Mothers' Perspectives and Experiences of Speech Generating Devices

Yeunjoo Lee, Ph.D.
California State University, Bakersfield

Luis A. Vega, Ph.D.
California State University, Bakersfield

Abstract

Families play a critical role in the lives of students who use a speech generating device (SGD). This study address (a) mothers' experiences of having a child who uses a SGD, (b) their perception of the effectiveness of a SGD(s), (c) their perceived impacts of SGDs on their family dynamics, and (d) their perception of decision making process. Data were collected through surveys and individual phone interviews. The results show the mothers' needs for continued support and training in programming and integration of the technology in children's daily lives. Implications for teacher preparation programs are presented.

Mothers' Perspectives and Experiences of Speech Generating Devices (SGDs)

Assistive technology (AT) allows students with disabilities to develop, maintain, and enhance their abilities. In 1997, the Individuals with Disabilities Education Act (IDEA) recognized the importance of AT and mandated that Individualized Education Program (IEP) teams must consider AT for every child with a disability. As such, special education personnel need to have training and knowledge of AT to adequately serve students with disabilities. In reality, training for special education personnel is lacking (Lee & Vega, 2005). According to Lee and Vega (2005), 22 percent of special education personnel had received more than 40 hours of AT training while 48.7 percent had no training or less than 5 hours of training. Special education related personnel in their research described limited knowledge as the biggest barrier to using AT (41%). Their report is alarming and seeks for more attention from teacher educators.

Communication is a crucial survival skill to exchange ideas and information and allows individuals to meet their social needs and define who they are. Children who are nonverbal or have unintelligible speech require additional supports to accomplish their goals to be an independent communicator. More than often, those children use various types of AT, including Augmentative and Alternative Communication (AAC). AACs are all forms of supports designed to assist individuals to communicate and can be unaided (e.g., sign language, gestures, or body language) or aided systems (e.g., electronic communication boards). Electronic communication boards have been used for decades and changed greatly with the advance of technology. Current electronic AAC devices can provide digitized or synthesized speech and multiple layers of picture icons to choose from (i.e., speech generating devices, SGDs).

While evaluating and/or using SGDs, home environments as well as classroom or clinical settings should be taken into consideration. Home is an integral part of a child's life, particularly for children with disabilities, and family members are respected contributors and participants in

the assessment and decision making process addressing their child's needs in home and school environments (Parette, Huer, & Hourcade, 2003; Parette, VanBiervliet, & Hourcade, 2000). Collaborative team work is imperative throughout process, and professionals should be keen to any challenges to build an effective team. Professionals may encounter family members' distrust and lack of understanding regarding their roles as a family member in decision-making process. Family members' apprehensions and frustration are to be acknowledged and respected, and conflicts need to be resolved or compromised through a collaborative team process to produce the best benefits of AT use.

Contrary to the collaborative team process, a traditional decision-making approach only focuses on a child within a classroom (Parette et al., 2003). Parette et al. reported that education personnel fail to consider family priorities and concerns and, instead, focus on the child within a classroom during the decision-making process. This issue becomes acute when families come from diverse backgrounds. Some minority groups may perceive education professional to be higher authority than them. It leads to a communication gap in decision making process and prohibits the family member from contributing to their child's education experience (McCord & Soto, 2004). They also have different perceptions of assistive technology, which may not be consistent with education personnel. A sound decision making team should take into consideration various factors (e.g., cultural, environmental, familial, physical, or cognitive) when selecting a SGD for a child.

Families and their children should be prepared by receiving training and services in order for them to benefit from AAC devices to their full extent (Kemp & Parette, 2000; Marshall & Goldbart, 2008). Education professionals need to be aware of families' needs and understand the similarities and differences between their own cultures and the cultures of the families that are serving (Marshall & Goldbart; McCord & Soto, 2004). Although researchers have repeatedly voiced the importance of family involvement, there has been limited research on the topic. Most published studies are informational (Kemp & Parette; Parette et al., 2003; Parette & Scherer, 2004; Parette et al., 2000) or involve professionals as participants (Parette, Huer, & Brotherson, 2001). More research is warranted to examine our current practices and to assist meeting the needs of families and their children.

