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**The Challenges and Perceptions of Raising a Child Who Uses AAC: A
Review of the Literature**

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Abstract

The purpose of this review was to examine the perceptions of parents and caregivers on raising a child who uses augmentative and alternative communication (AAC). Factors and overarching themes in existing literature affecting parent's perceptions were examined and condensed in this review. Seven research studies were chosen for analysis. A variety of common perspectives were found in the research and the conclusions relating to caregiver challenges and thoughts on AAC were categorized, including four thematic categories: problems with the AAC system; barriers to learning AAC; societal, family, and professional influences; and differences among individuals who use AAC. Information gained in this review may be used to improve professional development for speech-language pathologists (SLPs) and teaming between parents and SLPs.

Keywords: augmentative and alternative communication, speech-language pathology, perceptions of parents, challenges

INTRODUCTION

Raising a child with complex communication needs can be socially frustrating and emotionally demanding (Bailey, Parette, Stoner, Angell, & Carroll, 2006). The use of augmentative and alternative communication (AAC) systems can relieve many communication problems but may add additional stressors to the child and the family (Bailey et al., 2006). AAC is defined as a system that “utilizes symbols, aids, strategies, and techniques to supplement—or augment—an individual’s current way of communication” (King, 2010, p. 152). AAC systems encompass a variety of modalities: there are high-tech systems like iPads and speech generative devices, and there are low-tech systems like letter boards and Picture Exchange Communication System (PECS). AAC systems help users express wants and needs, transfer information, establish social closeness, and demonstrate social etiquette in multiple environments (King, 2010).

There is a strong need for evaluation of the perceptions of parents and caregivers on raising a child who uses AAC (Marshall & Goldbart, 2008). Practitioners can recommend a more suitable system for the child, conduct more valuable therapy sessions, and avoid AAC abandonment if they understand the needs of the parents (Johnson, Inglebret, Jones, & Ray, 2006). According to Lasker and Bedrosian (2001), there are several possible reasons for rejection of an AAC system. Avoidance of the device happens when a person and their family refuses to fully participate in training of the system. Device abandonment occurs after a period of device use, when the AAC system may be rejected because of dissatisfaction with the technology, changes in the communicators priorities and needs, or improvements to

the communicators speech that make the device less required (Phillips & Zhao, 1993 in Lasker & Bedrosian, 2001). There is limited data about family views of the factors that are affecting the use of AAC systems (Marshall & Goldbart, 2008; McNaughton, Rackensperger, Benedekwood, Krezman, Williams & Light, 2008). The purpose of this review of literature is to identify what the research says about parent perceptions and to identify limitations of the existing research.

METHOD

Search Strategies

Searches were made for scholarly and peer reviewed journal articles on the perceptions of raising a child who uses AAC. The search terms used to locate the studies were “AAC” “perceptions” “family” “parents” “augmentative alternative communication” “challenges” and “impact.” The search was conducted on online databases ComDisDom, MEDLINE and EBSCOhost. Studies were incorporated in this review if (a) they were published after 2001, (b) if their focus was on the parents or caregivers of AAC users, and (c) if they asked interview questions about the parents’ opinions on AAC devices.

Data Analysis

The data were organized by research questions, purpose of study, research design, sampling procedure, participants, sample size, procedure, results, significant findings, and implications. The conclusions relating to caregiver challenges and thoughts on AAC were categorized into 4 domains, each of which is broken down into several sub-themes.

RESULTS

Search Results

Seven research studies were chosen that followed the specified criteria. Six of the studies used qualitative analysis in the form of semi-structured or in-depth interviews. (Hines, Balandin & Tocher, 2011; Rackensperger, 2012; Bailey et al., 2006; Marshall & Goldbart, 2008; Dew, Balandin, & Llewellyn, 2011; McCorda, & Soto, 2004). One study used an online focus group discussion with questions to spark conversation topics (McNaughton et al., 2008). In McCorda and Soto (2004), the researchers used naturalistic observations and a review of the artifacts collected. The study was chosen because it specifically investigated perceptions of AAC in Mexican-American families, a minority culture where there is limited research on perceptions of AAC. (McCorda, & Soto, 2004). In Hines, Balandin & Tocher (2011), the researchers looked at the perceptions of older parents caring for an adult son or daughter using AAC.

