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An Examination of Parent Perspectives on Augmentative and Alternative Communication Systems in Children with Fragile X Syndrome

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PARENT PERSPECTIVES ON COMMUNICATION AND USE OF
AUGMENTATIVE AND ALTERNATIVE COMMUNICATION SYSTEMS
IN CHILDREN WITH FRAGILE X SYNDROME

By

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The purposes of this qualitative inquiry were as follows: (a) to understand how mothers of children with fragile X syndrome (FXS) used augmentative and alternative communication (AAC) systems in the home, (b) to capture their views regarding AAC use, and (c) to examine the support they received in the process. Data was collected using participant observations, semi-structured interviews and review of archival educational records and were analyzed using grounded theory methods. Results revealed that for children with FXS, the interplay of children's complex developmental challenges, mothers' internal struggles, and the absence of external supports leads to limited and variable use of AAC in the home.

Dedication

This dissertation is dedicated to all the families of children with FXS and other related developmental disabilities that I have come to know and admire. They have provided me with the inspiration to complete this study and have inspired me to continue to improve the communication between children and their families through the use of AAC.

Acknowledgements

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Chapter 1: Introduction

The acquisition of strong communication skills is crucial to a child's

development. Communication is more than the acquisition of language; it is a reciprocal

social exchange of information between a sender and receiver of information (Downing,

2002). Communication impacts all aspects of a child's life from making choices, to

exerting control over the environment, sharing ideas, and developing friendships

(Downing, 2002; Sevcik, Romski, & Adamson, 2004). A child's ability to communicate

is essential for meaningful participation in everyday activities in the home and successful

inclusion in school and in the community. The child with strong communication skills

will be able to initiate and maintain conversations and social interactions that are critical

to establish and maintain relationships with family members and others, as well as for

learning (Stephenson & Dowrick, 2005).

Although the development of language and communication is a complex process

that begins at birth, for typically developing children this process is acquired in a

relatively easy manner over time. But for many children with disabilities, the ability to

communicate can be difficult, in spite of the development of speech (Downing, 2002).

The inability to communicate effectively with others places children at an increased risk

for decreased social interactions, communication breakdowns, and learning and behavior

problems in a multitude of contexts, particularly in the home (Romski & Sevcik, 2005).

In addition, children who fail to acquire effective communication skills are likely to

experience frustration, dependency, social isolation, and lack of employment later in life

(Warren, 2000).

The development of communication skills in children with developmental conditions remains a serious challenge for families and professionals, and there is a great need for targeted communication interventions. According to the American Academy of Pediatrics, nearly 5 million children in the United States (approximately 15%) have a disability. Among those children with disabilities who are attending school, more than 20% have significant communication impairments. Conditions that cause communication impairments include cerebral palsy, autism spectrum disorders (ASDs), intellectual disabilities, and many genetic syndromes such as Fragile X (Desch & Gaebler-Spira, 2008).

Among those with significant communication impairments in need of targeted interventions are children with Fragile X syndrome (FXS). According to the National Fragile X Foundation (NFXF, 2010), FXS is a genetic syndrome caused by changes in the fragile X mental retardation 1 gene, and symptoms range from learning disabilities (more common in girls) to more significant intellectual impairments (more common in boys). The gene appears in three forms that are defined by the pattern of DNA (the chemical that makes up the gene) of the X chromosome called cytosine/guanine/guanine (CGG) repeats: individuals with less than 60 CGG repeats have a normal gene; individuals with 60–200 CGG repeats have a premutation, meaning that the Fragile X gene can be passed on from one generation to the next; and individuals with over 200 CGG repeats have full mutation FXS.

In the United States, approximately 1 in 4,000 to 6,000 females and 1 in 3,600 males have FXS and 1 in 250 females and 1 in 800 males are premutation carriers. FXS is also the most common cause of inherited intellectual disability and the most common

known single-gene cause of autism. Approximately one third of all children with FXS have some degree of autism or features of autism and 2 to 6% of children with autism have FXS. Most children diagnosed with FXS exhibit significant communication impairments and behavioral symptoms such as aggression, social avoidance, repetitive speech patterns, hyperactivity, anxiety, and impulsivity (NFXF, 2010).

One language-intervention approach for children with FXS and related disorders to promote the development of communication skills is the use of augmentative and alternative communication (AAC) systems. AAC is a multimodal system that involves the use of unaided and aided forms of communication in addition to natural speech that are used by individuals to express wants, needs, and ideas (Desch & Gaebler-Spira, 2008). Unaided forms of communication are gestures, body language, or signs, and rely on children's use of their body to convey a message. Aided forms involve the use of external tools such as manual communication boards with symbols, pictures, or written words and programmable devices that produce voice or written output. While unaided systems are convenient and in some sense more natural, the gestures or signs may be too abstract or idiosyncratic to comprehend and may require some degree of motor planning and fine motor development for children to use effectively; aided forms of communication, in contrast, make language visual, tangible, and comprehensible to all. Ultimately, an AAC system that incorporates the use of unaided and aided forms is optimal for children who have little or no functional speech or who have language but are ineffective communicators. It is important to keep in mind that the purposes of AAC systems for children with FXS are to support the child's use of natural speech and provide a functional means to communicate meaningfully and interact with family

members and peers across various topics and in different settings (Wilkinson, & Hennig, 2007).

There are many benefits to using AAC for children with FXS and related disorders. In addition to increasing a child's communication skills, AAC interventions have been shown to increase speech production and decrease challenging behaviors (Roberts, Chapman, & Warren, 2008). For children who are acquiring speech it is important to note that AAC has been shown to augment language and does not inhibit a child's acquisition of natural speech (Hanline, Nunes, & Worthy, 2007). AAC systems also provide children with a means to increase opportunities to make choices and to develop autonomy (Romski & Sevcik, 2005). Lastly, for young children in particular, AAC interventions can help build the solid foundation in language that is essential to subsequent literacy learning (Sturm & Clendon, 2004).

When devising AAC systems for children, the role of families is integral to the child's successful use of the AAC, particularly in the home (Downing, 2002). Parents are key communication partners because they can provide important social experiences, especially in the very early years, and opportunities to practice using AAC systems to facilitate communication, language development and social interactions. For these reasons, families need to be involved in the process to successfully integrate and support the use AAC by the child in the home (Parette & Angelo, 1996). Furthermore, it is necessary that parents are trained to be communication partners to support their children's communication development through the use of AAC (Starble, Hutchins, Favro, Prelock, & Bitner, 2005).

The problem is that although the use of AAC as part of children's language intervention holds tremendous promise for children with FXS and related disorders to promote the development of strong communication skills, research indicates there is a high degree of abandonment when parents start to use AAC with their child and then give up (Angelo, 2000); underuse when parents who do not know about AAC (Parette & Angelo, 1996); lack of professional support in using AAC in natural environments, particularly in the home (R.L. Bailey, Parette, Stoner, Angell, & Carroll, 2006); and limited knowledge of how AAC systems are used in the context of the home (Granlund, Bjorck-Akesson, Wilder, & Ylven, 2008). Also, parent involvement has historically been minimal when professionals make decisions regarding the use of AAC (Parette & Angelo, 1996). Lastly, little is known about how culture impacts parents' decisions to use AAC in the home and how professionals support families from diverse backgrounds (Parette, Brotherson, & Huer, 2000).

Hence, for AAC use to be successful families need support. The responsibility for ensuring that children with FXS and related disorders have effective means of communication through the use of AAC must also be a shared commitment between family members and professionals (Stephenson & Dowrick, 2005). Close collaborations and the building of strong partnerships between professionals and families can help reduce or even eliminate frustration, nonuse, and underuse of AAC systems (Parette & Brotherson, 2004; Parette et al., 2000). Professionals also need to understand how to individualize and tailor AAC intervention to include not only the child but also the family (Goldbart & Marshall, 2004), including those from diverse cultures. How to accomplish family-centered and culturally responsive AAC interventions may be especially

challenging when considering families from diverse cultures (Parette & Brotherson, 2004).

