum (Alli et al., 2015; Hines et al., 2011). For instance, some parents in the study by Hines et al. (2011) reported limiting public outings and interactions to avoid public breakdowns and behaviors that they considered embarrassing or stressful. In both studies that explored communication experiences generally and those that explored AAC experiences specifically, parents reported taking on a number of roles and responsibilities beyond those expected of most parents. These included seeking out information about services, supports, and AAC options from a variety of sources (e.g., professionals, other parents, the internet; Serpentine et al., 2011); learning a new mode of communication and implementing it at home with their child (Alli et al., 2015); implementing their child’s therapy program at home (Utami et al., 2018); organizing and maintaining their child’s schedule, including school and therapy services (Utami et al., 2018); and managing safety and behaviors (Doak, 2021; Hoppe, 2005). Parents also commented on the demands of their general caregiving responsibilities (Utami et al., 2018, Doak, 2021).

Parents experienced complicated emotions related to their child’s communication. These included stress and anxiety (e.g., around keeping the child safe or avoiding public communication breakdowns and resulting behavioral challenges; Hines et al., 2011; Doak, 2021). For some parents, feelings about their child’s communication and communication challenges were intertwined with their hopes and fears for the future (Doak, 2021).

Supports, challenges, and barriers related to communication and AAC implementation

Parents discussed specific supports, challenges, and barriers to communication and use of AAC. The primary support discussed by parents across the studies reviewed was professional communication services, with some parents expressing that services had led to improvements in their child’s communication skills (Alli et al., 2015; Hines et al., 2011). Specific benefits of
services included improved ability to indicate preferences, increased ability to tolerate changes in routine, and a reduction in frustration and challenging behaviors (Hines et al., 2011).

Despite these benefits, parents also described challenges and barriers to communication and use of AAC related to the professional services they had received. With respect to communication services generally, parents reported that services were often difficult to access (Alli et al., 2015; Wilson et al., 2021). For example, parents of adult children cited lack of funding for supports and services, lack of information about what services were available, and prerequisites for obtaining services or funding (Wilson et al., 2021). An additional service-related barrier was high staff turnover that led to frequent service interruptions while new providers got up to speed (Wilson et al., 2021). With respect to AAC services specifically, reported barriers included prohibitive cost and child lack of interest (Serpentine et al., 2011).

A number of parents discussed barriers that specifically impacted the use of AAC in the context of daily life. Sometimes AAC approaches that worked in a therapeutic setting did not carry over effectively into the home environment (Alli et al., 2015, Doak, 2021). For instance, AAC was sometimes described as time-consuming and restrictive in a natural setting (Alli et al., 2015). Some parents reported that they did not understand how AAC could be useful at home, and that they did not know how to use the systems that had been introduced to their child (e.g., they did not understand manual signs; Doak, 2021).

The studies summarized above provide a first step to explore the communication experiences of parents of children on the autism spectrum. However, there is currently a lack of research investigating the communication and AAC experiences specifically of parents of young children on the autism spectrum who are beginning communicators. Only three of the studies reviewed above (Doak, 2021; Jaswal et al., 2020; Wilson et al., 2021) specified the language abilities of the children. Of these, two studies included parents of children who were described as having limited speech (though their language abilities using modes of communication other than
natural speech were not specified) and one (Wilson et al., 2021) included grown children whose language was described as age-appropriate. Of the two studies that included children with minimal speech, one (Jaswal et al., 2020) targeted primarily older children (5-14 years) and did not explore AAC experiences specifically. The other (Doak, 2021) investigated communication and AAC experiences of parents of children ages 6-8 years old in the UK. Due to potential differences in areas such as educational policy, funding structures, support services, and service delivery models, it is likely that parents living outside of the UK may have unique experiences and perspectives to add to those shared by the parents in Doak (2021). Thus, there has been very limited research specifically aimed at understanding the communication and AAC experiences of parents of young beginning communicators on the autism spectrum, and there remains a need to better understand the perspectives of these parents.

**Study aim and research questions**

This study aims to address the following questions: (a) What are parents’ communication experiences with their children on the autism spectrum who are beginning communicators? What challenges and supports do parents face relative to their child’s communication?; and (b) What are parents’ experiences surrounding use of AAC systems with their children on the autism spectrum who are beginning communicators? What challenges and supports to they face relative to use of AAC systems?
Chapter 5

Method

Research design

This study used a phenomenological qualitative design. Qualitative research is appropriate when the goal is not to test a predetermined hypothesis but to approach a question with an open mind and allow the experiences of participants to guide the researcher to an understanding of a situation or experience (Creswell, 2013). It allows the researcher to develop a rich understanding of a phenomenon that cannot be quantitatively measured, and to report on experiences from the point of view of the individuals who are actually living those experiences (O’Day & Killeen, 2002).

With a phenomenological approach, the researcher attempts to understand and describe participants’ experiences around a lived phenomenon (Creswell, 2013; Morse & Field, 1995; Moustakas, 1994). Phenomenological research involves identifying a phenomenon (an aspect of human experience) to be explored, collecting data from multiple individuals who have experienced that phenomenon, and developing “a composite description of the essence of the experience for all of the individuals” (Creswell, 2013, p. 75). This is in contrast to other major qualitative research approaches such as narrative research (which explores the life of a single individual), grounded theory (which aims to develop a theory grounded in data from the field), ethnography (which describes a culture-sharing group), and case study research (which seeks to develop an in-depth description of one or more specific cases; Creswell, 2013). Because this study attempts to understand the lived experiences of parents of beginning communicators on the autism spectrum around communication and AAC, a phenomenological approach is appropriate.
Participants

Recruitment

Ethics approval for this study was obtained from the Penn State University Office of Research Protections prior to commencement of any research activities. The IRB approval letter is provided in Appendix A.

Convenience sampling was used in this study (Guest et al., 2013; Robinson, 2014). Convenience sampling is appropriate for exploratory studies (Guest et al., 2013). Participants were recruited via an informational flyer distributed through (a) emails to professionals (e.g., speech language pathologists), personal contacts, and organizations serving individuals on the autism spectrum and their families; and (b) social media (e.g., groups likely to cater to parents and caregivers of young children on the autism spectrum). The flyer included a brief description of the goals and procedures of the study and information on how to contact the principal investigator (PI) if interested in participating. The flyer can be found in Appendix B.

Interested participants contacted the PI directly according to the information on the recruitment flyer. They were provided with additional information about the study and a copy of the consent form for review. Appendix C includes the email sent to participants who expressed interest, and Appendix D includes a copy of the consent form. Participants were also sent a list of screening questions to verify eligibility to participate, should they be interested (available in Appendix E). Individuals who were interested in participating after reviewing the consent form and discussing the study, and who were eligible to participate based on their responses to the screening questions, were sent a demographic questionnaire (available in Appendix F) to be completed and returned to the researcher via email. An interview was then scheduled at a time that was mutually convenient for the researcher and the participant.
Inclusion criteria

To be eligible to participate in this study, participants were required to meet the following criteria: (a) must be the parent or caregiver of a child with a diagnosis of ASD who is 3-8 years old, who is a beginning communicator, and who has used AAC either currently or in the past; (b) must live in the United States; (c) must speak English fluently at home; (d) must be willing to participate in a single virtual interview lasting approximately one hour; and (e) must have access to the internet and technology to participate in the interview. For the purposes of inclusion and throughout the study, AAC was defined as any aided (e.g., device with speech output) or unaided (e.g., gestures, manual signs) option for supporting communication (Beukelman & Light, 2020). The child age range for this study was chosen in order to capture participants who were likely to be receiving similar speech and language services (i.e., preschool or center-based services as opposed to home-based services offered through birth to three programs), and who had enough experience with AAC to be able to talk about and reflect on it. Eight years was selected as the upper limit to allow for children who may have received a diagnosis at a later age, or who may have started to receive AAC services after leaving early intervention. Children were considered to be beginning communicators if they were reported by their parents or caregivers to communicate single concepts or two- to three-word combinations but were not yet combining words into a variety of clausal structures or sentences on a regular basis (Tager-Flusberg et al., 2009). All inclusion criteria were verified by parent/caregiver report.

Sample size

Nine parents or caregivers responded to the recruitment flyer and expressed interest in participating after reviewing and discussing the consent form. All nine met the inclusion criteria
based on responses to the screening questions. One parent who completed the consent and screening steps did not arrive at the scheduled interview time and did not respond to a follow-up email. Two participants were members of the same family who completed the interview together. Thus, a total of seven interviews, involving a total of eight parents or caregivers, were conducted.

Recommended ranges for sample size in phenomenological interviews vary; for instance, Creswell (2007) recommends between five and 25 interviews, Morse (1994) recommends at least six interviews, and Kuzel (1992) suggests 6-8 interviews. Some have provided a rationale for keeping sample sizes relatively small. For instance, Rossman and Rallis (2017) explain that qualitative research often includes relatively few participants as this type of research values depth of information over breadth. Guest et al. (2013) point out that when looking for shared themes across participants, smaller samples are needed than when looking to understand all possible variation within a population. Guest et al. (2013) also review research demonstrating that theoretical saturation of the data (i.e., the point at which little or no new information is emerging from the data) is typically reached after 6 interviews. Furthermore, since generalization to the broader population is not a goal of qualitative research, there is less of a need for very large samples (Creswell, 2013; Guest et al., 2013). The seven interviews conducted in this study fall within the ranges for phenomenological interviews recommended above while still being small enough to allow for in-depth exploration of each participant’s experience within the study timeline. Additionally, this sample size is consistent with previous studies examining parent/caregiver perspectives within the field of AAC (e.g., O’Neill & Wilkinson, 2020; Bailey et al., 2006).
Participant descriptions

Of the seven interviews (involving eight total participants) that took place in this study, six were conducted with parents. One interview was conducted with a grandmother and grandfather who together played a significant caregiving role in their grandchild’s life. Table 5-1 provides demographic information for the participants and their children/grandchild.
Table 5-1: Participant demographics.

<table>
<thead>
<tr>
<th>Parent Information</th>
<th>Elyse</th>
<th>Gillian</th>
<th>Olivia</th>
<th>Tess</th>
<th>Una</th>
<th>Thomas/ Nora</th>
<th>Vanessa</th>
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</thead>
<tbody>
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<td>Parent</td>
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<td>Spouse/ partner; 2 children</td>
<td>3 children</td>
<td>Spouse/ partner; 3 children</td>
<td>Spouse/ partner; 1 child</td>
<td>Spouse/ partner; 1 child; mother and father</td>
<td>Spouse/ partner; 1 child; mother (part time)</td>
</tr>
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<tr>
<td>Pseudonym</td>
<td>Sam</td>
<td>Allegra</td>
<td>Leo</td>
<td>Jack</td>
<td>Elliot</td>
<td>Adam</td>
<td>Oliver</td>
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<tr>
<td>Age (years)</td>
<td>3</td>
<td>4</td>
<td>8</td>
<td>4</td>
<td>3</td>
<td>8</td>
<td>3</td>
</tr>
<tr>
<td>Gender</td>
<td>Male</td>
<td>Female</td>
<td>Male</td>
<td>Male</td>
<td>Male</td>
<td>Male</td>
<td>Male</td>
</tr>
<tr>
<td>Diagnoses</td>
<td>ASD</td>
<td>ASD; developmental delay; epilepsy</td>
<td>ASD, developmental delay; Language disorder</td>
<td>ASD; developmental delay; SPD; Sleep disorder; ADHD</td>
<td>ASD; Global developmental delay; Language disorder</td>
<td>ASD</td>
<td>ASD</td>
</tr>
<tr>
<td>Age of ASD dx</td>
<td>2 years</td>
<td>3 years</td>
<td>2 years, 1 month</td>
<td>1 year</td>
<td>2 years</td>
<td>1 year</td>
<td>2 years, 3 months</td>
</tr>
<tr>
<td>School Setting</td>
<td>Developmental preschool</td>
<td>Partial inclusion</td>
<td>Not reported</td>
<td>Homeschooled</td>
<td>Not reported</td>
<td>Partial inclusion</td>
<td>Reverse inclusion</td>
</tr>
<tr>
<td>Services</td>
<td>Speech; OT; ABA</td>
<td>Speech; ABA</td>
<td>Speech</td>
<td>Speech; OT; PT; ABA; Feeding therapy</td>
<td>Speech; OT; ABA</td>
<td>Speech; OT; ABA; APE</td>
<td>Speech; OT; ABA</td>
</tr>
<tr>
<td>Number of Words Understood</td>
<td>1-73</td>
<td>260 or more</td>
<td>Not reported</td>
<td>None yet</td>
<td>1-73</td>
<td>158-259</td>
<td>1-73</td>
</tr>
<tr>
<td>Number of words Produced (speech)</td>
<td>1-2</td>
<td>20-93</td>
<td>“Functionally non-verbal”</td>
<td>None yet</td>
<td>20-93</td>
<td>94-296</td>
<td>3-19</td>
</tr>
<tr>
<td>Number of Words</td>
<td>3-19</td>
<td>94-296</td>
<td>Not reported</td>
<td>1</td>
<td>20-93</td>
<td>94-296</td>
<td>20-93</td>
</tr>
<tr>
<td>Approx. language stage&lt;sup&gt;a&lt;/sup&gt;</td>
<td>Preverbal</td>
<td>First words</td>
<td>Preverbal or First Words</td>
<td>Preverbal</td>
<td>First Words</td>
<td>First words</td>
<td></td>
</tr>
<tr>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td></td>
</tr>
<tr>
<td>Combining words</td>
<td>Not yet</td>
<td>Often</td>
<td>Sometimes</td>
<td>Not yet</td>
<td>Sometimes</td>
<td>Often</td>
<td></td>
</tr>
</tbody>
</table>

### Expressive Modalities, (current and/or past)
- Speech
- PECS<sup>®</sup> 3
- Visual schedules
- Sign language
- Visual schedules
- iPad<sup>®</sup> with Snap-Scene<sup>®</sup> 6
- iPad<sup>®</sup> with Touch-Chat<sup>®</sup> 7
- iPad with GoTalk NOW<sup>®</sup> 8
- iPad with FTVS-HD<sup>®</sup> 9
- iPad with Mouth works<sup>®</sup> 10
- Speech
- Gestures
- Sign language
- PECS<sup>®</sup>
- Nova-Chat<sup>®</sup> 4
- Visual schedules
- iPad<sup>®</sup> with Visuals2Go<sup>®</sup> 11
- iPad with Touch-Chat
- iPad with Visuals2Go<sup>®</sup> 11
- iPad with Touch-Chat
- iPad with Visuals2Go<sup>®</sup> 11

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**Note.** ASD = autism spectrum disorder, SPD = sensory processing disorder, ADHD = attention deficit hyperactivity disorder, OT = occupational therapy, ABA = applied behavior analysis, PT = physical therapy, APE = adapted physical education, PECS = Picture Exchange Communication System, FTVS-HD = First Then Visual Schedules-HD.

<sup>a</sup>Estimates are based on all communication modalities, using the Tager-Flusberg et al. (2009) benchmarks.
Of the eight parents or caregivers who participated, six provided their exact age. The mean age of these six was 48 years (range: 28-70). One additional parent reported that she was over 40 years old but did not provide an exact age. Six parents were female, one was male, and one did not report their gender. Five participants were white, one was both white and black or African American, and two did not report race. Participants were located throughout the United States. Two had advanced degrees, two had college degrees, two had attended some college, and two did not report their education. Family structure varied; seven of the participants lived with a spouse or partner and at least one child, one participant lived with children and no spouse or partner, and two (who were grandparents of a child on the autism spectrum) lived with their grandson and his parents. All of the participant spoke English as their primary language in the home. One participant and her family also spoke Italian and Spanish.

The children of the parents in this study were an average age of 4;8 (years;months; range: 3-8). Six were male and one was female. According to parent report, all of the children had received a diagnosis of autism spectrum disorder; three had additional diagnoses such as developmental delay, sensory processing disorder, or ADHD. The educational setting of the children varied. At the time of this study, most of the children were attending school in a modified format due to the COVID-19 pandemic. Under non-pandemic circumstances, three of the children attended a school program that offered at least some inclusion opportunities. One was reported to attend a developmental preschool, one was homeschooled, and two parents did not report the details of their child’s educational setting. All of the children were reported to receive services such as speech therapy, occupational therapy (OT), and applied behavior analysis (ABA).

To determine the language abilities of the children, parents were asked to report the number of words that their children produced using speech alone and using all modalities. The results were compared to the age equivalent scores on the MacArthur-Bates Communicative
Development Inventory (MCDI; Fenson et al., 2007), a measure of vocabulary development based on parent report, and children were then assigned an approximate language development stage according to the guidelines provided by Tager-Flusberg et al. (2009). These guidelines are outlined in Table 5-2. It should be noted that Tager-Flusberg et al. (2009) did not provide specific criteria to define the preverbal stage. In this study, children were considered to be in the preverbal stage if they did not meet minimum criteria for the first words stage (i.e., age equivalent of 15 months on the MCDI).

Table 5-2: Criteria for assigning language development stages.

<table>
<thead>
<tr>
<th>Stage of Language Development</th>
<th>Minimum Criteria</th>
</tr>
</thead>
<tbody>
<tr>
<td>Preverbal</td>
<td>Not applicable</td>
</tr>
<tr>
<td>First Words</td>
<td>Age Equivalent of 15 months on Parent Report Measure (e.g., MCDI)</td>
</tr>
<tr>
<td>Word Combinations</td>
<td>Age Equivalent of 24 months on Parent Report Measure (e.g., MCDI)</td>
</tr>
<tr>
<td>Sentences</td>
<td>Age Equivalent of 36 months on Parent Report Measure (e.g., MCDI)</td>
</tr>
</tbody>
</table>

Note. Criteria are based on those provided by Tager-Flusberg et al. (2009). MCDI = MacArthur-Bates Communicative Development Inventory (Fenson et al., 2007).

Six of the children were reported to produce fewer than 300 words using either speech alone or all modalities (e.g., speech, manual signs, aided AAC), placing them approximately in the preverbal or first words stages of language development (Tager-Flusberg et al., 2009). One child’s (Leo’s) expressive vocabulary size was not explicitly reported; however, he was described by his mother, Olivia, as producing few spoken words and using a limited number of manual signs or visual symbols, suggesting that he also met the criteria for the preverbal or first words stage. Two of the children were not yet combining words, three were reported to combine words
some of the time, and two were reported to combine words often. Parents of children who had started to combine words often described a limited variety of word combinations, many of which involved memorized phrases that were repeated in multiple contexts.

It should be noted that children may be placed in the preverbal stage according to Tager-Flusberg et al. (2009) even if they produce some speech, as long as they have not yet met the minimum criteria for entering the first words stage (i.e., age equivalent of 15 months on a parent report measure such as the MCDI). Additionally, it is possible for a child to be placed in the preverbal stage even if they use symbols to communicate in other modalities, as the Tager-Flusberg et al. (2009) benchmarks are based on spoken language milestones. In the current study, all participants fell within the preverbal or first words stages based on their use of speech, as recommended by Tager-Flusberg et al. (2009), and also remained within those categories when use of other modalities was considered.

It should also be noted that the language stages assigned to participants in this study are estimates; they are based on the age equivalent scores for parent report on the MCDI (as recommended by Tager-Flusberg et al., 2009), which was not actually administered to the parents or caregivers (rather, parents/caregivers were simply asked to estimate the total number of words used by their child/grandchild). Additionally, Tager-Flusberg et al. (2009) recommend considering multiple domains of language (e.g., phonology, vocabulary, grammar, pragmatics) to understand a child’s developmental stage. Due to COVID-related constraints and a desire to reduce demands on participants’ time, vocabulary was the only domain considered in this study. Moreover, it is important to note that the stages outlined by Tager-Flusberg et al. (2009) are defined based on speech production. Thus, the children in this study were classified as beginning communicators based on their speech production alone; comprehension and literacy skills were not considered and may have varied across the children.
All of the children were described as multi-modal communicators. All seven used unaided forms of communication, such as behaviors, speech, gestures, and manual signs. Six used aided AAC, including both low tech AAC (e.g., PECS, visual schedules) and iPads with communication apps (e.g., TouchChat, SnapScene). Only one participant was reported to have used a dedicated communication device (a NovaChat).

**Data collection**

Data were collected via semi-structured interviews (Brinkmann & Kvale, 2015; Kallio et al., 2016). Interviews allow the researcher to understand individual perspectives, to gain understanding of events and experiences, and to gather insights into participants’ thinking (Rossman & Rallis, 2017). They are a commonly-used method of data collection in phenomenological studies (Brinkmann & Kvale, 2015; Creswell, 2013; Seidman, 2019). Using a semi-structured interview approach, the researcher poses open-ended questions and allows the participant to talk at length. The researcher may also ask follow-up questions to request elaboration or elicit specific examples. This approach allows the researcher to explore broad topics of interest but leaves room for the participants to bring up new topics that may be relevant to their lived experiences. Semi-structured interviews have previously been used to gather information about the lived experiences of parents/caregivers of individuals on the autism spectrum (e.g., Hines et al., 2014), including individuals on the spectrum who use AAC (e.g., Hines et al., 2011; Serpentine et al., 2011), and parents/caregivers of individuals with complex communication needs generally (e.g., Bailey et al., 2006; Crisp et al., 2014; O’Neill & Wilkinson, 2020).

It should be noted that one participant (Una) initially contributed to an online focus group of parents that addressed the same questions posed in the interviews. The focus group was
Una had already responded to questions 1-9 in written form as part of the focus group. She responded to questions 10-14 via semi-structured interview. During the interview, she also had the opportunity to elaborate on responses previously provided in the focus group. During the focus group, Una answered the focus group questions directly but did not respond to any of the other participants’ contributions; therefore, the responses discussed in the results of this study were not a result of co-constructed conversations with other participants. Of the 253 total thought units contributed by Una, 109 thought units (43%) came from the focus group responses and 144 thought units (57%) came from the semi-structured interview. Appendix G provides detailed information about the focus group, including a rationale for the focus group approach, materials (e.g., instructions provided to participants), and focus group procedures.

**Materials**

This study made use of a semi-structured interview guide (Brinkmann & Kvale, 2015; Kallio et al., 2016) that included questions designed to lead the discussion toward the topics of interest in this study. The interview guide can be found in Appendix H. Questions were developed after reviewing literature related to the study topic and identifying gaps in knowledge. Additionally, questions were informed by reviewing literature on (a) developing semi-structured interview guides in general (e.g., Brinkmann & Kvale, 2015; Kallio et al., 2016; Whiting, 2008) and (b) conducting semi-structured interviews with families of children on the autism spectrum (Cridland et al., 2015).

Phenomenological interviews typically include questions that encourage participants to (a) discuss their life history relative to the topic, (b) discuss specific details regarding present experiences of the topic, and (c) reflect on the meaning of their experiences (Rossman & Rallis,
Interview questions aimed to accomplish these goals. They asked participants to provide background information, to describe their current experiences surrounding communication and AAC, and to reflect on those experiences by discussing supports and barriers with respect to communication and AAC.

The interview guide began with a warm-up question to help set the scene and establish rapport. This was followed by questions aimed to encourage increasingly more in-depth descriptions of experiences related to the study questions. The interview guide concluded with a question inviting participants to discuss anything additional they wanted to add. This served as a way to conclude the interview (Whiting, 2008) while also helping to ensure that participants had a chance to talk about all topics and experiences that were relevant to them without being overly constrained by the interviewer’s questions. Questions were open-ended to encourage participants to reflect on their experiences. They were brief, simple, and clearly worded (Brinkmann & Kvale, 2015; Kallio et al., 2016; Whiting, 2008). The interview guide was reviewed by an expert in the field who provided feedback on the content and format of the questions. This review was conducted by the same individual who also served as the peer reviewer for this study (see below).

**Procedures**

**Semi-structured interviews**

Semi-structured interviews were conducted over a period of two months between September and November, 2020. Though phenomenological interviews are typically conducted over a series of separate sessions (often three), it is also possible to cover the important content in fewer (Seidman, 2019). In the current study, each participant completed a single interview in order to minimize the demands on participants’ time and simplify scheduling.
Interviews were scheduled at a time that was mutually convenient for the participant and the researcher. All interviews were conducted by the primary researcher, a doctoral student in Communication Sciences and Disorders and a Speech Language Pathologist (SLP) with extensive experience working with individuals on the autism spectrum and their families. The average length of the interviews was 48:06 (minutes:seconds; range: 20:03-58:38). Excluding the shortest interview, in which the participant had previously responded to the majority of the questions within the focus group, the average length of the interviews was 52:42 (range: 46:16-58:38).

Interviews were conducted virtually in order to protect the health and safety of participants (Roberts et al., 2021) and as required by Penn State University during the COVID-19 pandemic. Virtual interviews have been found to be convenient and cost-effective for participants (Archibald et al., 2019). They also allow participants from various geographic regions to participate without having to travel, which may widen the region represented (DeFelice & Janesick, 2015; Roberts et al., 2021). Interviews were conducted via Zoom\textsuperscript{13}, an online video conferencing platform. Previous research indicates that Zoom is a viable platform for conducting interviews for qualitative research, with benefits for participants including ease of use and cost effectiveness (Archibald et al., 2019).

Interviews were audio recorded for later transcription. Video functionality was active during the interviews to support rapport-building (Roberts et al., 2021) and to allow for viewing of nonverbal cues that might aid in understanding participants’ responses (Brinkmann & Kvale, 2015). To protect participant privacy, no video was recorded. Participants were informed of the audio recording during the consent process and notified at the beginning of each interview when recording was about the start. They were reminded that they were free to request that the recording be paused or stopped at any time. Both the researcher and the participant were located in quiet, private locations, such as an office or home, throughout each interview.
Best practices for semi-structured interviews, as described by Brinkmann and Kvale (2015) were followed throughout the interview process. Specifically: (a) the researcher used a semi-structured interview guide with prompts to help keep the discussion relatively short, focused, and to-the-point; (b) the participants did most of the talking throughout the interview; and (c) the researcher asked clarifying questions, probed for more information on topics relevant to the research questions, and attempted to verify interpretation of participants’ statements throughout the interview by summarizing or asking questions and providing the participant a chance to confirm or disconfirm.

**Data analysis**

Thematic analysis was used to identify themes within the data (Braun & Clarke, 2006). Thematic analysis is “a method of identifying, analyzing and reporting patterns (themes) within data” (Braun & Clarke, 2006). It is a flexible tool for qualitative data analysis that “can be applied across a range of epistemological and theoretical approaches” (Braun & Clarke, 2006; p. 78), including phenomenological approaches. Thematic analysis has previously been used in phenomenological research within the field of AAC (e.g., O’Neill & Wilkinson, 2020; Clarke & Williams, 2020).

Data analysis in this study followed an inductive approach, in which codes and themes emerge from the data as it is collected (Miles et al., 2020, p. 74; Rossman & Rallis, 2017; Vaismoradi et al., 2013). This is in contrast to deductive coding, in which the researcher fits the data into a pre-determined coding scheme that has been developed based on a thorough review of previous research and the hypotheses that emerge from that review (Morse, & Field, 1995). An inductive approach is preferred when little is known about the phenomenon of interest and the
goal is to allow new and possibly unexpected patterns to emerge from the text (Vaismoradi et al., 2013; Seidman, 2019; Morse & Field, 1995).

In this study, the steps for thematic analysis outlined by Braun and Clarke (2006) were adapted to include unitization of the data and development of a codebook (O’Neill & Wilkinson, 2020). The steps included: (a) familiarize, (b) unitize and assign preliminary codes, (c) identify/refine themes and create codebook, and (d) assess inter-coder reliability and finalize coding.

**Familiarize**

The familiarization process included two steps. First, the interviews were transcribed. Then the lead researcher and a research assistant (a graduate student in communication sciences and disorders with previous experience conducting research and working clinically with individuals on the autism spectrum) engaged in repeated readings of the transcripts and reflection on meaning, patterns, and big ideas.

**Transcription of the interviews**

Interviews were transcribed by the lead researcher, who also conducted the interviews, using Microsoft Word. According to Vaughn et al. (1996), it is appropriate for qualitative data to be transcribed by the researcher who collected the data and who will be responsible for the data analysis. This researcher is positioned to note details that are important to the analysis (e.g., the specifics of AAC systems that were demonstrated during the interviews; Brinkmann & Kvale, 2015).
According to Brinkmann and Kvale (2015), there is no universal form or code for transcription of research interviews. Therefore, decisions about the transcription procedures should be made based on the aims of the research project. In the current study, interview recordings were transcribed verbatim with the following 3 exceptions:

1. Comments directed to someone other than the researcher (e.g., a child) and unrelated to the study were omitted, but noted to have occurred.

2. All portions of the interview recording that were partially or completely unintelligible were marked as such within the transcripts.

3. All potentially identifying information (e.g., names of people, clinics, schools, hospitals, or local landmarks; participants’ geographic location; information about participants’ insurance policies) was omitted from the written transcripts.

Detailed description of paralinguistic features was not included as this is not a priority when the goal of the study is to conduct a thematic analysis (Schreier, 2014). A detailed list of transcription conventions was developed for this study based on a modified version of those recommended by Poland (2003). These are provided in Appendix I.

**Trustworthiness of transcripts**

According to Brinkmann and Kvale (2015), it is not possible to develop a single correct, valid transcription of a recorded interview, as there is “no true, objective transformation from the oral to the written mode” (p. 213). Written transcripts do not include visual cues, and require the transcriber to make judgements (e.g., regarding the use and placement of punctuation or notation of emphasis and pauses) that might potentially influence how a reader interprets the meaning of the text (Poland, 2003; Brinkmann & Kvale, 2015; Kowal & O’Connell, 2014). However, Poland (2003) discusses strategies for increasing the trustworthiness of interview transcripts, including
(a) maximizing the quality of the recording, (b) establishing a notation system to ensure consistency across transcribers, and (c) training transcribers, all the while recognizing that there is no such thing as a transcript that can perfectly capture a spoken interview. In the current study, the computer’s internal microphone was used and a test recording was created to ensure that the sound quality would be high. To ensure consistency, transcription rules were developed as referenced above, and only one transcriber was used.

Repeated readings and reflection

In addition to transcription of the data (see description above), familiarization involves engaging in repeated readings of the data (transcripts), reflection on meaning and patterns, and notation of initial big ideas (Braun & Clarke, 2006). During this phase, the primary researcher created two separate folders using an online, password-protected file sharing platform (Box at Penn State). Fully de-identified copies of the transcripts were placed in each folder, and one folder was shared with a research assistant (a doctoral student in communication sciences and disorders with previous experience working with families of children on the autism spectrum). Then, the main researcher and the research assistant each engaged in repeated readings of the interview transcripts. As they read, they reflected on the meaning of the data and highlighted noteworthy passages of text (Seidman, 2019). Additionally, team members used the “notes” feature within Box to add comments regarding noteworthy ideas or possible patterns. Research team members met repeatedly throughout this process to discuss the transcripts and review ideas that were emerging from the text. The lead researcher took notes during these meetings which, together with the highlighted passages and notes on the transcripts, served as the basis for developing an initial set of codes. Potential codes were listed in a Microsoft Word document. Formal definitions for each code were not yet developed.
Unitize and assign preliminary codes

In the next phase, data were unitized and a preliminary code was assigned to each unit of data.

