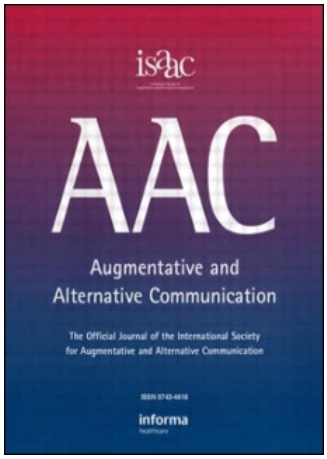

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"A child needs to be given a chance to succeed": Parents of individuals who use AAC describe the benefits and challenges of learning AAC technologies

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"A Child Needs to be Given a Chance to Succeed": Parents of Individuals who use AAC Describe the Benefits and Challenges of Learning AAC Technologies

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Seven parents of individuals with cerebral palsy who used augmentative and alternative communication (AAC) devices participated in a focus group discussion on the benefits and challenges of learning AAC technology. The focus group was conducted on the Internet over a 9-week period. Six major themes emerged from the discussion: (a) issues in the selection of AAC technology; (b) knowledge and skills needed to use AAC technology; (c) barriers to learning AAC technology; (d) teaching the individual; (e) educating society; and (f) recommendations to others. Important supports to learning how to make effective use of AAC technology included opportunities for individual exploration, use of the technology in role play activities, organized instruction, and opportunities for functional use in the community.

Keywords: Augmentative and Alternative Communication; Assistive Technology; Cerebral Palsy; Focus Group; Internet; Learning; Instruction; Parent

INTRODUCTION

AAC technologies, including speech generating devices, offer new communication opportunities for individuals with complex communication needs (Beukelman & Mirenda, 2005; McNaughton & Bryen, 2002). Despite the potential communication "magic" of AAC technologies, there are significant learning costs (Beukelman, 1991; Light & Lindsay, 1992). Individuals must learn not only how to operate what is sometimes a sophisticated computer-based device, but also how to use the technology to successfully participate in communicative interactions (Light, 1997). Typically the device is just one part of an individual's AAC system, which may also include the use of signs, gestures, speech approximations, and picture/word displays, to communicate in different situations and with different communication partners (Beukelman & Mirenda, 2005).

It is vital for a child who uses AAC and his or her family to be active members of the intervention team, so as to support the learning process and promote successful outcomes (Parette, Huer, & Brotherson, 2001). Past research (Angelo, Kokosa, & Jones, 1996; Goldbart & Marshall, 2004) has provided information on the benefits and challenges to a child's use of AAC, as perceived by parents. At present, however, there is only limited information concerning parents' perceptions about the process of learning to use AAC technology. The purpose of this study was to gain a better understanding of parents' perspectives on the technology learning experiences of children who use AAC.

METHOD

A focus group methodology was implemented in order to gain a better understanding of the perspectives of parents of individuals who use AAC technology. In this study, a modified approach was used in order to conduct the focus group discussion

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on an Internet bulletin board system (Rackensperger, McNaughton, Krezman, Williams, & D'Silva, 2005). Past research provides evidence that information obtained from online focus groups can be comparable in quantity and quality to that provided by face-to-face focus groups (Underhill & Olmstead, 2003). Using an online approach enabled the participants to contribute to the discussion at a time and place that was convenient for them, regardless of geographic location or time of day (Williams & Robson, 2004).

The current study was guided by the principle, "Nothing about us without us" (Charlton, 1998), which meant that the research team included individuals who used AAC (TR and MW), as well as a family member of an individual who used AAC (CK). The moderator for this focus group, TR, was an individual who used AAC. She brought personal knowledge and insight to the development of the questions used in the focus group script, and to the ad-libbed questions used to ask participants to expand on comments they had posted to the discussion. She had a demonstrated record of achievement in scholarly activities and presentations on the use of assistive technology. By involving an individual who used AAC to lead the focus group, we gained a perspective different from that obtained in past research projects led by university-based researchers who did not use AAC.

Participants

Participants were selected based on the following criteria: All were the parents of individuals who: (a) had cerebral palsy, (b) had speech that was inadequate to meet their daily communication needs, and (c) used AAC technology as part of their AAC system to communicate with others. Participants were recruited through postings to an email listserv, ACOLUG.[1] ACOLUG has more than 450 subscribers, including individuals who use AAC, family members, and professionals with an interest in AAC.

Description of Participants

All eligible respondents who completed the informed consent procedures (two men and five women) participated in the study. The education levels of the participants ranged from completion of high school to the completion of a doctoral program. A summary of the demographic information for each participant is included in Table 1. The participants described their children's use of a number of different AAC devices including the Dynavox 3100™, the Pathfinder™, and the Liberator™. At the time of the study, the children ranged in age from 6 to 30 years of age.