The field of AAC is a relatively new area of clinical research and practice and there remains a paucity of research regarding family-centered and culturally responsive AAC practices. In the last 30 years, much of the existing AAC research regarding children has involved descriptive studies (e.g., survey, case studies, focus groups) that have identified patterns of behavior and implications for interventions, but few studies have included observations of AAC use in the context of the home to understand how parents communicate with their children who use AAC in everyday interactions. Furthermore, the few studies that have focused on the families of children who use AAC have focused on parent perceptions regarding the benefits and challenges of children's use of AAC systems, but the extent to which these systems are incorporated into everyday activities in the home is still unclear. Also, there are limited qualitative studies that have focused on parents' experiences in the AAC implementation process and their perceptions related to the support they receive in that process. Lastly, there is a paucity of research addressing issues of cultural and linguistic diversity with regard to AAC. In order to guide clinical practice using AAC interventions and to maximize communication outcomes for children with FXS and related disorders, further qualitative analysis is needed to understand the perspectives of parents on communication and use of AAC in the home and the process parents undergo when making decisions to use AAC for their children. Qualitative methods will offer a more comprehensive insight to understand parent perspectives of AAC interventions for children with FXS, as well as how parents use AAC with their children in the context of the home.

There are many reasons to study FXS and AAC use. Emerging newborn screening for genetic conditions such as FXS present unique opportunities for professionals to offer early support to families that will maximize early intervention and treatment options for communication through the use of AAC. According to D. B. Bailey, Armstrong, Kemper, Skinner, and Warren (2009), emerging newborn screening and the study of genetic conditions such as FXS provides a coherent model for researchers and professionals to develop procedures that will empower families to access accurate and understandable information, seek out support from professionals and other parents, receive periodic screenings and active surveillance of their child's development, and plan for general and targeted interventions mutually agreed upon by professionals and parents. What we learn about FXS will have significant implications for how to plan interventions and support parents of children with related disorders such as autism, especially as it relates to use of AAC as a targeted intervention to promote communication.

Information about AAC strategies used by children with FXS and their caregivers in natural contexts would be very useful for both professionals and families. Most importantly, families often question professionals and other parents about expected development for their children, but there is currently little information available to convey (Brady, Skinner, Roberts, & Hennon, 2006); and parents may be hesitant to introduce AAC strategies without access to accurate and understandable information (D. B. Bailey et al., 2009). Therefore, the purposes of this study were (a) to examine the perspectives of mothers of children with FXS on communication and the use of AAC in the home, (b) to examine how these mothers participated in the process of implementing

AAC in the home, and (c) what support they received in that process. To answer these questions, qualitative analyses were required. This study contributed to information forthcoming from previous studies and expanded our understanding of how mothers of children with FXS view AAC intervention as a method to promote communication in everyday interactions with family members at home. Understanding their perspectives will help guide professionals working with families to plan appropriate training and support for parents of children with FXS.

Chapter 2: Review of the Literature

AAC is one language-intervention approach that can improve communication for children with FXS and related disorders. A review of the communication development in FXS by Roberts and colleagues (2008) indicated that children with FXS might be well suited for AAC interventions due to significant impairments in communication as a result of moderate to severe delays in all aspects of language. Children with FXS often display poor speech intelligibility, repetitive and tangential speech, and poor topic maintenance that affect their conversation abilities (Brady et al., 2006). Although many children with FXS, particularly boys, do not learn to speak until very late, some do not learn to speak at all, and those who do learn how to speak may be difficult to understand (Roberts et al., 2008). Furthermore, the presence of cognitive, behavioral, and/or oral-motor problems may also contribute to deficits in communication for children with FXS (NFXF, 2010). These challenges are complicated by the fact that approximately one third of children with FXS also have autism and present with stereotypic behaviors such as hand-flapping, restricted interests, and aggressive behaviors that impact communication and social interaction (Roberts et al., 2008). Based on these difficulties, children with FXS may benefit significantly from AAC interventions.

Although there is only one research study involving AAC and FXS (Brady et al., 2006), there is a growing body of research that has shown that targeted AAC interventions can ameliorate the significant communication deficits of children with other developmental conditions, by improving their ability to be understood by others, assisting with the maintenance of conversations, and increasing social interactions with others. Because children with FXS share similar deficits in communication, it will be important

to understand how the use of AAC impacts their communication development. This will also have implications for promoting communication development in related disorders (Brady et al., 2006). Moreover, research has shown that in order for AAC interventions to be effective, parents need to be actively involved throughout the implementation process (Granlund et al., 2008). Hence, understanding the perspectives of parents of children with FXS will be crucial for AAC interventions to be effective.

The purpose of this chapter is to review the literature relevant to understanding the perspectives of parents of children with FXS about their children's communication and use of AAC in the home. A search of literature on the topic of AAC use in families of children with FXS revealed only one study (Brady et al., 2006). A more general search of literature on the topic of AAC use in families revealed a limited body of research. Electronic searches via ERIC, Medline, and Psych Info databases, *Augmentative and Alternative Communication* journal, and a hand search from reference lists of secondary sources of books, chapters, and review articles was conducted. Despite the limitations of the research, five main themes emerged as important aspects of AAC use by children: (a) evidence of AAC use as a promising practice; (b) underuse of AAC; (c) limited parental input in the implementation of AAC; (d) need for attention to cultural issues in families' support of AAC use; and (e) lack of detail on how AAC is used in the home. In addition, I conducted a small preliminary case study that indicated the potential for AAC use to be an overwhelming process for parents. Five themes and the case study will be discussed below.

Evidence of AAC as a Promising Practice

A review of research on AAC systems for children with related developmental conditions, who exhibit complex communication needs, revealed that AAC promoted positive child outcomes and parental experiences. Child outcomes related to AAC use included increasing speech production, decreasing challenging behaviors, improving communication skills (Roberts et al., 2008), and promoting learning (Sevcik, 2006). It was also found that many parents are hesitant to use AAC intervention approaches for fear that AAC will replace or inhibit their child's natural speech development. Fortunately, research findings suggest that this fear is unwarranted and that AAC systems do have a positive impact on natural speech production (Light & Drager, 2007; Millar, Light, & Schlosser, 2006; Sigafoo, Didden, & O'Reilly, 2003; Schlosser & Wendt, 2008). Only one study, by Brady and colleagues (2006), in which 55 mothers of young children with FXS were interviewed, revealed that over half the children in the study were reportedly beginning to talk and learning to communicate using AAC. These mothers reported that AAC use diminished as their children's speech increased and improved.

In addition, a body of research has also shown that AAC use decreases challenging behaviors in children with autism and related disorders (Durand, 1999; Mirenda, 1997). Challenging behaviors frequently observed in children with autism may include aggressive behavior to self and others, restricted interests, or stereotypic and repetitive actions. Since one third of children with FXS also meet criteria for autism and exhibit similar behavior challenges, AAC may be a viable strategy to reduce challenging behaviors in children with FXS (Roberts et al., 2008).

