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PERSPECTIVES OF PARENTS OF CHILDREN WITH CEREBRAL PALSY ON
THE SUPPORTS, CHALLENGES, AND REALITIES OF INTEGRATING AAC INTO
EVERYDAY LIFE

A Dissertation in

Communication Sciences and Disorders

by

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ABSTRACT

In order to ensure long-term adoption and use of augmentative and alternative communication (AAC) technologies, they must be designed to support children to participate within everyday activities and routines that are prioritized by families. Nine parents of children with cerebral palsy who used AAC technologies participated in semi-structured interviews to provide their perspectives of how AAC technologies were integrated into the functional contexts of everyday life. Five major themes emerged from the discussions: (a) integrating AAC into life, (b) AAC technologies, (c) child needs and skills, (d) parent responsibilities and priorities, and (e) AAC process and decision-making. Children were able to use AAC technologies within a variety of everyday contexts with various partners; however, challenges included access to AAC within physical and outdoor activities and partners who lacked knowledge regarding operational competencies and effective interaction strategies. In order to integrate AAC technologies into life, parents prioritized technology features including ease of programming, improved physical design (e.g., lighter, wearable, easy to mount, durable), features to enhance efficiency and ease of access (e.g., brain-computer interface, sentence prediction), and availability of multiple functions and features (e.g., facial recognition software, augmented reality, projection capabilities, capability to control wheelchair). AAC manufacturers and mainstream technology developers should work to ensure that technologies are responsive to the supports, limitations, and ideal features identified by parents. Future research should seek input from a larger group of stakeholders and use longitudinal methods to examine perceptions of AAC technologies over time.

Keywords: technology design, augmentative and alternative communication, parents, cerebral palsy, service delivery
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Jeremiah 29:11
Chapter 1

Introduction and Review of the Literature

Almost 8% of children between the ages of three to 17 in the United States experience communication disorders (Black, Vahratian, & Hoffman, 2012). For children with the most significant communication disorders, speech cannot meet all of their communication needs. In these cases, children often benefit from aided augmentative and alternative communication (AAC) technologies such as speech generating devices or mobile technologies with communication applications (“apps”). AAC is an evidence-based intervention to improve communication and enhance meaningful participation for children that experience complex communication needs (Beukelman & Mirenda, 2013).

In order to experience these positive effects, children must be provided with AAC technologies that match their needs and accommodate their skills (Blackstone, Williams, & Wilkins, 2007). Johnson, Inglebret, Jones and Ray (2006) surveyed speech-language pathologists about the factors they perceived to be related to long-term success of AAC systems. “System characteristics and fit” was identified as a primary factor contributing to the long-term success of AAC systems. Portability, ease of access, variety of communicative functions, ease of programming, and fit with the users’ physical and cognitive needs were perceived to contribute to long-term success (Johnson et al., 2006). Wilkinson, Light and Drager (2012) and Wilkinson and McIlvane (2013) expanded on the concept of “system fit” and suggested that the fit between the visual-perceptual characteristics of the AAC display and the visual processing abilities of the user would be another factor contributing to success. Empirical evidence with young children and individuals with developmental disabilities demonstrates convincingly that changes in the visual-
perceptual features of AAC technologies produce reliable changes in how users visually process AAC displays (e.g., O’Neill, Wilkinson, & Light, in preparation; Wilkinson, O’Neill & McIlvane, 2014). Therefore, evidence exists that the design of AAC technologies can be changed in order to achieve a better fit between the technology and the underlying processing skills of the user.

Children do not exist in isolation; rather, they exist as part of a family system (Minuchin, 1985). Technologies should not only be designed to fit with the underlying processing skills of the child, but also to fit with family values, goals, priorities, and lifestyle (Granlund, Akesson, Wilder, & Ylven, 2008). Family members must be able to support their child in using AAC technologies (Anderson, Balandin & Stancliffe, 2014), and technologies must support children in working towards family-identified goals (Calculator, 2014). A mismatch between the technology and the priorities, preferences, and lifestyle of the family will likely result in abandonment (Jones, Angelo & Kokoska, 1998; Johnson et al., 2006; Parette, Brotherson & Huer, 2000). Alternately, considering family needs, priorities, and values will result in greater system adoption and long-term use (Granlund et al., 2008). In fact, Johnson et al. (2006) found that the degree to which the technology was valued by partners as a means of communication was one of the leading factors contributing to long term success.

While speech language-pathologists have provided their perceptions of the AAC system features that contributed to success (Johnson et al., 2006), and empirical research has begun to map out the actual system features that influence performance of users (e.g., O’Neill et al., in preparation, Wilkinson et al., 2014), little research to date has investigated the perceptions of family members regarding the AAC technology features that contribute to long term success with AAC. Evaluating the perceptions of family members regarding the features that enhance or inhibit their children’s use of AAC technologies within the functional contexts of everyday life represents a critical area for research. The introduction will (a) summarize previous research regarding optimal AAC system design to match individual children’s needs; (b) present a
Designing AAC Technologies to Match with the Needs of Individual Children

Various factors may be important to consider in matching the design of AAC technologies with the needs and skills of the children who use them. Some important factors include the representation of language concepts, the organization and layout, selection technique, and system appeal (Light & McNaughton, 2012). Table 1-1 provides a description of various system design features under consideration when designing an AAC system.

A growing body of research evidence has evaluated AAC system design features and how they affect the performance of users. While a full review of this body of evidence is beyond the scope of this manuscript (see Light & McNaughton, 2012, for a full review), it is valuable to consider at least some of the primary findings. Therefore, this section reviews research related to several key features that offer evidence for the importance of matching AAC technologies to the skills and needs of the children who use them.

Table 1-1. Components of system design, definitions, and specific design features

<table>
<thead>
<tr>
<th>Component</th>
<th>Definition</th>
<th>Specific design features</th>
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<tr>
<td>Representation</td>
<td>Depiction of concepts</td>
<td>• type of representation (e.g., line drawing, written word, or photograph)</td>
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<td></td>
<td></td>
<td>• personalization of representation</td>
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<tr>
<td></td>
<td></td>
<td>• use of animation</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• use of color (e.g., symbol internal color, background color)</td>
</tr>
<tr>
<td>Layout and organization</td>
<td>Design layout and grouping of symbols</td>
<td>• grid-based versus visual scene display</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• method for sub-grouping symbols</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• number of symbols</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• size of symbols</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• spatial arrangement of symbols</td>
</tr>
<tr>
<td>Selection technique</td>
<td>Method of choosing or activating messages</td>
<td></td>
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<tr>
<td>---------------------</td>
<td>------------------------------------------</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• direct selection</td>
<td></td>
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<tr>
<td></td>
<td>• scanning</td>
<td></td>
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<td></td>
<td>• eye gaze</td>
<td></td>
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<tr>
<td></td>
<td>• brain-computer interface</td>
<td></td>
</tr>
<tr>
<td>System appeal</td>
<td>Features to enhance the appeal of AAC systems</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• integration of play and communication</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• various output options (e.g., sound effects)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• aesthetic appeal (e.g., lights, bright colors)</td>
<td></td>
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<td></td>
<td>• personalization (e.g., personal themes)</td>
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*Note.* Adapted from Light & McNaughton (2012), Light & Drager (2007)

**Representation**

For children who are not yet literate, vocabulary is most often represented using two-dimensional symbols. These symbols can range from more iconic representations that closely resemble the referent (e.g., photographs) to less iconic representations that less closely resemble the referent (e.g., commercially available symbol sets such as Picture Communication symbols¹, DynaSyms², Symbolstix³, etc.). The iconicity of vocabulary representations has been extensively studied, and the research indicates that children more easily recognize, learn, and recall representations that are more iconic compared to those that are less iconic (e.g., Mirenda & Locke, 1989; Schlosser & Sigafoos, 2002).

However, young children’s representations of language concepts differ substantively from traditional AAC symbol sets (Light et al., 2008), and current commercially available symbols sets include abstract representations that are hard for young children to learn and use (Light & McNaughton, 2012). In an effort to improve the design of AAC representations (i.e., symbols), Worah, Light, McNaughton, and Benedek-Wood (2015) designed a symbol set that was more congruent with children’s understanding of the concepts. The developmentally appropriate symbols contained whole people, objects, and activities that were embedded in meaningful activities and used color and size to draw attention to the primary subjects and
objects. They found that young typically developing children who were provided with more developmentally appropriate symbols were able to correctly identify more symbols than children using traditional AAC symbols. In addition to research with children regarding how various representations impact performance, speech-language pathologists have also been surveyed regarding their practices in designing AAC displays, and they considered type of symbol representation (i.e., symbols vs. photographs) as fairly or extremely important (Thistle & Wilkinson, 2015).

Two additional considerations when representing vocabulary concepts are the use of color and the use of animation. Clustering together symbols that share internal color promotes efficiency of search in school-age children who are developing typically and individuals with autism and Down syndrome (Wilkinson et al., 2014; Wilkinson & McIlvane, 2013). Background color is another feature included frequently in current technologies, often to cue word-class categories (i.e., subjects are yellow, verbs are green, adjectives are blue, etc.). However, young children with typical development and youths with Down syndrome are no faster in finding target symbols that have background color compared to those without background color (Thistle & Wilkinson, 2009, 2017; Wilkinson & Snell, 2011; Wilkinson & Weiss, 2017). Even though there is no empirical basis for the use of background color to aid in efficiency, clinicians report including background color frequently within AAC displays (Thistle & Wilkinson, 2015). With regards to animation, Jagaroo and Wilkinson (2008) suggested that animation may be an effective within AAC systems will help to attract attention and highlight conceptual relationship between symbols and their referents. Evidence suggests that animation positively impacts understanding of concepts by young children (e.g., Mineo et al., 2008; Schlosser et al., 2012).
Layout and organization

Grid-based displays and visual scene displays are the two primary layouts in existing AAC technologies. Grid-based displays include single meaning symbols, typically organized in a row-column grid. Visual scene displays depict a meaningful event within a photograph with vocabulary concepts embedded as hotspots (Wilkinson et al., 2012). Visual scene displays may offer language learning advantages for beginning language users because they preserve meaningful contexts to support conceptual learning (Light & McNaughton, 2012). Research with young typically developing children indicates that toddlers (i.e., 2.5 years) locate vocabulary more accurately using visual scene displays than grid displays (Drager, Light, Curran-Speltz, Fallon & Jeffries, 2003); however, children who are 4 or 5 years of age perform with similar accuracy with grid displays and visual scene displays (Light et al., 2004). There are a number of commercially available AAC apps that now include options for visual scene displays (Tuthill, 2014). However, Thistle and Wilkinson (2015) found that a high percentage of speech-language pathologists surveyed (83%) used visual scene displays less than 25% of the time, suggesting that grid-based displays are used most frequently in practice.

For children using grid-based displays, the four primary types of symbol organization are schematic, taxonomic, semantic-syntactic, and alphabetic (Light & Drager, 2004). A taxonomic organization includes vocabulary organized within hierarchical categories (e.g., foods on one page, people on another page, etc.), whereas a schematic organization groups items together based on event schema in the child’s life (e.g., getting ready for bed, circle time). In a semantic-syntactic organization, words representing the same grammatical category are grouped together on the display in an order that mirrors a sentence (i.e., subjects on the left, verbs in the middle, objects on the right). An alphabetic organization organizes vocabulary alphabetically according to first letters. Fallon, Light and Achenbach (2003) found that young typically developing children
aged 4 and 5 years are more likely or organize vocabulary based on event schema than taxonomic relationships. Therefore, the organization of existing technologies may impact children’s performance.

**Selection technique**

Individuals that use AAC utilize either direct selection or scanning techniques. A child using direct selection directly points to (selects) symbols with a body part (e.g., finger, hand, eye) or an adapted tool (e.g., mouse, laser pointer). Children who are unable to select items directly due to motor challenges rely on scanning “a process whereby a person or device sequentially presents choices or groups of choices to the communicator, who signals when the desired item is reached” (Treviranus & Roberts, 2003, p. 216). Research suggests that learning to scan is difficult for typically developing preschool children (e.g., White, Carney & Reichle, 2010), due to sensory, perceptual, motor, and cognitive demands, as well as the slow rate of communication via scanning (Fager, Bardach, Russell, & Higginbotham, 2012; Wagner & Jackson, 2006).

The use of animation can improve scanning for young typically developing children around 2 years of age who are using both traditional grid displays (McCarthy et al., 2006), as well as visual scene displays (McCarthy & Boster, 2017). McCarthy and colleagues found that when items became larger within a grid or animated to match the functions of the item in a visual scene display (e.g., door opening), young children performed better than when there was no animation (McCarthy et al., 2006; McCarthy & Boster, 2017). Current AAC technologies allow for changing multiple scanning parameters including speed, direction, patterns, and feedback to support more efficient access (Fager et al., 2012). However, scanning may still pose significant demands on users, especially individuals with motor impairments who have difficulty timing their movements with precision to select the switch when the target is highlighted (Fager et al., 2012).
There have been significant advances in eye gaze technologies that provide a promising method of direct access for individuals with severe motor impairments (Fager et al., 2012). These technologies project infrared light to the users’ eyes, that is then recorded by sensors in the technology to determine the exact point of eye gaze on the display. Research demonstrates that adults with acquired conditions can become proficient in using eye gaze technologies in a short amount of time (e.g., Ball et al., 2010). Less research exists for the efficacy of eye gaze access with children. Borgestig and colleagues (2016) conducted a longitudinal study of children with significant motor impairments ages 1 to 15 using eye gaze technologies within everyday life, and they found that children needed about 15 to 20 months to develop fast and accurate eye gaze performance. Little research has investigated parents’ perceptions of the efficiency of this access technique (Borgestig, Sandqvist, Parsons, Falkmer, & Hemmingsson, 2016).

Brain-computer interfaces have also received considerable attention as a possible AAC access option for individuals with severe speech and physical impairments (e.g., Akcakaya et al., 2014; Brumberg, Pitt, Mantie-Kozlowski, & Burnison, 2018; Fager, Beukelman, Fried-Oken, Jacoks, & Baker, 2011). Brain-computer interfaces allow individuals to control technologies using brain activity alone, without requiring any overt movement or behavior (Wolpaw, Birbaumer, McFarland, Pfurtscheller, & Vaughan, 2002). Most brain-computer interfaces record brain signals noninvasively via electroencephalography (EEG), in which electrodes are placed on the scalp. These non-invasive methods allow users to access communication interfaces, rather than directly accessing their thoughts, utterances, and speech motor plans from the brain (Brumberg et al., 2018). There is some evidence that individuals with acquired neurological and neuromotor impairments (e.g., ALS) can learn to operate technologies using non-invasive brain-computer interfaces (e.g., Sellers & Donchin, 2006); however, they are currently not considered a practical and dependable option, and more research is needed in this area.
Other considerations: System appeal and mobile technologies

Intervention with AAC is more likely to be effective if AAC systems are highly appealing to their users. Light and colleagues suggested that enhancing the appeal of AAC technologies will result in greater system use, enhanced self-esteem, and improved interactions with other children (Light & Drager, 2002; Light, Drager & Nemser, 2004; Light, Page, Currin & Pitkin, 2007). Light et al. (2004) compared and contrasted the features of popular children’s toys with the features of AAC technologies and found that compared to toys, AAC technologies were less likely to utilize bright colors, have different shapes, have movable parents, incorporate sound effects, and incorporate popular children’s themes. They suggested that incorporating some of the features of commonly available toys (e.g., bright colors, sound effects, children’s characters) may increase the appeal of AAC technologies (Light et al., 2004). Light et al. (2007) asked young children about their ideas for the design of AAC technologies, and children suggested that technologies should serve as companions, integrate multiple functions (e.g., communication, social interaction, play, etc.) and be easily personalized to reflect the users’ interests.

Mobile technologies may offer enhanced appeal for young children. McNaughton and Light (2013) suggested that mobile technologies offer several benefits such as increased awareness and social acceptance of AAC, as well as increased adoption of technologies. Additionally, mobile technologies incorporate features identified by Light and colleagues (Light et al., 2004; Light et al., 2007) to increase appeal such as personalization, popular themes, games and music, and integration of multiple functions. Recently, Therrien and Light (2016) found that an iPad with an AAC app was an effective tool to facilitate interaction between preschool children who use AAC and their peers, which lends some support to the notion that the “child-friendly” nature of mobile technologies may increase appeal for users.
While the availability of mobile technologies has increased the social acceptability and accessibility to technologies for some, individuals with the most significant developmental challenges may not realize the same benefits. Mobile technologies often require complex fine motor skills (e.g., pinching, swiping, touching) making them inaccessible for children with severe physical impairments (Fager et al., 2012; McNaughton & Light, 2013). Some changes have been made to enhance the accessibility of mobile technologies (e.g., switch access, screen reader programs). Additionally, developments are underway to provide eye gaze access on mobile technologies (see Boster & McCarthy, 2017a). For example, Tobii Dynavox produces a small, relatively inexpensive clip-on eye-tracker that can be attached to a Windows tablet to allow access to the tablet via eye gaze. However, there is still work to be done in order to enhance accessibility to mainstream technologies for individuals with severe motor impairments.

**Summary**

The research summarized above illustrates some of the key findings regarding how the design of AAC technologies may be optimized to meet the needs of individual children, as well as the current practices of speech-language pathologists with regards to system design. This body of evidence indicates that system design can make a critically important difference in adoption and efficient use of systems by children with complex communication needs.

**Designing AAC Technologies to Match with Family Needs**

For the technology to be truly effective it is critical to evaluate how technology design may be matched to the needs, priorities, and preferences of the families of those children, who are also interacting with the AAC technology. This section considers the theoretical and empirical
issues in family systems. It is followed by a review of the research that has been conducted to date concerning family perceptions of AAC.

**Theoretical framework: Family systems theory**

Family systems theory is one of the predominant theoretical perspectives in family therapy and family interventions (e.g., Dilworth-Anderson, Burton & Klein, 2011; Minuchin, 1985). Application of family systems theory has advanced beyond family therapy as a conceptual framework to understand functioning within families that include a member with a disability (Turnbull, Turnbull, Erwin, Soodak, & Shogren, 2015). The family systems framework describes several key characteristics of families and family functioning. First, families are *interdependent*, meaning that families are dynamic, interconnected systems in which all members are linked to one another (Minuchin, 1985). Second, families must be viewed and understood as a *whole*; the characteristics of a family cannot be reduced to individual members (Whitchurch & Constantine, 1993). When viewing the family as an interdependent whole, it is necessary to consider the needs and skills of a child with complex communication needs within the context of the family system.

Recently, Mandak, O’Neill, Light and Fosco (2017) described a family systems framework for understanding functioning within families that include a child who uses AAC. Integrating AAC technologies into the family system requires an understanding of family processes, which are an element of the family systems framework. The process of *adaptation* refers to the functional responses or adjustments that families make in response to stress and the demands of daily life (Gallimore, Coots, Weisner, Garnier, & Guthrie, 1996; Olson, Sprenkle & Russel, 1979). Families exist in a state of *homeostasis*, which is a constant internal environment or equilibrium, that may make them resistant to adaptation (Minuchin, 1985). Families of children who use AAC often experience multiple demands and stressors in caring for their child with
complex medical and communication needs that require adaptation (Angelo, 2000; Goldbart & Marshall, 2004; Jones et al., 1998). On top of these demands, AAC technologies introduce additional responsibilities and roles within the family system. Families may be responsible for technical upkeep and programing of the technology (e.g., Goldbart & Marshall, 2004; McNaughton et al., 2008), and they also often have the responsibility of helping their child learn to communicate using the technology (Bailey, Parette, Stoner, Angell, & Carroll, 2006; Meder & Wegner, 2015). Families have indicated that their ability to engage in the AAC process fluctuates over time as they manage the competing demands of parenting (Goldbart & Marshall, 2004).

When working to integrate AAC into the family, it is also important to consider the structure of the family and the relationships within it. The nuclear family system (also called the microsystem; Bronfenbrenner, 1979) includes members of the family (i.e., parents and children), as well as other individuals that the family interacts with on a regular basis over extended periods of time, such as extended family members (Turnbull et al., 2015). The microsystem is divided into subsystems that include relationships with other family members (Turnbull et al., 2015). These subsystems include the parental subsystem (parent-child), the interparental subsystem (parent-parent) and the sibling subsystem (sibling-sibling). Oftentimes, the parental subsystem is a central focus within AAC interventions (Mandak et al., 2017).

Families do not exist in isolation, but rather they function and interact with other contexts such as their schools, communities and societies. These broader contexts (i.e., nested systems) include individuals beyond the family such as teachers, service providers, peers, medical professionals, etc. (Bronfenbrenner, 1979). The people in these various systems exert reciprocal influences on the family (Nichols & Everett, 1986). Parents often value their child’s use of AAC in these broader school and community contexts (e.g., Bailey et al., 2006; McNaughton et al., 2008), and they may have expert opinions regarding the AAC design features that facilitate or present barriers to integrating AAC within these broader contexts. Interactions with these outside
systems can be complex and involve managing various therapies and medical needs and working with various professionals in different fields (e.g., occupational therapists, speech-language pathologists, physical therapists, assistive technology consultants, teachers). Therefore, the integration of AAC into families includes not only a consideration of immediate family members, but also their interactions with individuals in these broader contexts (e.g., educational and medical professionals, neighbors, related service providers).

Given the additional demands imposed by the introduction of AAC technologies, families may demonstrate resistance to the integration of AAC technologies into their family system, in order to maintain their existing family homeostasis (Mandak et al., 2017). Ultimately, AAC technologies must be designed in order to minimize demands on family members and match with existing family routines and lifestyle in order to become a part of that family’s functioning. AAC technologies designed to meet only the needs of the child with complex communication needs will not be effective without considering the integration of that technology into the family system.

Parents can provide valuable input regarding how AAC technologies can be tailored to meet child and family needs. Parents are often primary stakeholders and interventionists in the AAC process (Granlund et al., 2008). They have expert knowledge about the needs and skills of their child, as well as their family’s priorities and preferences for the assessment and intervention process (Goldbart & Marshall, 2004). Therefore, the focus for this study was gaining information from parents, and it primarily focused on the parental subsystem (parent and child with CP who used AAC), rather than the entire family system.

Previous research regarding family perspectives on AAC

A literature review was conducted to identify previous research on family perspectives regarding AAC. Studies included in the literature review met the following criteria: (a) published
in a peer-reviewed journal; (b) included perspectives of caregivers or family members of children who used AAC regarding experiences of using AAC with their children, as well as their needs, priorities, and preferences; and (c) all participants were family members of children who used AAC in their everyday lives. Table 1-2 provides a summary of the aim, methodology, participants, and key results or themes from these studies. The summary that follows synthesizes the results with respect to the priorities, challenges, and supports identified by parents.
Table 1-2. Summary of previous research investigating parent perspectives on AAC

<table>
<thead>
<tr>
<th>Author(s)</th>
<th>Aim</th>
<th>Methodology</th>
<th>Participants</th>
<th>Key results</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anderson, Balandin &amp; Stancliffe (2014)</td>
<td>To explore the perspectives of parents of children with SGDs regarding service access, service coordination, and the parent-professional relationship</td>
<td>Semi-structured interviews</td>
<td>6 Australian parents; children aged 2-18 with ASD or CP</td>
<td>Parents identified barriers to service access such as long waiting lists and limited therapist expertise, identified ongoing collaboration and discussed responsibilities for parents versus therapists</td>
</tr>
<tr>
<td>Anderson, Balandin &amp; Stancliffe (2015)</td>
<td>To explore parents’ opinions towards alternative service delivery methods for families of children who use an SGD</td>
<td>Semi-structured interviews</td>
<td>7 parents (6 Australian, 1 German) of children aged 2-18 with ASD or CP</td>
<td>Parents endorsed alternate service delivery models, particularly for remote and underserviced clients, benefits of alternative service delivery models included reduced travel time, enhanced information access, and advocacy for parents</td>
</tr>
<tr>
<td>Anderson, Balandin &amp; Stancliffe (2016)</td>
<td>To identify key areas that parents feel should be addressed in training for families who have received an SGD.</td>
<td>Semi-structured interviews</td>
<td>7 parents (6 Australian, 1 German) of children aged 2-18 with ASD, CP, and/or ID</td>
<td>Parents endorsed several areas for inclusion in family SGD training including: technical guidance and customization of SGDs, aided language development, and home practices strategies (e.g., responsivity and aided language stimulation)</td>
</tr>
<tr>
<td>Angelo (2000)</td>
<td>To examine the types of impact and extent of impact that AAC devices have on families</td>
<td>Survey</td>
<td>114 American (PA) caregivers of children aged 1-21 with various diagnoses</td>
<td>Parents generally did not perceive restrictions on their lifestyle due to AAC devices; however, half of parents found devices difficult to use, parent felt devices improved communication and peer relationships for their children</td>
</tr>
<tr>
<td>Angelo, Jones &amp; Kokoska (1995)</td>
<td>To determine the needs, priorities, and preferences of parents of children who use assistive devices</td>
<td>Survey</td>
<td>91 American parents (PA) of children aged</td>
<td>Parents identified needs for: increasing knowledge of AAC, planning for the future, integrating</td>
</tr>
<tr>
<td>Study</td>
<td>Objective</td>
<td>Method</td>
<td>Participants</td>
<td>Findings</td>
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</tr>
<tr>
<td>Angelo, Kokoska &amp; Jones (1996)</td>
<td>To determine the needs, priorities, and preferences of parents of adolescents who use assistive devices</td>
<td>Survey</td>
<td>97 American parents (PA) of children aged 13-21 with various diagnoses</td>
<td>Parents identified needs for: increasing knowledge of AAC, planning for the future, integrating devices into community and at home, social opportunities with typically developing peers, and knowledge to maintain and repair devices</td>
</tr>
<tr>
<td>Bailey, Parette, Stoner Angell, &amp; Carroll (2006)</td>
<td>To examine families’ perceptions of the management and use of AAC devices at home and in school</td>
<td>Interviews</td>
<td>6 American caregivers of junior and high school students with moderate or severe disabilities</td>
<td>Benefits of AAC use included increased independence and communicative competence, facilitators to AAC use were ease of learning and effective teaming, barriers to AAC use included AAC device limitations, inadequate training, and ineffective teaming</td>
</tr>
<tr>
<td>Calculator (2013)</td>
<td>To explore parents reports of patterns of AAC use, including communication systems used and exposure to and acceptance of electronic AAC devices</td>
<td>Survey</td>
<td>182 parents of children with Angelman syndrome from infancy through adulthood (USA, Canada, &amp; UK)</td>
<td>Children used a variety of aided and unaided communication modes, 60% accepted most advanced devices, 40% abandoned most advanced devices</td>
</tr>
<tr>
<td>Calculator (2014)</td>
<td>To explore parents’ perceptions of the relative importance of various modes of communication for their children and the status of children’s usage of their most advanced devices</td>
<td>Survey</td>
<td>271 parents of children with Angelman syndrome from infancy through adulthood</td>
<td>Parents assigned the highest ratings to non-symbolic methods of communication, 79% of parents reported some level of acceptance, rejections of devices were uncommon (&lt;4%)</td>
</tr>
<tr>
<td>Study</td>
<td>Purpose</td>
<td>Methods</td>
<td>Sample</td>
<td>Findings</td>
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<tr>
<td>Calculator &amp; Black (2010)</td>
<td>To seek evidence that experts’ opinions regarding best practices in AAC reflected parent’s preferences regarding communication skills they felt would have the greatest impact on their child’s quality of life</td>
<td>Survey</td>
<td>32 parents of children with Angelman syndrome from 3-19 (USA)</td>
<td>Parents rated best practices in the generally to strongly favorable range. Parent priorities for communication included: expressing wants and needs, communicating with a wide range of partners, acquiring functional skills, and initiating and maintaining conversations.</td>
</tr>
<tr>
<td>Crisp, Draucker &amp; Ellett (2014)</td>
<td>To identify barriers and facilitators to the use of high technology SGD’s by children from their parents’ perspectives</td>
<td>Interviews</td>
<td>12 parents of children ages 5-23 with various diagnoses</td>
<td>Barriers to use of AAC included device limitations (e.g., weight, poor voice quality, and complexity of programming), as well as societal factors (e.g., lack of professional support, long waiting periods, and negative reactions). Supports to use of AAC included device supports (e.g., user-friendly design, ease of programming, portability) and societal supports (e.g., financial services, professionals, positive reactions).</td>
</tr>
<tr>
<td>Goldbart &amp; Marshall (2004)</td>
<td>To explore the lived experience of parents of children who used AAC and the ways in which AAC may impact family life and communication</td>
<td>Interviews</td>
<td>11 caregivers of children ages 3-10 with various diagnoses</td>
<td>Parents provided perspectives on their children’s communication skills and social interaction. Parents identified wider societal issues that impacted use of AAC. Parents viewed themselves as experts on their children and identified demands placed on them in order to support their child’s use of AAC.</td>
</tr>
<tr>
<td>Jones, Angelo &amp; Kokoska (1998)</td>
<td>To explore the stressors and social supports identified by mothers and</td>
<td>Survey</td>
<td>59 families of children ages 4-12</td>
<td>Families identified acceptance and demandingness of child as stressors.</td>
</tr>
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</tr>
<tr>
<td>Researcher(s)</td>
<td>Study Description</td>
<td>Methods/Techniques</td>
<td>Sample/Group Description</td>
<td>Findings/Results</td>
</tr>
<tr>
<td>-------------------------------</td>
<td>------------------------------------------------------------------------------------</td>
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<tr>
<td>McCord &amp; Soto (2004)</td>
<td>To describe and interpret the experiences of four Mexican-American families of individuals with complex communication needs regarding the impact of using AAC devices</td>
<td>Open-ended interviews, observations, review of artifacts</td>
<td>Four parents of children with CP aged 7-20</td>
<td>There were differences between mothers and fathers regarding the helpfulness of social supports</td>
</tr>
<tr>
<td>McNaughton et al. (2008)</td>
<td>To gain a better understanding of parents’ perspectives on the technology learning experiences of children who use AAC</td>
<td>Online focus group</td>
<td>7 parents of children with CP aged 6-30</td>
<td>AAC devices were not perceived to be useful for interactions at home or to improve the fluency of conversations</td>
</tr>
<tr>
<td>Meder &amp; Wegner (2015)</td>
<td>To explore the wants, needs, and preferences of families of children with communication disabilities relative to mobile technologies</td>
<td>Survey</td>
<td>64 caregivers of children with various diagnoses (USA, Canada, UK)</td>
<td>Ease of use and affordability were identified as the most important characteristics in mobile technologies</td>
</tr>
<tr>
<td>Parette, Brotherson &amp; Huer (2000)</td>
<td>To identify what families of different ethnic backgrounds want professionals to know about AAC decision-making</td>
<td>Focus groups and structured interviews</td>
<td>23 families of children who used AAC</td>
<td>Families wanted information, education, and training about AAC</td>
</tr>
</tbody>
</table>

Note. ASD= autism spectrum disorder; CP= cerebral palsy; PA= Pennsylvania; SGD= speech generating device; UK= United Kingdom
Parent priorities

Parents of children who use AAC have expressed a strong desire to be involved in decision making surrounding their children’s AAC technologies (Anderson et al., 2014; Calculator & Black, 2010; Goldbart & Marshall, 2004; Parette et al., 2001). They have expressed a desire for professionals to recognize their expert knowledge on the unique needs and skills of their child, as well as the aspects of AAC systems that could match with family values and lifestyle (Goldbart & Marshall, 2004). Parents have also expressed that they value AAC for their children (e.g., Calculator, 2014). Parents have reported expectations for AAC to help their children fulfill various goals related to participation (e.g., education, employment), socialization (e.g., friendship), and communication (e.g., communicating with strangers, expressing needs and wants) (Angelo, 2000; Bailey et al., 2006; Calculator & Black, 2010; Goldbart & Marshall, 2004). Parents would like their children to use AAC in a variety of settings including school, work, the community, and home (Bailey et al., 2006).