Unitize

There are multiple ways to unitize data from interview transcripts; for instance, transcripts may be divided into meaning units or into pre-determined blocks of text to be coded (i.e., line-by-line coding; Campbell et al., 2013). In this study, transcripts were divided into meaning units (thought units). Use of meaning units is considered appropriate in exploratory research because it is more likely to capture the context surrounding participants’ statements whereas coding predefined chunks of text risks losing some of the context surrounding the passage being coded (Campbell et al., 2013). Thought units were defined as the smallest piece of information that is informative by itself (Vaughn et al., 1996, p. 106; Fraenkel, 2006). This definition of a thought unit has precedence in the AAC literature (e.g., McNaughton et al., 2008; O’Neill & Wilkinson, 2020).

Data were unitized by the same researcher who conducted the interviews. It has been argued that thought units should be determined by someone who is intimately familiar with the data (Vaughn et al., 1996; Campbell et al., 2013). According to Campbell et al. (2013), “the ability to see meaningful conceptual breaks depends very much on the qualifications of the coder and his ability to discern not only obvious meanings, such as specific words, phrases, or organizational names, but also more subtle meanings of a respondent’s statements” (p. 11). In this project, the lead researcher bore primary responsibility for conceptualizing the project, collecting the data, and completing the analysis; therefore, she was best positioned to unitize the text. To
generate thought units, the researcher used the “return” key within a Microsoft Word document to start a new line of text at the beginning of each new thought unit. Thought units varied in length from a portion of a sentence to a full paragraph (Campbell et al., 2013).

**Assign preliminary codes**

Once the transcripts had been unitized, the thought units were copied and pasted into a Microsoft Excel spreadsheet that included the following columns: Participant ID, thought unit number, interview question number, unitized data (the text for each thought unit), and code. Working from the preliminary list of codes developed during the familiarization phase, the lead researcher assigned a preliminary code to each unitized piece of data. According to Braun and Clarke (2006), “it is important in this stage to ensure that all actual data extracts are coded” (p.89), and that the researcher code for as many potential patterns as possible. Therefore, potential new codes were added to the initial list as needed. This helped to ensure that each thought unit received equal attention and that even ideas that departed from the dominant themes were considered (Braun & Clarke, 2006).

After assigning preliminary codes to all of the thought units, the updated code list was shared with the same research assistant who participated in the familiarization process. Both team members discussed the list and considered whether some of the codes could potentially be collapsed/combined. They also considered whether some types of information might not ultimately get coded, such as statements of agreement with the researcher (e.g., “uh huh”) and comments that were specific to experiences during the COVID-19 pandemic and not relevant to typical daily life experiences. A decision was made to omit comments specific to experiences during the COVID-19 pandemic in an attempt to understand typical experiences of the participants and their families. The code list was adjusted based on this discussion. This process
resulted in an initial list of 88 preliminary codes that served as the basis for a formal codebook. These included the following types of codes: descriptive codes (e.g., services received, AAC goals); in vivo codes (e.g., other people don’t “get it,” communication is a “guessing game”); process codes (e.g., finding the right fit, working to help others understand my child); concept codes (e.g., isolation, patience, advocacy); emotion codes (e.g., uncertainty about the future, grateful for AAC); and evaluation codes (e.g., AAC is inconvenient, technology is expensive). These code types are appropriate for use during the initial coding process (when codes are assigned to individual units of data; Miles et al., 2020). Specifically, descriptive codes capture the basic topic of a passage and provide an inventory of topics that can be categorized; in vivo codes use words or phrases from the participants’ own language and are especially appropriate for studies that prioritize and honor the participants’ voice; process codes capture actions and change over time, and are particularly useful for studies that explore interactions; concept codes attempt to capture “big picture” meaning or ideas in the data and are useful for helping to progress toward the big ideas suggested by the study; emotion codes are appropriate for studies that explore participants’ experiences and perspectives; and evaluation codes are used when a study explores the merit, worth, or significance of programs or policies (Miles et al., 2020). It is considered acceptable to use multiple types of codes within a single study (Miles et al., 2020).

Identify/refine themes and create codebook

Once all units of data had been assigned an initial code and a preliminary list of codes had been developed, these codes were grouped into potential themes and sub-themes. According to Braun and Clarke (2006), “a theme captures something important about the data in relation to the research question, and represents some level of patterned response or meaning within the data set” (p. 82). Each code was written on an individual index card. These cards were sorted into piles
in order to begin to develop possible groupings of themes and sub-themes. Additionally, a preliminary thematic map illustrating the main themes, sub-themes, and the relationships between them was created.

At this stage, operational definitions for each code, theme, and sub-theme were developed. Working from the Microsoft Word document with the list of all 88 preliminary codes, the code list was sorted to reflect the themes and sub-themes identified. The list included headings for each theme and sub-theme. Under the heading for each sub-theme was a bulleted list of codes encompassed within that sub-theme. The research team met to discuss the list, paying attention to whether the overall organization captured the main ideas discussed by the participants and whether the groupings of the codes made sense (Hruschka et al., 2004). Members of the research team also discussed some of the issues to consider when developing operational definitions for the codes (Hruschka et al., 2004). As a result of these discussions, the list of codes was refined. Redundant codes were eliminated and some codes were rearranged under new themes or sub-themes. The themes and sub-themes themselves were also adjusted, and the thematic map was updated to reflect these changes.

Based on these discussions and the resulting updates to the list of themes, sub-themes, and codes, the lead researcher created a codebook. According to Hruschka et al. (2004), it is customary for the lead researcher to take responsibility for codebook development. The codebook was created according to the guidelines laid out by Campbell et al. (2013) and MacQueen et al. (1998). It included each code along with its operational definition, example text, and decision rules for inclusion/exclusion when needed. The codebook was organized according to preliminary themes and sub-themes identified through the processes described above. At this stage, there were a total of 64 codes organized into 18 sub-themes which were in turn grouped into 5 main themes.
Assess reliability and finalize coding

The final step of the data analysis process was to code the individual thought units using the updated codebook and assess inter-coder reliability. The issue of whether or not to assess reliability in qualitative research is a contentious one (e.g., Hruschka et al., 2004; O’Connor & Joffe, 2020). It has been argued that inter-coder reliability is too positivist for qualitative research; it is an attempt to show that results of a study represent an objectively “true” reality, even though no single true reality exists, and other quality indicators (e.g., researcher reflexivity, thick description, member checks) are therefore more appropriate (Balandin & Goldbart, 2011; Lincoln & Guba, 1985; O’Connor & Joffe, 2020). On the other hand, arguments in favor of calculating inter-coder reliability include:

1. It allows the reader to assess the rigor and transparency of the coding system, and to ensure that it has meaning that extends beyond the individual researcher.
2. It helps to ensure readers that the data analysis was conducted in a conscientious manner.
3. It helps to facilitate discussion between members of the research team regarding possible conflicting interpretations of the data and to support refinement of the codebook.
4. It assists in the dissemination process (e.g., by satisfying journal editor or reviewer requirements for a measure of inter-coder reliability), especially in fields where quantitative research is the norm and inclusion of a concrete quality indicator may facilitate trust in the results. As O’Connor and Joffe (2020) state, “…in certain scholarly communities, [inter-coder reliability] has become mainstreamed as a standard and expected step in a qualitative analysis” (p. 3).

Recent qualitative research studies in AAC have included a measure of reliability (e.g., Clarke & Williams, 2019; McNaughton et al., 2008; O’Neill & Wilkinson, 2020). This study therefore
included a measure of inter-coder reliability in addition to other quality indicators recommended for qualitative research (see below).

Assessment of reliability involved an iterative process of coding the data and calculating inter-coder reliability (Hruschka et al., 2004; Campbell et al., 2013). This process consisted of several coding rounds, each consisting of coding, calculating inter-coder reliability, codebook modification, and re-coding (Hruschka et al., 2004). First, the lead researcher emailed the codebook to the same research assistant who had participated in previous steps of the data analysis process. Extensive training in use of the codebook was not provided given that this research assistant had already been part of ongoing discussions regarding the themes, sub-themes, and operational definitions for the codes. However, the lead researcher did provide an overview of the updated codebook during a meeting with the research assistant. During this meeting, the lead researcher first described the overall organization of the codebook, including the main themes and sub-themes. The lead researcher then provided an overview of each of the codes within the themes and sub-themes. This overview involved talking through each code and key components of their operational definitions. Questions were discussed. Then, the researcher and research assistant each coded a randomly selected subset of the data (20 thought units from each interview). Responses were compared and discrepancies were discussed until 100% intercoder agreement was achieved. This concluded the overview of the codebook.

Next, using the revised codebook, both members of the research team coded a randomly selected 20% of the data from the first two transcripts (O’Connor & Joffe, 2020). To select the data subset for reliability coding, the lead researcher randomly chose one of the thought units from each of the interviews to be coded. Counting from that thought unit as a starting point, 20% of the total thought units within that transcript were highlighted. Two copies of a spreadsheet containing the highlighted thought units and columns for assigning themes, sub-themes, and codes were created, and one copy was shared with the research assistant. The lead researcher and
the research assistant then independently assigned a theme and sub-theme to each of the highlighted thought units.

A spot check was conducted after reliability coding of the first two interviews had been completed (Campbell et al., 2013; Hruschka et al., 2004; O’Connor & Joffe, 2020). While reliability was determined to be sufficient during this spot check (kappa = 0.73), a discussion of disagreements led the research team to make several modifications to the codebook (O’Connor & Joffe, 2020). Following these modifications, a second round of reliability coding commenced using the updated codebook. In this round of coding, both members of the research team again coded a randomly selected 20% of the thought units from each interview (for the interviews that had been previously coded and spot checked, a new sub-set of thought units was randomly selected for the second round of reliability coding). Spot checks were conducted after 20% of each of the first four interviews had been coded by both members of the team. During these spot checks, reliability was determined to be sufficient and no further adjustments to the codebook were made. Therefore, reliability coding for all interviews was completed.

Following completion of reliability coding, inter-coder reliability was calculated using Cohen’s kappa (McHugh, 2012; O’Connor & Joffe, 2020). Unlike percent agreement, Cohen’s kappa is a statistic that accounts for chance agreement (Hruschka et al., 2004; O’Connor & Joffe, 2020). Additionally, it allows the research team to see which specific themes and sub-themes are the source of any disagreements; this in turn allows for targeted modifications to clarify the codebook as needed. Kappa was calculated manually using the procedures outlined by McHugh (2012). Calculations are available in Appendix J. Kappa values of 0.61 and above are considered to indicate substantial (0.61-0.80) or almost perfect (0.81-1.00) agreement (Cohen, 1960). In this study, kappa was found to be 0.75 at the sub-theme level and 0.76 at the theme level, indicating substantial agreement. Disagreements were resolved through discussion. Then, the lead researcher coded the rest of the dataset using the finalized codebook (available in Appendix K).
To conclude the data analysis process, the lead researcher reviewed the finalized codebook and generated a series of short statements to concisely summarize the main messages captured within each study theme or across multiple themes. These statements were shared with the research assistant who reviewed them and provided suggestions. Additionally, both members of the research team met to discuss the statements and compare them against the list of important messages generated during the familiarization process. This was done to ensure that the summary statements accurately reflected the important main ideas that emerged from the data. Summary statements can be found in the Discussion section below.
Quality indicators

It has been argued that the concepts of reliability and validity are too positivist (i.e., cause-and-effect oriented and deterministic based on a priori theories; Creswell & Poth, 2018) for qualitative research (Lincoln & Guba, 1985). Instead, qualitative researchers often employ alternative means of establishing quality and trustworthiness. They consider the concepts of credibility, transferability, dependability, and confirmability (Creswell & Poth, 2018; Lincoln & Guba, 1985; Sundler et al., 2019). These concepts have been applied within qualitative studies in the field of AAC (Balandin & Goldbart, 2011), and are used in the current study.

Credibility

In qualitative research, credibility is considered to be parallel to internal validity. To achieve credibility, a qualitative researcher strives to ensure that the results presented are an adequate representation of the experiences of the participants (Lincoln & Guba, 1985). Lincoln and Guba suggest the following procedures for ensuring credibility of qualitative studies: (a) triangulation, (b) peer review, and (c) member check.

Triangulation

Triangulation refers to corroboration of the data from multiple different sources, methods, and/or investigators (Lincoln & Guba, 1985; Miles et al., 2014). In the current study, triangulation was supported by including multiple members of the research team throughout the data analysis process and by conducting a measure of inter-coder reliability. Multiple sources of data were not included.
Peer review

Peer review offers an opportunity for an experienced peer to critique the study and question the researcher’s assumptions and conclusions (Lincoln & Guba, 1985). In the current study, the data and procedures were reviewed by an individual who was familiar with the research to provide a check of the research process, play devil’s advocate, and serve as a sounding board. Peer review took place on an ongoing basis throughout the research process (Caron & Light, 2015). The first author’s advisor served as the peer reviewer in this study.

Member check

A member check is one of the most important techniques for establishing the credibility of a qualitative study (Lincoln & Guba, 1985; Seidman, 2019). During a member check, the results and conclusions of the study are shared with the participants who provided the data, and participants are given a chance to react (Lincoln & Guba, 1985). This helps to ensure that the results and conclusions presented by the researcher are adequate representations of the lived experiences of the participants.

In the current study, member checks were conducted at two time points. First, during the interviews, the researcher continually summarized participants’ statements or asked for clarification in order to ensure proper understanding. Second, at the conclusion of the data analysis process, participants were invited to review the results of the study and offer feedback. Following the recommendations of Lincoln and Guba (1985) as well as procedures used in previous AAC research (e.g., Caron & Light, 2016; Datillo et al. 2008; McNaughton et al., 2008; O’Neill & Wilkinson, 2020; Therrien, 2019), all participants were emailed a summary of the themes, sub-themes, and topics that emerged across interviews. This summary is available in
Appendix L. The topics that were discussed by each participant were highlighted in red font on the summary sent to that participant; thus, all participants received the same overall summary, but different topics within that summary were highlighted to denote those that were discussed by each individual participant. Participants were invited to review the summary to ensure that it was an accurate and complete representation of their experiences. Specifically, they were asked the following two questions:

1. Do the topics in red font accurately represent the topics we discussed in your interview?
2. Is there anything else you would like to add?

Three out of the eight participants responded to the member check. All three indicated that the topics accurately represented those discussed in the interview, and none had anything additional to add.

**Transferability**

Transferability is considered to be parallel to external validity. Unlike quantitative studies that strive to apply results from a sample to the entire population of interest, generalizability is not a goal of qualitative research (Lincoln & Guba, 1985). Because the researcher only knows the context of their own study, they cannot make any statements regarding the transferability of the results to other contexts. Lincoln and Guba argue, therefore, that the responsibility of the researcher is to provide sufficient “thick description” to allow readers to understand the context of the study and its results, and to make judgements for themselves regarding the transferability of the results to their own context of interest. To achieve thick description, Lincoln and Guba recommend (a) providing a thorough description of the setting in which the study took place, and (b) providing a thorough description of the study methods. This was achieved in the current study
through inclusion of a detailed methods section that provided information about the participants, the research team, the data collection process, and data analysis.

**Dependability**

Dependability in qualitative research relates to the extent to which the study was conducted with quality and integrity (Miles et al., 2014). Dependability is roughly parallel to the concept of reliability in quantitative research (Lincoln & Guba, 1985). To establish dependability, the current study took the following measures recommended by Miles et al. (2014):

1. The research questions were clearly stated.
2. The theoretical framework for the study was clearly specified.
3. Data were collected across appropriate settings and respondents.
4. Data collection protocols were specified.
5. Inter-coder reliability was calculated with adequate results.
6. A peer review was conducted (see above).

**Confirmability**

Confirmability refers to the objectivity of the study, including the freedom from researcher bias or explicit discussion about the biases that exist (Miles et al., 2014). Qualitative researchers may attempt to reduce bias by bracketing themselves (Creswell & Poth, 2018; Moustakas, 1994; Rossman & Rallis, 2017). Bracketing involves setting aside one's own experiences and biases in order to take a fresh perspective toward the phenomenon of interest (Creswell & Poth, 2018). However, it has also been argued that complete bracketing of investigator perspectives may be difficult or impossible (Moustakas, 1994); therefore, an
alternative approach is for the investigator to reflect on their own experiences, and the biases they bring to the study, throughout the research process (LeVasseur, 2003). The researcher remains open to and curious about participants’ statements while simultaneously being aware of their own assumptions and biases (Brinkmann & Kvale, 2015). The process by which the researcher continually reflects on their own assumptions and questions their understanding of the data and the themes that emerge is referred to as reflexivity (Sundler et al., 2019).

The current study incorporated two strategies to help the researcher practice reflexivity. First, the coding process was collaborative. Collaborative coding supports reflexivity because co-researchers can question the assumptions of the lead researcher or bring perspectives that help the lead researcher to reflect (Sundler et al., 2019; Cornish et al., 2014). Second, the lead researcher wrote an interpretive autobiography (Brinkmann & Kvale, 2015) and consistently reflected on personal experiences and potential bias. This also allows the reader to understand the lens through which the results are reported, and to decide for themselves how valid the findings are (Brinkmann & Kvale, 2015). In phenomenological studies, it is common for the interpretive autobiography to be placed at the beginning of the manuscript (Creswell & Poth, 2018). Therefore, this dissertation begins with a personal statement that addresses the background and biases of the lead researcher.

In addition to the reflexivity practices described above, the current study included the following measures, recommended by Miles et al. (2020), to support confirmability:

1. The study’s methods and procedures were described explicitly.
2. The process of collecting, processing, condensing, transforming, and displaying the data were described.
Chapter 6

Results

Results are presented according to the five main themes and 16 sub-themes identified during the coding process. Themes, sub-themes, and examples of topics discussed by participants within each sub-theme\(^{14}\) are summarized in Table 6-1.

Table 6-1: Themes, sub-themes, and topics discussed by participants.

<table>
<thead>
<tr>
<th>Theme</th>
<th>Sub-themes</th>
<th>Example Topics</th>
</tr>
</thead>
<tbody>
<tr>
<td>Daily life, family, and community</td>
<td>Child description and development</td>
<td>• Child interests, strengths, sensory, temperament</td>
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<tr>
<td></td>
<td></td>
<td>• Child behavior</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Developmental history</td>
</tr>
<tr>
<td>Daily life and family dynamics</td>
<td></td>
<td>• Routines and activities</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Services</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Family dynamics</td>
</tr>
<tr>
<td>Caregiver roles and responsibilities</td>
<td></td>
<td>• General caregiving</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Obtaining, coordinating, and overseeing services</td>
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<tr>
<td></td>
<td></td>
<td>• Helping others understand the child</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Researching supports and solutions</td>
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<tr>
<td></td>
<td></td>
<td>• Obtaining, preparing, and maintaining AAC</td>
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<tr>
<td></td>
<td></td>
<td>• Teaching the child</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Preparing and maintaining AAC</td>
</tr>
<tr>
<td>Support, acceptance, and feelings</td>
<td></td>
<td>• Positive and negative experiences around support from family</td>
</tr>
<tr>
<td>of belonging</td>
<td></td>
<td>• Positive and negative experiences around support from community</td>
</tr>
<tr>
<td>Caregivers’ feelings about</td>
<td></td>
<td>• Joy and gratitude toward child</td>
</tr>
<tr>
<td>their child and the future</td>
<td></td>
<td>• Worries and uncertainties about the future</td>
</tr>
<tr>
<td>Child-caregiver</td>
<td>Communication description</td>
<td>• Communication modalities</td>
</tr>
<tr>
<td>communication</td>
<td></td>
<td>• Communication functions</td>
</tr>
</tbody>
</table>
• Achievements, progress, and success stories
• Communication goals

Strategies to support interaction and learning
• Child interaction strategies
• Partner interaction strategies
• Effective instructional approaches
• Ineffective instructional approaches

Communication and learning challenges
• Early concerns with speech/language development
• Comprehension challenges
• Expression challenges
• Challenges with social pragmatics
• Communication is a “guessing game”
• Loss of skills
• Slow learning/progress
• Impact of challenges on child

Caregivers’ feelings about communication
• Importance of communication
• Roles of communication
• Feelings about child communication difficulties
• Hopes for the future

Integrating AAC systems to support child-caregiver communication

Challenges of implementing AAC systems
• Care and maintenance of technology
• AAC is inconvenient/impractical
• Learning to use AAC is a process

Role and effectiveness of AAC
• Parents’ positive attitudes toward AAC
• Parents’ neutral or negative attitudes toward AAC
• Child attitudes toward AAC

“Every child is different”

Impact of child health and development on communication
• Cognitive development
• Motor development
• Age
• Conceptual knowledge
• Health
• Social-emotional development
• General readiness to learn

Finding the right fit: AAC system
• AAC system features
• Finding the right fit is a process
Daily life, family, and community

In this theme, parents described their experiences of life with their child at home, with family, and as part of a broader community. The five sub-themes within this theme included: (a) child description and development; (b) daily life and family dynamics; (c) parent roles and responsibilities; (d) support, acceptance, and feelings of belonging; and (e) parents’ feelings about their child and the future.

Child description and development

Parents provided rich and insightful descriptions of their child’s characteristics, including interests, strengths, behavior, sensory needs, and overall temperament. All of the parents discussed their child’s interests. For example, in describing her son’s love of Star Wars, Una
shared, “so he has like nine of the ghost ships. Because it’s a plane! It’s a plane, and so he takes it everywhere.” Elyse, described her son’s love of active play:

He loves to jump. He’s now gone from just jumping like he would on a trampoline to – I can jump OFF stuff! So he loves to jump off our couch, he loves to jump off his bed, and I’m just like, son! You’re gonna give Momma a heart attack! Stop this! (Elyse)

Some parents discussed interests that were particularly strong or specific. Tess shared, “Jack only responds to Mickey Mouse. Or Puppy Dog Pals. Only two things. Goofy, Donald Duck, could care less. If it’s Mickey or Minnie, he’s ok. He’ll respond to it.” Thomas shared, “He’ll take a particular movie or tv show and watch it for days. And then he’ll just all of a sudden switch to something else and then he’ll do that for days. So there’s a lot of repetitive stuff.”

Parents also discussed their child’s strengths. Thomas described his grandson’s literacy skills, saying, “He’s not only good at reading, he’s very good at spelling. He has taken a lot of letters and all of a sudden we’re coming in and there’s this big word spelled out on the floor.”

Gillian described her daughter as a problem-solver, saying, “She’s a great problem solver. She figured out how to open a gate with a piece of string when she wasn’t quite two yet.”

Three parents discussed behaviors that were characteristic of their child, or that were particularly notable. When these behaviors posed challenges, parents often attributed them to factors outside of the child’s control such as the child’s age/developmental level, a recent transition to a new school, or the child’s autism. Vanessa described her son’s behaviors as expected for his age, saying, “his behaviors are three year old behaviors. A lot of his behaviors are not necessarily rooted in his speech delays or issues, but because he’s three.” Thomas and Nora attributed aggression to a recent transition to a new school, saying, “So he unfortunately has shown some aggression, reaching out or kicking or even biting lately. I think it was the transition into the new school.” Tess described behaviors that she attributed to autism, saying, “So we have a lot of the same very key behaviors and activities in the sense of, you know, fecal smearing.
Screaming. Rocking. Flapping. We have very key characteristic behaviors that scream, ‘I’m autistic.’”

Parents discussed sensory differences or needs observed in their child. Sometimes sensory needs were described as all-consuming, or as sources of notable discomfort for the child. For instance, Olivia stated, “Because he has so many other sensory needs and sensory issues, he’s not comfortable in this world. This is not a world made for him. He’s comfortable when he’s watching turbines spin.” Tess also described her son’s sensory needs:

I would say he spends 98% of his day seeking sensory… So he’ll come out to the patio, jump on the trampoline for five minutes, and then go back in the house, walk around, touch some blankets, touch the pillows, sometimes scream in the pillow if he has to. (Tess)

Parents described their child’s developmental history, including medical history and early developmental concerns. Sometimes these concerns led parents to suspect autism before their child was diagnosed. As Elyse explained, “I had somewhat concern about autism with him, because he arm flapped a lot. I’d never really seen that before, so it threw me off.” However, several parents also emphasized that many aspects of their child’s early development progressed typically. Vanessa said, “He met all his milestones in terms of physical and growth development, and he babbled and stuff like that early on. And made more sounds.” Elyse shared, “He was getting all of his physical milestones right on time. Actually before he should have, technically.”

Daily life and family dynamics

All of the parents described the activities and routines of their daily lives. They discussed jobs held by themselves or their partner; family activities; and the services their children received, which were often numerous. One parent, Vanessa, indicated that professional services occupied a great deal of her child’s time and sometimes presented scheduling challenges within the family.
We go to everything. His days are packed…and then what happens also cause I’m teaching right now, and he has ABA at 4:30, sometimes there’s not enough time between when I get done with my stuff to drive [my mother] home and back in time for his ABA. (Vanessa)

Parents described their family’s structure and the ways in which autism impacted family dynamics. The impact of autism on family dynamics was captured in several statements from Tess:

But we all have an agreement – especially going out and doing family events. Okay, here’s the main things we’re going for. We’re gonna go to the pumpkin patch. I want ten pictures…but you need to come and sit with me for half an hour. 45 minutes, because he doesn’t last that long. So we’re only going for a half hour. And while you’re there, I need your help in making sure that we keep an eye on your brother. It’s not just your dad and I, it’s you too. There’s six sets of eyes on my son at all times, because the second you drop his hand or something like that to pick up something else? He’s gone. (Tess)

When Jack’s behaviors are starting to escalate and HIS anxiety is escalating, it in turn escalates both dad and I. So both dad and I are walking on eggshells, and with Jack we’re getting at each other. Our other kids are affected by it because we’re trying to figure out what’s going on and our oldest one’s just trying to appease everybody. (Tess)

**Parent roles and responsibilities**

All of the parents discussed their roles and responsibilities within the family. Five parents described general responsibilities related to caring for their child and the family. Tess described the work and sacrifices involved in providing this care:

I was at one point teaching and have left that to take care of my family and my kids, and I now work through the state of [name of state] to take care of my son, Jack, in keeping him out of homes or having caregivers from the state come in and take care of him because of the demand of how much care he needs. (Tess)

Five parents described responsibilities related to obtaining, coordinating, and overseeing their child’s services. These responsibilities included arranging daily and family life to ensure that their child could access or participate in services; advocating for appropriate services; attending appointments; and teaching professionals how to work with their child. Olivia described moving
her entire family in pursuit of services, saying, “So I literally moved to [name of state] for services.” Gillian described advocating for her daughter’s services:

And then I insisted on having her IEP meeting this June anyway, let’s just do it, because she’s a July baby so I said let’s just do it anyway. And I’m kind of glad I did, because now that also qualified her for the extended school year part of the program as well as making sure that, once we started school again in the fall, that she could just kind of continue on. (Gillian)

Tess discussed her role in overseeing her son’s services, saying, “You can never leave them alone. ABA can never be left alone. There always has to be an adult here at all times, within ear shot.” She further stated:

We’re doing all the training instructions and overseeing, and making sure that they’re doing what they’re supposed to be doing, and if they’re not then we’re stepping in and re-training or re-teaching something or telling them no, you cannot do that with him. (Tess)

Parents discussed their efforts to help other people understand their child. Elyse described acting as her child’s voice saying, “We are their voice. We need to be able to help them now so they can help themselves in their own future.” Elyse and Vanessa both described efforts to help others understand and accept their child’s communication:

And then something else that we’ve learned is, we made a page of his information and what he likes, what he dislikes, what happens, you know if he dislikes something, like what he does. And [it] has our information on it in case for some reason we get separated or whatever. (Elyse)

I think just the social aspect of it is that as he’s older, now it’s not, oh give him time. It’s like well what’s wrong with him. I know that that’s a reality of what’s to come… from society or classmates or things like that. So we’re working really hard to reduce that, and we take his device out into the community when we do go. (Vanessa)

Parents discussed responsibilities related to researching supports and solutions to enhance their child’s communication, such as seeking out information about therapy approaches or AAC.

Una described this process:

When our son lost his words around his first birthday, I began searching for other means of communication by following autism Facebook groups and even a couple of well-known Facebook Video-bloggers. I learned of tablets and apps, PECS, and more about sign language. I had to teach myself and husband sign language to then be able to teach our son. (Una)
Three parents described responsibilities related to obtaining appropriate AAC for their child, including advocating for a particular AAC system, advocating for change when current AAC was not meeting the child’s needs, and coordinating AAC device trials. For instance, Elyse described struggling to convince her son’s therapist to try something new when the current approach was not working:

We really struggled at first with our speech therapist, with communication, because she would not switch from sign language to PECS. It took me about seven, eight months before I finally got her to switch over. And to me, seven or eight months on two signs is a little too long to be working on that. (Elyse)

Una described a similar struggle when she observed that the current AAC approach being used in therapy was not meeting her son’s needs. She said, “I had to really fight to move away from PECS because it just wasn’t working. And it’s not that I didn’t think it would work eventually, but I needed a fix now, and not in a year from now.” Vanessa talked about her role in helping to manage her son’s AAC device trial, including requesting the device in the first place and helping to ensure that data was collected to properly document trial outcomes:

The regional center is how we got his device. And I was the first parent that had ever asked for it. And then I asked [my coordinator], I said so do we collect data? What do we do? And I think that made her a little nervous. Because she was like actually, they don’t require us to do any data, it’s all subjective. And I was like oh that’s so weird. So then she made data sheets for us. (Vanessa)

Four parents discussed responsibilities related to teaching their child. Elyse provided an example of what this teaching looked like for her child as she described her role in helping her son learn how to use PECS:

Because with phase one you have somebody behind (unintelligible) help them hand-over-hand to figure out what they need to do. And then as you continue to grow you’re not doing it as much. But yesterday I had to do hand-over-hand a lot with him with the big and little because he didn’t understand it. (Elyse)
Similarly, Vanessa discussed her efforts to create rich learning opportunities for her son at home and in the community, saying, “Last summer I was making up a whole school for him. I was trying to do receptive language…like, ‘where’s the cookie?’ and things that he liked.”