Furthermore, a strong common finding in the research revealed that AAC use improves a child's functional communication by repairing communication breakdowns; increasing initiations, requesting, and interactions; and improving comprehension (Bock, Stoner, Beck, et al., 2003; Brady, 2000; Dicarlo & Banajee, 2000; Durand, 1999; Johnston, Nelson, Evans, & Palazolo, 2003; Light & Drager; Romski, Sevcik, Adamson, et al., 2010; Romski, Sevcik, & Adamson, 1999; Sevcik, 2006; Sevcik et al., 2004; Sigafoo et al,. 2003; Sigafoo, Drasgow, Halle et al., 2004). AAC systems can be integrated into the user's own repertoire of communication skills to enhance conversations with others (Romski et al., 1999). Studies on AAC interventions also indicated that not only does AAC use have a positive effect on the child's social interactions and communication exchanges, but that AAC use increased the number of familiar and unfamiliar communication partners (Romski et al., 1999; Sevcik, 2006). For example, Romski and colleagues (1999), in their investigation of 13 youth with intellectual disabilities with and without their AAC systems, found that the youth were able to convey more appropriate, clearer, and more specific information to unfamiliar partners with their AAC systems.

A review of research on the use of AAC systems in young children by Light and Drager (2007) revealed that, in addition to increased speech production and communication skills, young children with communication impairments use multiple modes to communicate, including unaided and aided AAC systems. The review of research also identified priorities for future research that included the need to consider the preferences of young children and their families in order for AAC systems to be effective. In addition more research is needed to identify children who would benefit

from AAC intervention sooner rather than later, as well as to identify better support for parents and other communication partners in the operation, maintenance, customization, and implementation of AAC systems.

The extant research on parent experiences revealed that parents of children using AAC reported enhanced communication, increased independence of the child, better relationships with their children, and overall positive experiences and attitudes. (Angelo, 2000; Angelo, Jones, & Kokoska, 1995; Angelo, Kokoska, & Jones, 1996; R.L. Bailey et al., 2006; Brady et al., 2006; Hetzroni, 2002; Sevcik et al., 2004) Parents identified their main priorities as increasing knowledge of AAC, finding trained professionals and advocacy groups of other AAC users (Angelo, 2000; Angelo et al., 1995, 1996). A descriptive study on the impact of AAC systems on families indicated that parents gained considerable knowledge about devices, educational and social opportunities were increased, and an overall sense of satisfaction and positive outcomes were achieved as a result of their AAC experience (Angelo, 2000). A more recent study investigating parent experiences and priorities conducted by R. L. Bailey and colleagues (2006), revealed that parents' perceived impact of AAC on their children included increased independence, communicative competence, communication partners, and communication opportunities.

Underuse of AAC

Despite the perceived benefits of an AAC system, many parents who start to use AAC with their children give up on the use of AAC systems in the home. The research on AAC has largely focused on understanding the reasons why there is a high degree of parent abandonment and underuse of AAC with children (Parette & Angelo, 1996). Possible reasons for AAC abandonment included increased demands on the families,

primarily mothers, as well as on professionals, less of a need for AAC use in the home, lack of knowledge about AAC, and limited support (Angelo, 2000; Angelo et al., 1995, 1996; R.L. Bailey et al., 2006; Goldbart & Marshall, 2004; McNaughton, Rackensperger, Benedek-Wood et al., 2008; Stephenson & Dowrick, 2005) Other family factors that have contributed to abandonment of AAC include perceptions that the AAC system is inefficient and cumbersome, the device is difficult to use, and the AAC system fails to increase the child's independence (R. L. Bailey et al., 2006; Goldbart & Marshall, 2004; Stephenson & Dowrick, 2005).

A study by Goldbart and Marshall (2004) on parent views and experiences with AAC revealed that parents felt that AAC use was effortful and time-consuming and they reported increased demands in the implementation of AAC in the home. In another study parents had developed their own ways of communicating with children and felt less of a need to use AAC in the home (R.L. Bailey et al., 2006). McNaughton and colleagues (2004) found that many parents learned to use AAC on their own by reading manuals, calling the manufacturer, and attending AAC training courses and felt that professionals did not have sufficient knowledge or experience with AAC. Brady and colleagues (2006) found that over half of the mothers who reported using AAC with their children with FXS were doing so without input from their children's speech and language pathologist (SLP). A study by Stephenson and Dowrick (2005) revealed that where schools had introduced formal AAC systems, parents were not always in favor of its use at home and some parents reported not having access to the AAC system in the home.

Limited Parental Input in Planning for AAC Use in the Home

A review of research on parental involvement indicated that parents have much information to share with professionals, as well as clear expectations and priorities regarding AAC use (Angelo, 2000; Angelo et al., 1995, 1996; Goldbart & Marshall, 2004; McNaughton et al., 2008; Parette et al., 2000). Parents and other family members play a key role in facilitating language, communication, social interactions, and successful outcomes in AAC, and it is important that they be involved in the AAC decision-making process (Angelo, 2000). Because parents spend much time with their young children, they may serve as effective interventionists (Granlund et al., 2008). Actively involving parents and other family members in the process of AAC intervention has the potential to enhance the child's use of AAC, especially in the home (Nunes & Hanline, 2007). Another important reason to support and involve families in the process is that well-informed parents can become valuable resources for other families (Angelo, 2000).

In order for AAC interventions to be effective, professionals need to communicate and collaborate with parents. Research investigating parental involvement in the use AAC systems revealed parents often play an inactive role and professionals do not always address their perspectives during the AAC decision-making process (R. L. Bailey et al., 2006; McNaughton et al., 2008; Parette & Brotherson, 2004). Through semistructured interviews with 6 families, R.L. Bailey and colleagues (2006) found that school professionals made AAC decisions first before including parents. Parette and colleagues (2000) through focus groups with 5 families found that families want to be included in the AAC decision-making process.

Research also indicated lack of collaboration and ineffective teaming (a single meeting or conversation) leads to poor AAC decisions (R.L. Bailey et al., 2006; Brady et al., 2006; Goldbart & Marshall, 2004; Hetzroni, 2002; McNaughton et al., 2008). Goldbart and Marshall (2004), through ethnographic interviews of 11 parents and caregivers of young children who were beginning to use AAC, found that parents had much information that could be of use to therapists and teachers who worked with their children. For example, parents gave rich descriptions of their children's level of communication, comprehension, intelligibility, and how the children communicated choices. Most parents in the study felt that they needed to be assertive to obtain services for their children and reported ongoing struggles to keep professionals active on behalf of their children. In a study conducted by Brady and colleagues (2005) mothers reported learning about and using AAC on their own, while their children's SLPs were focused on speech production. In a survey of 74 family members who are current or potential users of AAC in Israel, Hetzroni (2002) found that only 21% of families reported that they were involved in the development of the AAC system; it was mainly speech-language pathologists (48%), teachers (14%), or school team members (15%) who developed the AAC system. These findings point to the need for professionals to better understand the wide range of parents' perspectives about AAC in order to develop strong collaborative partnerships with parents.

Another study on parent views on team decision making indicated that families want to be included in providing information during the AAC decision making process and families want professionals to recognize that children may refuse to participate with new team members. Families reported wanting professionals to establish rapport with

their children and to respect their values, beliefs, and culture. Families expressed the need for support to use AAC systems (Parette et al., 2000). Snell, Chen, & Hoover (2006) reviewed and synthesized AAC research from 1975 to 2003 and concluded that few studies described how AAC decisions were made suggesting the lack of collaboration between professionals and parents.

A study by R. L. Bailey and colleagues (2006) involving semi-structured interviews of 6 family members of children using AAC devices in school settings revealed the need for improving collaborations between families and professionals. Similarly, a study by Parette and colleagues (2000) involving focus groups and structured interviews with families suggested that intervention abandonment occurred with families who were initially committed to AAC intervention, as a result of lack of parent support and training. Overall, previous research on family perspectives have focused on needs, priorities, and preferences of parents of children who use AAC; further research is needed to understand the influence of family needs on AAC intervention service delivery in the home (Parette et al., 2000; Snell et al., 2006).