No research has directly asked parents about the features of AAC technologies that parents perceive to enhance or inhibit participation in these family goals and priorities. Parents have expert knowledge regarding how children are able to use technologies within the functional contexts of everyday life. Tapping into this expert knowledge will support the identification of specific design features that allow children to work towards family goals, as well as the features of AAC technologies that can be improved to achieve a better match with family goals and priorities.
Challenges identified by parents

Parents have also reported that challenges exist in supporting their children to use AAC. There has been some discussion by parents of specific technology features that present barriers for their children’s use of the technologies. These limitations include high cost of learning, reliability issues, slow rate of communication, weight, and available voices (Baxter, Enderby, Evans & Judge, 2012; Bailey et al., 2006; Crisp, Draucker, & Ellett, 2014; Marshall & Goldbart, 2004; McCord & Soto, 2004; McNaughton et al., 2008; Parette et al., 2000). Parents also have described the inefficiency and demandingness of alternate access methods for their children. They have described scanning and switch access as “complicated” (Goldbart & Marshall, 2004, p. 200), “slow” (McCord & Soto, 2004, p. 219), “not natural” (McNaughton et al., 2009, p. 49), and “too hard” (Anderson et al., 2014, p. 79) for their children. As noted in the previous section on AAC technology features, there have been significant advances AAC technologies over time, particularly with access methods; therefore, it is important to evaluate if parents perceptions of the challenges of AAC technologies have changed over time.

Parents often take a primary role in technical upkeep of AAC technologies (e.g., Neimeijer, Donnellan, & Robledo, 2012); however, they have described the process of learning to implement aided AAC technologies as stressful, time consuming, demanding, and overwhelming (Bailey et al., 2006; Goldbart & Marshall, 2004; McNaughton et al., 2008; Parette et al., 2001). Parents report that the challenges of learning to implement AAC technologies are often exacerbated by a lack of adequate training on the technical upkeep of the system, as well as training on how to support their children in using the technology (Anderson et al., 2014; McNaughton et al., 2008; Meder & Wegner, 2015; Parette et al., 2001).

Unsuccessful collaborations with professionals have been an additional challenge for parents in integrating AAC technologies into family life. Parents have described challenges
including a lack of shared goals, lack of family involvement, and lack of trained professionals as barriers to forming successful collaborative relationships (Anderson et al., 2014; Bailey et al., 2006; McNaughton et al., 2008).

**Supports and needs identified by parents**

In order to improve AAC service delivery and the design of AAC technologies to better meet family needs, it is critical to gain information from parents regarding the most effective supports and strategies to address these challenges. Currently, there is limited research regarding the most effective supports and strategies for families; the available evidence is reviewed here.

Parents have discussed several aspects of the design features of AAC technologies that have supported their child’s use of AAC such as icon prediction to enhance efficiency, environmental controls to enhance independence, and personally relevant vocabulary (Anderson et al., 2016; McNaughton et al., 2008). Recently, parents in one study identified ease of programming as a support that assisted with their implementation of technologies (Crisp et al., 2014). In a survey, parents of children using apps on mobile technologies indicated that ease of use (37%) or affordability (22%) were the most influential characteristics in purchasing apps, while a notable proportion (12%) indicated visual appeal for the child was also important (Meder & Wegner, 2015). Even less research has directly solicited parents’ opinions regarding the development of future AAC technologies and applications to better meet individual and family needs. One known study, Boster and McCarthy (2017b), performed focus groups with parents to identify appealing features of AAC apps. Parents were shown various AAC interfaces and asked questions about the benefits and drawbacks of features meant to enhance appeal. Several parents preferred features including animation of selected symbols, use of colored categories, inclusion of popular children’s characters, videos, and incentives to increase the appeal of AAC applications.
In addition to benefits and supports of technologies, parents have also discussed needs related to supporting their child to use technologies. Parents have indicated a need for more extensive training regarding AAC that includes information regarding technical operation and customization of technologies, development of aided language, and effective interaction strategies to use at home (Anderson et al., 2016). Meder and Wegner (2015) found that parents of children using mobile technologies identified training on supporting their child to use AAC as a need; however, only a small proportion (13%) identified a need for support on the technical upkeep and programming of the device (e.g., customization, navigating, technical support). This could reflect that parents are becoming more comfortable with mainstream technologies (McNaughton & Light, 2013), and thus AAC technologies may be less intimidating and easier to use for parents. More evidence is needed to support or refute this claim. Finally, across several qualitative studies, parents have indicated a need for greater sensitivity from professionals regarding the demands, needs, routines, and realities of family life (Goldbart & Marshall, 2004; McNaughton et al., 2008; Parette et al., 2000).

**Aim and Questions**

Existing research has evaluated the AAC technology features that can support use for children. Separately, parents have provided their input regarding the process of supporting their child to use AAC, and clinicians have been surveyed about the features they consider when designing AAC displays. It is critical to gain parents’ input regarding the AAC technology features that support or inhibit the integration of AAC technologies into the functional contexts of everyday life, while respecting their family lifestyle and minimizing the additional demands of AAC technologies. Ultimately, parents’ input will allow us to tailor the design of AAC technologies to match with family goals, priorities, and lifestyle.
Very little research to date has directly asked parents what features of AAC technologies facilitate or present barriers to use of AAC within the family context and routines of daily life. In addition, in the existing body of research there has generally been a lack of a family systems focus. For example, previous studies have asked: what are your experiences using AAC with your child? However, this study moves beyond that to place a greater emphasis on family functioning and integration of AAC into family life by asking how AAC technologies may or may not be integrated into the functional contexts of everyday life. Finally, much of the existing research on family needs and priorities was done before the advent and subsequent explosion of mobile technologies. It is possible that parents are becoming more comfortable with technologies and may cite fewer programming and implementation barriers than in previous work. Related to that, this study is important to serve as a reminder to app developers and technology manufacturers to continue to advance accessibility for mainstream mobile technologies. Consequently, the aim of this study was to gain parent perspectives on how AAC technologies support family goals and fit into family life. The two primary questions were: (1) What are parents’ perceptions of how AAC technologies support their child’s participation in family goals and the functional contexts of everyday life?, and (2) What features of AAC technologies present challenges or supports to participation and integration of technologies into the functional contexts of everyday life?

Much of the previous research has been done with heterogeneous populations of participants. Because the realities and goals of family life are different for children with different diagnoses and resulting communication challenges (e.g., King et al., 2006), this study investigated these questions within one group. Families of children with cerebral palsy represent one group of critical stakeholders with valuable input regarding how AAC technologies match with family lifestyle. Cerebral palsy (CP) is a group of disorders of movement and posture (Rosenbaum et al., 2006). It has been estimated that 60-85% of children with CP exhibit significant difficulties with communication (Bax, Tydeman, & Flodmark, 2006; Hustad, Allison,
McFadd & Riehle, 2014), making them frequent candidates for AAC (Pennington, 2008). In addition to motor and communication impairments, children with CP often have associated impairments in sensation, perception, cognition, and behavior (Rosenbaum et al., 2006), which require an array of medical, educational, rehabilitation, and community services. Due to the complex nature of the disorder, it has significant lifelong implications for both children with CP and their families. Parents have reported that caring for a child with CP presents challenges including demands on physical health, difficulty maintaining social relationships, restricted freedom, and financial burden (Davis, Shelly, Waters, Boyd, Cook, & Davern, 2009; Reid et al., 2011). Considering the impact that CP has on both the child and the family, it is critical to design AAC systems that are responsive to the needs of the family and that involve parents as key stakeholders. CP was the population of focus for this study.
Chapter 2

Method

Research design

This study used a qualitative research design involving semi-structured interviews. Qualitative research approaches are appropriate for describing human behavior and lived experience from the perspective of participants (Bogdan & Bilken, 2007; Damico & Simmons-Mackie, 2003). Qualitative research attempts to make sense of and interpret phenomena in natural settings by understanding the meanings that participants bring to them (Denzin & Lincoln, 2005). It allows for understanding participant viewpoints and stories and uncovering salient issues that can later be studied using more structured methods (Tracy, 2013). Because the goal of this study was to better understand the experiences and perspectives of parents regarding the integration of AAC technologies into their family lives—and because little is currently known about the topic—a qualitative research methodology was appropriate.

This study used a phenomenological qualitative approach. A phenomenological study describes the common meaning of a lived experience of a phenomenon for several individuals (Creswell, 2012). It involves collecting data from individuals who have experienced a specific phenomenon and developing a description of what they experienced and how they experienced it (Moustakas, 1994). Semi-structured interviews were used to gain information from participants regarding their experiences. Interviews have been defined as guided question-answer conversations, or an “interchange of views between two persons conversing about a theme of mutual interest” (Kvale & Brinkmann, 2009, p. 2). Interviews provide in-depth information about participants’ experiences and viewpoints of a particular topic (Turner, 2010).
Participants

Recruitment

Ethics approval was obtained from the Human Research Protection Program prior to commencing the study (see Appendix A for Institutional Review Board approval letter). Participants were recruited though direct contact with family-members, speech-language pathologists, and other professionals who work with children who use AAC at various schools, private practices, and hospitals. These individuals and institutions were identified through personal contacts of the principal investigator (PI) and the PI’s colleagues, as well as internet searches. They were contacted and provided with a recruitment advertisement using various methods including (a) web postings to internet listservs (e.g., ASHA community discussion groups for AAC, Research, and SLPs in the Schools), (b) postings to social media sites (i.e., Facebook and Twitter), and (c) direct emails to clinicians, researchers, and other professionals (e.g., assistive technology consultants, administrators, teachers). Interested participants who viewed the recruitment advertisement contacted the PI by email or phone. Participants who inquired about the study were sent an email containing detailed information about the objectives of the study and study requirements, along with the consent form (see Appendix B) that explained the study procedures.

Criteria for participation

In order to participate, individuals were required to be English-speaking parents or primary caretakers of a child who: (a) had cerebral palsy, (b) was between the ages of 6-14, (c) had complex communication needs, whereby speech was inadequate to meet all of his/her daily communication needs, and (d) used a high-technology AAC system in the last year. In this way,
the study used a criterion sampling method, in which all participants meet the same criteria (Miles & Huberman, 1994).

**Description of participants**

Fourteen parents or primary caretakers responded to the recruitment flyers and expressed interest in participating in the study. Four parents were excluded because they did not meet the inclusion criteria. Reasons for exclusion were: (a) children were older than the specified age range, (b) children had a diagnosis other than CP, or (c) parents could not participate in a video or phone interview. Another parent expressed interested in the study, but failed to respond to follow-up attempts to schedule an interview.

Nine parents (eight mothers, one father) of eight children who met the inclusion criteria participated in the study. Seven interviews were conducted with mothers, while one interview included both parents (i.e., mother and father). Table 2-1 presents demographic information for each parent and child. Pseudonyms for parents, children, and other family members were used to protect confidentiality. Five of the parents were between 25 to 39 years and four were between 40 to 54. Eight parents had 4-year or professional degrees, while one parent reported completing some college. All parents indicated their race and ethnicity was White, not Hispanic or Latino. Seven parents resided in United States and two parents resided in the United Kingdom. The seven parents from the United States represented six different states in a variety of geographical regions including four parents from the Southeast, two parents from the West, and one parent from the Midwest. Parents had between one to four children.
<table>
<thead>
<tr>
<th>Parent Information</th>
<th>Allison &amp; Jacob</th>
<th>Amelia</th>
<th>Lucy</th>
<th>Bailey</th>
<th>Jackie</th>
<th>Kelli</th>
<th>Emily</th>
<th>Shannon</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age</strong></td>
<td>40 to 54</td>
<td>25 to 39</td>
<td>25 to 39</td>
<td>25 to 39</td>
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<td>40 to 54</td>
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<td><strong>Education</strong></td>
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<td>4-year degree</td>
<td>4-year degree</td>
<td>Professional degree</td>
<td>Professional degree</td>
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<td>White, not Hispanic</td>
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<td>White, not Hispanic</td>
<td>White, not Hispanic</td>
<td>White, not Hispanic</td>
<td>White, not Hispanic</td>
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<td><strong>Location</strong></td>
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<td>East South Central, USA</td>
<td>Pacific, USA</td>
<td>East North Central, USA</td>
<td>Pacific, USA</td>
<td>England, UK</td>
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<tr>
<td><strong>Children</strong></td>
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<td>1</td>
<td>3</td>
<td>1 (+2 step-siblings)</td>
<td>4</td>
<td>3</td>
<td>1</td>
<td>3</td>
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</table>

<table>
<thead>
<tr>
<th>Child information</th>
<th>Zane</th>
<th>Julia</th>
<th>Jackson</th>
<th>Felix</th>
<th>Hayden</th>
<th>Taylor</th>
<th>Sadie</th>
<th>Luke</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age</strong></td>
<td>9</td>
<td>7</td>
<td>8</td>
<td>11</td>
<td>6</td>
<td>14</td>
<td>12</td>
<td>10</td>
</tr>
<tr>
<td><strong>School setting</strong></td>
<td>Inclusive</td>
<td>Home-school</td>
<td>Inclusive</td>
<td>Segregated</td>
<td>Segregated</td>
<td>Inclusive</td>
<td>Inclusive</td>
<td>Inclusive</td>
</tr>
<tr>
<td><strong>Vision limitations</strong></td>
<td>N</td>
<td>Y (CVI)</td>
<td>N</td>
<td>N</td>
<td>N</td>
<td>Y</td>
<td>N</td>
<td>N</td>
</tr>
<tr>
<td><strong>Hearing loss</strong></td>
<td>N</td>
<td>N</td>
<td>Y</td>
<td>N</td>
<td>N</td>
<td>N</td>
<td>N</td>
<td>N</td>
</tr>
<tr>
<td><strong>Expressive vocabulary</strong></td>
<td>&gt;500</td>
<td>11 to 20</td>
<td>200</td>
<td>300-400</td>
<td>&gt;50</td>
<td>&gt;500</td>
<td>250</td>
<td>&gt;50</td>
</tr>
<tr>
<td><strong>Receptive vocabulary</strong></td>
<td>WNL</td>
<td>&gt;50</td>
<td>&gt;50</td>
<td>3,000-5,000</td>
<td>&gt;50</td>
<td>WNL</td>
<td>2nd grade level</td>
<td>&gt;50</td>
</tr>
<tr>
<td><strong>GMFCS</strong></td>
<td>Level I</td>
<td>Level IV</td>
<td>Level V</td>
<td>Level III</td>
<td>Level IV</td>
<td>Level V</td>
<td>Level V</td>
<td>Level V</td>
</tr>
<tr>
<td><strong>AAC device</strong></td>
<td>Proloquo2-go® on iPad®</td>
<td>Proloquo2-go® on iPad®</td>
<td>PRC accent 1400®</td>
<td>NOVA Chat 10®</td>
<td>NOVA Chat 12®</td>
<td>Tobii i5®</td>
<td>Tobii i12®</td>
<td>Tobii i12®</td>
</tr>
<tr>
<td><strong>Time using device</strong></td>
<td>6 years</td>
<td>2+ years</td>
<td>2 years</td>
<td>2.8</td>
<td>2.6</td>
<td>3 years</td>
<td>10 months</td>
<td>5;6</td>
</tr>
<tr>
<td><strong>Selection technique</strong></td>
<td>Direct-finger</td>
<td>Direct- fist</td>
<td>Direct- eye gaze</td>
<td>Direct-finger</td>
<td>Direct-finger</td>
<td>Direct- eye gaze</td>
<td>Direct- eye gaze</td>
<td>Direct- eye gaze</td>
</tr>
</tbody>
</table>
Note. CVI= cortical visual impairment, GMFCS= Gross Motor Function Classification System, UK= United Kingdom, USA= United States of America, WNL= within normal limits
Table 2-1 also contains demographic information for the children who had CP and used AAC. The children were between the ages of 6 to 14. Five children were served in inclusive school settings with their typically developing peers, two children were served in mostly segregated settings (i.e., self-contained schools or classrooms), and one child was home-schooled. Parents generally reported that their children could both understand and express more than 50 words or symbols. Vision and hearing were within normal limits for the majority of participants; one child experienced a cortical visual impairment, while another experienced some hearing loss.

According to the Gross Motor Function Classification System (GMFCS; Rosenbaum, Palisano, Bartlett, Galuppi, & Russell, 2008), children experienced a range of abilities related to their motor skills, ranging from walking without restrictions (Level I) to experiencing severe limitations in self-mobility (Level V). See Table 2-2 for a complete description of GMFCS levels. Children used a variety of AAC technologies; two children used apps on mobile technologies (i.e., Proloquo2go), while the remaining children used dedicated AAC technologies (e.g., PRC Accent, NOVA Chat, Tobii i15). Children had a range of experience in using their current technologies, from ten months up to six years. Some children had used other devices prior to their current device. All of the children used direct selection to access their devices. Four children used eye gaze access, three children used their fingers, and one child used her whole hand.

Table 2-2: Description of gross motor function classification systems (GMFCS) levels

<table>
<thead>
<tr>
<th>Level</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>I</td>
<td>Children walk inside and outside and climb stairs without limitations. Children perform gross motor skills such as running and jumping, but speed, balance, and coordination are reduced.</td>
</tr>
<tr>
<td>II</td>
<td>Children walk inside and outside without assistive devices, but experience limitations walking on uneven surfaces, inclines, in crowds, or in confined spaces.</td>
</tr>
<tr>
<td>III</td>
<td>Children walk inside and outside on a level surface with an assistive mobility device. Depending on upper limb function, children propel a wheelchair manually or are transported when travelling for long distances or outdoors on uneven terrain.</td>
</tr>
<tr>
<td>IV</td>
<td>Children experience some level of self-mobility, with limitations. Children are transported or use power mobility outdoors and in the community.</td>
</tr>
</tbody>
</table>
V  

Children experience severe limitations in self-mobility, even with the use of assistive technology. Physical impairments restrict voluntary control of movement and the ability to maintain head and trunk postures. Some children achieve self-mobility using a power wheelchair with extensive adaptations.

Note. Adapted from Palisano et al., (2009)

Allison, Jacob, and Zane

Allison was a former high school math teacher. Her husband, Jacob, was a senior technologist at a technology consulting and engineering services company. In addition to Zane, Allison and Jacob had one other child who was 12 years old and typically developing. They had extended family in neighboring states that they saw monthly. Their family enjoyed activities such as going to the playground together, going to museums, and visiting the zoo.

Zane was 9 years old and attended fourth grade in an inclusive elementary school setting. He would be transitioning to middle school next year. Zane’s receptive language was within normal limits, and he was able to express more than 500 vocabulary concepts. His parents reported that his vision and hearing were within normal limits. He was classified as Level I on the GMFCS, indicating that he was independently ambulatory, although he did experience difficulty with some fine motor skills (e.g., holding a pencil). He was fed via a g-tube.

He began to use high-technology AAC when he was around 3 years old, and he had been using Proloquo2Go on the iPad since then. He accessed his iPad via direct selection with his finger. He was able to formulate multi-symbol utterances of four to six words using his AAC technology. Typical utterances that Zane expressed using his AAC technology included: “Can I have my iPad please,” “Can I go to mall,” and “I want to watch sports.” His parents reported that in addition to his AAC device, he communicated via additional modes including speech and speech approximations, signs and sign approximations, gestures, and a low-tech communication
board during swimming class. His speech was often unintelligible for unfamiliar partners. Some of his favorite activities were playing with his brother, going to swimming class, riding elevators, and listening to music. His parents described his intelligence and motivation as areas of strength for Zane, while he had difficulty with social interaction with peers and literacy (i.e., reading and writing).

**Amelia and Julia**

Amelia was a former nurse and her husband was a pilot in the army. Amelia stayed home with Julia in order to do her home-schooling and caretaking, and her husband worked full-time. Due to her husband’s position in the army, they moved quite frequently and had worked with a variety of professionals. Julia was their only child. Their extended family members (i.e., aunt and grandparents) lived in another state, and they interacted with them via video calls frequently.

Amelia and Julia met weekly with another child who used AAC and her mother. They went on outings together such as trips to the theatre, orchestra, and thrift stores.

Julia was 7 years old, and she was home-schooled. She was able to understand more than 50 vocabulary concepts, and expressed between 11 to 20. Julia had a cortical visual impairment (CVI). Amelia described the CVI as Julia experiencing “holes in her vision,” and Julia often moved her head back and forth in a lateral motion in order to “make a full picture.” Julia also had a medical history of early hearing loss; however, her hearing was now within normal limits. She was classified as Level IV on the GMFCS, indicating that she required significant support to stand and walk and relied on a manual wheelchair for mobility. She was able to stand with assistance and could remain standing with support (i.e., a table in front of her). She was fed via a g-tube.
Julia received her first AAC device at the age of 3, and it was a high-tech device accessed via eye gaze (Tobii i15). She experienced challenges related to using eye gaze as an access method, and at the time of the interview, she had been using Proloquo2Go on an iPad for over two years. She accessed the iPad via direct selection with her whole hand, and Amelia reported that her finger isolation skills were improving. Julia’s current device was not mounted on her wheelchair; however, Amelia was in the process of acquiring a dedicated device and wheelchair mount. Julia communicated using primarily one-word utterances on her AAC technology (e.g., “stop,” “go,” “eat”). Her mother reported that she recently combined two symbols independently to express “I want eat.” In addition to her AAC device, Julia communicated through additional modes including body movements, facial expressions, vocalizations, and low-tech communication boards. Some of Julia’s favorite activities were riding her adapted bike, doing sit-to-stands, reading books, playing games on the iPad, and listening to music. Amelia described that more recently, Julia had been enjoying extracurricular activities such as the attending the children’s theatre.

Lucy and Jackson

Lucy’s family included her husband and her three children. Jackson was the oldest, and he had two younger siblings (ages 5 and 2). Lucy organized a parent support group for parents of children who used AAC. Lucy and her son met regularly with another young girl who used AAC. Lucy’s mother visited her family regularly, and she was a frequent communication partner for Jackson.

Jackson was 8 years old and attended third grade in an inclusive elementary school. This was his first year being fully mainstreamed. Jackson was able to express about 200 vocabulary concepts and could understand more than 500. Lucy reported that his approximate grade level
equivalent was 2nd to 3rd grade, and his cognition was within normal limits. His vision was within normal limits, and he experienced some hearing loss, which generally did not impact his day-to-day functioning. He was classified as a Level V on the GMFCS, indicating that his self-mobility was severely limited, and he had difficulty controlling his head and body posture in most positions. He achieved mobility using a manual wheelchair.

Jackson had been using his PRC Accent 1400 for two years, and this was his first high technology device. He accessed his device using direct selection via eye gaze. He formulated multi-symbol utterances of two to four words using his AAC technology. Typical utterances that Jackson expressed using his AAC technology included: “Watch hockey,” “want to go mall,” “go outside yes yes,” and, “I feel excited.” Jackson also used pre-stored phrases in order to share news, greet people, and tell jokes. His family was in the process of identifying a switch site to provide access to AAC in situations when eye gaze was not available (i.e., in sunlight). In addition to his AAC device, Jackson communicated using several additional modes including: (a) reliable facial gestures for yes, no, and “I have a problem”; and (b) low-tech screenshots of his device that served as a backup and were accessed via partner assisted scanning. Jackson was a “huge sports fan,” and he enjoyed attending live basketball, baseball, and football games. His strengths were that he was a good student and performed well at school.

**Bailey and Felix**

Bailey had previously been an adjunct professor, and at the time of the interview she was a full-time student completing her degree in speech-language pathology. She and her son Felix lived at home. Felix’s family also included his father and step-mother, as well as two younger step-siblings, ages 5 and 3. Felix also interacted frequently with his grandparents, his “sitter,” and
Bailey’s fiancé and his son, who was the same age as Felix. Together Bailey and Felix enjoyed walking to the train tracks, riding the train into the city, going on errands, and playing games.

Felix was 11 and, and he attended a private self-contained multi-needs school. He had recently transitioned to that school from a public school in an effort to increase use of AAC throughout the school day. He was able to express 300-500 vocabulary concepts and understand between 3,000 to 5,000. His vision and hearing were within normal limits. He was classified as a Level III on the GMFCS. Felix walked around the house independently, and he could go on short walks outside with a walking aid. He was in a manual wheelchair when at school and in the community. He was fed via a g-tube.

Felix had been using some form of AAC since he was a toddler or infant. When he was very young, he used picture cards around the house. When he was a toddler, he used a Dynavox and Proloquo2Go on the iPad. At the time of the interview, he had been using a NOVA chat 10 for almost three years. When he was in his wheelchair, his device was mounted to his chair. He accessed his device via direct selection with his finger. Felix formulated multi-symbol utterances of three to five words using his AAC technology. Typical utterances that Felix expressed using his AAC technology included: “go Polar Express,” “Bryan Zoe come with us,” “play with my mom,” “I don’t eat that,” “go Grandma Grandpa house,” and “turn it off.” In addition to his AAC device, Felix communicated using several different modes including gestures, vocalizations, and a low-tech print out of his NOVA chat that he used at school. Some of his favorite activities included riding his recumbent bike, taking train rides, playing games, reading books, listening to records, singing, and playing with Play-Doh.
Jackie and Hayden

Jackie’s family included herself and her four children, a 9-year old daughter, 6-year old son (Hayden), and 1-year old twins. She also mentioned Hayden’s father; however, she did not disclose whether he lived at home. Jackie worked two part-time jobs. Jackie’s parents and sister also lived close by and interacted with the family frequently. Hayden also interacted frequently with his homecare aide and dedicated para-professionals at school.

Hayden was 6 years old and attended first grade in a self-contained “options” classroom where he received one-to-one instruction. He was in a general education classroom for physical education, recess, and special events. His vision and hearing were within normal limits. He was classified as a Level IV on the GMFCS. He was able to roll and army crawl independently, and he had good head control; however, he was unable to sit without support. He was in the process of acquiring a power wheelchair. Hayden was tube fed and had epilepsy.

Hayden had been using his current device (NOVA chat 12) for about 2½ years. Prior to acquiring the device, he used the TouchChat12 app on the iPad for several months while he was acquiring the NOVA chat. His device was mounted to his wheelchair. He accessed his device via direct selection with his finger, with a keyguard on the device. Hayden formulated utterances using one to two symbols with his AAC technology. Typical utterances that Hayden expressed using his AAC technology included: “play ball” and “go.” In addition to his AAC device, Felix communicated using several different modes including facial expressions, gazing at objects or events, and gesturing. He had previously used a low-tech picture book in preschool. Hayden liked sitting at his high-low chair and playing with toys (cars, planes, trains), swinging, watching other kids, and watching TV.
Kelli and Taylor

Kelli’s family included her husband, who worked as a programmer, and her three children. Taylor was the oldest, and she had a younger brother who was 12 and a younger sister who was 8. Other important people her family interacted with frequently included Taylor’s care aide and a few of her close friends.

Taylor was 14 years old, and she attended a mainstream school. Her hearing was within normal limits and she experienced some functional limitations with vision, although it did not affect her use of AAC. Her mother reported that her receptive language was within normal limits, and that she had “no associated learning disability.” She was classified as a Level V on the GMFCS, indicating severe limitations in motor functioning. Taylor had little head motor control, and she was dependent on others for all physical activities. She achieved mobility in a manual wheelchair.

Taylor had been using some form of AAC since she was a toddler. As a young child, she made choices by looking at objects presented by her communication partners. When she entered preschool, she began to use a low-tech communication book accessed via eye gaze with partner assisted scanning. She received her first high-tech device at the age of 7, a Tellus¹³ which she controlled via switch access and visual row-column scanning. She began using her first eye gaze device at the age of 9. At the time of the interview, she used a Tobii i15 that was mounted to her wheelchair. Taylor combined symbols on her AAC technology to form multi-symbol utterances. In addition to her AAC device, Taylor communicated using several different modes including: turning her head towards symbols on her wheelchair headrest to indicate yes and no; a tablet version of her low-tech communication book; and vocalizations and facial expressions. Taylor’s strengths were in cognition and comprehension. Her favorite activities included watching TV, listening to audio books, and playing cards and board games.
Emily and Sadie

Emily’s family included her husband and Sadie, their only child. Other important people in their family life included a tutor that had been working with Sadie since birth, an AAC instructor, her physical therapist, and her dance teacher. Emily was an attorney. Her family enjoyed doing activities together such as going for walks in the park, going to the pool, and going grocery shopping.

Sadie was 12 years old and attended fifth grade in a fully inclusive school that included a physical disabilities program. Her family was in the process of identifying an appropriate middle school placement for her. Her approximate grade level equivalent was 1st to 3rd grade. Sadie was classified as Level V on the GMFCS and experienced severe limitations in her motor abilities. Sadie had also experienced a progressive deterioration of her fine motor skills due to a genetic disorder that co-occurred with CP. She achieved mobility via a power wheelchair.

