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Perceived Expectations of Roles in Training and Maintenance of Augmentative and Alternative Communication Devices

Kathlene Talladay

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Perceived Expectations of Roles in Training and Maintenance of Augmentative and Alternative
Communication Devices

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Thesis

Submitted to the Department of Special Education

Eastern Michigan University

as a component for the degree of

MASTER OF ARTS

in

Speech-Language Pathology

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Ypsilanti, MI

DEDICATION

*To my parents, Gary and Darlene Slaven, who taught me the meaning of dedication and support.
And to my husband, Timothy Talladay, who taught me the value of relationships and the
importance of communication.*

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ABSTRACT

Augmentative and Alternative Communication (AAC) devices are invaluable tools for people who have difficulties communicating verbally. However, advancements in technology accentuate the need for training to utilize devices effectively. This qualitative research study examined the perceptions and experiences of parents and speech-language pathologists (SLPs) regarding the training in and maintenance of AAC devices. Previous literature reveals the commonality that parents encounter difficulties in learning AAC technologies, as well as updating their child's devices. Interviews were conducted with parents of children with autism, as well as SLPs, to better understand their expectations concerning who is responsible for assuming specific roles in device training and programming. Results indicated that although parents and SLPs hold some similar perceptions of requirements, as well as opinions of ways to improve AAC services, deliberate role delegation does not occur early in the implementation process. This study identified gaps in perspectives and communication between parents and SLPs and discussed how these mismatches may lead to inappropriate assumptions by those involved in AAC intervention. Based on participants' responses, conclusions were drawn that may facilitate better communication between families and clinicians and, ultimately, a better experience for all parties involved in the intervention process. Finally, the results of this study suggested directions for future research in the area of autism and AAC intervention.

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Chapter 1: Introduction

Background Information, Problem Statement, Justification, and Significance

According to the American Speech-Language-Hearing Association (ASHA, 2011), augmentative and alternative communication (AAC) includes all forms of communication other than speech “that are used to express thoughts, needs, wants, and ideas” (para. 1). AAC refers to any approach used to enhance, support, or adjust communication in individuals who are not able to communicate independently. An AAC system should include a collection of devices, techniques, and strategies to aid the person in communicating (Mineo, 1990). This collection ranges in level of complexity, all of which require users and their families to be trained in their use.

AAC is typically divided into two broad categories: those systems that do not require much technology, if any (usually referred to as “low-tech” devices), and those devices that do implement electronic technology (typically referred to as “high-tech” devices). “Low-tech” AAC approaches may be implemented in isolation, but they are commonly used as a component of a more comprehensive communication system. Two examples of “low-tech” devices are communication boards and the Picture Exchange Communication System (PECS; Charlop-Christy, Carpenter, Le, LeBlanc, & Kellet, 2002). According to Mineo (1990), the term *communication board* refers to any display containing vocabulary choices that an individual can choose to create a message. These “low-tech” boards are those without electronic components. They can be made from a variety of materials—from the use of simple, handmade poster board displays, notebooks, and paper—to more complex, designer-made plexiglass and wood products (p. 2). Mineo (1990) also mentioned six factors that need to be considered when developing a communication board. These include the physical technique the individual will use when

selecting the message, the types of symbols to be used on the display, the vocabulary items to be included, the arrangement of the vocabulary items on the communication board, the interaction strategies the communicator will use, and the attitude and communication style the user and potential partners will uphold. The next example, PECS, may be one of the most common “low-tech” AAC approaches, especially with children with autism. Charlop-Christy et al. (2002) define PECS as a system that uses basic behavioral principles to teach children functional communication using pictures. The pictures are held in a notebook, and the child is taught to select certain pictures to create sentences to request an object from a communicative partner.

“High-tech” AAC approaches include more complex features due to the increase in technological components used in their design. Mineo (1990) describes several valuable features that these “high-tech” devices possess. The first feature is the capacity of most devices to hold at least 2,000 vocabulary entries compared to the small number of items that can be included on a “low-tech” communication board. Output displays are also a helpful element that “high-tech” systems contain. Most devices have a LED or LCD area that displays the message the individual is about to communicate. This permits the user to review the message and serves as a medium of communication between partners. Probably the most significant advancement in AAC technology is the availability of speech output. “Any utterance that can be entered as a text string can be produced, resulting in the potential for unlimited vocabulary” (Mineo, 1990, p. 3). Another feature of “high-tech” AAC systems, according to Beukelman and Mirenda (2005), is rate enhancement techniques. These techniques include programs such as word prediction and abbreviation routines that recognize items frequently used by the communicator and allow longer utterances to be produced with fewer key strokes. This advancement greatly increases the

efficiency of communication. Last, because each individual has unique communication needs, these “high-tech” devices allow for each system to be customized for a specific user.

Communication is the groundwork for all human interactions; and AAC devices can aid children with autism in achieving all its benefits. Effective communication between parents and speech-language pathologists (SLPs) is a critical element for successful use of AAC devices among children. When parents and professionals collaborate effectively, children can become more effective users of AAC devices, operating them more independently, and further developing their communication skills. These skills are essential for enhancing relationships and independence, two areas in which children with autism have significant difficulties (Wetherby, Prizant, & Hutchinson, 1998).

AAC has always been considered complex but has most likely become even more so due to these advancements in technology. Given the complexity of AAC systems, both parents of children using these devices, as well as SLPs who recommend and direct their intervention, become overwhelmed with learning these new technologies. Several studies have revealed that parents perceive lack of training and unfamiliarity with device programming as primary stressful barriers to their child’s use of AAC (Jones, Angelo, & Kokaska, 1999; Angelo, 2000; Bailey, Parette, Stoner, Angell, & Carroll, 2006; McNaughton, Rackensperger, Wood, Krezman, Williams, & Light, 2008). SLPs have reported that lack of family training and lack of time for maintenance are common factors that lead to the abandonment of AAC devices (Johnson et al., 2006). Although studies have identified common perceived factors by SLPs and parents as being related to neglect of AAC systems, no study to date has explored and compared the perceived expectations of SLPs and parents regarding their roles in the training process and maintenance of AAC devices. This study explored the personal experiences and expectations of parents of

children with autism and SLPs involved with AAC, identifying potential barriers in training and mismatches between parent and professional role expectations.

Purpose of the Study

Having over five years of experience working with children with autism who use AAC devices, as well as the professionals who serve them, this researcher has observed firsthand the stresses, concerns, and joys that come with implementing AAC. Parents are enthusiastic that their child will have an easier means to communicate; however, the new technology is, many times, difficult to master and update as their child progresses. Children with autism usually depend on parents and professionals for programming, maintaining, and adjusting their AAC systems. In addition, parents and SLPs may develop negative feelings when role expectations are not defined; each party presumably takes on a different perception of responsibilities, and lack of or slow progression may be apparent. This lack of explicit communication may impact the child's advancement in his/her AAC goals. Parent and SLP collaboration is an important factor in the AAC intervention process.

The purpose of this study was to gain an understanding of the expectations and actual experiences of parents of children with autism and SLPs in regard to training and maintenance of AAC systems. More specifically, this study compared the expectations of parents with those of SLPs regarding training and maintenance of AAC devices and identified similarities and inconsistencies in thinking. By better understanding these comparisons and perspectives, both parents and SLPs can become aware of the potential areas in which communication breakdown may occur in their own situations. Additionally, a goal of this study was to bring to light actual experiences of parents and SLPs in order to provide suggestions for enhancing the success and efficiency of future AAC intervention procedures.

Research Questions

The purpose of the study was to identify the perspectives and personal experiences of parents and SLPs involved in AAC intervention and compare their expectations to actual experiences. The study attempted to answer the following questions: What are parent and SLP perspectives on training and maintenance assistance available for AAC? How do parents believe they should be trained to use AAC? How do SLPs believe parents should be trained to use AAC? Who do parents/SLPs expect to complete the maintenance and programming for the child's device? Are the expectations explicitly laid out by both parties? If so, when and how? How do their actual experiences compare to their expectations?

Chapter 2: Review of the Literature

Understanding the Views of Parents

Multiple studies, covering various disorders, have investigated parents' perspectives about the use of AAC technology for their children. Included in these perspectives are not only the benefits of AAC but also the obstacles that families face due to the range of complexity of these systems (Huer & Lloyd, 1990; Angelo, Jones, & Kokaska, 1995; Angelo, Kokaska, & Jones, 1996; Jones et al., 1999; Angelo, 2000; Parette, Brotherson, & Huer, 2000; Bailey et al., 2006; McNaughton et al., 2008).

The most common obstacle to successful use of AAC reported by parents is inadequate training in AAC technologies. This theme includes operational competence such as technical operation and upkeep, strategies for programming, and solutions to technological breakdowns (McNaughton et al., 2008). In Bailey et al. (2006), the authors explored factors that were perceived to affect students' use of AAC devices, family expectations, and benefits of AAC devices. They interviewed six family members of seven children who primarily use AAC devices to communicate in the school environment. Family members' concerns about inadequate training increased proportionately with the device technology level. With "low-tech" devices, participants mentioned ease of programming without any need for training. Conversely, more training was required to operate the device correctly as its technological complexity increased. When information and training needs are not met, the AAC user may not have an effective means of communication (Angelo, 2000).