Need for Attention to Cultural Issues in Families' Support of AAC Use

According to Parette and colleagues (2000), there is a growing need for cultural sensitivity with regard to families and for professionals to better understand family's needs, concerns, and priorities when identifying and developing AAC systems for children with disabilities. In spite of its importance, cultural sensitivity is not a widespread practice in AAC service delivery. These researchers found two major issues for families from different cultural backgrounds regarding how they want professionals to build family–professional partnerships: First, families expressed the need for

professionals to minimize jargon, be straightforward, and communicate clearly. Second, families expressed the importance of being involved in team decisions. Regarding cultural sensitivity, the issue of stigma associated with being a member of a minority group and having a disability was mentioned. Parents in the study spoke of not wanting to draw more attention to their child. Stigma was also related to the need to have their child accepted into the community and accepted into peer groups. Many family members expressed the importance of considering and including extended family and siblings in the AAC decision-making process. Also, families wanted professionals to be sensitive to the demands, needs, routines, and realities of the home. Lastly, families in the study expressed a need for information and training on how to use the AAC system with their child in the immediate and extended family.

Previous studies investigating AAC and culture have mostly dealt with concerns from a broad cultural perspective. Studies of specific cultural groups in the United States revealed that families from different cultural groups have different perceptions regarding the use of AAC systems in different settings and their role in the AAC decision-making process (McCord & Soto, 2004; Parette, et al., 2000; Parette, Huer, & Wyatt, 2002). In an ethnographic investigation of 4 Mexican-American families, McCord and Soto (2004) found that AAC was consistently valued as a communication tool in specific environments. For example, families recognized the value of using the AAC device at school for educational purposes. However, language barriers and work schedules interfered with parents' ability to participate in AAC team meetings. Parents were less inclined to use the AAC system at home because they did not know how to support or maintain the system at home. Parents also expressed that the device itself was not

functional for home use because they could not derive meaning from icons or programmed messages on the device or understand the English voice programmed on it.

Smith-Lewis (1992) reported that African American and Hispanic parents of children with severe disabilities frequently resisted the use of AAC systems and perceived AAC as unnatural and in some cases stigmatizing (as cited in Harry et al., 1995). Similarly, Parette and colleagues (2004) interviewed 6 first-generation Chinese American families. They expressed concerns regarding the possible social stigma attached to using AAC devices. They expected ongoing training and support from schools and preferred that their children not become dependent on their AAC device to communicate. The limitations of these studies included a small sample size and the need to study other cultural groups to better understand the AAC-related concerns and challenges experienced by other cultural groups. More research and attention to cultural issues is needed to identify and remove barriers to support families' use of AAC in the home.

Lack of Detail of How to Use AAC in the Home

In a review of research, most studies that considered AAC in family settings has focused on gathering evidence of the effects of AAC interventions, rather than on implementing evidence-based strategies in everyday practice to improve outcomes (Granlund et al., 2008). In addition, there remains a paucity of research on how young children use AAC systems in home settings with parents as the facilitators (Sigafoos, O'Reilly et al., 2004). Snell, Chen, and Hoover (2006) reviewed 40 studies of AAC interventions involving children and only 6 of the 40 studies included parents implementing the AAC interventions. In addition, only 8 of 40 focused on conducting

AAC interventions in home environments. Much of the AAC research was largely based on questionnaires, focus groups and interviews, lacking specificity to AAC use in the home (Grandlund et al. 2008). More research is needed to examine the extent of AAC use in the home and the use of AAC systems for children with FXS. Such studies could provide a model to understand how to enhance language development for other children with developmental disabilities and their families.

Although practitioners and researchers recognize the critical importance of evidence-based AAC interventions, more research is needed to understand the perspectives of parents of AAC users, to design AAC systems that support not only the child but also the parent. To date only minimal research is available to investigate the perspectives of parents and use of AAC in the home. Research on the use of AAC in the home suggested that training parents to be interventionists and coaching parents to be communication partners in AAC intervention resulted in increased child engagement, enhanced communication, and positive parent experiences (Kent-Walsh, Binger, & Hashman, 2010; Nunes & Hanline, 2007; Romski & Sevcik, 2010; Sevcik et al., 2004; Sigafoo, O'Reilly, Seely-York, et al. 2004). The preferences and priorities of parents and young children need to be better understood to effectively use AAC systems with young children with complex communication needs (Light & Drager, 2007).

In an exploratory study conducted by Kent-Walsh and colleagues, 6 parents of children using AAC were trained to be communication partners and results revealed that parents learned to implement the communication partner AAC intervention strategy and all children increased turn taking and language use. Nunes and Hanline (2007) investigated the effects of a parent implemented AAC intervention in the home that

resulted in the increase use of 2 communication strategies (environmental arrangement and modeling the use of the device) across 2 home routines following treatment. The children increased frequency of initiations and responses. Romski and Sevcik (2010) found that a parent coached AAC intervention had a positive effect on the children's communication. The children increased their comprehension and use of targeted vocabulary words. These studies suggest that parent coaching and training parents to be interventionists are viable approaches to integrate AAC interventions in the home.

Case Study

As a pilot study of parental use of AAC, I conducted a case study to examine the perspective of 1 mother of a young child with severe speech and language impairments who was beginning to use AAC. This study involved two separate interviews with the mother and the school team and two observations: a team meeting at school and a meeting with the AAC specialist at the child's home. Field notes of the observations and transcripts of the interviews were analyzed using grounded theory. The mother reported that the decision to use AAC with her child was an overwhelming process. She described the term *overwhelming* in two distinct ways: both as an emotion and as representative of too many things going on at once. The mother expressed the overwhelming feeling of hoping her child would talk and the frustration of trying to figure out what to do. The recorded transcript of the interview, revealed how this mother described *overwhelming*:

> It has been a hurricane this past 2 years and the different stages from in the beginning, when you think there is nothing wrong, and your kid doesn't need any help to … I mean this has made me a better person. It makes me want to do what you are doing. I would love to go back to school and do something to help other kids and that never crossed my mind before having Timothy. It has been exhausting to get to the point where we are. I am suddenly starting to feel calm and he is in great hands and I have done everything that I could. ... I would hate regretting having not done something for him. But I totally feel confident that I

have done everything that I can and that keeps me at peace. However, it turns out I know that I have done everything.

The mother also used the word *overwhelming* to represent many things going on at once. For example, she explained how overwhelming it was to take her son to and from school, which was sometimes a 3-hour commute, and for different therapy appointments recommended by professionals, and meetings with experts to understand her child's diagnosis and treatment. Other persons involved with this child also experienced the feeling of being overwhelmed. For example, the teacher described feeling overwhelmed when the communication device was first introduced by the school AAC specialist and the mother used overwhelming to describe the experience of her son having too many things (AAC, school, therapies) going on at once.

The decision to use AAC was also driven by the mother seeking to understand her child's needs, to confirm the diagnosis, and her need to determine how aggressively she should pursue AAC. Her decision to use AAC was also reinforced by her attitude and belief that supported the use of AAC. For example, the mother described the importance of continuing to use the AAC device with her child who was beginning to talk more:

> I understand, but my husband doesn't understand everything that he says. That is why I am still pushing the communication device just because he is talking, I don't think we are clear yet. It might take a couple of years before he is clear to other people.