To further understand the unique role that SGD plays and the needs that it serves, within the context and perceptions of students with disabilities and their families, this research sought to answer the following questions: (a) Mothers' perception of decision making process, (b) their knowledge of a SGD(s), (c) their perception of the effectiveness of a SGD(s), (d) their perceived impacts of SGDs on their family dynamics, and (e) their experience of having a child with a SGD(s).

Method

A mixed methodology (qualitative and quantitative) was employed to answer the research questions. Participants were requested to complete a questionnaire and a voluntary follow-up phone interview.

Data Sources

Participants were recruited from a mid-sized city in California and a listserv of AAC users and their families. This listserv has over 300 members who are AAC users or have family members

who use AAC systems (Institute on Disabilities, 2011). An email was sent to the members of the listserv to describe the purposes and procedures of the research. Participants in the local area were recruited through the use of flyers.

A total of 24 parents expressed interest in this study, and 20 of them completed a survey. Of the final list of participants, two of the respondents were from the local area, and 18 were from the AAC listserv. All of the participants were biological or adopted mothers of children with speech generating devices (SGDs).

The survey participants were mothers with an average age of 44.8 (range = 33 to 57, SD=6.5). Their children ranged from 6 to 20 years old ($M = 12.95; SD = 4.17$) and used a SGD for two to 15 years ($M = 7.8, SD = 4.17$). Sixty five percent ($n = 13$) of the children had orthopedic impairment, and 30 percent ($n = 6$) had mild/moderate intellectual disabilities. Table 1 shows the detailed demographic information of parents and their children.

Table 1. *Demographics of Survey Participants*

Primary Language **($N = 20$)**	**English**	**19 (96%)**
	Spanish	**1 (4%)**
Participant Age **($N = 19 ;M = 44.84 ; SD = 6.50$)**	**30-35 years old**	**2 (10.5%)**
	36-40	**4 (21.1%)**
	41-45	**2 (10.5%)**
	46-50	**8 (42.1%)**
	51-55	**2 (10.5%)**
	56-60	**1 (5.3%)**
*Child Age ($N = 20 ; M = 12.95 ; SD = 4.17$)	**6-10**	**6 (30%)**
	11-15	**8 (40%)**
	16-20	**6 (30%)**
Child's Disability	**Mild/Moderate Intellectual Disabilities**	**6 (30%)**
	Moderate/Severe Intellectual Disabilities	**2 (10%)**
	Behavior Disorder	**1 (5%)**
	Learning Disability	**1 (5%)**
	Autism	**2 (10%)**
	Traumatic Brain Injury	**1 (5%)**
	Hearing Impairment	**1 (5%)**
	Orthopedic Impairment	**13 (65%)**
	Cerebral Palsy	**9 (45%)**
	Visual Impairment	**2 (10%)**
Years of AAC use ($N = 20 ; M = 7.8 ; SD = 4.17$)	**1-3**	**3 (15%)**
	4-6	**5 (25%)**
	7-9	**4 (20%)**
	10-12	**4 (20%)**
	13-15	**4 (20%)**

*note: there are families with more than one child with AAC.

Ten of the twenty participants agreed to participate in a phone interview after completing a survey. A phone interview was selected because of physical distances between the interviewer and participants. Interviews were conducted during the participants' preferred time and in their

primary language. Nine interviews were conducted in English, and one in Spanish. Phone calls were made from the first author's office by a female graduate-level research assistant. Interviews were conducted in a semi-structured format, tape-recorded, and transcribed verbatim by the research assistant. Each interview lasted between 45 minutes to an hour. The interview questions are presented in Table 2. Table 3 contains demographics of the participants obtained through phone interviews.

Table 2. *Interview Questions.*

Interview Questions
1. Tell me a little bit about your child.
2. When your child's teacher or other school personnel mentioned about using the AAC device for your child, what was your first thought?
3. How do you feel about using the AAC device now?
4. If a parent asks you about an AAC device for their child, what would you suggest?
5. How did the AAC change your family's life?
6. How did the AAC change your child's life?
7. How did the AAC change your life?
8. What are some barriers to effectively using your child's AAC device?
9. What are some things that you would like to change in your child's AAC device?
10. Please tell us anything that teachers or other professionals can do to be more helpful to you and your family.
11. Have you met and shared your experience with other parents whose children use an AAC device through a meeting or over the internet?
a. Tell me your experience of it.
b. How did you meet them?
c. If no, go to #12.
12. What suggestions would you give to future parents whose child uses an AAC device?