Parette et al. (2000) point out that inadequate training also results in time and management issues related to programming and maintaining the devices. The researchers interviewed 58 parents who were the primary caregivers of children with cognitive or

developmental disabilities who were identified as needing an AAC device. The parents reported that programming was overwhelming and time-consuming, and suggested that professionals improve their instruction in AAC use.

Family members often play a large role in programming devices, troubleshooting problems, and daily maintenance such as battery charging and cleaning (Angelo, 2000). In Angelo's (2000) study, 15 families of children with physical disabilities, developmental delays, and autism who used AAC devices were interviewed to determine the support they received from professionals and how they managed the time and stress issues. The majority of the respondents who participated in this study perceived that their personal investment of time and energy was greatly increased with the introduction of their child's AAC device, as well as their level of stress. Conversely, almost half of the parents reported not spending a lot of time programming devices. One limitation of this study is that there was no report as to who was completing the responsibilities for these parents. Unless children are able to do this independently, they must rely on the parents and/or professionals to program and update their devices on a regular basis.

McNaughton et al. (2008) conducted a focus group discussion study on the benefits and challenges of learning AAC technology. Seven parents of individuals with cerebral palsy participated in the focus group. The parents in this study reported that they learned how to operate their child's device by reading manuals, attending training courses, and using the telephone support provided by the manufacturers. Learning how to program the device was a major challenge for the majority of the participants. Training from an SLP, free online courses, and self-teaching were strategies used to counter this obstacle; however, parents felt like the trainings lacked detailed information necessary to organize vocabulary. Some parents mentioned that even some professionals lacked the knowledge and skills necessary to address the technical

problems. One parent reported that it was the assistive technology specialist, not the SLP, who played an active role in teaching her child how to use the AAC device. Training provided by the manufacturers was described as an important resource for both parents and children.

In the Bailey et al. (2006) study, parents indicated that school professionals were responsible for providing training and technological support to families. All six participating parents in this study mentioned that the school managed the technical problems and occasional other problems that occurred with their AAC devices. The device representative's role was limited to initial meetings to discuss the selection of a device.

Bailey et al. (2006) emphasized that adequately training and supporting parents in their programming efforts, as well as communicating with them frequently about difficulties, may alleviate some of the stress associated with using AAC devices. Professionals should be very clear with their expectations and limitations and forewarn parents about the time and effort required for operation.

Another factor pointed out as affecting the use of AAC devices is an ineffective team. Parents in the Bailey et al. (2006) study reported that decisions involving their child's AAC device were often made by the school professionals before the parents received any training or consultation. Effective teams, on the other hand, made efforts to understand the family, accepted responsibility for personal roles, and gave the family opportunities to contribute to the team. Parents' own level of team involvement with school professionals varied across participants as reported by Bailey et al (2006).

In the Jones et al. (1998) study, parents of AAC users emphasized the importance of social supports. Groups of people identified as "most helpful" were professional helpers and school staff (p. 202). Although it has been reported that professional insensitivity to family

issues may cause additional frustration for families, many parents identified professionals at schools and other programs as a primary source of social support.

Angelo et al. (1996) conducted a survey to identify the needs, priorities, and preferences for AAC services held by mothers and fathers of older children who use AAC. A total of 132 parents representing 97 families of children aged 13 to 21 reported as having physical disabilities, speech impairments, multiple handicaps, developmental delays, and cognitive or visual impairments responded to the survey. The authors found that parents put a high priority on “planning for future communication needs” with the AAC team (p. 17). Planning for future communication involved upgrading assistive devices and ensuring access to services to meet those needs. Not only do parents need information about access to information, but they also need information on services that support the child’s changing communication requirements. Families want empowering partnerships with professionals related to support for AAC use in their current and future lives at home and in their community. They expressed significant needs for acquiring and updating their knowledge about AAC over time.

Huer and Lloyd (1990) compiled and summarized perspectives of 165 AAC users, following a content analysis of 187 first- and third-person articles, published between the years 1982 and 1987. Of the 165 participants, 36 were children (12 years old and younger), 44 were teenagers and young adults (13-24 years old), and 48 were adults (25 years of age and older). Many diagnoses were described in the article including cerebral palsy, cerebral injury, cognitive impairment, degenerative neurological diseases, amyotrophic lateral sclerosis (ALS), laryngeal cancer, spina bifida, hearing impairment, and multiple handicaps. Only one participant was identified as having autism. The topic of frustration appeared more frequently than did other topics in the data. The reason for this frustration often centered on the family’s interaction with

professionals. Children using AAC reported that they and their parents frequently criticized professionals such as doctors, educators, and speech-language pathologists. While this study does not discuss parent opinions directly, their views are displayed through the descriptions of the AAC users themselves. The perspectives of AAC users are invaluable to the therapy process and should be acknowledged whenever possible. The main finding of frustration due to interactions with professionals only enhances the need for the study at hand. Although these data are somewhat dated, studies continue to report families' frustration caused by interaction with professionals (Jones et al., 1999; Angelo, 2000; Bailey et al., 2006; McNaughton et al., 2008). When families become frustrated with professionals (i.e., not considering family needs, preferences, and priorities), parents often do not wish to comply with their recommendations, communication begins to breakdown, and the devices may become abandoned.

Parents of AAC users recognize several areas that need improvement in the AAC therapy process. As described in the Bailey et al. (2006) study, parents listed the following four suggestions to improve learning of AAC technologies: (1) Manufacturers and representatives should become integral partners for technical support and maintenance; (2) Technical support should still be available once children become proficient with using their device, especially during transition periods; (3) Professionals should demonstrate knowledge about AAC devices in initial team meetings; and (4) Time is needed for training and collaboration between families and professionals.

In the McNaughton et al. study (2008), seven parents of children with cerebral palsy who used AAC devices offered advice and recommendations for improving learning and teaching processes for professionals and parents who support children who use AAC. Their advice for professionals included sensitivity to personal needs of each individual and family. They also

clearly expected professionals who work with their children to know the basic technical operation of an AAC device and to be prepared to teach the information to others, as they described many communication and educational professionals as being unfamiliar with AAC technology. In addition, they pointed out that having technology supports built into the devices would also be helpful for them.

Parents in the McNaughton et al. (2008) study also mentioned that professionals should create organized instructional programs for families. The parents reported that they need to be prepared to take a leadership role in obtaining services and to become experts themselves in both AAC technology and instructional programs. Parents often reported frustration with their efforts to obtain appropriate assistive technology services. As a result, parents in this focus group study pointed out a clear need for improved training for professionals in three main areas. First, training in current AAC technology is needed at the pre-service level as well as ongoing professional development at the in-service level. Second, education and rehabilitation professionals need to make effective use of a wide range of research supported practices; and third, there is a need to provide professionals who deliver AAC services with training that focuses on the problem-solving and communication skills needed to work effectively as part of a team.

Angelo et al. (1996) emphasized that professionals should focus on helping families gain knowledge to make informed choices and decisions about technology and services for their children. Experts need to make family members feel competent rather than dependent on professionals and services. Knowing the roles family members assume, professionals can support them in their existing and evolving roles related to AAC practices. These researchers

recognized that assisting families in finding social supports is another way in which professionals can empower families.

According to Angelo (2000), family members typically endorse the idea of AAC with expectations of anticipated benefits. It is important for professionals to understand how and to what extent devices affects families. They must also have an understanding of family needs, priorities, and preferences related to AAC devices and services. Families might be unprepared for the responsibilities of programming and learning to use the device, so they must be provided assistance in order to develop their knowledge of AAC processes. Indeed, Bailey et al. (2006) recognized the need for future research to include investigating teaming relationships, roles, and responsibilities, as well as parents' education and training habits in AAC devices.

Understanding the Views of Speech-Language Pathologists

To get a comprehensive picture of the factors underlying the success versus the abandonment of AAC systems, it is important to consider the perspective of all stakeholders involved. Most studies have focused on AAC users and their parents to understand the phenomena of success and abandonment of AAC systems. Just a few studies have focused on the perspective of SLPs on such topic (Johnson et al., 2006).

Johnson et al. (2006) described the perspectives of SLPs regarding the success versus abandonment of AAC technologies. The SLPs in their study had 1-30 years of experience. Factors leading to long-term success of AAC reported by the SLPs included support from various family members and team members, ongoing training to team members, and ease of use. Common factors that led to abandonment of AAC included lack of training, lack of support, and failure to maintain or adjust the system. "It is likely that a system will not fit the needs of a user

if there is a lack of ongoing adjustments, time for programming, collaboration, system maintenance, or opportunity to use the system” (p. 96).