The mother, seeking input from professionals and getting many different opinions, demonstrated her deep desire to understand and meet her child's needs. This mother reported researching by reading books, perusing the Internet, attending conferences and workshops, and speaking to experts to make decisions regarding not only AAC, but also appropriate schools, and other interventions and therapies. She also actively learned language-intervention techniques such as Voice Output Communication

Aids (VOCAs), Picture Exchange Communication System (PECS), other visual-graphic communication boards, oral motor therapy, and the use of sign language to support the interventions at home. In her pursuit of AAC devices and interventions at school, the mother also emphasized preparing for the Individualized Education Program (IEP) meeting by learning about the process, figuring out what her son needed to know, what to ask for, and learning about the supports available through the school district. The mother described how she prepared for the initial IEP meeting:

> Just learning what IEP means and I even learned that you can hire a lawyer for IEP meetings, which I would never do but it made me think, wow this is something serious that I need to really read up on and not just show up but I need to really know what to expect and know what do I want for him. I mean I wasn't even sure what I wanted, I wasn't even sure I wanted to send him to school. I had no clue what to expect and what to ask. So what I learned was to do my homework and figure out what is an IEP, what I am trying to decide what is this going to do to him on his record in 3 years, 5 years.

The mother also expressed a willingness to share information with others by speaking up and "pushing for it." For example, at the beginning of the pre-kindergarten school year the mother asked for an AAC evaluation. She also provided information to the school team at the initial IEP meeting. She created handouts and a portfolio about her son that contained a photograph of him, all previous evaluations from private specialists, information about his diagnosis, and treatment recommendations from experts. She also prepared an outline of goals and priorities for the school team to consider. In the interview the mother described presenting the portfolio to the school team:

> Yeah and I made like 10 copies and I did not know how many people were going to be there. My husband was embarrassed and I was handing it out and he was like, "I can't believe she did this." But at the end he was like, "Thank God you did that." He was looking at me like … and even the teacher said that it was amazing. And for the 4 hours of the meeting we just used the presentation. So I do not know what we would have used without it. We would have just ended up talking and we wouldn't have a guide or an agenda to follow. … So it helped out a lot.

It was also evident from reports by the school team and mother that the child

responded positively to the AAC intervention. The child quickly outgrew the VOCAs

and PECS that were implemented at home and school. As recorded in the field notes, the

SLP described the child's ability with the device:

> The SLP comments that she is amazed at how well he uses the device and that he
> "navigates it like a whiz." She adds that he comes up with phrases on his device
> that she did not even teach him.

His mother and the school team discussed how the child has been using the device

to communicate with others. At school his teacher reported that he uses the AAC device

to say, "Good morning" and "How are you?" His mother also stated that he uses the

device to say, "I am excited!" and "I love you!"

The school team was receptive to the information shared by the mother. They

quickly established rapport with her and the child and were open to the child's use of the

device, as well as to the goals and priorities outlined by the mother. The school

personnel discussed reading the reports and information provided by the mother that

helped them make the decision to initiate AAC services through the school district.

When interviewing the school team, the teacher communicated her thought about the

packet of information that was provided by the mother:

> I think initially the first staffing is when she gave us an amazing packet about him
> which I still have in his folder with his picture and the things he is doing at home
> and the goals that she wants for him and some of his behaviors and all that stuff
> and I think it was that initial meeting which I think was in July or August where
> she talked about the things that he was doing at home … so we just figured to
> carry some of that over.

The teacher and SLP at the school described a willingness "to go beyond to do what is

right" for the child. They had a positive attitude and belief that supported the use of

AAC. The teacher discussed the importance of working collaboratively with the SLP,

paraprofessional, and mother as a team, and seeking AAC support and training through the school district.

Finally, the school district had policies and procedures established that facilitated the decision to use AAC with the child. The school district had adopted policies for the consideration of AAC as mandated by the federal Individual with Disabilities Education Act. The school district had developed procedures such as an Assistive Technology Implementation Plan AAC decision-making procedure to assist teachers to select AAC tools and strategies. Lastly, the school district provided AAC support specialists to assist teachers, school teams, and parents in selecting, maintaining, and training on the use of AAC devices and strategies. The findings also raised additional issues of culture, socio-economic status, and educational level.

Results of the case study on parent involvement in the AAC decision-making process revealed that the decision to use AAC for a young a child with severe speech and language impairments was an overwhelming process that was driven by a mother's strong determination to understand her child's needs and eagerness to share information with others, and was mediated by the child's response to AAC intervention. In addition, the process was influenced by school personnel's receptiveness to the shared information and willingness to "go beyond to do what is right" and the school system's establishment of policies and procedures. The literature on the use of AAC for young children states the importance of parent involvement in the decision-making process and the findings of this case study support that assumption.

While the results of this preliminary case study increased the understanding of the importance of parents in the AAC decision-making process, this small study led me to

ask the following questions: (a) How do mothers communicate with their children with complex communication needs who use AAC, (b) What are their experiences regarding communication and use of AAC in the home, and (c) How were they supported in their decision to use AAC. To understand the nature of AAC use in the home and the experiences of mothers, qualitative methods involving observations and interviews were necessary. This study increased the understanding of mothers' experiences regarding FXS, communication, use of AAC, and challenges associated with using AAC in the home for children with FXS. The research questions for this study were as follows:

1. How do mothers communicate with their children with FXS who use AAC in the home?

2. What are their perceptions regarding FXS, communication, and AAC?

3. How were these mothers supported in their decision to use AAC?

Chapter 3: Methods

A qualitative multi-case study research design was used to investigate the experiences of mothers of children with FXS regarding communication and use of AAC systems in the home. Qualitative research is the study of naturally occurring experiences of people where fieldwork is required to gain an understanding of what people are thinking and doing surrounding a particular experience (Patton, 2002). According to Strauss and Corbin (1998), qualitative inquiry is a "nonmathematical process of interpretation, carried out for the purpose of discovering concepts and relationships in raw data and then organizing these into a theoretical scheme" (p. 11). There are many different approaches to qualitative inquiry such as ethnography and phenomenology that are used by social scientists in many fields such as anthropology and sociology.

Qualitative research is commonly used to understand a phenomenon when little is known, to gain a new perspective on things when much is known, or to gain more comprehensive insight that maybe difficult to convey quantitatively (Strauss & Corbin, 1998). Features of qualitative inquiry involve (a) the study of real-life experience as they occur naturally; (b) systematic data-collection procedures that use purposive sampling, selecting cases that contain useful information on the phenomenon of interest, participant observations, in-depth interviewing, and review of archival documents; and (c) inductive analysis of the data that involve the immersion of detail and interpretations to develop a theory (Bogdan & Biklen, 1998; Lincoln & Guba, 1981; Patton, 2002). The main reasons for choosing to use qualitative methods for this study included seeking to understand the experiences of mothers related to communication and use of AAC, exploring a topic on which little information is known about how mothers of children with FXS use AAC

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systems, and seeking an in-depth exploration of mothers' perceptions regarding the AAC use in the context of the home.

In this study I collected data through semi-structured interviews, review of archival documents, and participant observations. Semi-structured interviewing is a process in which a general interview guide is developed and the researcher probes more deeply on topics and issues initiated by the participant that relate to purpose of the study. Review of archival documents includes the use of relevant documents that supplement information obtained through observations and interviews. In participant observation, the researcher participates in or experiences the setting under study in order to get an insider's view, simultaneously remaining aware of being an outsider. The challenge in participant observation is to combine participation and observation in order to understand the setting as an insider while describing it from an outsider perspective (Patton, 2002). Bogdan and Biklen (1998) used the term *participant/observer continuum* to discuss the degree to which a researcher participates in an observation. On one end of the continuum the researcher is merely an observer and does not participate in the observation at all; on the other end is complete involvement with little discernible difference between the researcher's and participant's behaviors. The researcher must decide what and how much participation is appropriate depending on the study and should stay somewhere between the two extremes on the continuum.

Grounded Theory Approach

Data for this study were analyzed using grounded theory methods. Grounded theory, developed by sociologists Glaser and Strauss is an inductive approach that consists of a systematic and flexible process for collecting and analyzing data to construct

theory that is "grounded" in the data (as cited in Charmaz, 2006). The components of grounded theory include the simultaneous process of data collection and analysis, construction of analytic codes and categories derived from the data, constant comparison at each level of the analysis, development of theory, and memo writing to elaborate categories (Charmaz, 2006).