Finally, parents talked about their roles and responsibilities related to preparing and maintaining their child’s AAC, and ensuring that it was ready and available to use at all times. These responsibilities included making materials, remembering to bring the AAC system along when leaving the house, and anticipating problems and planning for possible solutions. Tess described this experience:

I have extras of everything. I always have two of everything just because it’s easier for us. It costs us more, but it’s less stress and anxiety for both dad and I if we have one that stays in the car, or goes strictly with the stroller, versus we have to find the book, we have to put it in the backpack, we have to bring it with us, where did Jack leave the ‘I want’ strip. (Tess)

Sometimes parents incurred financial costs as a result of their efforts to prepare and maintain their child’s AAC system. Elyse explained:

I had to buy a laminator. And I make my own PECS for him now. And I make extras for backup, so say he destroys one during therapy, I have another one to immediately replace it. So it’s constantly like, something always going on. It never seems to fail, there’s some type of barrier that you just have to try and work through. Whether it’s, he’s destroyed the picture, now what are you gonna do? Well, I went and bought a laminator so now I can make my own. You know – you gotta do something. (Elyse)

Support, acceptance, and feelings of belonging

Parents discussed both positive and negative experiences around support, acceptance, and feelings of belonging. Family members and other parents were identified as positive sources of both practical and emotional support. Parents also discussed the challenges that arose when other people, especially family members, did not understand the realities of their daily lives with their child.
Parents described the ways in which family members provided practical assistance, such as childcare, as well as emotional support. For instance, Elyse said, “I talk with my mom a lot, back home. I have a half brother that’s autistic so she gets it.” Vanessa also viewed her mother as a source of support:

My mom moved out here when I was very pregnant, like a couple weeks before I gave birth, and retired. And she’s his primary caregiver when we’re working. She doesn’t live with us, but she’s here all the time. She’s probably here at least 50 hours a week because she does all his Zoom with him and most of his therapies. (Vanessa)

Parents also acknowledged that family was not always supportive, highlighting the challenges that arose when extended family members didn’t understand the realities of daily life with their child.

Our family doesn’t get it. They don’t want to get it, in a way. They’re like, oh, he’ll talk when he’s ready. I don’t know how many times I heard that and it’s so frustrating cause it’s just like no, he won’t. You don’t get it. (Elyse)

For myself and my husband to turn around and go to our parents and say hey, Jack did this today…they don’t know what to say. They don’t know how to be supportive. Sometimes what they say actually makes things worse. Because they don’t know. They don’t know the life of a severe autism child. (Tess)

Other parents were also identified as positive sources of both practical and emotional support. All of the participants who found support from other parents discussed connecting with these other parents via social media specifically. They described receiving information or emotional support from other parents as well as providing support to others. Elyse said, “I know the tablets, that’s fairly new. In fact I really didn’t know about tablets until I started getting involved with the online support group.” Una, Tess, and Vanessa also shared positive experiences connecting with other parents via social media. They described parent networks as sources of both information and emotional support:

They always say that if you meet one autistic kid you’ve met one autistic kid. But it’s been very interesting to find kids similar to mine, and their parents, and what are they doing and what works for them or what doesn’t work for them. And so I’ve learned a lot of different techniques. I’ve learned more about PECS than I knew before, and more about the use of tablets. And so learning all those different things, the different apps that
[name of online group] used…made it easier for me to figure out what worked best for my kid. (Una)

When you’re in the trenches with your two and three year old, or your three, four, and five year old who are sitting here beating their heads, screaming for seven hours straight nonstop and you don’t know what else is going on….know that there’s other families who 1) are right there with you at the same time, 2) there’s parents who have been there, and 3) there’s parents that are coming into that. You can all be there to support, you can go in after ideas…what works guys? I’m at a loss. Any ideas to help me with this? (Tess)

I have a friend who I’ve met through a support group. And she was struggling to get a wheelchair for her daughter. And I go no, this is how you do it. And sure enough we got her a wheelchair, a bed, and a car seat in a matter of three months. Because I told her exactly how to do it. This is exactly what I did. (Tess)

My mom has an Instagram where she puts a lot of his AAC stuff. And people message her or message me, like how do I get started, I don’t think my kid can do it, I don’t think they’re ready. And so we tell them about that free app that I have, or I’m always willing to email PECS, if you want to try PECS I have a bunch, I can send them to you and you print them out and try that. (Vanessa)

Despite receiving support from other parents of children on the autism spectrum, participants in this study expressed a need for broader societal understanding and acceptance of autism. For instance, Tess noted, “It’s things like that that people don’t understand or don’t get about autism. That they don’t sleep through the night.”

**Parents’ feelings about their child and the future**

Three participants discussed their feelings and emotions related to their child and their child’s future. In discussing their child, all three expressed feelings of joy and gratitude. Thomas said, “We always say that he’s a challenge but he’s a joy.” Elyse echoed this sentiment, saying, “He’s amazing. I love that kid, and the adventure he’s put me on with him, and all of the things that I’m learning through him.”

Feelings about the future were more complicated, with parents expressing a mix of worry, uncertainty, and optimism. Elyse talked about worry and uncertainty, saying, “I freak out
when I start thinking about it too much. What happens if something were to happen to me tomorrow, what would happen to my son?” Thomas echoed this sense of uncertainty and also discussed feelings of hope and optimism:

There are some sleepless nights to be had, worrying about what’s going to happen. But…there are some very heartwarming things to say well this is gonna be a life that’s certainly worth pursuing, and there are some great things that can happen. (Thomas)

**Child-caregiver communication**

Parents described their experiences surrounding child-caregiver communication. Four sub-themes within this theme included: (a) communication description and modalities; (b) strategies to support interaction and learning; (c) communication and learning challenges; and (d) parents’ feelings about communication.

**Communication description**

Parents described their child’s communication, including communication modalities used both expressively by the child and by partners when providing input, the child’s communicative functions, communication successes, and goals that their child was working toward.

All of the parents described communication modalities used expressively by the child and/or provided examples of how they are used. Children were frequently reported to use a variety of communication modalities effectively, including behavioral communication, speech, manual signs, and multiple types of both high and low-tech aided AAC.

Our little man has used sign language, PECS, picture schedules and an iPad with the app SceneSnap…We used the app to take a picture in real time and could then circle the items in the picture and record audio to name said item. This commonly worked the most effectively during meltdowns or for items that my son did not yet know the signs for. We have used this more intermittently as of recently as his sign language and prompted more verbal communication. (Una)
We have a board that says Jack wants, or Jack’s choices, that has food, iPad, walk, bath, trampoline, at home, that he can just go grab and hand me so we’re not depending so much on that book. I can keep that tucked away. I did order extra PEC pieces so I have the same level of what I had with the PEC book but just in a different version, it’s just a larger version. We have the free versions of Proloquo2go, Let me Talk. There’s different apps that different people have said to try so we do have those on his iPad so he can have that. (Tess)

In some cases, the children used tools available to them in creative ways that were not necessarily taught but that were highly effective. Thomas and Nora described how their grandson spontaneously began drawing scenes based on his experiences. The drawings provided information for his communication partners and served as conversation starters.

So, he started drawing things. And sometimes we’d ask him – “What is that?” And he said, “It’s a playground! And he’ll say, “It’s a playground!” And oh my god! I see the swing! I see it now! You know. And so we’ve taken pictures of a few of them. Cause some of them were pretty good! So you know, he’s communicating a little drawing now. (Thomas and Nora)

Parents also discussed use of various modalities for providing input when communicating with their child. Tess described using speech and manual signs in combination, saying, “We’ll sign good job as we tell him good job.”

Parents discussed progress and success stories related to their child’s communication, including general comments about having made progress, descriptions of specific goals that the child had reached (e.g., making unprompted comments or asking questions), and instances of successful communicative exchanges. Several parents also noted specific communication goals that their child was still working toward, such as learning adverbs or identifying shapes and colors.
Strategies to support interaction and learning

Parents and their children used a variety of strategies to help support successful communicative interactions. Children were sometimes described as problem-solvers who used existing communication tools in innovative ways to get their point across (e.g., by modifying signs or using previously-heard phrases in new contexts). For instance, Tess described her son’s use of modified signs, saying, “But Jack does have an abbreviated sign and it’s because he’s abbreviated it as his own way of saying “please,” and he goes like this (demonstrates).” Thomas described his grandson’s use of previously-heard phrases:

He’ll take scripting that he hears elsewhere and he uses it in (unintelligible). Sometimes it’s just random but there are times where he’ll answer you or something, or ask you something appropriately based on something you’ve seen. (Thomas)

Parents also modified the environment or the interaction to support their child’s success. They did so by making items available to support behavioral communication, by providing multi-modal input to support comprehension, and by re-framing questions or providing answer choices so that their children were more likely to be able to understand and respond. Elyse described modifying the environment, saying, “And so we have a little bookcase beside it, and we would have stuff on it so he could just grab it and bring it to us if he wanted something.” Olivia described use of multi-modal input, saying, “Everything needs to have a visual paired with it…I think it’s important to be able to hear, see, and to have all those senses working for him.” Olivia also described modifying the nature of her spoken language to support her son’s comprehension:

Our whole house for probably five years was nothing but singsong. Because he responded better to it. Even the commands, like, ‘you wanna take a bath?’ We’re probably sing-songing Broadway showtunes about taking a bath. (Olivia)

All seven parents provided insight into the instructional approaches that were effective for their children. They all described specific approaches or tools that worked. These included consistency, repetition, provision of adequate time for learning, and patience. In discussing the
role of repetition, Elyse said, “It’s gonna take repeating the same thing over and over and over before they get it. It’s not something where you can do it a few times and they’re gonna just pick up on it. It takes time.” Elyse and Una both spoke to the importance of patience. Una said, “I think if we’re as patient with ourselves and with our kids and it’s like hey, we don’t have to tackle everything today, we just need one word. Just one. To make life easier.” Elyse said:

Give your kid patience. Don’t try and force it on them. If you see them getting frustrated and upset, give them a break. Let them go do something they enjoy. And then come back and work on it later. Don’t feel like you have to sit down for an hour straight and work on it with them. (Elyse)

Additional instructional approaches that were reported to be effective included use of visual supports for instruction such as social stories, visuals to help illustrate or provide practice with difficult concepts (e.g., fast/slow, answering “wh” questions, safety concepts), or reward charts; modeling of AAC within meaningful contexts; working actively to engage the child in interactive activities or prompting them to apply specific skills; and “starting small,” then building knowledge/skills gradually over time. Una spoke about the role of motivation and reward:

He had to know that if you see this, I will give you whatever it is you’re asking. As long as you’re communicating with me. So instead of just being like oh, if I do what mom’s doing I get to eat something...well if I do what mom’s doing and I get my airplane, now he was more predisposed to do whatever it was I was trying to teach him. Because he knew that meant that he was going to get something out of it. (Una)

Two parents also identified specific approaches that had not worked for their child. These included choosing goals that did not add anything new, important, or meaningful to the child’s current communication repertoire; providing instruction that did not facilitate independence; and providing intensive instruction without a break. Olivia provided an example of instruction that was frustrating and ineffective for her son:

So Leo can say all day, ‘I want juice, I want juice, I want juice,’ or he can take the three seconds to my counter or fridge and grab himself juice. He’s never gonna use ‘I want juice’...So I could go over there and I could hold back juice...I could hold back the juice
and say, ‘tell me what you want,’ and I can actually get him to produce speech … but then that’s just gonna annoy him. (Olivia)

**Communication and learning challenges**

Although parents described success stories, they also discussed challenges related to communicating with their child and the communication learning process. All seven parents described challenges with comprehension, expression, and/or social pragmatics; often, difficulties in these areas were intertwined in complex ways. Vanessa explained, “I think the receptive is harder right now than the expressive. And that can be part of the social significance of things, for him understanding what’s going on.”

Parents did not just talk about challenges in terms of the child’s skills. They noted that both the child and the communication partner played active roles in interactions; communication breakdowns within these interactions were often described as a ‘guessing game,’ with both participants struggling to understand one another.

Cause I feel that that’s been her main point of communication is to just point to something and then we kind of go through the laundry list of ok, what do you want? Do you want this, do you want that, you know, trying to guess and figure out what she wants. So that makes it kind of hard for us to figure out, what is it that she’s really upset about? Is it because she’s upset she can’t communicate with us? Or is she upset because her sock feels funny? It’s different things like that that we’re not always 100% sure of reading the situation correctly with her. (Gillian)

He wanted [the tv] on and I put it on something, and 5 seconds later he would be back in here grabbing the remote like ‘change it!’ And I’m like, ‘what do you want it on!’ Cause, it was always a guessing game with him. (Elyse)

Parents described the communication learning process as iterative. Many noted that it could be slow and challenging, and five noted that their child had at some point lost or stopped demonstrating skills that were previously acquired. Elyse spoke about the demands of the learning process, saying, “The thing I’m having to realize is, not everything is going to be a piece
of cake. If it was a piece of cake then we wouldn’t be having to do what we’re doing therapy-wise with him.” She also described how her son’s skills fluctuated over time:

He has randomly said different words. Especially when he started. He was able to say bubbles. And then it would stop and go away. And then he would start saying the word again, and it stopped and gone away. And he used to say all done at the end of therapy, and now he doesn’t say it. Words come and go for him. And that is definitely a challenge because I felt like we’re getting somewhere and we’re gaining with him...but then it’s like we’re taken back two steps with his vocabulary. (Elyse)

Parents noted that communication challenges and breakdowns were often a source of distress for their children. Gillian said:

I think she gets upset and frustrated because she can’t formulate the words correctly, or associate that particular thought with her feeling. So it could just turn into a complete meltdown that (unintelligible) in that frustration and anger. (Gillian)

Parents’ feelings about communication

Parents discussed their feelings about the importance of communication in their child’s life. All seven described communication as important, with six parents specifically expressing that communication was a priority. Parents provided specific reasons why they believed communication was important for their child, including: prevention of frustration, aggression, and self-harm resulting from communication breakdowns; expression of wants and needs; fulfillment of communication as a basic human right; expression of emotions; discussion of pain and discomfort; connection with others; and ability to navigate the world independently. Una described the importance of communication for preventing frustration related to communication breakdowns for both her son and her family members, saying, “His increase in communication has been life changing for us and for him. The more he has been able to communicate the less behaviors he had and the meltdowns decreased in intensity and frequency.” She also spoke about the importance of communication as a means of expressing basic wants and needs:
I remember one of his therapists asked of me, if you had a magic wand and you just could only just get one word that would make life easier, what would it be? And I was like, eat. If I could differentiate when he was hungry vs. when he was tired or sleepy or something, that is a basic human need that I could then fulfill and cut down on frustration. (Una)

Vanessa also talked about the role of communication in expressing basic wants and needs:

To determine between bacon and cookies, ok, tell me what you want. Or his drinks, do you want water or do you want milk? What do you want to drink? Having a say in your life I think is important. (Vanessa)

Parents also discussed their feeling and emotions surrounding their child’s communication difficulties and future communication abilities. Feelings were complicated, and often included worry, frustration, and grief. Elyse shared, “It’s just constant worry and frustration. I don’t know what’s wrong with my kid, to help him.” Vanessa said:

To think that your kid’s never gonna be able to call you mom? Or know who you are? Is really really just terrible. And I think it’s ok to grieve the thought of maybe my kid will never verbally speak. (Vanessa)

One parent discussed the difficulty of comparing their child’s progress to that of other children.

You hear her daughter just talking up a storm making these complete sentences. And then I look at my son and I’m like, he can’t do that. And you try SO hard not to compare your child to others. You really do. But when it’s right there, in your face, it’s SO hard not to. It is. It’s so hard. (Elyse)

Parents expressed a strong desire to connect with their child, and for their child to be able to connect with others and to get their needs met through communication. Elyse spoke about this desire to connect, saying, “As a parent that’s all that you want, you just want to be able to communicate with your child and help them any way you can.” Una echoed this desire, saying, “We were so desperate just to get to know our son.” Elyse also talked about the desire for her son to be able to get his needs met through communication, saying, “That’s all I guess I can ask for, in a way, is just...to where he’s not having to sit there in silence suffering. He can speak in some form, he can communicate.”
Two parents discussed feeling hopeful about their child’s future progress while also acknowledging that hope sometimes comes hand in hand with discouragement or uncertainty.

I would just say just never give up. I think it’s so easy to. But I see moms with children that are in their teens that are starting to talk. For the first time! And I’m still new to this, my kid’s only three, but every word he gets is added to his word count and it’s so amazing to see that happen. (Una)

As a mother, I just want to hear my son say ‘I love you Mommy.’ And I don’t know if I’ll ever hear those words come out of my son’s mouth. I have hope of it happening. But you just have to keep going until like he reaches that point, hoping he’ll reach that point. (Elyse)

**Integrating AAC systems to support child-caregiver communication**

Parents described what it’s like to implement AAC within child-partner interactions. Two sub-themes within this theme included: (a) Role and effectiveness of AAC and (b) Challenges of implementing AAC.

**Role and effectiveness of AAC**

Parents overwhelmingly expressed positive attitudes toward AAC, with all seven describing beliefs that it had helped their child or discussing specific ways in which AAC had supported their child’s communication. Perceived benefits of AAC included: supporting requesting; helping to reduce frustration and behavior related to communication difficulties; supporting conversation about topics outside of the immediate context; supporting interactions with less familiar communication partners; assisting the child with understanding schedules and expectations; building vocabulary; helping the child to understand and express feelings; and facilitating use of speech. Elyse and Una described some of the benefits of AAC:

He’s done so much more with it. He can tell us foods he wants. We have specific things off of YouTube that he likes so we’ve made little pictures of it so he can bring that to us so we can get a better sense of what he wants. And the behaviors have gone down from
what they were. It’s been amazing what that has done for us, with our son. It’s changed the whole environment with him. (Elyse)

With sign language he is able to request basic needs such as eat, drink, bath, nap, more, done as well as some preferred items like airplanes, mom, bubbles, open and go. Sign language has been his biggest and most successful aid in communication. Almost all the words that my son now knows he first learned from sign language and now combines the sign with the word. (Una)

Parents emphasized the validity of non-speech forms of communication. Vanessa said, “I don’t care how he talks, whether it’s sign or a device or verbal,” and Una said:

Even if it’s not verbally, even if it’s non-verbally or through sign language or a device, I feel that it’s just a basic human right to be able to communicate. And I don’t think that people always consider things that are outside of verbal in the realm of communication. Even behavior is communication, that they can’t handle this or that they’re misunderstood. And I think that it’s important for everybody to know that. (Una)

While attitudes toward AAC were mostly positive, two parents also expressed reservations about AAC, including doubts that AAC would be able to effectively meet their child’s communication needs. Gillian discussed her reservations:

Last summer when we did her IEP I was like ok yeah, that sounds like a good idea. Not sure, but yeah ok. And now that we’re a few months into school and stuff, I’m feeling like I don’t know if that would benefit her. I have a feeling she would probably rely on that more instead of actually speaking, just because of the ease of it. (Gillian)

According to the parents in this study, their children often had mixed feelings about the role and effectiveness of AAC. Sometimes children seemed to like AAC or find it helpful. Gillian described her daughter’s positive reaction to visual schedules, saying, “I know that she really enjoys [the visual schedule], just because obviously she can see what’s going to happen, she knows what’s going to happen.” Una described her son’s joy at learning to sign “airplane,” saying, “By him being able to do airplane! I was like, oh yeah! Ok yeah, let’s get your airplanes out, let’s play airplane! And you could just see the joy on his face in that.” Child perceptions of AAC were not always positive, however. Children also seemed to find AAC frustrating at times, and they did not always seem to find AAC to be a useful tool for meeting their communication needs. Olivia described her son’s lack of interest in using AAC, saying, “He doesn’t want to use
it. It's all practice at this point. It’s all initiated by us.” Similarly, Thomas described how his grandson sometimes found it easier to meet his needs independently than to communicate about them using aided AAC. He said, “So the barriers I think are – from his standpoint – that it’s easier to just go and grab. Or to point.”

**Challenges of implementing AAC**

Despite expressing generally positive attitudes about the role and effectiveness of AAC for their children, parents also discussed numerous challenges to implementation of AAC systems within daily life. Some of these challenges related to the care and maintenance of technology. Specifically, parents discussed the challenges of keeping high tech devices charged, For instance, Vanessa said, “I think one of the challenges for us, with the iPad, is if it dies.” They also discussed the vulnerability of these devices to being broken or destroyed.

They have talked about possibly eventually moving up from that to a digital device, a tablet device for him. The only thing that worries me about that is you need to have a backup because you never know when they’re gonna get upset and throw it, and that’s their communication. And so then if that happens and they don’t have it, then that causes even more issues. (Elyse)

Parents also expressed that AAC, including both aided and unaided AAC, could be inconvenient and impractical. Tess discussed the sometimes cumbersome and inconvenient nature of aided AAC systems:

I have to bring a diaper bag for Jack, a diaper bag for the baby, my purse, remember to lock the front door, and oh yeah, I have to remember to bring the PECS book bag! I have enough stuff going on in remembering, like, does Jack have his shoes on to walk out of the house? (Tess)

Tess also noted that certain contexts posed particular challenges to implementation of AAC systems, saying, “Getting up and getting the PECS book at three in the morning is not
happening. It’s not gonna work.” Elyse and Vanessa both discussed the challenges of adding and maintaining sufficient relevant vocabulary:

But then it’s like, how do you make room for all those details? We’ve run out of room in his book. I had to ask his ABA for more inserts for his PECS book for us to be able to put more pictures on there because we don’t have enough room! I can’t put a picture of Sun Chips and Cheetos and Cheez-Its, and all this stuff. (Elyse)

If it’s a new thing he’s been exposed to and the word isn’t on his device yet, sometimes that can cause frustration for us and for him because...can see him trying to communicate but...if we didn’t get a chance to add it, that’s a little bit hard. (Vanessa)

Olivia described how AAC systems could be impractical outside of a community that is familiar with the system, saying, “Doing sign language, it’s not practical. For the future. Unless you’re in a deaf community where people can understand.” Thomas and Nora explained how they found a way to make low tech AAC work for their family and their grandson as a more practical alternative to high tech AAC systems:

Sometimes getting all of this technology set up and paying for it and stuff – you tend to say, well, if there’s an easier way of doing it, let’s just…. because he does respond to it, if you just write down, and then he’ll just read it right back to you. (Thomas)

Parents also discussed challenges related to the process of learning to use AAC. While the learning process was not necessarily described as a barrier to AAC use, parents discussed the time and effort required to learn how to implement AAC effectively. Specifically, they described knowledge and skills that their child needed to acquire in order to implement AAC, including (a) an understanding of the symbols used within their AAC system and how those symbols could be used to communicate about real world contexts, and (b) operational competencies such as navigation and use of the message window. Elyse described the need to teach AAC symbols, saying, “So we really had to work on getting him to realize this is the cracker, for Cheez-It. Or this is chips, for Sun Chip or Cheetos.” Una also emphasized the need to learn symbol meanings in order to use them effectively for communication:
He couldn’t quite intellectually understand that if I give mom a picture of an orange, I get an orange. And so that kind of teaching had to happen first. So that was a big barrier in regards to the tablet… (Una)

Una also described the process of learning to navigate using a dynamic display AAC system:

I would have to go in and be like okay, is maybe this page what you want? Food? But if that wasn’t quite it then we had to switch to a different page...and that concept of waiting or continuing to look for something was his biggest barrier. (Una)

Parents also discussed knowledge and skills that they as parents needed to acquire in order to support their child in implementing AAC. They talked about learning curves related to technology generally, to AAC as a concept, and to the various AAC apps and devices available to their child. Una talked about her initial lack of experience with AAC and the need to learn about different forms of communication:

For our family I feel the biggest barrier was the lack of experience in different forms of communication. Before our son, my husband and I had minimal to nonexistent experience in other forms of communication. We were both aware of sign language and even computers that could talk for people that couldn't but neither of us knew anyone personally who needed to communicate in another form than verbal. (Una)

Olivia described the learning curve related to technology, saying, “I didn’t always grow up with a cell phone, I didn’t have my first internet or computer until college. So although I can use all these things much easier than my mom can, there are still gaps.” She also noted that there may be a need to learn multiple devices or systems:

I’m glad that there’s access to so many different types of devices, but at the same time…it’s going to take a lot of work and a lot of proficiency to get good at them. And they’re all different. But you have to be willing to learn. (Olivia)

Finally, one parent discussed challenges related to societal attitudes toward AAC. Olivia talked about misconceptions surrounding high tech AAC and screen time, saying, “And then, because he’s in an IDD [intellectual and developmental disability] population, they’re like, ‘does he really need that much screen time?’ Yeah, we gotta get over that. So you have all of those kind of societal things.” (Olivia)
“Every child is different”

Parents discussed the uniqueness of each child and the need for communication and AAC supports and services to be personalized based on that child’s skills, interests, and needs. Three sub-themes within this theme included (a) impact of child health and development on communication, (b) finding the right fit in an AAC system, and (c) recognizing and adapting to individual needs and characteristics.

Impact of child health and development on communication

Parents discussed factors related to each individual child’s health and development that impacted that child’s communication, learning, and use of AAC. These included factors related to age, overall health, cognitive development, motor development, social-emotional development, and general readiness to learn. For example, Olivia touched on the role of motor skills when using AAC, saying, “We did a little bit of sign but his gross motor at that time was a hot mess too.” She also highlighted her child’s unique response to pain as a factor that needed to be considered when understanding his communication and conceptual knowledge. She explained, “His pain response is different than other people so that’s difficult. When that’s an abstract concept of what hurts me vs. what hurts you.” Vanessa described the role of age/maturity and her son’s general readiness to learn:

I don’t know if it was just was like, he was almost 2.5 and now he had enough skills and he has kind of closed some of the gaps in the other areas where he was able to start learning and things like that more...(Vanessa)
Finding the right fit: AAC system

All of the parents discussed the personalized nature of AAC. They described the ways in which the features of a particular AAC system, including the system’s symbols, overall appearance, and design (i.e., how the child interacts with the system, how the system interacts with the child’s sensory preferences), contributed to the fit and usefulness of that system for their child. For instance, Vanessa described how AAC systems with Velcro were a poor fit for her son, saying, “You have the sensory component of PECS that makes it very difficult if you don’t like things that feel like Velcro. Or you don’t like the sound of it ripping off.” Tess, Gillian, and Olivia provided examples of how the symbols and overall appearance of an AAC system needed to be the right fit for their child’s needs and preferences:

Jack doesn’t understand cartoon pictures. It doesn’t register with him. Unless it’s Mickey Mouse. Or Puppy Dog Pals. But a picture of eggs isn’t gonna ring a bell with him unless it’s the eggs out of the refrigerator. It has to be the ones Jack uses. It has to be Jack’s sippy cup. Not somebody else’s picture of a sippy cup. So we do all the pictures, Jack’s snack container, not just a regular little bowl, it’s Jack’s actual snack container that he uses at home. (Tess)

I think that for her, seeing concrete evidence – like the visual schedules – concrete evidence, this is what’s happening, I know I need to sit for circle time, I know we’re gonna read a book, I know we’re gonna sing a song. Those are much more concrete and I think for her the sign language is a little too abstract. (Gillian)

It was very important not to have anything that looked like an iDevice. That all went into his evaluation. Cause he’s had access to an iPad before. So anything that had the same buttons as an iPad, even though you can disable the home, that creates a lot of tension and frustration. (Olivia)

Parents acknowledged that finding the right fit in an AAC system was a process that often required time, patience, and work. Many described AAC systems that their child had tried in the past that were not a good fit. For instance, Gillian explained, “They tried a few different signs with her and she just was not having it. But they said some kids like it and some kids will take to it. It wasn’t the thing for her.” Often, multiple AAC systems were trialed in an effort to
find what worked. Olivia noted, “we’re now on our 5th different trial device.” Similarly, Elyse described trialing numerous AAC systems with her son:

> When he was doing speech at school they would try sign language. He never picked up on it. The only signs they ever worked on were “all done” and “more,” and he just never got it. So we finally got him to switch to working with PECS. And we were stuck in phase one and phase two for a long time. And then we tried sign language. And he could let me do hand over hand with him to sign more, but he could never do it himself. (Elyse)

Parents also discussed possible ways in which their child’s AAC needs might evolve in the future. They portrayed the process of “finding the right fit” as one that might need to be ongoing, continuing to unfold over time as their child changes and grows and as more communication options are introduced. For instance, Olivia wondered about introducing text in the future:

> Even if he can spell I’m not sure what that would look like in the future, like if he wanted to type to talk. You know how all the AACs have that as an option? I don’t know if that would be an option for him in the future. (Olivia)

Parents stressed the need to be flexible and open-minded when exploring AAC options. Elyse encouraged parents and professionals to be open to changing course when necessary, saying, “And be like, this is not working, we need to try something different. And try a different venture!”

**Recognizing and adapting to individual learning style**

Parents discussed their child’s unique strengths, needs, and learning style, and the process of adapting to these unique characteristics. They talked about providing their child with adequate time and space to learn or communicate at their own pace and capitalizing on individual strengths and interests. Parents encouraged both professionals and other parents to get to know each child as an individual, and to approach the child’s communication with their unique profile in mind.
I think also, from a family perspective, not just patience but also just allowing a little extra space in that whole process. I think if people get too wrapped up and concerned with well they’re not speaking, or they’re not doing this within this timeline, like, oh my god something’s wrong. And it may not be something’s wrong…it’s just trying to figure out the best way of communicating with that person, child. (Gillian)

I would say my biggest recommendation would be to be open-minded. I think it’s easy when you’ve worked in field for so long to kind of be like, this works 80% of the time so we’re gonna push it for everybody, and that’s not necessarily the case. So I would say trying to not be so set in on just one form, and being open to whatever works best for that kiddo. (Una)

We all know, we’ve heard it a million times, none of these kids are alike. So everyone has different strengths and different weaknesses…and not that you should ignore the weaknesses, but, when he was a good reader we said ok, well let’s capitalize on that, you know, as an example. (Thomas)

Vanessa emphasized the need for individualized treatment plans that meets the child where they are and leverage the child’s strengths during instruction, regardless of where that child is in the language learning process:

I would never, as a professional, tell somebody, “your child is too impacted to learn.” Because that’s not true. And basically that’s what we had been told at certain points for Oliver. Well we just don’t think he’s ready for this. Well then what’s he ready for? Then you need to give me an alternative…and you need to have goals ready to propose, with the idea of the longer term goal being your child will find a way to communicate. Right now this is where they’re at, and focusing on strengths. The parents already know what their kids can’t do. You need to focus on what their kids CAN do. (Vanessa)

**External factors impacting communication**

Parents discussed factors external to the child/communication partner dyad that impact communication, learning, or use of AAC. Sub-themes within this theme included (a) professional services and communication team, and (b) healthcare and education systems.
Professional services and communication team

Parents described how factors related to the communication team (child, parents, and education/healthcare professionals) can impact communication, learning, and implementation of AAC. They discussed the role of therapy and other professional resources, the “fit” of individual providers for their child and family, coordination and consistency among team members, the importance of listening to parents, and the role of support and guidance for parents.

