PARENTAL EXPERIENCES IN AQUIRING AND USING AAC WITH THEIR YOUNG
CHILDREN

By

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Abstract

Purpose: The study was completed in order to help provide a comprehensive understanding of the experiences regarding AAC acquisition and use of parents of young children between the ages of 0-5 years.

Method: Seven parents of children who received or were currently receiving AAC intervention between 0-5 years of age were interviewed either in-person or via phone. The interviews were semi-structured, and the researcher asked questions related to their initial feelings toward AAC, their experience cooperating with SLPs and other individuals, their experience in regard to funding AAC devices for their child, and the impact of AAC intervention on their child's and family's quality of life. The interviews were audio-recorded, transcribed, and coded thematically.

Results: The parents in this study discussed experiences related to six different themes: 1) parent initial reaction to AAC, 2) SLP/ provider knowledge and provision of information concerning AAC, 3) communication with professionals/parental inclusion and consideration of family needs, 4) parent experience with AAC funding, 5) family and community reaction to AAC, 6) the impact of AAC on the child and family's communication and quality of life. Additionally, some parents provided additional information and advice for both other parents and SLPs.

Discussion: To the researcher's knowledge, this is the first study to specifically examine the experiences of parents of very young children (ages 0-5 years) regarding AAC acquisition and use with their child. Findings of this study were found to be very similar to prior studies which addressed parental experiences with AAC as well as research related to AAC and early intervention; however, several exceptions are explored. More research is needed in order to provide further information concerning the experiences parents of very young children who use AAC.

Dedication

This work is in dedication to my late grandmother, Ila McLennan. I am forever grateful for her relentless support of my education, as well as her love of learning which she passed on to me. I would not be the person I am today without her love and encouragement.

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Introduction

According to the American Speech Language and Hearing Association (ASHA), augmentative and alternative communication or AAC is defined as communication that "includes all forms of communication (other than oral speech) that are used to express thoughts, needs, wants, and ideas" (ASHA, n.d.). When an individual has difficulty communicating verbally, AAC can be used as either a supplementary or alternative modality. For centuries, people have regarded communication as a core component of what makes us human. In her widely regarded speech on AAC published in 1997, Janice Light said that "communication is the essence of human life" (Light, 1997, p. 61). Therefore, the pursuit of supplementary or alternative methods of communication for people with verbal communication deficits can play an extremely important role in endorsing the dignity of these individuals. Young children with complex communication needs (CCN) cannot meet their needs by conventional means, requiring the use of augmentative or alternative communication (Light & Drager, 2007). Research suggests that early AAC intervention can be vital for helping these children to build the strong basis of language and communication skills needed in order to reach their full communicative potential (Kaiser & Roberts, 2011; Romski & Sevcik, 2005).

AAC and Early Intervention

It is now widely understood that early intervention for children with communication deficits is crucial in order to provide a strong foundation for the development of these skills in the future. Research from Fox, Levitt, Charles, & Nelson at Harvard University suggests that children undergo a sensitive period in their development of speech and language skills that lasts from birth to approximately five years of age. During this period, the brain is extremely sensitive to any speech and language input; however, a child's ability to learn new communication skills

decreases as he or she becomes older (2010). Because some children lack the ability to communicate verbally due to physical, developmental, or cognitive delays or impairments, AAC provides them with a mode to communicate during this sensitive period so that they are able to develop a strong foundation for communication despite these deficits. Research indicates that children who receive early language intervention are more likely to exhibit socially appropriate behaviors that facilitate positive interactions with peers, and they are more likely to develop the language skills necessary for reading (Kaiser & Roberts, 2011). Additionally, AAC intervention with young children does not hinder the development of spoken language, and some children may actually increase their expressive vocabulary (Romski & Sevcik, 2005; Romski et al., 2010).

Indeed, researchers have addressed many questions regarding the use of AAC with infants and toddlers. Romski and Sevcik (2005) discussed a variety of prevalent myths regarding the use of AAC with infants and young children. In the first myth, they explained that although many parents and professionals may believe that AAC is a "last resort" intervention, using AAC early on actually supports the development of communication skills and helps to prevent communication failure. The second myth that they addressed is that "AAC hinders or stops speech development." Data from the literature indicates that not only does AAC not inhibit speech development, on the contrary, many children improve their speech skills following AAC intervention. A third myth that they discussed was that many people believe children need certain prerequisite skills before they can benefit from AAC intervention. They explained that many professionals believe that children must possess certain sensorimotor or cognitive skills in order to be considered proper candidates for AAC intervention. Conversely, the authors discussed evidence indicating that a lack of communication skills may actually interfere with the

development of early cognitive skills such as mean-ends skills and object permanence. They also argued that without providing young children with a mode of communication, some children are unable to demonstrate their true cognitive abilities.

Also addressing cognitive abilities, Romski and Sevcik discussed the fourth myth that "speech-generating devices are only for children with intact cognition" (2005, p. 178). They refuted this by stating that technology has undergone huge advancements, and the number of options regarding AAC have increased substantially, including very basic options such as switches all the way to complex speech-generating computers. This means that there are now options that require very little skill and can facilitate basic communication skills for young children as well as help them develop a stronger self-identity. The fifth myth stated that children need to reach a certain age before they can benefit from AAC. Romski and Sevcik (2005) mentioned research indicating that infants, toddlers, and preschoolers with a vast range of disabilities have been able to improve their communication skills through the use of AAC. Finally, the sixth myth that Romski and Sevcik addressed was that "there is a representational hierarchy of symbols from objects to written words" (Romski & Sevcik, 2005, p. 178). Refuting this, they cited research indicating that professionals do not need to implement a hierarchy of symbols beginning with photographs and ending with written words because children between 13-18 months old are still developing their ability to comprehend referents. Although a child's understanding of the relationship between symbols and referents may change as he or she continues to develop, in actuality, both abstract and iconic symbols may serve the same function for children during early development (Romski & Sevcik, 2005).

Further supporting the notion that AAC intervention with young children does not inhibit speech production, Romski et al. (2010) compared the effects of three different interventions by

training 62 parents of children between the ages of 21 and 40 months on one of the three interventions. The Spoken Communication Intervention (SCI) solely addressed spoken language, while the other two interventions targeted communication using AAC, in particular, speech-generating devices (SGDs). The Augmented Communication Input (ACI) intervention focused on the parents learning how to model communication to their child using the AAC device, while the Augmented Communication Output (ACO) intervention focused on encouraging the child to communicate using his/her AAC device. The results of the study revealed that all of the parents were able to be successfully trained to implement their assigned intervention, but the augmented communication interventions facilitated a higher use of the targeted vocabulary, with the ACI intervention being slightly more effective than the ACO intervention. The children with the augmentative communication interventions also learned approximately the same percentage of spoken words than the children provided with the SCI intervention, with the additional advantage of having access to another mode of communication to supplement their spoken language. A follow-up study by Romski, Sevcik, Adamson, Smith, Cheslock, and Bakeman (2011) also demonstrated that the augmented language interventions had a positive impact on the parent perceptions of their child's language development, while the spoken language intervention had a negative impact on parent perceptions. The authors explained that parents who participated in the augmented language interventions felt that their child's language difficulties had decreased, whereas the parents who participated in the spoken language intervention actually felt that their child's difficulties had increased. In their discussion, they noted that a possible reason for this perception of an increase in the children's language skills could be due to the fact that adding AAC as a communication modality may have decreased the stress that parents felt when they were unable to communicate successfully with their child (Romski et al., 2011).

Additionally, Sevcik, Romski, and Adamson (2004) described the case study of a four-year-old child with significant generalized developmental delays and a seizure disorder and very limited functional speech. In this study, the researchers implemented the System for Augmenting Language (SAL) which involved the introduction of a speech-generating device and an appropriate and individualized selection of vocabulary for symbols. The intervention also involved having the child use the device at home and in private therapy sessions, as well as teaching the child's parents how to supplement their own speech input to the child using his device. Feedback was provided to the child's communication partners in order to improve the quality of communication interaction. The intervention was employed over a 9 month period and the child's engagement and communicative attempts were found to have increased at home, with the parents reporting a successful implementation of the intervention in the home environment.

In order to provide a more comprehensive look at the existing evidence base for the effectiveness of AAC interventions concerning infants and toddlers with disabilities, Branson and Demchak (2009) reviewed the literature. The researchers identified 12 studies that addressed their research question, and found that 97% of a total of 190 participants improved their communication skills as a result of AAC intervention. All of the children participating in these studies were between 0-36 months old. Drager, Light, and McNaughton (2010) also described five areas of development in which AAC intervention has helped to support the language and communication of young children: functional communication skills, challenging behaviors, expressive language skills, receptive language skills, and speech production. They reported that AAC intervention can help children to express their wants and needs, reduce challenging behaviors, support social closeness, help to improve comprehension of verbal communication, and improve expressive language skills in the areas of pragmatics, semantics, and syntax. They

also expressed that adults can use AAC to model language and communication, and reiterated the research that AAC does not hinder speech production but actually helps to facilitate spoken language for most young children.