Survey Instrument
Survey items included questions on demographic information and families' perception of their child's SGDs. In addition, it contained questions that examined families' acceptance of SGDs, the effectiveness, and its impact on family dynamics. The questionnaire contained a total of 2 multiple-choice questions, 10 open-ended questions, and 16 likert-scale questions (*Strongly Agree* = 1, *Strongly Disagree* = 6).

A Spanish version of the survey was developed for one mother whose primary language was Spanish. The survey in Spanish was reviewed by the second author who is fluent in both English and Spanish. The Spanish version was revised according to the second author's feedback.

Interview Data Analysis

A qualitative approach was implemented to explore the experiences of mothers who have a child with communication impairments. This method is inductive in nature and produces descriptive information that enhances understanding of a particular group of participants (Brantlinger, Jimenez, Klingner, Pugach, & Richardson, 2001). In this method, researchers serve as an instrument to analyze rich data collected through interactions with participants.

Interviews in this study were audiotaped with participants' consent and transcribed in verbatim. Transcripts were analyzed using a constant comparative method (Merriam, 1998). In the first step of analysis, interview transcripts were reviewed to get a sense of the mothers' perspectives. After the first reading, the first author carefully reviewed each transcript while taking notes and comments. Then, notes and comments on each transcript were examined to develop themes. Themes from each interview were compared, and major categories were developed (Merriam, 1998). The second author then read the transcripts and examined the proposed categories for inter-rater agreement (100%), supporting a consensus model based on face validity.

Table 3. *Demographics of Interview Participants**

Participant	State	Age	Education	Child's Age	Years of AAC	Child's Disability
Marcy	CA	47	NA	13	7	CP, OI
Jenny	MA	53	NA	19	15	CP, OI
Mary	MS	43	High school	18	13	OI
Joan	PA	44	NA	15	10	Undiagnosed neuromuscular disorder
Teri	CT	46	NA	18	15	M/M, VI, CP
Anita	OH	49	NA	11	81/2	M/M, CP,
Penny	CO	53	College	12	5	OI,CP
Linda	DE	47	NA	20	10+	M/S, BD, LD, OI
Claire		41	College	15	8	CP
HJ	VA	54	Graduate	10	8	VI, OI
Konnie	CA	NA	NA	NA	NA	NA

Note: CP=cerebral palsy, OI=orthopedic impairment, M/M=mild/moderate intellectual disabilities, M/S=moderate/severe intellectual disabilities, VI=visual impairment, BD=behavior disorder, LD=learning disabilities, NA=Not Available.

* The information in this table was primarily provided by the interview participants (mothers).

Results

An analysis of the ratings of the Likert scale questions show that participants had a positive experience during decision making process. Ninety percent (*n* = 18) of the respondents strongly or moderately agreed that they were comfortable sharing their ideas with a decision making team (*M* = 1.4*; SD* = .099). A majority of the respondents (*n* = 16, 80%) also strongly or moderately agreed that the team members often asked their opinions during the evaluation (*M* = 1.75*; SD* = 1.16). While mothers seem to be respected and encouraged to involve in decision making process, they also reported some levels of emotional and financial stress. Nine participants (45%) stated that AAC devices added unexpected stress (*M* = 4.4*; SD* = 1.39), and six parents (30%)

agreed that the devices caused financial stress ($M = 4.25$; $SD = 1.77$).   Further, the survey results confirm that caregivers need more training and support to use a SGD.
More detailed results from the likert scales are shown in Appendix A.

Increased Independence and Competence
All of the interview participants were grateful for their child's SGD and expressed that the devices improved their child's social and communication skills and changed their lives. Mary, a mother of an 18 year-old child said,

> *The greatest thing is that it gives her other opportunities and different roles she can play because, like I said, she can babysit for her sister, she can call someone and sing happy birthday to them, for her it is very much the social aspect much more than communicating the basic needs…it has really opened up her social domain.*

Moreover, mothers also discussed their child's new ability to control environment. Jenny, a mother of a child who had used a SGD for 15 years, stated that "it opened up the ability that he can use a computer environmental control, so he has more power…the device has given him power that he just couldn't have like he can turn on lights, he can turn on radios…" Mary also agreed that the SGD improved their child's quality of life beyond communication and gave the child a sense of competency. Overall, SGDs permitted children to play different social roles and to experience new sense of control.