Most parents reported positive experiences with professionals and professional services. They believed that therapy and other educational services had helped their child acquire skills related to communication and use of AAC. For instance, Elyse said, “I don’t know if...if we didn’t have the therapy, if he would be where he is with PECS.” Tess described professionals as supportive, saying, “His teachers at school have been EXTREMELY helpful. They’re very very supportive.” Una described similarly positive experiences with professional support:

We have noticed that most increase in communication with the help of his ABA center. Our little man started back in September and we saw a huge jump in communication by consistently having one to one therapy time Monday-Friday. This with the continued support of his speech therapist has supported communication for our little man. (Una)

Parents also talked about how professional services helped them as parents learn how to better support their child’s communication. For instance, Vanessa explained:

His assistive technology SLP who got him the device, she was really great. She had like five sessions after it was approved, so we would talk, video conference, or she came over twice. And we would come up with ideas and games on how to target different core words, which was really helpful. And just ways of being creative, like, we can work on on and off with the light switches. So I think just being creative with activities to target different core words has been really helpful. (Vanessa)

All of the parents stressed that the “fit” between their child and the child’s provider could impact the effectiveness of the services provided. They talked about the importance of working with a provider whose knowledge, skills, and personality are a good match for the child and the family.
You take an inexperienced speech therapist and you throw her in a room with Leo? Speech therapists that like a lot of fine motor stuff, and games, and turn-taking? Yeah, so Leo’s like a bull in a china shop of that kind of therapist...so I think a lot of it goes into the practitioner. (Olivia)

ABA staff isn’t really trained very well on how to use anything that needs to be used. They’re not trained properly. So we usually don’t have them do any of it. Because it turns into, you’re not doing it right, don’t do it. (Tess)

A lot of the people, the ABA staff, cannot handle Jack physically. Jack’s a big kid, Jack is four and a half feet tall and is 70 pounds. At three. So he’s a big kid. And some of these girls come in here and they can’t lift him. Or they’re not firm enough with him to tell him to knock it off. (Tess)

That speech pathologist lasted a month with us because we did not like her. She talked very condescendingly to my husband and my mother. She (unintelligible) have you tried reading a book to him? Lady! We’re here taking a 17 month old to speech therapy, you think we’re not reading to him? Get out of here. So then we switched and we came across our wonderful [name of SLP] who’s been with him since he was 18 months. (Vanessa)

There have been a few people that I’ve quickly gotten rid of because it just wasn’t a good match or their style of teaching didn’t match what I think my child needs or what I agree with as a parent. (Vanessa)

Parents discussed the importance of coordination, communication, and consistency across all team members. They found it important for team members to implement supports and strategies in the same way across environments. For instance, Thomas advised, “Try to be consistent with whatever they’re doing and all get on the same page because otherwise it’s going to be confusing I think for the kid, or not as effective.” Similarly, Olivia said:

It’s not just me doing it with him. It literally has to be his dad, it has to be his brother, it has to be his sister. I think when service planning is implemented...enough time needs to be practice with everyone. This is how you do it. This is how we learn. Because if we don’t all learn it the same way? In a kid like Leo’s brain that’s super rigid, or super off-the-charts crazy and needs to be re-focused? Then it becomes useless. (Olivia)

Parents described how strong communication is important to achieving this consistency:

It wasn’t until I was there for a parent session where he hadn’t quite figured out how to do help. And so it looked a little different. And they didn’t know that that’s what he was asking for but I did. Which kind of helped us like ok, if we’re teaching him something at home, we had to make sure everybody knew exactly what that looked like. I know for quite awhile his speech and OT did a different sign for break than ABA did. And so he didn’t understand what they were asking him because one did break as in a bone, and
another did a break as in like they were gonna stop. And that was very confusing to him because they were supposed to both mean the same thing...that he got a break from therapy, that he didn’t want to do what they were doing anymore. (Una)

We talk to his speech therapist twice a week. The autism specialist once a week. He has a regular teacher and then he has OT, PT, and adaptive PE. So, we speak to a lot of people who are all on the same page when it comes to Jack and what devices we’re using…Everybody’s on board, everybody asks “how’s it working?” (Tess)

Four parents specifically emphasized the importance of listening to parents and recognizing them as integral voices among the team and as experts in their child.

Listen to the parents. We’re the ones who are with them 24/7 and we know them better than anybody else...I understand you have a degree, but I have my degree in my son. And … your book education isn’t gonna help you when you’re trying to figure out my son. It’s gonna help a little bit, but you need the extra pieces of it, and the only way you’re gonna do that is by listening to the parents. You have half the story. You have half the education of this kid. You know what he has…but you don’t know who he IS. And you need who he IS and what he HAS together in order to come up with a plan to help. (Tess)

Parents discussed their experiences surrounding the need for and provision of support and guidance for parents. Parents expressed desire for more support from professionals in general, particularly support to implement AAC, which they did not always feel prepared to do. For instance, Olivia said, “There needs to be basic, intermediate, and advanced using that all comes with a lesson! That you’re not learning on your own. I don’t need to learn this on my own. It’s too hard.” Tess suggested that this support may need to be ongoing, and not just when AAC is new:

Cause there’s steps and stages on how to use [AAC apps], and I don’t know them all, I’m not trained in it. I just need someone to teach me how to use it in the sense of how it’s supposed to be trained. And teaching it. Instead of me just doing it… you can’t just open up the app and say here you go, here’s the app, let’s start using it. That’s what I’ve been told is a huge no-no. By speech pathologists. They say that there’s a certain strategy and steps that you have to take in order to get them to use it correctly. (Tess)

Parents described the benefit of support that was tailored to their individual learning styles and preferences. For instance, Elyse preferred video examples to written instructions, and Vanessa described the benefits of seeing a professional provide modeling of interaction strategies.
I mean, I try to read through, like, they’ll send home the information ok this is the stage we’re on right now, and this is the stage we’re going to, and this is what we do. And you try to read through that information it’s just like...what? I don’t get that. Like, I don’t understand the terminology, or, this doesn’t make sense to me you know the way they, you know the way they use it. Um, so like when we started with ABA and we started with PECS, she showed me different YouTube videos of them, you know. And that’s me, I’m more of a hands on person, learner, than a read and figure it out person. Um, so for me, like, it’s really helped me too because I can see and watch what they’re doing with my child. (Elyse)

Even through Zoom his speech pathologist - cause his speech is also through Zoom right now - she has the same program at her clinic so she’ll model it which helps us as the caretakers know exactly how to do it. So that’s really supportive. (Vanessa)

**Healthcare and education systems**

Parents described how factors related to the healthcare and education systems could impact communication, learning, and/or implementation of AAC. They discussed the diagnostic process, availability and accessibility of communication technology, and availability and accessibility of services.

Parents described a number of difficulties related to the diagnostic process. These included long wait times and lack of provider willingness to diagnose a child until certain criteria had been met (e.g., the child reached a certain age or received a certain amount of therapy).

Parents described seeking out evaluations from numerous places in order to obtain an appointment in a timely manner.

We were trying to get him diagnosed with autism, get him evaluated. We finally found someone who would do it, because we had a hard time with no one wanting to evaluate him because he was under the age of three. And then we finally found through [name of hospital], their growth and development department would evaluate him at a younger age. So, we got a referral, we went there. Um, she said you’ve done everything we would have asked you to do, the only thing that I ask now is you wait until you’ve had six months of therapy before we evaluate him to make sure it’s not just a delayment, before we diagnose it as a disability. (Elyse)

We could have gone to [name of hospital], but we didn’t. It was a long wait. Four, five, six months wait. They had some kind of a program like this for somebody who was doing
research. And they were providing diagnoses. That was at [name of university] and so that’s where we went cause it would be a lot quicker. (Thomas and Nora)

Parents also discussed the lack of availability and accessibility of communication technology. Factors that negatively impacted the availability of communication technology included the high cost of technology, difficulties surrounding funding and insurance, and difficulty obtaining an AAC evaluation due to lack of qualified staff or the need to meet certain prerequisites.

We have been struggling with insurance almost since he was 15 months old, trying to get him a AAC device...they refuse to give him an AAC device unless he is cognitively three…and they don’t think he can do an AAC device. (Tess)

That stuff is not cheap. It costs a lot of money to have that. And it’s sad because there’s a lot of insurances that won’t cover it. There are some states luckily that have grants that will help with that kind of stuff, but then there are other states that don’t. And so, for me I’m like, well if we get to that phase, wait a second, are we gonna have a way to provide that for our son? And it’s just sad how hard it is to get those devices for your child. (Elyse)

The speech therapist from last year recommended an AAC device because she felt that it might help build up Allegra’s language faster. But we need to have her assessed by somebody, and there’s only two people at the school that are capable of assessing. (Gillian)

In discussing barriers related to insurance, several parents described how funding denials sometimes seemed illogical, or seemed to be based on arbitrary factors.

And a lot of it’s coming down to insurance. And insurance not wanting to pay for it. And I get it. I mean, my son has a wheelchair. My son has a safety bed, my son has a safety car seat, specialized car seat for him. He’s got a specialized bath chair. All this stuff is extremely expensive. My son has medical diapers. My son’s not a cheap child. By any means. And I get it. But if we get him this stuff NOW and early learning ... it’s almost like that disconnect between like insurance companies and...them not understanding what all the experts say about early childhood. Start them young. Get them in there learning young. Get them in there learning to love to read and love to write, and everything in preschool. Preschool, preschool, preschool. The first five years are so valuable. And they say the same thing about autism, the earlier you get them in, the earlier you get them therapies, the better off they are throughout life. But yet, we’re not gonna allow you to have an iPad. To speak. We’re not gonna give it to you cause I don’t want to spend the ten grand, but at the same time I’m willing to spend how much in psychiatry, and medication, and therapy bills for family and everybody else because - or even hospital bills for when he’s so aggressive because he can’t talk… Those are the things that, you know, those are the hospital bills that they’re not thinking about. The medication and
medicating these kids and how much the copay for medication is, and how much it is to talk to a psychiatrist. There’s so much more that goes into this that they don’t see and think about, than giving that child that AAC device. (Tess)

My insurance company essentially said he wasn’t smart enough to do it yet, even though they did the AAC genie as part of his assessment...and they used a truck...and they’re like find the truck - truck! Find the truck - truck! And it gets bigger, with a bigger grid. Truck, truck! I think he made like 5 errors and it was when they were really small. And I think one time he saw M&Ms, he’s like “oh, M&Ms!” You know? But they were like, he’s just not ready for such a complicated device. (Vanessa)

Finally, parents discussed difficulties surrounding access to and availability of therapy services. These included lack of available services, long wait times, lack of properly trained professionals, and the need to meet certain prerequisites before receiving services. Parents were sometimes frustrated by the fact that services were so difficult to obtain when they felt that their child so clearly needed them. Gillian described the process of “jumping through hoops” to obtain services that she felt should have been readily available:

I feel sometimes you’re just constantly jumping through one hoop after another to get the necessary support. To me it should just be obvious. They need X, Y, and Z and they should just have it. Instead of, well, we need medical proof, we need this proof and we need that proof. To prove that they actually need it. It’s obvious that she needs speech. But we have to go through these hoops to make sure that she could access speech, whereas it should just be given. (Gillian)

Vanessa expressed similar frustration after receiving advice to wait until her son was older before starting therapy services:

I was told, he’s a boy, give him more time. He’s only one, give him more time. Well then it was 15 months, he’s 15 months, let’s give him one more month. And my thing is… early intervention literally doesn’t hurt anybody. And who cares. We have all this research that proves that early intervention is key. So why would we delay it, right? (Vanessa)
Chapter 7

Discussion

The current study adds to the body of literature investigating the experiences of parents of children with limited speech surrounding communication and AAC. Specifically, it amplifies the voices of parents of beginning communicators who are on the autism spectrum. The results provide insight into the experiences of these parents, including challenges and supports to communication generally and to implementation of AAC specifically. Several key messages emerged from the results, and these are listed below. Each message summarizes key points from within one of the main study themes with the exception of message number three which crosses multiple themes.

1. Young children on the autism spectrum with limited speech have a profound impact on parents and the entire family.

2. Parents often devote enormous amounts of time, energy, and other resources to ensure the best life and outcomes for their child and their family. Often, supporting their child requires them to make substantial sacrifices and to take on roles and responsibilities that go beyond those required of many other parents.

3. Parents often have positive experiences with AAC professionals, but also have to work to seek out additional support, including practical support, emotional support, and information about topics including but not limited to AAC, to enhance quality of life for themselves, their child, and their family. Parents often seek support and information from other parents of children on the autism spectrum.

4. Parents of beginning communicators on the autism spectrum value communication and consider it a priority.
5. Parents consider AAC to be beneficial; however, the practical challenges of obtaining, learning, and implementing AAC can be numerous, and these challenges are often ongoing as child and family needs and skills (and, therefore, the best fit in an AAC system) evolve over time.

6. Every child and every family is different. What works for one family may not work for another. Each child and family’s unique needs are dynamic, changing over time as skills develop and priorities shift.

7. Communication outcomes are impacted by factors external to the child and the family, including the healthcare and education systems.

8. The communication team (child, parents, and professionals) is a system that thrives on mutual respect, communication, and collaboration. Parents must be recognized as experts in their children and given opportunities to both share their knowledge and to receive training from professionals that meets their specific learning and support needs.

Figure 7-1 provides a conceptual map to illustrate the relationships between the main themes that emerged in this study. The study themes are labeled using upper and lower case text. Unlike other labels in the figure, “communication context” does not denote a theme in this study. It is capitalized to distinguish it as a category encompassing two of the main themes (daily life, family, and community; and external factors impacting communication).

The figure shows caregiver-child communication (including use of AAC systems) embedded within a broader context that includes experiences of daily life at home and in the community as well as factors external to the family (e.g., the healthcare system) that impact communication. Thus, like the bioecological model (Bronfenbrenner, 1979), this model captures the caregiver-child microsystem, the family system, and factors external to the child and the family, all of which serve as a context for and influence on communication. Additionally, in this
model, child individuality (captured within the theme titled “every child is different”) runs across all other themes.
Figure 7-1: Relationships between themes.
The following discussion explores the results in detail and suggests implications for communication and AAC services for children on the autism spectrum who are beginning communicators and their families. It begins by exploring how parents situated communication and AAC within a broad environmental context that includes parent-child interactions, family systems, professionals and professional services, and society generally (i.e., all layers within the bioecological model). It then discusses the role of individuality of each child and family, which permeates across multiple layers of environmental systems. Finally, it outlines implications for communication and AAC services.

**Situating communication and AAC within a broad environmental context**

The parents in this study situated their communication and AAC experiences within the broader context of daily life at home and within a community. They discussed their interactions with their child; their family life and daily activities; their own roles and responsibilities as parents, which were often numerous; and the practical and emotional supports available to them from family, community, and professionals. Parents identified a number of factors that impacted communication and implementation of AAC both positively and negatively such as child characteristics, cost and availability of AAC technology, and availability and fit of professional services and service providers. These findings lend support to the bioecological model (Bronfenbrenner, 1979; 1986), which emphasizes the many environmental factors that influence development, including communication development, across the microsystem (e.g., family system), mesosystem (e.g., interactions between parents and professionals), exosystem (e.g., parents’ support groups or networks), and macrosystem (e.g., special education laws that govern service provision).
While factors across all systems within the bioecological model can impact communication (e.g., Hoff, 2006), factors within the microsystem and the mesosystem are the most relevant to AAC professionals who work with families (Mandak et al., 2017). Parents in this study provided insight into communication and AAC implementation within these systems. At the level of the microsystem, parents discussed the caregiver-child subsystem and the family system. At the level of the mesosystem, parents discussed their experiences with professionals and professional services.

**Caregiver-child sub-system**

Parents in this study discussed their interactions with their child. This discussion included descriptions of communication modalities used by the children as well as challenges related to the receptive language, expressive language, and social pragmatic skills of the children. It is interesting to note, however, that parents’ descriptions of their interactions with their child focused not only on the child’s communication (e.g., modalities, functions, challenges), but also on the role of the caregiver. For instance, parents described different modalities used by communication partners when conversing with their child (e.g., manual signs, visual schedules) and ways in which partners modified the environment or interactions to support success (e.g., by offering answer choices to support their child in responding to questions). Moreover, when discussing communication challenges, parents did not just describe the communication skills with which their child needed support; they also described interactions with their child as a “guessing game” in which both partners worked to understand one another and were emotionally impacted when breakdowns occurred.

Given that traditional service delivery models in speech language pathology focus on identifying and remediating communication difficulties attributed to the child (Ganz, 2015; Lund
& Light, 2006), it is interesting to note that the parents in this study did not focus solely on their child’s communication but instead discussed how caregivers and children together played important roles within an interaction. When children with typical development who are beginning communicators interact with caregivers, both communication partners shape the interaction by imitating and responding to one another (e.g., Masur & Eichorst, 2002; Masur & Olson, 2008; Tamis-LeMonda et al., 2001). Research has shown that this is also the case for beginning communicators on the autism spectrum and their parents (Davidoff, 2018). The results of this study offer support for these findings by highlighting the active participation of both communication partners and the need to consider each partner’s role to effectively support the interaction overall.

**Family system**

In addition to describing caregiver-child interactions, the parents in this study talked about their families as a whole. They described the structure and dynamics of their immediate family, illustrating the fact that families function as units. They described ways in which their daily lives as parents were impacted by having a child on the autism spectrum, describing numerous roles and responsibilities beyond those of most parents. They also described ways in which the entire family was impacted by having a child on the autism spectrum. For instance, one mother described how communication breakdowns could lead to frustration for her son, who then expressed his frustration through loud vocalizations that scared the baby and led to a cascade of reactions among family members as the stress within the home escalated.

Parents also described experiences receiving support and acceptance from extended family. These experiences were both positive and negative, and involved various family members other than the child’s biological parents. For instance, one parent talked about the critical role her
own mother played in caring for her child on the autism spectrum (e.g., taking him to therapy sessions); this individual was a crucial communication partner for the child and an important source of practical and emotional support for the mother. These results are consistent with previous research that has found that having a child on the autism spectrum impacts the entire family (Alli et al., 2015; Cassidy et al., 2008; Estes et al., 2009; Hines et al., 2011; Karst & Van Hecke, 2012; Walton & Tiede, 2020), and extends this finding specifically to families of beginning communicators on the autism spectrum who use AAC. Furthermore, these results support previous findings that both parents of children who use AAC (Anderson et al., 2014; Angelo, 2000; Goldbart & Marshall, 2004; McNaughton et al., 2008; O’Neill & Wilkinson, 2020) and parents of children on the autism spectrum (Doak, 2021; Utami et al., 2018) often face enormous demands and take on responsibilities that go above and beyond those of most parents.

Experiences with professionals and professional services

Parents discussed their experiences with communication and AAC professionals and support services. They described the services their children received, discussed the importance of finding a knowledgeable provider who is a good fit for the child and the family, and described intervention approaches that were or were not effective for their child.

Parents also discussed their experiences interacting with professionals as part of their child’s communication team. Consistent with previous research focused on families of children who use AAC (Anderson et al., 2014; Bailey et al., 2006; Goldbart & Marshall, 2004; McCord & Soto, 2004; McNaughton et al., 2008; Parette et al., 2000), parents in this study expressed the importance of involving parents in AAC decision-making, emphasized the importance of good communication and coordination among team members, stressed that parents should play an
integral role within that team, and expressed a desire for professionals to respect them as experts in their children whose insight can greatly enhance outcomes when considered.

Also consistent with previous research involving parents of children who use AAC (e.g., Anderson et al., 2015; Crisp et al., 2014; McNaughton et al., 2008; O’Neill & Wilkinson, 2020) and parents of children on the autism spectrum (e.g., Alli et al., 2015, Hines et al., 2011, Wilson et al., 2021), the parents in this study described both positive and negative experiences working with professionals. Though many of them described these services as helpful and supportive of their child’s communication, they also described instances in which a particular professional or instructional approach was not a good fit. Furthermore, while they described ways in which professionals had helped them in supporting AAC implementation with their child, they also described seeking out information about AAC and support for implementation from other sources, such as the internet or other parents. Implications for improving professional support for parents are discussed below.

**Child and family individuality**

In this study, individuality was a theme across children, families, and external environments. As all of the parents emphasized, there is no “one size fits all” approach when it comes to communication and AAC. Parents in this study highlighted the role of individuality in (a) identifying appropriate AAC systems for their child, (b) identifying effective instructional approaches, and (c) providing effective communication partner training. Additionally, they discussed the ways in which individual child skills and needs change over time.
AAC systems

Parents described the process of “finding the right fit” in an AAC system. This process often involved a great deal of trial and error. Individual child characteristics and features of the AAC systems themselves both played an important role in determining what worked best for each child and family, and each parent described a unique combination of communication modalities and strategies that worked in their situation.

Some of the parents in this study talked about a lack of professional guidance in choosing AAC systems and described challenges related to AAC assessment (e.g., lack of qualified professionals) and/or access to appropriate AAC systems (e.g., lack of funding through medical insurance). These pose potential barriers to finding and accessing an AAC system that is the right fit for a child and a family. These results suggest a need for increased training at the pre-service and in-service levels to improve AAC competency among professionals so that they can provide more effective support for children and families as they explore AAC options. They also suggest a need for policy change to improve access to funding. Implications for AAC services are discussed further below.

Instructional approach

The parents in this study had an understanding of the types of instructional approaches that had and had not work for their child. These varied from family to family. Parents emphasized the need to recognize individuals’ learning styles and to capitalize on individual strengths during instruction. They also discussed the importance of finding providers who were a good fit for the child and the family. In many cases, efforts to identify effective instructional approaches were ongoing at the time of the study.
Communication partner training

Parents in this study expressed the need for support to implement AAC with their child. The need and desire for parent support in AAC has been well documented in previous studies (e.g., Parette et al., 2000). However, the results of this study suggest that simply increasing the amount of training provided may not be sufficient. Parents in this study wanted training that was tailored to their individual needs and learning style (e.g., available in video format or as live, real-time modeling of AAC in meaningful contexts), and that was provided on an ongoing basis.

Some parents talked about seeking information from other parents (e.g., via social media) as they searched for the right AAC solutions for their child. While parent support networks (such as social media groups) offer exciting opportunities for parents to connect with one another, parents should not have to rely solely on input from other families as they make AAC decisions. Families require comprehensive AAC assessment and intervention services from knowledgeable providers that consider individual needs, skills, and resources, and support families to acquire knowledge and skills that empower them to make the best AAC decisions on behalf of their child; these services are an important complement to information provided by other families via social media and other social support networks (McNaughton & Light, 2013). These results suggest that AAC professionals may need to provide information that is more accessible and comprehensible to families. Additional implications are discussed further below.

Change over time

Parents in this study discussed how the unique skills and needs of their children change over time. Child communication skills were described as dynamic. Parents discussed ways in which their child had made progress over time, highlighting communication skills their children
had achieved and sharing success stories. Several parents also discussed loss of skills; they reported that their children had demonstrated communication abilities at one point in time that they later ceased to demonstrate, or that they were currently working toward once again.

Parents also described finding the right fit in an AAC system as a process that unfolds over time. Many families had tried multiple AAC systems in the past, and some anticipated ways in which their child’s communication and AAC needs might change in the future. They discussed features that might become important later on, such as features to support development of literacy skills or use of text-based communication.

Implications for AAC services

The results of this study suggest a number of implications for provision of AAC services. The following discussion outlines implications related to (a) the need to think in terms of family systems, and (b) the need for family-centered AAC services.

Implications for use of a family systems model

The experiences of these parents affirm the need to think in terms of the entire family system to enhance AAC services (Minuchin, 1985; Mandak et al., 2017). Family systems theory emphasizes the concept of interdependence, which holds that “family members are integrally linked to one another and can only be considered within the context of the family system” (Mandak et al., 2017, p.35). Thus, understanding a child and their communication and AAC needs requires an understanding of the family system, including all important communication partners and the relationships between them. The results of this study support the argument that AAC services must attempt to involve all relevant family members and must consider the
functioning of the family as a unit rather than simply the expressive and receptive communication skills of the child (Mandak et al., 2017). Mandak and colleagues (2017) provide resources to support AAC professionals in identifying important members of the family system, determining individual roles and responsibilities within the family, and understanding communication supports and barriers among family sub-systems to determine areas for further development.

Family systems theory also emphasizes the concepts of homeostasis and adaptation (Minuchin, 1985). Homeostasis refers to the maintenance of family equilibrium and resistance to change that disrupts current family patterns. Adaptation refers to change in response to situational or developmental stress. It has been argued that communication and AAC services (including AAC systems themselves) should be integrated into daily life without increasing the burden on families and children or interrupting family homeostasis (Mandak et al., 2017; O’Neill & Wilkinson, 2020). It has also been argued that professionals should be sensitive to a family’s unique demands and stressors, recognize how introduction of AAC impacts the family, and recognize that families continually adapt as both the family and AAC needs change over time (Mandak et al., 2017; O’Neill & Wilkinson, 2020). The results of this study, in which parents described busy lives, numerous responsibilities, complex family dynamics, and changing communication skills and needs over time, support these arguments. Mandak et al. (2017) provide resources to support AAC professionals in identifying each family’s unique needs and providing supports that align with their priorities.

Also consistent with the concepts of homeostasis and adaptation, the results of this study highlight the need for services to adapt along with the child and the family as their situation and needs change. For instance, they suggest that (a) AAC providers should be aware of what has and has not worked for an individual and their family in the past when considering AAC options; (b) AAC assessment should be ongoing; what works at one point in time may not remain the best fit in the future; and (c) AAC funding sources (e.g., insurance) and device manufacturers should
accommodate the need for change over time by providing ongoing access to trial AAC systems and reimbursement for AAC system replacements and upgrades, without restriction, as needs change.

Family systems include a number of sub-systems (e.g., parent sub-system, sibling sub-system; Minuchin, 1985; Mandak et al., 2017). The participants in this study provided particular insight into the caregiver-child sub-system. Specifically, they discussed the active role of both caregiver and child within communicative interactions. Most traditional service delivery models in speech language pathology focus on identifying and remediating communication difficulties attributed to the child (Ganz, 2015; Lund & Light, 2006); however, the experiences of the parents in this study suggest that it might be more appropriate to focus on interactions, with intervention plans considering how the needs of all communication partners can be better met to support overall communication success. This is true not only of service delivery in general but also of AAC services specifically. As others have argued, and as the results of this study affirm, AAC must support both children and their partners to interact successfully (Light et al., 2019; Lund & Light, 2006). It must be easy and intuitive for both to implement (Light et al., 2019), and it must aim to enhance the overall interaction rather than simply meeting the expressive communication needs of the child. Additionally, support for AAC implementation should focus both on the child (e.g., by working to enhance linguistic, operational, social, and strategic competence; Light, 1989) and on the communication partner (e.g., by supporting parents in developing operational competence and confidence in using AAC when interacting with their child).

Implications for provision of family-centered services

The results of this study affirm the need for family-centered interactions and services in AAC (Mandak et al., 2017; Mandak & Light, 2018). Family-centered services respond to child
and family needs and priorities, treat families with dignity and respect; share information to support informed decision-making and honor families’ choices; involve multiple family members; build on family strengths; establish partnerships; collaborate in flexible and individualized ways; and aim to produce optimal child, parent, and family outcomes (Dunst, 2002; Turnbull et al., 2007). The results of this study suggest several implications for the provision of family-centered AAC services. These include implications for (a) provision of support for parents; (b) design of AAC systems; (c) adoption of a personalized approach to AAC, (d) consideration of stakeholder-defined outcomes; (e) provision of AAC provider training in family-centered services, (f) provision of support for building caregiver competencies, and (g) design of AAC service delivery models.

**Support for parents**

Previous research has found that AAC is more likely to be implemented when it is able to be supported within the home environment (Anderson et al., 2014; Bailey et al., 2006; McNaughton et al., 2008; McCord & Soto, 2004; Parette et al., 2000). The parents in this study situated communication within the context of busy lives, and described the numerous roles and responsibilities they took on each day. In fact, the results of this study support previous findings that both parents of children who use AAC (Anderson et al., 2014; Angelo, 2000; Goldbart & Marshall, 2004; McNaughton et al., 2008; O’Neill & Wilkinson, 2020) and parents of children on the autism spectrum (Doak, 2021; Utami et al., 2018) often face enormous demands and take on responsibilities that go above and beyond those of most parents.

Parents in the current study had inconsistent support in managing their many responsibilities. Some received practical and emotional support from extended family and some found support from other parents of children on the autism spectrum, often through social media.
Parents also reported that other people don’t always “get” what it’s like to have a child on the autism spectrum, and this can be a source of stress.

To provide more family-centered AAC services, it is important for professionals to be aware of the demands that these parents face and the efforts that they are already expending on a daily basis to support their child and their family. Professional services must be able to fit into daily life in a way that does not add further stress. Moreover, parents may benefit from supports beyond those typically provided by AAC professionals. For example, access to affordable childcare or respite care may help parents meet the many demands of caregiving in addition to the other demands they take on each day (Breithaupt et al., 2017).

**Design of AAC systems**

To further improve family-centered services, it is important for AAC systems to be user-friendly to support uptake by both children and caregivers without requiring large amounts of time and energy spent on learning, programming, and upkeep. As Light et al. (2019) point out, many current AAC systems and technologies are not intuitive for young children and may impose significant learning demands. Additionally, these systems are often difficult and time-consuming for parents to program. As a result of these limitations, AAC systems may not always meet the growing vocabulary needs of beginning communicators. They may also be difficult to implement within the context of the naturally occurring interactions between parents and children that are important for language development. Light et al. (2019) call for the development of AAC systems that are easier for both parents and children to learn, implement, and maintain over time so that these systems can more readily be integrated into everyday interactions, and the authors review research on features such as visual scene displays and just-in-time programming to improve usability and reduce learning demands. The results of the current study support the need for such
features and for continued research to develop AAC systems that are intuitive and easy for children and their communication partners to use.

**Personalized intervention in AAC**

The results of this study affirm the need for AAC services – including AAC assessment, AAC intervention, and communication partner training – to be individually tailored to the needs and preferences of the individual with complex communication needs and the family. This study therefore adds to the growing evidence base in support of a personalized intervention approach to AAC (Reflections from the fellows of ISAAC, 2016; Light et al., 2021). Personalized AAC grows out of the movement toward personalized medicine, a service delivery model in which intervention is tailored to each individual. With this approach, interventions take into account the individual’s unique characteristics and anticipated response to the intervention, as well as the evidence base (Beukelman, 2016; Hamburg & Collins, 2010; Light et al., 2021). The focus is on identifying what works for whom and under what conditions, and there is an effort to carefully monitor the individual’s response to intervention so that goals and instructional techniques can be modified as needed. Personalized AAC stands in contrast to a one-size-fits-all approach in which the same intervention is provided across individuals regardless of their unique needs and characteristics (Reflections from the fellows of ISAAC, 2016; Light et al., 2021).