Though research indicates many benefits to using AAC with young children, the implementation of AAC intervention largely relies on SLPs' and other early interventionists' knowledge and opinions concerning AAC. In their study investigating the perspectives of 967 early intervention providers, Wilcox, Guimond, Campbell, and Moore (2006) conducted a phone survey across 33 states. From this survey, the researchers sought to investigate how early intervention providers (including SLPs) utilized assistive technology in their practice, as well as the existence of any specific beliefs held by these practitioners that might possibly impact their decisions concerning the use of assistive technology. These decisions included the providers' beliefs about when or when not to implement assistive technology, how early intervention providers viewed their access to resources that would support the use of assistive technology, and any differences regarding these responses in terms of the provider's' specific discipline. Additionally, providers were asked about their beliefs in accordance with several pervasive myths regarding the use of assistive technology with infants and toddlers. Results from the survey revealed several relevant findings. In general, the providers who were surveyed had a good base of knowledge regarding both high tech and low tech assistive technology options, but were inclined toward a greater use of low tech options. Additionally, the researchers found that the providers who reported the most training in assistive technology were more apt to implement it in their practice than those who reported less training. As a whole, the providers seemed to recognize the potential of assistive technology in facilitating the participation and interaction of young children, and they were more disposed to report that the attitudes of parents regarding

assistive technology was a key factor concerning whether or not assistive technology interventions were used with a child. Also, although most of the providers disagreed with many of the common myths concerning the use of assistive technology with young children, they were inclined to base their decisions regarding the use of assistive technology more on a child's particular skillset rather than his or her participation needs. Finally, the early interventionists who were implementing AAC strategies did not usually begin these interventions until a child was two or more years old. This finding parallels results from Hustad, Berg, Bauer, Keppner, Schanz, and Gamradt (2005) who reviewed data concerning children receiving AAC services at the University of Wisconsin- Madison, and found that between 1999 and 2004, 80% of the initial referrals were not made until a child was older than two. This means that most children requiring AAC have little to no means of communication during the early stages of development, unlike their typically developing peers who usually begin speaking their first words around 12 months of age.

Although it is vital to understand the attitudes and beliefs that SLPs and other early interventionists have regarding AAC intervention, it is important to recognize that reported beliefs do not necessarily impact clinical decision-making. In a follow-up study, Dugan, Campbell, and Wilcox (2006) sought to determine how the early interventionists' beliefs about assistive technology compared with their actual decision-making practices regarding this technology. The researchers randomly recruited 424 of the original participants in their previous study in order to try to compare interventionists from 13 different states that represented "differences in geographical location, population size, and administration of Part-C-funded early intervention programs" (Dugan, Campbell, & Wilcox, 2006, p. 26). The study involved an initial telephone survey which required the participants to express whether or not they agreed or

disagreed with four statements that represented some of the most commonly reported reasons in the literature for the lack of use of assistive technology with very young children. These consisted of reasons related to the belief that certain prerequisite skills need to be present in order for a child to use assistive technology, this technology requires additional effort from a child in order to be used successfully, the use of assistive technology in intervention means that parents and interventionists are "giving up" on "natural" skills, and the idea that decisions should not be made regarding assistive technology until a child is older, because the technology is expensive, and a child may be too young to determine whether or not the intervention would be successful. An additional follow-up survey with the same participants required them to answer questions regarding specific situations and intervention strategies for children in three different age groups: 0-12 months, 13-24 months, and 25-36 months. The participants responded to questions related to case studies of infants and toddlers. These questions addressed the participants decision-making regarding interventions targeting specific skills, low tech assistive technology, or high tech assistive technology. Notable findings from the study included the fact that most of the participants did not agree with the four myths provided, most interventionists did not select the use of assistive technology until a child was 24 months or older. Furthermore, when assistive technology was chosen as an intervention, it generally involved the use of low tech rather than high tech options. Overall, the results of this study suggested that the beliefs held by early interventionists did not necessarily correlate with their decision-making concerning assistive technology. In general, the results highlighted a notable discrepancy between early interventionists' knowledge and opinions concerning assistive technology and their actual employment of these interventions. Similarly, Kaiser and Roberts (2011) reported that despite many advances in early intervention related to communication including AAC, a significant gap

still subsists between the existing knowledge and its application to intervention services provided by SLPs and other professionals.

Nevertheless, there is a definite need for SLPs who are able to provide skilled AAC intervention with young children. Light and Binger (2006) surveyed 144 SLPs from 11 different agencies in Pennsylvania in order to obtain information about the demographics of preschoolers between 3;0 and 5;11 enrolled in special education and requiring AAC in the state of Pennsylvania. The results of their study found that 12% of these preschoolers enrolled in special education services required the use of AAC. The authors indicated that this represents the need for SLPs that work with preschoolers to be prepared to provide AAC intervention services. Also confirming the need for more SLPs that are knowledgeable about AAC, Hustad and Miles (2010) assessed 22 young children with cerebral palsy from the upper-Midwest with a mean age of 54.3 months, in order to determine how much they would likely benefit from AAC intervention. The researchers then took the data from the assessments and compared it to the children's IEP goals for speech and language. Although they determined that 95% of the children could benefit from AAC intervention, they discovered that only 57% of these children had AAC-related goals in their IEPs.

Parents and AAC Intervention

The current model of early intervention uses a transdisciplinary team approach. This means that all of the child's service providers work collaboratively and have knowledge of one another's respective disciplines in order to best meet the needs of both the child and the family. One primary care provider such as an SLP, physical therapist, occupational therapist, or early childhood teacher is then chosen to implement all of the child's services across disciplines based

upon the child's most significant developmental needs (Boyer & Thompson, 2013). (Boyer & Thompson, 2013). It is important to consider the opinions and attitudes of parents towards intervention approaches (Weitzner-Lin, 2004). Indeed, because parents of young children with complex communication needs play a key role in the intervention process, their involvement in intervention and relationship with the SLP are very important for successful intervention outcomes (Pretis, 2011). Part C of the Individuals with Disabilities Education Act (IDEA) requires the development of an Individualized Family Service Plan (IFSP), which is a document created by a child's family and service providers in order to establish intervention goals that the family believes are important for the child to achieve (IDEA 2004). This law also mandates that "to the maximum extent appropriate to the needs of the child, early intervention services must be provided in natural environments, including the home and community settings in which children without disabilities participate" (34 CFR §303.12(b)). The purpose behind the family-centered model established by this law is to help facilitate the ability of the families to meet the needs of their young children (Paul & Roth; 2011; IDEA 2004). Paul and Roth (2011) describe four guiding principles for SLPs working in early intervention. In order to best meet the needs of the child and family, they suggest that services must be: "family-centered and culturally and linguistically responsive; developmentally supportive, promoting children's participation in their natural environments; comprehensive, coordinated and team-based; and based on the highest quality evidence available" (p. 320). Given the language of IDEA Part C, the parents and family members of children with complex communication needs must be considered as necessary and crucial members of the early intervention team.

As mentioned previously, not only did Romski et al. (2010) and Sevcik, Romski, and Adamson (2004) demonstrate the efficacy of AAC intervention with young children, they also

illustrated that parents can successfully implement AAC interventions for their children when provided with sufficient training by an SLP. With the knowledge that AAC interventions improve the communication skills of young children and that parents play a key role in the early intervention process, it follows that the opinions and experiences of parents regarding AAC intervention must be considered by professionals.

Parette and Angelo (1996) discussed the impact of AAC on families and the necessity of SLPs and other professionals to consider the unique needs of each family before prescribing a specific AAC system. They emphasized the importance of family-centered decision making in order to avoid increasing family stress, which could lead to decreased use or abandonment of AAC. Additionally, they addressed the need for professionals to provide support and guidance concerning the maintenance and ongoing use required for many AAC devices as well as the changing needs of the child and family as both educational and personal transitions occur.

Angelo, Jones, and Kokosa (1995) surveyed 81 parents in the state of Pennsylvania who had children using AAC devices that were between the ages of 3 and 12 in order to determine their needs, priorities, and preferences regarding augmentative and alternative communication. The authors reported that both mothers and fathers indicated that they wanted more information regarding speech-generating devices as well as information about planning for the future needs of their child. Mothers of the children often expressed a need for more trained professionals and advocacy groups, while fathers tended to report the need for finding volunteers to work with their children, obtaining funding, and finding more information about how to support their child and use the device at home.

Similarly, Goldbart and Marshall (2004) desired to explore the experiences of 11 caregivers in the UK who had children in the early stages of AAC use. Interviews with these

parents were transcribed and analyzed, and the authors identified three major themes discussed by parents: the child's communication or interaction, wider societal issues, and parents' views and experiences. Throughout the interviews, the parents expressed the need for parents and professionals to identify the strengths and needs of their child and spoke of the importance of communication in relation to the child's social inclusion. They explained that their children's interactions within the community were generally positive with unfamiliar adults; however, they emphasized that they as parents needed to facilitate the interactions. Parents also mentioned the financial burden that they faced in paying for the AAC and/or finding funding sources. Regarding the parents' views and experiences, the researchers noted six organizing themes within this global theme which included demands on parents, parent as expert, parents' feelings and emotional responses, parent's explanatory models and reflections, and parents' views of services. The parents emphasized their expertise concerning their own child, and expressed varying desires in terms of how they wished to be included in the AAC decision-making process.

McNaughton et al. (2008) sought to determine the benefits and challenges that seven parents of individuals with cerebral palsy experienced while learning AAC technology. The researchers created a nine week online focused group discussion and then analyzed the discussion for themes. Through their analyses, six major themes were identified: "AAC device selection, knowledge and skills needed to use AAC, barriers to learning AAC, teaching the individual, and educating society" (McNaughton et al., 2008, p. 43). Parents discussed the challenges and supports they experienced when selecting their child's device, their frustration over a lack of trained professionals, the time and effort required to learn and teach their children to use their devices, and the challenges of teaching both their children and other communication partners how to interact using the device. The parents also offered advice to both professionals

and parents. They expressed the importance for professionals to consider the needs of the child and family, the need for professionals to be knowledgeable about AAC and able to teach parents how to use the device in a structured fashion, and emphasized the importance of communication amongst team members. For other parents, they stressed the need to become knowledgeable about AAC, the need for parents to take the lead in terms of obtaining AAC devices and intervention, and the importance of finding motivating activities to help their children learn to use AAC.

In another study investigating family perceptions of AAC use, Bailey, Parette, Stoner, Angell, and Carroll (2006) conducted semi-structured interviews with six caregivers of seven children who mainly used AAC devices to communicate at school. Four major themes identified from the interviews included expectations, facilitators, barriers, and benefits of AAC device use. Caregivers discussed desires that AAC would help their children to improve their communication skills, increase their child's independence, and allow their children to communicate more frequently and with a greater number of individuals. Aspects reported by caregivers that helped to facilitate the use of AAC were easy-to-use devices and effective communication and collaboration with the child's team members. Reported barriers to AAC use included limitations regarding the child's device, a lack of adequate training on the devices, a child's ability to successfully communicate and be understood without the device, and a lack of effective communication and collaboration amongst team members. Concerning the benefits of AAC use, the caregivers reported that the devices helped to increase the independence of their child as well as improve his or her overall ability to communicate.