DISCUSSION

Through research of the current literature on perceptions of parents/caregivers of children who use AAC, central themes have been selected to categorize the qualitative data collected and to determine current barriers and facilitators. The factors contributing to parental views on raising a child who uses AAC are presented in four themes, each with three to six sub-themes. The themes comprise of Problems with the AAC Device; Barriers to Learning AAC; Societal, Family, and Professional Influences; and Differences Among Individuals who use AAC. The themes will be reviewed thoroughly in order to find implications for future practitioners and researchers.

Theme 1: Problems with the AAC System

Issues that are most directly related to the AAC systems and their inherent characteristics characterize the domain of Problems with the AAC Device. Four research articles were found to relate to this domain (Bailey et al., 2006; Marshall & Goldbart, 2008; McCorda & Soto, 2004; McNaughton et al., 2008). The factors found in current research that contributed most to parents' perceptions of AAC systems are speed of conversations, malfunctions, vocabulary, and cost.

Speed of Conversations

AAC can be a slow and exhausting form of communication for some children, which caused parents to allow and often encourage their children who communicated faster non-symbolically to put away their AAC devices at home (Bailey et al., 2006). Parents encouraged non-symbolic communication such as body gestures, intonation of vocalizations, and facial expressions because of how quickly they got a message across (Bailey et al.). Familiar communication partners may easily interpret non-symbolic forms of communications, however, unfamiliar communication partners may have trouble deriving meaning from them. One reason many families do not always practice using AAC at home is that there is too little emphasis on using multi-modal communication and too much focus on non-symbolic communication (Bailey et al., 2006if).

According to Marshall and Goldbart (2008), parents frequently expressed concern about their child's speed of conversations. Often, they purposely overlooked recommendations of speech-language pathologists and constantly asked

their child closed ended questions in order to save time. Even when parents knew that their child was capable of communicating more and that using complex sentences was educational and beneficial, they often found situations where they purposely cut their son or daughter short for the sake of time (Marshall & Goldbart, 2008).

McCorda and Soto (2004) found parents were concerned about their child's slow speed of conversations when AAC was used. Depending on the physical limitations of the child, communicating with AAC may seem inefficient compared to other modes of conversation. Mexican- American families often chose speed over more complex conversations (McCorda & Soto, 2004).

One reason that AAC can be so slow is the level of effort many children have to put forth to communicate (McNaughton et al., 2008). Due to severe physical/motor limitations, children may have difficulties accessing messages stored in an AAC system. Therefore, users may need alternative access methods, or adapted equipment to access their system. In McNaughton et al (2008), a mother described her son's use of the AAC device as "effortful" because her child's physical strength and mobility made it difficult to even use a switch device. However in comparison to verbal speech the device made communication much easier physically for many children (McNaughton et al., 2008). In McNaughton et al (2008), a participant reported that she would get irritated and angry with communication partners who would walk away before her child finished preparing his message. Parents who are more understanding of the extra time their child takes to communicate find it frustrating when others are less understanding. A child requires frequent and consistent training and practice to increase efficiency at using a device, but if

speed of conversation is always a concern and the child's time is cut short, his or her proficiency and speed using the device will not improve.

Malfunctions

When working with an electronic device, there is a possibility it will malfunction. A device malfunction can be upsetting to the user if the device is heavily relied on for education, safety, and social participation. In Bailey et al. (2006), research showed parents were disappointed by the length of time a device needed to be in the shop for repair. The parent also complained about not having a technical support number to call during a device malfunction (Bailey et al., 2006).

In addition to being discouraged by the length of time it took to repair a device, parents were also discouraged by how frequently the AAC device malfunctioned (Bailey et al., 2006). Malfunctioning devices prevented users from communicating in times of need. For example, in McCorda and Soto (2004), a participant reported that without their device, her son could not participate fully in his IEP meeting and plans had to be rescheduled, delaying progress.

Parents consistently blamed technical breakdowns as a leading cause for their frustration, and linked malfunctioning devices to interruptions in learning, limitations in communication, and device abandonment (McNaughton et al., 2008).