**Stakeholder-defined outcomes**

The majority of AAC research for beginning communicators on the autism spectrum involves efficacy studies that focus on child skills such as frequency of communication turns, vocabulary, and requesting (Ganz, 2015). This contrasts with outcomes studies that are concerned
with the impact of an intervention on the individual’s overall quality of life (Lund & Light, 2006). In the current study, parents discussed communication and AAC as being integrated within a daily life that is busy and complex. They discussed the ways in which communication challenges and breakdowns impacted their own emotional experiences as well as those of their child (e.g., by describing how communication breakdowns could lead to frustration). They talked about communication as a priority, and gave numerous examples to show why communication was important within their daily life and their child’s (e.g., for being able to express basic wants and needs, talk about health and comfort, and connect socially). Parents also discussed ways in which communication impacted family dynamics. For these participants, communication was integrally linked with quality of life for children, parents, and families. These results support the suggestions of others that meaningful outcomes should consider overall quality of life for the child with complex communication needs as well as their entire family (Lund and Light, 2006).

Moreover, meaningful quality of life outcomes must be defined by the individual with complex communication needs and the family rather than by professionals (Lund & Light, 2006).

**AAC provider training**

The results of this study suggest the need for additional training for AAC professionals, including training to build competence in AAC generally as well as training to support family-centered interactions and services. Though professionals often believe they are providing family-centered AAC services, this is not always the case (Mandak & Light, 2018). Mandak et al. (2020) have begun to develop training in family-centered services for pre-service speech language pathologists. The results of the current study suggest that there is also a need for in-service training for SLPs and other professionals on provision of family-centered AAC services that
highlight family individuality and prioritize parent/family voices in the assessment and intervention process.

**Support to build caregiver competencies**

Parents in this study discussed the need for support to implement AAC with their children. They also reported busy lives and numerous responsibilities, highlighting the importance of support that is easy to understand and access, and that is directly tailored to the needs of the individual and the family. Previous research involving parents of children who use AAC, including children on the autism spectrum, has also found that parents desire support to implement AAC with their children (e.g., Anderson et al., 2015; Crisp et al., 2014; Doak, 2021; Parette et al., 2000). It has also been suggested previously that this support should be available consistently over time, and that it should be easily accessible in terms of scheduling and location (Anderson et al., 2015). The results of this study support these recommendations. Recent research has begun to explore the use of AAC trainings that are available online or via an app, that are self-paced, that are relatively brief so as to be easily consumed within the context of busy lives, and that can be revisited as often as needed to support learning (Mandak et al., 2020; Gormley & Light, 2019). Features such as these may allow families to access information at their convenience, and as often as is needed.

**AAC service delivery models**

The results of this study suggest a need to reassess current AAC service delivery models for children over the age of three years on the autism spectrum and their families. For children with disabilities under the age of three years in the United States, educational services, including
AAC services, are governed by Part C of the Individuals with Disabilities Education Act (IDEA; Centers for Disease Control and Prevention, 2020). These services are individualized, and they are provided within the child’s natural environments (including home and community settings). They can include support and training for parents. Additionally, the strengths, resources, and needs of both the child and the entire family are considered during assessment and when determining goals (American Speech-Language-Hearing Association, n.d.d). In contrast, for children with disabilities over the age of three years in the United States (who receive services under Part B of IDEA), AAC services are often delivered at school or at a practice (American Speech-Language-Hearing Association, n.d.b). Often, insurance does not reimburse services provided in the home or the community unless the individual is physically unable to leave the home (American Speech-Language-Hearing Association, n.d.c). Furthermore, once children turn three, special education services focus primarily on the child’s goals rather than the family’s goals (Centers for Disease Control and Prevention, 2020), and family support is not currently a Medicaid reimbursable service (Turnbull et al., 2007).

To support a family-centered approach, it is important for AAC services to be designed around a child’s and a family’s needs. Services should be provided in whatever communication contexts are important to the child and the family. They should include support for families that is ongoing, that includes AAC training for communication partners, and that aims to support the functioning of the entire family system rather than just the expressive and receptive communication skills of the child. The results of this study suggest that children on the autism spectrum with limited speech who are over the age of three years may continue to benefit from many of the services and supports that are mandated under Part C of IDEA, such as service provision in natural environments, support for parents and families, and prioritizing of family goals and outcomes in addition to child outcomes. If instruction is provided only in a school or clinic environment, it is difficult for professionals to fully understand the child’s communication
contexts or the family’s needs, resources, and preferences. It is also difficult to consult with parents on an ongoing basis, and to provide hands-on training in meaningful communication contexts as needed. Services provided within the context of a child’s daily life may help to facilitate communication between caregivers and professionals and provide opportunities for meaningful training, including training in communication supports and strategies for parents (provided by professionals) and training for professionals in the child’s communication, needs, preferences, and other unique factors (provided by the parents).

**Limitations**

Although this study adds to the literature on parents’ experiences surrounding communication and AAC, its limitations must be noted. Several limitations relate to the participant sample. The diversity of the participants in this study was limited. Participants were primarily white, monolingual (English-speaking) mothers. The population of the United States is diverse with respect to race, ethnicity, cultural background, language, socioeconomic status, and more (United States Census Bureau, 2021); the participants who volunteered for this study did not represent the full range of diversity within the United States. Additionally, demographic information collected from the participants did not include data on socioeconomic status (SES). Evidence suggests that race, ethnicity, SES, and language status have the potential to impact experiences surrounding education, healthcare, and AAC (e.g., Huer et al., 2001; Kemp & Parette, 2000; Parette et al., 2001; Peterson-Besse et al., 2014), and it is notable that this study did not capture the diversity of these experiences. Moreover, although this paper used the bioecological model of development and family systems theory as guiding frameworks, it explored only the perspectives of parents and caregivers. Family systems must be defined to include all individuals that are considered relevant by the family (Mandak et al., 2017; Minuchin, 1985). Additionally, the bioecological
model recognizes influences on development outside of the family system. The factors influencing success for beginning communicators on the autism spectrum cannot be fully understood without considering the experiences of other family members and important individuals in the child’s life.

The characteristics of the children of the parents in this study also present potential limitations. Two of the children were eight years old while the others were substantially younger (3-4 years old). All participants were beginning communicators; however, older children at the beginning stages of language development have had more language exposure, more life experience, and potentially more experience with AAC than younger children; this creates some variability within the study sample. It should be noted that the children in this study were classified as beginning communicators based on their speech production alone (though all participants also met the study’s criteria to be considered a beginning communicator when expressive communication across all modalities was taken into account). Comprehension and literacy skills were not considered, and it is possible that children may have had more advanced language skills in some domains than the term “beginning communicator” implies. It should also be noted that child characteristics reported in this study are based solely on parent report. Language abilities were not assessed by the research team, nor were child diagnoses verified (e.g., through assessment or record review). The benefits of relying on parent report include minimizing demands placed on the children and the possible stress associated with undergoing an assessment, as well as minimizing demands on parents’ time.

Unlike quantitative research, the goal of most qualitative research is not to obtain results from a sample that can then be generalized to a population. Instead, the goal is to gain a rich understanding of human experience through the study of specific cases (Creswell, 2013; Polit & Beck, 2010). The current study did not involve methods that would support generalization to a population, such as random sampling (Campbell & Stanley, 1963; Polit & Beck, 2010); the
results cannot be assumed to represent the experiences of all parents of beginning communicators on the autism spectrum. However, transferability of the results (i.e., application of results to individuals outside of the study sample; Lincoln & Guba, 1985; Polit & Beck, 2010) is supported in this study through use of thick description (i.e., thorough description of the research setting, participants, and procedures; Lincoln & Guba, 1985; Polit & Beck, 2010). As Lincoln and Guba have argued, thick description allows readers to make their own judgements regarding the applicability of the results to their own contexts.

As with all qualitative research, the results of this study are influenced by the experiences and perspectives of the researcher. The lead researcher in this study had previously worked as an AAC practitioner, and also brought experience as a parent (though not a parent of a child on the autism spectrum) to the analysis of the results. The research assistant in this study also had a background as an AAC practitioner but was not a parent. A different research team analyzing the same transcripts would likely have presented different results due to different life experiences that would have influenced the lens through which the data were viewed (Creswell, 2013; Moustakas, 1994). It has been argued that it is not possible for researchers to fully set aside their biases (Moustakas, 1994). However, researcher bias was addressed in the current study through inclusion of an interpretive autobiography (Creswell & Poth, 2018; Brinkmann & Kvale, 2015), which makes the researcher’s position explicit and allows readers to understand the biases that may have influenced the results.

Another limitation of this study is that only three participants responded to the member check conducted after the data analysis was completed. Member checks are an important technique for establishing the credibility of a qualitative study as they allow the researcher to verify that the results and conclusions presented by the research team accurately reflect the lived experiences of the participants (Lincoln & Guba, 1985; Seidman, 2019). Although it is unfortunate that there was a limited response to the member check conducted upon completion of
data analysis, it should be noted that member checks also occurred throughout each interview as
the researcher continually summarized participants’ statements and asked for clarification as
needed in order to ensure proper understanding.

An important potential limitation to this study relates to the historical time period during
which it was conducted. Data collection took place during 2020, at the beginning of the COVID-
19 pandemic. Parents were not provided with any explicit instructions as to whether they should
discuss their experiences prior to the pandemic, during it, or both. Some participants made
comments that were specific to their experiences during the pandemic; comments that were
specific to conditions during the pandemic and unlikely to be applicable to life outside of
pandemic circumstances were not coded or included in the data analysis. This was done in an
attempt to capture general experiences rather than those specific to a unique point in time;
however, it is important to note that the historical context may have impacted parents’
experiences both positively and negatively, and this impact may be reflected implicitly in the
data.

Finally, the fact that one participant contributed a portion of her responses via online
focus group and a portion via semi-structured interview, while the other participants responded
only via semi-structured interview, is a limitation. Online focus groups and virtual semi-
structured interviews each have strengths and limitations, and the differing nature of these data
collection methods may have impacted the type of information collected through each. In the
focus group, the moderator posed a question at the beginning of each week and did not participate
in the discussion beyond that. In contrast, during the semi-structured interviews, the researcher
was able to ask follow-up questions, request clarification if needed, and confirm her
understanding of the participants’ comments (Brinkmann & Kvale, 2015; Kallio et al., 2016).
This may have reduced the likelihood of misunderstanding or misinterpretation of participants’
responses within the interview format (Reisner et al., 2018). Additionally, the focus group
required written responses that were submitted in an asynchronous manner, at the participants’ convenience. This allowed participants to consider their answers and post when ready whereas the interviews required a more immediate response (Reisner et al., 2018). The interview format may have been better able to capture the spontaneity of responses; however, the focus group may have captured responses that resulted from more thorough and careful reflection on the topics, and that may have been more detailed (Reisner et al., 2018). Based on the limited participation within the focus group as a whole and the number of thought units collected from the focus group as compared to the interview with the parent who participated in both, it seems likely that the interview yielded richer information. During the interview, the parent who had previously answered some focus group questions was offered a chance to elaborate on her previous responses. This may have helped to reduce limitations related to the different data collection methods.

**Future directions**

The results of this study provide a foundation for considering future research directions to improve outcomes for beginning communicators on the autism spectrum and their families.

**Increased participant diversity**

The current study investigated the experiences of parents. Participants were primarily white, monolingual (English-speaking) mothers. Future studies should elicit the perspectives of other key stakeholders such as children on the autism spectrum who use AAC, siblings, fathers, and extended family members representing a wider range of demographic groups. As previously noted, factors such as race, ethnicity, SES, and language status have the potential to impact
experiences surrounding education, healthcare, and AAC (e.g., Huer et al., 2001; Kemp & Parette, 2000; Parette et al., 2001; Peterson-Besse et al., 2014). Future studies should ensure that these experiences are captured to more fully understand the communication and AAC experiences of parents from various backgrounds.

**Family-centered services**

Future research should continue to focus on improving family-centered services in AAC. To this end, there is a need for research that examines what types of outcomes are important to children, parents, and families. This could potentially help to inform discussions between providers and families regarding the goals that will make the biggest difference in their daily lives and the interventions that will help to effectively meet these goals. Future research should also continue to identify effective communication partner training approaches that are personalized, readily available, and easy to access.

Research is needed to explore potential adjustments to service delivery models that would help to better facilitate communication across team members, development of goals that are meaningful within the context of a child’s daily life, and delivery of personalized communication partner training. Turnbull et al. (2007) argue that while research has yielded information about how to provide family-centered services for children with disabilities (e.g., by honoring parents’ choices, involving multiple family members, building on family strengths, establishing partnerships, and collaborating in flexible and individualized ways), it has not provided information about what specific types of supports and services families want and need. The authors argue that, in the early childhood context, it is not simply a matter of asking families what they need or what they would find helpful; families may be so busy caring for their child that they have not had a chance to reflect on their needs. Furthermore, they may not be aware of the
available options or informed regarding the evidence base for various approaches. Turnbull et al. argue that families need to know what their options are in order to be empowered to make choices. The current study provides the basis for future research that explores what services may be helpful to families. This information in turn can help to inform discussions between providers and families surrounding the types of services and supports that would benefit them most. Research in this area might aim to identify family preferences with regards to service provision (e.g., location, frequency, types of services offered) and evaluate the impact of various approaches on family satisfaction, well-being, and communication. Future studies might also explore ways to harness parent and other support groups, including groups on social media, to increase supports for families and advance their knowledge and skills.

To support a family-centered approach in AAC, future research should adopt a consumer-driven approach in which individuals with relevant life experiences play an integral role. As Rackensperer et al. (2005) state, “there is a greater chance of asking meaningful questions, using appropriate research tools, and successfully analyzing results if individuals with relevant life experiences play central roles.” (p.182) Outcomes may be improved if families are integrally involved in every step of the research process, from helping to identify research priorities, to designing the study, to implementation, to analysis and interpretation of results, to dissemination.

**Impact of AAC on caregiver-child interactions**

Parents in this study described the dyadic nature of communication with their child; they did not talk only about the child’s communication abilities, but about the interactions that took place between themselves and their children. There is currently a lack of research examining the interaction patterns of parents and their children on the autism spectrum who are beginning communicators and who use AAC. During the early stages of language development, the
interaction patterns between children and communication partners play an important role in language learning. For instance, factors such as quantity and quality of language input by parents (e.g., vocabulary amount and diversity) and parent responsiveness to child communication can impact later child communication outcomes (e.g., Hoff, 2006). It is not currently known how the addition of an AAC system impacts these interactions. It is reasonable to wonder whether the vocabulary availability, navigation requirements, cognitive demands associated with use of AAC (for both parents who are modeling AAC and children who use it expressively) and other factors might impact the quantity and quality of language used by parents, the topics discussed, parents’ ability to respond with rich language input to their child, and other aspects of interactions. Future observational research might explore parent-child interactions that involve AAC to better understand the nature of these interactions and identify ways to better support both parents and children to participate.

**Conclusion**

This study investigated the communication and AAC experiences of parents of young beginning communicators on the autism spectrum with limited speech. The results suggested the following:

1. Young children on the autism spectrum with limited speech have a profound impact on parents and the entire family.

2. Parents often devote enormous amounts of time, energy, and other resources to ensure the best life and outcomes for their child and their family. Often, supporting their child requires them to make substantial sacrifices and to take on roles and responsibilities that go beyond those required of many other parents.

3. Parents often have positive experiences with AAC professionals, but also have to work to seek out additional support, including practical support, emotional support, and
information about topics including but not limited to AAC, to enhance quality of life for themselves, their child, and their family. Parents often seek support and information from other parents of children on the autism spectrum.

4. Parents of beginning communicators on the autism spectrum value communication and consider it a priority.

5. Parents consider AAC to be beneficial; however, the practical challenges of obtaining, learning, and implementing AAC can be numerous, and these challenges are often ongoing as child and family needs and skills (and, therefore, the best fit in an AAC system) evolve over time.

6. Every child and every family is different. What works for one family may not work for another. Each child and family’s unique needs are dynamic, changing over time as skills develop and priorities shift.

7. Communication outcomes are impacted by factors external to the child and the family, including the healthcare and education systems.

8. The communication team (child, parents, and professionals) is a system that thrives on mutual respect, communication, and collaboration. Parents must be recognized as experts in their children and given opportunities to both share their knowledge and to receive training from professionals that meets their specific learning and support needs.

The results affirm the need to think in terms of family and ecological systems when considering communication and AAC services, and they highlight the importance of a family-centered approach to AAC services. The results also suggest avenues for future research aimed at (a) improving family-centeredness within the field of AAC and (b) supporting the interactions that take place between children who use AAC and their communication partners.
The Social Pragmatic view represents only one approach to understanding how language is acquired (Ambridge & Lieven, 2011). It has been suggested, for example, that innate cognitive processes such as attention and memory also play an important role (Hollich et al., 2000). A complete discussion of theories of language acquisition is beyond the scope of this paper; the social pragmatic approach is highlighted because it helps to illustrate the importance of understanding the experiences of parents who, as important communication partners for young children, play a role in supporting their language development through daily interactions.

The preferred language for referring to people on the autism spectrum is currently a matter of discussion (e.g., Botha et al., 2021; Bottema-Beutel et al., 2021; Bury et al., 2020; Kenny et al., 2016; Vivanti, 2020). Person-first language (PFL; e.g., person with autism, child with autism spectrum disorder) has been considered the preferred approach in recent decades (Botha et al., 2021). However, growing evidence suggests that many individuals within the autism community find PFL to be offensive and ableist, and use of such language is now being reexamined (e.g., Botha et al., 2021; Bottema-Beutel et al., 2021; Vivanti, 2020). An alternative approach is to use identity-first language (IFL; e.g., autistic person, autistic child), which frames autism as an integral part of a person's identity, inseparable from the person as a whole. Recent surveys of adults on the autism spectrum have indicated that many prefer IFL, but this preference is not universal (e.g., Bury et al., 2021; Kenny et al., 2016) and there remains a lack of consensus within the literature regarding the terminology that best reflects the preferences and values of individuals within the autism community as a whole. Qualitative researchers have an ethical responsibility to maintain respectful relationships with participants, including avoiding use of labels that participants do not embrace (Creswell, 2018; Weis & Fine, 2000). In the current study, participants were not asked directly about their preferred terminology. However, an examination
of the transcripts reveals that some of the participants used PFL while others used IFL when referring to their children. In an effort to respect the preferences of all participants, one approach would have been to use both PFL and IFL throughout this paper (e.g., “autistic child/child with autism;” see, for example, Leaf et al., 2021). However, PFL is not merely the less-preferred option for many autistic adults; it is often described as being highly offensive, leading Bottema-Beutel et al. (2021) to argue that this terminology should be avoided altogether. An alternative approach is to follow guidance from Botha et al. (2021) who suggest that, in cases where a compromise is needed, the term “on the autism spectrum” may be used. This term has been found to be the least polarizing and least offensive to members of the autism community (e.g., Bury et al., 2020; Kenny et al., 2016). The current paper adopts this latter approach in an effort to honor the preferences of all participants without using language that is known to be offensive and stigmatizing to some.

3 The Picture Exchange Communication System (PECS)® is a communication system developed by Andy Bondy and Lori Frost and available from Pyramid Educational Consultants, New Castle, DE, USA. [https://pecsusa.com/pecs/](https://pecsusa.com/pecs/)

4 NOVA Chat is a speech generating device produced by Saltillo, Wooster, OH, USA. [https://saltillo.com/products](https://saltillo.com/products)

5 iPad is produced by Apple, Inc. of Cupertino, CA, USA. [https://www.apple.com/](https://www.apple.com/)

6 SnapScene is a communication application produced by Tobii Dynavox, Pittsburgh, PA, USA. [https://us.tobiidynavox.com/products/snap-scene](https://us.tobiidynavox.com/products/snap-scene)

7 TouchChat® is a communication application produced by PRC-Saltillo of Wooster, OH, USA. [https://touchchatapp.com/](https://touchchatapp.com/)

8 GoTalk NOW is a communication application produced by Attainment Company, Inc. of Verona, WI, USA. [https://www.attainmentcompany.com/gotalk-now](https://www.attainmentcompany.com/gotalk-now)
First Then Visual Schedule HD (FTVS-HD) is a communication and scheduling application produced by Good Karma Applications. [https://www.goodkarmaapplications.com/](https://www.goodkarmaapplications.com/)

10 MouthWorks is an educational app produced by Saritasa Technology Solutions, New York, NY, USA. [https://www.saritasa.com/portfolio/mouthworks-educational-app/](https://www.saritasa.com/portfolio/mouthworks-educational-app/)

11 Visual2Go is an educational app produced by Bo Innovations Pty Ltd., New South Wales, Australia. [https://www.visuals2go.com/](https://www.visuals2go.com/)

12 Data Collection for the current study took place in the fall of 2020 during the COVID-19 pandemic. The pandemic affected all aspects of life across the globe. As a result of the pandemic, there were restrictions placed on face-to-face interactions, making it impossible to conduct research in person and necessitating virtual data collection during this study. Additionally, many schools were unable to offer instruction in person, or could do so only on a limited basis. As a result, many children of the parents in this study were participating in classes and receiving support services, including services from AAC professionals, virtually. Often, virtual learning was coordinated and overseen by parents, placing additional demands on their time. The added demands on parents’ time, as well as the stress associated with adjusting to life under pandemic circumstances generally, may have contributed to the reduced participation in the focus group.

13 Zoom is a video conferencing application available from Zoom Video Communications, Inc., San Jose, CA, USA. [https://zoom.us/](https://zoom.us/)

14 To illustrate participants’ lived experiences, results include quotations from the transcripts. In some cases, quotations were edited for clarity. Speech often contains run-on sentences (Poland, 2003) and can feel disjointed when converted to text (Brinkmann & Kvale, 2015). To avoid potential stigmatization of participants, Brinkmann and Kvale recommend converting verbatim transcripts to a more fluent writing style prior to member check or publication. Additionally, editing quotes can improve their readability and, potentially, their impact (Poland, 2003). All
editing was done by the same researcher who conducted the interviews and who was best positioned to edit quotes without altering their meaning (Poland, 2003).

15 This may have been a misstatement that intended to refer to a communication application called SnapScene (see note 6, above).
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https://doi.org/10.1177/1525822X980100020301


http://dx.doi.org/10.1080/07434618.2016.1271453


[https://doi.org/10.1080/13682820701267444](https://doi.org/10.1080/13682820701267444)


Moorcroft, A., Scarinci, N., & Meyer, C. (2020). ‘We were just kind of handed it and then it was smoke bombed by everyone’: How do external stakeholders contribute to parent rejection and the abandonment of AAC systems? *International Journal of Language and Communication Disorders, 55*(1), 59-69. [https://doi.org/10.1111/1460-6984.12502](https://doi.org/10.1111/1460-6984.12502)


racial/ethnic groups: a scoping review of the literature. *Medical Care, 52*(10), S51-S63.

https://doi.org/10.1097/MLR.0000000000000195


https://doi.org/10.1016/j.ijnurstu.2010.06.004


https://doi.org/10.1080/07434610500140360


https://doi.org/10.1177/1049732317705355


https://doi.org/10.1080/14780887.2013.801543


https://doi.org/10.1177/1525740109353938


https://doi.org/10.1002/nop2.275

https://doi.org/10.1017/S0305000909009477


https://www.jstor.org/stable/1132453

https://doi.org/10.1080/07434618.2019.1599065


Appendix A

IRB Approval Letter

EXEMPTION DETERMINATION

**Date:** April 22, 2020  
**From:** Michelle Covert,  
**To:** Emily Laubscher

<table>
<thead>
<tr>
<th>Type of Submission</th>
<th>Initial Study</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Title of Study:</strong></td>
<td>Communication and AAC use for beginning communicators with autism spectrum disorder and limited speech: parent perspectives</td>
</tr>
<tr>
<td><strong>Principal Investigator:</strong></td>
<td>Emily Laubscher</td>
</tr>
<tr>
<td><strong>Study ID:</strong></td>
<td>STUDY00014987</td>
</tr>
<tr>
<td><strong>Submission ID:</strong></td>
<td>STUDY00014987</td>
</tr>
<tr>
<td><strong>Funding:</strong></td>
<td>Not Applicable</td>
</tr>
</tbody>
</table>

**Documents Approved:**  
- Demographic questionnaire.docx (0.01), Category: Data Collection Instrument  
- Focus Group Questions.docx (0.01), Category: Data Collection Instrument  
- Protocol 4.19.20.pdf (0.02), Category: IRB Protocol  
- Screening Questions - adults.docx (0.01), Category: Other  
- Screening Questions - school aged and adolescents.docx (0.01), Category: Other  
- Screening Questions - young children.docx (0.01), Category: Other

The Office for Research Protections determined that the proposed activity, as described in the above-referenced submission, does not require formal IRB review because the research met the criteria for exempt research according to the policies of this institution and the provisions of applicable federal regulations.

Continuing Progress Reports are **not** required for exempt research. Record of this research determined to be exempt will be maintained for five years from the date of this notification. If your research will continue beyond five years, please contact the Office for Research Protections closer to the determination end date.

Changes to exempt research only need to be submitted to the Office for Research Protections in limited circumstances described in the below-referenced Investigator

---

We would like to know how the IRB Program can better serve you.  
Please fill out our survey; it should take about a minute: [https://www.research.psu.edu/irb/feedback](https://www.research.psu.edu/irb/feedback)
Manual. If changes are being considered and there are questions about whether IRB review is needed, please contact the Office for Research Protections.

Penn State researchers are required to follow the requirements listed in the Investigator Manual (HRP-103), which can be found by navigating to the IRB Library within CATS IRB (http://irb.psu.edu).

This correspondence should be maintained with your records.
Appendix B

Recruitment Flyer

Seeking parents of children with autism!

Can you help us learn how to improve communication supports and interventions?

We are seeking parents to participate in a short Zoom interview about communication and communication supports.

Who Can Participate?
- You live in the US
- Your child is 3-8 years old with autism
- Your child is not yet using sentences on a regular basis
- Your child has used communication supports such as sign language, pictures, or communication apps now or in the past

What will I do?
- Parents will participate in one interview via Zoom, at a time of your choosing
- The interview will last approximately one hour or less
- We will ask you about your experiences around your child’s communication and use of communication supports

For more information, please contact the head of the research study, Emily Laubscher: Email: EKL189@psu.edu Phone: 617-504-7982

This study has been approved by the Pennsylvania State University IRB. Emily Laubscher, M.S., CCC-SLP is a licensed and ASHA certified Speech Language Pathologist with over 10 years of experience working with children with ASD and their families. She works with Dr. Janice Light at Penn State.
Appendix C

Recruitment Email

Title of Project: Communication and AAC use for beginning communicators with autism spectrum disorder and limited speech: parent perspectives

Principal Investigator: Emily Laubscher, M.S., CCC-SLP
308A Ford Building
University Park, PA 16802
EXL189@psu.edu
Phone: (617) 504-7982

Other Investigators: Janice Light, Ph.D

RECRUITMENT EMAIL:

Thank you for your interest in the study!

Let me tell you a little more about the study so you can decide if you’d like to participate.

For beginning communicators with autism, interactions with parents provide an important opportunity to develop communication and language skills. In order to maximize these learning opportunities, professionals who work with beginning communicators, such as speech language pathologists, should consider family experiences and perspectives when developing goals and communication supports. Understanding parents’ experiences will help professionals to provide communication support services that are more family-centered.

The aim of this study is to understand the experiences of parents of beginning communicators with autism. Specifically, we aim to understand parent experiences relative to their child’s communication and use of communication supports (such as sign language, pictures, devices with voice output, and communication “apps”).

During this study, the following will occur:
• The researcher will ask several questions to ensure that you meet the inclusion criteria
• If inclusion criteria are met and you are eligible to participate, you will be asked to complete a short questionnaire about yourself and your child
• You will complete a short (about one hour) interview with the researcher. The interview will be conducted virtually using Zoom. The interview will be audio recorded so that we do not miss anything you say. No video will be recorded.
• After the interview is complete, the research team will type up your responses.
• Once all participants have been interviewed, you will receive a summary of all responses. You will have the opportunity to ask questions, clarify responses, or add additional thoughts.

We hope that this will be an opportunity for parents around the country to share what they know and help us improve communication services and supports! If you are interested in participating, please answer the following questions. If you are eligible for the study, I will send you a demographic questionnaire to fill out at your convenience and we can set up a time to conduct the interview.

Thank you once again for your interest! I hope that you are able to participate!

Best,

Emily Laubscher, M.S., CCC-SLP
Doctoral Candidate, Communication Sciences and Disorders
The Pennsylvania State University
EXL189@psu.edu
Phone: 617-504-7982
Title of Project: Communication and AAC use for beginning communicators with autism spectrum disorder and limited speech: parent perspectives

Principal Investigator: Emily Laubscher

Address: 308A Ford Building, University Park, PA 16802

Telephone Number: 617-504-7982

Faculty Advisor: Dr. Janice Light

Faculty Advisor Telephone Number: 814-863-2010

We are asking you to be in a research study. This form gives you information about the research.

Whether or not you take part is up to you. You can choose not to take part. You can agree to take part and later change your mind. Your decision will not be held against you and there will be no penalty or loss of benefits to which you are entitled.

Please ask questions about anything that is unclear to you and take your time to make your choice.

1. Why is this research study being done?
   This research is being done to learn about the experiences and perceptions of parents of beginning communicators with autism spectrum disorder (ASD). Specifically, we aim to learn about your experiences relative to communication with your child and use of communication supports such as sign language, pictures, and communication devices.

   Approximately 60 people will take part in this research study nationwide. About 30 of these will participate in online focus groups, and 30 will participate in interviews. We are asking you to participate in the interview portion of the study.

2. What will happen in this research study?
   If you are interested in participating in this study, the following procedures will occur:
   • The researcher will ask several questions to ensure that you meet the inclusion criteria
   • If inclusion criteria are met and you are eligible to participate, you will be asked to complete a short questionnaire about yourself and your child
You will complete a short (about one hour) interview with the researcher. The interview will be conducted virtually using Zoom. The interview will be audio recorded so that we do not miss anything you say. No video will be recorded.

After the interview is complete, the research team will type up your responses.

Once all participants have been interviewed, you will receive a summary of all responses. You will have the opportunity to ask questions, clarify responses, or add additional thoughts.