At the time of the interview, Sadie had been using a PRC Accent 1400 for 10 months, which she accessed via eye gaze. Prior to the Accent 1400, Sadie used several other high-technology devices including a Tobii accessed via eye gaze, a Dynavox accessed via eye gaze and scanning, and a PRC Vantage14 that she accessed via direct selection with her hand. Sadie formulated multi-symbol utterances of two to four words using her AAC technology. Typical utterances that Sadie expressed using her AAC technology included: “Awesome!”, “My name is Sadie,” and “I like.” In addition to high-tech AAC, Sadie communicated using several different modes including facial expressions, vocalizations, idiosyncratic signs, and a reliable yes/no (i.e., looking right for yes and left for no). Some of her favorite activities included playing eye gaze video games on her device, doing ballet, going to therapeutic horseback riding, and socializing with friends. Emily identified Sadie’s greatest areas of need related to literacy, fluent communication, and improved syntax.
Shannon and Luke

Shannon’s family included her husband and two children, Luke and his younger 7-year-old brother. Shannon and her husband both worked full time. Other important people who interacted with their family regularly included Luke’s grandparents, his in-home care aides, and his communication partners at school (teachers, assistants, and staff at after school club).

Luke was 10 years old and attended a mainstream school. He was classified as a Level V on the GMFCS. His mother reported that his cognition and receptive vocabulary were within normal limits. He had poor control over his arms and very little fine motor control with his hands. He recently acquired a power chair and was learning to use it to achieve independent mobility via switches. His vision and hearing were within normal limits.

Luke started using a high-tech eye gaze AAC device when he was 5. He accessed the keyboard on his AAC technology to generate multi-word utterances. Prior to his high-tech device, he used a low-tech communication board. In addition, he used vocalizations and made choices with his eyes. His parents presented choices by holding up their two hands, and he looked at the desired choice. Luke’s favorite activities were watching TV and listening to music. His strengths were cognition, engagement, and comprehension skills.

Materials

A short demographic questionnaire was used to gain background information from participants prior to completing the interview (see Appendix C). The first part of the questionnaire included screening questions to ensure that participants met the inclusion criteria. This included parental report of the child’s diagnosis of CP. The second part asked about the personal characteristics of the parent (e.g., race/ethnicity, age, location, education). The third part
included questions about the intrinsic characteristics of the child with CP who used AAC (e.g., vision, hearing, motor, cognition, and language). The final part of the questionnaire asked about the current and previous AAC technologies the child used. The survey was housed on Qualtrics (Qualtrics, Provo, UT), an encrypted online survey software.

A semi-structured interview guide was utilized that included a set of pre-determined, open-ended questions (see Appendix D). The questions from the interview guide were developed based on a thorough review of the literature in several different areas. First, the questions were based on best practices in gaining information from families (e.g., McWilliam, 2010; Crais, 2011), as well as the participation model that has been used in speech and language intervention to support communication and family involvement (e.g., Wilcox & Woods, 2011). Second, the questions were based on the existing qualitative research on family perspectives of AAC and were specifically created to fill gaps in existing knowledge. The interview guides from previous qualitative investigations (Anderson et al., 2014; Anderson et al., 2015; Crisp et al., 2014; Bailey et al., 2006; McNaughton et al., 2008; Goldbart & Marshall, 2004; Parette et al., 2000) were reviewed to ensure that the questions for the present investigation were unique. Finally, the questions had a theoretical basis in family systems theory and how AAC technologies can match with family process and functioning (e.g., Mandak et al., 2017; Minuchin, 1985).

After developing the questions based on theory and a review of the literature, the PI sought feedback from three researchers. The researchers were chosen because they had: (a) expertise in AAC, (b) experience with conducting qualitative research, and (c) clinical experience working with families of children who used AAC. Each of the researchers was sent an electronic version of the interview guide and asked to provide feedback on its content. Additionally, a pilot interview was conducted with a clinician who had extensive experience working with parents of children with CP who used AAC technologies. The researchers and clinician provided feedback regarding question wording, question order, and question presentation. For example, several
probes included more than one question. The researchers provided feedback to ask one question at a time and to break some questions into two parts. Based on feedback from the researchers and clinician, modifications were made to the wording, order, and number of questions (Creswell, 2012; Kvale & Brinkman, 2009; Turner, 2010).

QuickTime Player\textsuperscript{15} version 10.4 was used to audio record all of the interviews. In addition, an external Evistr L57\textsuperscript{15} mini voice recorder with built-in speakers was used as a back-up recorder.

**Procedures**

Participants who contacted the PI after viewing the recruitment advertisement were sent an electronic copy of the consent form that explained study objectives, requirements, and procedures (see Appendix B). After reviewing the consent form, parents who agreed to participate were sent a link to the background questionnaire on Qualtrics. Participants were assigned an alphanumeric code. Participants entered this code on the questionnaire in order to maintain their confidentiality. Participants completed the questionnaire in about 5 minutes on average (range of 3 minutes to 11 minutes).

**Data collection**

Interviews were completed via phone or web-conference, in order to access participants in various geographic areas. Interviews were scheduled at a time what was convenient for parents and via their preferred method. All interviews were conducted by the PI, a speech-language pathologist with experience working with parents of children who use AAC. The interviews lasted about 60 minutes on average and ranged from 45 to 80 minutes. The interviews were
conducted over a period of 2 months. Table 2-3 contains information regarding the method and length of interviews for each participant.

Table 2-3. Interview method, length, and number of thought units for each participant.

<table>
<thead>
<tr>
<th>Participant(s)</th>
<th>Method</th>
<th>Length (minutes)</th>
<th>Number of thought units</th>
</tr>
</thead>
<tbody>
<tr>
<td>Allison &amp; Jacob</td>
<td>Video conference</td>
<td>72</td>
<td>318</td>
</tr>
<tr>
<td>Amelia</td>
<td>Video conference</td>
<td>73</td>
<td>264</td>
</tr>
<tr>
<td>Lucy</td>
<td>Video conference</td>
<td>60</td>
<td>240</td>
</tr>
<tr>
<td>Bailey</td>
<td>Video conference</td>
<td>55</td>
<td>237</td>
</tr>
<tr>
<td>Jackie</td>
<td>Video conference</td>
<td>45</td>
<td>222</td>
</tr>
<tr>
<td>Kelli</td>
<td>Phone</td>
<td>80</td>
<td>473</td>
</tr>
<tr>
<td>Emily</td>
<td>Phone</td>
<td>59</td>
<td>241</td>
</tr>
<tr>
<td>Shannon</td>
<td>Video conference</td>
<td>57</td>
<td>281</td>
</tr>
</tbody>
</table>

The interviewer followed the semi-structured interview guide (see Appendix D) to ensure that data collection was systematic across respondents. Probes (e.g., Can you tell me more about that?) were used to obtain more detail, ask for elaboration, and make clarifications in order to gain important information that the interviewer was seeking. Follow-up questions were used to explore topics in more depth that were raised by the parents (Padgett, 2012; Patton, 2012). The interviewer used a relationship-focused, interactive interview approach that was aimed at establishing rapport, empathy, mutual respect, and mutual trust (Kvale, 1996; Patton, 2015). Various strategies were used in order to create an interactive, conversational interview style. The interviewer used preface statements to alert participants to the nature of the question and direct their attention, while giving them time to organize their thoughts before responding. In addition, the interviewer provided feedback to maintain the flow of communication and re-iterated the purposes of specific questions at strategic points throughout the interview in order to increase the motivation of the interviewee to respond openly and in detail (Patton, 2015). Finally, each interview was ended with a final question that allowed the participant to have a final say and add anything that was not discussed (Patton, 2015).
The interviewer took notes during interviews. The notes served to provide reminders of follow-up questions in order to seek further detail. The interviewer also wrote key phrases, major points made by the interviewee, and key words in quotation marks to capture the participant’s own language (Patton, 2015). These notes facilitated later analysis by providing a preliminary descriptive summary of the data that would be expanded upon throughout data analysis (Hays & Singh, 2014). Within 2 hours of completing each interview, the interviewer completed the contact summary sheet (see Appendix E), in order to identify initial salient ideas and additional questions to be asked in subsequent interviews (Hays & Singh, 2014).

All audio recordings were transcribed verbatim by the first author or trained undergraduate research assistants (RAs). Non-verbal information such as extended pauses, laughter, and sighs were included in the transcripts (Dresing, Pehl, & Schmeider, 2015). Appendix F contains a detailed description of the transcription conventions used for this study. Four undergraduate RAs were trained on the transcription conventions. In order to demonstrate mastery of transcription conventions, each RA was responsible for transcribing a portion (i.e., 10 minutes) of a transcript that the PI had transcribed. Transcriptions were compared to the PI’s transcription who made a subjective assessment of their adherence to transcription conventions (McLellan, MacQueen, & Beidig, 2003). The RAs were responsible for transcribing four interviews, and the PI transcribed the other four interviews. For each interview that was transcribed by an RA, the PI listened to the full recording to check for accuracy and to fill in words that were incomprehensible, if possible (McLellan et al., 2003).

A fidelity check was also performed by an RA to assess adherence to the interview guide. For each interview transcript, the RA indicated whether or not the PI asked each of the questions from the interview guide (see Appendix G). Fidelity was calculated for each interview as the number of questions on the interview guide that were asked divided by the total number of interview guide questions (i.e., 11). Fidelity was 94% on average across interviews. Fidelity was
100% (i.e., 11/11) for three of the interviews, and it was 91% (i.e., 10/11) for the other four interviews. The PI did not ask the question *Tell me a little more about [child’s name]* in three interviews because the parents told about their child in response to the first question that asked about the family. During one of the interviews, the PI did not ask the final question *Is there anything else you’d like to add?* because the parent had to attend to another obligation.

**Data Analysis**

Data analysis commenced from the beginning of data collection. By beginning data analysis early in the process of data collection, the researcher was able to move back and forth between the collected data and strategies for collecting new data. This added to the depth and quality of the data analysis. Ideas introduced by participants during the first several interviews could be probed in future interviews (Creswell, 2012; Hays & Singh, 2014; Liamputtong, 2009).

Data were analyzed based on an adapted version of Braun and Clarke’s (2006) recommendations for thematic analysis. Thematic analysis is “a method for identifying, analyzing, and reporting patterns (i.e., themes) within data” (Braun & Clarke, 2006, p. 79). Thematic analysis is a flexible research tool that provides a rich, detailed, and qualitative account of the data (Braun & Clarke, 2006; Vaismoraldi, Turunen, & Bondas, 2013). Data analysis took an inductive approach, in which themes emerged from the data and were grounded in the participants’ experiences (Creswell, 2012). The steps recommended for thematic analysis by Braun and Clarke (2006) were adapted to include a consideration of unitization (e.g., Campbell, Qunicy, Osserman & Pedersen, 2013; Vaughn, Schumm, & Sinagub, 1996), codebook development (e.g., MacQueen, McLellan, Kay, & Milstein, 1998), and intercoder reliability (e.g., Campbell et al., 2013; Hruschka et al., 2004; Miles & Huberman, 1994).
Data analysis included the following steps: (1) familiarize and identify big ideas, (2) unitize and organize text, (3) code data subset and develop initial codebook, (4) identify and define themes, (5) refine codebook and assess reliability, and (6) resolve discrepancies and sort data. Figure 2-1 provides a schematic of the data analysis process. Data analysis was a team approach, including the PI and the four RAs. The RAs were provided with a detailed description of the project and its objectives, and they were involved throughout the data analysis process.
<table>
<thead>
<tr>
<th>Familiarize and identify big ideas</th>
</tr>
</thead>
<tbody>
<tr>
<td>o Read and re-read data</td>
</tr>
<tr>
<td>o Highlight important text</td>
</tr>
<tr>
<td>o Note initial analytic observations</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Unitize and organize text</th>
</tr>
</thead>
<tbody>
<tr>
<td>o Segment data into thought units</td>
</tr>
<tr>
<td>o Organize text into table with columns for participant, question, data, and code</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Code data subset and develop initial codebook</th>
</tr>
</thead>
<tbody>
<tr>
<td>o Develop codebook with definitions and examples for each code from a data subset</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Identify and define themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>o Write codes on index cards</td>
</tr>
<tr>
<td>o Sort codes into piles of related categories (themes)</td>
</tr>
<tr>
<td>o Name and define themes</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Refine codebook and assess reliability</th>
</tr>
</thead>
<tbody>
<tr>
<td>o Develop detailed code and theme definitions</td>
</tr>
<tr>
<td>o Circulate codebook to research team</td>
</tr>
<tr>
<td>o Train research team on using codebook</td>
</tr>
</tbody>
</table>

**Coding:** Team members independently code data subset

**Assess consistency:** Team members compare codes using subjective agreement

**Modify codebook**

**Coding:** Two independent coders code subset of data

**Assess reliability:** Calculate intercoder reliability. Is intercoder agreement >80%?

- **YES**
- **NO**

**Resolve discrepancies and sort data**

| o Perform consensus coding (negotiated agreement) to resolve discrepancies |
| o Sort data by codes |

Figure 2-1. Data analysis process.
Familiarize and identify initial ideas

The research team began data analysis by repeatedly reading the transcripts in an active way to immerse themselves in the data (Braun & Clarke, 2006; Creswell, 2012). This step involved reading and re-reading the text, highlighting portions of the text that were meaningful, and noting “initial ideas” and analytic observations in the margins for each portion of highlighted text. Vaughn et al. (1996) indicates that this initial familiarization step is important prior to unitization (i.e., dealing with smaller bits of data), to ensure that the researcher does not “miss the forest for the trees” (p. 8). The “initial ideas” generated during this step created the basis for codes and themes which are revisited later in the data analysis process (Steps 3 and 4).

This first step of data analysis commenced from the beginning of data collection. As each new interview was transcribed, every team member familiarized themselves with the data from that interview and identified initial ideas. The RAs were trained on this step of data analysis during a team meeting, in which every team member highlighted and noted observations for one portion of a printed interview transcript. Following the initial training, team members performed this first step of data analysis using word processing software (i.e., Microsoft Word17) for each interview transcript. The Word document for each transcript contained data arranged in a table, with the left column occupied by the data and right column for noting initial ideas. The RAs shared their documents with the PI, and the research team met and discussed their initial impressions of each interview. During the meeting, the team discussed what struck them about each transcript and compared their initial ideas. The PI documented these discussions, and they served as the initial codes for the codebook (Step 3). After completing this first step of data analysis for several interview transcripts, the team had a discussion about ideas that were emerging across the interviews, as well as ideas that were unique to a single interview. This helped in identifying when saturation was reached, or the point in which no additional themes
were found from the reviewing of successive data (Ando, Cousins, & Young, 2014; Glaser & Strauss, 1967).

**Unitize and organize text**

The second step of data analysis began with unitization, (Campbell et al., 2013; Vaughn et al., 1996) also referred to as text segmentation (Guest, MacQueen & Namey, 2014; MacQueen et al., 1998). This refers to the process of identifying the units of information that later become the basis for applying codes. The text was segmented into thought units. A thought unit has been defined as “the smallest amount of information that is informative by itself” (Vaughn et al., 1996). Thought units ranged in length from a short phrase to a sentence or a short paragraph. Thought units help to organize text into manageable units. This can serve to eliminate confusion when comparing the codes of two or more coders, in order to ensure that all coders are applying codes to the same segments of data (Campbell et al., 2013). Participants contributed an average of 285 thought units (range of 222 to 473; see Table 3-1).

The PI was responsible for unitizing the data. Independent unitization of the data by the PI has precedence in both qualitative research methodology (e.g., Campbell et al., 2013; Vaughn et al., 1996), as well as recent qualitative work in the field of AAC (e.g., Mandak & Light, 2018). Campbell et al. (2013) and Vaughn et al. (1996) have argued that the individual who performs the unitization should have a thorough understanding of the theoretically motivated questions guiding the study. Additionally, the task of identifying meaningful conceptual breaks requires a recognition of both obvious and more subtle meanings in the participants’ responses (Campbell et al., 2013). The PI had greater knowledge in the interview subject matter than the undergraduate RAs and was responsible for completing this step of the data analysis.
Unitization was conducted using Microsoft Word. The PI pressed the “return” key to separate distinct thought units on the transcript. The unitized transcript was then transferred to Microsoft Excel where each meaning unit occupied its own cell. The data were organized into a four-column table in Excel including the following columns organized from left to right: participant, question number (sequence), unitized data, and code.

Code data subset and develop initial codebook

In step 3, the PI coded a subset of the unitized data (i.e., three transcripts) by applying one code to every thought unit within each transcript. Codes have been defined as “tags or labels for assigning units of meaning to the descriptive or inferential information compiled during a study” (Miles & Huberman, 1994, p. 56). Three primary types of codes were assigned in the generation of initial codes: descriptive codes, in vivo codes, and process codes (Miles, Huberman & Saldaña, 2014). Descriptive codes assigned labels (most often nouns) to summarize the basic topic of a passage of data (e.g., device selection, social goal, physical design). In vivo codes referred to a word or short phrase from the actual words of the participant found in the data (Saldana, 2009; Strauss, 1987). In vivo codes were placed in quotation marks to differentiate them from researcher-generated codes (e.g., “hit the ground running,” “all on our own,” “come a long way”). Finally, process codes used gerunds (“—ing” words) to note action in the data including observable actions (e.g., prompting, programming) as well as conceptual action (e.g., educating, advocating) (Miles et al., 2014).

Data coding involved a process of constant comparison, whereby the PI used the existing coding scheme to code each interview as it was completed and added codes to the codebook for new pieces of data that were not included into the existing coding scheme (Lincoln & Guba, 1985). The codes generated during line-by-line coding were used to develop an initial codebook.
The initial codebook included code names, code definitions, and an example piece of data for each code (MacQueen et al., 1998). The initial codebook also contained codes that emerged from the first step of data analysis (familiarization) that was completed by the entire research team. This enhanced the validity of the constructs that emerged from the data. In other words, the codes were shared constructs developed by the research team, not simply the codes that the PI developed independently (Kurasaki, 2000). The initial coding resulted in the identification of 61 distinct initial codes based on how the text was interpreted and described by the PI, with input from the entire research team.

**Identify and define themes**

Step 4 involved identifying and defining themes. Identifying themes involves convergence, or determining the pieces of data that “chunk together” (Guba, 1978). Recurring regularities in the data revealed patterns that could be sorted into themes or categories (Patton, 2015). The process of identifying themes was conducted via consensus. Each of the 61 codes identified within the preliminary version of the codebook was written on its own index card. The PI and her adviser, an expert in AAC, along with a second doctoral student, organized the codes into piles based on codes that related to one another. Ultimately, the 61 codes were reduced and combined into five major themes, each with at least two subthemes (range of two to five). Names and operational definitions were developed for each of the themes and subthemes. An additional theme was identified for quotations that were unrelated to the primary topic, such as general descriptions.
Refine codebook and assess reliability

Step 5 involved refining the codebook and assessing reliability. The PI developed an updated version of the codebook that included organization by themes and subthemes (see Appendix H). Based on recommendations from MacQueen et al. (1998) on codebook development, the PI had primary responsibility for developing, managing, and updating the codebook. This involved the following responsibilities: (1) adding new codes that emerged from the data, (2) developing operational definitions for codes, (3) identifying data examples for codes, (4) eliminating codes that were unused, (5) and maintaining a log of modifications made to the codebook based on team discussions.

The PI reviewed the codebook with the research team by discussing the major themes, subthemes, and codes. Then, the RAs each independently practiced coding a subset of data (i.e., half of one transcript). It is standard that “learning” the coding scheme in qualitative research occurs on a subset of the data (Campbell et al., 2013). After each member coded the data subset, the PI facilitated a discussion regarding the coding process. The team discussed the codes assigned to each thought unit and assessed the consistency of code application via subjective assessment. Coders discussed thought units for which they did not agree, discussed the reasons for the discrepancies, agreed on a solution, and recoded the data accordingly (Guest et al., 2014). A quantitative measure of reliability was not yet calculated. However, the codebook was reviewed and revised. This concluded the training phase on using the codebook.

In order to enhance reliability, intercoder agreement was calculated in the next sub-step of the coding process. Intercoder agreement is the extent to which two independent data analysts code the same data in the same way (Guest et al., 2014). Several methods have been used to calculate intercoder reliability including percent agreement (Boyatzis, 1998; Campbell et al., 2014; Miles & Huberman, 1984), Cohen’s kappa statistic (Cohen, 1960), and Krippendorff’s
alpha (Krippendorff, 1995). There has been discussion in qualitative research regarding the most appropriate metric to use for intercoder reliability (e.g., Burla et al., 2008, Campbell et al., 2013; Guest et al., 2014, Hruschka et al., 2004; MacQueen et al., 1998; MacPhail, Khoze, Abler & Panganathan, 2016). Several have argued that use of Cohen’s kappa or Krippendorff’s alpha are the most appropriate because they control for chance agreement (Burla et al., 2008; Hruschka et al., 2004; MacPhail et al., 2016). However, use of percent agreement has been advocated by others (Boyatzis, 1998; Campbell et al., 2013; Miles & Huberman, 1994). Specifically, Campbell et al. (2013) provided several compelling reasons for using percent agreement rather than a statistic that controls for agreement by chance (e.g., kappa, alpha). First, the use of alpha or kappa are based on the assumption that all codes have an equal probability of being used, which was not the case in this study. Second, the use of alpha or kappa assume that all coders have the same qualifications, which again was not true in this case, with the PI being more knowledgeable than the RAs. Third, there were a large number of subthemes (15), which reduced the likelihood that coders would agree by chance. Finally, since this was an exploratory study, percent agreement was deemed to be an acceptable approach. Moreover, it has been used in a recent qualitative study in the field (Mandak & Light, 2018).

Therefore, percent agreement was used to assess intercoder reliability. It was calculated as the number of agreements divided by the number of agreements plus disagreements (Miles & Huberman, 1984). After the training phase, each undergraduate RA was responsible for coding a subset of the data (two entire transcripts). The PI also coded every transcript and intercoder reliability was calculated for each transcript at the level of the 15 subthemes. Intercoder agreement was calculated after each team member completed coding for one transcript, and then again after the second transcript was coded. The aim was to achieve intercoder reliability of 80% to 90%, which is considered an acceptable level of agreement (Guest et al., 2014; Miles & Huberman, 1984). If an acceptable level of agreement was not reached, modifications were made
to the codebook and the data were recoded using the updated codebook. If an acceptable level of agreement was reached, the team members moved on to the final step of data analysis. Agreement was 83% on average across transcripts and coders, with a range of 80% to 89%. Agreement was generally at or above 80% after one round of coding, with the exception of one transcript by one RA that required a second round of coding to reach 80%. Clarifications were made to the codebook in order to reach an acceptable level of agreement on the second round of coding.

Resolve discrepancies and sort data

The final step of data analysis was resolving discrepancies in coding. Any discrepancies in codes between the PI and the RA were resolved through discussion until consensus for the final code was reached (Campbell et al., 2014; Hruschka et al., 2004). Finally, the data were sorted, so that all of the data assigned a certain code were grouped together (Braun & Clarke, 2006). This assisted with identifying participant quotations for each theme for the results.

Research Quality Indicators

Credibility

In order to establish methodological rigor in the current study, several indicators of research quality were considered. First, there were considerations of credibility (also referred to as believability; Lincoln & Guba, 1985), which is somewhat analogous to internal validity in quantitative research. Several strategies were used to enhance credibility. First, a peer review was completed (Creswell, 2012; Hays & Singh, 2014), which is an external check of study procedures and results by an individual external to the study who has expertise in the area. The PI’s adviser
served as the peer reviewer by asking questions about data collection and analysis procedures, methodology, meanings, and interpretations throughout the investigation. A second strategy to enhance credibility was triangulation, which refers to “using multiple forms of evidence at various points of qualitative inquiry to support and better describe findings” (Hays & Singh, 2014, p. 207). Specifically, this study utilized triangulation of investigators, by using a team data analysis strategy (Hays & Singh, 2014). This helped to ensure that the themes identified were not based on only the PI’s interpretation of the data, but rather a larger team of investigators. A third strategy used to enhance credibility was simultaneous data collection and analysis. This allowed the PI to identify important questions for future interviews, in order to probe areas identified by parents (Hays & Singh, 2014). The final strategy used to enhance credibility and minimize researcher bias was bracketing. According to Fischer (2009), “bracketing refers to an investigator’s identification of vested interests, personal experience, cultural factors, assumptions, and hunches that could influence how he or she views the study’s data.” The PI wrote a bracketing statement (see Appendix I) that summarized the lens used to view the study, personal biases, and past experiences with the phenomenon of interest. Additionally, the PI repeatedly used self-reflection processes throughout data collection and analysis to further bracket personal biases and to ensure that interpretations reflected participant experiences (Moustakas, 1994).

**Transferability**

Generalizability (i.e., external validity) is not a goal in qualitative research; however, transferability is a goal. Hays and Sigh (2014) suggest that the goal of transferability in qualitative research is “to provide a detailed enough description of participants, settings, and time frame so readers can make decisions about degree to which findings are applicable to individuals or settings in which they work” (p. 200). In order to enhance transferability, this study aimed to
provide a “thick description,” (Geertz, 1983) or a detailed account of the research process and outcome. Specifically, the PI aimed to provide a thick description of researcher questions, recruitment, participants, data collection procedures, data analysis steps, participant verbatim quotes, and trustworthiness strategies.

**Reliability**

Reliability refers to the consistency of results across researchers (Lincoln & Guba, 1985). Two strategies were used to enhance reliability. First, intercoder agreement between the PI and an independent RA coder was calculated to determine the extent to which independent data analysts coded the data in the same way. When percent agreement was below 80%, modifications were made to the codebook and data were recoded to reach acceptable levels of agreement. In addition, any discrepancies that existed after re-coding were resolved via consensus coding (Tracy, 2013). Assessing and achieving reliability between coders ensured that the codebook was a reliable instrument for measuring the thematic content of the data (Hruschka et al., 2004).

**Confirmability**

A final aspect of data quality in qualitative research is confirmability, which refers to the degree to which findings are genuine reflections of the participants investigated. Triangulation of investigators, simultaneous data collection and analysis, and think description were several strategies used to increase confirmability. Additionally, member checking was used. A member check asks participants to evaluate whether the researcher’s interpretation of their experiences is accurate (Given, 2008). Member checking was an ongoing process during data collection. The
interviewer asked for clarification and elaboration in response to participants statements’ during interviews and provided summarizing statements to ensure that the parents’ opinions were captured accurately. In addition to ongoing member checking during interviews, a member check was also completed after data analysis was completed. The PI shared the themes, subthemes, and examples with participants and solicited their feedback. See Appendix J for the document that was shared with participants. The PI asked the participants two questions: (1) Are these themes consistent with your experience, and (2) Is there anything that seems to be missing?

Six parents of six different children (i.e., 75% of participants) responded with feedback to the member check. All of the participants indicated that the themes and subthemes identified were consistent with their experiences. Three participants responded with additional comments. The additional comments were most often ideas that had been identified through the data analysis as codes; however, they were not explicitly listed on the data summary sheet shared with parents. As an example, one parent responded to the member check and identified the importance of modeling the use of AAC. This idea was captured within the parent roles subtheme; however, it was referred to as “interaction strategies.” Two parents made comments that had not emerged from the data or been captured in the coding scheme. One mother identified “assume competence” as an important idea, and she described this saying: “Just because a person may not respond to your communication initially, this is no reason to stop trying or to assume that they don't or cannot understand.” Another parent identified an addition to the integrating AAC theme. He stressed the importance of community acceptance, understanding and normalizing of AAC, saying, “The more people use it in public, the more comfortable they will be.” This additional data was included in the data analysis and write up of results.
Chapter 3

Results

The results are presented according to the five major themes that were identified: integrating AAC into life, AAC technologies, child needs and skills, parent responsibilities and priorities, and AAC process and decision making. Appendix K contains additional example data for each theme and subtheme.

Figure 3-1 provides a visual representation of the connections between the themes and their related subthemes. Three themes (i.e., AAC technologies, parent responsibilities and priorities, and child needs and skills) were encompassed in the overarching theme of integrating AAC technologies into life. This organization reflects how the degree to which AAC technologies were integrated into life was related to factors included within those three themes. As one specific example, the degree to which technologies were integrated into life was related to the supports and limitations of technologies within the AAC technologies theme. Technologies that included supports such as access to games and leisure activities increased their appeal and enhanced how well they were integrated into everyday life. Alternatively, the physical design limitation of AAC technologies, described by one parent as, “a bulky object between her [daughter] and the world” presented challenges for integrating them into life. The arrows between the three themes within the integrating AAC into life theme represent the reciprocal interactions between themes. As one example of this bi-directional relationship, children’s developmental and communication skills impacted how they were able to use AAC, and their use of AAC helped to advance their developmental and communication skills. One parent’s reflection that, “The device is limited because her mobility is limited,” (Amelia) demonstrated this relationship between developmental skills and AAC technologies. Finally, the process and decision-making theme is placed in an arrow at the bottom of the diagram, which reflects parent’s interpretation of the dynamic nature of
the process of supporting their child to use AAC within the functional contexts of everyday life and the changes that occur over time.

Figure 3-1. Diagram visualizing the relationships between themes.

The discussion will begin by introducing the integrating AAC theme, followed by a discussion of the three themes within, and end with a discussion of the AAC process and decision-making theme. The themes are organized and presented in this way in order to highlight the innovative results of this study compared to previous work, and to emphasize the themes that are related to the two research questions.
Integrating AAC into Life: Supports, Success Stories, Challenges, and Realities

Parents discussed the supports, success stories, challenges, and realities of integrating AAC into life. This theme included two subthemes, family and school and community. Table 3-1 provides a summary of codes and examples within each subtheme.

Table 3-1. Integrating AAC: Subthemes, codes, and examples

<table>
<thead>
<tr>
<th>Subtheme</th>
<th>Codes</th>
<th>Examples</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Family Supports and success stories</td>
<td>• Use of AAC in various family routines</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Use of multiple modalities</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Use of AAC with various family members</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Supports for family functioning</td>
</tr>
<tr>
<td></td>
<td>Challenges and realities</td>
<td>• AAC not available in all family routines (e.g., morning and evening care routines)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Little use of AAC with some family members</td>
</tr>
<tr>
<td>School and community</td>
<td>Supports and success stories</td>
<td>• Use of AAC in various contexts outside of the home</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Successful use of AAC with various partners</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Supportive partner interaction strategies</td>
</tr>
<tr>
<td></td>
<td>Challenges and realities</td>
<td>• Knowledge and training needs for partners</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Communication partner responses and attitudes</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• AAC not available in all contexts (e.g., physical activities, outdoors)</td>
</tr>
</tbody>
</table>

Integrating AAC into family life

Use or lack of use in family routines

Parents discussed success stories, challenges, and realities for integrating AAC into family routines. Children were able to successfully use AAC within family activities, such as games, play, book-reading activities, and mealtimes. One parent described how both she and her son were able to use his AAC device within one of her son’s preferred activities:
He’ll play the Play-Doh dentist. And he will talk during that, so he’ll be like, “teeth” and I’ll be like, “yeah, I know they’re gross… oh ‘gross’ isn’t there, let’s program that in.” And I program that in and forever after he knows what gross is. He’ll talk about the colors he wants and he’ll make requests for what color next. So we do incorporate it into activities and games at home. (Bailey)

While AAC was integrated into some family activities, parents also described challenges of integrating AAC into family routines. Morning care and bedtime routines were a particularly challenging time to integrate AAC, especially for parents of children using eye gaze devices that were primarily available when mounted on their children’s wheelchairs. Shannon described her son’s morning care routine saying:

So he doesn’t have access to it until the moment that he comes through once he’s dressed. You know so that sort of, when you’re lying in bed, and then someone’s dressing you, and then you’re being moved into a wheelchair, you know that’s quite hard to have a device available at those periods.