Purpose

The primary purpose of this study was to better understand the experiences of parents who have undergone or are currently undergoing the process of acquiring funding and/or support in using one or more types of AAC with their young child between the ages of 0-5. Reaching a better understanding of parents' experiences is essential in order to understand factors that may impact the parent's decision to use AAC. Research supports the use of AAC with very young children to help them to understand the power that communication offers, and that it quite often helps children to develop their speech. It is essential for speech-language pathologists (SLPs) and other professionals involved in the acquisition and use of AAC with young children understand how their knowledge, communication with families, and provision of support impact the outcomes of AAC intervention as well as the child's and family's quality of life.

Methods

Participants

Seven parents of children who received or are currently receiving AAC intervention services between the ages of 0-5 participated in a semi-structured interview regarding their experience during the process of implementing AAC intervention for their child. A speech-language pathologist from a non-profit clinic in northeast Wisconsin as well as a clinical supervisor from a university clinic in north central Wisconsin, contacted current or former parents of clients who met the inclusion criteria of having a child who received AAC intervention services of any type between ages 0-5 in order to ask if they would be willing to participate in an interview. If interested, they then signed an informed consent form describing the study, completed a short case history form, and their contact information was provided to the

researcher. This study was approved by the institutional review board at the University of Wisconsin- Stevens Point.

Interviews

Participants in the study were given the option to participate in either an in-person, phone, or Skype interview. Before the interview, they completed a brief history about their child and his or her use of AAC (see appendix A). During the interview, parents were asked to respond to a variety of open-ended questions regarding their initial feelings toward AAC, their experience cooperating with SLPs and other individuals, their experience in regard to funding AAC devices for their child, and the impact of AAC intervention on their child's and family's quality of life (see appendix B). Follow-up questions were asked as needed in order to seek clarification or obtain additional information. All of the interviews were audio-recorded using a Marantz Digital Recorder PMD-620.

Data Analysis

All of the recorded interviews were transcribed into Microsoft Word documents. The interviews were read and analyzed by the researcher during three separate occasions, and the most relevant information from each response to an interview question was highlighted for future reference. The researcher then organized this highlighted information from the parents' responses to each question into separate Microsoft Word Documents in order to compare the answers more easily and look for commonly occurring themes. Each interview question was then placed into one of six identified themes. These consisted of parent initial reaction to AAC, SLP/ provider knowledge and provision of information concerning AAC, communication with professionals/parental inclusion and consideration of family needs, parent experience with AAC

funding, family and community reaction to AAC, and the impact of AAC on the child and family's communication and quality of life. Additional information and advice from parents was also included.

Results

Throughout subsequent analysis of the parent interviews, several themes emerged. The first theme involved the parents' initial thoughts and feelings toward AAC when they were first introduced to it as an option for their child. The second theme was comprised of the parents' thoughts about the knowledge of SLPs and other professionals concerning AAC intervention along with how they felt regarding the types and amount of information about AAC and communication intervention. The third theme included the parents' experiences with regard to communicating with SLPs and other professionals, as well as how the parents' thought that these professionals considered the needs of their child and family. Throughout theme four, the parents' experiences with funding their child's AAC systems was explored. Within theme five, the parents discussed the responses they and their child received from both family and community members concerning their child's use of AAC. The impact of AAC on the child's and family's quality of life is examined in theme six. Finally, theme seven consisted of additional information and advice that the parents wished to share during their interviews.

Theme 1: Parent Initial Reaction to AAC

Each of the parents initially expressed either excitement or curiosity about the use of AAC with their young child, or skepticism towards AAC interventions. A slight majority of the parents who were interviewed expressed the excitement that they felt at the prospect of acquiring and using AAC with their child.

P01   We didn't know there was such a thing. So we were elated that there was such a thing and, 'Wow! This is going to solve all our problems.'

P02   They discussed the device with us for [Child2] and um we were excited about it.

P04   I was very excited about it because I knew Child4 was very bright and very capable but yet, this was all trapped inside because she didn't have the ability to vocalize like a typical kid her age.

P04   I was ecstatic to give her something that she could control, because of the limitations of her disease, she wasn't able to move hardly at all. So she had something she could control, she could manipulate, and I was very excited about it.

P06   I think I was open and positive and curious about it because knowing that she can't speak, and she can't sign because her muscle disorder. She can't like, signify her fingers and so how else is she going to be able to tell you…So I was curious what is out there that is going to work for her.

The other parents expressed skepticism about the use of AAC with their child for a variety of reasons. One parent discussed her confusion over how using a device was going to help her daughter to develop speech.

P03   I really honestly didn't understand how it was going to help her talk…I thought that if she has a machine to talk for her, why would she ever learn to talk? ...So I kind of really never pushed the issue of getting one because that's how I felt about it.

Another parent expressed her fear that some forms of AAC appeared to be quite cumbersome. She also discussed her doubts about how her child was going to be able to comprehend how to use other forms of AAC besides sign language, which he was already using with quite a bit of success.

P05   Uh some of the first initial thoughts were that some of the things were cumbersome…So sign language I was all for because I didn't need anything for that…but when you're talking about the Go Talks and the big buttons and the, you know, it's like 'okay, I'm going to carry around the Staples 'that is easy' button everywhere I go."

One parent also spoke about her mixed feelings concerning the use of an AAC device with her child due to how advanced this kind of technology was at the time. She also recalled not being

able to imagine how her son would be able to use a device due to his physical limitations. However, she remained open to the idea of pursuing an AAC device because of the guidance of an SLP who was very knowledgeable about AAC and the research supporting its use with young children. Another parent expressed her fear that some forms of AAC appeared to be quite cumbersome. She also discussed her doubts about how her child was going to be able to comprehend how to use other forms of AAC besides sign language, which he was already using with quite a bit of success.

> P07   …And remember, this was fifteen, seventeen years ago whatever…so when he told me that they would put a computer on, within Child7's reach and he could touch buttons on a screen and a voice would say things, I thought he was talking- I don't know, it just seemed so futuristic and unbelievable to me and I couldn't fathom what that would look like…
>
> P07   …and then when people demonstrated, it's clearly different than how my severely disabled son would use and function with it.

Throughout theme seven, the parents shared their initial reactions toward the use of AAC with their young child. Many of the parents expressed excitement and curiosity about the use of AAC, while others explained their initial skepticism. One reason for uncertainty regarding AAC intervention included the belief that AAC may hinder speech development. Another reason was that for one parent, the technology was very advanced when her child was young, and she had difficulty imagining him using an AAC device given his physical limitations. Finally, one parent explained that she felt that carrying around a device would be burdensome, and she was also unsure of whether or not her child would understand the purpose of AAC. Although the parents expressed a variety of initial reactions to AAC, each of them chose to pursue this option by consulting with an SLP.

Theme 2: SLP/ Provider Knowledge and Provision of Information Concerning AAC

All of the parents expressed that they felt that the SLPs at both clinics specializing in AAC were

very knowledgeable and helpful. Most of the parents who reported that their child's school SLP

was involved in the initial stages of acquiring AAC also reported satisfaction with these

professional's knowledge concerning AAC.

> P02 …the clinic was very knowledgeable and had a lot of information on, on it. So I knew what they were talking about when we had a lot of questions.
>
> P04 ...the person that we were working with [at the clinic], he was very knowledgeable that gave great suggestions [to] the students that we worked with in helping us set up stuff that wasn't just toys or games for her, it was actually, you know, getting to the initial stages of communication, and they had, they had some good ideas, so that was helpful.
>
> P05 Oh, well, especially in comparison to mine, clearly he knew what he was doing. Um no, very well thought out…he was very knowledgeable, definitely knew what he was talking about, was willing to put it into lay-men's terms so that I could understand.
>
> P06 …since coming [to the clinic], I mean it's just been awesome. The knowledge of the therapist at the time- and then you know him instructing the students and working with her and knowing like what to go from, from one to another-If that's not working, okay try this. If that's not working try this, and with Child6, you have to think outside the box.

Of the parents that reported birth to three SLPs as being their child's first service provider

concerning communication intervention, a majority reported that they were at least somewhat

unsatisfied with the SLP's knowledge regarding intervention with their child and/or their

knowledge about AAC.

> P04 Um to be honest, I wasn't very impressed with the birth to three speech person. Like I said, she wasn't used to the level of need that Child4 was, she was used to more working with kids who had language and speech issues if that's how you define it, versus someone who was completely non-verbal…

Two of these parents also reported that the birth to three SLPs focused their intervention on establishing strength and movement of the articulators.

> P01   And I don't mean to-I'm not saying that birth to three didn't give it to him. We started way on the end of that. Um, so we really didn't- we tried mouth exercises, we tried you know anything to strengthen. You know, suck from a straw just to get that verbalization, those mouth muscles toned.

> P06   I think in birth to three, 'cuz they were starting young, I don't, I felt like they didn't have a lot of knowledge about it but then again I think they were also focusing on trying to facilitate if there was going to be any movement in the mouth or with the tongue or anything like that…

Additionally, one parent spoke extensively about the lack of both knowledge and any effort to acquire information concerning AAC demonstrated by her son's initial school SLPs and teachers at a time when speech generating devices were not as common as they are today. She discussed her exclusion from the decision-making process with the school when her child was young, as well as the school's poor implementation of the device for communication in the school environment.

> P07   Definitely going into the schools I saw a huge change…because there were some SLPs and teachers who had been in the- in, around for a long time, and weren't even comfortable with computers much less a communication device.

> P07   They were completely ignorant, and rather than admitting that and, and getting the knowledge, they just basically didn't want to deal with it in some cases.