Stresses, Challenges, and Barriers
Even though their child's improved independency lowered parents' frustration levels, participants experienced financial burden, unexpected stress, and additional responsibilities related to their SGDs (n = 11, 55%). The participants shared the challenges and barriers of having SGDs during interviews. One parent stated that "it takes a lot of time; I mean a lot more time, programming and setting it up and trying to put things in the right place."

HJ, who has a 10-year old boy, stated the following:
> *The stress of programming it…I think there is a lot of stress associated with it, though it's very unclear as to how to really organize the communication aspect of it. I mean, the technical aspect of it is simple, you know you can learn to program it…but to really learn how to really communicate and to sort of motivate a child to learn to use it effectively and for the school system to provide effective support for the teachers [it is not easy].*

While interview participants expressed that they were comfortable operating the system, their challenge was in how to integrate SGDs into their lives and how to encourage their child to use SGDs. This concern is consistent with the survey results that demonstrated lack of training for parents and provides critical aspects to improve the services for children and their parents.

Of equally important, professional and public knowledge, skills, and attitudes towards SGDs were often perceived a challenge. Anita stated that,

> *I think the biggest thing is community at large, and that would also include, basically anyone who works with your child who doesn't believe in the device... my daughter had a*

school speech therapist for five years who refused to use the communication device, and I think the bottom line was she just was intimidated by it.

Likewise, Jenny expressed that people did not know how to respond to a child's SGD. The fear or lack of experience to SGDs are not limited to the public. According to Penny, whose child had used a SGD for 5 years, her child's speech therapist told that her daughter would become less verbal if she used a SGD. Joan added that her speech language pathologist did not know how to teach language with the device. She commented that

We really had a hard time with, we didn't have as hard time with getting the technology as we did getting the supports and services and we really didn't get a speech therapist that was qualified to work with him until he was like in the ninth grade because they, they don't have AAC background.

Coupled with professionals' knowledge, their open communication and willingness to collaborate was discussed during the interviews. Anita, made a reference to education personnel by stating the following:

I'm really comfortable with communication devices... I really don't know a whole lot about this, but with what you know, let's talk about what your child can do, let's talk about what your expectations are. Not only of what your child can do with this or what you want your child to do with this, but how I, the professional, can support and challenge your child in making these, or meeting these goals.

Professionals' limited support and knowledge prompted some parents to transform their roles as parents and advocates. Linda stated,

We had a wonderful speech pathologist in the fact that she cares so much for Sarah and wants her to use the device effectively, but [she] doesn't really understand, wants to understand, or gets involved in the programming of it. She just sends me notes on what she wants done, which I really don't have a problem with 'cause half the time I don't like what she wants done anyway.

The partnership between Linda and the speech pathologist was successful in making the best use of their SGD and provides an alternate idea of the relationship between parents and professionals. Half of survey participants (*n* = 10) confessed that their child did not use a SGD as much as they expect him/her to do. The above mentioned challenges should be resolved to further improve educational services to families and children with SGDs.

Discussion

Mothers expressed their perceptions and experiences of having a child with a SGD in this study. They were mostly positive about decision making process. Seventeen of 20 participants expressed that they have adequate knowledge to maintain the devices (*M* = 1.4). Fifteen mothers reported that they received some degree of training on their AAC device while five mothers expressed that they received limited or no training at all. Phone interviews emphasized the needs

for continued support and training in programming and integration of the technology in their daily lives.

The results of this research confirms that family members experience additional responsibilities and stresses that come with the use of AAC devices (Bailey, Parette, Stoner, Angell, & Carroll, 2006; Jones, Angelo, & Kokoska, 1998; Marshall & Goldbart, 2008). The challenges should be addressed promptly and effectively since they prevent families from using SGDs to their full extent (Parette & Angelo, 1996). Family members' stress and challenges can be exaggerated by lack of knowledge and continuous supports. Issues of support and training for families were repeatedly raised in other literature (Angelo et al., 1996; Marshall & Goldbart, 2008; McCord & Soto, 2004; Parette et al., 1996).