Despite the challenge of integrating AAC technologies in these contexts, parents described the use of various communication modalities in order to incorporate AAC. For example, children used facial gestures for yes/no, partner assisted scanning on static communication boards, and low-tech communication books and boards. One parent discussed how they had low-tech communication boards hanging on different rooms throughout their house, and on the wall in the shower, in order to provide access to AAC within everyday routines. Additionally, some parents preferred to rely primarily on unaided communication at home:

At home when it’s just us we use a lot of nonverbal communication, she’s very expressive. Her expressions and her tones when she makes noises and so forth, and we also use our own sign language with her, is a lot of our communication. We don’t necessarily use her talker all the time. She doesn’t always sit in her power chair, she might be sitting in an easy chair or lying on the couch or something. So it’s sort of our own personal style. (Emily)
Use or lack of use with various family members

Parents also described success stories and challenges of using AAC with various family members and individuals that were frequently in their homes. Use of AAC within sibling relationships was one topic parents discussed. Some parents described success stories, including sibling’s involvement with programming, modelling use of the technology, or charging batteries. Allison described a positive experience: “Our older son, knows how to do it [add vocabulary]. He has added things when they’re playing. So he will add dialogue for Zane. He’ll make up names for people and add them.” Other parents described challenges or realities of integrating AAC technologies into sibling relationships. For some children, their interactions with their siblings using AAC technologies were primarily needs-based (e.g., asking their sibling to do something for them). For other children, they were able to talk about their siblings using their device (e.g., “brother’s here”); however, they did not use it within actual interactions with their siblings. Instead, some children relied primarily on unaided AAC with siblings (facial expressions, gestures, body language). Parents also described use of AAC technologies with extended family members and other people at home including grandparents, other relatives, and home care aides. Allison described her son’s use of AAC with extended family members saying: “They are all comfortable with the talker to differing degrees, they all like to try to get him to use it.”

Supports for family functioning

A final important topic that parents discussed with regards to integrating AAC into family life were the supports for family functioning, which included other families of children who used AAC, home care aides, and online blogs and support groups. Regular interactions with other families of children who used AAC were a support for some families:
What we’ve found really helpful is finding other families who are AAC users. I don’t think we would be where we are today if I hadn’t found other families that were successful… locally, we were able to find a family that has a little girl that is really similar to my son… so I think that that has opened a lot of doors for us. (Lucy)

Families also described home care aides or “sitters” who came into their home several days per week to assist with their child’s care or provide respite services on weekends. Finally, online blogs and support groups were a source of support for some parents, one parent described them as a “good community of information” (Allison). Another parent (Lucy) described how she used the information available online: “I think that I’ll learn about something then I’ll kind of think about it and see if it fits into our lifestyle.”

**Integrating AAC into school and community**

**Use of AAC with various partners**

Parents discussed the supports, challenges, and realities of using AAC with multiple partners in school and community, which included discussion of knowledge and training needed for partners and communication partner attitudes and responses. Several parents discussed the knowledge and training needed for partners as a challenge:

One of the challenges for him is having people with him that know what they’re doing with the Tobii. So being with an unexpected person, or someone that’s not used to using it is a challenge. Because they might not know, you know, “How do I get this out of Luke’s school bag and put it on his stand and switch it on?” So, he always needs someone— But it is an added barrier that you have to have people who are familiar with the device. (Shannon)

Parents described communication partner attitudes and responses as both a support and a challenge. Several parents described partners’ use of effective interaction strategies to promote their child’s use of AAC at school as a support. School professionals (e.g., paraprofessionals, teachers) who modeled use of AAC, added vocabulary, and made sure the device was “part of
things” (Emily) served as a support for several children. Parents also described some success stories of using AAC with peers. One parent described how the eye gaze video games on her daughter’s device facilitated interactions with peers. Another parent described how peers supported her son to use AAC at Sunday school by clearing his message window and changing the volume, and she reported that the other kids “love it because it looks like an iPad to them” (Lucy). Other parents described challenges of using AAC with various partners. One particular challenge was that partners often did not have the skills or patience to provide their children with adequate wait time to formulate their utterances. Several parents described how this was particularly challenging for peers:

So I think if you’re in a social situation with a bunch of 8-year olds, and kids are moving, it’s just really hard because of the time it takes my son to get out whatever he wants to say. Kids have often times moved on. (Lucy)

Parents also explained that interaction with multiple partners was sometimes difficult because partners were “hesitant to touch” their children’s devices, and school staff were often “protective” of their devices, not allowing other children to touch them. However, parents wished that other children at school would be allowed to “experiment” with the technology when interacting with their children. Finally, parents described negative attitudes or responses of communication partners in the community as a challenge. Some partners only responded to “perfectly formed sentences,” while other partners looked to the parents for a response rather than the child.

**Use of AAC in multiple settings and contexts**

Parents discussed both success stories and challenges related to using AAC in multiple settings and contexts. Several parents discussed how their child was able to successfully use AAC throughout their school day:
The first thing they do when she gets in there is get the device mounted. And then throughout the day she’ll be using that for her recording of work, and communication, and answering questions in class or whatever it is. So it stays on all day at school. (Kelli)

However, several other parents reported that they felt that their children’s devices could be integrated more fully into the school day. Parents also discussed challenges and supports surrounding their child’s use of AAC in community, outdoor, and physical activities. Parents discussed challenges of integrating AAC technologies into physical activities, such as swimming, riding bikes, walking in a stander, riding horses, taking walks, and going to dance lessons. Due to the challenge of integrating AAC into these types of activities, the reality for many children was that AAC technologies were “not always available” (Jackie). Some parents described the use of low-tech AAC within physical activities, such as stop and go symbols when riding a bike, or a low-tech swimming page. Parents also described challenges of using technologies outdoors due to weather (i.e., rain and sunlight), or uneven surfaces. The parents of children who used eye gaze-controlled devices discussed inability to access their technologies in the sunlight, which caused frustration. Similarly, several parents brought up challenges with rain. A few parents also described challenges with having AAC technologies mounted on a wheelchair when going over uneven surfaces:

If you go over a little imperfect surface, and the chair wobbles a little bit, obviously the device is mounted higher above the chair, so that wobbles more than anything else…so it only really functions as a tool for speech inside, on a nice smooth surface, if you’re not moving around too much. (Kelli)

Due to these challenges, several parents discussed how technologies were mainly used indoors. Shannon summed up the challenges of integrating AAC into physical activities and outdoor settings:

He’s really dependent on it, and he really needs it with him all the time, but there are still these times or situations where you have to suddenly take away his voice, just because of the reality of where technology is at.
AAC Technologies

Given the challenges surrounding the effective integration of AAC into life, another theme discussed was AAC technologies which included supports of existing technologies, limitations of existing technologies, and ideal technologies. Table 3-2 provides a summary of the subthemes and examples.

Table 3-2. AAC technologies: Subthemes and examples.

<table>
<thead>
<tr>
<th>Subtheme</th>
<th>Examples</th>
</tr>
</thead>
</table>
| Supports | • Variety of vocabulary concepts available  
• Ease of programming (on the fly)  
• Access to multiple functions and features (e.g., environmental controls, internet, multiple languages, various software programs, games)  
• Appropriate design to fit with child’s needs (e.g., organization, selection technique)  
• Accessibility (portability, mounting)  
• Efficiency (word prediction, pre-programmed phrases) |
| Limitations | • Limited academic and interest related vocabulary  
• Programming challenges  
• Challenges finding and/or using other applications (e.g., social media)  
• Inappropriate design for child’s needs (e.g., representation, organization, voice output, morphosyntax)  
• Poor physical design (heavy, blocks partners, mounting challenges, lack of durability)  
• Inefficient and/or effortful selection technique  
• Unreliable (e.g., glitches) |
| Ideal | • Library of vocabulary folders to support ease of programming  
• Capability to program offline and edit across pages  
• Greater functionality with more features (e.g., control wheelchair, facial recognition software, projection)  
• Integrated (augmented reality applications)  
• Better representations  
• Age appropriate voice output options  
• Improved physical design (lighter, smaller, wearable, easier to mount, durable)  
• Features to enhance efficiency (brain-computer interface, sentence prediction, quick access) |
Supports of existing technologies

Parents discussed supports related to vocabulary and programming. The vocabulary available on their children’s devices served as a support that allowed their children to express a variety of concepts, including interest-related vocabulary, important people, physical state vocabulary (e.g., emotions and pain), academic vocabulary, core vocabulary, and displaced talk vocabulary. One parent discussed how the vocabulary on her son’s device allowed him to express discomfort, as well as to request items that were not available in the immediate environment, which were concepts he had been unable to express without his device. Several parents also discussed the ease of adding new vocabulary items as a support, describing programming as “easy,” “very straightforward,” and “very quick.” Parents generally indicated that they were able to add vocabulary “on the fly” within everyday interactions. Jackie described this saying, “We were watching a garbage truck, and he didn’t have garbage truck he had fire truck, ambulance, every other truck but no garbage truck. So it’s easy enough to add in on the fly.”

Parents also discussed supports related to design functions and features and how well various design features were matched to their children’s needs. Children’s ability to access multiple functions and features such as environmental controls, games and leisure activities, software programs, internet, multiple languages, and other communication tools (e.g., social media, email, Skype, Alexa) was another support of existing technologies. Access to games and leisure activities (e.g., painting, making music) also enhanced the appeal of technologies and increased children’s motivation and participation. Elizabeth described how the eye gaze video games on her daughter’s device were “one of her favorite things to do.” Allison described how the multiple languages feature supported another Zane to participate in Spanish class, “You push a button, it changes the whole thing to Spanish—which is actually kind of cool.” The fit between the design of the technology (e.g., organization, selection technique) and the child’s needs (e.g.,
motor skills, cognition) was another support. For example, several parents of eye gaze users discussed that selection technique as the most efficient and least effortful for their children compared to scanning methods: “Nothing else has worked but the eye gaze” (Kelli). Other parents discussed how the number of symbols and organization of their child’s technologies were appropriate to meet their needs.

Finally, parents described supports for accessibility and efficiency. Parents described physical design features that supported accessibility, such as portability and mounting. Parents of children using mobile technologies indicated that they were able to easily take their children’s devices on various outings. Parents of children who spent much of their time in wheelchair due to motor challenges discussed how mounting their children’s devices on their wheelchairs helped to ensure that it was accessible at all times: “Once it was mounted on her wheelchair and it then followed her everywhere. Finally, she can say what she wants to say when she wants to say it” (Kelli). Finally, parents described system features that enhanced efficiency such as word prediction and pre-programmed phrases.

Limitations of existing technologies

In addition to the supports reviewed above, parents also discussed limitations related to vocabulary and programming. One particular challenge parents discussed was a limitation in available academic vocabulary, which created challenges for effective participation at school. This limitation was exacerbated by challenges of adding large numbers of vocabulary words, which could be time consuming. As one parent explained, although programming was “pretty easy”, she went on to add that: “It’s not intuitive. You definitely have to learn how to do it. And, there are a lot of keys involved” (Emily). Other parents described that while adding vocabulary was easy for them, it was not as easy for other partners (e.g., father, grandparents). Another
programming limitation expressed by one parent was that changes made to one page did not carry across pages in the device, which she described as a “horrible design flaw.” (Bailey)

Parents also discussed limitations related to design functions and features and how well various design features were matched to their children’s needs. Parents described limitations in their children’s ability to access multiple functions and features, such as Facebook. For example, Kelli’s daughter had difficulty with the eye gaze precision needed to effectively utilize Facebook:

We don’t have a nice easy user interface for Facebook. She has to actually go in through the web browser and actually go into Facebook, the same way that anybody else will. But for her, eye pointing with her eyes, instead of with her hand on the mouse, it’s just really tricky because everything is so tiny. And you have to have such incredible accuracy to hit the like button for example, or to hit the comment box and then type in your comment.

Finding appropriate software and games that could be accessed via eye gaze was also a challenge, with one parent indicating she “beat the bushes” to find eye gaze video games for her daughter. Parents also reported limitations in technologies due to a lack of fit with their child’s needs. This included inappropriate organization or layout, inaccessible operational functions, inappropriate voices, and failure to support morphosyntax. For example, one parent discussed how her child’s system was organized alphabetically, even though he was not literate. Another parent described how the placement and size of the on/off button was inaccessible for her son: “We got a newer model, and they didn’t think about being able to turn it on. So like it’s a pretty small button, and it’s flat, and so he can’t turn on the device” (Jackie). Parents described the voices available as another feature that were not well matched to their child’s needs. Finally, several parents brought up limitations in current systems to support morphosyntax. Bailey said:

Morphology is kind of non-existent in some of them, like we just don’t use it sometimes because it seems distracting to the main idea, why is it distracting? Maybe it is because my son doesn’t know the difference between present progressive and past. Maybe he just doesn’t know. Maybe he would have if I would have had a better way to teach him, and a better system that supported that.
The physical design of technologies was another limitation discussed by parents, and this included discussion of size, weight, position between child and the world, and durability. One of the primary limitations was that technologies blocked children from engaging with partners:

If she wants to communicate with the device she’s basically forced to look on a screen all the time and it’s a bit cold, you know. It’s not a good situation for someone who is as socially in tune as she is. (Emily)

Other parents brought up the size and weight of the technologies, and the challenges this created for finding effective and robust mounting solutions. Lack of durability was also a limitation.

Several parents described current systems as “fragile” and prone to hardware issues, such as the USB port for the charger breaking.

Finally, parents discussed issues of efficiency, cost of use, and reliability. With regards to cost of use, parents described effortful access methods, describing access as “exhausting” and “so much work.” Lucy described the challenges of using eye gaze for her son:

I had hoped that it would be a simpler thing for him that he would just select it with his eyes…but because his eyes are attached to his head and his head is attached to the rest of him he never stays still. Even though this is his access method he still has major access issues.

Parents also described that the exact position needed to successfully utilize eye gaze methods was a challenge, particularly for providing access to AAC when their children were not in their wheelchairs. The slow rate of aided communication due to inefficient selection techniques was also a challenge. A final limitation reported by parents was reliability issues including crashes and glitches in technology (e.g., screen freezing, operating slowly).

**Ideal technologies**

Parents discussed features of ideal technologies to support programming, which included capability to program offline, access to a “library” of vocabulary folders, ease of adding
photographs, and capability to edit across pages when making modifications. Allison described
the idea of the vocabulary “library” to support addition of curricular vocabulary: “I would love a
library…where I could just hook his app into the school curriculum and just download it.”

Parents also described the functions and features that would be included on ideal
technologies in order to improve their functionality and use within daily activities, which
included facial recognition software, ability to control a wheelchair, projection onto the wall, and
augmented reality applications. Lucy described how facial recognition software, as part of a
“smart home,” could allow her son to live more independently in the future:

I would love for facial recognition technology to be available. I mean if he had a
smart home where there were cameras and he could open his mouth. The camera
could see that he opened his mouth, so he wouldn’t necessarily need a human
being there, but he could use his existing, very successful facial gestures…And I
think we’re getting close to technology that would allow him… If iPhones can
use your face to unlock their phone, why couldn’t he have cameras in certain
areas of his home that he could activate with his facial gestures?

Other parents hoped that their children could achieve greater independent mobility in the future,
by using their AAC devices to control their wheelchairs. Another parent discussed a projection
feature would be ideal, so her daughter would not always have to look at her device, and her AAC
display could instead be projected onto the wall. Parents discussed ideas such as “Google glass”
or “augmented reality glasses” having applications to their children’s AAC devices so that
technologies were more “integrated.” Jacob described this saying, “the AAC needs to be a natural
part of the person’s existence.”

Parents also provided suggestions for the physical design of ideal technologies such as
smaller, lighter, wearable, more discrete, improved mounting solutions, and more durable. In
order to address the issue of the device blocking partners, several parents suggested technologies
could be wearable and more discrete. Emily described this dream saying:

I would love to see something that would be more discrete. You know maybe
something in an eye glass, something that she could be using that weren’t such a
bulky object between her and the world.
Parents also discussed how mounting systems could be improved, so that there were a greater variety of affordable, accessible, and reliable mounting options. Finally, several parents described the technologies as more durable, describing ideal technologies as “robust,” “sturdy,” and able to “withstand a banging.”

Several parents described features of ideal technologies that would better fit with their child’s needs, which included better representations, age appropriate voices, and greater appeal. Better representations (symbols) of vocabulary items was a feature identified by several parents, with one parent indicating some of them were “unrecognizable” for her daughter. Another parent hoped for improvements in available voices, so her daughter could have a voice that was “unique to her as she becomes older” (Kelli). Finally, a few parents suggested that the appeal of technologies could be improved. Emily suggested that an ideal technology would be, “something really cute that a little girl would like.”

All parents described features of ideal technologies that would decrease the cost of use and improve efficiency, which included brain-computer interfaces, sentence prediction, and improved eye gaze access. Parents identified the potential to use “EEG sensors” and brain-computer interfaces for their children to have a more efficient and less effortful access method. Parents of children with significant motor limitations saw particular value in this feature:

I would love a world where his thoughts could be vocalized. He clearly is thinking what he wants to say—so I’d love that in some future world where that could be vocalized without the need to have all of this difficulty with muscle coordination going on. (Shannon)

Several parents also suggested sentence or phrase prediction would be an ideal feature to increase their child’s rate of communication.
Child Skills and Needs

The next major theme discussed by parents was the needs and skills of the child that related to his or her ability to use AAC effectively, which included developmental skills and needs, communication skills and needs, and psychosocial skills and needs. Table 3-3 provides a summary of the subthemes, codes, and examples for each code.

Table 3-3. Child skills and needs: Subthemes, codes and examples

<table>
<thead>
<tr>
<th>Subtheme</th>
<th>Codes</th>
<th>Examples</th>
</tr>
</thead>
<tbody>
<tr>
<td>Developmental skills and needs</td>
<td>Motor skills</td>
<td>• Finger isolation</td>
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<tr>
<td></td>
<td>• Motor control, spasticity</td>
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<tr>
<td></td>
<td>Cognition</td>
<td>• Intelligence</td>
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<td></td>
<td>• Attention</td>
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<td></td>
<td>• Memory</td>
<td></td>
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<tr>
<td></td>
<td>Sensory-perception</td>
<td>• Cortical visual impairment</td>
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<tr>
<td></td>
<td></td>
<td>• Hearing loss</td>
</tr>
<tr>
<td>Communication skills and needs</td>
<td>Operational skills</td>
<td>• Turning on/off device</td>
</tr>
<tr>
<td></td>
<td>• Navigating between displays</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Changing languages</td>
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<td></td>
<td>• Adjusting volume</td>
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<tr>
<td></td>
<td>Linguistic skills</td>
<td>• Semantics (knowledge/use of vocabulary)</td>
</tr>
<tr>
<td></td>
<td>• Syntax (combining symbols)</td>
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<tr>
<td></td>
<td>• Literacy skills</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Comprehension/receptive language</td>
<td></td>
</tr>
<tr>
<td>Social skills</td>
<td>• Conversational skills</td>
<td></td>
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<tr>
<td></td>
<td>• Use of a variety of communicative</td>
<td></td>
</tr>
<tr>
<td></td>
<td>functions</td>
<td></td>
</tr>
<tr>
<td>Strategic skills</td>
<td>• Use of telegraphic utterances</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Use of multiple modalities</td>
<td></td>
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<tr>
<td></td>
<td>• Communication breakdown repairs</td>
<td></td>
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<tr>
<td></td>
<td>(e.g., “sounds like” strategies)</td>
<td></td>
</tr>
<tr>
<td>Psychosocial skills and needs</td>
<td>Motivation</td>
<td>• Drive to communicate</td>
</tr>
<tr>
<td></td>
<td>Attitude</td>
<td>• Feelings or emotions regarding communication</td>
</tr>
<tr>
<td></td>
<td>Self-advocacy</td>
<td>• Asking for help</td>
</tr>
<tr>
<td></td>
<td>• Providing input on preferred</td>
<td></td>
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<tr>
<td></td>
<td>vocabulary</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Taking ownership of technology</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Personality</td>
<td>• Sense of humor</td>
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<td></td>
<td></td>
<td>• Demeanor</td>
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</tbody>
</table>
Developmental skills and needs

Parents discussed the developmental skills and needs of their children, and how these skills facilitated or presented challenges for using AAC technologies. Three codes within this subtheme were motor skills, cognition, and sensory-perception. In terms of motor skills, parents discussed how spasticity, lack of motor control, and difficulty with fine motor skills such as finger isolation created challenges for using AAC technologies. Amelia’s daughter Julia used direct selection with her whole hand, due to difficulties with finger isolation, and Amelia discussed how this limited the number of symbols that she could include on Julia’s AAC system:

There may be a word that she really wants, but there’s no way to give her that… I really can’t give her a slew of choices because of the motor…so I would say the device is limited because her mobility is limited.

Parents also discussed how their child’s cognition (i.e., intelligence, attention, memory) impacted their use of AAC. Parents described their children as “bright,” “fully aware,” and “super intelligent” which made learning and using AAC easier. Other parents discussed difficulties with attention and distraction that created some challenges for using AAC. Finally, Amelia discussed a history of hearing loss and her daughter’s cortical visual impairment, which impacted decisions regarding AAC, such as the number of symbols per page.

Communication skills and needs

Parents discussed children’s skills and needs related to operational and linguistic competence. Children employed various operational strategies to use AAC effectively such as turning on/off the device, switching languages, navigating between displays, changing the volume, using selection techniques (e.g., eye gaze), controlling other apps and communication tools, and producing reliable unaided codes that could be interpreted by partners (e.g., open
mouth for yes and blink for no). Some children were skilled in various operational competencies, while other children had difficulty with operational skills and required support. For example, one parent (Kelli) indicated that her daughter was an “expert” in using eye gaze as a selection technique, while other parents indicated that this was a skill their children were continuing to refine. Parents also discussed linguistic skills related to their children’s ability to use various vocabulary concepts, combine symbols on their AAC technologies, understand spoken language, and demonstrate literacy skills. Parents described how their children were able to independently form multi-symbol utterances; however, several parents indicated their children had difficulty with placing symbols in the correct order:

Her sentences and her syntax… don’t sound that natural. She’ll put a sentence together and the word order will be very jumbled. On Valentine’s Day she was trying to tell us she loved us and she said something like, “Sadie I love mommy daddy you. (Emily)

With regards to literacy skills, most children had emerging literacy skills, and were beginning to explore typing on their technologies, while one child (Luke) had advanced literacy skills and relied on typing to generate his messages.

Parents also discussed skills and needs related to the use of AAC within daily interactions (social skills and strategic skills). Children demonstrated various social skills and needs related to engaging in conversations, using greetings, and using a variety of communication functions. Several parents discussed how their children’s communication primarily concerned wants and needs, and they had difficulty with conversational skills. Other parents discussed how their child had progressed in their social skills, and their language had become more “witty,” “colloquial,” “chatty” and “funny.” One parent described her son’s improved social skills saying: “You can see a personality more now than in the past” (Shannon). Finally, parents described strategic skills that their children used to maximize the efficiency and effectiveness of their communication. Specific strategic skills that parents discussed included use of multiple modalities, communication
breakdown repair strategies, and use of telegraphic utterances to increase rate. Children used a
variety of communication modalities, including both aided and unaided modes (e.g., gestures,
vocalizations, body language, facial expressions) as a strategy to increase the effectiveness and
efficiency of their communication. Children also used strategies to compensate for limitations in
vocabulary on their devices. For example, Kelli indicated that her daughter used “sing” + “poor”

to communicate Singapore or “brown” + “knees” to communicate brownies.

**Psychosocial skills and needs**

Another subtheme discussed by parents was the child’s psychosocial skills and needs, and how these skills impacted use of AAC. This included discussion of the child’s motivation, attitude, self-advocacy, and personality. Parents discussed the child’s determination or desire to communicate. Motivation could serve as a support when the message was “important” to the child; however, motivation could be affected by the effort of using the technology:

> If he’s motivated enough he can get to every button on the screen. It’s just—it’s a lot of work for him and by the end of the day at school he’s just done. He has to want to do it. (Jackie)

Some parents discussed how motivation impacted development of social skills due to limited motivation to interact with various partners (e.g., peers) and preference for several highly preferred topics over others. Children had feelings and emotions surrounding use of AAC technologies. Parents described positive feelings associated with using AAC effectively such as “empowering,” “happy,” and “proud.” Challenges using technologies also contributed to negative feelings (e.g., “frustrated” or “mad”). Finally, children demonstrated various self-advocacy skills (e.g., choosing vocabulary, taking ownership of device, asking for help). One parent discussed how her son took ownership of his AAC device:
He’ll carry it to the table when he wants to sit down, he’ll carry it to the couch if he’s moving to the couch…So it’s really wonderful to see. Feeling like, I know what this is for and it’s helpful. (Bailey)

Parent Priorities and Responsibilities

The next major theme discussed by parents was parent priorities and responsibilities, which included two subthemes, parent roles and parent goals. Table 3-4 provides a summary of the subthemes, codes, and examples for each code.

Table 3-4. Parent responsibilities and priorities: Subthemes, codes, and examples

<table>
<thead>
<tr>
<th>Subthemes</th>
<th>Codes</th>
<th>Examples</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parent roles</td>
<td>Leadership</td>
<td>• Taking the lead on supporting child</td>
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<td></td>
<td></td>
<td>• Expert on child</td>
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<td></td>
<td></td>
<td>• Advocacy</td>
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<td></td>
<td></td>
<td>• Educating self and others</td>
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<td></td>
<td></td>
<td>• Everyday care (e.g., feeding, dressing)</td>
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<td></td>
<td></td>
<td>• Preparing for future</td>
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<tr>
<td></td>
<td>Device related</td>
<td>• Programming</td>
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<td></td>
<td></td>
<td>• Technical upkeep</td>
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<tr>
<td></td>
<td></td>
<td>• Supporting navigation</td>
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<td></td>
<td>Interaction strategies</td>
<td>• Modeling use of AAC</td>
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<td></td>
<td></td>
<td>• Waiting</td>
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<td></td>
<td></td>
<td>• Prompting</td>
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<tr>
<td></td>
<td></td>
<td>• Contingent responding</td>
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<td></td>
<td></td>
<td>• Providing choices</td>
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<tr>
<td></td>
<td></td>
<td>• Asking questions</td>
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<tr>
<td>Parent goals for child</td>
<td>Communicative competence</td>
<td>• Increased complexity of utterances</td>
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<tr>
<td></td>
<td></td>
<td>• Literacy skills</td>
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<tr>
<td></td>
<td></td>
<td>• Communication with peers</td>
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<tr>
<td></td>
<td></td>
<td>• Conversational skills</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Greater number and variety of partners</td>
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<tr>
<td></td>
<td></td>
<td>• More efficient communication</td>
</tr>
<tr>
<td></td>
<td>Independence and inclusion</td>
<td>• Use of multiple functions on device to support independence</td>
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<tr>
<td></td>
<td></td>
<td>• Inclusion with typically developing peers, in family and community</td>
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</table>
Parent roles

Parents described leadership as a primary responsibility. Parents discussed taking the lead on supporting their child with AAC:

We aren’t going to rely on anybody else to do it. We’re doing it…He would not be at the place where he is if we hadn’t taken it on. (Allison)

Parents took the lead by finding appropriate devices, serving as the primary communication partners for their children, and determining reliable communication methods (aided and unaided). Parents were experts on their children and their needs, and they advocated to make these needs known to professionals and companies funding their children’s technologies and equipment. Some parents described their advocacy role as having to “fight for” (Kelli) their child and make sure others “respect use of AAC and adapt to it” (Shannon). Parents also felt a responsibility to educate themselves and other communication partners about AAC and how to support their child in using AAC. This included educating home care-aides, teachers, spouses, extended family members, and other school professionals. Finally, parents took the lead on everyday caretaking responsibilities (e.g. feeding, dressing), as well as preparing their children for the future. Lucy described her role in supporting her son’s independence: “I’m his mom and I know where I want him to be as an adult and I feel like, it’s my responsibility to get him there.”

Parents also discussed specific device related roles and interaction strategies they used to support their child’s use of AAC. Parents reported adding academic, personal, and interest-related vocabulary, often times on the fly within everyday activities. Parents also described roles in technical upkeep of devices by running updates and finding software programs for their children to engage in leisure activities. Parents used various interaction strategies to encourage their child’s use of AAC, such as modeling use of the device, prompting, providing wait time, responding contingently, providing choices, and asking questions. The interaction strategy discussed most often by parents was modeling the use of AAC. Emily described this:
If I’m saying “Do you want to go to the pool today?” I’ll either use “want”, or “pool”, or “today” as part of what I’m saying. I’ll say it and I’ll hit that key at the same time. You know, just trying to involve it in what I’m saying.

**Parent goals**

Parents discussed the goals they had for their children that AAC could support, including increased communicative competence, independence, and inclusion. Several parents expressed priorities for their children to improve their linguistic skills, by forming more complex utterances and/or improving their literacy skills. Parents also had goals related to their children’s operational skills (e.g., email and internet use). Parents most often prioritized their children’s social skills including use of a variety of communication functions, improved conversational skills, expression of humor and personality, and interaction with a variety of partners, especially peers. Social skills were often priorities over other communication goals:

I would love to Julia to be able to express what she knows academically. But above and beyond that I would just love for her to be able to express what she’s thinking about anything. Just if it’s about whatever is funny about what she’s doing. If she sees something and she’s like, ‘Oh my gosh Mom, look at this… do you see this?’ Just those very basic things that people take for granted. Any kind of commenting. I feel like that could get her far in life. Even if she can’t do long division and know osmosis, I don’t really care. Because it would get her farther in life to have those interpersonal communication skills. (Amelia)

Finally, parents discussed priorities related to increased independence and inclusion for their children (i.e., in school, community, society). Parents discussed goals for independent living and inclusion with typically developing peers.