> P07   …so the, the SLP at the school… [would] come to the IEP meetings and say, 'Oh, he's only getting it right about fifty percent of the time.' And we, every time we'd go to one of these meetings, she was kind of saying that same thing. That he's not really progressing or getting this. And, and at home he was clearly showing an understanding. He would be selecting TV shows, and he would be telling us what he'd want to play, and, and so we couldn't understand why this wasn't translating to school and we realized they weren't using it as a communication device, they were using it as a teaching thing. So, they had like a house, a boat, um I don't know, say there was a ball and a, a kite or whatever, and so they'd ask him to find this same object. Well, anybody would be bored with that after a short period of time. No wonder he was only getting fifty percent. He was like 'I'm done with this. What's my reward for getting this right? What's, what's the purpose of doing this?'

However, this parent later expressed that as her child became older, the SLPs in the schools became more accepting and knowledgeable concerning the use of AAC with her child.

> P07   In the schools, you know, we've been pretty fortunate, most of our SLPs have been pretty outstanding too. There's been a couple that, probably in the younger day, when, when the device was so new and new to the whole world that they, they struggled more. But as the time went by and finding the right fit, then that worked out so much better.

When asked what kind of information they were initially provided with regarding speech and language intervention services available for their child, most of the parents reported that they were first told about speech and language services by a pediatrician or another medical specialist. Parents expressed mixed reactions when they were asked about how they felt concerning the amount of information they were provided with in regard to speech, language, and AAC services available to their children. Two parents reported that they felt satisfied with the amount of information they were provided with, one emphasizing the need for parents to be intentional about asking for the information they need.

> P02   [The child's doctors] have a whole list of providers in our area…I thought [the amount of information] was perfect.
>
> P05   …because Child5 came home from China with a cleft lip and palate, we were already down at the Hospital with the cleft lip and palate team. So they have a speech pathologist on that team. And actually now that you say it, she was probably the very first one who ever mentioned the clinic to me… So, we were already working with somebody through the cleft lip and palate team… there was a doctor there that had recommended that to us, and had given us a lot of the information.
>
> P05   I think you have to seek [the information] out, I think you have to seek it out. I mean, I think you have to ask the questions…how are they supposed to know who needs that help and who doesn't if you're not, as a parent, not saying something?

Conversely, many of the parents felt unsure about the amount of information they received for a variety of reasons. One parent felt that information concerning speech, language, and AAC intervention could have possibly been introduced to her earlier so that therapy for her child could have begun sooner, but also felt that the timing for receiving this information may have been appropriate for that family at the time. Another parent expressed that she did not think the information about intervention was explained well enough, but she also felt that it may have also been her responsibility to ask more questions. Two parents also explained that they felt unsure about the amount of information they were provided with, as they also had other concerns that they were focused on beside communication.

P01	We are glad [with] what we were given when we were given it, I think [it] was very appropriate. Now were some people- could they have shared [the information] sooner or would it have done any more? The only point is this talker could have been introduced sooner, the communication device. Should it have been?.. Maybe it was introduced at the right time.
P03	I think maybe it was I don't want to say too little, but maybe, maybe it wasn't explained well enough…Or maybe I didn't ask enough questions. I'm not sure.
P06	That's kind of hard to answer because when you're in on this side of the situation, you know nothing. So you don't know what's all out there and what can be provided to you and what not. So you just accept what, what's being given to you. Unless I suppose if you're a research hound, and you know, you've done a lot of research. But what, in a situation like mine, I don't have time to be like googling every single thing. So, I don't know, that's a difficult one to answer.
P07	In the beginning, oh I so desperately wanted to connect with other families who had a similar circumstance to us. I was, that was what I was really seeking, I wasn't really seeking information about SLPs specifically. 'Here's my son, he went from being a healthy, active, normal little boy, was brain-injured in a car crash, and all a sudden he's laying there, hardly recognizing us. What am I supposed to do with him now?' kind of thing. 'What's the future going to look like, what, how do I get through these days? How am I going to manage this emotionally?' That's the stuff I was probably more focused on at the beginning stages. Then as time goes on with the internet and comm- you know, things like that, you know, you can find information pretty easily and stuff. But did I really do a whole lot of research specifically on SLP stuff? No.

As a whole, most of the parents reported satisfaction with at least one of their child's SLP's knowledge concerning AAC intervention when the child was young. Parents whose children received communication interventions through birth to three all expressed some level of dissatisfaction with the SLP's familiarity with and understanding of AAC. In regard to the amount of information that parents initially received from healthcare providers concerning communication intervention services available for their child, parents either felt satisfied with the amount of information or uncertain about the amount of information. Reasons for uncertainty included the fact that some of the parents were overwhelmed with additional concerns about their child, they felt that they should have asked more questions about services, and one parent felt that information concerning AAC could have been provided earlier but expressed that she was unsure as to whether she would have been able to handle all of that information early on. Parents then proceeded to discuss their interactions with professionals involved in the process of acquiring and using AAC, and how they thought these individuals considered the needs of their child and family.

Theme 3: Communication with Professionals/Parental Inclusion and Consideration of Family Needs

When asked to describe the interaction among professionals and themselves, the parents reported that for the most part, they felt satisfied by their interactions with SLPs concerning what their child was working on in therapy and how they were progressing with their communication skills.

> P01 …we get a daily report because it helps us again with a non-verbal child to give talking points of- we can say 'How was your day?' Well he's not going to say something, so we can talk about something specific and then that gives us...you can just see it in him, or he'll now he'll use his device and talk about that thing of the day. So having that communication back from the teacher- on top of that we would get emails from the therapist which we have just learned, and they've learned that this is my best means of communication.

P02   Well the speech therapist in his team at the hospital keep us very well informed of…we see them once a year, and they keep us informed of when his next surgeries will come up. They keep us well informed on how his speech therapy's going throughout the year and how he's developed over the years…And then his speech therapist at the clinic and at school… we're well informed from both of them. We're in the loop all the time. If there's a problem or what he succeeds in, they call us no matter what.

P05   …so at the school we use IEPs and then we also have a notebook that we communicate back and forth in, or his speech therapist over there will just give me a call and, and talk to me or shoot me an email, so they're pretty good about it. But primarily through IEPs… For [the clinic's] it's again, you know it's not considered an IEP, but it's really an individualized plan for Child5. So we go through what his goals are and how they've set them. So through our meetings on a semester basis, you know, that's usually when we get together and, and it's been very helpful for me to be able to see the progress.

P06   Well, birth to three I was usually there, just like I am [at the clinic]. So I see, and hear, and know everything, so I, there's no communication breakdown at all.

Two of the parents discussed the difficulties they have encountered concerning communication and the sharing of information amongst their children's various service providers.

P04   I guess it was basically whatever we told them. I mean we were the link between the speech therapy and the doctors, I mean, there was no communication between the speech therapists and the doctors directly. So it would have been- we would have gone in and gave the updates of what was going on…there wasn't direct communication between doctors and therapists. Now, now there might be. I mean, now I can give doctors more because I can go in with her IEP file and things like that, but initially there wasn't really anything.

P06   …we have created a little communication notebook, that, is, stays on her wheelchair, and anybody like, having concerns or making changes and stuff like that are supposed to write in that notebook. Because that was a huge thing at school, and that's something that I would probably share with other kids with special needs too is, OT, PT, speech: nobody knew what anybody was doing. So then that's when I created this notebook, and I'm like "you guys need to know what each other's doing so when you work with her, and you do anything different or there's something you want done a specific way, you need to write it in the notebook, that way I can read it, the next person can read it, and be like 'oh okay,

wow, we're supposed to sit in this chair or sit in that chair or use-use this device or, whatever.'" So, the communication between everybody with speech, with OT, with PT, I think is like super important for somebody with special needs, especially high special, high needs. And I think because I go to school with her one day a week, I come into the therapies with her, um, um, so I'm in the loop…

One of the parents expressed that she has had varying experiences depending upon the SLP or professionals her son was working with; however, she felt that overall, the communication amongst her and other service providers was good.

> P07   …it depends on the professionals you're working with. Some are better than others, but I always sign releases, and I always invite people from the clinic to attend IEP meetings. Sometimes they can, sometimes they can't, but they, I try to get them to exchange email and know that they can communicate with each other. They're invited to come observe each other and stuff like that. Some do, some don't, just depends on where Child7's on- at, at stuff. You know, whether they feel they need to be observing to see what other people are doing and stuff. But yeah. I feel like most of them who care and are really doing their job well, are, are really good about that, and communicating and sharing and wanting to collaborate and work together on this rather than each trying to do their own thing. 'Let's pool our resources and knowledge together' kind of thing is best.

In terms of describing their level of involvement in their child's speech therapy, all of the parents reported being very involved. Parents who discussed birth to three explained that their involvement in therapy was very hands on. Most of the parents explained that their involvement in therapy at school occurred mainly through written and/ or verbal communication with SLPs either on the phone or during IEP meetings; however, one parent reported that she spent one day a week with her child in the school environment. When discussing their involvement in speech therapy in a clinical setting, some of the parents reported being directly involved in therapy activities, while others observed the sessions and implemented those strategies in the home environment.

> P01   …when he was in birth to three, we were with him every minute. So we were with the process, we heard what the therapist was doing, there was no disconnect really. We sent him off to school and we felt 'gosh what's happening?'... So at

home, we play games. You know, so I try to think of what kind of things they're working on and we try to do the same thing at home…

P02   Our involvement is… we take him to the clinic, we stay there for that hour with him. And we uh, the things that they do with him to help him with speech, we're right there with him, involved with the speech therapist.

P05   I would say as far as my involvement, anything going on in the clinic, anything I see going on at school, I try to mimic that at home as much as possible in a real life setting.

P06   …I go to school with her one day a week, I come into the therapies with her… Yeah, completely involved. Because I'm [at the clinic] and I'm with her, I bring her, I sit in class, the session, whatever you call it…I'm always there to answer questions or help guide, or say 'she likes this' or 'she does it this way' or like, you know. So, I guess my involvement would be helping you guys when you start and getting yous comfortable with her, and get you to know her, and what works and what doesn't.