TABLE 1 Demographic characteristics of the participants and participants' children.

	Daniel	Fred	Katrina	Barbara	Julie	Rosie	Carla
Parent education	Some college	DDS degree	Two-year degree	N/R	Ph.D.	B.Sc.	N/R
Child age	13	6	30	20	20	17	23
AAC system	Pathfinder™ with Unity, word/ picture board, eye gaze, facial expression, vocalization	DynaVox™ 3100, speech, gestures	Liberator™ with Unity, speech, facial expression	PathFinder™, facial expression, eye gaze, vocalization	Delta Talker™ with Unity, eye gaze, vocalization	AlphaSmart™ with word prediction, picture board, sign language (Signing Exact English)	Pathfinder™ with Unity, natural speech
Access	Single switch scanning, head	Finger	Single switch (Morse code), left heel	Single switch scanning	Optical head pointer	Finger	Finger
Mobility	Power wheelchair	Stroller type wheelchair, crawling	Power wheelchair	N/R	Power wheelchair	Manual wheelchair	Power wheelchair

Materials

The focus group discussions were conducted using Phorum 3.3.2,[2] a password-protected Internet bulletin board system that allows multiple individuals to read and contribute to text-based discussions on a number of topics. The research team developed an interview guide (Vaughn, Schumm, & Sinagub, 1996) for the questions posted by the moderator at the focus group discussion site. The questions focused on four areas relevant to the consideration of learning: (a) the content to be learned, (b) the characteristics of the learner, (c) the nature of the instruction, and (d) the type of assessment used (cf. Jenkins, 1979). Additional questions were developed to probe for more detailed information about the process of learning to use AAC technology, as well as to obtain specific recommendations for education and rehabilitation professionals regarding supports for learning to use AAC technology. See Appendix A (http://mcn.ed.psu.edu/dbm/SupportMaterials/AppA_AppB.htm, http://mcn.ed.psu.edu/dbm/SupportMaterials/AppA_AppB.pdf) for a complete list of questions as they appeared at the website.

Procedures

Once participants had provided their consent to participate, they received a brief email questionnaire. The questionnaire was used to collect demographic information about the parents as well as their children's previous and current use of AAC systems.

Traditional procedures recommended for focus group activities (Vaughn et al., 1996) were used throughout the discussion, with minor modifications as required via the Internet (Rackensperger et al., 2005). Prior to the discussion, participants received training in accessing and posting messages to the site. After all participants had completed the necessary training, the moderator presented the first discussion topic (see Appendix A). A new topic was introduced on the site every 4 to 7 days.

During the 9 weeks, the participants posted a total of 30,587 words to the site. 4 of the 7 participants posted responses for all 11 questions posted by the moderator, 2 posted to 10 questions, and 1 posted to 4 questions. In addition to addressing the questions posed by the moderator, participants posted informal comments in reaction to the posts of others ("We had a similar experience"), and a small number of informal questions ("What kind of AAC device does your child use?"). Parents also posted three questions as *new topics* at the discussion site: how to help their child deal with inexperienced communication partners, how to support interactions between their children and other individuals who use AAC, and how to deal with inappropriate comments from the public.

The moderator posted the 11 questions and an additional 41 messages summarizing the ongoing discussion, encouraging participation, and thanking participants for their comments. Approximately 8 weeks after the final posting, a letter was sent to all participants thanking them for their participation and summarizing the themes and sub-themes discussed on the site. This letter served as a *member check* (Vaughn et al., 1996), giving participants the opportunity to read the summary and validate it as an accurate representation of the discussion. Participants were also asked to provide additional contributions to the discussion themes as desired. All seven participants confirmed that the summary was accurate and complete, and no additional comments were made.

Data Analysis

Data analysis was a five-step process. Step 1 involved unitizing the participants' contributions to the discussion pages according to Fraenkel's (2006) definition of a *thought unit* as the "smallest meaningful piece of information" (p. 251). Inter-rater agreement on the identification of thought units was 99%. Participants posted an average of 120 thought units (range = 30 – 181). During Step 2, the unitized data were organized in a table that contained four columns: (1) participant's identification code; (2) title of the discussion strand in which the posting was entered; (3) numeric code (for the coding theme); and (4) unitized datum (i.e., participant's comments).

In Step 3, coding themes were developed post hoc based on a review of the participants' contributions, and operational definitions were created for each theme (Vaughn et al., 1996; Yin, 1994). These operational definitions were used to code samples of text, and the operational definitions were reviewed and modified, as necessary. Six major themes were identified: (a) issues in the selection of an AAC device; (b) knowledge and skills needed to use AAC technology; (c) barriers to learning AAC technology; (d) teaching the individual; (e) educating society; and (f) recommendations to others. See Appendix B (http://mcn.ed.psu.ed./dbm/SupportMaterials/AppA_AppB.htm, http://mcn.ed.psu.ed./dbm/SupportMaterials/AppA_AppB.pdf) for operational definitions of the coding themes.