**AAC Process and Decision Making**

The AAC process and decision-making theme included various components and responses that related to supporting children’s ongoing use of AAC over time. It included five
subthemes: (a) device selection and customization, (b) learning AAC technologies, (c) feelings and emotional responses, (d) changes over time, and (e) collaboration with professionals. Table 3-5 provides a summary of subthemes and examples.

Table 3-5. AAC process and decision-making: Subthemes and examples.

<table>
<thead>
<tr>
<th>Subtheme</th>
<th>Examples</th>
</tr>
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<tbody>
<tr>
<td>Device selection and customization</td>
<td>• AAC assessment and device acquisition (trialing, funding)</td>
</tr>
<tr>
<td></td>
<td>• Parents role in process</td>
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<tr>
<td></td>
<td>• Customizing technologies (e.g., changing number of symbols)</td>
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<tr>
<td>Learning AAC technologies</td>
<td>• History of AAC use (e.g., starting early)</td>
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<tr>
<td></td>
<td>• Lack of training for families</td>
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<td></td>
<td>• Cost of learning</td>
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<td></td>
<td>• Independent exploration by children</td>
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<tr>
<td>Feelings and emotional responses</td>
<td>• Feelings about future (positive, unsure)</td>
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<td></td>
<td>• Accepting situation (diagnosis, lack of speech)</td>
</tr>
<tr>
<td>Changes over time</td>
<td>• Transitions (new school, new therapists, new technologies)</td>
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<tr>
<td></td>
<td>• Progress</td>
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<td></td>
<td>• Technology changes</td>
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<tr>
<td>Collaboration with professionals</td>
<td>Positive collaboration:</td>
</tr>
<tr>
<td></td>
<td>• Supportive professionals</td>
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<td></td>
<td>• Buy-in</td>
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<td></td>
<td>Negative collaboration:</td>
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<tr>
<td></td>
<td>• Uneducated, disinterested, or mistrusting professionals</td>
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Device selection and customization

The device selection and customization subtheme involved discussion of AAC assessment and device acquisition, parents’ role in the assessment process, and customizing technologies. Parents who participated in formal assessments described the long wait time for acquiring the device after the assessment. Many parents were very “hands on” in the selection process and purchased their child’s device themselves. Emily discussed how her family purchased her daughter’s eye gaze device due to issues with her daughter’s school allowing her to bring home her device:
We made the decision to buy her device, and I think that was a great decision, and I’m glad that issue is resolved. That this is her voice and this is what she’s using and that subject is closed.

Parents also described the process of customizing technologies by changing the number of symbols, determining appropriate selection techniques, and changing voices. Jackie discussed the process of determining the appropriate number of symbols per page on her son’s device:

We started at 12 [symbols per page] then he went to 16. More buttons, he needed more buttons. They [school] had gone up to 48 buttons per [page]. We tried it for a little while and I said this is too much. So we backed it down to 42.

Other parents described the process of determining selection techniques. For example, several children had used scanning access in the past and had changed and were currently using eye gaze access.

**Learning technologies**

Parents discussed the process of learning technologies, for themselves and their children. This included discussion of history of AAC use (unaided, low-tech, and hi-tech), lack of training for families, cost of learning, and independent exploration by children. Parents indicated that their children started using some form of AAC from an early age, which included low-tech symbols and unaided modes (e.g., facial gestures for yes/no). Parents also described the process of learning high-tech devices. Several parents indicated lack of training on AAC as a challenge that could be “bewildering.” One parent described the learning process: “We didn’t know what we were doing… so we were just figuring it out as a family” (Allison). Parents indicated that technologies often had a “steep learning curve” upfront.
Parents’ feelings and emotional responses

Parents discussed feelings and emotional responses surrounding their child’s use of AAC and their role in the process, which included emotional responses related to competing demands and feelings about the future. One parent described the competing demands she experienced:

I feel like her dietician and her nutritionist, I feel like her therapist, I feel like her teacher. And finally there comes a point where I also want to feel like Mom… And even my husband told me, I feel like we’re just so consumed with doing and trying to get her where she needs to be that you forget that there’s a whole other aspect of life. (Amelia)

Parents felt a mix of emotions about the future, some expressing positive emotions such as hopefulness, indicating that there was “loads of potential” in the future. Other parents felt more unsure about the future and what their child would be able to achieve. One parent discussed how she was unsure about realistic expectations for her daughter: “What is she capable of? What’s going to happen? What can we expect here? Is there going to be a big break through? I don’t know. Are my expectations too high? Or are they too low?” (Emily)

Changes over time

Parents discussed changes that occurred over time throughout the process of supporting their children to use AAC, which included discussion of transitions, progress, and technology changes. Transition times were a challenge, especially when families moved or children changed schools, because it required families to “start over” with a new group of professionals. Parents discussed improvements in technologies over time, such as improved ability to hear devices, lighter technologies, more storage, and greater reliability. Kelli described the changes in technology saying, “The technology does move on all the time, who knows what the next device is going to look like or how it’s going to behave.”
Collaboration with professionals

The final subtheme discussed by parents regarding the process was collaboration with professionals, which included both positive and negative experiences. Parents discussed positive collaboration with professionals who helped to program and modify technologies, provided training for school staff, and shared information to support informed family decision making. Parents used words such as “passionate,” “awesome,” “smart,” “enthusiastic,” “supportive,” “willing to learn,” “open-minded,” “wonderful,” and “great” to describe professionals. Shannon described her family’s positive experience with professionals:

We are very lucky that we have managed to get really enthusiastic speech and language therapists who have been really up for this and have pioneered this in their department and have pushed themselves to learn new things and have really been very very supportive and put a lot of time into it.

Parents also discussed negative experiences collaborating with professionals which generally involved mistrusting professionals, uneducated professionals, or lack of “buy-in” from professionals at school. Parents discussed that professionals at times doubted what their children were capable of and were hesitant to recommend hi-tech devices despite parents’ interest. Professionals sometimes didn’t have the “skill set” in using devices. Finally, several parents discussed a lack of “buy-in” from professionals or schools to support their child in using AAC.
Chapter 4

Discussion

As noted in the Introduction, AAC technologies should be designed not only to fit with the underlying processing skills of the child, but also to fit with family values, goals, priorities, and lifestyle. The aim of this study was to gain parents’ perspectives on the features of AAC technologies that facilitated or presented barriers to use of AAC within functional contexts of daily life (i.e., family routines, contexts in which use of AAC was valued by families). Parents indicated that AAC technologies supported their children to work towards family-identified goals. Parents were able to support their children using AAC technologies, and they felt “hopeful” about the potential of technologies in the future. Nonetheless, they recognized that challenges still remain, which require “a lot of work to be done” in order to truly integrate technologies into life.

The discussion will overview each of the five themes described in the results. The discussion of each theme will include a consideration of how the findings of this study align with, differ from, or provide additional information from previous research and theory, as well as a consideration of the implications for practice and/or the design of AAC technologies. Table 4-1 provides a summary of each theme and implications, that are expanded upon in the text.

Table 4-1 Summary of themes and implications

<table>
<thead>
<tr>
<th>Theme</th>
<th>Summarizing statement(s)</th>
<th>Implications</th>
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<tbody>
<tr>
<td>Integrating AAC into life</td>
<td>• Children were able to use AAC technologies with various partners and in various contexts, both within the family and outside of the family</td>
<td>• Talk to families to identify meaningful activities that children and families participate in frequently in which families value the use of AAC technologies, and brainstorm ways for families to integrate AAC into those activities (if they aren’t already)</td>
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<td></td>
<td>• AAC was not always available, particularly during physical activities, outdoor activities, and morning and evening care routines</td>
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<td></td>
<td>• Children and families often relied on multiple modalities, including</td>
<td>• Support communication partners in knowledge and skills required to</td>
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<tr>
<th><strong>unaided AAC and low-tech AAC as a strategy to support communication when technologies were not available</strong></th>
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<td>• Partners who used effective interaction strategies served as a support, while partners who lacked knowledge regarding how to operate technologies and use appropriate interaction strategies presented a challenge</td>
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<tr>
<th><strong>operate AAC technologies and use effective interaction strategies</strong></th>
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<tr>
<td>• Support continued use of multi-modal communication techniques</td>
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<tr>
<td>• Develop technologies that can be more easily integrated into life, to ensure that AAC is always available (e.g., durable, lightweight, greater accessibility in rain and sunlight, augmented reality features)</td>
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<th><strong>AAC Technologies</strong></th>
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<tr>
<td>• Current AAC technologies had features that supported participation in functional contexts of everyday life and also features that presented barriers for participation</td>
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<td>• Parents had unique ideas for improving the design of technologies</td>
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<tr>
<th><strong>Continue to provide families with access to features that support their child’s and family members’ participation (e.g., ease of programming, environmental controls, games and leisure activities, features to support accessibility and efficiency)</strong></th>
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<tr>
<td>• Conduct future research and development with a multi-disciplinary approach that includes individuals who use AAC and their families, clinicians, researchers, rehabilitation engineers, and mainstream technology developers in order to address design limitations and improve the design of technologies</td>
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<tr>
<th><strong>Child Needs and Skills</strong></th>
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<tr>
<td>• Children were developing skills that contributed to communicative competence</td>
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<tr>
<td>• Developmental needs and skills and psychosocial factors contributed (positively or negatively) to their ability to effectively use AAC</td>
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<th><strong>Seek parents’ expert input on their child’s developmental and psychosocial needs and skills</strong></th>
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<td>• Use parents’ expert knowledge to customize technologies to meet the needs of individual children</td>
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<td>• Empower parents to support their children to develop communicative competence, especially social and linguistic skills</td>
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<tr>
<th><strong>Parent responsibilities and priorities</strong></th>
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<tr>
<td>• Parents took a leadership role in supporting their child to use AAC by advocating for their child’s needs, programming technologies, and using interaction strategies to support their child’s use of AAC</td>
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<tr>
<td>• Parents prioritized their children’s development of communicative</td>
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<tr>
<th><strong>Demonstrate sensitivity to the competing demands of everyday family life</strong></th>
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<tr>
<td>• Assist with programming and technical upkeep of technologies</td>
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<tr>
<td>• Provide supports for parents to model use of AAC technologies and use other supportive interaction strategies</td>
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</table>
Parents discussed supports and success stories for integrating AAC technologies into life including use of AAC with various partners at home (e.g., siblings, extended family members, care aides), in various family routines (e.g., playing games, dinner times), at school, and in the community. Parents descriptions of children’s use of AAC in various family subsystems and in nested systems outside of the family context reflect theoretical understanding of the structure of families (Bronfenbrenner, 1979; Minuchin, 1985). Previous research has indicated that AAC technologies support children to interact in a wider variety of settings and with a greater variety of partners (e.g., Bailey et al., 2006). Communication partners who were knowledgeable about interaction strategies (e.g., modeling, providing wait time) and operational competencies (e.g.,
programming, technical upkeep) supported the integration of AAC into various routines at home, school, and in the community.

Parents also identified supports for family functioning that facilitated positive family adaptation to stressors and maintenance of a healthy family homeostasis (Gallimore et al., 1996; Olson et al., 1979), such as interactions with families of other children who used AAC, online blogs and support groups, and home care aides. For example, Lucy’s sentiment that, “It is very important for our family to have a supportive community of AAC families” demonstrated how support from other families promoted her family’s positive adaptation. Families also benefitted from online blogs and support groups, which provided a “good community of information” (Allison). Other families relied on home care aids and respite services as a source of support, one mother (Shannon) stating, “We rely quite heavily on support systems.” Previous research has demonstrated that perceived social supports and support networks foster positive family adaptation to the stressors of raising a child with a developmental disability (e.g., Barnett, Clements, Kaplan-Estrin, & Fialka, 2003; Greef & Nolting, 2013; Hauser-Cram et al., 2001). The experiences of parents in this study demonstrated that families of children who used AAC also benefitted from these social supports.

The parents in this study also provided unique insights regarding the challenges and realities of integrating AAC into everyday life. Parents identified some of the same challenges that have been identified in previous research, such as negative reactions from partners, poor communication skills of partners, and difficulty handling device breakdowns (e.g., Crisp et al., 2014; Goldbart & Marshall, 2004; McNaughton et al., 2008). An additional challenge discussed by parents was the reality that AAC was “not always available,” particularly during physical activities, outdoor activities, and care routines. Devices controlled via eye gaze were not accessible in the sunlight, and uneven surfaces caused mounted devices to “wobble,” which often
meant that devices were mainly used indoors. Children’s use of multiple modalities of communication was useful in situations when technologies were not available.

**Implications for practice and the design of technologies**

The parents in this study were able to integrate AAC effectively in a variety of activities; however, some families may value their child’s use of AAC within everyday activities but require additional support from professionals to integrate AAC effectively (e.g., Anderson et al., 2016). Professionals can work collaboratively with these families to identify contexts in which families value their child’s use of AAC and then brainstorm with families about ways to integrate AAC into those activities. The use of routines-based intervention and support of communication within natural contexts has extensive support in speech-language pathology and early intervention (e.g., McWilliam, 2010; Woods, Kashinath & Goldstein, 2004; Woods, Wilcox, Freidman, & Murch, 2011). For example, O’Neill, Mandak and Wilkinson (2017) proposed that home-based family leisure activities may be a supportive context for the integration of AAC. Professionals may use tools such as the Interest-Based Everyday Activity Checklist (Swanson, Raab, Roper & Dunst, 2006) or identifying Family Activities and Routines Conversation Starters (Woods-Cripe & Lindeman, 2012) to work collaboratively with families to identify routines that they value for integrating AAC. Integrating AAC into existing activities should be less disruptive of family routines and serve to maintain the family’s homeostasis (Mandak et al., 2017).

Environmental supports must be in place to ensure that children are able to use AAC technologies within these valued contexts (Light & McNaughton, 2014a). While the parents in this study had advanced knowledge regarding operation of their children’s devices and use of supportive interaction strategies, this was not always true of other partners that their children interacted with frequently. This presented a challenge for children in using AAC across multiple
environments. Professionals (i.e., speech-language pathologists) can support various partners in knowledge and skills to operate AAC technologies and use appropriate interaction strategies.

There is also a need for future research and development so that AAC technologies can truly be integrated into everyday life and used across environments and contexts (e.g., physical activities, outdoor activities, care routines, noisy environments). Parents prioritized features such as being lightweight, durable, and water resistant. While mobile technologies are quite lightweight (e.g., iPad weighs 1.03 lbs.), dedicated devices accessed via eye gaze are often not this lightweight. For example, the weight of use gaze devices used by children in this study ranged from 5.9 lbs. (PRC accent 1400) to 8.4 lbs. (Tobii i15). Tools such as the PCEye mini from Tobii Dynavox, which can attach to a tablet and allow children to access tablets via eye gaze, may provide access to more lightweight options for some children. Weight should not come at the price of durability, another feature prioritized by parents. It appears that technology manufacturers have begun to make advancements in the features that support the integration of technologies into life. For example, Tobii Dynavox, recently released a new device (i.e., I-110) that they described in a press release, “With its highly durable and water-resistant design, it offers fully integrated features such as powerful outward facing speakers that project clear speech and sound in any environment, even when in a crowd or on a playground” (Tobii Dynavox, 2017). It is critical that AAC manufacturers and technology developers engage in participatory design research with individuals who use AAC and their families in order to address the design limitations of existing technologies and work towards developing technologies that meet the needs of individual users (Muller & Druin, 2009).

Another key takeaway from this investigation was that current AAC technologies were not always available to the children who used them, which deserves attention. Communicating via AAC requires a physical device that is external to the child. For children that use their finger to access devices, this means that their hands must be free to access the device. For children that
use eye-gaze controlled devices, it means that they must be positioned in a particular way, often sitting with their device mounted to their wheelchair, and out of any direct sunlight. Due to these realities, AAC technologies are not always available, particularly during care routines, within physical activities, and outdoors. One technology advancement that has the potential to provide access to communication that is truly integrated into life, or “a natural part of the child’s existence,” is the use of augmented reality (Boster & McCarthy, 2017a; Richtsmeier & Light, 2016). Augmented reality (AR) is a medium in which digital information is overlaid directly on the real-world experience of the individual using the technology via 2-D or 3-D holographs (Craig, 2013; Hong, Yeom, Jang, Hong & Lee, 2014). Microsoft recently released Hololens—a holographic computer built into a headset that allows users to see, hear, and interact with holograms overlaid on real-world environments. For individuals that use AAC, AR technologies have the potential to make AAC a natural part of the environment. For example, words, messages, or symbols could be super-imposed on real objects/events in the environment that children could select to communicate. However, existing AR technologies rely on both head and body movements, which would make them inaccessible for many children with severe motor impairments such as CP. Additionally, potential applications of AR to AAC technologies have been untested, and there could be come disadvantages, such as disengagement from real-world interactions and visual perception and processing overload (Boster & McCarthy, 2017b; Richtsmeier & Light, 2016). Nonetheless, AR technologies have the potential to support integration of AAC technologies into life, and potential applications of AR to AAC technologies deserves attention from technology developers.
Summary and consideration of previous research

The overarching idea from parents’ discussion of the limitations, supports, and features of ideal technologies was summarized by one parent when he said: “They’ve improved it [the technology], but it still needs improvement” (Jacob). Parents recognized that technologies were able to support their children in participating in everyday activities, and technology design had improved over time; however, they recognized that additional improvements were needed order to maximize efficiency and minimize demands of use. With regards to limitations, parents discussed some of the same features that have been identified in previous research investigations of parents’ perspectives on AAC including lack of appropriate vocabulary, programming challenges, inappropriate voices, heavy devices, inefficient access techniques, and technical reliability issues (Bailey et al., 2006; Crisp et al., 2014; Goldbart & Marshall, 2004; McCord & Soto, 2004; McNaughton et al., 2008; Parette et al., 2000). Very little research to date has asked parents about their preferences for ideal technologies to meet children and family needs (although see, Boster & McCarthy, 2017b). The features of ideal technologies identified by parents in this study mainly concerned functionality, integration of multiple features, and efficiency (e.g., ease of programing, facial recognition software, better representations, age appropriate voices, improved physical design, projection capabilities, brain-computer interface, and durability).

The introduction reviewed four components of AAC system design that speech-language pathologists have considered clinically (e.g., Thistle & Wilkinson, 2015) and that have been researched empirically: representation (e.g., Worah et al., 2015) organization and layout (e.g., Drager et al., 2003; Fallon et al., 2003) selection technique (e.g., McCarthy et al., 2006; 2017), and system appeal (e.g., Light et al., 2004; 2007). These four areas were also discussed by parents
to some extent, although some components (e.g., selection technique, system appeal) received more attention than others (e.g., representation, organization and layout). Overall, while parents recognize some of the same features prioritized by clinicians and researched empirically, this investigation demonstrated that they also have unique and varying insights.

**Implications for the design of AAC technologies**

It is incumbent on technology manufacturers, app developers, and clinicians to work to consider parents’ input when designing AAC technologies and displays. Specifically, we must continue to provide families with access to features that support their child’s participation in the functional contexts of everyday life and address the technology design limitations identified by parents. In order to meet these goals, future research and development should involve a multidisciplinary approach that includes children who use AAC and their families, clinicians and practitioners, AAC researchers, rehabilitation engineers, and mainstream technology developers. Mainstream technology developers should work to increase accessibility to mobile technologies and apps for individuals with significant motor impairments. Ultimately, the benefits of using AAC must outweigh the challenges experienced by children and their families to ensure adoption and long-term use of technologies. The suggestions provided by parents in this study provide an excellent step in working towards this goal.

Research by technology developers has begun to investigate some of the ideal features identified by parents. The viability of brain-computer interfaces as an access option has received considerable attention (e.g., Akcakaya et al., 2014; Brumberg et al., 2018). However, brain-computer interfaces are generally not as efficient as existing AAC access methods, and they do not yet have the ability to directly translate thoughts or speech plans into communication (Brumberg et al., 2018). Invasive brain-computer interfaces that involve implantation of
electrodes on the brain are just beginning to investigate the ability to directly access thoughts, utterances, and speech motor plans from the brain (e.g., Chakrabati, Sandberg, Brumberg & Krusienski, 2015). Therefore, it is possible that one mother’s dream of a world where her son’s “thoughts could be vocalized” could be feasible in the future; however, brain-computer interfaces are not currently a viable access option for children with CP, and much more research has to be done in this area.

Several other features that parents identified have received some research within technology development research, including capability to create unique voices and features to enhance efficiency. Individuals who use AAC can create custom digital voices using VocaliD\textsuperscript{21}. VocaliD is a system that combines voice characteristics of the AAC user (i.e., from prolonged vowel-like utterances) with the characteristics of an age-matched healthy speaker using voice transformation techniques, in order to create personalized voices (Jreige, Patel & Bunnell, 2009). In regards to efficiency, technology is currently under development to design a new AAC technology to increase the speed of face-to-face communication by using phrases suggested by a co-constructor, as well as word and phrase prediction (Jakobs & Fried-Oken, 2014). It is critical that future research continue to examine ways to enhance efficiency for children that use AAC with varying levels of literacy and motor skills.

**Child Skills and Needs**

**Summary and consideration of previous research and theory**

The same skills and needs of children that have been identified from a theoretical, empirical, and clinical perspective as important considerations when designing AAC technologies were recognized by parents in this study. Theoretically, it has been argued that the design of AAC
technologies should be sensitive to children’s developmental needs and skills across the domains of communication, cognition, sensory-perception, and motor skills in order to achieve a good fit with the child (Light & McNaughton, 2014b; O’Neill & Wilkinson 2017). Clinically, speech-language pathologists also identify the cognitive and motor skills of the child as important considerations (Johnson et al., 2006; Thistle & Wilkinson, 2015). Additionally, empirical evidence is starting to map out how the various design features of AAC technologies do in fact produce reliable changes in how children respond to and use AAC technologies (e.g., Liang, Wilkinson & Sainburg, 2018; O’Neill et al., in preparation; Wilkinson et al., 2014). Parents in this study validated the importance of considering these various developmental needs and skills.

Parents reported that their children were able to demonstrate various operational skills (e.g., navigating between displays, using environmental controls), linguistic skills (e.g., forming multi-symbol utterances), social skills (e.g., using a variety of communicative functions) and strategic skills (e.g., using multiple modalities to increase communication effectiveness) within functional contexts of daily life. Parents also recognized some areas of difficulty, particularly related to advanced conversational skills and syntax (i.e., forming sentences in the correct order). Light (1989, 2003) and Light & McNaughton (2014a) recognized the importance of knowledge, judgment, and skills in these four inter-related domains in order to achieve communicative competence. Research has indicated that children can develop various communication skills across these domains using AAC technologies within structured intervention contexts (e.g., Binger & Light, 2007; Binger, Maguire-Marshall, & Kent-Walsh, 2011; McCarthy et al., 2006; Sigafoos et al., 2004). This study provided evidence from parents that children are able to develop these skills using AAC technologies within functional settings of everyday life.

Important psychosocial factors recognized by parents (e.g., motivation, attitude) have also been discussed both theoretically and clinically. Light and McNaughton (2014) recognized the importance of psychosocial factors that impact a child’s use of AAC. Speech-language
pathologists have also recognized the importance of psychosocial factors, ranking “the degree to which the person using the system experiences success” (Johnson et al., 2006, p. 91) and “the degree to which the system is valued by the user” (Johnson et al., 2006, p. 91) as the two leading factors contributing to the long-term success of AAC technologies. Parents in this study discussed how motivation could act in a positive way when children had to desire to communicate using their technologies, or it could act in the negative way, when the demands of using the system outweighed the benefits.

**Implications for practice and the design of AAC technologies**

Parents are experts on their children, and they have expert input regarding the developmental needs and skills and psychosocial factors that facilitate or present barriers to their children’s use of AAC; therefore, professionals should seek this input from parents and utilize it to design displays that match with individual children’s needs. Additionally, professionals should support parents to help children develop knowledge and skills in various domains of operational, linguistic, social, and strategic competence. In particular, families may need additional support in helping their child to develop more advanced social conversational skills and morpho-syntactic skills. Finally, professionals should encourage the use of multiple modalities of communication in order to maximize communicative efficiency and effectiveness.
Parent responsibilities and priorities

Summary and consideration of previous research

Parents took a leadership role in the AAC process by assuming various responsibilities such as researching and purchasing their child’s device, using interaction strategies, educating others partners, advocating for their child’s needs and programming technologies. Some previous research has indicated that parents take a leadership role in decision-making, programming, and supporting their child’s use of AAC (e.g., McNaughton et al., 2008), while other research has indicated that parents feel that teaching the child and establishing the device should be a primary responsibility of professionals (e.g., Anderson et al., 2014; Parette et al., 2000).

Parents reported being able to successfully model use of their children’s technologies, and they reported positive communicative gains in their children as a result of this aided input. Modeling use of AAC by parents has received little attention in previous parent reports. It is a technique where communication partners point to symbols on the child’s AAC system while interacting with him/her. It has been referred to by various names in the literature (e.g., aided AAC input, aided language stimulation, aided language modeling, partner augmented input; Binger & Light, 2007; Drager et al., 2006; Harris & Reichle, 2004; Romski et al., 2010; Senner & Baud, 2017). Modeling is an evidence-based intervention to improve both comprehension and expression for children that use AAC (Allen, Schlosser, Brock, & Shane, 2017; O’Neill, Light & Pope, in press). Previous research indicates that parents can learn to model within structured intervention contexts (e.g., Kasari et al., 2014; Kent-Walsh, Binger & Hasham, 2010; Romski et al., 2010.), and parents have expressed a desire for training on strategies to support their child’s use of AAC (e.g., Anderson et al., 2016; Meder & Wegner, 2015). This study suggests that parents are using these strategies within everyday life.
Parents in the current study identified goals for their children related to communicative competence (i.e., linguistic, social, and operational skills) and independence and inclusion. Parents generally placed greatest emphasis on social skills such as conversation and communication with peers. This was reflected by one mother who prioritized “interpersonal communication skills” over “knowing long division or osmosis.” With regards to achieving independence, parents felt that their children’s ability to use the various functions and features on the device (e.g., environmental control, accessing internet) were important goals to support their independence. Parents have expressed similar goals for improved social interactions, greater independence, and communication in a variety of settings with a variety of partners in previous research (e.g., Bailey et al., 2006; McNaughton et al., 2008).

**Implications for practice**

Parents experiences reflected that the introduction of AAC technologies into family systems required adaptation—parents and other family members were required to manage various roles and responsibilities due to the introduction of AAC technologies. Professionals must be sensitive to the competing needs and demands of everyday life (McNaughton et al., 2008). Professionals can play a role in supporting families to adapt to AAC technologies and make them part of the family’s homeostasis. Professionals may be able to help parents by managing some of the programming and technical upkeep of AAC technologies. Parents in this study who did receive professional assistance with programming valued this support, while others who received little support expressed a desire for more support. Professionals may also be able to support parents in using specific interaction strategies such as modelling use of AAC.

Professionals should engage in collaborative goal-setting with families in order to ensure that AAC technologies are responsive to their priorities and needs and allow children to work
towards goals that are prioritized by the family (King & Chiarello, 2014). In this study, there was variability regarding the extent to which AAC technologies helped children to meet parent-identified goals. For example, parents valued their children’s development of advanced linguistic skills and social conversation skills; however, they indicated that children continued to have difficulties with these skills. Collaborative goal setting involves a process of teaming with parents in order to identify and prioritize meaningful outcomes and ensure that AAC services and technologies help the child and family to meet these outcomes. Professionals may ask questions such as: What would you like your child to be doing that he/she is not doing now? (Crais, 2011). How might we help him/her to achieve this goal? By aligning the AAC services and technologies with family priorities, there will be a greater likelihood of long-term success with the AAC system. Additionally, it is likely to result in an improved partnership, enhanced feelings of competence, and greater parent engagement (King & Chiarello, 2014).

**AAC Process and Decision-Making**

**Summary and consideration of previous research**

Many parents reported taking the lead in the device selection, customization, and learning process, with parents often purchasing dedicated devices or mobile technologies without a formal assessment. Parents decided to do this for various reasons, including the long time required to acquire a device, disagreements with professionals regarding the most appropriate device for their child, or school districts not allowing children to bring their technologies home. In contrast, previous research has often reported a lack of family involvement in device selection (e.g., Anderson et al., 2014; Bailey et al., 2006; Goldbart & Marshall, 2004). Given the widespread availability of mobile technologies, it is possible that parents are becoming more comfortable
with technologies, which is empowering them to take the lead in acquiring and using AAC technologies.

While collaboration was not the focus for this study, it was discussed by all parents, which highlights the importance that parents place on this component of the AAC process. Previous research with parents has identified challenges surrounding collaboration (e.g., untrained professionals, lack of buy-in; Anderson et al., 2014; Bailey et al., 2006; Crisp et al., 2014 McNaughton et al., 2008). Parents in this study did recognize some of these same challenges with collaboration; however, they also described positive experiences. The mix of both positive and negative collaborations with professionals could be related to policy changes and pre-service training in AAC and working with families. As of 2005, “augmentative and alternative communication modalities” became of the nine content areas in which speech-language pathologists must demonstrate knowledge and skills. Therefore, graduate programs are increasingly offering or requiring courses dedicated to AAC at the pre-service level (Costigan & Light, 2010; Ratcliff, Koul, & Lloyd, 2008), which may be resulting in an increased number of speech-language pathologists who are prepared to provide AAC services. However, speech-language pathologists continue to report low levels of perceived competence and limited use of evidence-based practices when actually serving students who use AAC (e.g., Marvin, Montano, Fusco & Gould, 2003; Siegel, Maddox, Ogletree, & Westling, 2010). In addition to the lack of training in AAC, professionals have reported even less preparation at the pre-service level for working effectively with families (e.g., Mandak & Light, 2018). Professionals have also cited challenges to achieving collaborative relationships with families including lack of time, lack of success, and lack of training (Kent-Walsh, Stark & Binger, 2008). These challenges could relate to the continued negative collaborative relationships that parents reported in this study.
Implications for practice

Professionals must seek to form collaborative relationships with families that are characterized by mutual trust and respect, information sharing, and recognition of parents as experts on their children’s needs (Dunst, 2002; Dunst, Trivette & Hamby, 2007; King & Chairello, 2014). This is important for ensuring optimal outcomes for the child and family, and it is also one of the eight domains of speech-language pathology according to the American-Speech-Language-Hearing Association (ASHA) scope of practice: “Collaboration requires joint communication and shared decision making among all members of the team, including the individual and family, to accomplish improved service delivery and functional outcomes for the individuals served” (ASHA, 2016). In particular, professionals should engage in participatory help-giving practices that are aimed to actively involving families in decisions and choices, responding to family concerns and priorities, demonstrating sensitivity to family needs, and collaborating to achieve desired goals and outcomes (Dempsey & Dunst, 2004; Dunst, 2002). These types of practices have been found to be strongly related to a range of positive family outcomes (e.g., parental perceptions of control over life events, program satisfaction, child positive behavior functioning, family well-being, parenting behavior) (Dunst et al., 2007). Ultimately, this will allow professionals to empower families to make informed decision when purchasing AAC technologies, to ensure that they are well-matched to their children’s developmental needs and skills.