P07   …there's involvement and then there's, sometimes your kid works better for a non-parent than if the parent's in the room. So I try to, you know, stay behind the mirror and watch and stuff. The first couple of sessions I might be more involved, to kind of get them acquainted and show them how Child7's communicating, or get them familiar with the Dynavox before I step out and let them kind of take over and stuff, and I'll just step in if they need a little assistance, or Child7 can't find something on his Dynavox they need or whatever. So I, here at the clinic the students are really good, and they catch on really fast and it's fun to watch and observe.

Two of the parents also described the emotional difficulty they faced as their child transitioned into the school environment. This meant that they had to allow the SLPs to have more control, as they were no longer able to attend therapy in this environment.

P01   …I had the teacher once say, 'cuz I wanted to be so involved and 'cuz we were so used to that. 'Tell us, what should we do what should we'- and she just said, 'You need to be his parents. You just be his parents. I'll tell you if there's something specific, but you don't need to be stressing about this and worrying and trying to, you know, do all this homework per say', or um, but of course we still work with- you know that's why we share those communications like, 'We did this today, maybe see if he can do this for you at home.'

P07   …I was telling you about how I get stressed out about those rules, it was many years later that I kind of came to the realization that those IEP goals are their goals. They're written, legal material that they have to follow, and if we focus on those goals, we're so focused on the goals that we're not seeing the big

picture…So I, I just really realized that my job was to step back, and make sure that he was getting all the services he needed, they can write their own goals. They have to set goals that are achievable and attainable by them that, you know for, Child7 can achieve, so what they want to write is irrelevant. That's not my goal, that's their goal.

All of the parents reported that they were highly involved in the decision-making process regarding decisions about the type(s) of AAC systems their child would use as well as the type of intervention their child would receive. However, three of the parents spoke about how they relied heavily upon the knowledge and expertise of the SLPs to guide their decisions.

P01   You know when you want choices, you always say well "I didn't have a choice, I want all these- you know." We were given tons of choices and it was almost overwhelming like, "Whoa, somebody just tell us what we need." So it's kind of a Catch-22: you want, but you don't want.

P03   The therapist was really good about that. She I think retested a couple different ones to see if there was one that we preferred, gave me a bunch of information to read on different ones, and we went through a lot of trial and error which ones we thought were going to work for Child3 and which ones we didn't. And the therapist gave a lot of good input to help us pick the right machine for her…And also the speech therapist from school actually came down too and helped us.

P05   …so they're really open to our input as parents, and I feel like we have a lot to say about it because, in the end, if I don't want Child5 to use an AAC device, he's not going to use it…I don't feel pressured to go one way or another, at least not here. I feel like, you know, the therapist has been real open with what her thoughts are, you know, and she will share her opinion, but then she'll leave it at that and then she'll say 'now I want you to think about that, and see if you think maybe we should.' But again, I think it's a two way street, so as much as therapists are willing to share that information, parents have to be willing to say 'okay, well this is what you went to school for, this is your specialty.'

P06   …I guess I was just told what they suggested would work best and, because they're the professionals or yous are the professionals and, I mean I'm open and willing to try whatever, so I was like "okay"…

The parents also discussed how they felt that SLPs considered the needs of their family including the types of activities the therapists incorporated in therapy, the training they received concerning AAC, and their overall impression of the services they received. When asked about

how SLP's considered their family's needs, the parents' responses were quite positive. Although some of the parents stated that some of the therapists they worked with were not as considerate, they were generally very pleased with the sensitivity therapists demonstrated when considering the needs of the families.

> P03   Oh all of them are very excellent with any problems or concerns, or anything that they have or they uh, I get emails all the time, I get phone calls if there's problems, or if she does something good. You know, she does something in therapy. I've got phone calls- they include all of us.
>
> P04   Overall I think with the exception that who we worked with with birth to three, everyone has been very understanding of Child4's needs and tried to work towards her strengths and, and make sure that we were listened to I guess is just what I'm kind of saying in that they definitely would consult us when they had an idea of what to introduce with Child4 before going ahead with it, so that was helpful.
>
> P05   …we have had therapists come to the house, just to kind of see how we can take what we're learning in therapy and apply it at home. We've had them be really good about being open with, you know, 'What do you want Child5 to learn? In the process of learning to communicate and to speak, what is it that you want him to learn in that process?'…I think that they've also asked us, you know, in regards to AAC, which device do we like best. Is there one way that we think we would prefer to go, and for us at one point, it was sign language, and we did a lot of sign-language. 'Cuz Child5 was picking up on that, and he just wasn't picking up on everything else. So they've been really good about taking into consideration what we say, and I really feel like we're more of a team, you know, I'm part of that team rather than the parent being the onlooker.

The parents also described a wide variety of activities that the SLP incorporated in therapy. Some discussed play activities that encouraged their child to make requests or comments. One parent spoke about her son using his device to put concepts such as shapes and colors into the correct category. She also discussed the initial use of food as a motivator to get her child using his device to make requests. Another talked about her child using her device to make comments and predictions during book reading activities. She also mentioned that a large portion of therapy

was dedicated to figuring out how to best calibrate the device for her child. Finally, another

parent discussed how her child's sibling was involved in therapy

> P01 …one of the big things was grouping. And I think he's good with that. Of course shapes, colors, numbers, you know, that kind of thing, um which is funny 'cuz we- he's a smarter kid than we ever gave him credit for, and it's still hard for him to express some things, but when you talk about colors or numbers, damn he's got it. He's got to think a little bit…When we first got the talker our- they always say food is a good bribery. So that's all we focused on. Then we struggled to get him off the food page to say, 'Let's try some other things.' This talker is not just to get you food.

> P04 …we were having a lot of trouble with calibration of the device, so unfortunately, a lot of the time especially the first- both this summer and last summer, was spent with fighting with calibration of the device versus activities themselves. So once they actually would get in and do it, it was a lot of like reading books. Last summer there was books like "Brown Bear, Brown Bear" or "Hungry, Hungry Caterpillar." There was the different- like she has like to go through a progression of what happens next, and she has to indicate that.

> P05 ...we've done music, pretend play. I love that for instance, when we first came in, they were asking us what kind of approach we liked… [With the iPad they do] both structured and unstructured play time. The structured play time and activities, I think are a must because with Child5's autism he thrives on structure, and he can- if he's not in a controlled setting, he can get pretty wild.

> P07 …we dragged [his sister] with us to therapy and stuff, I'm sure a lot of that interaction was based on, you know, play activity with her in the beginning stages. And she was all into that… And so yeah, she was really involved in the beginning days. Blowing bubbles and being, you know, they'd give her the job of blowing the bubbles and then they'd try to get Child7 to communicate 'I want to', so he'd have to tell them, 'I want to the next bubble to be blown'…and things like that.

Two of the parents explained that the school SLPs were currently focusing on facilitating their

child's speech. One parent discussed how her child used the device in the classroom in order to

better communicate with teachers and peers, but explained that the SLP had begun to concentrate

on spoken communication during therapy. The other parent indicated that the child was no

longer using her device at school, but when she had in the past, it was in the classroom setting; the SLP used therapy time to develop the child's spoken communication.

> P02 Actually now he's using more of his speech. They used his device last year more than this year…he uses the device more at school for the teachers and his peers… It's easier for the teachers to understand what he's trying to say and easier for the classmates to understand what he's trying to say.

> P03 Yeah. I know that they used- when they had the device at school, they had a program for every aspect of her day. But like in therapy, copying sounds, I know they worked a lot on that.

Regarding the AAC-related training that the parents received, the parents shared that they felt they either received a sufficient amount of training, or they reported that the companies selling the devices provided little to no training concerning the device.

> P02 The clinic, we had training sessions scheduled with the person at the clinic…and she would schedule sessions with my husband and myself and Child2 on the device…So yeah, so we- yeah like I think there were four sessions on how to work things on the device and download things on the device and update the, the programs on the device off the computer and they gave us the address, so we would get the newsletters on our computer. And we just have to download it to the, to the Nova Chat to the Samsung tablet.

> P04 Um, that's a good question. Mmm, none. It was all basically just me exploring it, yeah, that's what I meant with the lack of support from- so we were supposed to get a three hour session built in and that apparently never, that never happened. So it was kind of just I got the initial- the vendor just kind of came out and just kind of showed us like a demo, and what not, just to kind of sell the product I guess you would say, but then when the actual device arrived, we were completely on our own. I just set it up on my own and picked all of the programs in on my own and everything.

> P06 Well, I guess the only training would be like sitting and being in the session and watching what they're doing and having them explain that, how to do things in a certain way, a certain length of time, a certain amount of times a day, so the training part of it is just like being there and watching how the service provider is working with her and how they do things and just kind of mimicking it. So, training-wise, up until this AAC thing, which there is hardly no training, or this Tobii thing, this Tobii Dynavox-It's kind of, it's kind of like 'here, you paid nine thousand dollars for this, now you can figure it out.'

When asked about their overall impressions of the speech therapy services provided for their children, the parents expressed that they were very satisfied with the quality of services provided by the majority of the SLPs that worked with their children.

P03   But I think everybody that we work with does a good job. I don't know. I kind of expected sometimes some people to be not so good, but most of the time they are…Yeah, I'm impressed with all of her therapists, everybody- it seems like they all care.

P04   I guess it depends on which time. Overall, the majority of the people she's worked with have done well…they definitely always challenge her and, and push her.

P05   Oh, we've loved it. I think they've been great. Overall, it's um- impression is that they are well educated and have a genuine, I guess genuine desire to do what they're doing. You know, they enjoy what they're doing, and definitely have care for the kids which is huge.