In Step 4, the third author (EB) assigned a numeric code to the unitized data, based on the

content of the statement and the operational definitions of the themes. After all of the data were coded, a reliability check was performed. Twenty percent of the data were selected at random to be coded by a second coder, a graduate student in the Department of Communication Sciences and Disorders, who had received training in the operational definitions of the coding themes and coding procedures. An agreement score of .82 was calculated using Cohen's Kappa (Suen & Ary, 1989). Landis and Koch (1977) have suggested that Kappa values above .81 can be considered as almost perfect. Disagreements were resolved through discussion.

RESULTS

The results of this study are presented as per the five major coding themes of interest. A summary of themes, sub-themes, and examples in Table 2.

Selection of an AAC Device

The first major theme parents discussed dealt with selecting an appropriate AAC system for their children, including two sub-themes: challenges to assessment and decision-making, and supports to assessment and decision-making.

TABLE 2 Coding themes, subthemes, and examples of issues discussed by participants.

Themes	Subthemes	Examples
AAC device selection	Challenges to assessment and decision-making	• Lack of family involvement • Difficulty obtaining services • Difficulty obtaining funding
	Supports to assessment and decision-making	• School involvement • Family members assuming a leadership role
Knowledge and skills needed to use AAC	Operational competence	• Technical operation and upkeep • Strategies for programming • Solutions to technology breakdowns
	Linguistic competence	• Vocabulary selection • Skills needed to create sentences
	Social competence	• Gaining attention • Asking partner-focused questions
	Strategic competence	• Introducing the system to others • Using a variety of modalities • Dealing with breakdowns in conversation
Barriers to learning AAC	Lack of trained professionals	• Limited knowledge and experience of professionals • Failure to create communication opportunities
	Challenges to supporting ongoing use of the device	• Difficulty mounting device • Physical fatigue • Inefficient access techniques • Device breakdowns
	Challenges in promoting AAC-based communication in the community	• Negative attitudes of others • Lack of communication opportunities • Poor communication skills of partner
	Costs of learning	• Time and effort needed to learn device
Teaching the individual	Independent exploration	• Trial and error • Increased self-confidence
	Imaginary play	• Model device use in play activities
	Drill and practice	• Independent practice with manuals
	Instruction and practice with family members	• Support in setting up instructional materials • Need for parents to learn device
	Learning from other individuals who use AAC	• Importance of mentors
	Instruction and practice with professionals	• Help in learning vocabulary and grammar • Help in promoting social interaction • Assistance in identifying other instructional opportunities
	Technology supports	• Use of icon predication
	Manufacturers' training and technical assistance	• Benefit of training • Use of telephone technical support
	Evidence of success	• Independent use • Spontaneous communication • Positive feedback from communication partners
Educating society	Skills needed by child	• How to introduce self • Increased self-esteem
	Skills modeled by adult	• Appropriate communication

Challenges to Assessment and Decision-Making

Many parents described the challenges confronted throughout the assessment process (e.g., lack of professional interest in family involvement, difficulty obtaining services, and difficulty obtaining funding). Most parents reported that they had little to no input in selecting a device for their child. Parents described the negative outcomes that resulted from a failure to include parents. Katrina wrote:[3]

> They [evaluation team] said it [the device recommended by evaluation team] was the most sophisticated on the market and that she was a good candidate for it. We really didn't have anything to compare it to, so we went along with their decision . . . right away my daughter was having trouble using her head wand trying to hit the keys without constantly hitting the 'erase' button that was right next to the 'enter' button. Not to mention the device was ugly and not friendly looking.

Fred reported difficulty in obtaining an evaluation for his daughter. He discussed his frustration that he received no support from professionals, and that he and his family were not aware that AAC was an option.

> Unfortunately, even though my child was making NO progress at verbal speech, an AAC option was NEVER mentioned by the school nor any professionals . . . I found an advertisement for a Blackhawk . . . in Exceptional Parent Magazine and ordered it (without school testing, funding, approval, etc.) . . . For now, it [selection of device] was 100% our choice. The school offered nothing and NO information . . .

For all parents, obtaining funding was a major concern. Several parents stressed the importance of using the correct terminology when requesting funding for an AAC device. Katrina wrote:

> When Medicaid paid for my daughters, it was most important that the evaluation and assessment went heavy on the need for safety . . . they could not mention that it was for school or they [insurance company] would expect the schools to pay for them and the schools here were not about to do that for us. [A manufacturer] gave us examples of letters that were accepted by Medicaid. The buzz words were 'for the individual's safety . . .'