Sampling

This study made use of purposive sampling, whereby participants for the study were selected who were "information rich" and representative of the phenomenon of interest (Patton, 2002). Participants were recruited through the South Florida Fragile X Research Consortium Registry, which is a data repository of individuals who either have FXS or that have a family member with FXS. One of the purposes of the registry is to provide a database for FXS researchers to find people who are interested in participating in research studies. I contacted the registry with a description of the study. This yielded no participants. I also used a variety of methods to make eligible individuals aware of the research. I enlisted the help of those individuals or groups/organizations that already have a relationship with eligible participants, such as healthcare professionals, educators, assistive technology specialists, SLPs, and support groups. I provided these individuals with information, such as flyers, or approved text to disseminate directly to interested individuals. The Florida Fragile X Families Foundation also assisted in spreading the word. As a result of these efforts, 3 interested mothers contacted me to participate in the study.

In addition, theoretical sampling was used in which additional participants were added to explain categories that emerged from the data (Charmaz, 2006). One mother

named Kathy, whom I met at an international FXS conference, was added to the study because she offered an insightful perspective regarding AAC use in the home. She was successfully using AAC in her home with her two young sons with FXS. However, she did not meet criteria because she did not live locally so an amendment was submitted to the Institutional Review Board to include her in the study. The decision to include her in the study came about after the home visits and interviews with the other three mothers yielded limited information regarding how these mothers were using AAC in the home. Therefore, it became apparent that adding another mother's perspective would help in validating the emerging themes regarding AAC use in the home.

Family Demographics

A visual representation of the families in this study can be found in Appendix A. The 4 mothers each had at least one child with FXS. One mother, Beverly, lived in Broward County Florida; 2 mothers, Carolina and Rosemary, lived in Miami-Dade County Florida; and the 4th mother, Kathy, lived on the west coast in Oregon.

Beverly is married and is the mother of two children with FXS: Mary age 11, and Gary age 8, who was diagnosed with full mutation FXS at age 2. Carolina is married with two sons with FXS: Robert age 26 and Manny age 12, who was diagnosed with full mutation FXS when he 2 years old. Gary and Manny were diagnosed with full mutation FXS after their older siblings were diagnosed. Rosemary is married with three children: Walter age 9, who was the first family member diagnosed with full mutation FXS at age 3; Allison age 7 who is a premutation carrier; and Abigail, age 1, who was recently diagnosed with full mutation FXS although her development is on target for her age. Lastly, Kathy is married and has two young sons with FXS: Greg age 6 and Tom age 4.

Greg was diagnosed at Age 2.5 years and Tom was diagnosed at 6 months as a result of

Greg's diagnosis. All mothers are premutation carriers.

Data Collection

This study used three types of data collection: (a) open-ended semistructured

interviews, (b) participant observations, and (c) review of archival educational records to

gather the mothers' perspectives regarding AAC use in the home. The 3 mothers who

lived locally received 6 to 8 home visits each. Each home visit consisted of an

observation and interview for a 60- to 90-minute time period. Many home visits needed

to be divided into shorter segments at the discretion of the mothers; therefore, additional

home visits were necessary. In addition, I was only able to recruit 3 local mothers, rather

than 4, so I decided it would be important to schedule additional home visits with each of

the 3 participants to spend more time in the homes investigating the emerging themes.

The 4th mother who was added to the study participated in six 30- to 60-minute

telephone interviews. All mothers provided copies of education records for the five

children in the study.

A field log was used to record notes and observations and a digital audio recorder

was used to record the interviews and observations during each home visit. The

audiotapes were transcribed verbatim using a transcription service. I checked the

transcripts for accuracy by simultaneously listening to the audiotapes and reading the

transcripts to fill in any missing information, as needed.

All mothers who participated in the study were informed of the purpose,

procedures, and alternatives to participation. Mothers were contacted by telephone to set

up a time to obtain consent and to do the first home visit. Mothers were asked to

determine a time for the meeting with me at their home. Consent was obtained in person

during the initial home visit from the 3 mothers who met inclusion criteria and who

indicated an interest in participating in the study. In addition, a waiver of written consent

was obtained for family members who were present at home visits and included in the

observation. An amendment to the Institutional Review Board was submitted to allow

the 4th mother, who lived in another state, to participate in the study. In this case,

consent was obtained by telephone.

After consent was obtained, the initial home visit for 3 of the mothers consisted of

a 30- to 90-minute interview and served as an opener to establish rapport and to work to

make them feel comfortable with my presence. The purpose of the initial interview was

to ask preliminary questions on background information about the child and family (see

Appendix B). Follow-up questions were based on the guiding interview questions that

directly related to the stated purpose of the study.

At the conclusion of the initial home visit, subsequent home visits were explained

and scheduled. Mothers were asked to determine two or three activities that they

typically do with their children, such as play at the park, visit the library, eat out at a fast-

food restaurant, where I could accompany them to observe the children using AAC to

communicate with their mothers and/or other family members (see Appendix C)

Subsequent home visits consisted of 30- to 60- minute participant observations to observe

mother–child interactions surrounding a typical and natural activity in which I could

observe the mothers communicating and interacting with their children who use AAC

systems. A participant-observation method was used to establish rapport with the

mothers, whereby I participated minimally in the experiences of the mothers in the field

so as to get an insider view of communication and AAC use while remaining an outsider. Subsequent home visits also involved a 30- to 90-minute interview (see Appendix D). The purposes of these interviews were to ask more specific questions related to the family and child's communication and use of AAC.

To establish rapport and make the mothers comfortable with my presence, I remained relatively passive, while showing interest in what I was learning about the family. General questions during the interview and observation were used to provide the mothers an opportunity to talk. I remained polite and friendly as I was introduced to the family. During the participant observation, I remained somewhat detached. As rapport was established with the mothers, I was asked to participate in family activities. For example, during an outing to the library with Beverly and Gary, I helped them search for a favorite book about trains. The goal was to maintain the role of a researcher collecting data related to the purpose of the study while ensuring that the family felt as comfortable as possible with my presence.

The final 60- to 90- minute home visit with each mother served as a member check and was scheduled after the data were initially analyzed. This visit served as a formal member check to assess the adequacy of the data and preliminary results. During this visit I reviewed emerging ideas with the participants for their verification and asked follow-up questions to clarify and elaborate on information gathered in previous home visits. In the member check with Kathy, the mother of two young sons who was successfully using AAC in her home, I reviewed emerging categories and themes derived from the analysis of data to inquire whether and to what extent these categories and themes fit her experience.

Mothers were also asked to gather and provide copies of the following educational records: previous psychoeducational evaluations, speech and language evaluations and therapy progress notes, and IEPs. Field notes were used to document information that related to the purpose of the proposed study.

Data Analysis

Field notes and transcripts were coded using the analytic procedures of grounded theory and the qualitative data-analysis software program, ATLAS.ti, version 6.0 to manage the codes. A constant-comparison method was used to inductively analyze the data throughout the study, whereby the data were coded and compared to initial and emerging codes, categories, and themes to either merge or create new codes, categories, or themes until no new codes, categories, or themes emerged. The first step involved open coding to identify patterns of words and phrases in the field notes. In this step I closely analyzed the field notes line by line to begin conceptualizing my ideas. This step yielded hundreds of open codes. In the second step, these initial codes were compared and refined using a procedure called focused coding. In this step I separated, sorted, and synthesized the initial codes that resulted in 30 refined and distinct open codes. The third step involved grouping the refined codes into 10 conceptual categories, also referred to as axial codes. The fourth step involved integrating the data into common themes and relating them to the purpose of the study. This step yielded four main themes. In the final step the four themes were integrated and constructed into one core finding that reflected their relationship to explain how mothers used AAC with their children with FXS in the home.