**You are free to skip any questions that you prefer not to answer, or to end the interview at any time.**

**You are free to withdraw from the study at any time.**

3. What are the risks and possible discomforts from being in this research study?
   This study involves minimal risk. There are no physical, psychological, social, legal, or economic risks.

   There is a risk of loss of confidentiality if your information or your identity is obtained by someone other than the investigators, but precautions will be taken to prevent this from happening. The confidentiality of your electronic data created by you or by the researchers will be maintained as required by applicable law and to the degree permitted by the technology used. Absolute confidentiality cannot be guaranteed.

4. What are the possible benefits from being in this research study?
   4a. What are the possible benefits to you?
   There is no guarantee that you will benefit from this research. The possible benefits you may experience from this research study include:
   - Opportunity to contribute to research that helps professionals better understand the needs and experiences of families, and potential avenues for improving experiences around communication for individuals with ASD.

   4b. What are the possible benefits to others?
   The results of the research may help scientists to better understand parent experiences, including barriers and supports to communication and use of communication technology for individuals with ASD.

5. What other options are available instead of being in this research study?
   You may decide not to participate in this research study.

6. How long will you take part in this research study?
   If you agree to take part, it will take you about 1 hour or less to complete the questionnaire about you and your child. The interview will last approximately 1 hour.

7. How will your privacy and confidentiality be protected if you decide to take part in this research study?
   7a. What happens to the information collected for the research?
   Efforts will be made to limit the use and sharing of your personal research information to people who have a need to review this information. Reasonable efforts will be made to keep
the personal information in your research record private. However, absolute confidentiality cannot be guaranteed.

Your research records will be labeled with your user name (pseudonym) and will be kept in a password-protected secure online space. Any printed research records will be labeled with your user name (pseudonym) and stored in a locked lab on the PSU campus. Only the members of the research team will have access to your records.

In the event of any publication or presentation resulting from the research, no personally identifiable information will be shared.

We will do our best to keep your participation in this research study confidential to the extent permitted by law. However, it is possible that other people may find out about your participation in this research study. For example, the following people/groups may check and copy records about this research.

- The Office for Human Research Protections in the U. S. Department of Health and Human Services
- The Institutional Review Board (a committee that reviews and approves research studies) and Penn State’s Office for Research Protections.

We will use and disclose your research records when we are required to do so by law. This includes laws that require us to report child abuse or abuse of elderly or disabled adults.

Your research records can be opened by court order. Your records also may be provided in response to a subpoena or legal request for the production of documents.

7b. What will happen to my research information and/or samples after the study is completed?
Your research information will be stored for three years following completion of the study, after which it will be deleted or destroyed.

9. Will you be paid or receive credit to take part in this research study?
You will not receive any payment or compensation for being in this research study.

11. What are your rights if you take part in this research study?
Taking part in this research study is voluntary.
- You do not have to be in this research.
- If you choose to be in this research, you have the right to stop at any time.
- If you decide not to be in this research or if you decide to stop at a later date, there will be no penalty or loss of benefits to which you are entitled.

If you decide to stop participating in the study, research activities will end immediately. Your research data will not be included in the results of the study.

12. If you have questions or concerns about this research study, whom should you call?
Please call the head of the research study (principal investigator), Emily Laubscher at 617-504-7982 if you:

- Have questions, complaints or concerns about the research, including questions about compensation.
- Believe you may have been harmed by being in the research study.

You may also contact the Office for Research Protections at (814) 865-1775, IRB-ORP@psu.edu if you:

- Have questions regarding your rights as a person in a research study.
- Have concerns, complaints, or general questions about the research.
- You may also call this number if you cannot reach the research team or wish to offer input or to talk to someone else about any concerns related to the research.

You may visit the Office for Research Protections’ website at https://www.research.psu.edu/irb/participants for:

- Information about your rights when you are in a research study;
- Information about the Institutional Review Board (IRB), a group of people who review the research to protect your rights; and
- Links to the federal regulations and information about the protection of people who are in research studies. If you do not have access to the internet, copies of these federal regulations are available by calling the ORP at (814) 865-1775.

**INFORMED CONSENT TO TAKE PART IN RESEARCH**

Your participation implies your voluntary consent to participate in the research. Please keep or print a copy of this form for your records.
Appendix E

Screening Questions

Screening Questions – Young Children
The Pennsylvania State University

Title of Project: Communication and AAC use for beginning communicators with autism spectrum disorder and limited speech: parent perspectives

Principal Investigator: Emily Laubscher, M.S., CCC-SLP
308A Ford Building
University Park, PA 16802
EXL189@psu.edu
Phone: (617) 504-7982

Other Investigators: Janice Light, Ph.D

SCREENING QUESTIONS

Is English the primary language spoken in your home?

Do you live in the United States?

Do you have a child with autism spectrum disorder?

Is your child between the ages of 3 and 8 years old?

Have you seen your child use at least one word, sign, or picture to communicate?

Does your child regularly produce phrases and sentences that they have never heard before? That is, does your child use sentences that are not repeated from another person, a video, or a tv show?

Has your child ever used gestures, sign language, pictures, or devices with voice output, such as an iPad, to help them communicate?

Will you be able to participate in a Zoom interview lasting approximately 1 hour?
Appendix F

Demographic Questionnaire

Code: __________ Date: __________ Time: __________ Mode: __________

Demographic Questionnaire
The Pennsylvania State University

Title of Project: Communication and AAC use for beginning communicators with autism spectrum disorder and limited speech: parent perspectives

Principal Investigator: Emily Laubscher, M.S., CCC-SLP
308A Ford Building
University Park, PA 16802
EXL189@psu.edu
Phone: (617) 504-7982

Other Investigators: Janice Light, Ph.D

Instructions: Write or type your answers in the boxes provided. For multiple choice responses, place an X on the appropriate line. You are free to skip any questions you prefer not to answer.

ABOUT YOU

Age:

Gender:

Race
___American Indian/Alaskan native
___Asian
___Hawaiian or other Pacific Islander
___Black or African American
___White

Ethnicity
___Hispanic or Latinx
___Not Hispanic or Latinx
Location (just list state): 

Highest level of education completed (check one): 
___ Some high school 
___ High school graduate 
___ Some college 
___ College degree 
___ Some graduate school 
___ Advanced/graduate degree 

Who do you live with at home? Check all that apply. 
___ Spouse/partner 
___ Children (total number: _____) 
___ Extended family (briefly list below) 
___ Other (briefly list below) 

Is English the primary language spoken in your home? 
___ yes 
___ no 

Other than English, list any languages that you use when talking to your child: 

ABOUT YOUR CHILD 

Current age: 

Gender: 

Has your child received a formal diagnosis of autism spectrum disorder (ASD) from a qualified professional? 
___ yes 
___ no
How old was your child when they were diagnosed with ASD?

Does your child have any developmental diagnoses other than autism spectrum disorder?
  • If no, leave blank
  • If yes, please list:

School setting:
  ___Inclusive
  ___Substantially separate
  ___Other (briefly describe below)

Mark all services that your child receives:
  ___Speech therapy
  ___Occupational therapy
  ___Physical therapy
  ___ABA (Applied Behavior Analysis)/Behavior support
  ___Other (briefly describe)

Continued on next page.
ABOUT YOUR CHILD’S COMMUNICATION

Beginning communicators are learning to understand and use words. These words may include:

- Sound effects and animal sounds (e.g., vroom, woof woof)
- Names of people (e.g., mom, dad)
- Foods and drinks (e.g., banana, milk)
- Action words (e.g., eat, drive)
- ...and many others!

Estimate the number of words that your child understands.

<table>
<thead>
<tr>
<th></th>
<th>___None yet</th>
<th>___1-73</th>
<th>___74-157</th>
<th>___158-259</th>
<th>___260 or more</th>
</tr>
</thead>
</table>

Estimate the number of words that your child produces.

- Include word approximations if you can understand them consistently.
- Do not include words that your child uses when repeating phrases from songs, videos, books, rhymes, or similar.

<table>
<thead>
<tr>
<th></th>
<th>Using speech signs</th>
<th>Using all modalities (speech, signs, pictures, communication device)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>___None yet</td>
<td>___None yet</td>
</tr>
<tr>
<td></td>
<td>___1-2</td>
<td>___1-2</td>
</tr>
<tr>
<td></td>
<td>___3-19</td>
<td>___3-19</td>
</tr>
<tr>
<td></td>
<td>___20-93</td>
<td>___20-93</td>
</tr>
<tr>
<td></td>
<td>___94-296</td>
<td>___94-296</td>
</tr>
<tr>
<td></td>
<td>___297-547</td>
<td>___297-547</td>
</tr>
<tr>
<td></td>
<td>___548 or more</td>
<td>___548 or more</td>
</tr>
</tbody>
</table>

Has your child begun to combine words yet, such as “nother cracker” or “doggie bite?”

<table>
<thead>
<tr>
<th></th>
<th>___not yet</th>
<th>___sometimes</th>
<th>___often</th>
</tr>
</thead>
</table>

If you answered “sometimes” or “often,” please list the three longest phrases you have heard your child use recently.

1.
2.
3.
Describe how your child uses the following modalities to communicate.

**Gestures (e.g., wave bye, nod yes)**
___uses currently
   About how long has your child used gestures? _____ years; _____ months
___used in the past
   For about how long did your child use gestures in the past? _____ years; _____ months
___has never used

Briefly describe your child’s use of gestures.

---

**Sign language**
___uses currently
   About how long has your child used signs? _____ years; _____ months
___used in the past
   For about how long did your child use signs in the past? _____ years; _____ months
___has never used

Briefly describe your child’s use of sign language.

---

**PECS (Picture Exchange Communication System)**
___uses currently
   About how long has your child used PECS? _____ years; _____ months
___used in the past
   For about how long did your child use PECS in the past? _____ years; _____ months
___has never used

Briefly describe your child’s use of PECS.
**Visual Schedules** *(e.g., pictures of what will happen today, or during an activity)*

___ uses currently

About how long has your child used visual schedules? _____ years _____ months

___ used in the past

For about how long did your child use vis. schedules in the past? ____years ___ months

___ has never used

Briefly describe your child’s use of visual schedules.


**Tablet with communication app(s)**

Many children use multiple communication devices and apps. Below, please list all tablets and apps that your child has used, to the best of your memory. Do not include educational apps (e.g., apps designed to teach math skills, phonics skills, etc.).

<table>
<thead>
<tr>
<th>Tablet (e.g., iPad, Samsung Galaxy)</th>
<th>App</th>
<th>When used?</th>
<th>For approximately how long?</th>
<th>Brief description of use</th>
</tr>
</thead>
<tbody>
<tr>
<td>Name (e.g., Proloquo2go, TouchChat, GoTalk NOW, LAMP Words for Life, Speak for Yourself, Snap Core First)</td>
<td></td>
<td>currently</td>
<td>years months</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>in the past</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>never</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>currently</td>
<td>years months</td>
<td></td>
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<tr>
<td></td>
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<td>in the past</td>
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<td>never</td>
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<td>currently</td>
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<td>currently</td>
<td>years months</td>
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<td>currently</td>
<td>years months</td>
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<td></td>
<td></td>
<td>in the past</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>never</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
### Dedicated device with voice output (e.g., NovaChat, Accent)

Please list all dedicated devices that your child has used, to the best of your memory.

<table>
<thead>
<tr>
<th>Device name (e.g., NovaChat, Accent)</th>
<th>Page set if known (e.g., MultiChat 15, Word Power 60, Unity 60 sequenced)</th>
<th>When used?</th>
<th>For approximately how long?</th>
<th>Brief description of use</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>___ currently ___ in the past ___ never</td>
<td>___ years ___ months</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>___ currently ___ in the past ___ never</td>
<td>___ years ___ months</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### Other

Please describe any other communication supports your child has used.

*****END*****
Appendix G

Focus Group Explanation and Method

A portion of the data from one participant in this study (Una) came from an asynchronous online focus group. Focus groups are appropriate when the goal is to gain understanding of an issue or experience from the perspective of participants who have shared a common experience (Khan & Manderson, 1992; Tracy, 2012). Online focus groups are particularly appropriate when topics are potentially sensitive as they allow participants to communicate openly and anonymously (Turney & Pocknee, 2005). Additionally, an online format allows busy parents in different geographic locations to participate at their convenience (Caron & Light, 2015). Online focus groups have been previously used within the field of AAC to understand stakeholder experiences (e.g., McNaughton et al., 2008). Past research shows that information obtained from online focus groups can be comparable in quantity and quality to that provided by face-to-face focus groups (Underhill & Olmstead, 2003).

Recruitment and participants

Participants were recruited via an informational flyer (see below) that was distributed through (a) emails to professionals (e.g., speech language pathologists), personal contacts, and organizations serving individuals with ASD and their families; (b) social media postings; (c) posts to online discussion boards associated with the American Speech-Language Hearing Association (ASHA); and (d) events for families of individuals with ASD (e.g., resource fairs). The flyer included a brief description of the study and information on how to contact the PI.

If interested in the study, potential participants contacted the PI based on the recruitment advertisement. Upon initial contact, parents were asked to answer a set of screening questions to
determine eligibility (see below). If participants met inclusion criteria, they were sent a series of follow-up emails with (a) additional details about the focus group requirements (e.g., participants will spend at least one hour per week responding to the questions; they will answer questions and comment on others’ responses); (b) instructions on how to create a user name and participate on blogger.com, which was the platform used for the focus group; (c) a demographic questionnaire to obtain additional background information on participants and their children; and (d) a consent form. The emails, Blogger instructions, demographic questionnaire, and consent form are provided below. Twelve parents expressed interest in the study; of these, five elected to continue after receiving more information about the study, and three completed the process to set up a username and log in to the blog. Additional details regarding participant demographics are available on request but are not provided because, with the exception of one participant (described in detail within the main manuscript), data from these participants were limited and were therefore not analyzed.

**Materials**

The focus group was conducted on Blogger.com, a password-protected website that allows the creation of online discussions boards where participants can read and comment on posts under an anonymous username. Focus group questions were developed based on guidelines provided by Krueger (1998; p.22). Specifically, questions were designed to be clear, brief, and jargon-free, and to include the following: (a) opening question(s) to help participants get acquainted and connected; (b) introductory questions(s) that provide a chance to reflect on the topic overall and an overview of how participants have experienced a phenomenon; (c) transition question(s) that move from an overview of the topic to key questions surrounding the topic; (d) key questions (typically 2-5 total) that aim to obtain insight on areas of central concern to the
study; (e) ending question(s) that provide a chance to reflect, clarify, and bring closure to the study; and (f) final question that provides a chance to add any additional or missing information. Focus group questions are provided below.

**Procedures**

The focus group began after all participants were recruited and continued for 8 weeks from July-August, 2020. The moderator posed one to two questions each week and sent email reminders to participants to complete their responses if necessary, but otherwise did not participate in the discussion. Participants were instructed to spend at least one hour per week responding to the questions, reading other participants’ responses, and commenting on the responses of others.

Unfortunately, although five participants consented to take part in the focus group, only three completed the procedures to log in to the online discussion platform. Of these three, one participant responded to the first four questions (out of 14), one responded to the first five questions, and one responded to the first nine questions. None of the three participants responded to another participant’s comments.

After the focus group ended (after all questions had been posed), participants were offered the opportunity to complete their responses via semi-structured interview. One participant (Una) consented to do so, and her responses from both the focus group and the follow-up interview are included in the data analysis for this study. The decision was made not to analyze the focus group responses from the other two participants due to their limited nature and the lack of interest from participants in participating in a follow-up interview.
**Title of Project:** Communication and AAC use for beginning communicators with autism spectrum disorder and limited speech: parent perspectives

**Principal Investigator:** Emily Laubscher, M.S., CCC-SLP  
308A Ford Building  
University Park, PA 16802  
EXL189@psu.edu  
Phone: (617) 504-7982

**Other Investigators:** Janice Light, Ph.D

**SCREENING QUESTIONS**

Is English the primary language spoken in your home?

Do you live in the United States?

Do you have a child with autism spectrum disorder?

Is your child between the ages of 3 and 8 years old?

Have you seen your child use at least one word, sign, or picture to communicate?

Does your child regularly produce phrases and sentences that they have never heard before? That is, does your child use sentences that are not repeated from another person, a video, or a tv show?

Has your child ever used gestures, sign language, pictures, or devices with voice output, such as an iPad, to help them communicate?

Do you have access to the internet?

Will you be able to log on to the focus group website and type your answers to the questions?

Are you willing to participate in an online focus group for 6-8 weeks?
The discussion website used in this study is private. I will grant access to each participant using their Google email address (your email will not be shared with other participants). Do you have a Google account, or would you be willing to create one for the purposes of the study?
Recruitment Email 1: Screening
The Pennsylvania State University

Title of Project: Communication and AAC use for beginning communicators with autism spectrum disorder and limited speech: parent perspectives

Principal Investigator: Emily Laubscher, M.S., CCC-SLP
308A Ford Building
University Park, PA 16802
EXL189@psu.edu
Phone: (617) 504-7982

Other Investigators: Janice Light, Ph.D

RECRUITMENT EMAIL:

Thank you for your email! I’m so happy that you are interested in the study!

Let me tell you a little more about the study so you can decide if you’d like to participate.

For beginning communicators with autism, interactions with parents provide an important opportunity to develop communication and language skills. In order to maximize these learning opportunities, professionals who work with beginning communicators, such as speech language pathologists, should consider family experiences and perspectives when developing goals and communication supports. Understanding parents’ experiences will help professionals to provide communication support services that are more family-centered.

The aim of this study is to understand the experiences of parents of beginning communicators with autism. Specifically, we aim to understand parent experiences relative to their child’s communication and use of communication supports (such as sign language, pictures, devices with voice output, and communication “apps”).

During this study, the following will occur:

- There will be an online focus group (discussion board) that includes approximately 10 parents of beginning communicators with autism. The online discussion board will be on a secure, private space that is accessible only to study participants and the researchers. Your name will not be used on the discussion board.
• The focus group will last for a total of 6-8 weeks.
• On each Monday, I will post 1-3 questions on the discussion board.
• Each participant will use the week to answer the questions and respond to other participants.
• I am asking you to devote at least one hour per week to answering the questions and responding to others. You can answer the questions at any time that is convenient for you.

For 6-8 weeks, you will have the opportunity to discuss your experiences surrounding communication with your child with other parents around the country! If you are interested in participating, please answer the following screening questions (below my signature). Feel free to just copy and paste the questions into a new email and answer yes/no for each one. If you are eligible for the study, I will send you a demographic questionnaire to fill out at your convenience and further instructions for accessing the online discussion board.

Thank you once again for your interest! I hope that you are able to participate!

Best,

Emily Laubscher, M.S., CCC-SLP
Doctoral Candidate, Communication Sciences and Disorders
The Pennsylvania State University
EXL189@psu.edu
Phone: 617-504-7982
Recruitment Email 2: Consent, Demographic Form, Gmail

The Pennsylvania State University

Title of Project: Communication and AAC use for beginning communicators with autism spectrum disorder and limited speech: parent perspectives

Principal Investigator: Emily Laubscher, M.S., CCC-SLP
308A Ford Building
University Park, PA 16802
EXL189@psu.edu
Phone: (617) 504-7982

Other Investigators: Janice Light, Ph.D

RECRUITMENT EMAIL:

Thank you for responding to these questions! Everything looks great.

Next we have a few logistics to take care of, and then we can get you set up on the discussion board website.

First, I have attached a consent form to this email. Please take a moment to review it. It is important for you to understand that your participation in this study is completely voluntary. You are free to drop out at any time, and you are free to skip any questions that you prefer not to answer. Just let me know if you have any questions. Please keep a copy of this form for your records. You do not need to return the form to me.

After you have reviewed the consent form, please fill out the attached demographic form and return it to me at your earliest convenience. The form is a Word doc so you should be able to type your answers directly on it. Let me know if you have questions.

Finally, please let me know the Gmail address that you would like me to use to grant you access to the discussion board. You will use the Google account linked to that address to log into the discussion. No one will see this email address except for the study team. If you do not have a Google account, or would like to create a new one for the purposes of the study, I have attached a “how to” sheet for creating a new account.

Once I receive your demographic form and Gmail address, I will send you information about next steps!
Title of Project: Communication and AAC use for beginning communicators with autism spectrum disorder and limited speech: parent perspectives

Principal Investigator:  Emily Laubscher, M.S., CCC-SLP  
308A Ford Building  
University Park, PA 16802  
EXL189@psu.edu  
Phone: (617) 504-7982

Other Investigators:  Janice Light, Ph.D

RECRUITMENT EMAIL:

Thanks so much for sending the demographic form and your Gmail address! I will use this Gmail address to grant you permission to the discussion website.

Before I grant you access, you will need to set up your anonymous username (your “display name”). This is the name that other people will see when they read your posts. It is the name that you wrote on the demographic form that you returned to me.

To set up your display name, you will need to log into your Google account, open up the Blogger “app,” and set your display name within the Blogger settings. I have attached a document with instructions for how to do this. Just let me know if you have any questions.

After you have set up your display name, email me to let me know that the name is all set up. Then I will send you instructions for accessing the discussion and submitting your first post.
Recruitment Email 4: Logging in and Posting
The Pennsylvania State University

Title of Project: Communication and AAC use for beginning communicators with autism spectrum disorder and limited speech: parent perspectives

Principal Investigator: Emily Laubscher, M.S., CCC-SLP
308A Ford Building
University Park, PA 16802
EXL189@psu.edu
Phone: (617) 504-7982

Other Investigators: Janice Light, Ph.D

RECRUITMENT EMAIL:

Great to hear that you were able to set up your username! You are all set to access the discussion board!

To get started, you will need to accept my email invitation and log into the discussion website for the first time. This email will come from a sender called “Moderator.” If you need help, instructions for accepting the invitation and logging in are attached to this email.

Once you have accepted my invitation and logged in for the first time, you can return to the discussion any time you want by going to: (address redacted)

After you are able to log on to the discussion, please provide a short introduction so that others can get you know you. Click on the post called “introduce yourself” and tell us a little bit about you!

If you need help posting on the website, I have also attached instructions for using the website, including how to post, respond to others, and navigate. The key points are: 1) before you post, double check to be sure that your display name is listed correctly (please don’t post under the name “anonymous”) and 2) after typing your response, click “publish” to post it.

The discussion will start once all of the participants have set up their display names and posted an introduction. I’ll be in touch with updates and I will let everyone know when the first discussion questions are up! In the meantime, please also take a minute to check out the “Procedures and Ground Rules” document attached to this email.
Please let me know if you have any questions as you post your introduction. I’m so excited to get started!
Instruction Sheet: How to Create a Google Account

1. On your internet browser, go to www.google.com

2. Click the “sign in” button at the top right corner of the screen

3. Click “create account”

4. The signup form will appear. Complete the form and click “next.”
5. Review the Google terms of service and privacy policy and click “next step.”

6. The “create a profile” page will appear. Click “next step” to move on.

7. Your account will be created and the welcome page will appear. Remember to keep track of your email address and password. You can log into your new Google account any time by going to www.google.com, clicking “sign in” at the upper righthand corner of the screen, and entering this information.

8. To log out of your Google account, click the icon with your initial at the top right of the screen and then click “sign out.”
Instruction Sheet: Setting up your Anonymous Display Name

Our focus group discussion will take place on a website called blogger.com. Blogger is accessed through your Google account.

Before you can participate in the discussion, you will need to set up your anonymous display name. This is the username you selected when you filled out your demographic form. It is the name other people will see when they read your posts.

1. Go to google.com and log into the google account that you will be using for the study.

2. Click the grid of dots (the “Google apps” icon) at the top right of your screen.

3. Scroll down and click the icon that says “blogger”

4. Click “sign in” in the upper right hand corner. Then, choose the gmail address you are using for the study.
5. The welcome screen will appear. You will see an empty box where you are asked to type in your display name. In this box, type the anonymous name you will be using to post your responses during the discussion.

Welcome to Blogger

Confirm Your Profile

The profile that readers will see when they view your posts is shown below.

You will be seen as...

Blogger profile
Display Name: [Anonymized Name]

Continue to Blogger

6. Click “continue to blogger.”

You will not see any content yet. However, if you wish, you can change your personal settings now by clicking on settings → user settings → edit user profile.

*** The process may work differently for some people. If the above does not work, try the following: ***

1. Go to google.com and log into the google account that you will be using for the study.

2. Click the grid of dots (the “Google apps” icon) at the top right of your screen.
3. Scroll down and click the icon that says “blogger”

4. On the left side of the screen, click “settings”
5. Under “General” you will see an option to edit your user profile. Click “edit.”

6. Under “Identity” you will see an option to type in your “Display name.” Type your chosen name here.
7. Scroll all the way down to the bottom of the screen and click “save profile.”

*** Congratulations, you have set up your display name! ***
Instruction Sheet: Logging in to the Discussion

Logging in for the first time

1. Once you have sent me your Gmail address and set up your anonymous username, you will receive an email invitation to view the blog. The email invitation will arrive at the Gmail address you are using for the study. It will come from a sender called “Moderator.”

2. Open up the email and click “accept invitation.”

3. You will be prompted to sign in the blog. Click “sign in.”

IMAGE DELETED DUE TO VISIBLE URL
4. You will be prompted to sign in again to verify your identity. Click “next.”

5. Enter your password and click “next.”

6. You will be prompted again to accept the invitation to join the blog. Click “accept invitation.”
7. Your will be notified that your invitation was accepted. Click “view blog” to access the blog!

IMAGE DELETED DUE TO VISIBLE URL

Once you have entered the blog, click on the post that says “Introduce yourself” and tell us a little bit about you!

**Returning to the discussion later on**

You can access the blog any time you wish to post your responses and leave comments.

1. Go to (URL redacted)

2. If you have signed out of your Google account since your last visit to the discussion, you may be prompted to sign in again.

**Signing out of the discussion**

To sign out of the discussion, close the discussion and log out of your google account.
Instruction Sheet: Procedures and Ground Rules

Dear Parents,

Welcome to the focus group! I’m so glad that are here. I can’t wait to learn from all of you.

Each week on Monday, I will be posting 1-3 questions on the Blogger.com discussion website. For each question:
• Please respond to the question
• Please comment on at least one other person’s response

I am asking you to spend at least 1 hour per week answering the questions and responding to others. This is a time for all of you to discuss your experiences together, so I will not play a large role in the conversation.

You are free to skip any questions that you do not feel comfortable answering.

Please be sure that you are always responding using the same anonymous username that you created for yourselves at the beginning of the study. Contact me if you have any questions.

Please review the group ground rules below before we get started.

Thank you for sharing your experiences!!

Ground Rules

1. **Be respectful.** Everyone has different experiences and we can all learn from each other!

2. **Protect each other’s privacy.** Please do not capture screen shots or share content from our discussions with people outside of the group (including on social media).

3. When referring to yourself and your family members, **feel free to use initials or a pseudonym** (made-up name) if you wish!
Instruction Sheet: Navigating the Discussion Website and Posting Comments

1. Go to (address redacted)

2. If you have logged out of your Google account since your last post, you will be prompted to log in again.

TO RESPOND TO A QUESTION

3. Click on the title of the post you wish to respond to.

4. Click in the box that says “enter your comment”
5. Be sure that you are commenting under the username you set for yourself. This name should appear by default. Do not comment using your real name or “Anonymous.”

6. Type your comment and then click “publish.” *If you do not click publish, your comment will not be posted.*
1. Click the “reply” button under the comment you wish to respond to.

2. Click in the box that says “enter your reply” and type your response.
3. Click “publish”

CONGRATULATIONS!
You now know how to answer questions and respond to others.

You can return to the home page and navigate to a new question at any time by clicking the “back” arrow.
Introduce yourself

Tell use a little bit about yourself and your family.

-----------------------------------------------

Moderator  May 1, 2020 at 11:47 AM
I live in the Boston area with my husband and our dog. I love to go running and hiking.

Parent  May 1, 2020 at 12:03 PM
I love hiking too!

REPLY

-----------------------------------------------

Enter your comment...
Demographic Questionnaire
The Pennsylvania State University

Title of Project: Communication and AAC use for beginning communicators with autism spectrum disorder and limited speech: parent perspectives

Principal Investigator: Emily Laubscher, M.S., CCC-SLP
308A Ford Building
University Park, PA 16802
EXL189@psu.edu
Phone: (617) 504-7982

Other Investigators: Janice Light, Ph.D

Instructions: Write or type your answers in the boxes provided. For multiple choice responses, place an X on the appropriate line.

ABOUT YOU

List the screen name you will use for the discussion*

*Should not include your real name or anything that will identify who you are

Age:

Gender:

Race
___American Indian/Alaskan native
___Asian
___Hawaiian or other Pacific Islander
___Black or African American
___White

Ethnicity
___Hispanic or Latinx
___Not Hispanic or Latinx

Location (just list state):


Highest level of education completed (check one):
___ Some high school
___ High school graduate
___ Some college
___ College degree
___ Some graduate school
___ Advanced/graduate degree

Who do you live with at home? Check all that apply.
___ Spouse/partner
___ Children (total number: ______ )
___ Extended family (briefly list below)
___ Other (briefly list below)

Is English the primary language spoken in your home?
___ yes
___ no

Other than English, list any languages that you use when talking to your child:

ABOUT YOUR CHILD

Current age:

Gender:

Has your child received a formal diagnosis of autism spectrum disorder (ASD) from a qualified professional?
___ yes
___ no
How old was your child when they were diagnosed with ASD?

Does your child have any developmental diagnoses other than autism spectrum disorder?
  - If no, leave blank
  - If yes, please list:

School setting:
  ___ Inclusive
  ___ Substantially separate
  ___ Other (briefly describe below)

Mark all services that your child receives:
  ___ Speech therapy
  ___ Occupational therapy
  ___ Physical therapy
  ___ ABA (Applied Behavior Analysis)/Behavior support
  ___ Other (briefly describe)

Continued on next page.
ABOUT YOUR CHILD’S COMMUNICATION

Beginning communicators are learning to understand and use words. These words may include:

- Sound effects and animal sounds (e.g., vroom, woof woof)
- Names of people (e.g., mom, dad)
- Foods and drinks (e.g., banana, milk)
- Action words (e.g., eat, drive)
- ...and many others!

Estimate the number of words that your child understands.

<table>
<thead>
<tr>
<th>None yet</th>
<th>1-73</th>
<th>74-157</th>
<th>158-259</th>
<th>260 or more</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Estimate the number of words that your child produces.

- Include word approximations if you can understand them consistently.
- Do not include words that your child uses when repeating phrases from songs, videos, books, rhymes, or similar.

Using speech signs device
<table>
<thead>
<tr>
<th>None yet</th>
<th>1-2</th>
<th>3-19</th>
<th>20-93</th>
<th>94-296</th>
<th>297-547</th>
<th>548 or more</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
| Using all modalities (speech, pictures, communication
| None yet | 1-2 | 3-19 | 20-93 | 94-296 | 297-547 | 548 or more |
|          |     |      |      |       |        |             |

Has your child begun to combine words yet, such as “nother cracker” or “doggie bite?”