In this study, mothers struggled to program SGDs and had difficulty integrating them into daily lives (Angelo et al., 1996; Bailey et al., 2006a; McCord & Soto, 2004). Thunberg and colleagues (2009) researched whether parent training would make any differences in child-adult daily communication at home. The results showed that interaction between parents and their child with Autism Spectrum Disorder was increased. Moreover, children's irrelevant and unnecessary verbalizations were decreased during home activities (Thunberg, Ahlsen, & Sandberg). Thunberg et al.'s research provides positive outcomes of parent training and suggests to provide parent training before introducing SGDs. Education for parents should include hands-on experience along with modeling on how to integrate SGDs in a daily life.

Professionals are not and should not be the only source of support and information for families. Families can obtain information through formal and informal sources, including internet, support groups, books, and/or workshops. Supports from other parents who have similar experiences would empower and enlighten families who go through similar situation (Marshall & Goldbart, 2008). As important as it is to increase self-determination and efficacy of children with disabilities, it is also just as important for family members to feel empowered and encouraged to be their child's advocates.

Mothers in this study were strong advocates for their child and were actively involved in their child's education. Half of the interview participants requested to their school district to evaluate their child as a potential SGD user. Whereas family members asked for information and training in previous studies (Angelo et al., 1996), parents in the current study did not rely on schools and agencies. Some parents in this study spent many hours trying to understand and use their AAC devices and transform themselves as parent-educators and experts. They even created a website and conducted workshops for AAC users and their families. In particular, one mother urged that parents should take a leading role and be involved with using AAC since children spent most of the time with their families.

The current study suggests that professionals modify their practices from child-centered to family–centered (Starble, Hutchins, Favro, & Prelock, 2005), have ongoing conversations related to families' needs, and encourage and empower SGD users and their families (Angelo et al., 1996). Families change as their children grow. Professionals need to be sensitive to the changes and needs that come along with children's maturation. While doing so, education personnel must pay great attention to the impact of an AAC device on family dynamics and cultural differences

(Bailey et al., 2006; Parette et al., 1996; Vanbiervliet & Parette, 2002). Culture shapes and defines the roles of AAC devices in each family. Families experience different types and levels of stress, depending on their socioeconomic status, experience, education, language, years with AAC devices, and cultural backgrounds. Education professionals will need to recognize the stressors and support families to adjust to ever-changing environments.

Education professionals' attitudes and knowledge have been discussed as a barrier of using AAC devices in previous literature (Bailey, Stoner, Parette, & Angell, 2006b; Huer, Parette, & Saenz, 2001; Marshall & Goldbart, 2008). Their training issues should be addressed from two directions. First, teacher and therapist training programs ought to increase instruction on assistive technology, including AAC during their professional preparation programs. Second, school districts should make conscious efforts to provide continuing education and supports for teachers and related professionals. Pre-service special education teachers receive only 1 or 2 years of training in teacher preparation programs, and only few or none of the courses are devoted to AAC. The lack of training on AAC contents is also apparent in pre-service speech language pathologists and occupational therapists (Cistigan & Light, 2010). While speech language pathologists take a lead implementing an AAC device and supporting children and their families, special education teachers are required to accompany the pathologists throughout the way. The roles of both special education teachers and speech language pathologists are critical to successfully implement and support children to be an effective communicator.

Upon the graduation of respective training programs and entering the workforce in a classroom, local school districts take over the responsibility of providing professional development activities in collaboration with teacher training programs. Particularly, school personnel who work with an AAC user will require extra planning and training time to get acquainted and learn about the devices. The training should involve discussions of using the devices in school settings; enhancing literacy skills; and integrating the devices in home environments. Another important emphasis should be on educating communicative partners to be effective and responsive (Bailey et al., 2006a). Effective and efficient use of communication systems requires considerable time investment and collaboration efforts among educational personnel, parents, and students (Bailey et al., 2006b). It should be noted that professional knowledge and collaboration are major features that guarantee access to all students and their families (Fitzpatrick & Brown, 2008).

Teachers indicated that the biggest challenge of using assistive technology is the lack of time (Bailey et al., 2006b; Lee & Vega, 2005). Current practices focusing on accountability and testing, coupled with limited budgets contribute to less time for teachers to learn, plan, and implement effective use of assistive technology and collaborate with other team members. Budget deficits also impede teachers from attending workshops and conferences to share and update their knowledge and skills. School personnel and administrators should find ways to overcome this economic hardship. Numerous workshops can be offered via internet using video conferencing or online courses. Webinars and email listserves are also effective ways of sharing information about AAC devices.