The authors also recognized that there is a continued need to obtain direct input from all the stakeholders involved with an AAC device. Knowing the differences in priorities would lead to fewer “erroneous judgments” among team members and a better appreciation for the “motivation underlying each team member’s degree of participation” (p. 97).

The lack of research identifying the expectations of SLPs and the consistent findings in the research on parent perspectives serve as a solid foundation for the study at hand. Lack of specific investigations into the interaction between the expectations of parents and SLPs, as well as their actual experiences, provides justification and significance of the current research project.

Chapter 3: Methodology

Study Design

Considering the nature of this study and its reliance on parents and SLPs sharing their perspectives and experiences, a qualitative research approach was used. Parents of children with autism and SLPs were interviewed to gain a better understanding of their perceived roles in training and maintaining AAC devices, as well as the personal experiences that have led them to uphold these perspectives and expectations.

Semi-structured interviews were conducted to identify parents' and SLPs' perceived expectations contributing to the roles of AAC training and maintenance. The interviews included open-ended questions as well as probing questions for further clarification. According to Bogdan and Biklen (1998), "The qualitative research approach demands that the world be examined with the assumption that nothing is trivial..." (p. 6). Everything the researcher encounters has the potential to lead to a more comprehensive discovery of what is being studied. Further, the researcher was concerned with the "process" rather than solely focused on the outcomes (p. 6).

Participants

Participants in this study included a group of nine parents of children diagnosed with autism and users of AAC devices, and a group of nine SLPs (six private SLPs and three school SLPs) serving those families. Table 1 outlines the demographic characteristics of the participants in this study, as well as those of the corresponding children. The children's ages ranged from 7 to 19, and they had one to five years of experience with their current device. Eight of the nine children were currently using "high-tech" AAC systems. These devices included Dynavox Maestro™, Prentke-Romich ECO2™, Prentke-Romich Vantage Lite™, and

the Apple® iPad™ applications Proloquo2Go® and TouchChat™. Only one child (Abby) primarily used the PECS “low-tech” system. Each parent reported that their child was successful with the device at the requesting level of communication, but they were expecting more progress to be made in the future. For example, S. B. stated during her interview, “I think he’s successful in certain functions of communication with the Dynavox™. He’s certainly successful in requesting with the Dynavox™. He uses ‘I want’ very proficient, very fluently. So, success in terms of him being able to ask for what he wants, I would call that highly successful. I think that we still have a lot of work to do helping him expand his use of the device, and expand his language skills across other domains.” One parent (C.G.) revealed that her child (Steven) was beginning to comment on items and events, and another parent (G.C.) reported that her child (David) was very successful with commenting and incorporating humor into his daily conversations. David, however, was the oldest child in the group (age 19) and had been using AAC since age 4. Although he had been using his current device for only one and a half years, this was his third device throughout his lifetime.

Participants were recruited from a variety of settings (i.e., local schools, clinics, and hospitals) in the state of Michigan via formal flyers and email. They were informed, orally and in writing, of all research procedures and goals prior to their agreement to participate in the study. Each participant was asked to meet for an individual and private interview lasting approximately 60 to 90 minutes. Informed consent forms were given to the participants prior to the interview and explicitly emphasized the voluntary nature of participation and permission to withdraw participation at any time. In addition, SLPs were only contacted and recruited upon written consent from parents. No participants were excluded due to health, disability, age, gender, race, ethnic background, or sexual orientation. Pseudonyms and random initials were

used throughout this document to keep participants and institutions anonymous to the extent required by the Human Subjects Approval.

All parents indicated that their children received both school and private services; and, as noted in Table 1, all of them signed a written consent for the researcher to contact the private SLP. However, only four parents gave consent for the school SLP to be contacted for an interview. In addition, three SLPs served more than one parent involved in this study. P2 was the private SLP for Oliver and Stefanie; P5 was the private SLP for Cameron, Steven, and Bobby; and S1 was the school SLP for Janine and Stefanie. These clinicians were only interviewed once; however, they were encouraged to answer each question as it pertained to the specific families, recognizing any differences in expectations and experiences with respective parents.

Table 2 provides a description of the SLPs who participated in this study, including a detailed description of their caseload in regard to AAC at the time of the interview. The SLPs had between 7 and 39 years of experience in the field, and they all reported that the children of the parents participating in this study were at least partially successful with their devices at the requesting level of communication. They indicated that progress was being made; however, each child had his/her own pace of improvement.

Table 1

Participant Demographic Characteristics and Corresponding Children with AAC Systems

| Parent | Child (Years of Age) | Device (Years of Use) | SLP | |
|--------|-------------------------|--|-------------|------------|
| | | | Private (P) | School (S) |
| S.A | Janine (7) | Dynavox Maestro™ (2) | P1 | S1 |
| S.B. | Oliver (9) | Dynavox Maestro™ (1.5) | P2 | S2 |
| G.C. | David (19) | Prentke-Romich ECO2™ (2) | P3 | * |
| K.D. | Abby (8) | PECS (5) | P4 | * |
| K.E. | Stefanie (11) | iPad™—ProloQuo2Go® (1.5) | P2 | S1 |
| T.F. | Cameron (7) | iPad™—ProloQuo2Go® (1) | P5 | * |
| C.G. | Steven (7) | iPad™— ProloQuo2Go®/TouchChat™ (1.5) | P5 | * |
| I.H. | Bobby (9) | iPad™—TouchChat™ (3) | P5 | S3 |
| Y.I. | Alexa (7) | Prentke-Romich Vantage Lite™ (1) | P6 | * |

* No signed consent to contact

Table 2

SLP Experience and Caseload Characteristics

| SLP | Setting | Years of Practice (Years with AAC) | Number of Clients | Percentage AAC |
|-----|------------------|---------------------------------------|----------------------|-------------------|
| P1 | Private Practice | 13 (10) | 10 (Part Time) | 30 |
| S1 | Public School | 28 (27) | 19 (Part Time) | 26 |
| P2 | Private Practice | 13 (10) | 7 (Part Time) | 57 |
| S2 | Public School | 7 (2) | 43 | .09 |
| P3 | Private Practice | 27 (26) | 27 | 89 |
| P4 | Private Practice | 39 (37) | 7 (Part Time) | 71 |
| P5 | Private Practice | 9 (9) | 17 (Part Time) | 47 |
| S3 | Public School | 9 (9) | 64 | 19 |
| P6 | Private Practice | 15 (15) | 5 (Part Time) | 80 |

Data Gathering Procedures

With the permission of each participant, the interviews were audiotaped and transcribed by the researcher. During the scheduled interviews, the participants were asked both open-ended and probing questions in a semi-structured format, allowing them to expand on personal experiences with AAC technologies. Interview questions included:

Parent interview questions:

- What type of device(s) does your child use?
- How long has your child been using the device?
- How often does your child use the device?

- How proficient/successful do you believe your child is using the device?
- How helpful is the device/system for your child’s communication?
- Who is responsible for programming/maintaining your child’s device?
- Describe your experience with learning and updating your child’s device—from when you first acquired it to now.
- Did you feel prepared for the responsibilities/challenges involved with programming/maintaining your child’s AAC device?
- Do you feel that the time devoted to device maintenance and training is appropriate? Please explain.
- What are your expectations of your responsibilities regarding training in AAC technology and updating or programming new content for your child’s device?
- What are your expectations of the responsibilities of the SLP regarding the training of the device and updating or programming of new content?
- Have you attended any outside (formal or informal) trainings on your child’s device? If so, please describe and explain their value? How did you find out about their availability?

SLP interview questions (“X child” refers to the specific cases included in this study):

- How long have you been working with children who use AAC technology?
- Describe how you plan sessions with your clients who use AAC technologies. Do you include any training and/or maintenance?
- What are your expectations of the responsibilities of parents (and the X child’s parents in particular) regarding training of the device and updating and programming content?

- What are your expectations of your responsibilities regarding the training of parents (and the X child's parents in particular) in the use of AAC technologies and updating or programming new content for their child's device?
- What is your method of communication with clients regarding their AAC device features?
- Do you recommend, lead, and/or attend any outside training sessions for parents of children who use AAC devices? And how about the X child's parents in particular?
- Do you offer any suggestions for parents (and the X child's parents in particular) to help them manage the demands of their child's device? Please explain.
- How often does X child use the device?
- Who is responsible for programming/maintaining X child's device?
- How proficient/successful do you believe X child is using the device?
- How helpful is the device/system for X child's communication?

Chapter 4: Data Analysis and Findings

The data collected during the qualitative interviews were coded and analyzed for common themes and experiences (Bogdan & Biklen, 1998). The coding was completed in several steps. During the first step, the researcher read each interview transcript and identified major themes. Personal quotations were extracted in order to develop data categories. The second step involved finding common themes among the participants to build connections between the data categories. Once the themes and categories were identified for both the parent and SLP groups, the researcher then cross-referenced the findings from both groups in step three. Common themes and gaps in perceptions and expectations between the groups were identified.