Vocabulary

Participants in four studies emphasized their concerns with vocabulary (Bailey et al., 2006; Marshall & Goldbart, 2008; McCorda & Soto, 2004; McNaughton et al., 2008). In Bailey et al. (2006), parents voiced a need for their

child to access vocabulary that would make it easier to carry on a conversation. Although parents described wants and needs of everyday items to be the most common communication topics at home, many parents found it challenging to talk about events that happened outside the home (Bailey et al., 2006). Parents were often disappointed by limitations for word storage on the AAC systems. Most parents believed AAC assisted their child's ability to converse about complex issues and abstract ideas but due to limitations in vocabulary it did not completely resolve the problem (Marshall & Goldbart, 2008).

Most parents were happy with the increased opportunities that AAC brought in the form of vocabulary. However, they found it very time consuming and frustrating they had to program in each new word in order for their child to expand his expressive vocabulary (McCorda & Soto, 2004). An issue that makes AAC less accessible for use at home in Mexican-American households is the lack of vocabulary built into the system that is appropriate for bilingual families. A participant was disappointed in the practicality of vocabulary available to her daughter (McCorda & Soto, 2004).

Parents of children who use AAC agreed that AAC required a high level linguistic competence. Linguistic competence refers to the innate knowledge of grammar and what allows a person to make meaning out of sounds and words (Fernandez & Smith Cairns, 2010). For example, most people can identify if a sentence is contradictory or doesn't make sense, even without a formal lesson on the grammar used in the sentence (Fernandez & Smith Cairns, 2010). For many children with limited language proficiency and experience, it could be challenging to select appropriate vocabulary and to create

understandable sentences (McNaughton et al., 2008).

The capabilities of vocabulary on AAC systems often pleased parents. Parents were thankful for the technological supports built into many AAC systems. For example, a participant was happy her child's device had an icon-prediction system because it helped her daughter learn new vocabulary (McNaughton et al., 2008).

Cost

For many parents, the cost of AAC systems is a major concern (McNaughton et al., 2008). More specifically, parents were concerned about obtaining funding for the best AAC systems for their children (McNaughton et al., 2008). One example of concern came from a family who believed that the only way to use Medicaid for funding was if they wrote a report stressing their need for safety purposes. In their situation, if it were mentioned the device was for education the school would be expected to pay and could deny that device and choose another that may only be beneficial for current IEP goals, with less room for growth. Parents felt stressed by the need to strategically and carefully word these requests.

In a separate study, parents were under the misconception that if the school district paid for certain devices their child would not be allowed to take them home, thus making them pay out of pocket for equipment that was accessible in the home environment (Marshall & Goldbart, 2008). It can be time consuming, stressful, and intimidating for parents to fill out paperwork for grants or reimbursement on devices, despite how funding systems and special needs laws have been improving (Marshall & Goldbart, 2008).

Theme 2: Barriers to Learning AAC

There are several barriers in learning with and about an AAC system. The research completed in this area found that accessibility of AAC systems within various environments, misconceptions on speech therapy services related to AAC capabilities, training and programming, and the ease of use and care are all contributing factors in parents' perceptions of raising a child who uses AAC. Five studies conducted interviews or discussions to determine how these barriers affected the parental views on AAC. (McNaughton et al., 2008; Hines et al., 2011; Bailey et al., 2006; Marshall & Goldbart, 2008; McCorda & Soto, 2004).

Accessibility

According to McNaughton et al. (2008), participants believed it was very important for children to have constant and consistent access to their AAC devices in order to be comfortable with them and maximum proficiency. The problem for many individuals who require a wheelchair for ambulation is that the devices can only be used when seated in their electric wheelchair (McNaughton et al., 2008). If the child went somewhere that was not wheelchair accessible, like relative's and friend's homes and parks, the device could not be used (McNaughton et al., 2008). Also, users of AAC who do not have a mounted device may find the device less accessible in certain situations because devices could be heavy or bulky. According to the results of McNaughton et al. (2008), it is very important for SLPs to interview families to find out where they desire to use AAC before choosing a device.

Misconceptions on Speech Therapy and AAC Capabilities

Hines et al. (2011) addresses the perceptions of families who did not pursue the use of AAC because they believed that the difficulties of raising an older son or daughter with autism were inevitable and unfixable. Most parents' reasons reflected an incorrect understanding of the opportunities that AAC could provide their child. Regular use of an AAC system can improve a child's communication competence, expressive vocabulary, memory, and sentence structure (Bailey et al., 2006). According to Hines et al. (2011), many parents did not seek speech therapy for their children because they believed therapists would be focused solely on articulation rather than language development or AAC. A semi-frequent concern of parents is whether their child is getting premium services from their SLP. Parents recognize the limitations of professionals, but worry whether they are getting optimum quality and quantity of therapy (Hines et al., 2011).