P06   Good. My- I'm a total positive outlook on that. It's come a long way, we've tried a lot of different things, on, and then having the, having people with creative minds to think outside the box, is necessity with children like Child6, too. If you're very "okay, this is how it's done", it's going to work for, like I said, ninety percent of the kids or maybe half of the kids or whatever the percentage is, but then you get somebody like Child6 in here where it's like, none of that's going to work and have to try to adapt and figure something else out.

Although some of the parents reported that some of the SLPs they interacted with were more difficult to communicate with and less considerate of the needs of their child and family, every parent reported having worked with at least one SLP when their child was young that was great at sharing information with the family and other service providers. They also felt that these SLPs were responsive to their ideas and always asked for the family's input when making decisions. When asked about the amount of training that they received, many of the parents felt that they received adequate training regarding programming AAC devices and using AAC with their child. However, some of the parents focused on the lack of training that they received from device vendors, not SLPs. Overall, each parent shared that they were highly involved in their

child's therapy, but as their child became older, their involvement was less hands-on and

involved observing and hearing about how the SLP interacted with their child, then trying to

implement some of the same techniques in the home environment. Finally, all of the parents felt

that a majority of the SLPs who worked with their young child provided high quality services.

After this portion of the interview, the parents were asked to tell about their experiences

concerning funding of AAC intervention and speech-generating devices.

Theme 4: Parent Experience with AAC Funding

Concerning financial experiences, some parents reported that they either had a fairly easy time

working with Medicaid, insurance companies, vendors, and other parties involved with funding

their child's AAC devices, or that the process was very difficult. Two of the parents expressed

that the funding process was relatively simple due to the fact that the SLP handled the majority

of the process for them.

> P03 The therapist handled all that for me. I mean. She did. The only person I had to
> deal with was the therapist. Yeah, so I guess maybe she kind of spoiled me a
> little bit there. But yeah, she just told me what had to be done, what we had to do,
> um and we did it, and she dealt with, she dealt with all the insurance, I didn't deal
> with any of it…Yeah, it was very nice. Because she was telling me how difficult
> it could be and I'm like "oh God I don't want to do this."

> P04 Oh yeah let's see so with the funding actually was fairly painless, I mean it was-
> we stretched it over a long period of time, but it wasn't a whole lot of back and
> forth like things we had to do, it was just obviously a lot of paperwork. But…
> other than time-consuming, it was fairly painless.

Four of the parents found the funding process to be challenging, even with the support of an

SLP. One of these parents expressed that the process was long and difficult due to unusual

circumstances.

> P01 Yes. We ran into um- and I don't want to focus too much on that, because I don't
> think that's geared toward anything specific. But that was a very sour moment for
> us … we didn't know the big picture, and that was hard because we would have

known because we would have known "Well, oh, you're going to do trials for three months and then we'll, then we'll pick one." You get a different, you know, light on it versus, "Okay now she tells us to come back again. Okay well, oh! Now we're gonna try another one? Oh." You know, you get to see the big picture.

P01   …we were going to make a decision on D-day basically, and she said, 'Well you know what? You can um, you can make your decision up until this day. We won't do any more trials, but if there's conversations you want to have or the therapists or something, we don't physically need to hit the 'go' button today.'…And then she was no longer with the company…And then, that was a whole month of "why isn't she returning my email? Why isn't she not returning my phone call?'…Then we went for probably- July, August, September, October- then we went for five or six months with NONE. And he was real fixed because "you gave me this for three months, and now I have nothing to talk to you with for five months."

Another parent had a difficult experience receiving funding for the device, but she was very

satisfied with the support she received from the SLP and other healthcare professionals.

P02   Well, the insurance company flat-out denied anything like that. They're very hard to deal with. As far as Medicaid, like I said, we had to fight for it. And it took over a year. But the professionals, like from his doctors to his speech therapist to his dentist and things like that, we got plenty of letters of recommendation stating that why this device would enhance Child2's everyday living skills.

Parent 6 expressed a great deal of frustration with the funding process, not only for AAC, but for

all of the other equipment her child needs due to her physical limitations.

P06   …the providers of the equipment that is an extremely challenging area of communication. Since, we waited like almost a year for approval on that Tobii. And didn't get it because so many people dropped the ball...It's always the end of it with the people with the equipment end of it.

P06   …it's everything, it's not even communication devices, it's everything. *Very frustrating*...Yeah, all of her equipment. Her- all of it. Her wheelchair, her stander, her gait trainer. I mean everything. Everything. Everything…It is a lot, and it's like you know, if I didn't work outside the home, you know, and I just was home and could be on the phone all day babysitting everybody is really what it boils down to because 'okay, you didn't do your job so now we, this has delayed this whole process because you didn't do what you were supposed to do'…So, it's really frustrating. It's a full-time job just to do that…

Parent 7 explained her experience of the resistance of her son's school to provide funds for his

first AAC device.

> P07   …we invited school through every step of the way. We did a whole evaluation
> process of testing and trials and things like that. Um, they chose not to attend,
> even though they were invited. When the people came, the vendors came here
> personally with products for us to see and try and ask questions about, they didn't
> attend…And they kept putting us off, and we had meeting after meeting and they
> speculated that he was too motorically challenged, and cognitively challenged,
> and physically challenged, and they just didn't think that this would be the, you
> know, right thing for Child7. That it just would be a huge expense, it would just
> be all for waste.

> P07   And they kept putting me off, and finally at the end of the year, they called a
> meeting and they had all the school people involved at the meeting, but guess
> what? They didn't invite the parents to the meeting. And they presented us with a
> written document at the end that said 'Child7 would be a candidate in the future
> for the device.' Guess what? They just broke the law. You can't have an IEP
> meeting without the parents. So Child7's county caseworker called the head of
> pupil services…He said, 'I'm going to override their decision and buy the
> device'… And then, we had to deal with their, you know, their cattiness or
> whatever about us going over their heads and that. And they were really very
> resentful of the steps we took to get that device, and I am not apologetic at all.
> Because I had to do what I had to do.

Finally, one parent described a very positive experience with a private organization that provided

her son with an iPad, after she decided not to pursue a device through Medicaid due to the

complexity of the process.

> P05   Well, the first route that we were talking about going with the Tobii-Dynavox, I
> was quite surprised at the process that was going to require because of having to
> go through Medicaid and different things…the therapist did a lot of the
> communicating with the vendor to find out pricing and what not all…And when
> we just absolutely we like 'oh my goodness, we're never going to pay that' she
> was very open to us then pursuing the iPad route. And looking into Proloquo2Go,
> and, versus the Dynavox Compass app. And, so the therapist did a lot of that for
> us, where she communicated with the vendors and on your end just to find out if
> indeed we could use certain apps on the iPad versus on this ten thousand dollar
> Dynavox… So she was an integral part in that they- the companies, we got copied
> in on the emails. They were very open and honest with it because obviously they

want to make the money, but they were open and honest about what other options there were.

P05 And, as far as working with the place that we actually got the iPad and the app from, they just- they were fantastic. They just had us fill out an application, it's not based upon income which is such a huge blessing because most places it is based on income and so we don't ever qualify.

Many of the parents interviewed for this study expressed that they found the funding process to be fairly simple, as the SLP was in charge of handling most of the paperwork. Others expressed that it was a tedious, frustrating, and time consuming process. Although these parents acknowledged receiving support from their child's SLP, many of them shared about the difficulty they experienced communicating with vendors, insurance agencies, and school administrators as well as receiving approval for the funding of their child's device. After discussing their experience with funding, the parents answered questions related to their family and community's reactions to their child's use of AAC.

Theme 5: Family and Community Reaction to AAC

When asked about how family members and close friends reacted to their child's use of AAC, the parents reported that overall, once people understood the purpose of AAC, they were very curious, accepting, and excited about it. Some of the parents expressed that it was difficult to explain the purpose of AAC to young children, but many reported that older siblings, cousins, and peers responded very positively.

P01 Our family, meaning extended family- my parents, my husband's parents, and all of Child1's cousins...it was different. It was definitely like. 'Well why do you have pictures on your wall?' or, 'why do you have a toothbrush on your wall?' Or, now that he has his device, 'Well why does *he* have a tablet? What is that?...But we've always treated it, 'This is Child1's. No one touches it. This is...you know, you have a mouth. This is Child1's mouth.' You know, you're telling this to his little cousins…

P01 But they were very accepting, they too wanted to learn, and, and both my husband- both grandparents on both sides- it was learning experience, and we

would share with them as much as we knew because that was only going to help Child1…Now the kids think it's cool and awesome and Child1's cool and, the older cousins are trying to help him and... It's very cool. They're all excited.

P04   …for kids that are her same age, you know, be it friends or peers or cousins, they're a little bit confused by it … you know it takes longer to say something with AAC than it does just saying it aloud…But in terms of adults, it been very positive…she's been able to express, you know, her sense of humor. I mean, I always knew she had a sense of humor, but she is able to definitely show, prove that she has one through the, the eye gaze which is helpful.

P05   Oh they think it's cool. My other two biological kids especially. They just think it's neat that they can actually communicate with him. The sign language, the rest of the family hasn't picked up on a whole lot, because we're always with Child5… But we have seen family trying to pick up on it, they think it's neat that he can do signs…

P07   …in the beginning it was probably mostly just at home, and I think the excitement was for him, more so than for us. For him, the ability to say a few things, you know, and, and get what he want kind of thing stuff. And, and we were just excited that he had a means… that realization that 'this is your voice' you know, and yeah, that was- like I said, we, if somebody can't walk you put them on a wheelchair, if somebody can't use their arms, they find another way to do it, but communication is the essence of our soul and the way we connect with people, and without that you're just a body. And so that was so vital to me to find that way to- 'cuz you knew there was stuff going on in his head. 'How are we going to figure out what he's communicating?'

The parents also shared how people from the community reacted to their child's use of AAC and how they felt about those reactions. Aside from one parent who shared about some very negative experiences in the community, all of the parents reported that although people often stare and are unsure of how to interact or ask questions, they are generally very accepting and curious about AAC. Many of the parents also explained that they try to encourage questions, especially from children, because they want people to understand and feel comfortable around their child.