Data analysis indicated that SLPs and parents were congruent in some areas related to role identification in the AAC intervention process; however, gaps in expectations and assumptions were more prevalent. The introduction of a second clinician significantly impacted the cross-referencing of the data in that comparisons were not only made between parents and SLPs in general but also included parent and private versus parent and school SLP perceptions, as well as private SLP-to-school SLP comparisons. In addition, parents and SLPs relished the opportunity to offer suggestions for improving AAC services for children with autism. Overall, eight common themes emerged and are discussed in the following sections.

Theme A: Need for Additional Service Provider

All parents sought out the service of a second, private SLP in addition to the services their children received through the public school system. The inclusion of a second service provider was not a participation requirement and was unanticipated by the researcher. Parents reported disappointment with the amount and type of service provided by the school and felt the

need to seek out more intense support via the private realm of AAC intervention. As K. E. reported in Table 3, “The school is over-loaded and moving at just such a slow pace.” P2, K. E.’s private SLP, also recognized the impact that the school was having, or not having, on her daughter’s success with her device. “The schools aren’t doing it for them,” she replied. However, both parents and private SLPs recognized that the caseload demands of school SLPs greatly impact their AAC service provision. As noted in Table 2, all SLP caseloads varied greatly with respect to the number of years of experience, particularly with AAC intervention, as well as in the number of clients on their caseload and the percentage that used AAC. One can clearly see the discrepancy between private and public caseload numbers. In addition, when compared to the percentage of AAC users whom private SLPs served, the public school SLPs had considerably lower numbers. Less than half of the school SLP caseloads included AAC service provision, where only two of the six private SLPs (P1 and P5) were below 50 percent. One can easily understand why the quality and time of service for each child receiving speech and language intervention through the public school system would suffer.

Table 3

Examples of Cross-referenced Quotes Related to Theme A "Need for Additional Service Provider"

| Parent | Private SLP | School SLP |
|---|---|--|
| “The school is over-loaded and moving at just such a slow pace.” K. E. | “The schools aren’t doing it for them.” P2 | No mention of need for additional services; however, clinicians were aware that families received additional services. “I think she uses it [device] with her outside speech therapist.” S1 |
| “I have to bring in [P3, private SLP] to do the training for the [school] staff.” G. C. | “It becomes difficult working with the schools sometimes.” P3 | |
| “His teacher...more so than his SLP...seems to be the leader.” S. B. | | |

Parents were also dissatisfied with the public school SLPs' demonstration of knowledge of AAC devices and the implementation and maintenance components they involve. "I have to bring in [P3, private SLP] to do the training for the [school] staff" (G. C., Table 3). Related to this belief, S. B. commented, "His teacher...more so than his SLP...seems to be the leader." This was a common theme among many of the parents involved in this study. Whether it was the private SLP, the device manufacturer, or both, parents felt the need to have to pay out of pocket for the training of their child's school staff. It was unclear whether all the school SLPs mentioned in this study truly did lack the knowledge of the child's particular AAC system, or if their caseload demands also affected the time allotted to train other school staff on the device and implementation process.

The private SLPs also commented on the hardships they encounter when trying to work collaboratively with the school professionals. P3 mentioned that "It becomes difficult working with the schools sometimes." This sub-theme was seen throughout all private SLPs, for various reasons. Again, caseload demands make it difficult to contact school SLPs and work closely together on a specific case; and one private SLP (P3) discussed the differences in goals that are developed in the school and private settings. Public school professionals are required to address the educational component of communication and write goals that involve the child's participation in academic activities. Private SLPs, on the other hand, tend to address more functional communication skills that are needed in the home and community settings. For this reason alone, it may become difficult for professionals to take the time to develop rapport with each other to best serve the child in all areas of his or her life. Four private SLPs (P3, P4, P5, and P6) reported extreme cases of disagreement between them and the child's school professionals, making it impossible to collaborate for the child's success. P6 stated, "It has been

a really difficult thing in our county. The person that's in charge of AT [assistive technology]...the two of us don't see eye to eye at all." P4 also mentioned that she "can't speak to the school. They're supposed to be using it [device], but they can't figure out how to do it." She mentioned that she and K. D. (parent) had consistently tried to communicate with the school about Abby's AAC system, but the school professionals seemed to hold a "very closed system" of communication with outside services. All private SLPs conveyed how disappointing it was to hear about, and personally experience, this kind of relationship—not only for the professionals involved, but especially for the children and their families who were caught in the middle of these services.

Despite the parents' expressions of dissatisfaction with school intervention, no school SLP mentioned the existence of this disconnection of services. The researcher could not define whether the lack of commenting reflected unawareness on the part of the school SLP or personal choice not to reveal the negative issues involved in the workplace. It is a possibility that parents tend to develop a closer relationship with their private SLP due to the frequency with which they communicate and their preference for outside intervention. Furthermore, parents themselves may not fully relay their disappointment to the school SLP for fear of hindering the relationship, or simply due to lack of consistent communication. Nevertheless, this absence of recognition can hinder the success of the child's communication and progress of intervention.

Theme B: Expectations of SLP Roles

Parents had clear expectations of the private SLP's role, yet they made only general comments of expecting "more" from school SLPs. As noted in Table 4, S. B. summed up parent expectations of school SLPs well—"The school SLP should be doing more." All nine parents interviewed in this study were adamant that the school professionals, particularly the SLP,

should be leading their child’s AAC intervention process. Parents expected the school SLP to involve them in the device selection procedure, train them on the chosen device, program new content into the system, and drive the course of intervention. The reasons for the steep expectations for school professionals were not explicitly stated by parents. However, they implied that the amount of time their children spent in the school setting versus personally paid private sessions and the fact that their children were not making adequate progress given the slow-paced school intervention procedure were factors that may have contributed to this view. Parents did, however, bring up the point that the high demands of the school caseload will ultimately impact how much school SLPs can do for each client, and this circumstance greatly affects their expectations. For example, K. E. stated, “Well, my ideal and my realistic are quite different. I know that they’re understaffed...I would love for her to take control...But how would she ever have the time. And I get that. But that’s the way I’d love it to be—that she’s the one in charge.”

Table 4

Examples of Cross-referenced Quotes Related to Theme B "Expectations of SLP Roles"

| Parent | Private SLP | School SLP |
|---|---|--|
| “The school SLP should be doing more.” S. B. | “The school should do it [programming].” P2 | “I think it’s a team responsibility” S2 |
| “[The private SLP] should be thinking about where we can go next [implementation].” S. A. | “I need to be thinking about the next thing to work on.” P1 | “It’s the SLP’s role to decide what the language is.” S1 |

When asked what they expected the private SLP to be responsible for in regards to their child’s device, parents responded with more specific roles such as developing and tracking goals

related to device use. “[The private SLP] should be thinking about where we can go next [implementation],” reported S. A. Parents also mentioned that they did not expect the private SLP to be consumed with programming new content into the device. Due to the limited amount of time their child spent with the private SLP (typically a half hour to an hour a week), parents wanted that time to be spent on teaching their child how to use the device more effectively.

Private SLPs seemed to be cognizant of their expected roles, as they mentioned similar responsibilities of themselves as parents held of them. P1 mentioned that she, as a private professional, “need[s] to be thinking about the next thing to work on.” This corresponded directly with parent views of the private practice setting—implementation of device use should be the focus, not programming and maintenance. Private SLPs also agreed that if any professional should be completing the programming details of the system, it should be the school. P2, quoted in Table 4 as upholding this view, was interviewed as a private SLP for the purpose of this study, but she also works in the school system. She practices in the school setting during the day, and works from her private office during the after school hours and summer months. P1, another private SLP who also works in the school setting, says that if “I was seeing Janine in the school, I would be doing it [programming].” They believed that it was not their role as a private SLP to spend valuable time with their clients focusing on maintenance details that could be done outside of therapy, whether they are completed at home or school.

School SLPs emphasized their role in specific aspects of the intervention as well, similar to the way private SLPs were viewed but different from the expectations parents upheld for school professionals. When referring specifically to maintenance and programming of devices, S2 stated, “I think it’s a team responsibility.” She further detailed that school should be responsible for programming school content, and parents and caregivers should be responsible

for inputting home vocabulary. Another school SLP, S1 mentioned that “It’s the SLP’s role to decide what the language is.” These self-expectations reveal a gap in thinking, and most likely lack of communication between parents and school SLPs, as well as misunderstanding of the procedures of service delivery policies in the school setting, with parents upholding school SLPs to more rigid responsibilities throughout the AAC process. On the other hand, the fact that parent and private SLP expectations aligned more directly may be due to the closer relationship between these two populations.