Training and programming

After selection of an AAC device, a significant amount of time must be invested in programming it for the individual's needs, and training the individual on how it could be used (Bailey et al. 2006). According to Bailey et al. (2006), parents expected programming for an AAC system to be fully provided by professionals and school personnel. However, with so many students on an SLP's caseload, she or he may only have an hour a week to teach the child about the system. Parents are then required to help their child further learn at home (Bailey et al. 2006).

Programming barriers also influenced parents' perceptions on the devices. Many parents were concerned with the

responsibility and time involved in programming a device (Bailey et al., 2006). Programming was described as a burden and families often felt unprepared and would have benefited from more training. Concerns on training were proportionally related to the technological level of the device; training on the higher tech devices concerned parents the most. Even once the child is knowledgeable on the device, parents want readily available technical support. One parent voiced his stress from the lack of information and training for his son's device. The analysis of interviews showed that families want more education and training on the use and programming of AAC devices. Specific needs included more information on how to integrate the use of the AAC device in the community and home (Bailey et al., 2006).

According to Marshall and Goldbart, (2008), information on the use of AAC systems should be available to parents at various stages of their education. It was found that families could only absorb so much training at once and may need information repeated back to them during several meetings. Parent's often felt that the need for on-going AAC intervention was not made explicit during the introductory training period. This misunderstanding could affect the quality of the child's educational development (Marshall & Goldbart, 2008).

According to McCorda and Soto (2004), the Mexican-American families studied perceived that AAC was complex and mysterious. The majority of family members perceived that it required too much training and knowledge to program or repair the equipment. They did not think they had the skills or knowledge needed to anticipate the next steps in their child's communication development (McCorda & Soto, 2004).

According to McNaughton et al. (2008), a lack of confidence with computers and similar technologies greatly influenced parents' attitude towards AAC. Parents who were intimidated by computers had to overcome the additional challenges of programming. Parents stated that they learned how to operate the AAC device by reading manuals, attending trainings from the speech language pathologist, and using free courses and telephone support from manufacturers. Those who did not feel the training that they received was very helpful complained that the information was not detailed enough and lacked information on organizing vocabulary and programming the device (McNaughton et al., 2008).

Many parents were forced to take the primary responsibility of programming and teaching their child how to use a new device, but many also were satisfied with the help they received from the SLP (McNaughton et al., 2008). A mother commented on how much the SLP taught her child that she could not. The SLP taught different ways to express one's self and how to use proper sentence structure and pre-verbs. She was very impressed with the level of respect the SLP showed for her son and how she believed in his abilities (McNaughton et al., 2008).

Both parents and children found that training offered from device manufacturers was an important resource (McNaughton et al., 2008). Families had many positive perceptions on the assistance they received from technical representatives on manufacturers' telephone assistance (McNaughton et al., 2008).

Ease of Use and Care

Bailey et al. (2006) identified "ease of use and care" as one of the four most reported areas of satisfaction. A system's "ease of use and care" is determined by

how much effort a client and family has to put forth to become comfortable with navigating the system and keeping it running. Parents were appreciative of devices that were easy enough to maintain that even their children could learn how to charge them and use them. Parents were thankful that SLPs made caring for devices a goal in therapy, teaching clients how to charge them themselves. Parents expressed that the large amount of time they spent stressed while familiarizing themselves with the AAC system could have been reduced with better training. Although there are difficulties related to the care and use of AAC systems, parents agreed that the AAC systems were a necessary component to their children's communication and worth learning to care for and use (Bailey et al., 2006).

Theme 3: Societal, Family, and Professional Influences

External perceptions and attitudes towards AAC have a large impact on how parents and users feel about using communication devices (McCorda & Soto, 2004). Discouragement or negative attitudes from others associated with AAC can affect the user's confidence and level of use. This domain examines how four sub-themes affect perceptions of raising a child who uses AAC. The sub-themes are family member expectations, intimacy of device, support systems, and acceptance from familiar and unfamiliar communication partners. Of the seven studies examined, six offered insights in the areas of societal, family and professional influences (Bailey et al., 2006; Marshall and Goldbart, 2006; McCorda & Soto, 2004; Rackensperger, 2012; McNaughton et al., 2008; Lasker & Bedrosian, 2001).