In order for professionals to collaborate effectively with families, increased training is needed at both the pre-service and in-service levels. Training should be focused on improving professionals’ knowledge and skills related to AAC assessment and intervention, as well as knowledge and skills related to working effectively with families (Costigan & Light, 2010; Mandak & Light, 2018; Ratcliff et al., 2008).
Limitations and Future Research

Several limitations of this investigation warrant consideration. The results of this study only represent the experiences and perspectives of a small group of well-educated parents, and they cannot be generalized to all parents of children with CP who use AAC technologies. Parents of children from culturally and linguistically diverse backgrounds were unrepresented in the sample. There was also an uneven representation of fathers (one) versus mothers (eight), and previous research suggests roles and priorities differ between fathers and mothers of children who use AAC (e.g., Angelo, 2000; Angelo et al., 1995). Additionally, the findings do not include perspectives of other family members (e.g., siblings, grandparents, aunts, uncles), or the child using the technology, who may have different experiences and priorities. All of the participants were parents of children who had CP who were between the ages of 6 to 14, so this study does not provide information on parents’ experiences with children with various diagnoses (e.g., autism spectrum disorder, childhood apraxia of speech, acquired disorders) or of various ages. Furthermore, it is possible that the parents who were willing to participate were all highly involved. Parents who chose not to participate may have had different experiences with using AAC technologies or may have chosen not to use AAC technologies. Parents with limited resources may have lacked the capacity to join the study or may have missed recruitment through the professional organizations and social media groups.

The questions used within the semi-structured interviews and the follow-up probes are another potential limitation of this study. The PI’s decisions about the topics covered, how to phrase the questions, and the specific follow-up questions posed for each participant could have affected parents’ responses. Follow-up probes were meant to further investigate topics that were raised by participants in order to provide a richer account of their experiences; however, this meant that there was some variability between participants in the specific questions asked.
Finally, although several techniques were used to increase research rigor and data quality, additional strategies such as the use of second interviews with parents and triangulation from other data sources (e.g., interviews with other important stakeholders, observations, follow-up survey) may have further strengthened the results and should be considered in future research.

Given the limitations of this study, there are several areas for future research. Future research should attempt to gain input from multiple stakeholders within the family (e.g., fathers, siblings, extended family, child using AAC technology) and individuals who are interacting regularly with the child who uses AAC (e.g., home care aides, speech-language pathologists, teachers, para-professionals) in order to provide an in-depth perspective on how AAC is being used within functional contexts and with various partners in the child’s everyday life. A descriptive, in-depth case study that includes input from the various stakeholders identified and triangulation from multiple data sources (e.g., interviews, observations, photographs) could provide a rich and unique perspective on the barriers and facilitators for integrating AAC technologies into everyday life. Longitudinal research would also be beneficial in order to capture how experiences with AAC technologies change over time from the perspective of various stakeholders.

Future research should also seek to gain an understanding of the perspectives and experiences of a larger group of families and other important stakeholders. Research should include individuals with various disorders that use AAC technologies (e.g., autism spectrum disorders, Down syndrome, childhood apraxia of speech, acquired disorders, etc.) of various ages. The unique experiences of children with various diagnoses (e.g., behavioral issues in autism, vision issues in Down syndrome) will likely result in different experiences for families than those described by the parents of children with CP in this study. For example, work by Calculator (Calculator, 2013; Calculator, 2014; Calculator & Black, 2010) demonstrates that there are both similarities and differences between the priorities and preferences of parents of children with
Angelman syndrome compared to the parents of children with CP who participated in this study. These differences could be related to the characteristics of the diagnosis, length of time using AAC, and the changes in technologies that have occurred over time. Additionally, priorities and experiences will likely differ for very young children who are just beginning to use AAC technologies, as well as for older adolescents and young adults. Future research is necessary to investigate how priorities, preferences, and experiences vary by etiology and time spent using AAC. Given increasing global diversity (Hanson & Lynch, 2013), it is also critical to seek input from families of children from various cultural and linguistic backgrounds.

Future research should also use systematic surveys to evaluate the experiences of a larger group of stakeholders. The features of AAC technologies identified by parents in this study as important (e.g., physical design features, efficiency and cost of use, durability) could be used to inform a survey designed to gain information from a larger group of parents, family members, and other important stakeholders. Finally, it is critical that future intervention research evaluates the effects of providing families with the supports that parents identified and looking at the resulting changes for both children and families.

**Conclusions**

This study reported the perspectives of nine parents of children with CP regarding how AAC technologies supported their child’s participation in family routines and the functional contexts of everyday life. Parents reported that children were able to work towards developing communicative competence using their AAC technologies. Parents identified features of AAC technologies that supported their child’s participation, features that presented barriers to participation, and features of ideal technologies. Overall, parents’ perspectives revealed that there is still “work to be done” in order to improve the design of technologies and improve professional
practice. Ultimately, future research and AAC technology development should involve a multi-disciplinary effort that includes children who use AAC and their families in order to ensure that AAC technologies can truly be integrated into the functional contexts of everyday life so that, as one parent said, “hopefully in the future we [are] able to achieve much more” (Shannon).
Notes

1 Picture communication symbols (PCS) are colored line drawings developed by Mayer Johnson, part of Tobii Dynavox, Pittsburgh, PA, USA. https://mayer-johnson.com/pages/pcs-symbol-collections

2 DynaSyms are colored line drawings developed by Language Symbols, Unity, ME, USA. http://languagesymbols.com/dynasyms.html

3 Symbolstix are colored line drawings developed by n2y. https://www.n2y.com/symbolstix-prime/

4 Tobii Dynavox is a developer of dedicated AAC technologies, Pittsburgh, PA, USA. https://www.tobiidynavox.com/en-US/

5 Proloquo2go is an AAC application for iPad, iPhone, and iPod produced by AssistiveWare. http://www.assistiveware.com/product/proloquo2go

6 iPad is a product of Apple of Cupertino, CA, USA. https://www.apple.com/

7 PRC Accent 1400 is a speech generating device produced by Prentke Romich Company, Wooster, OH, USA. https://store.prentrom.com/accent-1400

8 NOVA Chat 10 is a speech generating device produced by Saltillo Millersburg, OH, USA. https://saltillo.com/products

9 NOVA Chat 12 is a speech generating device produced by Saltillo Millersburg, OH, USA. https://saltillo.com/products


11 Tobii i12 is a speech generating device produced by Tobii Dynavox, Pittsburgh, PA, USA. https://www.tobiidynavox.com/en-us/devices/eye-gaze-devices/i-12-communicator/

12 TouchChat app is a communication application iPad, iPhone, and iPod produced by Silver Kite. https://touchchatapp.com/
13 Tellus is a speech-generating device produced by Augmentative Communication Consultants Inc., Moon Township, PA, USA. [http://wwwacciinccom/tellus-5/]

14 PRC Vantage is a speech-generating device that was formerly produced by Prentke Romich Company, Wooster, OH, USA. [https://wwwprentromcom/]

15 Quicktime Player is a media player produced by Apple of Cupertino, CA, USA. [https://supportapplecom/downloads/quicktime]

16 Evistr L57 mini voice recorder is a digital voice recorder produced by Evistr. [http://blog.evistrcom/]

17 Microsoft Word is a word processing software produced by Microsoft. [https://wwwmicrosoftcom/en-us/]

18 Microsoft Excel is a spreadsheet software developed by Microsoft. [https://wwwmicrosoftcom/en-us/]

19 PCEye mini is a clip-on eye-tracker developed by Tobii Dynavox, Pittsburgh, PA, USA. [https://wwwtobiidynavoxcom/en-us/devices/eye-gaze-devices/pceye-mini-access-windows-control/]

20 Microsoft Hololens is a holographic computer developed by Microsoft. [https://wwwmicrosoftcom/en-us/]

21 VocaliD is a company that produces custom digital voices. [https://wwwvocalidco/]
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Appendix A

Institutional Review Board Approval Letter

Date: December 13, 2017
From: Philip Frum, IRB Analyst
To: Tara O’Neill

Type of Submission: Initial Study
Title of Study: Designing AAC Technologies to Meet Family Goals and Priorities: Perspectives of Parents
Principal Investigator: Tara O’Neill
Study ID: STUDY00008665
Submission ID: STUDY00008665
Funding: Not Applicable

Documents Approved:
- demographic questionnaire_paper (2.01), Category: Data Collection Instrument
- interview guide (1), Category: Data Collection Instrument
- link for online demographic questionnaire_Qualtrics.docx (1), Category: Data Collection Instrument
- revised protocol (2), Category: IRB Protocol

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 Manual. If changes are being considered and there are questions about whether IRB review is needed, please contact the Office for Research Protections.

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
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

Consent to Participate

CONSENT FOR RESEARCH
The Pennsylvania State University

Title of Project: Designing AAC Technologies to Meet Family Goals and Priorities: Perspectives of Parents

Principal Investigator: Tara O’Neill, M.S., CCC-SLP
401F Ford Building, University Park, PA, 16802
570) 772-6785; tao5012@psu.edu

Advisor: Krista M. Wilkinson, PhD
(814) 863-2206

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.

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?
The purpose of this study is to gain the perspectives of parents on their experiences using AAC technologies with their children and the extent to which current AAC technologies allow children to participate in family goals. We are asking you to be in this research because you have a child with cerebral palsy who uses an AAC technology.

2. What will happen in this research study?
If you decide to enroll in this study, you will begin by completing a brief questionnaire so we can find out a little about your family and your child from your perspective. You are free to skip any questions that you would not prefer to answer on the questionnaire.

After completing the demographic questionnaire, you will participate in an interview with the principal investigator. The interview may occur in person, over the phone, or via an online videoconference (Skype), depending on your preference and geographic location. The interview will be audio recorded so that we can analyze the interview after it is completed. You can request for the recording to stop at any time during the interview.
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 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?**
      You will have a chance to express your own perspectives and opinions regarding your child’s AAC technology.

   4b. **What are the possible benefits to others?**
      You will contribute to knowledge regarding family’s experiences with using AAC technologies, which should improve help to professional practice as well as the design of AAC technologies.

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

6. **How long will you take part in this research study?**
   If you agree to take part in this study, it will take approximately 15 minutes to complete the questionnaire. The interview will take about 45 to 60 minutes to complete, and it will not exceed 90 minutes. Your total time commitment will be roughly 1 to 2 hours. If you participate in person, you will make 1-2 visits to the research site.

7. **How will your privacy and confidentiality be protected if you decide to take part in this research study?**
   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.
   
   - A list that matches your name with your alphanumeric code will be kept separate from your research data in a password protected file on a secure cloud storage system- Box at Penn State. Thus, no personal identification will be attached to electronic or printed forms of data.
   
   - Your research records and audio recordings will be labeled with your alphanumeric code and will be kept on Box at Penn State. Only the principal investigator, her adviser, and trained students will have access to the records. The research records will be destroyed after at least 3 years of completion of the study.
• The list with your alphanumeric code and your research records will be not be destroyed, in order to be used in future undetermined research, unless you request otherwise.

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
• The Office for Research Protections.

Some of these records could contain information that personally identifies you. Reasonable efforts will be made to keep the personal information in your research record private. However, absolute confidentiality cannot be guaranteed.

8. Will you be paid or receive credit to take part in this research study?
There is no monetary compensation for participation in this study.

9. 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.

10. If you have questions or concerns about this research study, whom should you call?
Please call the head of the research study (principal investigator), Tara O’Neill at (570) 772-6785 if you:
• Have questions, complaints or concerns about the research.
• 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, ORProtections@psu.edu if you:
• Have questions regarding your rights as a person in a research study.
• Have concerns 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.

INFORMED CONSENT TO TAKE PART IN RESEARCH
Tell the researcher your decision regarding whether or not to participate in the research.
Appendix C

Demographic Questionnaire

In order to design effective AAC technologies, we believe it is important to make sure they match with the needs and skills of both the family and the child. This questionnaire will help us to gain more information about you and your family. We hope that it will allow us to tailor AAC technologies to unique child and family needs. Please know that this information is confidential. You will be assigned a pseudonym, so your identifying information will not be connected to your personal identity. **You may skip any questions that you do not prefer to answer.** This questionnaire should take about 10 to 15 minutes to complete.

**Part 1: Screening**

Your assigned code:

Are you the parent or primary caretaker for a child with cerebral palsy?

- [ ] Yes
- [ ] No

*Skip logic: If No Is Selected, Then Skip To: end statement*

Is the child between the ages of 6 to 14?

- [ ] Yes
- [ ] No

*Skip logic: If No Is Selected, Then Skip To: end statement*

Does the child experience complex communication needs, such that speech is inadequate to meet all daily communication needs?

- [ ] Yes
- [ ] No

*Skip logic: If No Is Selected, Then Skip To: end statement*

Has the child used a high-technology AAC device in the last year? (For example, this could be a mobile technology with an app or a speech generating device).

- [ ] Yes
- [ ] No

*Skip logic: If No Is Selected, Then Skip To: end statement*

**Part 2: Personal Characteristics**

The following questions ask for specific information about you and your family.
Your participant code:

In what age range do you fall?
- Under 24 years
- 25-39 years
- 40-54 years
- 55-69 years
- 70 years and over
- Prefer not to answer

Your location (just list state):

We ask the next three questions because we want to make sure we are including individuals from a range of ethnic, cultural, and socioeconomic backgrounds in our research.

Are you of Hispanic, Latino, or Spanish origin?
- Yes
- No
- Prefer not to answer

How would you describe your race? Check all that apply.
- White
- Black or African American
- American Indian or Alaska Native
- Asian
- Native Hawaiian or Pacific Islander
- Other, specify __________
- Prefer not to answer

What is the highest level of education that you have completed?
- Less that high school
- High school graduate
- Some college
- 2-year degree
- 4-year degree
- Professional degree
- Doctorate
- Prefer not to answer

Do you speak any languages other than English at home?
- Yes
If you speak any other languages than English at home, please list them here:

Part 3: Child characteristics

These questions ask about your child who has cerebral palsy and uses AAC.

Your child’s age (in years, months):

The next set of questions will ask about some of your child’s existing skills. We ask these questions because they all affect how the AAC technologies can be designed to meet your child’s needs.

Does your child experience functional limitations in vision? That is, vision loss that affects his/her ability to perform daily activities.

- Yes
- No
- Prefer not to answer

Does your child experience hearing loss?

- Yes
- No
- Prefer not to answer

How many signs, words, or other symbols does your child use to express him/herself?

- Less than 6
- 6 to 10
- 11 to 20
- more than 20
- more than 50
- Prefer not to answer

How many signs, words, or other symbols does your child understand?

- Less than 6
- 6 to 10
- 11 to 20
- more than 20
Does your child experience difficulty remembering things he/she just learned or experienced?
- Yes
- No
- Prefer not to answer

Does your child experience difficulty sustaining attention during tasks?
- Yes
- No
- Prefer not to answer

Does your child experience difficulty with fine motor skills, or the ability to use his/her hands to control objects? This could include things like drawing, using a knife and fork, buttoning, or writing.
- Yes
- No
- Prefer not to answer

Please read the following and mark only one box beside the description that best matches your child's movement abilities. My child...

- Has difficulty sitting on their own and controlling their head and body posture in most positions
  and has difficulty achieving voluntary control of movement
  and needs a specially supportive chair to sit comfortably
  and has to be lifted or hoisted by another person to move

- Can sit on their own but does not stand or walk without significant support
  and therefore relies mostly on a wheelchair at home, school, and in the community
  and often needs extra body/trunk support to improve arm and hand function
  and may achieve self-mobility using a powered wheel chair

- Can stand on their own and only walks using a walking aid (such as a walker, rollator, crutches, canes, etc.)
  and finds it difficult to climb stairs, or walk on uneven surfaces
  and may use a wheelchair when travelling for long distances or in crowds

- Can walk on their own without using walking aids, but need to hold the handrail when going up or down stairs
  and often finds it difficult to walk on uneven surfaces, slopes, or in crowds

- more than 50
- Prefer not to answer
Can walk on their own without using walking aids, and can go up or down stairs without needing to hold the handrail

and walks wherever they want to go (including uneven surfaces, slopes, or in crowds)
and can run and jump, although their speed, balance, and coordination may be slightly limited

Part 4: AAC Device
This final set of questions asks about the AAC device that your child uses.

What is the single most advanced electronic AAC device your child used over the last year? For example, this could be a dedicated AAC device or an AAC app on a mobile technology like a tablet.

How long has your child been using this device? Indicate answer in years and months.

What method does your child use to access the device?
- Direct selection with finger
- Switch scanning
- Head pointer
- Eye gaze
- Other, specify ____________________________

Has your child used any other electronic AAC device(s) in the past? If so, list the names:
Appendix D

Semi-Structured Interview Guide

Code: __________________ Date: ______________ Time: ____________ Mode: ________________

Introduction:

Thanks so much for your interest in this project, and for taking the time to talk with me. I’m interested in family perspectives on AAC systems and gaining the expert opinions of parents like you. I want to know about how AAC fits into your family, and what have been the barriers or facilitators to using AAC.

I’d like to record our conversation so I don’t take the chance of missing anything 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.

The interview should take around 45 minutes, and no more than an hour.

Do you have any questions before we get started?

1. Tell me a little about you and your family.
   Probes: Family composition, number of members, employment status of parents

2. Tell me a little more about [child’s name].
   Follow up probes based on answers to demographic questionnaire: language, motor, memory, attention, vision, hearing. Also: school placement, level of services, literacy

3. Families often report that their children communicate and express themselves in many different ways. How does [child’s name] communicate with you and your family?
   Probes: speech, vocalizations, gestures, sign language, picture or communication boards, PECS, SGD

4. What are some of the things that [child’s name] can do best and likes to do? (Crais, 2011)
   • How (if at all) does [child’s name] AAC technology help him/her to participate in these activities?

5. What are some of the things you’d like [child’s name] to be able to do? (things that s/he is not doing now) (Crais, 2011)
• *If parent does not mention communication:* What are your overall goals for your child’s communication? (not specific his/her AAC technology)

• How (if at all) could [child’s name] AAC technology help him/her to do these things?
  o What aspects of [child’s name] current AAC technology (if any) help him/her to achieve these goals?
  o What aspects of [child’s name] current AAC technology (if any) present barriers to meeting these goals?

6. Who are the most important people in [child’s name] life?
• Of these people, who (if anyone) does [child’s name] currently use his/her AAC technology to communicate with?
• Who (if anyone) would you like [child’s name] to be able to use his/her AAC device to communicate with?
  o What aspects of [child’s name] AAC technology help him/her child to interact with these individuals?
  o What aspects of [child’s name] AAC technology present barriers to your child interacting with these individuals?

7. One goal when providing AAC technologies is that they can fit into existing family activities and routines. I’d like to know a little bit about your child’s daily routines and activities. Tell me a little bit about your day. (McWilliam, 2010; Wilcox & Woods, 2011)
• What are the activities or routines that occur most often for you and your child?
  probes: morning/getting ready, mealtime, outings, etc.

8. How does AAC fit into these daily activities? (McWilliam, 2010; Wilcox & Woods, 2011)
• In which (if any) of these activities does your child currently use his/her AAC device?
• In which (if any) of these activities do you think your child could benefit from using AAC?
• What aspects of [child’s name] AAC technology help him/her to participate in these activities?
• What aspects of [child’s name] AAC technology present barriers to your child participating in these activities?

9. Parents may want to take different roles in supporting their child to use AAC. What do you see as being your role in helping [child’s name] use his/her AAC technology? (Anderson et al., 2014)
• Probes: For example, parents may want to be involved with adding vocabulary, programming messages, or modeling the use of the device.
• What aspects of the technology make it easy to do that?
• What aspects of the technology (if any) make it challenging to do that?

10. Imagine you were not limited to existing AAC technologies and you could design an ideal AAC device that would meet your child’s needs and your family’s needs. Tell me about what that system would look like.
• Probes: features for family, features for child, things you would like to do that you can’t
11. That covers the things I wanted to cover. Anything else you’d like to add?

Thanks for taking the time to participate in the interview. The information you provided will be really valuable to help to design AAC systems that match with the priorities and preferences of family members. If you have any questions or would like to add anything please feel free to contact me by email or phone. I may touch base with you after looking at your interview transcript to make sure I captured your opinions accurately. Do you have any questions?
Appendix E

Contact Summary Sheet

<table>
<thead>
<tr>
<th>Interviewer:</th>
<th>Interviewee:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Date of contact:</td>
<td>Today’s date:</td>
</tr>
<tr>
<td>Method of contact:</td>
<td>Method of interview:</td>
</tr>
</tbody>
</table>

1. What were the main issues or themes that stuck out for you in this contact?

2. What discrepancies, if any, did you note in the interviewee’s responses?

3. Anything else that stuck out as salient, interesting, or important in this contact?

4. How does this compare to other data collections?
**Appendix F**

**Transcription Conventions**

<table>
<thead>
<tr>
<th>Rule</th>
<th>Symbol (if applicable)</th>
<th>Example</th>
</tr>
</thead>
</table>
| The interviewer is marked by I: and the interviewed person by P: (for participant) | | I: Tell me about your daughter.  
P: My daughter is 9 years old |
| Every contribution by a speaker receives its own paragraph (each time the speaker changes, start on a new line) | | |
| Type words as they are spoken by the participant (dialect or informal contractions) | “Y’all” “gonna” “wanna” |
| Mark discontinuations of words or phrases by using a double dash (e.g., they start to say a phrase in one way and then re-word) | “I was worri—concerned”  
“I think that I—when I thought about it—I didn’t know what to do.” |
| Transcribe repetitions | “I went went to the store” |
| Indicate extended pauses using … | … I like to eat … pizza |
| Affirmative utterances by the interviewer (uh, yes, right) are not transcribed  
EXCEPTION: if the interviewer is answering a question | | |
| Words with a special emphasis are CAPITALIZED | The dog was HUGE |
| Nonverbal communication (laughter, sighs) are transcribed in parentheses | That’s hilarious (laughter) |
| Incomprehensible words are indicated with (inc.). If you are unsure of a word, put the word in parentheses with a question mark  
*Mark the time so another person can listen | (inc.) I went to (inc. 1:59) with my (brother? 2:02) |
| Fillers are transcribed (um, yeah, ya know, kind of)  
*If you miss a few, it’s ok! | I like to eat um (…) sushi |
| Use appropriate punctuation:  
-period ends a sentence, fragment, or phrase  
-first letter in each new sentence of fragment is capitalized  
-commas when participant pauses, where you would typically place them in written text | | |
| Include a time stamp at the end of each turn in parentheses | Format (hh:mm:ss) (00:48:12) |
### Appendix G

**Fidelity Check**

**Directions:** For each participant, place a 1 in the cell if the question was asked and a 0 if it was not asked.

<table>
<thead>
<tr>
<th></th>
<th>P001</th>
<th>P002</th>
<th>P003</th>
<th>P004</th>
<th>P005</th>
<th>P007</th>
<th>P008</th>
<th>P009</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Tell me a little about you and your family.</td>
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<tr>
<td>2. Tell me a little more about [child’s name].</td>
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<tr>
<td>3. How does [child’s name] communicate with you and your family?</td>
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<tr>
<td>4. What are some of the things that [child’s name] can do best and likes to do?</td>
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<tr>
<td>5. What are some of the things you’d like [child’s name] to be able to do?</td>
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<td>6. Who are the most important people in [child’s name] life?</td>
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<td>7. Tell me a little bit about your day.</td>
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<td>8. How does AAC fit into these daily activities?</td>
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<tr>
<td>9. What do you see as being your role in helping [child’s name] use his/her AAC system?</td>
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<tr>
<td>10. Imagine you could design an ideal AAC technology that would meet your child’s needs and your family’s needs. Tell me about what that system would look like.</td>
<td></td>
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<tr>
<td>11. That covers the things I wanted to cover. Anything else you’d like to add?</td>
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</tbody>
</table>
### Appendix H

**Codebook**

**THEME 1: CHILD NEEDS AND SKILLS:** Describes the developmental, communication, or psychosocial needs and skills of the child.

**Subtheme 1.1: Developmental needs and skills:** Describes the motor, cognitive, vision, or hearing skills of the child.

<table>
<thead>
<tr>
<th>Code</th>
<th>Definition</th>
<th>Example data</th>
</tr>
</thead>
<tbody>
<tr>
<td>Child developmental motor</td>
<td>Describes the child’s fine or gross motor skills including:  • ambulation,  • finger isolation,  • use of a wheelchair to achieve mobility,  • motor control  • spasticity.</td>
<td><em>We’re just getting to the point where she can isolate her pointer finger. And so we do a lot of activities with that because that’s how she’s going to be able to progress to more squares.</em></td>
</tr>
<tr>
<td>Child developmental cognition</td>
<td>Describes the child’s cognitive skills including:  • attention,  • memory, and/or  • intelligence</td>
<td><em>He is such a bright person. The school district assessed him and he is definitely age-appropriate cognitively.</em></td>
</tr>
<tr>
<td>Child developmental vision</td>
<td>Describes the child’s vision including:  • vision loss/limitations  • cortical visual impairment.</td>
<td><em>Some of the issues that we didn’t realize we were going to have was the vision issue. So the CVI... so she wasn’t totally blind. They called her technically blind at one point.</em></td>
</tr>
<tr>
<td>Child developmental hearing</td>
<td>Describes the child’s hearing including:  • hearing loss  • hearing aids</td>
<td><em>And then she wasn’t totally deaf but her ear drums were not vibrating and so we had all of these issues. And then she really couldn’t hear well.</em></td>
</tr>
</tbody>
</table>

**Subtheme 1.2: Communication needs and skills:** Describes the child’s operational, linguistic, social, or operational skills.

<table>
<thead>
<tr>
<th>Code</th>
<th>Definition</th>
<th>Example data</th>
</tr>
</thead>
<tbody>
<tr>
<td>Child communication operational</td>
<td>Describes the child using skills that are required to use technically operate the AAC system. This includes:  • turning on/off device  • changing languages or volume</td>
<td><em>It has groups, so he can hit groups and then he’s had to learn, like, the farm animals are under this button.</em></td>
</tr>
</tbody>
</table>
**Child communication linguistic**

Describes the child’s receptive and expressive language skills in the native language of community and in language code of AAC system. This includes:
- Combining symbols on the AAC technology (syntax)
- Using vocabulary concepts on the AAC system (semantics)
- Comprehension of spoken language
- Literacy (writing, typing, reading)

**Example data:**

- He’s able to whip out four to six words without any trouble.
- But her spelling, because she’s never been able to sound out her phonics, her spelling is not great.
- She’s fully aware of what’s going on and understands just as much as anyone else her age would.

**Child communication social**

Describes the child’s pragmatics (skills in initiating, maintaining, and terminating interactions) and interpersonal skills. This includes:
- Conversational skills (e.g., taking turns, asking questions, initiating topics)
- Using a variety of communicative functions (e.g., requesting, commenting, etc.)

**Example data:**

- And he’s actually come a long way, he knows that if he starts with, “Hi, what’s up?” then that tells people a lot about you. Like oh ok, you communicate age appropriately and that sort of thing.

**Child communication strategic**

Describes the child using compensatory strategies to maximize the effectiveness and efficiency of their communication. This includes:
- Using multiple modalities (e.g., unaided first because faster)
- Using telegraphic utterances to increase rate
- Using “sounds like” strategies (e.g., “brown knees” for brownies)
- Dealing with communication breakdowns

**Example data:**

- If he wants to say something, you know, 90% of the time, he’s going to try first with a gesture or his voice. Because it’s the fastest way, and we understand him for a lot of basic things.
- Well she didn’t have the word brownies on her device. So she used the color brown and then the body part knees.

---

**Subtheme 1.3: Child psychosocial needs and skills:** Describes the child’s attitude, motivation, self-advocacy, or personality.

<table>
<thead>
<tr>
<th>Code</th>
<th>Definition</th>
<th>Example data</th>
</tr>
</thead>
<tbody>
<tr>
<td>Child motivation</td>
<td>Describes the child’s drive to communicate or complete other tasks.</td>
<td>And he’s very determined at getting what he wants. So he’ll keep trying to communicate with you until you figure it out.</td>
</tr>
<tr>
<td>Code</td>
<td>Definition</td>
<td>Example data</td>
</tr>
<tr>
<td>------</td>
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</tr>
<tr>
<td>Child attitude</td>
<td>Describes the child’s feelings about communication or another task that are charged with emotion.</td>
<td>When she touches it, it doesn’t always talk to her. And so, and then she gets mad cause then she just hits it. And that doesn’t necessarily help.</td>
</tr>
</tbody>
</table>
| Child self-advocacy | Describes how the child makes his/her needs know to others. This includes:  
• asking for help,  
• playing a role in programming the device and deciding on vocabulary,  
• taking ownership of the device. | And he’ll tug on my arm and point to the talker and, that’s how I’ll know he wants me to add the characters from this movie or he wants to be able to talk about this TV show. |
| Child personality | Describes the child’s demeanor, such as being witty, funny, likes to make people laugh | She’s got her own voice, her own sense of humor, she’s very cheeky. |

**THEME 2: PARENT RESPONSIBILITIES AND PRIORITIES:** Describes the parents’ roles related to supporting their child and his/her communication, as well as their goals and priorities for their child.

**Subtheme 2.1 Parent roles:** Describes the parents’ role in supporting their child, that includes: advocacy, leadership, educating, preparing for the future, performing device related roles, using various partner interaction strategies, and everyday parenting responsibilities.