Theme C: Expectations of Parent Roles

Parents believed their main role in the AAC process was to advocate for their child in every way possible. For S. B. advocating meant to be constantly learning about new developments in AAC technology and where AAC would eventually take her child in life. “Advocating for my child, that’s what I should be doing. I want to keep learning more about it. I want to look at the big picture, thinking with his team and clinicians about where we are going next with AT, keeping up on the latest options...much more than I want to be the nitty gritty, programmer, day-to-day trainer.” This was also the priority of the parents who participated in the Angelo et al. (1996) study, as they reported the need for them to focus on planning for their child’s future communication necessities. Parents felt they should be the ones to organize their child’s AAC intervention, while delegating the hands-on work with the device to the professionals. “I feel like ultimately, it’s whatever primary parent that the child has to keep track of all the stuff,” reported T. F. Parents also expressed that they had many other responsibilities to tend to in regards to raising a child with autism, and that there was no time to include the technology aspects of an AAC system. This report is consistent with the Parette et al. (2000) description of time management issues related to programming and maintaining AAC systems.

The complexity of AAC technology can become a primary barrier to successful use as parents reported struggles with finding the time to learn and program their child’s device. Another possible explanation for this view that parents should not be the primary maintainers of AAC devices is that they may not view themselves as experts in AAC technologies. They seem to view themselves as experts in their children; and the role of advocating for their needs best fits this knowledge base.

Table 5

Examples of Cross-referenced Quotes Related to Theme C "Expectations of Parent Roles"

| Parent | Private SLP | School SLP |
|-------------------------------------|------------------------------|--|
| “Advocating for my child.” S. B. | “Parents have to own it.” P2 | “I would expect them to be proficient at it.” S2 |

SLPs, however, held a different expectation for parents. They expected parents to take ownership of their child’s device, in programming and maintaining the technology as well as in implementing the system outside of therapy. “Parents have to own it,” reported P2. Both private and school-based clinicians held the view that parents should know how to operate their child’s AAC device, how to program new content, where to go find help when needed, and use the system as much as possible. S2 stated that she “would expect them to be proficient at it” when discussing what she perceived parents’ role to be in AAC programming and maintenance. SLPs also recognized that parents have a lot of responsibilities in raising a child with autism, outside of the realm of AAC. However, it is reasonable to note that although parents may not have the formal training in AAC technology that SLPs may hold, they are the individuals who can make the most difference in their child’s life. By knowing the technology and understanding the

implementation procedure, parents can become equipped to best serve their child’s communication needs.

Theme D: Delegation of Roles

Neither the parents in this study, nor the SLPs mentioned initial delegation of roles when initiating the AAC process. Parents and SLPs indicated that roles were most often assumed. Parents stated that “It was a given” (K. D.), initially believing that responsibilities would be completed; but they soon realized that their assumptions were incorrect, or at least inconsistent throughout intervention. This notion seemed to reveal frustrations among the parents in this study. One parent (K. E.) also reported that once her initial assumptions were proven to be inaccurate, she began to feel uncertain as to what to do with her child’s system and felt as if she would have to be responsible for everything if her child were ever going to progress. The assumption that one feels unsupported can most definitely lead to the development of unnecessary stress and frustrations among parents.

Table 6

Examples of Cross-referenced Quotes Related to Theme D "Delegation of Roles"

| Parent | Private SLP | School SLP |
|-------------------------|--------------------------------------|--|
| “It was a given.” K. D. | “I believe it was understood.” P4 | “I guess the roles are defined. I mean, no one specifically said ‘You do this. You do that.’” S2 |

Private SLPs also “believe[d] it was understood” (P4), but reported that they were only speaking for themselves and had not held a conversation to discuss this matter with parents. P1 commented, “That’s a good question—whether or not she believes that to be. My understanding

is that we understand what our roles are.” One school SLP, stated, “I guess the roles are defined. I mean, no one specifically said ‘You do this. You do that.’” The fact that no formal discussion of role assignments took place at the outset of AAC intervention seems to have led to erroneous assumptions and negative feelings by all parties.

Theme E: Training Needs

Parents desired more AAC training from SLPs. As Bailey et al. (2006) reported inadequate training is the most common obstacle to successful AAC use that parents encounter with their children who use such systems. The parents in this study reported needs for training in device technology, such as programming and mechanical issues; and they also desired teaching in language selection and organization, as well as implementation techniques. This is consistent with the common parental desire for operational competence in the McNaughton et al. (2008) study. This theme of wanting to become more knowledgeable in AAC systems seems to be inconsistent with parents’ earlier claims of wanting the sole responsibility of child advocacy. Six of the nine parents in this study did not report an interest in becoming the primary programmer of their child’s device. Once parents become proficient in their child’s system, it may be anticipated that they take on some of the roles parents previously expected SLPs to uphold.

Table 7

Examples of Cross-referenced Quotes Related to Theme E "Training Needs"

| Parent | Private SLP | School SLP |
|---------------------------------------|---|--|
| “More training for parents.” I. H. | “I will teach them how to program it.” P5 | “I want to make sure they get initial training on the device.” S1 |

Contrary to parent expressions of training needs, both private and school SLPs claimed providing initial training, additional teaching upon request or demonstration of struggle, and additional resources for parents to access independently. S1, a school SLP, stated that she “want[s] to make sure they get initial training on the device.” Seven of the nine SLPs in this study also reported that they hold parent training as an important expectation of themselves as professionals. P3 mentioned that in the beginning of AAC therapy, she will “write objective that are, for example, the client/family will demonstrate the following goals to ensure safety and proper functioning of the device...So we incorporate that into treatment.” P5 also includes training in her sessions. “I will have them do it [program] right in the session. I will tell them and make them do it.” In addition, SLPs revealed that children have the best chance of success when parents understand and implement AAC at home and in the community. Direct therapy once or twice a week will not impact a child’s functioning unless it is carried over to other environments. P6 reinforces this idea with her method of training. “It’s always been my philosophy that I can’t just hand them the device and expect them to learn it on their own if I want that kid to succeed.” Lastly, because the SLP may not be available to the parents at all times, the professionals in this study reported the importance of giving parents a place to find the answers to the difficulties they may experience along the AAC journey. S2 stated “I think that’s a pretty big speech responsibility...helping the parents learn so if they can’t figure out something at home, knowing where to get the answer.”

This theme intensely shows that gaps in communication exist between parents and SLPs regarding understanding AAC technologies. SLPs claim to supply the training needs parents require; however, parents may not follow through on professional recommendations by seeking out the resources given by the SLP. This was reiterated by one private SLP, P5 “Sometimes

that's just a population of parents...that's another whole issue—just getting the parents to follow through on anything.” More prevalent familial issues tend to take preference, especially if the parents already understand their child's current means of communication. In contrast, if parents feel the need for more training in addition to what the SLP has provided, they may not communicate that need directly to the SLP. If SLPs do not recognize parents' needs for more training, and parents do not relay that need to clinicians, communication breakdown is sure to occur. As stated by Angelo (2000), when family and client training needs are not met, the child may not reach his true potential to become an effective communicator.

Theme F: Service Improvements

Parents and private SLPs offered suggestions for improving AAC services. School SLPs did not mention any recommendations at the time of their interview. Parents and private SLPs reported the need for more structured teaching methods for AAC implementation to children with autism. The participants compared the process of teaching children to use a “high-tech” AAC device to the structured six-phase protocol of PECS. “There has to be more of a sequential process for teaching device usage” stated parent, S. B. Children with autism tend to be very visual and structured learners, yet the process for teaching “high-tech” device usage is anything but sequential and organized. Especially for parents, a more sequenced protocol would greatly aid in their ability to engage their child in using his/her device outside of clinician supervision, and feel more confident that they are implementing it correctly.

Table 8

Examples of Quotes Related to Theme F "Service Improvements"

| Parent | Private SLP | School SLP |
|---|--|------------|
| “There has to be more of a sequential process for teaching device usage.” S. B. | “I’d love a training on how to teach [device usage].” P2 | No mention |
| “I wish there was an ‘Implementation Coordinator’” S. B. | “They should hire somebody to do it.” P2 | No mention |

Private SLPs also recognized the need for more research in the area of teaching AAC usage to children with autism. They reported lack of resources to aid in session structure and appropriate progression of goals. In addition, private SLPs mentioned that even device manufacturer trainings lacked the content necessary to serve this population. P1 relayed an experience she had with a Dynavox™ training she attended. “Like, the one [training] I went to, the guy didn’t have experience with kids with autism. So it [the client] could have been someone who was more communicative at the beginning...It’s very different if you are giving a device to someone who doesn’t know how to communicate and doesn’t really communicate with anyone, even nonverbally. They’re two very different people, and two very different profiles.” P2 held the same view when she said, “I’d love a training on how to teach [device usage].”

Parents and private SLPs also raised the need of another provider to be added to the team to facilitate AAC implementation. S. B. mentioned, “I wish there was an ‘Implementation Coordinator’ that somehow bridged the gap between school and private therapy and home; and would actually...be responsible for it [the device].” There may be many possible explanations as to why parents may want to hire a liaison. One possibility is the time constraints they face everyday in regards to programming and maintaining their child’s device as mentioned

previously; and another reason may be due to the lack of follow through on training and discomfort with operating the device. The private SLPs mentioned this idea of parents hiring a liaison to carry the responsibility of device maintenance if parents themselves were not going to take the time to learn and implement it on their own. Instead of using valued therapy time focusing on preparing the device for use, P2 said parents should “hire somebody to do it” so it is ready to use in sessions. However, this addition of another individual to AAC team may demand more collaboration efforts.