Family Member Expectations

In Bailey et al. (2006), parents were disappointed because of their initial expectation of immediate benefits from the AAC system. Much of this distress was attributed to the difference in outcome expectations of school professionals and parents. Parents desire to be acknowledged for the burden they are under and want to feel that their child's communication issues are a priority to professionals (Bailey et al., 2006).

Marshall and Goldbart (2006) found that parents expect to have their child's personality taken into account on AAC related decisions. Practitioners also must understand that families desire to develop different levels of expertise. Many families are comfortable with knowing only the basics of AAC use, while others will always wish to know more. Communication between the family and professionals about their expectations is necessary for effective teaming (Marshall & Goldbart, 2006).

Intimacy of the Device

According to McCorda and Soto (2004), Mexican-American families did not always consider the speech generative device to be equal to talking. They found it impersonal and only believed it to be important for special circumstances, like with new communication partners. One father did not allow his son to use the Dynavox™ in his home; he felt that unaided communication systems, such as eye-gaze, body posture, and facial expressions, were more intimate and natural. Despite his preference, he wanted his son to learn the device for use with less familiar or less intuitive communication partners. Another father considered his daughter's AAC device to be a barrier between communication partners as it barred more

intimate contact. He compared the impersonality of the device to be similar to the Internet. He stated that because he wouldn't talk "machine to machine" it was not a good enough goal for his daughter (McCorda & Soto, 2004).

Support Systems

A participant who uses an AAC system in Rackensperger (2012) attributed her academic success to family accommodation and support in aiding homework completion. Homework is a gigantic potential barrier to success academically, and the participant was thankful that her siblings helped physically write out her homework assignments after she communicated to them her answers through the AAC system. A family without helpful siblings may feel overwhelmed with the amount of homework they need to help with. Parents who had more time and the motivation to advocate for their child's education usually saw more academic success and were more satisfied with their child's improvements. Rackensperger's study reinforces the need to instill in parents the notion that their child with complex communication needs can be successful academically and attain a diploma.

Teaming between family, teachers, and professionals is most effective when participants felt included, respected, and valued (Rackensperger, 2012). School systems should make an effort to understand the family and give opportunities to contribute (Rackensperger, 2012).

Even with professional help, parents may wish for additional support from families in similar positions as theirs (Bailey et al., 2006). Bailey et al. (2006) found that parents desired more information on finding support groups.

According to Marshall and Goldbart, (2008), many parents believe that speaking with other parents of children with communication difficulties is useful and informative. They believe that those who have been through the struggle are the most knowledgeable (Marshall & Goldbart, 2008).

Bailey et al. (2006) discovered that families across ethnic groups desire some extent of involvement in AAC decision making with professionals. According to McNaughton et al. (2008), many parents did not feel satisfied with their level of input in selecting an AAC device for their child. One family reported that it was very difficult to get a thorough evaluation for their daughter, and the professionals gave little support and no information on AAC. Parents described the lack of AAC trained professionals as one of the barriers that hinder teaching and learning process for AAC. This shortage of trained professionals often resulted in delayed and/ or inappropriate interventions. Delayed intervention can be very detrimental to a child because it can be much harder to integrate AAC later in the child's development (McNaughton et al., 2008).

Parents reported feelings of isolation and frustration when they struggled with their school system (McNaughton et al., 2008). One family was frustrated with the limited knowledge that their SLP exhibited. The mother believed the SLP was not productive and wasted therapy time, most likely because of her inexperience. The father believed his daughter's SLP should have admitted a lack of knowledge in the area and referred her to a specialist (McNaughton et al., 2008).

Acceptance from Familiar and Unfamiliar Communication Partners

All seven participants in the Bailey et al. (2006) study perceived AAC as a successful facilitator in helping their children interact with a variety of communication partners. The AAC system bridged the communication gap between both unfamiliar and familiar partners when they showed a level of respect and acceptance for the different communication style (Bailey et al., 2006).