Supports to Assessment and Decision-Making

In addition to assessment and decision-making challenges they encountered, parents also discussed what they considered to be essential supports to the assessment/decision making process. Fred emphasized the importance of obtaining a recommendation from professionals as a means of enhancing acceptance of the device within the school system: "Although my daughter already had her second device by the time she finally had her school evaluation, the evaluator did recommend the device that she was already using. This made the device MUCH more acceptable to the school".

Daniel stressed that families often need to take a leadership role in the assessment/decision-making process. He emphasized the importance of families standing up for what they feel are the best decisions for their children, even when professionals do not agree: "[We] got a lot of negative vibrations from the public school system but . . . [we] held strong to what we felt was best for our child".

Knowledge and Skills Needed to Use AAC Technology

Another major theme discussed by family members was the knowledge and skills needed for a child to successfully use AAC technology. Four sub-themes were identified in this category: operational competence, linguistic competence, social competence, and strategic competence.

Operational Competence

Parents discussed three issues related to operational competence: technical operation and upkeep, strategies for programming, and solutions to technology breakdowns. Many participants reported that they learned how to operate their children's devices by reading manuals, attending training courses, and using the telephone support provided by manufacturers. Other popular resources included the manufacturer's web sites and online groups such as ACOLUG.

The parents who described themselves as having significant experience with mainstream technology (e.g., personal computers) were most apt to report the most successful experiences with AAC technology. For others, a lack of confidence with mainstream computer technology influenced their attitude towards AAC technology. For example, said Carla, "It took my husband and I a while before we were able to learn enough to help [our daughter] with it. As I remember, we were a little afraid of this new technology (kind of like I still feel about computers)".

Learning how to program the AAC device posed a major challenge for many of the parents, who identified a variety of resources to learn programming skills (e.g., training from a speech-language pathologist [SLP], free courses offered by the manufacturer, and self-teaching). Although many participants felt that the AAC device training they had received was helpful, others felt as though the training lacked detailed information about how to organize vocabulary and program the device.

Although parents tried to teach their children to perform some basic operational tasks, they reported that their children were left with no way to communicate when technical problems occurred outside of the home and family members were not present. Sometimes, even professionals who spent extended periods of time with children who used AAC devices lacked the skills needed to address technical problems. As Rosie wrote, "Unfortunately [her son's] attendant (at school) is not very helpful in resetting the device or knowing what to do if it's not working correctly. It usually comes home from school with a note for me to check it out".

Some participants developed ways to deal with technology breakdowns when familiar partners were not present. Carla wrote:

> With her previous device, it would freeze up dozens of times a day. We put a note on it telling how to 'reset' it. The reset button was in such an awkward place you had to practically be a contortionist to reset it while mounted on the chair...

Linguistic Competence

In addition to operational competence, the discussion also addressed linguistic competence; specifically, the challenges of selecting appropriate vocabulary and the skills needed to create sentences using the vocabulary. Commenting on the issue of vocabulary selection, Barbara noted: "I do not believe that anyone really knows what core vocabulary is yet, and I agree that it is not an easy solution. Depending on your age, situation, likes, and dislikes, your core vocabulary may differ".

As for learning to use the vocabulary available to create sentences and communicate effectively with others, Barbara spoke for many parents when she noted that, "Making sentences is not a naturally accruing thing for my son. Not only does he have to learn where all the words are stored, he has to figure out which words and in what order to use them".

Social Competence

Families reported two areas of knowledge related to social knowledge: gaining attention, and asking partner focused questions. They described their children's determination to communicate and the strategies they used to gain others' attention, including repeating and increasing the volume setting on the device. When discussing social competencies, some parents noted the importance of teaching question-asking skills. Julie wrote, "...I think it is very important for the young user to ask as well as answer questions. It makes them a little less self-centered and shows the world they are interested".

Strategic Competence

Parents discussed three skills related to strategic competence: introducing the system of communication to others; using a variety of modalities (e.g., eye gaze, vocalizations, facial expressions, and sign language); and dealing with breakdowns in conversation.

Rosie described messages that were programmed in her son's device to assist unfamiliar communication partners' understanding of how they can improve the quality of the conversation. She wrote, "He [son] also has a button that says 'Please do not read over my shoulder' and 'Please be patient while I type what I want to say'".

During discussions about communication modalities, parents mentioned that communication partners often try to finish their child's sentences, which resulted in a variety of reactions from their children. Rosie wrote, "My son HATES when I finish his sentences for him, or anyone else does for that matter!! It is especially aggravating if I am not correct and he meant to say something else". On the other hand, Katrina stated, "She [daughter] doesn't seem to mind when someone she knows well reads her display and finishes her sentences. It allows them to continue faster through a conversation".