Criteria for Quality

Broadly defined, research is a systematic and critical investigation to understand a phenomenon of interest. In traditional quantitative research from a positivist viewpoint, the researcher attempts to dissociate from the study as much as possible to test theories and show relationships between variables; whereas, in qualitative research in a constructivist paradigm, the researcher becomes immersed in the research to understand naturally occurring phenomenon (Bogdan & Biklen, 1998). Determining which approach is most appropriate depends on what the researcher wants to know. Researchers working in any paradigm must ascertain whether the findings are true, applicable, consistent, and neutral. In other words, positivists and constructivists must establish trustworthiness of the data. Positivists judge the quality of research by using criteria, such as internal validity, external validity, reliability, and objectivity. Similarly, in the constructivist paradigm, the criteria that are used to judge the quality of research are credibility, transferability, dependability, and confirmability (Lincoln & Guba, 1981). Lincoln (1995) further described the demands for these emerging criteria as relational; in other words, recognizing and validating the relationships between the researcher and participants, which are reciprocal in nature. Both paradigms involve strong standards that critically and systematically judge the quality of the research.

For this study a constructivist approach was used to establish trustworthiness. For credibility, the researcher must show that the inquiry was carried out such that the findings are credible and representative of the participants' views under investigation in the study. In this study I used the technique of triangulation, which involves analyzing multiple data sources. This study used three data sources: semistructured interviews,

participant observations, and review of archival records. I also used peer debriefing, in which a researcher who is not associated with the study (an external researcher) is asked to review the coded field notes (with all identifying data stripped away) and thematic analysis. For this study, peer debriefings were conducted with my dissertation chair, and I also met with a research colleague to review codes and emerging categories and themes. During these sessions codes were reviewed, refined, constructed, and clarified, as needed. Lastly, I used a member check, whereby analytic themes, interpretations, and conclusions were checked with the participants in the study. After each home visit the data were analyzed and member checks occurred throughout the study. A formal member check occurred at the final home visit.

Next, transferability is established by providing "thick description" to show that the findings are applicable in other contexts. Thick descriptions were captured as a result of large volumes of raw data generated from transcribed interviews, field notes of observations, memo writing, and review of educational records. Similar to the establishment of credibility, dependability refers to whether the findings, interpretations, and conclusions are supported in the data. To accomplish this, an audit trail involving the collection of raw data, data reduction and reconstruction products, and memos detailing the process and researcher reflections was used. I kept careful records of all documents collected throughout the study.

Finally, confirmability deals with the degree to which the findings are shaped by the views of the participants and free from researcher bias. Also, Lincoln (1995) discussed the addition of reflexivity as an emerging criterion for quality. Reflexivity is a process whereby researchers scrutinize their assumptions, interpretations, and decisions

that influence the study. Reflexive memos were kept throughout the data-collection and analysis processes.

Overall, a qualitative research design was appropriate to capture the feelings, attitudes, and beliefs of the mothers in this study. Theoretical sampling procedures provided the added depth to better understand how mothers were using AAC in the context of the home. Lastly, grounded theory methods and the criteria used to establish trustworthiness were appropriate and sound. Therefore, I am confident that my analysis is supported in the data I collected.

Chapter 4: Findings

Summary of Research Questions

The three main concerns of the study were (a) to understand how mothers of children with FXS used AAC systems in the home; (b) to capture their views regarding FXS, communication, and AAC use; and (c) to examine how mothers were supported in their decision to use AAC. These concerns were expressed in the following three questions and provided the focus for the research:

1. How do mothers communicate with their children with FXS who use AAC in the home?

2. What are their perceptions regarding FXS, communication, and AAC?

3. How were these mothers supported in their decision to use AAC?

Interviews, observations, and review of records were used to address these questions. The answers to these questions are summarized below.

First, mothers used AAC with their children in a limited and variable manner. They primarily used a combination of simple and static AAC tools for the purposes of getting needs met and managing behavior. AAC use in the home was complicated by their children's complex communication needs and challenges associated with FXS. Although mothers were in-tune and responsive to their children's needs, the communication strategies they used were inefficient, meaning that mothers exerted great effort that was, for the most part, ineffective in creating more elaborate conversations.

Second, mothers perceived AAC in a positive manner as a way to get their children talking and communicating. However, before making the decision to use AAC, mothers first needed to understand their children's diagnosis. While mothers had many

concerns regarding their children's overall development, most were concerned about their children's potential ability to talk and communicate. Mothers exerted great effort in their search for solutions to get their children communicating and ultimately talking. Because mothers struggled to understand AAC and determine how aggressively to pursue AAC interventions, they tended to delay the decision to use AAC. Ultimately, the decision to use AAC was supported by the belief that AAC would not prevent their children from learning how to talk, but rather to help them talk sooner. In addition, mothers' expectations for AAC use involved finding an efficient and effective AAC system to promote not only their children's communication but also to manage behavior and to improve independence and learning.

Lastly, the decision to use AAC was an informal process and mothers reported receiving limited support, learning about AAC systems "on their own." Mothers reported numerous "roadblocks" and "stymied progress" as a result of limited support, lack of services, and external stressors such as AAC system challenges, financial issues, family issues, and struggles with school. These external barriers interfered with mothers' decisions to use AAC in the home.

Thematic Analysis

Using grounded theory methods, data from 16 interviews, 12 observations, and review of 18 educational records were analyzed into 30 codes, which were then grouped into 11 conceptual categories and further analyzed into four core themes and one major finding. Those themes were (a) children's complex communication needs; (b) mothers' limited and variable use of AAC; (c) mothers' internal struggles; and (d) external barriers (see Table 1).

Table 1

Data Analysis Map

Core finding: The Complex Nature of AAC Use in the Home

For children with FXS, the interplay of children's complex developmental challenges, mothers' internal struggles and the absence of external supports leads to limited and variable use of AAC in the home.

Thematic analysis: (selective coding)	**Conceptual categories:** (axial coding)	**Open coding:** (based on observations, interviews and education records)
Complex Use of AAC in the Home: "It's Really Hard"	Complex communication needs	-Expressive skills -Receptive skills -Oral motor and motor planning issues -Social skills
	Challenges associated with FXS	-Behavioral issues -Cognitive challenges -Poor adaptive functioning
Mothers' Limited and Variable Use of AAC: "I'm the Biggest Barrier"	Strategies used	-Mother directed -Verbal prompting
	AAC forms and functions	-Simple AAC devices -Limited purposes -Children's response
	Kathy's unique experience	-Kathy's experience
Mothers' Internal Struggles: "Fighting the Fact"	Impact of FXS	- Concerns -"Fighting the fact" -Motherhood transformed
	Views on AAC	-Past and current experiences with AAC -future ideas
	Internal barriers	-Mothers' knowledge of AAC -Mothers' comfort level -Mothers developed their own system
External Barriers: "Roadblocks and Stymied Progress"	Need for support	-Seeking support -Networking
	"Lack of choices"	-Use of interventions -Medication "ebbs and flows"
	Stressors	-AAC system challenges -"Bartering for therapy" -Struggles with school -Siblings with and without FXS -Dealing with extended family members

These core themes provided detailed descriptions to understand how mothers used AAC to communicate with their children with FXS, their views regarding AAC use, and how they were supported in their decision to use AAC. These descriptive themes led to one core finding: For children with FXS, the interplay of children's complex developmental challenges, mothers' internal struggles, and the absence of external supports, led to limited and variable use of AAC in the home.