Theme G: Need for Collaboration Across Settings

Both parents and private SLPs reported the need for more team collaboration. Participants desired this community approach; however, for the majority of the individuals in this study, this was not the reality due to the many obstacles mentioned in previous themes such as erroneous assumptions, responsibilities of everyday life, and lack of recognition of needs. Parents expressed their longing for all members of their child’s team to work together to give their child the best possibility for success. “I would love an interdisciplinary approach... You’ve got all these people; so sometimes it’s too many hands in the cookie jar, so we just have to keep things consistent for him [her son],” T. F. expressed during her interview. Parents reported the struggle with keeping everybody’s thinking and actions aligned, as well as the hardships of relaying necessary information to all professionals involved in their child’s life. This disorganization may be due to the lack of a structured communication procedure among individuals of the AAC team.

Table 9

Examples of Quotes Related to Theme G "Need for Collaboration Across Settings"

| Parent | Parent | Parent |
|---|--|---|
| "I would love an interdisciplinary approach." T. F. | "I try to coordinate with the schools." P5 | No mention of struggle to collaborate with private SLP. |

Private SLPs mentioned their efforts to include the child’s school clinician in the intervention process, yet many were unable to do so to the extent that would be most beneficial. P5 mentioned, “I try to coordinate with the schools. It’s just...you have to figure out which way the school will do it with you.” Other private clinicians also mentioned the struggle to collaborate with the schools, but stated that they always make an effort to do so. On the contrary, the school SLPs in this study did not mention any struggle to collaborate with private SLPs; and, two of the three clinicians did not mention any efforts to contact the outside SLP at all. It was unclear from the data collected in this study whether these professionals were, indeed, successfully contacting private clinicians; or if they were unaware of the apparent disconnect between their services and those given by the private SLP. Each school-based clinician was aware of the private service these families received; yet, they seemed to keep their services within the realms of the school environment. These comments of struggle to collaborate with school clinicians, as well as the fact that school SLPs did not mention any efforts to reach outside the school setting, suggests that school-based professionals may be overwhelmed with the responsibilities the school setting requires and may encounter time and energy constraints that limit their ability to reach out beyond the educational system.

Never in the interviews did the school SLPs mention the child’s need for additional AAC service. Whether the clinicians were not aware of the parents’ feelings and needs, or they

did not wish to encounter the repercussions or portray a reputation that the high demands of the school setting may negatively impact AAC service, is unclear from the information obtained from this study. School SLPs tended to report the same level of functioning in regards to the child's success with their current system as the child's private SLP; yet they voiced no concern or recommendation for supplementary practice outside of the school's provision. This lack of responsiveness to parent and child needs may be considered a link to parents' initial outreach for private services. As Bailey et al. (2006) mentioned in their study, an ineffective team was another barrier parents perceived as hindering the use of AAC. Although this study referred specifically to including parents as part of a school team, the demands for team collaboration can be increased in a dual service provision, when a family is serviced by both private and school SLPs simultaneously. However, one could also argue that the children's communication success reported in the present study could be attributed to the dual service provision received by the children. Ultimately, the ramifications of division of members involved in the AAC team can influence the service dynamic and results of the intervention at hand.

Theme H: Parent Feelings and Actions

Parents reported different feelings regarding training and implementation of AAC devices such as excitement for new possibilities, but also frustrations associated with learning the technology. Reports of becoming easily overwhelmed with the numerous device features were also prevalent among parents. These features reflect the complexity of "high-tech" AAC as detailed by Mineo (1990) and Beukelman and Mirenda (2005). Even after a year of using the iPad™ with her son, T. F. emphasized that she is "still learning" how to program and use the Proloquo2Go® application. C. G. stated that it took "a lot of trial and error" to become familiar with her son's programs as well. Furthermore, G. C. felt as she had "no preparation due to

limited school resources” at the time her son was introduced to AAC. As reflected in these statements, a variety of feelings were reported by the parents in this study regarding their child’s AAC. Such feelings are disconcerting since, as reported in the literature, they can lead to abandonment of the AAC when left unresolved.

Table 10

Examples of Quotes Related to Theme H "Parent Feelings and Actions"

| Parent | Private SLP | School SLP |
|---|---|--|
| “Excited, but overwhelmed.” Y. I. | “We’re all overwhelmed.” P6 | No suggestions given during interview. |
| “I’m still learning.” T. F. | “Start small.” P5 | |
| “No preparation due to limited school resources.” G. C. | “Get comfortable with tech support.” P3 | “Make people comfortable.” S1 |
| “A lot of trial and error.” C. G. | “Make them [parents] independent.” P5 | |

Fortunately, the majority of SLPs in this study empathized with those parent feelings, and some private SLPs reported even sharing some of the feelings themselves. In response to the statement of feeling overwhelmed, P6 (a private SLP) commented that “we’re all overwhelmed” when learning a new system. She reported that she tells her clients that they are not the only ones who feel that way. It takes time for everyone, including professionals, to become accustomed to new technology and finding a way to adapt it to best fit a child’s needs. When professionals recognize and empathize with parents’ negative feelings, they are more likely to develop a trusting relationship; and parents may feel more empowered to stay persistent in overcoming the challenges of AAC. In this study, private SLPs seemed more inclined to acknowledge and share parent feelings than school clinicians. School SLPs did not mention

becoming overwhelmed with AAC technologies at the time of their interviews; neither had they reported recognizing such feelings among parents.

Private SLPs addressed parent feelings and gave suggestions to combat initial feelings of frustration. P5 recommended that parents “start small” when first beginning to learn an AAC system. By focusing on a single task, parents will begin to feel more confident in their ability to operate their child’s entire system. Moreover, the goal is to help parents become independent with the technology—but not all at once. The private SLPs, especially, considered it their responsibility to aid parents in reaching this goal.

Another suggestion private SLPs regularly gave to parents was to “get comfortable with tech support” (P3) for their child’s device. Clinicians realized that the sooner parents were less dependent on them to fix technical issues, the sooner parents developed ownership of the process. Lastly, only one school SLP mentioned any strategies she used to help parents battle the negative feelings that can accompany AAC. S1 stated that she wanted to be sure that parents were comfortable operating the technology their child was using. She did state, however, that this mainly occurred during initial trainings upon the child’s acquisition of the device. She did not provide further details as to whether she followed up regularly with parents throughout the invention process. Angelo (2000) suggested that professionals prepare parents for the obstacles they must overcome in learning AAC technologies at the outset of intervention. The SLPs in this study felt that they were preparing parents with the training they offered, as they viewed as a necessary component to AAC intervention.

Chapter 5: Discussion

The findings in the present study corroborate with other studies, indicating that perceived lack of training, time management, and ineffective teaming issues are among the common obstacles to successful and efficient AAC intervention. Table 11 outlines the perceived barriers parents and SLPs reported in this study that are related to those found in the literature.

Table 11

Perceived Barriers Reported in the Literature and Correlates from the Data

| Documented Barriers | Parent Correlates | SLP Correlates |
|--|--|--|
| (1) Inadequate or Lack of Training (Angelo, 2000; McNaughton et al, 2008; Johnson et al., 2006) | Parents perceived a need for more training from SLPs. | Private and school SLPs felt responsible for providing training. |
| (2) Time management issues related to programming (Parette et al., 2000; Johnson et al., 2006) | Parents reported lack of time to include AAC maintenance into daily routines. | Private and school SLPs recognized the outside responsibilities of parents as limiting time to address technical aspects of AAC. |
| (3) Ineffective Teaming (Bailey et al., 2006; Johnson et al., 2006) | Parents desired more teamwork among all professionals involved in the AAC process. | Private SLPs reported struggles in collaborating with school SLPs. <hr style="width: 20%; margin: 5px auto;"/> School SLPs did not mention struggle to collaborate with private SLPs. |

Although the participants in the current study relayed experiences with AAC that were consistent with those reported in the literature, the focus of this study was on the comparison of parent and SLP expectations of role identification in the AAC process. In addition, the dual

service provision involved in the sample of the present study had a great impact on the dynamic of the findings discussed in this study. New themes emerged as a result of the data analysis that revealed both differences and similarities in thinking among parents, private, and school SLPs. Table 12 outlines areas in which parent and SLP expectations aligned the most, and Table 13 summarizes those aspects in which parents and SLPs reported the most mismatch in expectations. As highlighted in the tables, similarities and mismatches varied across private and school SLPs.