<table>
<thead>
<tr>
<th>not yet</th>
<th>sometimes</th>
<th>often</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

If you answered “sometimes” or “often,” please list the three longest phrases you have heard your child use recently.

1.
2.
Describe how your child uses the following modalities to communicate.

**Gestures (e.g., wave bye, nod yes)**

___ uses currently

   About how long has your child used gestures? _____ years; _____ months

___ used in the past

   For about how long did your child use gestures in the past? _____ years; _____ months

___ has never used

Briefly describe your child’s use of gestures.


**Sign language**

___ uses currently

   About how long has your child used signs? _____ years; _____ months

___ used in the past

   For about how long did your child use signs in the past? _____ years; _____ months

___ has never used

Briefly describe your child’s use of sign language.


**PECS (Picture Exchange Communication System)**

___ uses currently

   About how long has your child used PECS? _____ years; _____ months

___ used in the past

   For about how long did your child use PECS in the past? _____ years; _____ months

___ has never used

Briefly describe your child’s use of PECS.


**Visual Schedules** *(e.g., pictures of what will happen today, or during an activity)*

---

___ uses currently

**About how long has your child used visual schedules? _____ years _____ months**

___ used in the past

**For about how long did your child use vis. schedules in the past? ___years ___ months**

___ has never used

Briefly describe your child’s use of visual schedules.

---

**Tablet with communication app(s)**

Many children use multiple communication devices and apps. Below, please list all tablets and apps that your child has used, to the best of your memory. Do not include educational apps (e.g., apps designed to teach math skills, phonics skills, etc.).

<table>
<thead>
<tr>
<th>Tablet  (e.g., iPad, Samsung Galaxy)</th>
<th>App</th>
<th>When used?</th>
<th>For approximately how long?</th>
<th>Brief description of use</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>currently</td>
<td>___ years ___ months</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>___ in the past</td>
<td>___ years ___ months</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>___ never</td>
<td>___ years ___ months</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>currently</td>
<td>___ years</td>
<td></td>
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<td></td>
<td></td>
<td>___ in the past</td>
<td>___ years</td>
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<td></td>
<td></td>
<td>___ never</td>
<td>___ years</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>currently</td>
<td>___ years</td>
<td></td>
</tr>
</tbody>
</table>
Dedicated device with voice output (e.g., NovaChat, Accent)
Please list all dedicated devices that your child has used, to the best of your memory.

<table>
<thead>
<tr>
<th>Device name (e.g., NovaChat, Accent)</th>
<th>Page set if known (e.g., MultiChat 15, Word Power 60, Unity 60 sequenced)</th>
<th>When used?</th>
<th>For approximately how long?</th>
<th>Brief description of use</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>___currently</td>
<td>___ years</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>___ in the past</td>
<td>___ months</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>___ never</td>
<td></td>
<td></td>
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<td>___ currently</td>
<td>___ years</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>___ in the past</td>
<td>___ months</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>___ never</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Other
Please describe any other communication supports your child has used.
Title of Project: Communication and AAC use for beginning communicators with autism spectrum disorder and limited speech: parent perspectives

Principal Investigator: Emily Laubscher

Address: 308A Ford Building, University Park, PA 16802

Telephone Number: 617-504-7982

Faculty Advisor: Dr. Janice Light

Faculty Advisor Telephone Number: 814-863-2010

We are asking you to be in a research study. This form gives you information about the research.

Whether or not you take part is up to you. You can choose not to take part. You can agree to take part and later change your mind. Your decision will not be held against you and there will be no penalty or loss of benefits to which you are entitled.

Please ask questions about anything that is unclear to you and take your time to make your choice.

1. Why is this research study being done?
   This research is being done to learn about the experiences and perceptions of parents of beginning communicators with autism spectrum disorder (ASD). Specifically, we aim to learn about your experiences relative to communication with your child and use of communication supports such as sign language, pictures, and communication devices.

   Approximately 30 people will take part in this research study nationwide. The study will include three different focus groups with approximately 10 parent participants in each group. You will participate in only one of the focus groups. You will be assigned to the appropriate group based on the age of your child.

2. What will happen in this research study?
   If you are interested in participating in this study, the following procedures will occur:
   - The researcher will ask several questions to ensure that you meet the inclusion criteria
   - If inclusion criteria are met and you are eligible to participate, you will be given instructions on how to access the online discussion board and how to create a user name.
   - You will introduce yourself to all other participants (approximately nine other parents)
   - You will log in to the website for at least 1 hour per week for 6-8 weeks
You will be asked to answer the moderator’s posted questions (1-3 questions per week) and to comment on others’ responses. You will respond under the user name that you chose for yourself. None of the other participants will know your real name.

- The focus group will last approximately 6-8 weeks
- At the end of the 6-8-week period, you will receive a summary of the responses
- After you receive the summary, you will have the opportunity to ask questions, clarify responses, or add additional thoughts.

**You are free to skip any questions that you prefer not to answer.
You are free to withdraw from the study at any time.**

3. **What are the risks and possible discomforts from being in this research study?**
   This study involves minimal risk. There are no physical, psychological, social, legal, or economic risks.

   There is a risk of loss of confidentiality if your information or your identity is obtained by someone other than the investigators, but precautions will be taken to prevent this from happening. The confidentiality of your electronic data created by you or by the researchers will be maintained as required by applicable law and to the degree permitted by the technology used. Absolute confidentiality cannot be guaranteed.

4. **What are the possible benefits from being in this research study?**
   4a. **What are the possible benefits to you?**
   There is no guarantee that you will benefit from this research. The possible benefits you may experience from this research study include:
   - Opportunity to meet and communicate with other parents who share similar experiences
   - Opportunity to contribute to research that helps professionals better understand the needs and experiences of families, and potential avenues for improving experiences around communication for individuals with ASD.

   4b. **What are the possible benefits to others?**
   The results of the research may help scientists to better understand parent experiences, including barriers and supports to communication and use of communication technology for individuals with ASD.

5. **What other options are available instead of being in this research study?**
   You may decide not to participate in this research study.

6. **How long will you take part in this research study?**
   If you agree to take part, it will take you about 6-8 weeks to complete this research study. You will be asked to log in to the discussion board for at least 1 hour per week, at a time that is convenient for you.

7. **How will your privacy and confidentiality be protected if you decide to take part in this research study?**
7a. What happens to the information collected for the research?
Efforts will be made to limit the use and sharing of your personal research information to people who have a need to review this information. Reasonable efforts will be made to keep the personal information in your research record private. However, absolute confidentiality cannot be guaranteed.

Your research records will be labeled with your user name (pseudonym) and will be kept in a password-protected secure online space. Any printed research records will be labeled with your user name (pseudonym) and stored in a locked lab on the PSU campus. Only the members of the research team will have access to your records.

In the event of any publication or presentation resulting from the research, no personally identifiable information will be shared.

We will do our best to keep your participation in this research study confidential to the extent permitted by law. However, it is possible that other people may find out about your participation in this research study. For example, the following people/groups may check and copy records about this research.
- The Office for Human Research Protections in the U. S. Department of Health and Human Services
- The Institutional Review Board (a committee that reviews and approves research studies) and Penn State’s Office for Research Protections.

We will use and disclose your research records when we are required to do so by law. This includes laws that require us to report child abuse or abuse of elderly or disabled adults.

Your research records can be opened by court order. Your records also may be provided in response to a subpoena or legal request for the production of documents.

7b. What will happen to my research information and/or samples after the study is completed?
Your research information will be stored for three years following completion of the study, after which it will be deleted or destroyed.

10. Will you be paid or receive credit to take part in this research study?
You will not receive any payment or compensation for being in this research study.

11. What are your rights if you take part in this research study?
Taking part in this research study is voluntary.
- You do not have to be in this research.
- If you choose to be in this research, you have the right to stop at any time.
- If you decide not to be in this research or if you decide to stop at a later date, there will be no penalty or loss of benefits to which you are entitled.
If you decide to stop participating in the study, research activities will end immediately. Your research data will not be included in the results of the study. However, it may not be possible to delete responses to the focus group questions that you have already provided.

12. If you have questions or concerns about this research study, whom should you call?
Please call the head of the research study (principal investigator), Emily Laubscher at 617-504-7982 if you:
- Have questions, complaints or concerns about the research, including questions about compensation.
- Believe you may have been harmed by being in the research study.

You may also contact the Office for Research Protections at (814) 865-1775, IRB-ORP@psu.edu if you:
- Have questions regarding your rights as a person in a research study.
- Have concerns, complaints, or general questions about the research.
- You may also call this number if you cannot reach the research team or wish to offer input or to talk to someone else about any concerns related to the research.

You may visit the Office for Research Protections’ website at https://www.research.psu.edu/irb/participants for:
- Information about your rights when you are in a research study;
- Information about the Institutional Review Board (IRB), a group of people who review the research to protect your rights; and
- Links to the federal regulations and information about the protection of people who are in research studies. If you do not have access to the internet, copies of these federal regulations are available by calling the ORP at (814) 865-1775.

INFORMED CONSENT TO TAKE PART IN RESEARCH

Your participation implies your voluntary consent to participate in the research. Please keep or print a copy of this form for your records.
Focus Group Questions
The Pennsylvania State University

Title of Project: Communication and AAC use for beginning communicators with autism spectrum disorder and limited speech: parent perspectives

Principal Investigator: Emily Laubscher, M.S., CCC-SLP
308A Ford Building
University Park, PA 16802
EXL189@psu.edu
Phone: (617) 504-7982

Other Investigators: Janice Light, Ph.D

FOCUS GROUP QUESTIONS:

Introduction
Tell us a little bit about yourself and your family.

Week 1
1. Tell us about your child with autism.
2. Tell us about your child’s communication.

Week 2
3. Is your child’s communication a priority? Why or why not?

Week 3
4. What are the challenges when your child communicates with you and your family?
5. What barriers make it more difficult for you and your family to communicate with your child?

Week 4
6. What supports have helped your child communicate?

Week 5
7. Tell us about your child’s use of communication technology and other communication aids*
   *Examples include use of AAC such as sign language, pictures, PECS, picture schedules, iPads with communication “apps” (like Proloquo2go,
TouchChat, or LAMP), or communication devices with voice output (like a NovaChat or Accent).

8. Have these communication aids been helpful for your child? Why or why not?

Week 6

9. What barriers have made it difficult for your child to use communication technology and other communication aids successfully?
10. What supports have helped your child use communication technology and other communication aids successfully?

Week 7

11. What advice would you give to professionals who work with beginning communicators with autism?
12. What advice would you give to other families of beginning communicators with autism?
13. We have discussed many topics over the past few weeks! Is there anything else you would like to add?
Appendix H

Interview Guide

Code: __________ Date: __________ Time: __________

Semi-Structured Interview Guide
The Pennsylvania State University

Title of Project: Communication and AAC use for beginning communicators with autism spectrum disorder and limited speech: parent perspectives

Principal Investigator: Emily Laubscher, M.S., CCC-SLP
308A Ford Building
University Park, PA 16802
EXL189@psu.edu
Phone: (617) 504-7982

Other Investigators: Janice Light, Ph.D

INTRODUCTION:
Thank you so much for your interest in the project and for taking the time to talk to me. I’m really interested in parent perspectives around communication and AAC, and I’m grateful for your willingness to share your experiences. The AAC field can learn so much from parents and caregivers so your input is extremely valuable! Your input will help so much in making a positive difference for kids and families.

I would like to record our conversation so I don’t miss anything that you say. If at any time during the interview you would like me to stop the recorder, just let me know. Does that sound ok to you?

After the interview, I will type up and analyze your responses. In order to protect your confidentiality, I will assign you a pseudonym, so your interview responses will not be connected to your personal identifying information in any way. During our conversation today, you are free not to answer any question, or to stop the interview at any time. Just let me know.

Do you have any questions before we get started?

Okay, I am starting the recording now.
1. Tell me a little bit about you and your family.

2. Tell me a little more about [child’s name].

Now I’m going to ask some questions that are specifically about communication.

3. Tell me about [child’s name]’s communication.

4. Is [child’s name]’s communication a priority? Why or why not?

5. What are the challenges when [child’s name] communicates with you and your family?

6. What barriers make it more difficult for you and your family to communicate with [child’s name]?

7. What supports have helped your [child’s name] communicate?

A lot of children with autism use communication technology or other communication aids. Some examples include sign language, pictures, visual schedules, and iPads with communication “apps.” These next questions are about your child’s use of these communication aids.

8. Tell me about [child’s name]’s use of communication technology and other communication aids

9. Have these communication aids been helpful for [child’s name]? Why or why not?

10. What barriers have made it difficult for [child’s name] to use communication technology and other communication aids successfully?

11. What supports have helped [child’s name] use communication technology and other communication aids successfully?

Now I’m going to ask about advice you would give to others.

12. What advice would you give to professionals who work with beginning communicators with autism?

13. What advice would you give to other families of beginning communicators with autism?
14. That covers everything I wanted to ask about. Is there anything else you would like to add?

Thank you so much for taking the time to participate in this interview. Your experiences and perspective are so valuable in helping us better understand how we can support beginning communicators and their families. If you have any questions or would like to add anything, please feel free to contact me. I may touch base with you after looking at your interview transcript to make sure I captured your responses accurately. Do you have any questions?
## Appendix I

### Transcription Conventions

<table>
<thead>
<tr>
<th>Rule</th>
<th>Symbol (if applicable)</th>
<th>Example</th>
</tr>
</thead>
<tbody>
<tr>
<td>The interviewer’s comments are marked by I: and the participant’s comments are marked by P: (for participant)</td>
<td>I: Tell me about your child’s communication. P: My son uses speech and PECS to communicate.</td>
<td></td>
</tr>
<tr>
<td>Each time a new person starts speaking, begin on a new line</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Type all words as they are spoken by the participant (e.g., dialect or informal contractions)</td>
<td>Y’all, gonna, wanna, ‘til</td>
<td></td>
</tr>
<tr>
<td>When the participant begins a word or phrase and does not finish it, mark with a double dash</td>
<td>–</td>
<td>and to not deny him that ability to use the equipment the right way. And last year she – and this year she has the same teacher.</td>
</tr>
<tr>
<td>Indicate extended pauses using …</td>
<td>…</td>
<td>Um, she…I feel that she understands far more than she can actually express.</td>
</tr>
<tr>
<td>Utterances by the interviewer that are intended to indicate attention/affirmation are not transcribed (e.g., mhm, uh huh, yeah)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Words with special emphasis are transcribed in ALL CAPS</td>
<td></td>
<td>Everybody, EVERYBODY here, has an AAC device</td>
</tr>
<tr>
<td>Include nonverbal communication (e.g., laughter, sighs) in parentheses.</td>
<td></td>
<td>That would have made things a little easier! (laughing)</td>
</tr>
<tr>
<td>The researcher will note key gestures, manual signs, and examples of visual supports shown during the video interview</td>
<td>I can just say “that” (points) instead of signing “more” for if she wanted more of something.</td>
<td></td>
</tr>
<tr>
<td>---</td>
<td>---</td>
<td></td>
</tr>
<tr>
<td>Mark unintelligible words with (unintelligible). If unsure of a word, it is marked as unintelligible.</td>
<td>it could just turn into a complete meltdown that (unintelligible) in that frustration and anger.</td>
<td></td>
</tr>
<tr>
<td>Fillers are included (e.g., um, yeah, you know, like)</td>
<td>And, um, so they use that type of visual cueing</td>
<td></td>
</tr>
<tr>
<td>All potentially identifying information is omitted and noted in parentheses with a generic label (e.g., child, clinic name, therapist name)</td>
<td>We live in (town, state)</td>
<td></td>
</tr>
<tr>
<td>We have a different speech therapist this year so we’re just trying to figure out...(laughing, talking to child)...</td>
<td></td>
<td></td>
</tr>
<tr>
<td>When the participant quotes another person’s utterance (in any modality), those utterances are noted with quotation marks</td>
<td>&quot; &quot;</td>
<td></td>
</tr>
<tr>
<td>When the participant quotes another person’s utterance (in any modality), those utterances are noted with quotation marks</td>
<td>So (child) can say all day, “I want juice, I want juice, I want juice,” or he can take the three seconds to my counter or fridge and grab himself juice.</td>
<td></td>
</tr>
<tr>
<td>Speech directed toward the child or other individual in the room, and not related to the interview, is not transcribed.</td>
<td>We have a different speech therapist this year so we’re just trying to figure out...(laughing, talking to child)...</td>
<td></td>
</tr>
</tbody>
</table>
### Appendix J

**Cohen’s Kappa Calculations**

![Cohen's Kappa Calculation Table]

| A | B | C | D | E | F | G | H | I | J | K | L | M | N | O | P | Q | R | S | T |
| 1 | 1.5 | 2 | 2.5 | 3 | 3.5 | 4 | 4.5 | 5 | 5.5 | 6 | 6.5 | 7 | 7.5 | 8 | 8.5 | 9 | 9.5 | 10 | TOTAL |
| 2 | 1 | 2 | 3 | 2.5 | 4 | 3 | 2 | 2 | 2 | 1 | 1 | 2 | 2 | 2 | 1 | 1 | 0 | 0 | 0.0 | 107 |
| 3 | 2 | 1 | 2 | 1 | 2 | 2 | 2 | 1 | 1 | 1 | 1 | 1 | 1 | 1 | 1 | 1 | 1 | 1 | 0 | 13 |
| 4 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 0 | 20 |
| 5 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 0 | 20 |
| 6 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 0 | 20 |
| 7 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 0 | 20 |
| 8 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 0 | 20 |
| 9 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 0 | 20 |
| 10 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 0 | 20 |
| 11 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 0 | 20 |
| 12 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 0 | 20 |
| 13 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 0 | 20 |
| 14 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 0 | 20 |
| 15 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 0 | 20 |
| 16 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 0 | 20 |
| 17 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 0 | 20 |
| 18 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 0 | 20 |
| 19 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 0 | 20 |
| 20 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 0 | 20 |

**Notes:**
- *κ* = 0.75
- Cohen's Kappa Calculations
Appendix K

Codebook

Final Codebook

THEME 1: DAILY LIFE, FAMILY, AND COMMUNITY
Sub-theme 1.1: Child description and development
Sub-theme 1.2: Daily life and family dynamics
Sub-theme 1.3: Caregiver roles and responsibilities
Sub-theme 1.4: Support, acceptance, and feelings of belonging
Sub-theme 1.5: Caregivers’ feelings about their child and the future

THEME 2: CHILD-CAREGIVER COMMUNICATION
Sub-theme 2.1: Communication description
Sub-theme 2.2: Strategies to support interaction and learning
Sub-theme 2.3: Communication and learning challenges
Sub-theme 2.4: Caregivers’ feelings about communication

THEME 3: INTEGRATING AAC SYSTEMS TO SUPPORT CHILD-CAREGIVER COMMUNICATION
Sub-theme 3.1: Challenges of implementing AAC
Sub-theme 3.2: Role and effectiveness of AAC

THEME 4: “EVERY CHILD IS DIFFERENT”
Sub-theme 4.1: Impact of child health and development on communication
Sub-theme 4.2: Finding the right fit: AAC system
Sub-theme 4.3: Recognizing and adapting to individual learning style

THEME 5: EXTERNAL FACTORS IMPACTING COMMUNICATION
Sub-theme 5.1: Professional services and communication team
Sub-theme 5.2: Healthcare and education systems
**THEME 1: DAILY LIFE, FAMILY, AND COMMUNITY**

Describes parents’ experiences of life with their child at home, with family, and as part of a broader community. Includes descriptions of the child and the child’s developmental history; daily life, routines, and activities; family dynamics; parent roles and responsibilities; support, acceptance, and feelings of belonging within family and community; and parents’ feelings about their child and the future.

**Sub-theme 1.1: Child description and development**

Describes child characteristics, personality, and behavior. Describes developmental history, excluding speech and language development.

<table>
<thead>
<tr>
<th>Code</th>
<th>Definition and Exclusionary Criteria</th>
<th>Example</th>
</tr>
</thead>
<tbody>
<tr>
<td>Child description: Interests</td>
<td>Describes general interests as well as interests that are very strong and/or specific.</td>
<td>(Child) only responds to Mickey Mouse. Or Puppy Dog Pals. Only two things. Goofy, Donald Duck, could care less. If it’s Mickey or Minnie, he’s ok. He’ll respond to it.</td>
</tr>
<tr>
<td>Child description: strengths</td>
<td>Describes or lists specific skills or skills areas in which the child is talented. Does not include comments specifically related to leveraging strengths to support learning, communication, or AAC.</td>
<td>“…he’s not only good at reading, he’s very good at spelling. He has like, taken a lot of um, letters and all of a sudden we’re coming in and there’s this big word spelled out on the floor, you know.”</td>
</tr>
<tr>
<td>Child description: Behavior</td>
<td>Describes child behaviors associated with ASD. Does not include discussion of behaviors that are a direct result of communication breakdowns.</td>
<td>So we have a lot of, you know, the same very key behaviors and activities in the sense of, you know, uh, fecal smearing. Um, you know, um, screaming. Rocking. Flapping. We do a lot - we have very key characteristic behaviors that scream “I’m autistic.”</td>
</tr>
<tr>
<td>Child description: Sensory</td>
<td>Describes sensory needs or differences and their impact. Does not include comments on the relationship between sensory needs/differences and the “fit” of an AAC</td>
<td>But because he has so many other sensory needs and sensory issues, he’s not comfortable in this world. I mean like, this is not a world made for him. He’s comfortable when he’s watching like, turbines spin. You know what I mean?</td>
</tr>
<tr>
<td><strong>Child description: Temperament</strong></td>
<td>Describes general personality traits related to activity level, biological rhythms, sensitivity, intensity of reaction, adaptability, persistence, distractibility, and mood.</td>
<td><em>Um, he’s a very chill kid</em></td>
</tr>
<tr>
<td>---</td>
<td>---</td>
<td>---</td>
</tr>
</tbody>
</table>
| **Developmental history: ASD** | Describes parents’ early concerns about ASD, including:  
  - “red flags”  
  - lack of early concerns/indicators of ASD. | “…because I had somewhat concern about autism with him, because he arm flapped a lot. So that just kind of, I’d never really seen that before. So it threw me off.” |
| **Developmental history: other areas** | Describes other areas of development (excluding ASD and speech/language), including:  
  - other areas of concern  
  - lack of concern/typical milestones met | *But he was kickin - I mean, he was getting his physical milestones like, right on time.* |

**Sub-theme 1.2: Daily life and family dynamics**
This sub-theme describes the rhythms, routines, and activities of daily life. It includes descriptions of the daily schedule, therapy services that the child participates in, and the role of routine in daily life. This theme also describes family dynamics (i.e., how members of the family interact and relate to one another), excluding comments related to emotional and practical support provided by immediate and extended family (consider sub-theme 1.4 instead).

| **Daily life: Routines and activities** | Describes daily routines and schedules, including:  
  - Parent work schedules  
  - Demands of a busy schedule  
  - Role/importance of routine | *Cause my husband is a, you know, a (industry) person...his hours are very different, like he’ll start work at noon and like work ’til 10. You know, that’s just how they operate as an industry, kind of, for most things. So it’s just very different.* |
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Daily life: Services</strong></td>
<td>Includes names or descriptions of specific services the child participates in, either currently or in the past.</td>
<td>“He was in music therapy for years.”</td>
</tr>
<tr>
<td>Sub-theme 1.3: Caregiver roles and responsibilities</td>
<td></td>
<td></td>
</tr>
<tr>
<td>--------------------------------------------------</td>
<td></td>
<td></td>
</tr>
<tr>
<td>This sub-theme describes parents’ roles and responsibilities within daily life. It includes roles related to general caregiving, roles related to coordinating and overseeing their child’s therapy services, parents’ efforts to help other people understand and communicate with their child, parents’ work with regards to researching communication and AAC supports, the work that parents put in to obtain/advocate for appropriate AAC and manage device trials for their child, parents’ efforts to teach their child and create learning opportunities, and the work parents do to prepare AAC so that it is ready for their child to use (e.g., making materials, programming devices).</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Roles and responsibilities: general caregiving</th>
</tr>
</thead>
<tbody>
<tr>
<td>Describes roles and responsibilities related to caring for the child and the family.</td>
</tr>
</tbody>
</table>

<p>| “I was at one point teaching and have left that to take care of my family and my kids, and I now work through the state of (state) to take care of my son, (name), in keeping him out of homes or having caregivers from the state come in and take care of him because of the demand of how much care he needs.” |</p>
<table>
<thead>
<tr>
<th>Roles and responsibilities: Obtaining, coordinating, and overseeing services</th>
<th>Describes parent roles and efforts in the process of establishing and maintaining appropriate services, including:</th>
</tr>
</thead>
<tbody>
<tr>
<td>“And then, you know, I mean, I’ll stay up, you know, 2 or 3 in the morning trying to get stuff done while it’s quiet. Just to get what my son needs and deserves.”</td>
<td>• Arranging daily/family life to ensure child can access services (e.g., moving to a new state for better services) • Fighting for appropriate goals • Advocating for appropriate and effective instruction • Teaching professionals how to work with their child • Fighting for access to services generally</td>
</tr>
<tr>
<td>“Um, so I literally moved to (state) for services.”</td>
<td>It’s we’re doing all the training instructions and overseeing, and making sure that they’re doing what they’re supposed to be doing, um, and if they’re not then, you know, we’re...we’re stepping in and re-training or re-teaching something or telling them no, you cannot do that with him. And you can never leave them alone. ABA can never be left alone. So ABA has to be...there always has to be an adult here at all times, within ear shot. “It’s like, you think I want to drive a three year old five times a week somewhere? Cause that sounds like a good time to me.”</td>
</tr>
<tr>
<td>Roles and Responsibilities: Helping others understand the child</td>
<td>Describes parents’ work to help others understand their child, including:</td>
</tr>
<tr>
<td>“Um, because we are their voice. You know, we need to be able to help them now so they can help themselves in their own future. When we go to visit others we’re just like, you know, don’t try and touch him. Don’t....let him come to you. And then, um, something else that we’ve learned is, we made a page of like, his information and, you know, what he likes, what he”</td>
<td>• Providing information about child or child’s communication • Acting as the child’s voice</td>
</tr>
<tr>
<td>Um, because we are their voice. You know, we need to be able to help them now so they can help themselves in their own future. When we go to visit others we’re just like, you know, don’t try and touch him. Don’t....let him come to you. And then, um, something else that we’ve learned is, we made a page of like, his information and, you know, what he likes, what he</td>
<td></td>
</tr>
</tbody>
</table>
dislikes, what happens, you know if he dislikes something, like what he does. Um, and like, has our information on it in case for some reason we get separated or whatever. Um, so we have that.

| Roles and Responsibilities: Researching supports and solutions | Describes parents’ efforts to seek out information about therapies, AAC, and other supports and solutions. | When our son lost his words around his first birthday, I began searching for other means of communication by following autism Facebook groups and even a couple of well-known Facebook Video-bloggers. |
| Roles and Responsibilities: Obtaining appropriate AAC | Describes parents’ role in obtaining appropriate AAC for their child, including:  
  - Advocating for a specific AAC approach  
  - Advocating to try a new approach when current one not effective  
  - Coordinating device trials | Um, like I had to really kind of fight to move away from PECS because it just wasn’t working. |
| Roles and Responsibilities: Teaching the child | Describes parents’ efforts to create learning opportunities for their child and teach skills related to communication and AAC. | “…last summer I was like, making up a whole school for him. I was trying to do like, receptive language….like, I was like, “where’s the cookie?” And like, things that he liked” |
| Roles and Responsibilities: Preparing and maintaining AAC | Describes parents’ efforts to prepare AAC so that it is ready/available for the child to use. Examples include:  
  - Making materials (e.g., PECS symbols)  
  - Adding vocabulary to devices  
  - Remembering to pack AAC when leaving the house | “so like, I had to buy a laminator. And I make my own PECS for him now.” |

Sub-theme 1.4: Support, acceptance, and feelings of belonging
This sub-theme describes positive and negative experiences around support, acceptance, and feelings of belonging within family and community (including social media). It excludes experiences with professionals/communication team (consider sub-theme 5.2 instead).

<table>
<thead>
<tr>
<th>Support and acceptance: positive (family)</th>
<th>Describes positive experiences around support and acceptance from immediate and extended family.</th>
<th>She doesn’t live with us, but she’s here all the time. Like, she’s probably here at least 50 hours a week. Um, because she does all his Zoom with him and most of his therapies</th>
</tr>
</thead>
<tbody>
<tr>
<td>Support and acceptance: positive (community)</td>
<td>Describes positive experiences around support and acceptance from the broader community, including • Local community • Social media</td>
<td>And, like, I know the tablets, that’s fairly new. In fact I really didn’t know about tablets, um, until really I started getting involved with the online support group.</td>
</tr>
</tbody>
</table>
| Support and acceptance: negative (family) | Describes negative experiences around support and acceptance from immediate and extended family. | “They’re like oh, he’ll talk when he’s ready. I mean, I don’t know how many times I heard that and it’s so frustrating cause it’s just like no, he won’t. Like, you don’t get it.”

“...because for myself and my husband and I to turn around and go to our parents and say hey, you know, (child) did this today...they don’t know what to say. They don’t know how to be supportive. You know? Sometimes what they say actually makes things worse. Because they don’t know. They don’t know the life of a severe autism child.”

| Support and acceptance: negative (community) | Describes negative experiences around support and acceptance from the broader community, including • Local community • Social media | Um, and, you know, I think just the social aspect of it is that as he’s older, now it’s not, oh give him time. It’s like well what’s wrong with him. |

Sub-theme 1.5: Caregivers’ feelings about their child and the future
This sub-theme describes parents’ feelings of love, joy, pride, and gratitude toward their child. It also describes parents’ feelings about the future, including worries, uncertainties, and hope.

This sub-theme *excludes* parents’ feelings related specifically to (a) their child’s communication and communication challenges; (b) hopes related to their child’s future communication abilities and achievements; and (c) parents’ feelings regarding the role and effectiveness of AAC (consider sub-themes 2.3 and 3.2 instead).

<table>
<thead>
<tr>
<th>Parent feelings: joy and gratitude toward child</th>
<th>Describes parents’ positive feelings and emotions surrounding their child, including</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>• Joy</td>
</tr>
<tr>
<td></td>
<td>• Pride</td>
</tr>
<tr>
<td></td>
<td>• Gratitude</td>
</tr>
</tbody>
</table>

And um, so uh, and, we always say that he’s a challenge but he’s a joy.