P01   …people are interested, and they look, and sometimes we'll get people to come up and talk and say something, and they're very accepting when I say um, just to, just to expose the person who's interested to what the device is, I will say something to Child1, 'Child1, why don't you say hello?' or, 'Child1, why don't you..' something…So that they see what, how it works… You know, I think people are

more um, they don't want to draw any attention and they don't want to make it like they're staring, but yet they're interested...So, I think I've just become more outward about it.

P04 …they might look, but they don't think much of it. Kids will ask questions, I love kids. They're so honest…it's so funny to watch the parents tell them to 'shush' and I go 'no, no, no, no, no don't shush them, because then they turn out like you and me. Let's let them understand this so that they don't turn out like us and be shush-y Americans.'

P06 You know, everybody's a little different. You've got the outgoing people who aren't really so afraid. And then you got people that are just uncomfortable, and they don't know. But I think first time people seeing her, they probably stand back and take it all in, but as people get to know her, then totally, they're, they can't help but like love her.

P07 People stare. It's funny I remember being in a store or a restaurant or something and a, you know, kids are just blatant, they'll just come right up to you and plant themself and stare. And parents are like mortified and I remember a mom grabbing her 'Don't stare!' and I said, 'Hey.' I said, 'That's okay he's staring at her too' 'cuz Child7 loves kids, so whenever there's kids he's staring right back… and I always would engage the kids, something like, 'That's Child7. Do you want to ask me any questions about Child7?'…I'm so cool with that. People are curious. They're not trying to be mean or rude typically, and so I try to take that in mind. I have to say that I never feel like I blend in anywhere though.

One parent expressed her frustration and anger concerning the negative reactions her child received from people in the community.

P03 I'm trying to think of where to start. It's not something that's accepted very well. Any store, whether it's- I just, we just live in a really small town. There's not very many people that live here at all. And even having it- taking her with it into the grocery store, ah, just dirty looks, staring. Just rude. Just irritating, and one day I got so pissed off I just left my cart in the middle of the store and we left. In Walmart, people just...I don't know, I don't get it, and it's probably because I have them, but people are just rude. They stare, they laugh, they point.

As a whole, the parents from this study explained that they typically receive positive responses about their child's use of AAC from family, friends, and community members. Many of the parents reported that it was often difficult to explain the purpose of AAC to very young relatives, but despite some initial confusion at times, family and friends were very supportive, curious, and

helpful in facilitating the child's use of AAC. Almost all of the parents discussed having positive

reactions from community members about their child's use of AAC. Many of them mentioned

that community members often feel afraid of being impolite or uncertain about how to respond to

their child's use of AAC; however, the parents shared how they became more forward in sharing

information about AAC and asking people if they had any questions about it. One parent

expressed that her child received many negative reactions that she felt were very rude from

people in the small town where she lived. Parent's then transitioned into answering questions

regarding the impact of AAC on their child's communication skills and the whole family's

quality of life after AAC intervention.

Theme 6: The Impact of AAC on the Child and Family's Communication and Quality of Life

When asked how their child's communication has changed as a result of AAC, three of the

parents reported that their child had begun to use more speech after beginning AAC

interventions. They shared that their child began to imitate the voice output from his or her

device, and they felt that this helped their child to develop more speech sounds and a template

for expanding his or her language and oral communication skills.

> P01   Since his device, he now says words. I understand them...when he pushes a button, he knows what it's supposed to say, and then he shares it. It's almost like it's clicking in the brain, 'Now I can say it.' I don't know.
>
> P02   He'll type the question on his device and press the button for it to talk and then he'll repeat it…It's not hampering his speech at all, it's helping him with his speech.
>
> P03   She started making more sounds and actually now, she, she talks quite a bit. She's not really clear, but it's easier to make out, but I would say that's the biggest thing that came from her using the device for so long, was that her, her skills developed…

Many of them also expressed that having AAC as a mode to communicate helped to decrease

their child's and family's stress and frustration, because child discovered an easier and more

effective way to communicate his or her wants and needs. This allowed parents to feel less

helpless when a communication breakdown occurred, because they could help to facilitate the

child's use of AAC as an alternative communication modality. Parents also expressed that they

felt AAC allowed their child to better express his or her knowledge and personality, which had

often remained hidden until the child began AAC intervention. With all of these factors

considered, parents stated that they believed AAC helped improve the overall quality of life for

both their child and family.

P03   And just less stressful. You know, not so stressed out...I think it had many, many benefits not just for her, but for everybody else.

P04   … she's got this great brain that does a lot of things, but it's trapped inside a body that doesn't work for her, so the AAC kind of helps get that out, and she's able to convey meaning…I can confirm it through the eye gaze, that yes, this is what, this is what she was trying to tell me, or that she does know how to do this.

P05   I don't think he's as frustrated… before I think we had a lot of tantrum throwing, a lot of aggression, a lot of, you know, just wanting to be in his own world…I think quite honestly, I think communication has drawn him out in a good way.

P05   I think it's helped solidify the family union, again, because he's able to respond and reply to express what his feelings are in the moment, even though he doesn't understand those abstract feelings, you know, he, if he has something he wants or that he needs, he's able to express that.

P06   I think it's had a, a big impact on us to, to open up that door of communication…So, gives you hope and hope for the future too, that as she gets out of this um child stage, that it will only grow and get stronger and better and be able to get her needs across and wants across, and, and to have a fun conversation with somebody. Somebody her own age, you know? So it's been a positive, I think it's been positive for everybody all the way around. And her especially…now she can be a part of making her decisions.

Overall, nearly half of the parents expressed that their child's speech improved as a result of the

use of speech-generating devices. Additionally, all of the parents shared that the use of AAC

with their child had improved the quality of life of the family, especially for their child. They

reported that their child began to understand that communication gave him or her power and

control over his or her environment, as well as a more effective and less frustrating modality to communicate their wants, needs, thoughts, and feelings. During the final portion of the interview, the parents shared other thoughts that were not addressed during the interview.

Additional Information and Advice from Parents

At the end of the interview, parents were given the opportunity to share any additional information that they felt was important. Three of the parents offered advice to other parents of children using AAC. One suggested that parents get insurance for their child's device in case it were to break. Another parent urged parents not to give up on AAC intervention, because she has witnessed the benefits that her son has gained from using AAC over the course of nearly twenty years of intervention.

> P03 …people that get these devices, really need to contact their insurance company, their home owner's, their renter's insurance or something, or see if they can take insurance out on the device. So when it breaks, you don't have a three thousand dollar bill for you ten thousand dollar machine…I wish somebody would have told me that. Because she would still have it then…I think that was like one of the biggest things was, I wish that I would have known that I could have had insurance just on that.

> P06 Just making sure you always keep parents involved. …most parents I think, even if they're not willing to come right out and say 'teach me how to do this or include me in this-'I think most parents do.

> P07 I guess, I just would need to tell and express that to people, and hopefully things are better now. You know, there's more people that have these, and you can see the success of them, and people know how to teach somebody how to use one. And I would just, you know, I'm just so glad I didn't give up. I'm so glad we stuck with it and saw it through and just kept pressing, and, and knew the potential and just the hope that it would help Child7 in some way…I mean here he is at twenty one and we're still, we're still seeing changes and improvement and, and, you know, he's still learning and changing.

In conclusion, the parents' responses during their interviews were categorized into six major themes. The first theme addressed the parents' initial attitudes toward AAC intervention, and it

was revealed that parents either responded with excitement or skepticism. Throughout the second theme, the parents expressed that overall, they felt that the knowledge of SLPs and other professionals concerning AAC intervention was satisfactory, with the exception of some of the Birth to Three and school SLPs working with their child in the initial stages of AAC intervention. The third theme included the parents' experiences regarding their communication with SLPs and other professionals, as well as how the parents' thought that these professionals considered the needs of their child and family. Most of the parents reported positive experiences communicating with SLPs about how their child was progressing in therapy. Some of the parents reported challenges facilitating communication between various service providers. Throughout theme four, the parents' experiences with funding their child's AAC systems was explored. Parents generally reported either very smooth experiences concerning funding or they expressed that this process was very difficult. Within theme five, the parents discussed the responses they and their child received from both family and community members regarding the use of AAC. All of the parents mentioned positive reactions from family members, although some of the younger cousins and other children had difficulty understanding the purpose of AAC. Throughout theme six, the parents described the positive impacts that AAC use had on their family and child's quality of life, reporting decreased frustration and improved relationship quality. Finally, parents offered advice to SLPs and other parents regarding their experience in acquiring and using AAC with their child. Overall, the parents all reported positive outcomes concerning their child's benefits from receiving AAC intervention.

Discussion

Although past literature revealed that many parents are skeptical about the use of AAC with their child due to common myths concerning AAC use (Romski & Sevcik, 2005), many of the parents in this study expressed their enthusiasm to begin AAC intervention. A possible reason for this finding may be that many of these children had very CCN such as severe physical limitations, making speech impossible or very difficult for the child. Due to the nature of their child's disability, these parents were perhaps excited to know that other communication options were available. Another unexpected finding was the parents' overall satisfaction with the SLPs' knowledge and services related to AAC with their young child. Past research indicated that many parents felt unsatisfied with many SLPs' lack of knowledge and training in regard to AAC intervention with children (Angelo, Jones, & Kokosa, 1995; McNaughton et al., 2008). It is possible that because the parents selected for this study had children who received services at clinics that provided specialized services in AAC, the SLPs providing services had more knowledge and training about AAC than clinicians working in other settings such as Birth to Three programs or schools. This specialized AAC support may also explain why some of the parents reported experiencing little to no difficulties during the process of funding and obtaining an AAC device for their child to use, which is often reported to be very challenging and time-consuming (Angelo, Jones, & Kokosa, 1995; Goldbart and Marshall, 2004; McNaughton et al, 2008). It was also somewhat surprising that some of the parents reported that their child's school SLPs abandoned the implementation of AAC intervention once the child began using more speech, as the parents reported that their child's oral communication skills were still limited, and they felt that their child was often difficult to understand. This may be due to the fact that school SLPs have a limited amount of time to work with students, perhaps causing them to focus solely

on one communication modality. This may implicate that school SLPs could benefit from more knowledge concerning the importance of incorporating multiple modes of communication during intervention with young children with complex communication needs, and more training on how to foster multi-model communication within the therapy setting and especially the greater school and community contexts. It is also notable that many of the parents expressed a strong willingness and desire to educate unfamiliar adults and children about their child's use of AAC. This seemed to indicate that parents were not discouraged by the apprehension of many unfamiliar people concerning how to interact with their child, but rather that the parents were eager to facilitate interaction with their child and excited by the opportunity to answer questions about their child's communication with AAC.