Table 12

Areas of Most Congruence in Expectations

| Area of AAC Intervention | Expectations | | |
|--|--|--|--|
| | Parent | Private SLP | School SLP |
| Theme A—Need for Additional Service Provider | Sought out private clinicians to supplement school services. | Recognized that parent needs were not being met by the schools. | *Aware of private clinicians; however did not mention parent need for additional services. |
| Theme B—Expectations of SLP Roles | Wanted the school to be responsible for technical components, while private SLPs focused on implementation. | Agreed that their role should involve teaching device use, and school clinicians should perform more programming. | *Desired a team approach to device maintenance and identified their role similarly to private SLPs—implementation. |
| Theme D—Delegation of Roles | Reported that roles were assumed. | Believed roles were “understood.” | No delegation of roles. |
| Theme F—Service Improvements | Desired a more sequenced teaching process. <hr/> Reported need for technical liaison to address device maintenance. | Searched for training on more structured means of teaching device usage. <hr/> Stated that parents should hire liaison if they could not complete required programming. | *No mention of any suggestions for future AAC intervention during study interview. |
| Theme G—Need for Collaboration Across Settings | Mentioned need for communication among all members of AAC team. | Reported failed efforts to collaborate with school SLPs. | *No mention of struggle to coordinate intervention with private SLP, but were aware of additional services provided. |

*Did not report on commonly-held theme.

Table 12 shows that parents concurred with private SLPs in the areas of need for additional services, SLP roles in AAC maintenance, lack of role delegation, suggested service

improvement, and the need for increased cooperation among parties involved in the process. School SLPs and parents did not report similar perceptions on any of the themes outlined in the above table, except for role delegation. This mismatch in report may be due to a closer relationship parent hold with their private clinicians; or the fact that the strict demands on school SLPs, and simply the nature of school-based service delivery, may limit the time available to develop better rapport with parents.

Private and school SLPs held similar thinking in their role identification. Both sets of clinicians perceived that their responsibility in AAC intervention was to focus on teaching the child how to implement the device, establishing and addressing goals pertaining to AAC usage. However, the school SLPs self-expectation was a complete mismatch to what private SLPs and parents expected school SLPs' role to be. In addition, although school SLPs recognized the private SLPs as an additional service provider, they did not report any role expectation for such group.

It is vital to note that school SLPs did not mention explicit expectations to four of the five areas in which parents and private clinicians seemed to agree. The lack of report on such key areas may be an indication of a mismatch in expectations and perceptions involved in the intervention process. Such mismatches may depict a potential lack of communication between school clinicians and parents, as well as private SLPs; the differences in the nature of school-based service versus private service delivery models; communication and awareness of parental wants and needs from the school system; and the time demands school clinicians face.

Table 12

Areas of Most Gaps in Expectations

| Area of AAC Intervention | Expectations | | |
|--|--|--|---|
| | Parent | Private SLP | School SLP |
| Theme C— Expectations of Parent Roles | Perceived their primary role as advocating for their children. | Expected parents to take ownership of their child’s device. | Congruent with private SLPs views that parents should become an expert in their child’s system. |
| Theme E—Training Needs | Desired more training from SLPs on AAC technology. | Perceived training parents as a primary role and reported consistently offering teaching and resources. | Congruent with private SLPs in role expectations and also provided training to parents. |
| Theme H—Parent Feelings and Actions | Mentioned variety of feelings with limited assistance from SLP. <hr/> Felt unprepared to operate devices. | Shared parent feelings and offered suggestions to battle them. <hr/> Reported importance of helping parents become independent. | No mention of sharing parent feelings. <hr/> Congruent with private SLPs’ views that it was their responsibility to make parents comfortable with AAC. |

Table 13 reveals that parents and SLPs held differing expectations in the areas of parental roles in AAC, the need for training, and addressing parents’ feelings with learning and operating AAC technologies. The fact that school SLPs held the same expectations as private SLPs in the area of parental roles in AAC seems to indicate that, regardless of the setting, SLPs have set expectations regarding parents’ roles. A possible explanation for the gaps in thinking about parent expectations may be the parents’ perception that SLPs are the experts in AAC technology; therefore, not identifying their role to include the technical components of AAC. In regards to training, SLPs reported giving parents resources to pursue knowledge on their own. Parents’

expression of the need for training may be referring to more explicit training by SLPs due to the lack of time to follow through on those resources. Lastly, the mismatch in perspectives on professionals acting on parent feelings may involve many possible explanations. Parents may hold different relationships with certain clinicians; and, therefore, may not outwardly express their true feelings. Likewise, school SLPs may not explicitly tell parents that they hold similar feelings about new AAC systems. SLPs also may not tell parents that they hold feelings of families in high regard, especially concerning the nature of AAC. Furthermore, suggestions that SLPs offer to parents to help battle negative feelings may not be presented as such; and, therefore, parents do not identify professionals as offering sufficient advice and support.

Chapter 6: Conclusions

The results from this study lend themselves to the development of conclusions and potential clinical implications that may improve the AAC intervention process, particularly for families of children with autism. It is important to note that both SLPs and parents in the present study considered the children to be using the AAC system successfully, at least at the requesting level of communication. However, all parties also emphasized the children's need for increased success in communicating with their devices. The report of limited communication skills seems to be consistent with the findings of Wetherby et al. (1998). They identified areas of social communication in which children with autism tend to differ from other children. Preschool and school-age children with autism tend to be limited in their ability to communicate for multiple reasons. "They communicate predominately or exclusively for behavior regulation functions" (p. 81). These functions include requesting something they want or need, or protesting something that they do not want or enjoy. Wetherby et al. (1998) also identified that these children show a lack of development or progression in communicating for joint attention purposes, which include commenting on an object to draw another's attention to the same item. "This pattern of deficit in communicating for joint attention appears to be a hallmark of autism/PDD in children... (p. 81).

The parents and SLPs in the current study identified issues perceived to impact their overall experience in the intervention process and ultimate need for seeking additional services. The findings in this study do not allow for conclusions related to factors that influence the children's success, but offer some perspectives that can ultimately improve the overall experience of those involved in an intervention process.

The dual service provision related to the sample of the present study greatly enhanced the dynamic of this study's findings, providing a qualitative cross-reference between expectations of service providers and families receiving the services. Table 14 portrays each theme as identified from data analysis, the expectation dynamics between participant groups, and the implications those dynamic trends hold for the AAC intervention.

Parents and private SLPs recognized that school SLPs' caseload demands impact their service and parents may choose to seek additional AAC intervention. However, school SLPs did not mention the potential shortcomings and the need for additional services provided by private SLPs. This lack of recognition of parties involved may hinder collaboration procedures and jeopardize the efficiency and success of AAC intervention. It is important to note that, with the recent passage of the Michigan Autism Insurance Reform legislation (October 15, 2012), there is potential for an increase in this dual service provision, that is, the provision of service by both school and private SLPs. According to the Michigan Department of Community Health (MDCH, 2013), under the Autism Reform, "health insurance companies regulated by the state of Michigan are mandated to provide an autism benefit to its insured members covering services related to the diagnosis and treatment of autism spectrum disorders (ASD)" (para. 1). This reform further instills the need for professionals to consider the possibility of multiple providers working with a child concurrently, and the necessity to collaborate with each other in order to provide an efficient and effective service, and ultimately improve the overall AAC intervention experience for parents and children.

Parent and private SLPs shared similar expectations of the roles of school and private SLPs. School SLPs, on the other hand, believed the responsibility for programming a child's device should be shared by all members of the team. High caseloads may lead to this view of a

team approach. Open communication of role expectations between parents and school SLPs appears absent; and the gaps in expectations between private and school SLPs suggests that the communication of these professionals is lacking as well. The mismatch of perceived responsibilities implies the need for more cooperative and open relationships among parents, private, and school SLPs.

Themes C and D portray the need for initial delegation of roles between parents and clinicians. Parents identified their role to be advocating for their child while private and school SLPs expected parents to take ownership of the device. This mismatch in perceptions suggests that role expectations may not be communicated openly and initially, leading to disagreement and negative feelings. Parents and private SLPs both mentioned the lack of initial role delegation at the outset of the AAC intervention process. Implementing a discussion of roles into an initial AAC meeting may alleviate negative feelings and instill the basis for open communication between parents and SLPs.