Statistical analysis performed by Lasker and Bedrosian (2001) found that family members ranked AAC digitized speech mode as the most favorable mode of communication for their family member with Aphasia. A large percentage of peers also ranked digitized speech as a preferred method of communication as opposed to watching the speaker "struggling" with aphasic speech. This finding indicates that unfamiliar adult peers are accepting of AAC, and that extreme anxiety over whether AAC may be accepted by unfamiliar communication partners is not always warranted (Lasker & Bedrosian, 2001).

Obtaining acceptance of the device within the school system is also crucial for optimum support and use (McNaughton et al., 2008). A father in McNaughton et al. (2008) emphasized that having a recommendation from a professional in the school system before purchasing a device would make the devices acceptance easier.

According to McNaughton et al. (2008), support from classmates is also important in encouraging communication. A mother noticed the impact that negative attitudes towards AAC had on her child. She believed that if more clubs and groups were available to her child he would have more to talk about with peers and would be more accepted by them. When dealing with difficult people parents believed it was part of their responsibility to teach others about acceptance and advocate for

their children, but were often discouraged due to rude comments. The more equipment their children used the stranger they seemed to outsiders (McNaughton et al., 2008).

Theme 4: Differences Among Individuals Who Use AAC

Besides the obvious differences that individuals with different disorders and diagnoses have, there are several factors that can change a mother or father's opinion on raising a child who uses AAC to communicate. Cultural differences, the child's level of independence, and the age of the child are three topics discussed in current literature. Five studies (McCorda & Soto, 2004; Bailey et al., 2006; Marshall & Goldbart, 2008; McNaughton et al., 2008; Hines et al., 2011) provide insights on how these differences among individuals may affect parent perceptions.

Cultural Differences

As the Spanish speaking population grows larger in the US, it is important to acknowledge the differences that Latin cultures and other minority cultures have on speech therapy in regard to AAC (McCorda & Soto, 2004). According to McCorda & Soto (2004), many families are overwhelmed by the high expectations from speech-language pathologists of parental participation in assessment and intervention. Results of the study found that social class, family members' literacy levels, cultural values, and previous related experiences may influence the amount of participation from parents. These barriers may be even more difficult to overcome for minority families. Parents report they feel like they do not have enough authority to claim their rights if they believe the partnership between the family and

higher-status professionals are not equal (McCorda & Soto, 2004).

An often forgotten barrier that is magnified by cultural and language differences is the transparency and relations of icons and picture cues (McCorda & Soto, 2004). Often manufactures organize icons by pairing a picture of an object with the letter it starts with. For less common languages than English, the device may require a lot of time-consuming customization. The semantic associations of the icons could also provide a challenge, as they are preprogrammed based on the dominant culture. Certain symbols may be very ambiguous and unclear for the children and their families (McCorda & Soto, 2004).

Mexican-American families recognized that the language system, including dialect, picture symbols, and order of symbol combinations, of the device was its largest obstacle to regular use at home (McCorda & Soto, 2004). Most of the families studied spoke primarily Spanish, yet the device synthesized English speech. Spanish speaking families studied reported that they did not perceive that the AAC device improved the fluency or speed of conversations in the home. This may be due to literacy and language differences between family members. The child may be learning English at school, therefore the AAC system uses English spoken output, but at home cannot communicate fully with family and friends. Even if a family member has a strong understanding of English, the mechanical voice output may be difficult to interpret because English is not their first language. In this case non-verbal communication may seem more effective (McCorda & Soto, 2004).

Independence

One of the most commonly reported areas of satisfaction with AAC devices in Bailey et al. (2006) is “increased independence and improved communicative competence.” With AAC, children improved in their ability to schedule their day and organize activities of daily living (Bailey et al., 2006). Parents of children with limited communication regularly feel isolated and exhausted from the additional responsibility in acting as an interpreter for their children (Marshall & Goldbart, 2008).

Although independence is a goal for every family, rapid changes in dependency can also leave parents feeling confused about their role in parenting (McCorda & Soto, 2004). After first introducing an AAC device parents may have to make changes in how they are involved with their child's education. One mother reported feeling threatened by the AAC device's capabilities. After her daughter became a better communicator, the teachers and therapists stopped sending home as many progress notes and messages, and the mother perceived she was no longer included (McCorda & Soto, 2004).