Participants discussed several strategies their children used for dealing with conversational breakdowns. Although repetition was a widely used strategy for repairing conversational breakdowns, parents also commented that repetition alone was not always sufficient, and that new strategies were needed, such as providing additional information or directing communication partners' attention to the screen on the device.

Barriers to Learning AAC Technology

Parents described many barriers that inhibited the teaching and learning processes for individuals who used AAC and their families, including: (a) the lack of trained professionals, (b) challenges to supporting ongoing use of the device, (c) challenges in promoting communication in the community, and (d) the "cost" of learning.

Lack of Trained Professionals

One of the most commonly reported problems was a lack of professionals trained in AAC, which frequently resulted in delayed or inappropriate interventions. Barbara described the impact of school officials' lack of knowledge and interest:

> When my son went to school so many opportunities were missed . . . The teachers knew nothing of the AAC, and wanted to know nothing. There is no acceptable reason that he was not expected, encouraged, or allowed to use the device in school. So many missed opportunities.

Attempts by parents to engage the school were often unproductive. Julie wrote, "She [daughter] had forms that we made, to encourage the teachers to send home the next day's topics, with some real questions that she could be prepared to answer. I don't remember anyone using the forms!"

Struggles with the school system often led to feelings of isolation and frustration. Rosie wrote:

> Unfortunately, no one helped him [son] learn signs but me, and he had little support in this until about sixth grade when they hired a classroom aide that knew sign language. To have AAC not be integrated into a child's life until middle school is sad and [makes it] very difficult for them to adjust.

Parents also reported frustration with the limited knowledge and experience of the SLPs who worked with their children. Barbara wrote:

> She [SLP] did not help to show teachers how to incorporate the AAC into the rest of his day . . . She did not visit his classes and they did not request it. She [SLP] often wasted his time. She did not have strong goals or a plan; if they felt like walking the corridors that's what they did. There should have been much more accomplished.

Katrina described the challenges of trying to find an SLP who would work with her daughter:

> My daughter did not receive help from an SLP to learn her device. We looked for two years before settling for a speech therapy student. I felt like we were pulling her [speech therapy student] along in baby steps. *Her* baby steps. She wasn't looking at my daughter's age or abilities when it came to assignments and programming phrases. Repeatedly, I tried to tell her [SLP student] my daughter's vocabulary was much more advanced than the three or four word commands and sentences she wanted my daughter to program and use . . . It came to be that her [SLP student's] supervisor did not like Minspeak. My daughter wanted to give it a try. The [SLP] student said we would have to part ways. GLADLY. I couldn't figure out why there was reluctance to this encoding method and gave up trying to find someone willing to work with my daughter with it.

Fred reported that failure to admit a lack of knowledge was his biggest problem with his daughter's SLP:

> An SLP may be terrific in teaching verbal speech, but can not effectively learn and teach AAC. At least my wife and I learned this early. So the worst thing is all of the SLPs that could not do AAC, but would not admit it, and would not refer us to someone that could.

Challenges to Supporting Ongoing Use of the Device

Several participants commented on how important it is for individuals to have constant and consistent access to their devices in order to develop competency. As Carla wrote, "Naturally, the more time you have access to the device, the more you learn and the more proficient you become". However, many of the individuals could only use their device when seated in an electric wheelchair, and many of the desired environments (relative's homes, parks) were not wheelchair accessible.

A number of parents noted the physical effort required to operate the device. Barbara described her son's use of his device:

> He tries very hard but it is not natural – it is an added effort. He is also very athetoid and hitting that switch is not easy. When he was younger I would see beads of sweat break out on his forehead as he worked to get the correct icon.

Participants discussed the negative impact of ineffective access strategies on the learning process. Julie described her child's experiences:

> The scanning was accomplished by a head switch, and was about as slow as chiseling on stone with a toothpick. This problem was further complicated by the computer's hard drive crashing about once a week. Needless to say, desire to communicate plummeted.

Many other parents also reported technical breakdowns, which often led to frustration and interrupted learning, and, sometimes, to temporary abandonment.

Challenges in Promoting Communication Opportunities in the Community

When discussing barriers, parents reported the problems they faced when trying to develop communication opportunities for their children in a variety of environments. Barbara, for example, noted the impact of often negative attitudes toward children who use AAC: "... all the negative vibes our kids get from society, it is a wonder that any of them feel any confidence". She also discussed the importance of peer support in promoting communication opportunities. No matter how hard you work, if the AAC user has nothing much going on in their lives, nothing much to talk about and control, then this will not work well, so I would also like to see more clubs and groups available..."