Many of the findings of this study aligned with past research concerning AAC use with young children, as well as parents' experiences surrounding AAC. Just as Kaiser and Roberts (2011) discussed that the gap between existing knowledge about AAC intervention and its implementation by SLPs working in early intervention, the parents whose children received speech and language services through Birth to Three also expressed dissatisfaction about these clinicians' knowledge and experience with AAC. This demonstrates the need for more training regarding AAC intervention for Birth to Three SLPs. Additionally, although some of the parents reported relative ease with regard to the AAC funding process and the training they received concerning AAC, some of them also expressed that they found the funding process unreasonably long and difficult. The latter is consistent with the findings of multiple studies of which the results indicated that parents were often unsatisfied with the training they received as well as the difficulty of the funding process (Angelo, Jones, & Kokosa, 1995; Goldbart and Marshall, 2004; McNaughton et al, 2008). Also, just as Dugan, Campbell, and Wilcox (2006) reported, the

children in this study did not receive any AAC intervention before the age of 24 months. However, the parents from this study also reported similar benefits to their child and family as reported by the current literature. For example, similar to the results of the Romski et al. study (2010), many of the parents stated that they felt their child's speech actually improved as a result of AAC intervention. Additionally, like Bailey, Parette, Stoner, Angell, and Carroll (2006), the parents interviewed for this study expressed that AAC intervention improved their child's ability to communicate, which decreased frustration for both the child and family and led to improved quality of life and relationships for both.

Limitations of the Study

One major limitation of this study was the fact that it had a small and very geographically limited sample size, meaning that it was not very representative of the population as a whole which is comprised of children of many different racial, ethnic, religious, and linguistic backgrounds. Additionally, this sample only included parents of young children who received services at one of two clinics that provided specialized AAC evaluations and interventions. This excluded parents whose children may have pursued AAC intervention by other means without the guidance of clinicians who specialized in AAC intervention. Another limitation was the fact that only mothers of these children were interviewed. Including fathers as part of the study may have provided differing or additional perspectives on the process of AAC acquisition and use. The children of these mothers ranged greatly in age (from age 4; 1 to 20;10) at the time of the interview, meaning that changes over time in technology, service delivery, research, and policies may have occurred leading to more differences in the parents responses. This may have also resulted in the possibility that some of the information these parents provided could differ from

parents' experiences presently with the use of AAC with their young children. Furthermore, even though these parents were given a comprehensive definition of AAC which include no tech and low tech options, most of the parents focused on their experiences with speech-generating devices. Also, due to the transdisciplinary approach used in early intervention, some of the parents' negative experiences with birth to three professionals may have been due to the possibility that the primary care provider was a professional from another discipline. The interviews from this study were also only coded by one researcher, so it is unknown if another researcher's results may have differed significantly. Finally, some of the questions were quite long, making it difficult at times for the parents to accurately interpret the question and address each of its components.

Suggestions for Future Research

Because the sample size was so small for this study, future research would be needed in order to more accurately represent the demographics of parents and their young AAC users. A larger sample population including both mothers and fathers from various cultural, socioeconomic, and educational backgrounds would provide a more comprehensive idea of parents' experiences in this area. The use of multiple coders would also improve the reliability of the results collected from similar studies. Additionally, creating a case history that would provide a more extensive timeline of AAC acquisition and AAC intervention would likely help parents to better organize their responses to interview questions, making comparisons amongst parent experiences less difficult for researchers. Future research involving parents of young children with less complex communication needs such as late talkers would also provide more information about these parents' reactions and experiences with AAC acquisition and

intervention. More research regarding AAC intervention with children under the age of 24 months would be helpful in order to investigate the most effective strategies with the intention of training clinicians and parents to be able to begin implementing AAC as early as possible with young children.

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Table 1. Demographics of the Participants.

Child	Age at time of interview	Diagnosis(es)	Age when first received AAC/ type	No-tech. AAC used (signs, gestures)	Low-tech. AAC used (communication books or boards, picture symbols)	Hi-tech AAC used (Speech-Generating Devices)
1	5;8	Hydrocephalus, Ventriculomegali, Chiari Malformation	2 yrs old/ low tech.	none	picture symbols	[1]Nova-Chat (age 4;5)
2	9;0	Cleft-lip and palate, ADHD	3 yrs/ no tech.	signs	None	[2]Nova-Chat 7 (age 4)
3	10;2	Microcephaly	< 1yr old/ no-tech, low-tech	Signs, gestures/ no-tech, low-tech as child became older	Communication books, picture symbols	SGD, not specified (approximately age 4)
4	4;1	Spinal Muscular Atrophy Type 1	Age 1;7/hi-tech	none	None	[3]Eye Gaze Edge (age 1;7)
5	6;9	Autism, PTSD, Sensory Processing Disorder	3 yrs old/ no-tech	Signs, gestures	PECS, photos	[4]Talk 4, switches
6	6;6	Schizencephaly, colpocephaly, underwent tracheostomy (dependent on ventilator)	2 yrs old/ low-tech	gestures	Picture symbols	[5]Tobii I-15 (age 4)
7	20;10	Traumatic Brain Injury (occurred at age 2)	2 yrs old/ no-tech, hi-tech	Signs, gestures	None	Switches (age 2) [6]Dynavox 3100 (age 4)

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[1] Device produced by Saltillo Corporation
[2] Device produced by Saltillo Corporation
[3] Device produced by LC Technologies, Inc.
[4] Device produced by Enabling Devices
[5] Device produced by Tobii
[6] Device produced by Dynavox

Case History

Child's Name_____ DOB_____

Name of Person completing form_____

Relationship to child_____

Child's diagnosis/diagnoses_____   Age of
diagnosis_____

Diagnosed by whom?_____

Speech and Language Development

What does your child do to let you know he/she wants something?

☐ Looks at object(s)   ☐ Vocalizes, just using sounds
☐ Points to objects   ☐ Uses single words
☐ Brings you to an object   ☐ Uses 2-3 word combinations
☐ Gestures   ☐ Uses simple sentences
☐ Cries   ☐ Tantrums
                                                        ☐ Other _____

If applicable, which of the following best describes your child's speech before beginning intervention services?

☐ Easy to understand
☐ Difficult for parents to understand
☐ Difficult for others to understand
☐ Understood only by family members
☐ Almost never understood by others

1. At what age was your child recommended for therapy related to their communication skills?

2. How long did it take between the assessment and starting therapy?

3. Who provided these services?

4. How frequently did your child receive speech therapy services? (e.g. 1/wk for 1 hour over the course of two years)

5. Was there a part of the AAC system that was initially included in the intervention plan? If not, how long did it take until your child starting an AAC system as part of intervention? (Note: For these purposes, AAC is defined as modes of communication that are used to support or replace speech including sign-language, gestures, communication books or boards, picture symbols, or speech-generating devices and computers.)

6. How did you initially obtain information about AAC?

7. What kind(s) of AAC does your child use? (Please refer to the definition of AAC in question 5 to answer this question.)

8. How was your child's AAC device or system funded?

9. How would you describe your overall experience in regard to funding the device or system?

10. How long did it take for your child to receive his or her device or system?

11. Did this seem reasonable to you?

Interview Questions

Say: *During the interview, I would like to ask you some questions about your child and your experiences related to AAC intervention services for your child. I am trying to gather as much information as I can from parents about AAC intervention for young children. I appreciate your willingness to share your experiences with me. I'll start with a question about your child's communication, and then I'll ask some questions related to your interaction or experience with speech-language therapists and other individuals who may have been involved in providing services related to your child's communication. Ready to begin?*

1. Who first told you about AAC and what were your initial feelings about it?

2. Describe your impression of the speech-language therapist's knowledge about AAC in general.

3. What kind of information did a pediatrician or another healthcare provider or professional provide to you concerning speech and language intervention services?

   3a. How did you feel about the amount of information concerning speech, language, and AAC intervention services available for your child?

   3b. [If they answer that there was not much information]: "Can you tell me how you sought out and acquired additional information?"

4. Tell me about the communication between your child's service providers and you. (If clarification is requested, "For example, how did your child's speech-language therapist keep you informed about what was happening in therapy?")

5. Describe your level of involvement in your child's speech therapy.

6. How were you involved in the decision making process and in choosing the type(s) of AAC intervention(s) your child would use?

7. Describe how the speech-language therapist considered the needs of your child and family?

    a. What kind of activities did the speech therapist incorporate during therapy?

    b. What kind of training did you receive concerning your child's AAC intervention(s)?

    c. What is your overall impression of the services that the speech therapist(s) provided for your child?

    d. (If applicable) How would you describe your experience(s) communicating with professionals, vendors, funding agencies, and other individuals involved with obtaining AAC intervention services

Say: *Before we end, I'm going to ask you some questions about the impact that AAC intervention has had on your child's and your family's life.*

1. Tell me about how members of your family or friends have reacted to your child's use of AAC?

2. Describe any reactions (both positive and negative) that you observed from community members or people in public. How did you feel about this?

3. How has your child's communication with you, your family, and other community members changed since beginning AAC intervention?

4. Overall, describe how AAC intervention has impacted the quality of life of your child and family?

5. Is there any additional information that we did not cover that you think is important for me to know?