In the McNaughton et al. (2008), the highest level of success reported by many parents was watching their child independently use an AAC device to communicate. One mother described her emotions when she heard her daughter first make a sentence without coaching. The relief of not having to probe her daughter with questions and strain to understand her unintelligible speech made the mother so happy she was brought to tears. Another mother loved how the device allowed her son to jump into conversations whenever he desired. Parents were also pleasantly surprised when the AAC device aided in independent learning. One father noticed and was excited that his daughter's vocalizations

improved just from playing with her device and listening to it repeat words (McNaughton et al., 2008).

Age of Child

According to Hines et al. (2011), parents were interviewed to provide insight into the experience of mothers and fathers caring for an adult with autism who has received an AAC system to communicate.

Only two of the thirteen families of Hines et al. (2011) reported active use of AAC systems, most had abandoned their AAC system over the years, although most reported a want for more meaningful conversation. Many families reported that conversation, both with and without the AAC system, was emotionally demanding, exhausting, and a burden. The article's implication to service providers is that more on-going and as-needed support and information needs to be provided to families of adults with autism (Hines et al., 2011).

As a child grows, relationships with peers and communication partners may change (Dew et al., 2011). A mother in the McNaughton et al. (2008) study noticed and was saddened by how peer relationships grew harder for her child as he grew older and entered a clique filled high school. She believed kids were more willing to play with her child in elementary school. The mother became less content with her child's communicative participation when he was a young adult than she was when he was a child (McNaughton et al., 2008). According to Hines et al. (2011), it is important that speech therapy is utilized throughout a client's adult life.

IMPLICATIONS

Implications for Speech-Language Pathologists

No matter the perceptions or attitudes of the parent with regards to an AAC system, it is the SLPs responsibility to recommend whichever AAC system is best for that child (Marshall & Goldbart, 2008). However, in order to promote successful implementation and maintenance of AAC systems, practitioners need to learn more strategies for working with parents. Speech-language pathologists need to have a plan for on-going and as-needed support for maintenance of the AAC system in order to address family concerns, device upkeep, identify and program additional vocabulary (Marshall & Goldbart, 2008), and ultimately avoid AAC system abandonment (McNaughton et al., 2008).

Successful implementation and maintenance of an AAC system requires collaboration amongst all stakeholders (McNaughton et al., 2008). If possible, practitioners should work with AAC users to identify their goals when using the AAC system. Speech-language pathologists should align their intervention goals with the goals identified by the AAC user and share the information with all invested parties including teachers and parents. Communication between team members can help divide the workload and allow for faster progress (McNaughton et al., 2008).

Results of research indicate a relationship between users' cultural backgrounds and their acceptance of and progress with AAC (McCorda & Soto, 2004). SLPs need to be aware and sensitive to the influences of the users' culture when choosing and programming an AAC system. Additionally, different cultures will require different service delivery methods and support. Professional stakeholders, such as SLPs, school personnel, and case managers, need to work to remove culturally biased

communication practice barriers in the area of AAC (McCorda & Soto, 2004).

AAC is an area within the field of speech-language pathology that impacts individuals of all ages, disabilities, severities, and cultural backgrounds. Therefore, all SLPs should evaluate their own professional knowledge and skills with regards to AAC systems. Those who do not feel confident with their knowledge and skills in AAC should seek additional training in current AAC technologies and evidence based practices for evaluation and implementation of AAC systems. There are an overwhelming number of parents who were frustrated by inexperienced SLPs (McNaughton et al., 2008). The parents' frustration may indicate that more SLPs and professional stakeholders need to research and learn about AAC in order to provide the appropriate support and information to key stakeholders.

Research showed families were more likely to abandon the AAC system when there was miscommunication between the SLP and parents (Hines et al., 2011). More specifically, parents tended not to share their concerns or challenges about the AAC device (McCorda & Soto, 2004). In order to address instances of miscommunication, the SLP could collect information from the parent using a survey. SLPs need to work to understand parents' perceptions of AAC, so that once understood, the SLP can work with the family to address their concerns and lack of training. One way to learn and record how parents feel is through a survey that is constructed based on the fifteen themes found in literature. The survey, at the end of this review, can be administered to parents in order to understand their perception of AAC.