<table>
<thead>
<tr>
<th>Code</th>
<th>Definition</th>
<th>Example data</th>
</tr>
</thead>
</table>
| Parent role leadership | Parents describe playing a big role in supporting their child and their child’s communication. This could involve:  
• managing multiple responsibilities,  
• taking the lead on organizing services, etc.  
• being an expert on the child and his/her needs (e.g., interpreting nonverbal communication. | I think I have a big role and I actually sometimes have to remind myself to have less of a role because you know I was the one who did the research and found the device |
| Parent role advocacy | Parents describe their role as being "pushy" or demanding by:  
• standing up for their child’s needs and  
• making their child’s needs known to other communication partners. | We were fighting for a long time to try and get the school district to do what we wanted |
| Parent role educating | Describes the parents’ role of educating:  
• themselves on AAC (e.g., reading, researching),  
• educating others (e.g., showing care aides how to setup device) and  
• educating society. | I went in and kind of trained them [school professionals] how to use it and what worked at home. |
| Parent role preparing (for future) | Describes parents as supporting the independence/autonomy of their child. | I’m his mom and I know where I want him to be as an adult |
child and reinforcing the value of communication. and I feel like, it’s kind of my responsibility to get him there.

**Parent role device (related)**

Describes specific technology related roles such as:
- programming and adding vocabulary,
- technical upkeep (e.g., finding software to use, running updates),
- providing access to AAC, and
- supporting the child’s navigation on the device

It’s always me that gets to do all the tech stuff with it. So when she wants vocabulary added or if we need to reprogram something or check out some new software for her to paint with or play music with, or anything like that.

**Parent role interaction (strategies)**

Describes the use of various partner interaction strategies to support the child’s communication including:
- modeling/aided input,
- prompting,
- providing wait time,
- contingent responding,
- providing choices,
- asking questions

As soon as the talker goes on if we want to encourage him, if he’s not jumping right into saying something, we start with like an open-ended phrase. So, my husband will say, “Dad is…”

**Parent role parenting**

Describes caregiving responsibilities related to everyday care such as:
- feeding,
- dressing,
- toileting, etc.

Another aspect of our day that really consumes our time is, since she’s on blenderized diet, it takes me 15 minutes to give water... And then 45 minutes later, so everything is cleared, then I can feed her.

**Parent role other**

Describes other roles not described above.

**Subtheme 2: Parent goals**: Describes the goals and priorities parents identify for their children including linguistic, social, fluency, independence, inclusion, motor, and other goals.

<table>
<thead>
<tr>
<th>Code</th>
<th>Definition</th>
<th>Example</th>
</tr>
</thead>
</table>
| Parent goal linguistic | Parents describe goal for the child to improve his/her morphosyntax, semantics, or literacy skills. This could include:  
- use of a wider range of vocabulary concepts,  
- formation of more complex or longer sentences, or  
- various literacy skills (writing, typing, reading, distinction between written and spoken communication) | Literacy is something that I would like to see her achieve because I think it would be a great gift to her and it’s you know so very enjoyable.                                                              |
| Parent goal social  | Parents describe goal for child to improve his/her pragmatics (skills in initiating, maintaining, and terminating interactions) and                                                                                         | I would like to see him being able to respond to conversation with some kind of wit or some kind of, other than, “that’s                     |
interpersonal skills. This could include:
• social communication with peers,
• looking at partners,  
• conversational skills,  
• having a greater number and variety of partners

Parent goal fluent (communication) Parents describe a goal for their child’s communication to be faster and more efficient.  

I think the next thing which we’re working on with speech and language therapy and experts that support them are faster—programs to make it faster.

Parent goal independence Parents describe a goal for their child to achieve greater autonomy. This could be by using environmental controls on device and/or using AAC across various settings.  

I can foresee him being able to be more independent if he can use his communication device to control the lights in his house or the locks on the doors. I think that would be really great for him.

Parent goal inclusion Parents describe a goal for their child to be included, for example, in:  
• a mainstream school,  
• with typically developing peers,  
• in society,  
• by a variety of partners

We feel really strongly about inclusion, and being around typical children. And so to me it’s really important for him to stay with, you know, the peers that we live near and that his brother is friends with.

Parent goal motor Parents describe a goal related to motor skills (e.g., being able to help more with mobility such as standing and transferring)  

Right now he’s really heavy. So my big things for him—I need him to either stand or help more with transfers—like he’s just really getting heavy, so we’ve been kind of working on having him help a little bit with that.

Parent goal other Parents describe a goal not encompassed in the codes above.

**THEME 3: AAC TECHNOLOGIES:** Describes the limitations or supports of existing AAC technologies, or ideas for features that would characterize ideal technologies. This does not include features of low-tech AAC systems (e.g., communication boards).

**Subtheme 3.1: Limitations of existing technologies:** Describes features of existing technologies that present challenges for use, either for the child in successfully using the technology, or for parents or other partners in supporting the child to use the technology.

<table>
<thead>
<tr>
<th>Code</th>
<th>Definition</th>
<th>Example</th>
</tr>
</thead>
<tbody>
<tr>
<td>AAC limitation inefficient</td>
<td>Describes inefficient (slow) rate of communication when using AAC technologies that causes frustration for</td>
<td>I mean it is exhausting for him to use the AAC, he would use it more if it wasn’t so much work for him to get that</td>
</tr>
<tr>
<td>AAC limitation</td>
<td>Description</td>
<td>Example</td>
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<tr>
<td>---------------</td>
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<tr>
<td>reliability</td>
<td>Describes technologies as unreliable due to:</td>
<td>They can be prone to you know crashing or not working or whatever — and that’s really bad when that happens. That’s really frustrating for him... So that sort of reliance on it, that can be an issue I think.</td>
</tr>
<tr>
<td>lack of fit</td>
<td>Describes a mismatch between the needs and skills of the child (e.g., motor, cognitive, vision) and the design of the system. This could be due to:</td>
<td>The extra actions and descriptions are alphabetized. “Actions A-Z” and like if you know if you wanna look for throw and you don’t know that throw begins with a “T” how are you ever gonna find that? You’re not, and so you’re just gonna have to say something else. That’s the big letdown about that</td>
</tr>
<tr>
<td>physical design</td>
<td>Describes how the size, weight, or position of the device presents challenges such as:</td>
<td>Then also just the blocking of his face. Cause if I’m having a conversation with you, you can see me and I can see you and we can make eye contact but for him sometimes if the person is talking I’ll notice he’s looking at them and then his eyes are out of the field because he wants, he’s very aware of how people are social so he’ll look at the speaker and then he can’t (voice cracks), you know, so that’s hard</td>
</tr>
<tr>
<td>vocabulary</td>
<td>Describes vocabulary available on the device as limited for the child (e.g., lack of academic vocabulary, lack of interest related vocabulary such as toys)</td>
<td>There’s a lot of specific vocabulary — and he doesn’t need to have everything, but he needs enough to be able to participate</td>
</tr>
</tbody>
</table>
AAC limitation programming

Describes challenges in modifying technologies. For example:
- adding vocabulary is not intuitive or slow,
- no options to program offline,
- changes on one page do not carry across pages,
- additional technology needed for programming offline

*I mean it’s not… it’s not intuitive. You definitely have to learn how to do it. And, there are a lot of keys involved.*

AAC limitation appeal

Describes technologies as unappealing, making children uninterested in using them. This includes voices that are not age appropriate or symbols that are not motivating.

*I mean I think it’s hard for her to uh get excited about using it.*

AAC limitation other

Describes other limitations not included above such as: variability between devices

**Subtheme 3.2: Supports of existing technologies:** Describes features of existing technologies support use by the child, or use by partners who are supporting the child to use the technology.

<table>
<thead>
<tr>
<th>Code</th>
<th>Definition</th>
<th>Example data</th>
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</thead>
</table>
| AAC support programming | Describes characteristics of the technology that facilitate programming, that is, adding vocabulary and making changes. This includes:
  - ability to easily add vocabulary on the fly,
  - the system recommends vocabulary,
  - search feature,
  - capability to program offline, and
  - changes made to one page that carry across pages. | *If the words aren’t in there, it recommends you can actually add some of the words that don’t already show up.* |
| AAC support vocabulary | Describes the vocabulary on the technology as a support for communication about:
  - likes, interests, important people,
  - pain,
  - things not available in the immediate environment,
  - core vocabulary. | *A couple times he’s been screaming pissed off mad at me and I can’t figure out what he wants. And I’ll get his talker out. He’ll want something, you know, out in the garage, that there’s no way he would be able to tell me that he wants to go on his bike or something.* |
| AAC support multiple functions and features | Describes how the AAC technology supports multiple functions such as:
  - environmental control,
  - internet use,
  - access to a camera, | *The Tobii is programmed to control the TV remote so that he can access television himself and change the* |
• social media, etc.
Also describes the features of the technology that promote use such as:
• prediction (to increase efficiency),
• access to multiple languages, and
• access to various software programs (e.g., document readers, literacy software, etc.).

**AAC support physical design**
Describes the physical design of the technology as a support for use by child and partners. This includes:
• portable or light
• mounting

Yep. It’s just like one of those rigid mounts and then it’s a quick release mount 2, a QRM2. It kind of just, you pull that thing back and you snap it in there and it just snaps in. (Inc., 10:12) and it’s flexible. It works pretty good

**AAC support fit with child**
Describes how the technology is well matched to the child’s needs in terms of the vocabulary available, selection technique, organization of vocabulary, etc. Also, describes fit with the child’s motor skills (e.g., via use of keyguard)

It has pretty much everything that he needs is on that setup—the 42. I mean the layout of the device is pretty good, I feel. It was pretty well thought out. I don’t know that you could do that any differently. Um, I think it is as good as it’s gonna be for what he needs

**AAC support other**
Describes an AAC technology support not encompassed in the codes above.

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**Subtheme 3.3: Ideal technologies**: Parents describe features of ideal technologies such as reliability, appeal, programming, efficiency, improved physical design, or others.

<table>
<thead>
<tr>
<th>Code</th>
<th>Definition</th>
<th>Example data</th>
</tr>
</thead>
<tbody>
<tr>
<td>AAC ideal reliable</td>
<td>Parents describe an ideal technology as being:</td>
<td>I wish that there were better icons. And a better selection of different icons.</td>
</tr>
<tr>
<td></td>
<td>• having adequate storage,</td>
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<tr>
<td></td>
<td>• working smoothly.</td>
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</tr>
<tr>
<td>AAC ideal appealing</td>
<td>Describes the technology as appealing/easy for the child to use, for example by having better voices or better representations.</td>
<td></td>
</tr>
<tr>
<td>AAC ideal programming</td>
<td>Describes an ideal technology as easy to program, manage vocabulary off of the device, edit across pages, etc.</td>
<td>it would be nice to be able to—be able to download like a folder for American history that was pre-built.</td>
</tr>
<tr>
<td>AAC ideal efficient</td>
<td>Described an ideal technology as quicker and easier to use/access. This includes features such as:</td>
<td>But it would be really neat if he could use brain waves because there’s always going to be a motor component to</td>
</tr>
</tbody>
</table>
### AAC ideal physical design

<table>
<thead>
<tr>
<th>Code</th>
<th>Definition</th>
<th>Example data</th>
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</thead>
<tbody>
<tr>
<td>Process selection</td>
<td>Describes the process of acquiring the AAC technology and customizing it. This also includes the process of trialing various low-tech and unaided methods of communication. Specific examples/descriptions included are: • trailing different devices and selection techniques, • AAC assessment, • funding, • time for acquisition, • cost of technology, • parents taking a leadership role in device acquisition (i.e., purchasing device). This also includes customizing the technology, for example, by changing the number of symbols.</td>
<td>We bought the device, we haven’t even, you know, gone through any sort of AAC trialing with the school</td>
</tr>
</tbody>
</table>

### AAC ideal other

Described other features of ideal technologies not described above.

### THEME 4: AAC PROCESS AND DECISION MAKING

Describes the process of acquiring and learning technologies, collaborating with professionals, and the changes that occur over time. It also includes the feelings and emotional responses of parents to this process.

**Subtheme 4.1: Device selection/acquisition and customization**

Describes the process of acquiring and customizing the device, as well as trialing various low-tech and unaided communication modes and determining the most appropriate ones.

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<thead>
<tr>
<th>Code</th>
<th>Definition</th>
<th>Example data</th>
</tr>
</thead>
<tbody>
<tr>
<td>Process learning</td>
<td>Describes the process of learning technologies and various forms of AAC for children and their families. This includes a description of: • the child’s history of AAC use (e.g., when started using AAC); • cost of learning (e.g., steep learning curve);</td>
<td>I didn’t really know what I was doing, I was trying to figure it out on my own for a while, probably about a year.</td>
</tr>
</tbody>
</table>
 trial and error (e.g., “learning as we go”);
• lack of training for parents/families;
• independent exploration for the child
• having a separate tablet for “fun” for the child

Subtheme 4.3: Feelings and emotional responses: Describes the feelings and emotional responses of parents and family members throughout the process of supporting their child to use AAC.

Process feelings
Describes feelings and emotional responses of parents including:
• accepting diagnosis and lack of speech/communication
• feelings about the future (e.g., hopeful, unsure)

You know, we can handle her struggling to eat, we can handle the mobility issues, but it’s the speech-or-in any form. You know we would take any kind of form.

Subtheme 4.4: Changes over time: Describes transitions, progress or technology changes that occur over time for the child and parents.

Process transitions
Describes transitions, for example:
• starting a new school
• new therapists/professionals
• new AAC system

We’re going to have to start over. It’s a whole new group of professionals all new people, we have to make our case again for what we want.

Process progress
Describes progress of the child or parents over time. This could include:
• improved communication skills for the child
• fewer behavioral issues
• more use of device in community by parents
• etc.

His MLU has grown pretty tremendously in the past year and a half it’s up from one to maybe 3, 4. Amazing. and he’s starting to use core a lot more frequently.

Process technology changes
Describes changes in technologies over time, for example:
• new software released
• more vocabulary available
• different voices released
• etc.

The devices have already changed so much since she was two. I can’t imagine that by the time she is an adult, they won’t be … you know things that – things I can’t even think of or something astounding.

Subtheme 4.5: Collaboration with professionals: Describes the parent-professional relationship, professional-professional relationship, or characteristics of the professionals.

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<thead>
<tr>
<th>Code</th>
<th>Definition</th>
<th>Example data</th>
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</thead>
<tbody>
<tr>
<td>Process collaboration positive</td>
<td>Describes positive relationships that parents have with professionals. This includes:</td>
<td>I think a lot of what she does is give me information. You know, educate me and I then can help navigate.</td>
</tr>
</tbody>
</table>
• professionals are well educated and informed about AAC, OR are willing to learn
• professionals help parents to set up device
• professionals provide training, recommendations, information to parents
• professionals provide training to school staff

Process collaboration negative

Describes negative relationships with professionals. This includes:
• uneducated professionals
• professional lack of time or large caseloads
• professionals disinterested in learning about AAC
• mistrusting professionals (don’t believe what parents tell them child can do)
• professionals disagree with parents about what child is capable of

The biggest stumbling block that we have is that teachers and SLPs are not familiar with AAC. They don’t know anything about or, or what they do know is wrong.

THEME 5: INTEGRATING AAC INTO LIFE: Describes the challenges/realities or supports/success stories of using AAC (unaided or aided) either within the family (at home, with family members) or outside the family (in school or community, with partners who are not family members).

Subtheme 5.1: Integrating AAC into family life: Describes the challenges/realities and supports/success stories of how AAC fits into relationships within the immediate family (e.g., with parents, siblings, extended family) AND how AAC fits into family routines that occur at home.

<table>
<thead>
<tr>
<th>Code</th>
<th>Definition</th>
<th>Example data</th>
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</thead>
<tbody>
<tr>
<td>Integrating AAC family supports (and success stories)</td>
<td>Describes the supports and success stories of using AAC in relationships within the immediate family and within family routines at home. This includes people coming into the home to care for the child (e.g., sitters, home care aides, nurses). For example: • successful use of AAC with family members • successful use of AAC within various routines at home • Use of multiple modalities (e.g., low tech symbols around home) • Supports for family functioning, such as other families, online forums, and respite care</td>
<td>He [brother] learned quite early on how to use the book as a communication partner, and things like that</td>
</tr>
<tr>
<td>Subtheme 5.2: Integrating AAC into school and community</td>
<td>Description of important people in family or family routines, that does not include a discussion of AAC or the barriers/supports.</td>
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</table>
| Integrating AAC outside supports (and success stories) | Describes the supports and success stories of using AAC with individuals outside of the immediate family members (e.g., paraprofessionals, medical professionals, peers, friends, instructors, teachers), and in settings/contexts outside of the family context (e.g., school, community). This includes:  
  - Successful use of AAC with various partners (e.g., care aides, paraprofessionals, teachers, peers)  
  - Using multiple modalities (e.g., low tech board during swimming, unaided AAC, backup system)  
  - Partners use interaction strategies (e.g., modelling)  
  They hook the nova chat up to a big tv now that's in the classroom. They'll have conversations with him and they'll say, “where do you want to go?” The therapist will hit it, and then he'll have to respond back, so they are modeling, and he responds. And I guess that’s like amazing and that’s working really well. |
| Integrating AAC outside challenges (and realities) | Describes the challenges and realities of using AAC with individuals outside of the immediate family members (e.g., paraprofessionals, medical professionals, peers, friends, instructors, teachers), and in settings/contexts outside of the family context (e.g., school, community). This includes:  
  You have to make a conscious effort to be patient and wait and that’s hard. And imagine what it’s like for children? Um and whether they’re going to stick around to engage with that you know?  
Integrating AAC family challenges (and realities) | Describes the challenges and realities of using AAC in relationships within the immediate family and within family routines at home. This includes people coming into the home to care for the child (e.g., sitters, home care aides, nurses). For example:  
  - Little use of AAC with some family members  
  - AAC not available within all family routines at home (e.g., morning care routines, bedtime, when out of wheelchair)  
  So some activities that we do, I don’t incorporate AAC. For the simple fact of, if we’re doing something really physical, I can’t do it. On the bike, I try to do things, because she has to hold on, and she really grips it. And so I will use it just for modeling, or I’ll have the taking bricks where she can say stop and go. |
<table>
<thead>
<tr>
<th>Challenges/realities related to using AAC with multiple partners such as:</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Knowledge and training needed for partners</td>
</tr>
<tr>
<td>• Communication partner responses and attitudes (negative, unsure of how to respond)</td>
</tr>
<tr>
<td>• Wait time needed (especially hard for peers)</td>
</tr>
<tr>
<td>• Communication between school and home needed (e.g., regarding academic vocabulary)</td>
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</table>

<table>
<thead>
<tr>
<th>Challenges/realities related to using AAC in multiple settings/contexts, such as:</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Eye gaze not available outside</td>
</tr>
<tr>
<td>• Device cannot be out in the rain</td>
</tr>
<tr>
<td>• AAC is not always available, especially during physical activates (e.g., riding bike, swimming, horse riding)</td>
</tr>
<tr>
<td>• AAC not accessible out of wheelchair</td>
</tr>
<tr>
<td>• Not used in community due to uneven surfaces and fear of falling</td>
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</table>

<table>
<thead>
<tr>
<th>Integrating AAC outside description</th>
<th>Description of relationships with individuals outside of the immediate family members and activities outside the home, without mention of AAC</th>
</tr>
</thead>
</table>

**Theme 6: Description and Uncoded**: Used for comments that describe the child, but are unrelated to developmental, psychosocial, or communication. Also used for descriptions of the parent/family unrelated to roles and responsibilities. Uncoded comments include interviewer questions, participant questions, and comments unrelated to child, parent or AAC

**Log of changes to codebook**

- **3/14/18**
  - “child communication multiple modalities code” moved under “child communication strategic competence” after discussion with undergraduate coders. We decided that the use of multiple modalities is a strategic skill to make communication more efficient, faster, more easily understood.

- **3/19/18**
  - Changed parent goals and priorities goal to a broader family goal that included 2 additional sub-themes
    - Important people
    - Routines

*But if we’re in direct sunlight she can’t see the screen. And you know we just go and if there’s bright sun on it, she will get frustrated.*
• 3/20/18 re-organization
  o Collaboration moved under process
  o Challenges and supports of integrating AAC into life combined into one theme
    (integrating AAC into life) with challenges and supports as subthemes
  o Some re-organization within the AAC limitations and supports theme (now 5
    themes rather than 6)

• 3/21/18
  o Removed “AAC limitations cost of learning” code
    ▪ This is covered under process learning technologies

• 3/28/18
  o AAC limitations size:
    ▪ now called “physical design”
    ▪ Mounting challenges moved into this subtheme
  o AAC limitations trade-offs
    ▪ Moved under “AAC limitations other”
  o AAC supports features
    ▪ Now called “multiple functions”
  o Child psychosocial needs and skills
    ▪ Definitions/examples added
  o Changes again to Family system theme
    ▪ Now back to parent roles, goals, and priorities
    ▪ Family system codes encompassed under integrating AAC into life…

• 4/6/18
  o Integrating AAC into life theme updated to include two subthemes rather than
    three. Subthemes are: family system and outside systems (school and
    community)

• 4/11/18
  o Clarified definitions for process collaboration and integrating AAC into life
    (some discrepancies regarding these two codes due to seeming overlap)
Appendix I

Bracketing Statement

I am a speech language-pathologist with three years of clinical experience working with children who used AAC and their families. My clinical experiences have provided me with some understanding of the experiences of families supporting their children to use AAC. I acknowledge that the short time that I have spent working with families gave me only a limited understanding of family experiences, compared to the expertise that families have with their children. Additionally, none of the students that I worked with who used AAC had cerebral palsy and/or experienced significant motor challenges, so I have little experience with the specific population in this study. I entered this study acknowledging my limited expertise and experience in the area, and recognizing parents as experts on their children and their needs.

In addition to my clinical experiences, I have a long-standing interest in families and family functioning, particularly families of children who have developmental disabilities and use AAC. I have completed coursework on theory regarding family functioning (i.e., family systems theory). My theoretical understanding of families that I gained through this coursework and subsequent writings has influenced how I think about families. I have a conceptual model based on family systems theory that is the lens through which I now view families. I view families as interdependent systems in which all members are integrally linked to one another, much like the elements in a mobile. If you pull on one element in the mobile, the whole mobile moves. Families members are linked to one another in the same way—if an event occurs that affects one member in the family, it affects all members of the family. This theoretical orientation has made me recognize the importance of viewing children who use AAC within the context of the family, which was one of the driving forces for this study. I recognized parents as critical stakeholders in
the AAC process with unique insights on how AAC technologies are used in everyday life. I acknowledge that my theoretical understanding and previous clinical experiences could influence how I interpret the data. I will use self-reflection processes throughout data collection and analysis to ensure that interpretations are reflective of participant responses and experiences.
Appendix J

Summary of Themes and Subthemes for Member Check

Child skills and needs
- Developmental: motor skills, cognition, vision and hearing
- Communication: linguistic skills, operational skills, social skills, strategic skills
- Psychosocial: motivation, attitude, self-advocacy, personality

Parent responsibilities and priorities
- Roles: advocacy, educating, leadership, device related, interaction strategies, parenting
- Goals: linguistic skills, social skills, fluent communication, independence, inclusion, motor skills

AAC technologies
- Limitations: inefficient, unreliable, programming challenges, limited vocabulary, unappealing, physical design (weight, position)
- Supports: ease of programming, variety of vocabulary, multiple functions and features, physical design (portable, accessible)
- Ideal: reliable, appealing, easy to program, efficient (brain-computer interface), physical design (lighter, smaller, wearable)

Process and decision making
- Selection & customization: assessment and trailing, funding, customizing
- Learning technologies: trial and error, cost of learning, lack of training
- Emotional responses: accepting situation, feelings about future
- Changes over time: transitions, technology changes, progress

Integrating AAC into life
- Family: supports and success stories, challenges and realities
- School & community: supports and success stories, challenges and realities
- Collaboration with professionals: positive, negative, changing roles
Appendix K

Additional Data Demonstrating Themes and Subthemes

<table>
<thead>
<tr>
<th>Subtheme</th>
<th>Code</th>
<th>Example data</th>
</tr>
</thead>
</table>
| Integrating AAC into Life | Supports and success stories | **Use with various family members:**  
|                  |                   | • In her first week she [sitter] was modeling on his device, and I was like, “Yes!”… so she’s awesome. (Bailey)  
|                  |                   | • You know sometimes they’ll have a sleepover and he’ll talk about that for several days in advance. It’s more to talk about them [siblings] than to talk to them. (Bailey)  
|                  |                   | • He [brother] learned quite early on how to use the book as a communication partner, and things like that (Kelli)  
|                  |                   | • If she’s up [in her chair], she uses her device to speak to us. (Kelli)  
|                  |                   | • They [siblings] tend to communicate with the Tobii. I mean I wouldn’t say that they—so his younger brother will talk to him, but they don’t interact probably quite as much as two brothers might in terms of talking. But, it tends to be more sort of needs based. So Luke will ask his little brother to do something for him, so he’ll use the Tobii to ask him to pick something up for him or to get something for him. So that’s probably the main way they communicate. (Shannon)  
|                  |                   | • Billy [Zane’s brother] is very good at communicating with Zane. And you know part of it is just because he’s his brother and they’re comfortable and you know he understands him. He also sees us using the AAC and modeling with Zane, and so he does the same thing (Allison)  
|                  |                   | • My mom and my sister they all ask him, you know, “Use your talker and tell me.” (Jackie)  
|                  |                   | **Use in family routines:**  
|                  |                   | • And then when he comes home after he goes to the bathroom the first thing we do is turn on the talker. (Lucy)  
|                  |                   | • He has his device in front of him whilst he’s being fed his breakfast. And at the moment, his device sits on a floor stand in the living area. (Shannon)  
|                  |                   | • When he gets up in the morning for breakfast the first thing that we do is—you know we get the talker and we put it on the table. It’s part of our routine (Allison)  
|                  |                   | **Use of multiple modalities in family routines:**  
<p>|                  |                   | • |</p>
<table>
<thead>
<tr>
<th>Challenges and realities</th>
<th>Realities of family life:</th>
</tr>
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<tbody>
<tr>
<td><strong>Her favorite book is ‘I Love you Stinky Face’. So now we’re just using descriptive words like stinky and love and things like that. And if she won’t use the hi-tech device, I use the talking bricks that I can put anywhere because I have Velcro attached to it. And then we will just stick them on that.</strong> (Amelia)</td>
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<td><strong>He’s using partner assisted scanning and his yes and no for toileting and all of that stuff</strong> (Lucy)</td>
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<td><strong>And she comes in [from the bus]. Then, usually we talk to her about her day, using you know verbal, signs, and expressions for about 15 minutes while she gets changed and has a snack</strong> (Emily)</td>
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<td><strong>And if she needs to say something [during morning routine], she’ll have to just shout until we realize that she wants to talk to us. And then we’ll get the tablet—the book—and she’ll use that one and tell us what it is.</strong> (Kelli)</td>
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**Family functioning:**

- The thing that I had discovered just reading blogs and interacting with parents, you know there’s different support groups and stuff. (Allison)
- And she does have a girl that’s 12 years old and she pretty proficiently uses Proloquo. And we probably get together at least once a week or more. So we do tons of activities. (Amelia)
- And he has carers that come in to help with some personal care in the morning. And they do some respite outings on the weekends sometimes. (Shannon)
- **We have a homecare aide that comes for four hours Monday through Friday. Helps get him ready for school and she does his laundry.** (Jackie)

**Use in family routines:**

- She’s lying on the bed. And when she’s not lying on the bed, the next thing she does is she’s sitting on the toilet, and then the last thing she does is she’s sitting in her chair getting her coats on and getting ready for the taxi. So through all of that she doesn’t really have a chance to sit and chat.
- **So some activities that we do, I don’t incorporate AAC. For the simple fact of, if we’re doing something really physical, I can’t do it. On the bike, I try to do things, because she has to hold on, and she really grips it. And so I will use it just for modeling, or I’ll have the taking bricks where she can say stop and go.** (Amelia)
• We’ve tried some mounts outside the wheelchair, like we tried one mount for her lying on the couch. And, she really didn’t like that. It was too difficult for her to use the eye gaze from a lying down position. (Emily)
• But it’s hard for her to be either in her wheelchair or on my lap and to be holding the book and utilizing either low-tech or high-tech. And so those challenges are really difficult. (Amelia)
• So he doesn’t have access to it until the moment that he comes through once he’s dressed. You know so that sort of, when you’re lying in bed, and then someone’s dressing you, and then you’re being moved into a wheelchair, you know that’s quite hard to have a device available at those periods. (Shannon)
• Then honestly, on school day there’s really not enough time to. Turn on his talker and have a conversation, like you don’t have dedicated conversation time, it’s like leave. So the talker doesn’t go on until he gets to school (Lucy)
• Basically the point at which he leaves the living room to go and get ready for bed, that’s the point in which he loses access to the Tobii. But as most children do, that sort of bedtime can be a time when there’s lots of—you know all kids have a means to ask for things once they’re in bed, or change their mind about what they want to do in bed. So that period can be—that’s an issue cause he’s lying down in bed and he doesn’t have access to it. And I haven’t quite figured that out how to do that yet. (Shannon)

*Use with multiple partners in family or at home:*
• And really all we’ve done is just kept it really really simple. And really just showed them [home care aides] the absolute basics. And then they arrive it’s already setup to go. It’s already mounted, it’s switched on. But that leaves us vulnerable to a situation that if something were to go wrong, some of these people might not have that extra knowledge on how to handle it. But there’s only so much you can do. (Shannon)
• Theirs [sibling communication] isn’t that great. She [his sister] won’t like go get his talker and have him say something to her. He more—their relationship is more, she does something entertaining and he laughs. So she mostly just tries to make him laugh. (Jackie)

<table>
<thead>
<tr>
<th>School and community</th>
<th>Supports and success stories</th>
<th>Use with various partners:</th>
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</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>They hook the nova chat up to a big tv now that’s in the classroom. They’ll have conversations with him and they’ll say, “where do you want to go?” The therapist will hit it, and then he’ll have to respond back, so they</td>
</tr>
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</table>
are modeling, and he responds. And I guess that’s like amazing and that’s working really well.