Sometimes, the most painful reactions parents experienced were the result of reactions from their child's peers. Julie described her exasperation with communication partners who leave before her child had finished preparing a message, writing, "Oh God, the WORST scenario goes like this:

> Partner: *Hi, how are you*?
> Child: '*Beep-Beep-Beep*...'
> Partner walks away".

She also discussed the challenges her daughter experienced trying to make friends as she grew older: "As far as peer inclusion, unfortunately, by high school, the other kids are so clique-ish that they want nothing to do with a disabled 'peer', unlike those adorable kindergartners who wanted to help and be friends". Fred wondered if his daughter was getting much value from her AAC system, writing:

> My daughter has been using devices for more than five years now and I am not sure that she can be said to be using it in 'the real world'. Although it is quite portable, she rarely uses it out of the house... she gets little to no encouragement from anyone other than professionals and immediate family.

Cost of Learning

Many parents discussed the cost, to both parent and child, of learning how to use an AAC device successfully. Barbara described this cost as "really high." Rosie agreed, but added that it was preferable to the even higher cost of missed opportunities:

> Is there a cost?... that's a tough one. Since my son has no social life to speak of, he wasn't missing anything by 'playing' on his DynaVox in that sense. The real cost has been the lack of a device for so many years and the reluctance of others to be patient when he needed to communicate.

Teaching the Individual

Another major theme identified by parents focused on activities that could facilitate learning how to operate an AAC device: independent exploration, imaginary play, drill and practice, instruction and practice with family members, learning from other individuals who use AAC, instruction and practice with professionals, technology supports (such as icon prediction), manufacturers' trainings, and manufacturers' technical assistance. Evidence of success was also discussed.

Independent Exploration

Several parents discussed the advantages of their children "fooling around" with their device as a method of learning. Katrina wrote:

> She spent hours 'playing' with her device to see where the tools and settings were and how she could make it personally hers... I cannot stress enough how important it is to let a new user 'play' with their device. Playing with the device makes it less threatening and discovering features on their own lets them surprise others and gives them a sense of pride and ownership. There were countless times my daughter would be working away in front of her device and shriek with excitement over something she had discovered. We called her a 'mad scientist'. She would do her rendition of a victory dance while sitting on the floor. I swear a few times I thought she was going to levitate.

Imaginary Play

One parent (Fred) discussed the importance of his child participating in play-based role-plays when first learning how to operate the device: "The best activities that enhanced her use of the device were engaging her in a three-way conversation (i.e., SLP, child, and doll) with all three using the same AAC device to 'speak'".

Drill and Practice

Many parents reported that their children increased their proficiency using the device through structured drill and practice. Katrina wrote, "She had her dad and I take out 30 pages at a time from the dictionary and she would sit in front of her Liberator practicing for hours. She [daughter] memorized the Morse code for each square at the same time that she was memorizing the Unity dictionary on her own".

Instruction/Practice with Family Members

A few parents discussed the role they played in teaching their children how to use an AAC device. Barbara reported that she was left with no choice but to do the majority of the teaching as a result of the school's lack of involvement, "I had to learn how to program and teach as the school was so angry that I went and did something without their OK that they refused to touch it". Most of the parents said that they first had to learn how to set up and use the device in order to teach their children how to use it.

Learning from Other Individuals who use AAC

A number of parents described the positive impact of learning about AAC from other individuals who use AAC. Katrina wrote:

> My daughter knew only one other person who used a communication device . . . before she received hers . . . my daughter was very excited to meet up with other AAC users at a forum she attended. They were all proficient users and for the first time in her life she felt like she was among instant friends with much in common . . . She saw the importance of being able to communicate with others independently and instantly.

Instruction and Practice with Professionals

In addition to independent practice, teaching by families, and learning from individuals who used AAC, parents also discussed instructional support provided by speech language therapists and other professionals. Opinions varied. One parent reported that the support provided by her child's SLP was not as effective as the instruction she herself provided; other parents felt that SLP's played very important roles in helping their children learn how to use their AAC devices. Barbara wrote:

> The speech therapist taught my son sentence structure, pre-verbs . . . and different ways to express himself . . . This really helped him a lot. She facilitated social interaction for my son with other students during some of his therapy sessions. She treated him with respect, got to know him and, most importantly, believed in him.

One parent (Rosie) reported that it was not the SLP, but the assistive technology specialist who played an active role in teaching her child how to use the AAC device.

Technology Supports

Some parents discussed the helpfulness of technology supports built into AAC devices. For example, Carla pointed out the benefit of using icon prediction[4] as a tool for learning new vocabulary, ". . . now my daughter goes into the main icons and lets the icon-prediction system lead her to explore (the vocabulary contained in)" sub-themes.