Implications for Parents

McNaughton et al. (2008) recommends that parents of AAC users seek out high-quality services and become experts in their child's technology. Parents can become advocates for their child's best interest by continuing education on global AAC topics or the particular AAC system their child uses, joining support groups for parents of children with similar disabilities, seeking out trained professionals in their area, and contacting SLP organizations for resources (e.g., American Speech-Language-Hearing Association). If parents utilize support groups they may feel less isolated in their struggles. Parents should also learn how to create motivating opportunities for their child to learn and use AAC.

Parents who are unsatisfied with their child's current means for communication and/or AAC system need to consult the SLP before disregarding recommendations. Parents need to report any changes in their child's communication capabilities, needs, and/or the AAC system to professionals immediately so assistance or modifications can be given.

ADDITIONAL CONSIDERATIONS

As technology rapidly changes, so does the type of AAC systems that are available to assist a person with complex communication needs. More data about caregivers' perceptions are needed to continue to stay up-to-date on the issues with AAC within the family dynamic (e.g., changing technology, availability of resources, support for AAC use and maintenance). Collecting more data would also aid in training professionals on how to address issues in order to better meet both AAC users' and their families' needs.

Individuals with complex communication needs are now more likely to outlive their parents, often placing the

caregiver responsibilities on siblings (Dew et al., 2011). There is a need to study the perception on AAC of siblings, study strategies to feel comfortable with AAC systems, and study strategies to foster use of the AAC system. In these cases, siblings step into a 'parent' role. The success of a sibling caregiver relationship is associated with several different factors. Dew et al., (2011) found in their study that siblings who lived and played together growing up were more welcoming in caring for their brother or sister. If the child were introduced to AAC early in life he or she would be more able to develop an intimate relationship with siblings. Siblings should be brought into the intervention process earlier and trained on strategies, programming, and troubleshooting. For those with communication impairments, remaining in contact with family can be aided by AAC, but not all forms work well over distances (Dew et al., 2011). Additional research is needed on sibling perspectives about their role as future caregiver with regards to communication and AAC.

CONCLUSION

When delivering AAC services to a family, every family must be looked at individually and uniquely to receive the best support. However, searching for common themes in research can help practitioners be better trained and prepared to address parents' typical concerns with raising a child who uses AAC and change the parents' opinion of AAC for the better. Current evidence shows parents have a clear need for consistent and on-going AAC training and programming, technical support, professional support systems and teaming, cultural acceptance and modifications, and help applying for funding for AAC systems.

Taking on the viewpoint of parents who are raising a child who uses AAC can be useful in successfully implementing AAC practices and avoiding device abandonment.

NOTE

1. 'Parents' can include other primary caregivers of a child, such as foster parents or grandparents.

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Survey for Parental Perceptions of AAC

The questions below are intended to help parents communicate their concerns to speech language pathologists. Please answer all questions honestly. You may circle N/A if the question is not applicable to your situation.

1. Do you believe that your child's AAC system allows for efficient conversation speed?

Yes No N/A Explain: _____

2. Are you disappointed in the amount of malfunctions associated with your child's AAC system?

Yes No N/A Explain: _____

3. Are you frustrated by limitations in vocabulary on your child's AAC system?

Yes No N/A Explain: _____

4. Are you satisfied with the amount of financial aid provided for your child's AAC system?

Yes No N/A Explain: _____

5. Are you pleased with the convenience and accessibility of your child's AAC system?

Yes No N/A Explain: _____

6. Are you content with your knowledge on speech therapy and AAC capabilities?

Yes No N/A Explain: _____

7. Do you believe that you and your child have received enough training to efficiently use your child's AAC system?

Yes No N/A Explain: _____

8. Do you find it easy to use and care for your child's AAC device?

Yes No N/A Explain: _____

9. Were your expectations of AAC fulfilled?

Yes No N/A Explain: _____

10. Does communication through your child's AAC system feel impersonal?

Yes No N/A Explain: _____

11. Are you happy with the level of support your child receives for AAC help?

Yes No N/A Explain: _____

12. Do you believe that communication partners respect and accept your child's AAC system?

Yes No N/A Explain: _____

13. Do you believe that your culture negatively effects AAC use for your child?

Yes No N/A Explain: _____

14. Do you believe that AAC increased your child's level of communication independence?

Yes No N/A Explain: _____

15. If your child who uses an AAC system is now an adult, does his or her age change the amount of time the AAC system is used?

Yes No N/A Explain: _____