He’s just um, he’s just, he’s amazing. I love that kid. And, um, just, kind of the adventure he’s put me on with him, and all of the things that I’m learning through him.

<table>
<thead>
<tr>
<th>Parent feelings: future</th>
<th>Describes parents’ feelings about the child’s future, including</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>• Worries</td>
</tr>
<tr>
<td></td>
<td>• Uncertainties</td>
</tr>
<tr>
<td></td>
<td>• Hope</td>
</tr>
</tbody>
</table>

Excludes hopes and desires related to future communication skills (consider sub-theme 2.3 instead).

because, um, you know, there are some sleepless nights to be had, worrying about what’s going to happen.

Um, but I think it’s hard because you just want your kid to be like, okay. So I think that’s, you know, that’s what’s hard I think.

You don’t know if your child’s ever going to talk. You don’t know if your child’s ever...and if they do talk, you don’t know if they’re actually going to be able to use it to communicate with you.

Um, I would just say just never give up.

**THEME 2: CHILD-CAREGIVER COMMUNICATION**
This theme describes the child’s communication, child-partner interactions, communication challenges, and parents’ feelings about the importance of communication and their child’s communication challenges.

The theme begins with descriptions of the child’s speech, language, and communication. It describes what current communication is like, including communication modalities and functions used by the child, input modalities used by communication partners, and strategies used by both children and partners to help support successful communication exchanges. It also describes communication achievements and goals that the child is currently working toward.

Next, it describes challenges related to communication and learning of communication skills (including regression/loss of skills).

Finally, it describes parent feelings about the importance of communication and about their child’s communication challenges.

**Sub-theme 2.1: Communication description**

This sub-theme describes communication modalities and functions used by the child, and input modalities used by communication partners. It also describes communication achievements and goals that the child is currently working toward.

<table>
<thead>
<tr>
<th>Communication modalities: Expressive</th>
<th>Includes descriptions of modalities used for expression, or examples of how they are used, including:</th>
<th>He uses a pacifier and he started calling it a “gaga” around 18 months</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>• Behavioral communication • Natural speech • Unaided AAC • Aided AAC</td>
<td>Um, so we are right now working with PECS um, we’re just starting PECS.</td>
</tr>
<tr>
<td></td>
<td>Excludes comments related to the effectiveness of AAC supports for expression.</td>
<td>So if he wants something he goes his hand straight to his mouth. And that we know is please.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Communication modalities: Receptive</th>
<th>Describes communication modalities used when providing input for the child, such as:</th>
<th>So the teacher will go, “okay, so we’re doing circle time today,” and there’s a picture of a circle. And then explaining exactly what’s going to happen during circle time. And then as she finishes then she puts the “all done” um, symbol – not symbol but the picture – over that</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>• Use of gestures • Aided AAC modeling • Use of multiple input modalities at the same time</td>
<td></td>
</tr>
</tbody>
</table>
| Communication functions | Describes functions of the child’s communication, including:  
  • Affection and social connection | Although he’ll, you know, take the stuffed animals and come up to you and go, “Oh, I love you,” and he looks at - you know, hugs you with his stuffed animals and...I mean, he shows that he loves us by coming up and giving us a hug and just say, “I love you!” And he does do that. |
| Achievements, progress, and success stories | Includes communication success stories and descriptions of progress the child has made, including descriptions of specific skills (e.g., skills demonstrated now that were previously | So, I mean, he has made leaps and bounds with, um, his language.  
And he’s definitely doing more unprompted either comments or questions, that’s been going on now for a couple years. |
| | | partcular activity so that the kids can see okay, we did – we did hello, we did our name, we did this, we did that, you know, and so they can follow along.  
Um, but like, they had pictures of things, like a picture – like attached to the desk to let you know that that’s a desk, and, you know, this is a chair. There was a picture attached to one of the chairs. Or, like this is the game center and so games are over here, or the books are over here.  
Or if we tell him something and we’re sitting here and he says, you know, we tell him oh good job. We’ll sign good job. As we tell him good job. We will sign it.  
Excluded:  
Um, she loves the visual schedule. That’s been helpful. Um, because then she knows what to expect. |
| Describes supports for organization/emotional regulation such as:  
• visual schedules  
• first-then displays  
• reward charts and token systems | Excludes comments related to the effectiveness of AAC supports for comprehension or organization/regulation. |
difficult) as well as general statements about having made progress. and, um, over time the joint attention has increased.

<table>
<thead>
<tr>
<th>Communication goals: Current</th>
<th>Describes communication goals that the child is currently working toward, such as:</th>
<th>They’re working on adverbs now. we wrote his IEP goals in May to like identify shapes and colors,</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>• Vocabulary goals</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Syntax goals</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Communicative functions (e.g., requesting)</td>
<td></td>
</tr>
</tbody>
</table>

**Sub-theme 2.2: Strategies to support interaction and learning**

This sub-theme describes strategies used by both children and partners to help support successful communication exchanges. It also describes teaching/instructional strategies that parents have found to be either successful or unsuccessful for their child.

<table>
<thead>
<tr>
<th>Interaction strategies: child</th>
<th>Describes innovative and sometimes unconventional strategies used by children to support communication success, including:</th>
<th>Um, but (name) does have an abbreviated sign and it’s because he’s abbreviated it as his own way of saying “please,” and he goes like this (demonstrates). but he’ll take scripting that he hears elsewhere and he uses it in (unintelligible). Sometimes it’s just random but there are time where he’ll, you know, answer you or something, or ask you something appropriately based on something you’ve seen.</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>• Meeting needs independently/without communicating</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Use of modified signs</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Scripting</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Interaction strategies: partners</th>
<th>Includes ways in which communication partners modify the environment or interaction to support communication success (e.g., by asking yes/no rather than open-ended questions)</th>
<th>Um, and we would try to like, we try to keep the uh, snacks that he liked at a level where he could reach them. Like our whole house for probably five years was like nothing but singsong. Because he responded better to it. Um. Even the commands. Like, you wanna take a bath. It’s not you wanna to take a bath, we’re probably like sing-</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Sub-theme 2.3: Communication and learning challenges</strong></td>
<td></td>
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<tr>
<td>--------------------------------------------------------</td>
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</tr>
<tr>
<td>This sub-theme describes and discusses the challenges that parents observe in their child’s communication and communicative interactions.</td>
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</tbody>
</table>

It begins by describing parents’ early concerns regarding their child’s speech and language development. It then describes the child’s current difficulties related to comprehension, expression, and social pragmatics. It then describes challenges related to child-partner interactions (e.g., communication with the child is a “guessing game”).

Next, it describes challenges related to learning (e.g., progress can be slow, there may be regression/loss of skills).

Finally, it describes the impact of communication difficulties and breakdowns on the child and their behavior.

<table>
<thead>
<tr>
<th><strong>Early concerns with speech and language development</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Describes early concerns or “red flags” that worried parents or led them to seek support.</td>
</tr>
<tr>
<td>Also includes statements about lack of early concern.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Communication challenges: Comprehension</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Describes language comprehension as a general area of difficulty as well as</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Effective instructional approaches</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Describes specific instructional approaches that parents perceive to be supportive of communication, learning, and use of AAC, such as “starting small.”</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Ineffective instructional approaches</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Describes specific instructional approaches that parents do not perceive to be supportive of communication, learning, and use of AAC.</td>
</tr>
</tbody>
</table>

| **And I think if we’re as patient with ourselves and with our kids and it’s like hey, we don’t have to tackle everything today, we just need one word. Just one. To make life easier.** |

| **So, all the correction is directed by the person guiding into it. So like, how you teach it is, you’re really doing it for them. And I don’t know how to make that better.** |

| **“And after that first birthday, um, even his first birthday I had concerns about his speech. Um, more out of a place of being hyper-aware as a special ed person.”** |

| **So, um, I think the receptive is harder right now than the expressive, for him to understand.** |
| Communication challenges: Expression | Specific examples of comprehension difficulties. | So at a very young age, you use like three words. Go to bed. You know? When kids are older you negotiate those things. You’re gonna go to bed, and you’re gonna wake up, and this is what you’re gonna do tomorrow. Um. We don’t even say “go to bed” to (child), because that is not something that is going to process. |
| Communication challenges: Social pragmatics | Includes statements about expression as a general area of difficulty as well as descriptions of challenges with specific skills such as:  
- Expressing wants and needs  
- Answering questions  
- Spontaneous expression | But, um, but yeah, I definitely feel she probably understands more than she’s able to say.  
Um, and so that is most of (child)’s communication, is rote memorization. Very little spontaneous. It has no meaning, it serves no purpose, so there’s no wants, needs, requests, anything like that. There’s no yes, no, |
| Communication challenges: communication is a “guessing game” | Describes the challenge of trying to figure out what the child is communicating and the communication breakdowns that occur during interactions with the child. | Yeah. I mean, he still needs an awful lot with social pragmatics.  
However, um, it’s still very difficult with peers. You know. And that communication.  
..and then we kind of go through the laundry list of ok, what do you want? Do you want this, do you want that, you know, trying to guess and figure out what she wants. |
| Communication challenges: Loss of skills | Describes skills that the child demonstrated for a period of time and then stopped demonstrating or is currently working to regain. | But then she’ll just keep repeating it, hoping that we kind of get it, but we may not get it. Because we have no idea what he wants. 99.5% of the time, whether he could have access to it or not. |
| Communication challenges: Slow learning/progress | Describes how the process of learning new communication skills can often be difficult, with slow progress. Excludes comments related specifically to learning how to use an AAC system. | So, there was definitely lost skills but it wasn’t, where some of these kids will have all these words and then they don’t have any anymore or they kind of fade away over time...he had like...one word. And, you know, it went away. So. and when he was little he would babble more, like the dada, mama, things like that. And then that kind of stopped. Or it wasn’t as much. Or - if we tried to get him to do it, he couldn’t....he couldn’t imitate it. And he used to say all done at the end of therapy, and now he doesn’t say it. |
| Impact of challenges: Child reactions and behaviors | Describes child frustration and behaviors resulting from communication difficulties and breakdowns. | And it’s gonna take repeating the same thing over and over and over before they get it. It’s not something where you can do it a few times and they’re gonna just pick up on it. And the thing I’m having to realize is, he may...not everything is going to be a piece of cake. |
| Lack of communication leads to behaviors and behaviors are then a form of communication for my lil man who has no other way of expressing what he means. |
Sub-theme 2.4: Caregivers’ feelings about communication
This sub-theme describes parents’ feelings about communication. It describes communication as a priority and discusses reasons why parents feel communication is a critical skill. It also discusses parents’ feelings and emotions about their child’s communication challenges, and hopes for their child’s future communication.

| Communication feelings: importance of communication | Describes communication as a priority. | I feel that it’s just a basic human right to be able to communicate. |
| Communication feelings: roles of communication | Describes specific reasons why parents believe communication is important for their child, including:  
- Addressing/avoiding frustration and challenging behaviors  
- Health and safety  
- Expressing basic needs and comfort  
- Social connection  
- Expressing emotions | ...because just sitting here watching your son hurt himself, you know, like, nobody should have to go through that just because you don’t have a form of communication with your child.  
Like If I could differentiate when he was hungry vs. when he was tired or sleepy or something, that is a basic human need that I could then fulfill |
| Communication feelings: child communication difficulties | Describes parents’ feelings and emotions about their child’s communication challenges, including  
- desire to help  
- difficulty of watching the child struggle  
- emotional responses to communication breakdowns | And, as a parent that’s all that you want, you just want to be able to communicate with your child  
And I think it’s ok to grieve the thought of maybe my kid will never verbally speak. |
| Communication feelings: hopes for the future | Describes communication goals parents would like to see their child to achieve. | Like, you know, I want you to be able to like, be social.  
But I want my kid to call me mom |
### THEME 3: INTEGRATING AAC SYSTEMS TO SUPPORT CHILD-CAREGIVER COMMUNICATION

This theme describes what it’s like to implement AAC within child-partner interactions. It includes descriptions of ways in which AAC implementation is challenging, as well as parent and child attitudes about the role and effectiveness of AAC.

### Sub-theme 3.1: Challenges of implementing AAC

This sub-theme describes the challenges associated with implementing AAC to support communicative exchanges. It includes demands related to care and maintenance of technology, AAC systems that are inconvenient or impractical to implement, and the often demanding and slow process of learning how to use an AAC system (for both parents and children).

<table>
<thead>
<tr>
<th>AAC implementation challenge: care and maintenance of technology</th>
<th>Describes challenges related to the care and maintenance of technology, including:</th>
<th>Right. (Unintelligible) battery charged, have always just have like three batteries, and then one comes off, pop one on. Um. That – I just thought of that right now, like what else annoys me about it. Um, the only thing that worries me about that is like, you know like I said usually, you know, you need to have a backup because you never know when they’re gonna get upset and throw it, and, you know, that’s their communication.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Devices need to be charged</td>
<td></td>
<td></td>
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<tr>
<td>Technology breaks/is often fragile</td>
<td></td>
<td></td>
</tr>
<tr>
<td>PECS and other low tech AAC can be destroyed</td>
<td></td>
<td></td>
</tr>
<tr>
<td>AAC implementation challenge: AAC is inconvenient/impractical</td>
<td>Describes ways in which AAC systems can be inconvenient and impractical, including:</td>
<td>Um. But you – and then, you know, doing sign language, it’s not practical. For the future. Unless you’re in a deaf community where people can understand.</td>
</tr>
<tr>
<td>Aided AAC is not always readily available</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Aided AAC can be a pain to cart around/a lot to juggle</td>
<td></td>
<td></td>
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<tr>
<td>Aided AAC symbols/vocabulary items are not always available in the moment they are needed</td>
<td></td>
<td></td>
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<tr>
<td>AAC requires a lot of planning and preparation</td>
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</tbody>
</table>

So like, I mean, we’ve run out of room in his book, like, I had to ask his ABA for more inserts for his PECS book for us to be able to put more pictures on there because I’m like, we don’t have enough room! I can’t put a picture of Sun Chips and Cheetos and, you know, Cheez-Its, and you know, all this stuff.
AAC implementation challenge: Learning to use/implement AAC is a process

<table>
<thead>
<tr>
<th>Describes learning to use/implement an AAC system as a process.</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Learning AAC takes time</td>
</tr>
<tr>
<td>• Can be slow, demanding, and/or frustrating.</td>
</tr>
</tbody>
</table>

I wish – I’m glad that there’s access to so many different types of devices, but at the same time...it’s going to take a lot of work and a lot of proficiency to get good at them. Right? And they’re all different. So.

**Sub-theme 3.2: Role and effectiveness of AAC**

This sub-theme describes positive, neutral, and negative attitudes regarding the need for and effectiveness of AAC. It includes parent attitudes and also comments regarding the child’s interest in or attitude toward AAC.

Parent AAC attitudes: positive

<table>
<thead>
<tr>
<th>Describes parents’ positive feelings about the effectiveness of AAC, including:</th>
</tr>
</thead>
<tbody>
<tr>
<td>• AAC is beneficial</td>
</tr>
<tr>
<td>• AAC holds potential</td>
</tr>
<tr>
<td>• Acceptance of AAC/non-speech forms of communication</td>
</tr>
<tr>
<td>• Grateful for AAC</td>
</tr>
</tbody>
</table>

Describes ways in which AAC has helped the child including:

Expression

| • AAC helps child communicate – general |
| • AAC helps child communicate with less familiar partners |
| • AAC Supports use of speech |
| • AAC Supports expression of wants and needs |
| • AAC supports connection/information sharing |
| • AAC gives the child “a voice” |

Yeah. And so then...I don’t think we’ve even scratched the surface of what he will be able to do on an AAC and almost all words he knows he first learned via sign language. And even if it was like he wanted to watch a show. You know like instead of us putting on Mickey Mouse but he really wanted to watch Toy Story, like he had that power to not just sit there and be like “ok well I guess I’ll watch it,” you know like, he had the power.
### Comprehension
- AAC Supports comprehension - general
- AAC Helps with understanding expectations
- AAC helps with understanding appropriate behaviors (e.g., via social stories)

Decreasing frustration and behaviors

### Parent AAC attitudes: neutral or negative
Describes parents’ neutral or negative feelings about the effectiveness of AAC, including:
- AAC is not necessary
- Unsure about the benefits

*Personally I don’t know if that’s necessary or if it’s really viable at this point, because I feel that she is using words more than she was before, you know, before this.*

### Child AAC attitudes
Describes child’s reactions to/attitudes toward AAC including:
- Lack of interest in AAC or lack of desire to use AAC
- Frustration with AAC
- Liking or appreciating AAC

*Um, she loves the visual schedule.*
*He doesn’t want to use it.*

### THEME 4: “EVERY CHILD IS DIFFERENT”
This theme addresses the uniqueness of each child and the need for communication/AAC supports and services to be personalized based on that child’s skills, interests, and needs. This theme addresses ways in which individual child health and development impact communication and learning, the process of identifying an AAC system and set of features that are the right fit for the child, and the need to adapt instruction for each individual.

#### Sub-theme 4.1: Impact of child health and development on communication
This sub-theme describes factors related to each individual child’s health and development that impact that child’s communication, learning, and use of AAC. This includes factors related to age, overall health, cognitive development, motor development, social-emotional development, and general readiness to learn.

#### Child health and development
Describes factors related to the child’s health or current stage of development.

*I don’t know if it was just was like, he was almost 2.5 and now he had...*
development that impact communication, learning, and/or use of AAC, either positively or negatively, including:

- Cognitive development
- Motor development
- Conceptual knowledge
- Health
- Age (e.g., some “challenges” are typical for the child’s age and don’t need to be remediated)
- Social-emotional development
- General readiness to learn

even skills and he has kind of closed some of the gaps in the other areas where he was able to start learning and things like that more...um...

Um, so yeah, I mean, and we – we did a little bit of sign but his gross motor at that time was a hot mess too.

<table>
<thead>
<tr>
<th>Sub-theme 4.2: Finding the right fit: AAC system</th>
</tr>
</thead>
<tbody>
<tr>
<td>This sub-theme describes how specific AAC system features (e.g., symbols, iPad resemblance) contribute to the fit of the system for the child.</td>
</tr>
<tr>
<td>It also describes how finding the right AAC system is a process that involves trial and error, requires flexibility, and often continues over time.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Finding the right fit: AAC system features</th>
<th>Describes how features of AAC systems contribute to the “fit” and usefulness of the system for that child. Examples of AAC system features include:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>• AAC symbols</td>
</tr>
<tr>
<td></td>
<td>• Peripherals (e.g., case, handle)</td>
</tr>
<tr>
<td></td>
<td>• iPad resemblance</td>
</tr>
</tbody>
</table>

| They had a picture and it had a big object and a small object on it, and it had an arrow pointing to one or the other. And he’s supposed to be able to realize that oh, that means that this, you know...he doesn’t get that. |

Some of them, they know that we’ve had to change and put, um, directly towards the actual pictures. Like real pictures. Not cartoon pictures. (child) doesn’t do well with those. Um, he does well with real pictures.
| Finding the right fit: it’s a process | Describes the process of finding an AAC system that would work for the child, and customizing that system, as a process that unfolds over time. Includes:  
- process of trial and error  
- need for flexibility  
- need for AAC system to change over time as the needs and skills of the child change.  
Describes AAC systems/strategies that were not a good fit. | And it’s got a little case to it with a handle that goes up and down, and a strap.  
Um. But, you know, they said oh, well, you know, some kids like it and some kids will, you know, take to it. It wasn’t the thing for her.  
(talking to child)  
Um, so you can have NovaChat 52,000 different ways, but we actually like this particular NovaChat.  
And it’s changing, and it needs updating,  
They have talked about possibly eventually moving up from that to a digital device, you know a tablet device for him.  
Um, because we were trying to use the signs they were showing us, and she just – you know, it wasn’t a complete blank stare but it was kind of like uhhhhh...I don’t...you know, just really puzzled, like “what are you doing? Like, just point instead.” You know. |
|---|---|---|
| Sub-theme 4.3: Recognizing and adapting to individual learning style | This sub-theme includes parents’ comments about recognizing their child’s unique learning style, and adapting accordingly. | Recognizing and adapting to individual learning style  
Describes parents’ observations about their child’s learning style and the process of adapting accordingly. Examples include:  
- providing time and space to learn at own pace  
Because I feel like some kiddos are automatic and they just kind of can do it. Um, but with her she’s just kinda, takes her sweet time and then she kinda figures it out. Figures out a way of communicating. |
• capitalizing on interests and strengths

Every - you know, I’ve come to realize, like, every child is different, so, you know, what takes one child a month to catch could take another child another, you know.

So everyone has different strengths and different weaknesses...and not that you should ignore the weaknesses, but, when he was a good reader we said ok, well let’s capitalize on that, you know, as an example.

THEME 5: EXTERNAL FACTORS IMPACTING COMMUNICATION

This theme describes factors that are external to the child/communication partner dyad that impact communication, learning, and use of AAC.

First, it includes factors related to professional services and the communication team, such as the role of therapy services, the “fit” of the provider, and the dynamics of the communication team as a whole (child, parent, educators, and other providers; may also include other key communication partners such as extended family).

Then, it discusses factors related to education and healthcare systems more broadly, such as access to services and AAC technology.

Sub-theme 5.1: Professional services and communication team

This sub-theme describes how factors related to the communication team (child, parents, and education/healthcare professionals) can impact communication, learning, and implementation of AAC.

Specifically, it discusses the role and effectiveness of therapy services in general, fit of providers, coordination and communication among team members, inclusion of parents as integral members of the team, and experiences surrounding the need for - and provision of - support and guidance for parents.

Professional support: therapy and other professional services

Describes therapy as a support for communication, learning, and AAC implementation, including:

• Ways in which therapy supports child learning/communication

But, um, you know I think it’s been helpful that we’ve been able to do outside speech to kind of supplement that.
<table>
<thead>
<tr>
<th><strong>Communication team:</strong></th>
<th><strong>Fit of provider</strong></th>
<th><strong>Coordination and consistency</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Ways in which therapy supports caregiver knowledge and skills</td>
<td>Describes the importance of working with a provider whose knowledge, skills, and personality are a good fit for the child and the family.</td>
<td>Describes how consistency can aid communication and learning:</td>
</tr>
<tr>
<td>Ways in which therapy empowers parents</td>
<td></td>
<td>• Consistency in how goals and supports are implemented across environments and communication partners</td>
</tr>
<tr>
<td>Describes other services/resources that are available and that have been generally supportive/helpful resources.</td>
<td></td>
<td>• The need for AAC to be implemented across multiple environments/in an immersive manner</td>
</tr>
<tr>
<td></td>
<td></td>
<td>So. We speak to a lot of people, you know, who are all on the same page when it comes to (child) and what...what devices we’re using, what, you know, whether it’s...you know...(unintelligible) or if it’s, you know, we’re using PECS books. You know. Everybody’s on board, everybody asks “how’s it working?” You know.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>So I would encourage people to like – yeah, it’s gotta become part of your everyday.</td>
</tr>
<tr>
<td>Communication team: Integration of parents’ input</td>
<td>Describes the need and desire for parents to be included as a valued part of the communication team, and the benefits of including them.</td>
<td>Um. Listen to parents. Take what they’re giving you, what they’re telling you about their children. Take it into mind,</td>
</tr>
</tbody>
</table>
| Communication team: support and guidance for parents | Describes experiences surrounding the need for and provision of support and guidance for parents, including:  
- The need for more information about AAC and AAC options  
- The need for more support to understand how to implement AAC with the child  
- Feelings of being unprepared to support AAC use, or not feeling empowered to use AAC with their child  
- Parents needing to ask for the help they need | And then it needs – so you go from basic, there needs to be basic, intermediate, and advanced using. That all comes with a lesson! That you’re not learning on your own. Yeah. Like I don’t need to learn this on my own. It’s too hard.  
and I don’t know sometimes. Like. I don’t know what I’m doing. |

**Sub-theme 5.2: Healthcare and education systems**
This sub-theme describes factors related to the healthcare and education systems that impact communication, learning, and/or implementation of AAC. It includes difficulty getting an ASD diagnosis, difficulties with access to communication technology, and difficulties accessing appropriate services.

| System barrier: Difficult or lengthy diagnostic process | Describes difficulties related to the process of receiving:  
- An ASD diagnosis  
- A speech and language diagnosis  
Specifically, describes difficulties related to  
- Long wait times  
- Unwillingness to diagnose until child has reached a certain age | because we had a hard time with no one wanting to evaluate him because he was under the age of three.  
Um, she said you’ve done everything we would have asked you to do. the only thing that I ask now is you wait until you’ve had six months of therapy before we evaluate him to make sure it’s not |
<table>
<thead>
<tr>
<th>System barrier: availability/accessibility of communication technology</th>
<th>Unwillingness to diagnose until other criteria have been met (prerequisites)</th>
<th>just a delayment, before we diagnose it as a disability.</th>
</tr>
</thead>
<tbody>
<tr>
<td>System barrier: Availability/accessibility of services</td>
<td>Describes barriers related to availability and accessibility of communication technology, including:</td>
<td>But it’s so hard to think, you know you say that but then you have to sit there and think oh my gosh. That stuff is not cheap. It costs a lot of money to have that. And, you know, it’s sad because there’s a lot of insurances that won’t cover it.</td>
</tr>
<tr>
<td>System barrier: Availability/accessibility of services</td>
<td>Describes difficulties surrounding access and availability of therapy services, such as:</td>
<td>But, you know, we have to go through these hoops to make sure that she could access speech. You know? Whereas it should just be given.</td>
</tr>
<tr>
<td>System barrier: Availability/accessibility of services</td>
<td>Describes difficulties surrounding access and availability of therapy services, such as:</td>
<td>But, um, but I feel like it’s so much more than that. I feel like it’s so much more than just being able to access the curriculum. And there are so many things that are, you know, intertwined with that. Um, so I kind of wish that the schools would do more in that regard. And so now that we’ve gotten her tested and have an actual diagnosis, now they’re like oh yeah well NOW you can access this. Whereas before it’s like, oh well she might be autistic, she might need this support. Um.</td>
</tr>
</tbody>
</table>

**NOT CODED**
The following types of thought units did not receive codes and were not included in the summary of results: Detailed descriptions of child’s birth or other medical procedures; statements listing specific medical or developmental diagnoses; false starts that were abandoned and could not be coded as complete thoughts (e.g., “Yeah, no, there’s a little –”); tangential discussions with other people passing through the room (including the child); informal discussion between participant and researcher; comments specific to conditions.
under Covid; comments unique to one participant and unrelated to the study questions (e.g., “but he has an appetite that, you know, he could eat all day!”); Medical details unrelated to communication or AAC (e.g., “He had torticollis as a baby”).
### Appendix L

**Summary of Topics for Member Check**

<table>
<thead>
<tr>
<th>Daily life, family, and community</th>
<th>Child-partner communication</th>
<th>Integrating AAC to support child-partner communication</th>
<th>&quot;Every child is different&quot;</th>
<th>External factors impacting communication</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Daily life and family dynamics</strong></td>
<td><strong>Communication description and modalities</strong></td>
<td><strong>Challenges of implementing AAC</strong></td>
<td><strong>Impact of child health and development on communication</strong></td>
<td><strong>Professional services and communication team</strong></td>
</tr>
<tr>
<td>General understanding, daily routines, and family interactions</td>
<td>Expressive modality: negative modalities; communicative functions: achievements, progress, and success stories; current goals</td>
<td>Care and maintenance of technology, AAC is inconvenient/impractical, learning to use/implement AAC is a process</td>
<td>Child health and development factors (e.g., cognitive, motor, conceptual knowledge, health, age, social-emotional development, readiness to learn)</td>
<td>Professional support from therapy and other resources, fit of provider, coordination and consistency among members of the team, &quot;Listen to parents,&quot; support and guidance for parents</td>
</tr>
<tr>
<td>Parent roles and responsibilities</td>
<td><strong>Strategies to support interaction and learning</strong></td>
<td><strong>Role and effectiveness of AAC</strong></td>
<td><strong>Finding the right fit: AAC system</strong></td>
<td><strong>Healthcare and education systems</strong></td>
</tr>
<tr>
<td>General caregiving, obtaining information, coordinating services, helping others understand my child</td>
<td>Child interaction strategies, partner interaction strategies, effective instructional approaches, ineffective motivational approaches</td>
<td>Parent positive attitudes toward AAC, neutral/negative attitudes toward AAC, child attitudes toward AAC</td>
<td>AAC system features (e.g., symbols, iPad accessibility), finding the right fit is a process</td>
<td>Difficult or lengthy diagnostic process, availability/accessibility of AAC technology, availability/accessibility of services</td>
</tr>
<tr>
<td>Support, acceptance, and feelings of belonging</td>
<td><strong>Communication and learning challenges</strong></td>
<td><strong>Recognizing and adapting to individual learning style</strong></td>
<td><strong>Reconsidering and adapting to individual learning style</strong></td>
<td><strong>Reconsidering and adapting to individual learning style</strong></td>
</tr>
<tr>
<td>Positive experiences with family; positive experiences in the community; negative experiences with family; negative experiences in the community</td>
<td>Early concerns with speech/language development, comprehension, expression, social pragmatics; communication is a &quot;guessing game.&quot; Less of skills, learning/progress can be slow, impact of challenges on child (cues, emotions)</td>
<td>Recognizing and adapting to individual learning style</td>
<td>Collaborating with therapists, finding the right fit is a process</td>
<td><strong>Healthcare and education systems</strong></td>
</tr>
<tr>
<td>Feelings about child and future</td>
<td><strong>Parents’ feelings about communication</strong></td>
<td><strong>Feeling the right fit</strong></td>
<td><strong>Finding a way</strong></td>
<td>Difficult or lengthy diagnostic process, availability/accessibility of AAC technology, availability/accessibility of services</td>
</tr>
<tr>
<td>Joy and gratitude toward my child, feelings about the future</td>
<td>Communication is a priority, reasons why communication is important; feelings about child communication difficulties, hopes for the future</td>
<td>Feeling the right fit</td>
<td>Finding a way</td>
<td><strong>Healthcare and education systems</strong></td>
</tr>
</tbody>
</table>
VITA

Emily Laubscher

Education

2022  Doctor of Philosophy in Communication Sciences and Disorders (expected)
      Pennsylvania State University, University Park, PA
2009  Master of Science in Speech-Language Pathology
      MGH Institute of Health Professions, Charlestown, MA
2004  Bachelor of Science in Psychology
      Colby College, Waterville, ME

Awards

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Health and Human Development Endowed Graduate Fellowship (2019), Penn State University
Robert Graham Endowed Graduate Fellowship (2017), Penn State University

Selected Publications


Selected Presentations


Laubscher, E., & Light, J. (2019, Nov.). *Effecting system change to improve outcomes for individuals who require AAC*. Poster presented at the ASHA annual convention, Orlando, FL.