Table 13

Clinical Implications from Emerging Themes

| Study Theme | Parent-SLP Agreement Dynamic | Implications for AAC Intervention |
|--|---|--|
| Theme A—Need for Additional Service Provider | <p>Parents and private SLPs agreed school caseload demands impact service.</p> <p>School SLPs did not mention disconnect.</p> | <p>Lack of school recognition may hinder collaboration.</p> <p>Insurance reforms, such as the Michigan Autism Insurance Reform, allow for potential increase in dual service provision and need for increased collaboration.</p> |

| | | |
|---|---|--|
| <p>Theme B—Expectations of SLP Roles</p> | <p>Parents and private SLPs agreed that school should complete more programming and private clinicians should focus on implementation.</p> <p>School SLPs wanted a team approach to programming and identified their role as teaching device usage.</p> | <p>Parent and private SLPs seem to have closer communication than parents and school SLPs.</p> <p>High caseload may lead to school SLPs' view of a team approach to programming.</p> <p>Parent-school and private-school communication of expectations appears absent.</p> |
| <p>Theme C—Expectations of Parent Roles</p> | <p>Parents identified their role to be advocating for their child.</p> <p>Private and school SLPs expected parents to take ownership of the device.</p> | <p>Role expectations may not be communicated openly and initially, leading to erroneous assumptions, disagreements, and negative feelings.</p> |
| <p>Theme D—Delegation of Roles</p> | <p>Lack of initial role delegation. Roles were assumed.</p> | <p>Implementing a discussion of roles into an initial AAC meeting may alleviate negative feelings and instill the basis for open communication between parents and SLPs.</p> |
| <p>Theme E—Training Needs</p> | <p>Parents desired more training.</p> <p>Private and school SLPs reported training and offering resources.</p> | <p>Following through on recommendations is essential for successful AAC use.</p> <p>Parents desire training but do not expect themselves to program devices.</p> |
| <p>Theme F—Service Improvements</p> | <p>Parents and private SLPs were congruent on the need for increased structure in teaching AAC use to children with autism.</p> <p>They also agreed on the idea of a technical liaison.</p> <p>School SLPs did not mention any improvements.</p> | <p>More structure in all aspects of intervention may prove successful.</p> <p>Introducing another member to the team may increase the need for collaborative efforts.</p> |

| | | |
|---|---|---|
| <p>Theme G—Need for Collaboration Across Settings</p> | <p>Parents desired an interdisciplinary approach to AAC.</p> <p>Private SLPs tried coordinating with school SLPs, but were not successful.</p> <p>School SLPs did not mention a struggle to collaborate with private SLPs</p> | <p>A structured collaboration procedure may aid the collaborative efforts of parent and SLPs.</p> <p>All members of the AAC team must be open to working cooperatively with other professionals in order to give the child the best chance for success.</p> |
| <p>Theme H—Parent Feelings and Actions</p> | <p>Parent reported negative feelings.</p> <p>Private and school SLPs offered suggestions to parents, but only private SLPs mentioned sharing parental feelings.</p> | <p>Parental relationships with specific SLPs may vary.</p> <p>Open and trusting relationships are necessary for developing rapport with families.</p> |

Parents desired more training on AAC technology; yet, private and school SLPs reported training parents and offering additional resources to increase their knowledge with those systems. This mismatch in thinking suggests that parents may not be following through on recommendations, which is essential for their learning AAC. An interesting implication that arose from this theme is the inconsistency between parents’ perspectives about the AAC process. Parents desire to learn how to operate their child’s device, but they do not expect themselves to program and manage the technical issues of the system. On a different note, this theme reveals that SLPs, no matter the setting, consider parent training an important role for clinicians to address. Professionals believe it is their job to equip parents with the necessary knowledge to lead their child’s journey through AAC. SLPs may need to keep parents accountable for seeking out those AAC resources.

The need for more structured teaching procedures to facilitate AAC implementation for children with autism was suggested by both parents and private SLPs. Children with autism are

typically most successful in highly controlled and structured environments, and AAC intervention tends to more loosely implemented. The development of a more rigid procedure may not only benefit the child, but also relieve the stress and frustrations of parents and SLPs.

Parents and private SLPs also suggested that the addition of an individual to act as a liaison between parents and professionals and attend to the technical aspects of the AAC device may aid parents in their struggle to complete and learn these tasks alone. By adding another professional to the team, however, the already-diminished collaboration among team members may be hindered even further. Yet, collaboration can become successful if explicit efforts are made that set specific roles and modes of communication among all team members. It can be very costly and inefficient to have professionals servicing families, when roles are only assumed and service is not provided to the fullest. In Theme G, parents and private SLPs desired more collaboration among those involved in the AAC process. School SLPs, however, did not mention a struggle with collaborating or communicating with the private SLPs. The development of a more structured, individualized collaboration procedure among parents and professionals may optimize the efforts that were found in this study. Furthermore, all members of the AAC team must be open to working cooperatively with other professionals in order to provide an efficient and successful service to the child and family.

In summary, role expectations were identified in this study; however, no initial delegation was established among participants. Lack of realization of role expectations can potentially lead to frustration. It is important for parents and SLPs to establish explicit roles for themselves at the onset of AAC intervention. Increased structure in all areas of AAC intervention may also decrease negative feelings. A detailed collaboration procedure developed during an initial meeting may foster communication among those involved and improve the overall use of AAC

devices among children with autism. Increased communication among all members of the child's team needs to be established, and increased structure may be a great place to begin this development. By strengthening the fundamental work parents and professionals provide, one can give children with autism the best possible opportunity for success in this world, as well as improve the overall experience for all parties involved in the AAC intervention process.

Limitations/Delimitations of the Study

While the findings of this study are partially generalizable to parents of children with autism, AAC users and the SLPs that serve them, qualitative studies, as defined by Bogdan and Biklen (1998), are not always generalizable in the truest sense of the word. The limited number of participants, the small geographical region, the higher socioeconomic status, and small range of varying demographic information, are all limiting factors of this study. In fact, this study is unique in investigating the perceptions and expectations of families and professionals who were involved in a dual service provision reality. Currently, this is not a reality for most of the children with autism who need AAC intervention, and most families do not have access to SLP private services.

Since it cannot be assumed that all parents and SLPs hold these same feelings, perceptions, and experience, the researcher attempted to outline general trends that were seen in this restricted population and that corresponded to previous literature published in this area. Based on those trends, implications and suggestions were offered that may benefit anyone involved in a parent-clinician relationship. Specific recommendations for improving services for children with autism were developed due to the nature of the study's participants; however, these recommendations may also benefit all those experiencing difficulties with AAC or other methods for teaching communication strategies. It is the researcher's intent to provide suggestions for

possible improvements to the overall AAC intervention experience so that all parties involved can receive the benefits that successful communication brings to one's life.

Directions for Future Study

Analysis of the data from this study revealed the need for future research in the area of AAC implementation for children with autism and collaboration efforts between parents and professionals. Whether an increase in the prevalence of dual service provision occurs with the passage of Michigan Autism Insurance Reform may be a topic for future investigations, as well as if the increase enhances the success of intervention. Awareness of this matter by all providers seems crucial for the development of collaboration and effective communication in the AAC implementation process.

Inquiry into the perspectives of AAC users in regards to their expectations of roles of themselves, parents, and professionals is also an important topic for future studies. The voices of the AAC users themselves are invaluable tools for parents and SLPs to incorporate into their intervention. By investigating their perceptions, experiences, and recommendations, intervention for nonverbal individuals can be greatly enhanced.

Additionally, this study did not evaluate parents and SLPs perceptions of a child's success with an AAC device. Future research may compare parent and SLP perceptions of a child's success and what factors they attribute to their evaluation. Stakeholders' perceptions of success influence the expectation they hold regarding the need for services and intensity of roles in the intervention process. Furthermore, investigations into AAC users' perception of their own success with their device will also yield valuable data that may enhance future AAC diagnosis and intervention services.

Lastly, future research may also investigate the development of a “high-tech” AAC protocol for children with autism. SLPs and parents in this study raised the need for a more structured procedure to implement “high-tech” AAC systems for children with autism. A future study could, for instance, investigate and document the progression of a child’s “high-tech” AAC use while being taught under an adaptation of the PECS protocol. Through the development of a more defined procedure for teaching individuals with autism to communicate using AAC, SLPs can more effectively contribute to the quality of life of these individuals and their families. There is a need to explore these concepts with the ultimate goal of improving the AAC intervention experience for future generations of parents, SLPs, and AAC users of all ages.

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Appendix A: Human Subjects Permission Letter

EASTERN MICHIGAN UNIVERSITY COLLEGE OF EDUCATION HUMAN SUBJECTS REVIEW COMMITTEE REVIEWER RESPONSE

Project Title: Perceived Expectations of Roles in
Training and Maintenance of
Augmentative and Alternative
Communication Devices

Principal Investigator (must be a faculty member): Dr. Ana Claudia Harten
Department: Department Here
Co-PI / Student Investigator: Kathlene C. Talladay
(For student projects, a faculty supervisor must be listed) Dr. Ana Claudia Harten
Reviewers: Jon Margerum-Leys, REVIEWER 1

Date: 8/6/12

This project is:

Exempt Not exempt
(If exempt, sign and return form. Otherwise, complete items 1-6.)

1. Have the potential risks to the subjects been adequately discussed? Are procedures adequate to minimize any risks to the subjects?
Yes
2. If there are potential risks, should the potential knowledge from the research be pursued? Do the benefits outweigh any risks?
Yes
3. Are procedures to be used by the researcher sufficient to insure that there is informed consent on the part of subjects and that their participation is voluntary? If not, make suggestions.
Yes
4. When necessary, are procedures sufficient to allow for confidentiality of information of individual subjects, both in gathering and disseminating information? If not, make suggestions.
Yes
5. Other comments:
Well thought out proposal, meets human subjects guidelines.

6. Please rate the proposed project and give the reason(s) for your rating.

Acceptable Acceptable with conditions Not acceptable

Reason(s):
RESPONSE

Revised 02/2011
jml

Reviewer's Signature



Date
August 6, 2012