Manufacturer's Training and Technical Assistance

Training provided by device manufacturers was described as an important resource for both parents and children. Rosie wrote, "He [son] went to a beginning class on the DynaVox and has even learned how to program it himself – mostly changing colors, font, verbal cues, labels and messages". In addition to formal training, many participants discussed and were positive about the assistance they and their children received from manufacturers' telephone-based technical representatives.

Evidence of Success

Although their children participated in a wide variety of learning activities, with a wide range of associated goals, many parents said that the key measure of success was their child's ability to independently use an AAC system to communicate. Katrina described her emotions the first time her daughter successfully used her AAC device without prompting or coaching:

> . . . I suppose most of you can recall the very first phrase your child said without any

> coaching. Ten years ago, my daughter was sitting on the living room floor watching T.V. with a borrowed Light Talker in front of her while I was in the kitchen cleaning up after dinner. I hear this 'voice' coming from around the corner, 'Hey mom, you got any of those chocolate chip cookies left?' It caught me by such surprise and took me a while to realize it was my daughter and not my son asking me. I laughed until the tears streamed . . . for the first time I wasn't playing 20 questions and straining my ears until I had a headache trying to understand her difficult speech.

Barbara described the importance of independent communication for her son:

> His brother's friends have become used to his device so he can get right into a chat with them, if they stay long enough in one spot to hear what he has to say. Positive feedback is a thrill for my son.

Parents also noted that practice with the AAC device sometimes produced gains in unexpected areas. Fred noted, for example, that "Using the device for many hours, listening to the voice over and over, is actually helping my daughter's vocalizations".

EDUCATING SOCIETY

Parents reported the need to educate others about individuals who use AAC, to prepare their own children for the negative reactions they might experience, and to find ways to facilitate communication between their children and members of the public. Julie, for example, described how she taught her daughter to introduce her AAC system to others, and wrote that the programmed introductory speech about her daughter, her disability, and her device ". . . often got the teachers to see my daughter's humanity". Julie also described a particular technique she used to encourage communication partners to talk directly to her daughter: "Just yesterday we programmed this into the Delta Talker: 'Hello! You can talk to ME!'"

Fred discussed the importance of educating and preparing his child for possibly negative reactions from others. "We can protect our children to SOME extent, but we cannot change human nature. We should at least work with our children on their self-esteem so that they can handle some of the cruelties of the world". Sometimes parents took a leadership role, as Barbara noted:

> We try to encourage the person to talk with him, you know, help out, try to let them know that 'he [son] asked you what your name is'. You can tell who is ready to learn and who isn't . . . I know that we need to teach, help, not alienate ourselves, but the job is very hard and people can be very rude, the more equipment you have the more bizarre you seem to them . . .

Katrina discussed how she models appropriate communication with her daughter when she introduces her AAC system:

> If she wants, I will tell people about how she communicates and then they are happy to listen. This gives them information right away that they do not have to shout at her or use baby talk to communicate with her.

In one case (which was much appreciated by the parent), a professional took responsibility for explaining a child's AAC system to school personnel. Rosie wrote, "The assistive technology specialist has tried to speak with each of my son's teachers (he is in high school) to explain the device and how it can be used and how my son is using it".

ADVICE AND RECOMMENDATIONS

Participants offered advice and recommendations for improving the learning and teaching processes to professionals and parents who support children who use AAC.

Advice for Professionals

A primary recommendation that arose out of a discussion of barriers associated with their children learning to use AAC was that professionals (including SLPs, teachers, and manufacturer's representatives) must be sensitive to the specific needs of each individual and family. Rosie spoke for everyone when she commented that, "Everyone learns differently, everyone's needs are different, their cognitive and physical abilities are different, their family lives are different, their support structure (will Mom learn too? the SLP? the aide? the classroom teacher? etc.) differs".

The parents also clearly expected professionals who work with their children to know the basic technical operation of an AAC device and to be prepared to teach this information to others. Rosie stated, "Everyone should get a basic 'this is how it works, this is what it can do, this is how we expect (the user) to use the device' type training".

Barbara spoke of the importance of professionals creating organized instructional programs:

> There needs to be demands put on the person, goals set, there is a lot to learn . . . Each child needs to be looked at as an individual who should be given the supports, adaptations and modifications that they require in order to reach their potential. A child needs to be given a chance to succeed.

Finally, parents stressed the importance of communication among team members. Katrina wrote:

> I think that when the speech therapist has an idea of what they are going to start to teach, this should be shared with the teachers or caregivers, and of course the AAC user, in fact if possible the AAC user should have some input as to what they want to be learning . . . I would like them to see the potential in their client before suggesting a course of action, confide in family as to where their client's communication abilities exist, and not censor what the client wants to say.