- His para, actually, was really good at it. She could add new stuff on the fly, like if they were reading a book, she would actually add like Brown Bear, like that stuff on the fly. (Jackie)
- She has a particularly good one-on-one aid this year who I think is doing a great job with modeling and making sure the device is, you know, really part of things. (Emily)
- The children in her class used the book with her (Kelli)
- She’s actually played video games with some kids or shown them what she can do and stuff. (Emily)

*Use in various settings:*

- I’m pretty sure they turn it on for the majority of class time (Lucy)
- He has his device most times during the day at school. (Shannon)
- He’ll sit in the Caroline’s Cart [at Target] and I’ll wear the device (laughs) and he’ll make fun-and like we’ll be walking down the grocery aisle and be like, “Beans, you need beans?” and he’ll just laugh, “Beans” and he doesn’t really want beans but he’ll make, he’ll joke with me about the errands and stuff (Bailey)
- He uses it at church on Sundays, he uses his talker at Sunday school. And that’s been really neat because he doesn’t have a person attending to him he just is with the other kids and the children in his class have learned some, like they know how to clear if he needs help clearing, they know how to turn his volume down, if he needs helps with that (Lucy)

*Multiple modalities:*

- So we printed out one page and laminated it that’s just a swimming page so he can communicate with the teacher if he needs to. (Allison)
- They have to just rely on yes/no questions if they need to talk to her about anything in the taxi. (Kelli)

**Challenges and realities**

*Use with multiple partners:*

- The problem with introducing somebody to the AAC device is that if you don’t know where stuff is, it’s hard to find to model. (Allison)
- But then when they ask her questions, the temptation is to look at whoever is pushing her wheelchair for the answer rather than waiting for Taylor to answer (Kelli)
- When we go to the supermarket and do the shopping for example, I think most people that see her out and about in her wheelchair probably just assume that she doesn’t
speak. But not being able to speak is not the same as not having something to say. (Kelli)

- You have to make a conscious effort to be patient and wait and that’s hard. And imagine what it’s like for children? Um and whether they’re going to stick around to engage with that you know? (Shannon)

- If other kids tried to touch it they [school professionals] would say, “No no no that’s Sadie’s, don’t do that.” (Emily)

- And I think the school staff… I don’t think that they want the other kids touching it because obviously, you don’t want the kids to think it’s a toy. And so I think the school is protective of it. But really, they need to allow the kids to experiment with talking with Zane with it, and I don’t really know how to encourage them to do it. (Allison)

- It’s just like a regular adult who’s never met him they’re VERY hesitant to touch it. They’re like, “You can’t touch it” and they think children can’t touch it (Lucy)

Use in multiple settings/contexts:

- When you need this device with you everywhere, all the time, they do get bashed about a bit unfortunately. Because they’re in and out of bags, going to school, going to after school club. I’m afraid it’s just the reality (Shannon)

- You know we’ve tried having him use it in public places it’s hard cause people can’t hear it or they’re not expecting it. So that’s a work in progress (Allison)

- If you were in a shopping precinct or a train station or something, it is quite hard to hear what she’s saying. (Kelli)

- It’s not much use for sort of physical things. It doesn’t help a huge amount with that. So obviously for swimming, there’s nothing—we can’t take it with us. (Shannon)

- He can’t use it when he’s in his stander at this point because we don’t have a rolling mount. So when he gets out for an hour in the stander he doesn't have it then either. (Lucy)

- One of the other pains I guess is that AAC is mounted on his wheelchair, and we live in a very rainy state. And if it’s raining, I have to take the talker off the chair and put it where it doesn’t get wet. (Jackie)

- There’s an issue in terms of rain and sunlight. So if you’re outside and it’s sunny, it’s not great, it’s not that good. And similarly if there’s rain—you can’t really use it if you’re outside for long periods of time. (Shannon)
- I think it’s hard to take it outside our house, because of the eye-gaze. If we’re in direct sunlight she can’t see the screen. And you know we just go and if there’s bright sun on it, she will get frustrated. (Emily)
- She doesn’t want Irene [device] to get wet if we’re out. And in the sun you can’t really see it anyway, so it only really functions as a tool for speech inside, on a nice smooth surface, if you’re not moving around too much. (Kelli)
- The talker is really only on inside and a place where balls aren’t flying and things like that. (Lucy)

<table>
<thead>
<tr>
<th>Subtheme</th>
<th>Code</th>
<th>Example data</th>
</tr>
</thead>
</table>
| AAC supports                     | Vocabulary and programming| • A couple times he’s been screaming pissed off mad at me and I can’t figure out what he wants. And I’ll get his talker out. He’ll want something out in the garage, that there’s no way he would be able to tell me that he wants to go on his bike or something. (Jackie)  
• One of the big things was knowing if he’s in pain. So sometimes in the middle of the night he’s woke up screaming, and I’ve been able to grab his talker and say, “What’s wrong? Are you hurt? Are you comfortable? Are you mad?” And he told me he was uncomfortable. And I went to body parts, and he told me his stomach hurt. So we’ve been able to use it for stuff like that. No way I would have been able to know. (Jackie)  
• We like to put in a few pre-stored phrases for his life that are just coming up that you know, you and I would not have to work to say, like “Happy New Year!” (Lucy)  
• His private SLP has added, “you’re driving me crazy!” so of course that’s a favorite thing to say (Bailey)  
• We have some of his favorite—you know we have Bruno Mars or Justin Timberlake—stuff like that (Allison)  
• On the fly I don’t mind. I can do it pretty quick. (Bailey)  
• If the words aren’t in there, it recommends you can actually add some of the words that don’t already show up (Jacob)  
• And now the teachers at school, because of the search function, that makes it a lot easier for them to either find or add vocabulary. (Allison) |
| Multiple functions and features   |                           | • She does use her device to operate the television, she uses the infrared controls on it. So she can change the channel herself and change the volume and stuff like that, which she finds quite empowering. Before we figured that out, she would have to ask for the next |
| and system fit                   |                           |                                                                                                                                             |
• The Tobii is programmed to control the TV remote so that he can access television himself and change the channel and record what he wants. (Shannon)
• You push a button, it changes the whole thing to Spanish—which is actually kind of cool. And it keeps the layout the same and all the pictures the same, so he knows. (Allison)
• She could also play games on it. And that was super motivating by the way with the eye gaze. She would look at these different things and it would splat it, and she’d start laughing. (Amelia)
• Well she really really likes playing eye gaze video games on her device. That’s like one of her favorite things to do. (Emily)
• It has pretty much everything that he needs is on that setup—the 42. I mean the layout of the device is pretty good, I feel. It was pretty well thought out. I don’t know that you could do that any differently. I think it is as good as it’s going to be for what he needs (Jackie)

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<tr>
<th>Subtheme</th>
<th>Code</th>
<th>Example data</th>
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<tbody>
<tr>
<td>AAC limitations</td>
<td>Vocabulary and programming</td>
<td><em>Programming:</em></td>
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<td></td>
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<td>• But then again if I try to teach my mother she has no idea. So these other people in his life—and his father, I don’t think he’s ever programmed on it and I’ve tried to show him but I just, so I don’t think it’s easy, it’s not easy for all of us that’s for sure (Bailey)</td>
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<td></td>
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<td>• You have to do it on the device. There’s no way to manage it on a website or your own app. (Jacob)</td>
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<td></td>
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<td>• I mean some of it is tricky to get your head around how it’s going to work, especially if we try to add a new piece of software. (Kelli)</td>
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<tr>
<td>Multiple functions and features</td>
<td>Multiple functions and features and system fit</td>
<td><em>Multiple functions and features:</em></td>
</tr>
<tr>
<td></td>
<td>system fit</td>
<td>• There’s just not a lot out there for eye-gaze either. In terms of software. I mean, I really beat the bushes for her to find games and stuff, because she really plays them. (Emily)</td>
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<td><em>Fit with child:</em></td>
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<td>• It has so many buttons that I think he can get overwhelmed sometimes. It’s like where do I go for this? But he does need all of those. Because like I said he talks about this book about the rain forest. So he needs rain forest animals. Or they talk about going to the store or the doctor. So he needs all of those buttons. (Jackie)</td>
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<td></td>
<td></td>
<td>• You know, and there are lots of kids who eventually get to this point where they really can say anything—they</td>
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(program to be put on and all that sort of stuff. So that gives her a bit of independence. (Kelli)
<table>
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<tr>
<th>Physical design</th>
<th>So you’re staring at a screen not looking at someone, so that doesn’t help in terms of… So we’ve said—things we are trying to do is—if someone talks to you, look at them. And that’s quite a hard skill when you’re used to staring at your screen, when you’ve got to divert and look at someone if they start talking to you. So that’s an issue. (Shannon)</th>
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<tr>
<td>Cost of use and efficiency</td>
<td>The way that she’s able to use the eye gaze the best is when she has the full support of her wheelchair and she’s in a slightly reclined position from the full sitting up position. (Emily)</td>
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<td></td>
<td>I mean it is exhausting for him to use the AAC, he would use it more if it wasn’t so much work for him to get that arm up and get it directionally on the exact button. (Jackie)</td>
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<td>At the moment I think the time delay is really frustrating. So the time it takes him to type out even a short sentence, even though he’s got predictive text and he’s pretty fast at it, it still really is a drag on the typical interaction people would have when they’re chatting. (Shannon)</td>
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<td>And if she’s missed it, she’s got to go all the way back around again, and this is just for one word or one letter. You know, so it was just such a painful slow process. And plus she’s just not got the motor control to use the switch effectively. (Kelli)</td>
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<td></td>
<td>So the reality is, great, this picks up your eyes. But you better be positioned just like this. And it better be in the exact same distance and height every time. Well the problem is when you’re a three-year-old, a lot of times they put you in a high-low wheelchair. Well I was just up and down up and down trying to get it lined up, and hook her eyes (Amelia)</td>
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</table>

want to be able to say anything and they’re limited by their device or by what they’re able to do. (Allison)

- The thing that I hate about the NOVA chat is that it’s not really good for people who aren’t literate because the extra actions and descriptions are alphabetized. “Actions A-Z,” and if you want to look for throw and you don’t know that throw begins with a “T,” how are you ever going to find that? You’re not, and so you’re just going to have to say something else. That’s the big letdown about that. (Bailey)
because he wants, he’s very aware of how people are social so he’ll look at the speaker and then he can’t… (voice cracks), so that’s hard (Lucy)

- I mean the device she has is not light. So we’ll have to carry it and push her chair at the same time. So if I don’t have somebody else with me, then that’s a big weight on your shoulder, and you can’t just stick it on the back of the chair (Kelli)

### Reliability

- It’s been in the shop like 6 times in the last year and a half because the USB port for the charger breaks. (Bailey)
- They can be prone to crashing or not working or whatever —and that’s really bad when that happens. That’s really frustrating for him…So that sort of reliance on it, that can be an issue I think. (Shannon)
- The battery life is so short so I can’t leave it on the whole time, cause it would die halfway through the day. (Jackie)

### Subtheme | Code | Example data
--- | --- | ---
AAC ideal | Physical design | • It would be sturdy—you could drop it, you could throw, it could withstand a banging and it would just be able to stay intact. (Bailey)
• I would like devices in the future to be much more robust in terms of the real sort of battering that these things do get. (Shannon)
• And it would be nice for him to be able to have some way to communicate more effectively without his talker in front of him. (Lucy)
• I’d like it to be lighter and a bit smaller if possible and the attachment system and mounting—that could all be much improved I think. (Shannon)
• So I’d like that, and I’d like something that was maybe wearable. Maybe tech that was wearable. Where it wasn’t a clunky thing that you have to carry around with you (Shannon)
• We can get augmented reality glasses, move away from using our hands for all these things. (Jacob)

### Efficient and easy to use

- I always wondered if there was a way to do sentence prediction, and then the same thing, “Is there a way to do sentence prediction with symbols? And what would that look like?” (Bailey)
- If it could read his mind that would be ideal. (Jackie)
- But it would be really neat if he could use brain waves because there’s always going to be a motor component to eye gaze, and he has a very severe motor impairment. (Lucy)

### Multiple functions and

- So I’m hoping one day, that she will get a voice which is unique to her, as she becomes older (Kelli)
<table>
<thead>
<tr>
<th>Subtheme</th>
<th>Code</th>
<th>Example data</th>
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</thead>
<tbody>
<tr>
<td>Developmental skills and needs</td>
<td>Motor skills</td>
<td>We’re just getting to the point where she can isolate her pointer finger. And so we do a lot of activities with that because that’s how she’s going to be able to progress to more squares. (Amelia)</td>
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<td></td>
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<td>Because her right arm is the doer. So if I want anything done, she wants to turn the page with the right arm, and then she’s going to have to use the right arm to touch the device. (Amelia)</td>
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<td></td>
<td></td>
<td>But he can isolate his pointer finger. It’s just his pinky sometimes hits the button. (Jackie)</td>
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<td>He has very poor control over arms and hands and really very, next to no fine motor control with his hands. (Shannon)</td>
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<td>She’s very very dependent physically on everything. She can’t hold anything, she can’t sit without support, she needs a head rest on her wheelchair. She hasn’t even got much head control really. (Kelli)</td>
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<td>The biggest challenge is that his spasticity increases as he is excited about something. So if there is a topic that he really wants to tell me, it’s that much harder for his body. (Lucy)</td>
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<tr>
<td>Cognition</td>
<td></td>
<td>So I think despite having all of those needs, I think it’s always been clear from very early on that Luke didn’t really have any sort of intellectual disability. (Shannon)</td>
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<td>He is such a bright person. The school district assessed him and he is definitely age- appropriate cognitively.” (Lucy)</td>
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<td>His intelligence is very good. (Allison)</td>
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<td>We think she’s bright. (Emily)</td>
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<td>He gets distracted really easily—everything has to be modified for him. (Jackie)</td>
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<tr>
<td>Hearing and vision</td>
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<td>She wasn’t totally deaf but her ear drums were not vibrating and so we had all of these issues. And then she really couldn’t hear well. (Amelia)</td>
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<td>She still has the vision issue, so we do this a lot (participant shakes her head back and forth in a lateral motion). Some of this people try to speculate is that stimulating, or is she making a whole picture. So we had seen for a long time a developmental ophthalmologist, she said a lot of her kids do this (participant shakes her head back and forth in a lateral motion) to make a full picture because there’s holes in their vision. (Amelia)</td>
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<tr>
<td>Communication skills and needs</td>
<td>Operational skills</td>
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<td>• We’ve now found a way that he can control that camera in his own settings. (Shannon)</td>
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<td>• She knows what the word is and where they are. So she’ll just go and find them and use them. (Kelli)</td>
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<td>• For a long time she’s been happily emailing people. (Kelli)</td>
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<td>• I mean she is quite an expert in having used it [eye gaze] for so long already, I don’t know if she’s ever get any more accurate then she is already. (Kelli)</td>
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<td>• You know if she’s got her verbs page up for example, if she presses it once it will say come, if she presses it twice it will be coming, if she presses it three times it will be came. (Kelli)</td>
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<td>• He likes to go to the sports (laughs) area and hang out there for a while. (Lucy)</td>
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<td>• He’s not able to type very well. You know he hunts and pecks—it’s not an efficient way. (Allison)</td>
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<td>• It has groups, so he can hit groups and then he’s had to learn, like, the farm animals are under this button. (Jackie)</td>
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<td>• The most that she has ever done independently is go 2 pages deep or three pages deep… I would say that it’s pretty difficult for her to go deeper and deeper, as of right now. (Amelia)</td>
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<thead>
<tr>
<th>Linguistic skills</th>
<th>Syntax and semantics:</th>
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<tbody>
<tr>
<td>• The other day I said cake, and he said, “I want it. I want it.” And I’m like, “that’s great!” you know. That’s one of his first perfect syntactic sentences right there. (Bailey)</td>
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<td>• And one thing he doesn’t do is put them in syntactic order…because often they’re not. And it’ll be a jumble (Bailey)</td>
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<td>• He’s able to whip out four to six words without any trouble. (Allison)</td>
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<td>• He’s got a couple single things like he’ll say “go” a lot.” (Jackie)</td>
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<td>• She’s putting together sentences with three or four words at least five or six times a day and that’s great for her. And she likes it and she’s using it independently. (Emily)</td>
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<th>Literacy/typing:</th>
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<td>• So he starts typing, like the first couple letters, and then it’s basically like predictive text (Shannon)</td>
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<td>• She likes to use the alphabet keys on her Unity. She’ll spell out words. Not everything she spells out is a real word. (Emily)</td>
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<td>• And she also has a keyboard page, so she can type in whatever word she wants. But her spelling, because</td>
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<td>Subtheme</td>
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<td>she’s never been able to sound out her phonics, her spelling is not great. (Kelli)</td>
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<td>Social skills</td>
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<tr>
<td>Strategic skills</td>
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<tr>
<td>Psychosocial needs and skills</td>
<td>Motivation</td>
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<tr>
<td>• He’s very determined at getting what he wants. So he’ll keep trying to communicate with you until you figure it out. (Jackie)</td>
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<td>• Before they unlocked that [game], she had no interest in looking at it. I mean none at all. (Amelia)</td>
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<td>• Yes in fact I wish he didn’t want to talk about sports because he was obsessed (laughs) and he sometimes won’t get off of a certain topic. (Lucy)</td>
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<td>• I’ll turn it on and he will just be frantically getting somewhere and that’s when he says his best stuff because... it’s really important to him and he’s clearly planned it ahead of time. (Lucy)</td>
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<td>• He has a lot of the same kids in his class every year. You know they’re very sweet to him, they’re very kind and they try to get them to interact with them, but he doesn’t always return it, and so some of that is not going not be helped by the AAC. (Allison)</td>
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<td>• I would say peer communication is less important for him (Shannon)</td>
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<td>• The Polar Express has been this all-encompassing thing. He can’t stop talking about it and it’s February. So that’s really limiting for us. (Bailey)</td>
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<th>Attitude</th>
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<td>• Sometimes, just like anybody (laughter)—he gets a little frustrated sometimes. (Allison)</td>
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<td>• Then she knocked it [device] off because I think she was mad. Cause she hollered out after that. (Amelia)</td>
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<tr>
<td>• When she touches it, it doesn’t always talk to her. Then she gets mad cause then she just hits it. And that doesn’t necessarily help. (Amelia)</td>
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<tr>
<th>Self-advocacy</th>
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<tr>
<td>• But often times then he’ll have to ask for help because he doesn’t know how to spell what’s he’s trying to find. (Jacob)</td>
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<td>• At times he will actually ask for the talker. He has a sign for it. (Jacob)</td>
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<td>• Often times now he’ll actually go to the pre-stored phrase and he’ll say it a few times and then he’ll look at me. It said, “Happy New Year!” and it’s mid-January and he’s going, “Happy New Year! Happy New Year!” and he’s giving me a look and I was like, “OH! Have we moved on? Do you want to take that away?” and he says, “yes.” (Lucy)</td>
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<tr>
<td>• If we go to the dog park, we usually take her power chair. A lot of times she will want to take her device. (Emily)</td>
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<tr>
<td>• He’ll tug on my arm and point to the talker and, that’s how I’ll know he wants me to add the characters from this movie or he wants to be able to talk about this TV show. (Allison)</td>
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</table>
Personality

- I think she’s just shy. (Kelli)
- She’s got her own voice, her own sense of humor, she’s very cheeky. (Kelli)
- So unity reconfigured, they have a 2.0 they just released and so he’s probably only had the 2.0 for a few months, but he’s totally on board with it now and it’s difficult, probably for me more. But he’s very adaptable. (Lucy)
- My son’s problem is that he likes to be silly. So he will give the wrong answer on purpose and it’s hard for them to assess what he knows and what he doesn’t. (Bailey)

Theme: Parent Responsibilities and Priorities

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<tr>
<th>Subtheme</th>
<th>Code</th>
<th>Example data</th>
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| Parent roles  | Leadership | • I think I have a big role, and I actually sometimes have to remind myself to have less of a role because I was the one who did the research and found the device (Lucy)  
• If I don’t do it, it’s not getting done. (Bailey)  
• And I really hit the school team hard this year. When I went to observe it wasn’t on his desk but for like 5 minutes of an hour, I was like, “Wait a second here, this is why we moved to this school.” And I talked to them about it and held the IEP back to make sure things were set straight. (Bailey)  
• So because we are with him all the time, I can see what he’s trying to do or what he wants to do or the things that he consistently is attracted to in the system. So I think being interpreter to speech and language therapists and others that are interacting with him. To say this is really the thing that he’s really interested in just now with the Tobii. I’ve seen him trying to do this. Could we make this thing easier or that thing easier? (Shannon)  
• And really all we’ve done is just kept it really really simple. And really just showed them [home care aides] the absolute basics. (Shannon)  
• Another role I suppose is to, to be his advocate around making sure that the people do respect his use of AAC and adapt to it. (Shannon)  
• I can pick up on cues just from the sounds she’s making (Emily)  
• We’ve asked year after year that our county provide actual instruction and teaching in the device. (Emily)  
• We were fighting for a long time to try and get the school district to do what we wanted. (Emily)  
• I went in and kind of trained them [school professionals] how to use it and what worked at home. (Jackie)  
• I again had to fight for [the mount]. You have to fight for everything here. (Kelli)  
• Another aspect of our day that really consumes our time is, since she’s on blenderized diet, it takes me 15
minutes to give water... And then 45 minutes later, so everything is cleared, then I can feed her. (Amelia)

- There’s always a lot of people who like to tell you that your kid doesn’t have any intelligence, or you know, might have some sort of intellectual disability because they’re not communicating. And we didn’t think that was the case. We still don’t think that’s the case. And so it became our personal mission to help him communicate. (Allison)

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<th>Device related</th>
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<tr>
<td>• His personal programming for example, that’s pretty much me. (Lucy)</td>
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<td>• I had to completely set up her whole program for her. (Amelia)</td>
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<td>• I will add like personal things. Like last week, when she had her birthday, I changed – she has a button that says “I am 11 years old,” and I changed it to “I am 12 years old.” (Emily)</td>
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<tr>
<td>• It’s always me that gets to do all the tech stuff with it. So when she wants vocabulary added or if we need to reprogram something or check out some new software for her to paint with or play music with, or anything like that. (Kelli)</td>
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<th>Interaction</th>
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<td>• As soon as the talker goes on if we want to encourage him, if he’s not jumping right into saying something, we start with like an open-ended phrase. So, my husband will say, “Dad is…” (Lucy)</td>
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<td>• We’d show her how to use it in the book so that she could then eye point to it and make her own decisions. (Kelli)</td>
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<td>• We try to model as much as possible. (Emily)</td>
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<td>• On the bike, I try to do things, because she has to hold on, and she really grips it. And so I will use it just for modeling. (Amelia)</td>
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<td>• I feel like part of my job is to just wait. And sometimes, 30 seconds to a minute feels like forever... Waiting and prompting without putting words in her mouth. (Amelia)</td>
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<td>• Anytime I’m modeling with him I’m using my finger to make the phrase and I try to sprinkle in maybe half and half if I’m having a conversation with him in front of his device. Half the time I’m just speaking and then half the sentence I’ll use the talker. Maybe just key words, like the noun and the verb. And then I just don’t really worry about articles and things like that because I don’t expect him at this stage to be meticulous about “a”, “the”, “and” -whatever. (Lucy)</td>
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<td>• If my daughter is swimming, I'll go to actions and I'll say, “What’s Eliza doing?” (Jackie)</td>
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So if we were playing a game for example, we would hold up two things in our hands and one would be a doll and one would be a train for example. And you’d sort of spread them apart in your hands. Which one do you want to play with—do you want to play with the doll or do you want to play with the train? (Kelli)

My role is to speak in the language… all the time. From many different areas using similar language until he learns that language and it transfers and to keep going there. (Bailey)

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<tr>
<th>Subtheme</th>
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<th>Example data</th>
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<tbody>
<tr>
<td>Parent goals</td>
<td>Communicative</td>
<td>• Hopefully he’ll be able to type at some point instead of having to rely on a grid. (Allison)</td>
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<td></td>
<td>competence</td>
<td>• Whereas we’re trying to get him to understand the difference of voices, so this is school work now, so it’s important that you write the sentence, that you use punctuation (Shannon)</td>
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<td>• But we would like him to improve his interaction with others as in, if somebody asks you a question, you don’t just ignore them. It’s like, “no, that person’s asked you a question. You respond to that first before you ask them whatever it is that you want to ask them about.” (Shannon)</td>
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<td>• If you’re going to have a measure of independence and use this device to help you communicate, you have to understand how people behave with each other and how we talk to each other. (Shannon)</td>
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<td></td>
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<td>• Literacy is something that I would like to see her achieve because I think it would be a great gift to her and it’s you know so very enjoyable. (Emily)</td>
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<td>• I would like to see him being able to respond to conversation with some kind of wit or some kind of, other than, “that’s funny” because he says that a lot”. (Bailey)</td>
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<td>• I’d like to see a lot less distractions. And a lot more ability to focus on a conversation that a person is trying to have without going to the pre-constructed kind of obsessive statements (Bailey)</td>
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<td>• Especially if she needs somebody to help her physically for her whole life. If she can have that expressive part, that would get her miles along. So obviously I really want that for her. (Amelia)</td>
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<td>• In addition to just being able to communicate to the people around him, I know he absolutely needs to be able to e-mail and use the internet functions of the talker. (Lucy)</td>
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<td>Efficient</td>
<td>communication</td>
<td>• I think the next thing which we’re working on with speech and language therapy and experts that support</td>
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<td>communication</td>
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them are faster—programs to make it faster. So that’s
another goal, to make it faster. (Shannon)

- When I was taught the difference between direct
  selection and scanning methods I just knew that if at all
  possible I had to give him every opportunity to be a
direct selector. (Lucy)

- We started doing assisted communication when she was
two, just simple communication devices. I had visions of
her at some point communicating more or less fluently
using a device. She’s still at the point where building
sentences is a lot of work for her. (Emily)

| Independence and inclusion | I need him to either stand or help more with transfers—
he’s just really getting heavy, so we’ve been kind of
working on having him help a little bit with that.
(Jackie) |
|----------------------------|-------------------------------------------------
|                            | I think we’re at a time right now where smart homes are
coming out, so I can foresee him being able to be more
independent if he can use his communication device to
control the lights in his house or the locks on the doors.
(Lucy) |

Theme: AAC Process and Decision Making

<table>
<thead>
<tr>
<th>Subtheme</th>
<th>Example data</th>
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| Selection and customization   | • I don’t know why it takes so long to get a device and an
  attachment for a wheel chair. I’m like, what is the
  problem? (Amelia)                                                           |
|                               | • Wait 6 months? He can communicate with this. We’re not going to wait 6 months. (Jackie) |
|                               | • I was just there to sign papers and say, “Yeah we’d like
  a device please.” …and all of the sudden it was like this
  is the one they are covering, this is the one you are
  going to get.                                                               |
|                               | • And so, when it came time to determine, “Oh, this is the
  assessment process and this is how long it’s going to
  take.” I couldn’t stand it and I decided we’re buying it,
  and we bought it. And that way, no matter what ever
  happened, it’s ours and no one could take it away from
  him. So we’ve been very hands on with the process
  (Lucy)                                                                     |
|                               | • We bought the device, we haven’t even, you know, gone
  through any sort of AAC trialing with the school
  (Allison)                                                                 |
| Learning technologies         | • He does a lot of exploration. Especially in bed at night, he’ll just like make all kinds of weird sentences (Jacob) |
|                               | • We go back in, pick it up, and have a few lessons and
  after that we’d be sent home with his device (laughs).
  Like, “Ok!” I was never trained on modeling. I was
  never trained to speak to him with it and stuff like that,
  and it was kind of bewildering. (Bailey) |
<table>
<thead>
<tr>
<th>Feelings and emotional responses</th>
<th>You always feel like there’s something more you could be doing. (Emily)</th>
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<tbody>
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<td>We can handle her struggling to eat, we can handle the mobility issues, but it’s the speech-or-in any form. You know, we would take any kind of form. (Amelia)</td>
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<td>I think there’s loads of potential in the future (Shannon)</td>
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<td>I mean that gives me hope because the more examples that you see of these people that can be fast, but if he can’t be fast, that’s ok! (Lucy)</td>
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<td>I think when Sadie’s father and I realized that she was pretty profoundly disabled we had this sort of vision of her leading a life of the mind, and we didn’t realize that profound motoric disabilities have an effect on literacy and also the intellect to a certain extent</td>
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<td>We just try to take things as they come. (Emily)</td>
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<th>Changes over time</th>
<th>We’re going to have to start over. It’s a whole new group of professionals all new people, we have to make our case again for what we want. (Allison)</th>
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<td>I would say maybe the biggest challenge is having to start over every time. I mean cause you don’t know them [professionals] and they don’t know you. (Amelia)</td>
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<td>His MLU has grown pretty tremendously in the past year and a half it’s up from one to maybe 3, 4. Amazing, and he’s starting to use core a lot more frequently. (Bailey)</td>
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<td>The devices have already changed so much since she was two. I can’t imagine that by the time she is an adult, they won’t be – things I can’t even think of or something astounding. (Emily)</td>
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<th>Collaboration with professionals</th>
<th>Positive:</th>
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<td>I think a lot of what she [speech-language pathologist] does is give me information. You know, educate me, and I then can help navigate (Lucy)</td>
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<td>They had somebody from Saltillo, from the actual company that makes the NOVA chat at school, and that</td>
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was a game changer. Then they [school professionals] were all—then they had the confidence. (Jackie)

- The school itself has been really wonderful and they have gone out of their way to do what they can to make sure Sadie’s well integrated and that the device is available at all times and all that. (Emily)

**Negative:**

- I think I did bring it up [hi-tech device] to one of the therapists when Julia was around three. And the response that I got at that point was—oh, that’s way too complicated for her. (Amelia)

- The biggest stumbling block that we have is that teachers and SLPs are not familiar with AAC. They don’t know anything about, or what they do know is wrong. (Allison).

- They would always look at us like, sure, he uses that, the device at home… Sure, sure. You know because he wasn’t really using it consistently. (Allison)

- We’ve had a lot of push back from you know people across the board. With implementing it at school. (Allison)

- At the beginning of the summer, the last day of school, Sadie came home without her device, her school-provided device. They had decided that she couldn’t have it for the summer. and it was like, “Ok she has no device anymore. She has no voice.”
VITA

Tara O'Neill

EDUCATION

Doctor of Philosophy, Communication Sciences and Disorders 2018
The Pennsylvania State University; University Park, PA

Master of Science, Communications Sciences and Disorders 2012
The Pennsylvania State University; University Park, PA

Bachelor of Science, Communications Sciences and Disorders 2010
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SELECTED PUBLICATIONS


SELECTED PRESENTATIONS


SELECTED AWARDS AND HONORS

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The Pennsylvania State University

AAC Leadership Project, U.S. Dept. of Education grant # H325D110008 2015-2017
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