Limitations of the Study

This study provides a snapshot of mothers' perspectives of using SGDs. There are several aspects that need to be considered to interpret the results. Only 20 participants completed a survey, and ten mothers participated in a phone interview. The results only represent a small number of mothers who volunteered to participate in the study and who were recruited through limited channels. The mothers may not be a representative sample of family members of a child who use a SGD. Furthermore, we might have different results if the study involved other family members (siblings, fathers, or other primary caretakers). It is recommended that future research involves higher number of participants and recruit other family members as well as mothers.

There is a paucity of studies that involved family members of children who use an AAC device. Further research is warranted to involve SGD users and their families with diverse backgrounds and to examine how children can most efficiently use SGDs. Another area is to examine the effectiveness of pre-service SGD training and the transferability of their training to their job settings. A longitudinal research study is also necessary to examine the adaptation process of SGDs for children and their families.

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Appendix A *(see following page)*

Number and Percentage of Responses in the Likert Scale Items. Item (N = 23)	Strongly Agree 1	Moderately Agree 2	Somewhat Agree 3	Somewhat Disagree 4	Moderately Disagree 5	Strongly Disagree 6	M	SD
1. I feel comfortable sharing my ideas with the evaluation team of my child's AAC device.	15 (75%)	3 (15%)	1 (5%)	0 (0%)	1 (5%)	0 (0%)	1.45	.99
2. Team members often asked my opinions during the AAC evaluation.	12 (60%)	4 (20%)	2 (10%)	1 (5%)	1 (5%)	0 (0%)	1.75	1.16
3. I have adequate knowledge on how to maintain the AAC device.	17 (85%)	0 (0%)	2 (10%)	0 (0%)	1 (5%)	0 (0%)	1.4	1.05
4. I feel comfortable operating the AAC device.	16 (80%)	2 (10%)	1 (5%)	0 (0%)	0 (0%)	1 (5%)	1.45	1.19
5. My child uses his/her AAC device at home.	14 (70%)	1 (5%)	3 (15%)	1 (5%)	0 (0%)	1 (5%)	1.75	1.37
6. The AAC device is helpful for my child.	15 (75%)	5 (25%)	0 (0%)	1 (4.3%)	0 (0%)	0 (0%)	1.25	.444
7. The AAC device generates unexpected stress.	0 (0%)	1 (5%)	7 (35%)	1 (5%)	5 (25%)	6 (30%)	4.4	1.39
8. The AAC device restricts family activities.	1 (5%)	0 (0%)	2 (10%)	1 (5%)	5 (25%)	11 (55%)	5.1	1.37
9. My child uses his/her AAC device as much as I expect him/her to.	7 (35%)	3 (15%)	4 (20%)	5 (25%)	1 (5%)	0 (0%)	2.5	1.36
10. The effects of the AAC device meet my expectation.	9 (45%)	8 (40%)	2 (10%)	1 (5%)	0 (0%)	0 (0%)	1.75	.85
11. The AAC device adds to the financial stress.	2 (10%)	3 (15%)	1 (5%)	2 (10%)	6 (30%)	6 (30%)	4.25	1.77
12. Family members assume additional responsibilities due to the AAC device.	5 (25%)	0 (0%)	6 (30%)	2 (10%)	5 (25%)	2 (10%)	3.4	1.73
13. The AAC device draws unnecessary or negative attention to my child.	1 (5%)	2 (10%)	2 (10%)	0 (0%)	5 (25%)	10 (50%)	4.8	1.64
14. I was informed of various AAC devices that were being considered for my child.	9 (45%)	1 (5%)	5 (25%)	1 (5%)	1 (5%)	3 (15%)	2.65	1.87
15. I received training on how to use the AAC device.	8 (40%)	3 (15%)	4 (20%)	2 (10%)	1 (5%)	2 (10%)	2.55	1.70

16. My input has been valued and taken into consideration for the selection of AAC device.	13 (65%)	5 (25%)	2 (10%)	0 (0%)	0 (0%)	0 (0%)	1.45	.69