Advice for Parents

The participants reported that parents need to be prepared to take a leadership role in obtaining services, and to become experts themselves in both AAC technology and instructional programs. When asked about ways that parents could help their children to learn how to use AAC, parents described the importance of providing motivating learning activities. Said Rosie:

> Find things that the child likes to do and 'program' those things into his device, such as card games, or cooking, or whatever. As others have mentioned, this is difficult when you have a severely physically disabled child – there is so little they can actually 'do' . . . The only other suggestion I have is to make a game of using the device itself. Say that YOU have to use the device instead of your own voice, as well as the child using the device. In this way you can model for them.

DISCUSSION

Parents of children with disabilities take on many roles (Parette & Angelo, 1996). The parents in this study acted not only as loving caregivers, but also as teachers, playmates, technical support personnel, and advocates. They frequently took a leadership role in the selection of the AAC device, teaching the functional use of the AAC system to their children, promoting the use of AAC in a variety of environments and with a variety of communication partners, and assessing progress and the need for new communication approaches and interventions.

As in other studies, parents often reported frustration with their efforts to obtain appropriate assistive technology services (Paradice & Adewusi, 2002; Parette, Brotherson, & Huer, 2000). They described many communication and education professionals as unfamiliar with AAC technology, and reported that appropriate opportunities for learning, for both the child and their potential communication partner, were rarely provided.

The parents in this focus group pointed out a clear need for improved training for professionals in three main areas. First, training in current AAC technology is needed at the pre-service level and as part of ongoing professional development at the in-service level. While it is unrealistic to think that all individuals who have contact with children who use AAC will be experts in all aspects of AAC, at a minimum those who work directly with children who use AAC are responsible for being familiar with the child's AAC system and being able to model its use. In addition, education and communication professionals need to "know what they don't know", and be ready to request additional expertise as needed.

Second, education and rehabilitation professionals need to make effective use of a wide range of research supported practices for developing the communication skills of individuals who use AAC. While the research base in AAC is, at present, relatively small, the thoughtful use of practices that have been demonstrated to be effective in facilitating communication with other populations (e.g., providing appropriate models of communication, developing motivating opportunities for communication) clearly holds promise (Campbell, Milbourne, Dugan, & Wilcox, 2006; Schlosser, Walker, & Sigafoos, 2006). If we recognize that communication is a transactional process, in which both sides must adapt to the skills of the other, then it is essential that training for communication partners be part of any intervention plan.

Third, there is a need to provide professionals who deliver AAC-based services with pre-service and in-service training that focuses on the problem-solving and communication skills required to work effectively as part of a team (Parette et al., 2000).

One cannot help but be struck by the frequency with which parents' efforts to obtain information and services were frustrated by the lack of an appropriate team response, and the lost opportunities for growth and development resulting from the failure to provide appropriate support. Interventions will need to be individualized; children who require AAC present with a wide range of skills and needs (Beukelman & Mirenda, 2005), and so do their families. AAC professionals must be prepared to work not only with parents who will require an introduction to AAC, but also with parents who are fully informed and who will expect respect for their in-depth knowledge of AAC (Angelo et al., 1996). The development of effective teams is one important step towards more positive outcomes (Kent-Walsh & Light, 2003; Parette, Brotherson, & Huer, 2000).

CONCLUSION

Parette et al. (2001) suggested that "Professionals who enter in collaborative arrangements with families must give complete loyalty to the partnership, provide families with relevant, accurate, and up-to-date information, and use effective communication skills so that trusting partnerships can be developed and enhanced" (p. 78). Fundamental to successful interventions is the recognition of the importance of the family in the assessment and intervention process, and the critical importance of partnerships between families and professionals. The parents who participated in this study have clearly demonstrated their willingness to substantively contribute to the process of teaching their child to communicate. A commensurate willingness by education and communication professionals to work as part of a team will ensure that children with complex communication needs receive the "chance to succeed" that they deserve.

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Notes

1 More information on ACOLUG is available at http://disabilities.temple.edu/programs/assistive/acolug/tacolug.html.

2 Phorum 3.3.2 is a password-protected internet bulletin board system that allows several individuals to participate in text-based discussions on a variety of topics. Additional information is available at www.caup.washington.edu/software/conferweb.

3 Because the Web based discussion did not easily support proofreading and editing functions for the participants as they posted their comments, the authors have made minor corrections of spelling and grammatical errors. Brackets are used to identify text inserted by the manuscript authors.

4 For devices that use icon sequences to store and retrieve vocabulary, "icon prediction" provides information on the icon sequences that begin with the selected icon.

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