Theme 1: Complex Use of AAC in the Home: "It's Really Hard"

In each of the homes, AAC use was limited and variable due to difficulties experienced by mothers in the implementation of AAC. Mothers had to address many obstacles in their attempts to figure out and learn how to use AAC tools and strategies. The great difficulty mothers experienced with implementing AAC in the home was captured by Beverly's statement, "Sometimes it's really hard. Sometimes it's only a little hard. Sometimes it's kind of easy hard but it's always hard." Two main issues contributed to this difficult process: their children's complex communication needs and challenges associated with FXS. The first obstacle was providing support for their children's complex communication needs.

Complex communication needs. The challenge surrounding children's complex communication needs included limitations in expressive and receptive skills, issues with oral motor functioning and motor planning, and difficulties in social skills. Rosemary shared her biggest concerns regarding communication:

> The communication is a big concern because he understands everything receptively. ... His expressive [communication] is what he has trouble with, and he has such anxiety about speaking that it's—what—we noticed that when he's the most relaxed, he can have a conversation. Things come out, you know, a lot clearer. ... But while he's worried about what he's trying to say, it just doesn't

come out and he, he speaks with like his mouth closed so a lot of the stuff you can't really understand, and I'm the one that understands him the most.

Expressive skills. All mothers reported significant concerns with their children's expressive communication. Three of the 5 children were considered verbal while the other two children were becoming verbal. Even for the children who were verbal, expressive skills were mainly characterized by short, 1–2 word phrases and simple gestures for the purpose of getting needs met. For example, to make requests and to avoid tasks. When asked how her 8-year old son, Gary communicates, Beverly replied:

> "Chips," you know, one word usually can get it—"TV, Mom," "Chips, Mom," is the norm. Then you'll hear things like—that started over 2 years ago, "Mary [his sister], come sit with me, come have a conversation with me." And she won't. She's getting better, if I—or Gary's getting better at getting her attention. Maybe it starts with their fighting over the remote because she wants to watch a different show than he's watching. So he'll communicate by, "Hey, give me that. Yawwwe," and he'll make these funny voices to try to make you laugh so you give him whatever he wants. He'll beg. I'm like, "Hey, Gary, there's no TV tonight." Well then he'll use emotional antics and get down on his knees with that little begging prayer stance with his hands up to his face in prayer mode and he'll just look. It's very cute. So he'll communicate with personality as much as with words.

Kathy described her 4-year-old son, Tom's, expressive skills like this:

> Well, I think that in general, Tom is really coming into his own ... and actually has been using a lot of language at school, and in fact, the teacher has sent home lots of reports, a few in fact, that he's used two words together, like "want yoghurt." A basic thing, but still, two together is pretty big right now. And he's been doing a lot of babbling, like trying out sounds with his mouth. So I think he, right now, [in] my mind, he's working on the motor planning of talking, and trying to figure that piece out.

Observations and review of educational records revealed that the children spoke very rapidly and their speech was highly unintelligible. Furthermore, the children frequently used repetitive phrases and had a limited vocabulary. For example, during a home observation, Carolina's 12-year old son, Manny, frequently used the word, "Amazing!" as a way to comment. During an outing to the local library, Gary, age 8

frequently used the phrase, "It's a mystery!" when looking for a book about trains at the library. Mothers also reported problems with their children's ability to recall prior events and to provide elaborate responses. All mothers reported that expressive communication was always better when their children were in a calm arousal state.

Receptive skills. While all mothers reported some problems with their children's understanding of language, the majority of mothers felt that their children understood much more than they could express verbally. Overall, the children exhibited poor auditory comprehension, evidenced by not following directions, complying with requests, or answering questions correctly. Mothers also indicated that their children had difficulties processing information and responding to *yes* or *no* questions. For example, Kathy stated,

> And so thinking about the auditory processing issue, if you think about it, if I say to you, "Blah, blah, potty," you're going "What?" But if I say "Blah, blah, blah, potty, yes, no?" ... You get that I'm expecting a "yes, no," and it kind of helps clarify what that question was.

In addition, the children were frequently off topic, nonresponsive, or exhibited poor responses to questions such as "how many" and "why."

Oral-motor functioning and motor planning. In addition to speaking rapidly, the children mumbled often and were very hard to understand due to poor oral-motor functioning. Mothers reported oral-motor issues (i.e., dysatharia) such as not being able to kiss and having low muscle tone. Two mothers reported that their children had trouble with motor planning and word retrieval (i.e., apraxia) and indicated the need to provide physical prompts to pace words and "get words out" to increase their children's intelligibility. All mothers reported oral, sensory-seeking behaviors such as their

children's frequent need to chew and bite objects. Beverly described her son's oral-

motor and motor planning issues like this:

> Yes, getting started and staying in it. It's a severe anxiety that tortures him
> because he wants to be able to talk, and then he's feeling such discomfort. Even
> in the excitement of wanting it, it's too much for him and he withdraws from that.
> And he might start the conversation and then give up because of that motor
> planning issue. ... Like we were working on our address, 38th. It's coming out
> 48th. He can't do 38 without stopping everything to motor plan 38th, and then he
> can't think of anything else to finish the address or he's exhausted from that. I
> don't know how to help him, aside from the traditional therapies with that. But I
> don't know. An augmentative device that has language that he can listen to and
> then copy and hear his voice probably could help him a lot.

Social skills. All children had the desire and interest to be social with family

members and peers. However, mothers reported their children's troubles in sharing about

events in the day and carrying on conversations. Beverly expressed frustration with her

son's inability to "get past hello." In addition, observations revealed that communication

was further complicated by children's difficulties maintaining focus and engagement, not

directing communication to their mother and frustration associated with mothers'

frequent demands for talking.

Challenges associated with FXS. The second obstacle related to children's

complex communication needs was addressing the many challenges associated with FXS,

apart from communication. One of the goals of this research was to understand the

impact of FXS on communication skills and use of AAC in the home. FXS is a genetic

disorder involving significant neurological impairments that are biological in nature and

affect communication. Behavior, learning, and adaptive functioning are also affected and

impact communication. While the disorder is complex and affects people differently in

range of abilities, there are distinct observable characteristics based on the DNA of the

FXS gene. This leads to poor internal scaffolds in the brain indicating poor cognition to

support the child's communication abilities. All the boys ranging in age from 4 to 12

years had full mutation FXS (i.e., more than 200 CGG repeats) and evidenced poor

cognitive functioning. Although somewhat variable in their abilities, all children

exhibited behavioral issues, learning challenges, and poor adaptive functioning in

addition to communication deficits.

Behavioral issues. Mothers described their children as "smart," "resourceful,"

"witty," "charming," "funny," "happy," "cute," "physical," "loving," and

"approachable." While all mothers reported some level of behavioral difficulties, 3 of the

4 mothers indicated significant challenges managing their children's behavior.

Observations during home visits confirmed the following behavioral challenges:

aggression to self and others such as pinching, picking at scabs, hitting, tantrums, and

outbursts to avoid or escape tasks described as "meltdowns when he doesn't get what he

wants," apprehension described as "anxiety" in novel situations, low frustration

tolerance, distractibility, impulsivity, short attention span, and sensory issues such as

sensitivity to sounds and smells, rocking and hand-flapping. Mothers also reported

obsessive behaviors and limited scope of interests such as using scotch tape to reorganize

the pages of a book, replaying certain parts of movies, and reading and talking about

trains. Some mothers described their children's behavior as "escape mode" or "tuning

you out" to avoid non preferred tasks or challenging tasks. In addition, some mothers

reported issues with eating too much, sleeping too little, and frequent bathroom accidents.

Mothers' management of behaviors involved frequent efforts to keep their

children engaged and focused so as to prevent behavioral outbursts and repetitive and

compulsive behaviors. Mothers also discussed seeking medications and interventions

such as applied behavioral analysis (ABA) to manage behavior problems. Observations

revealed that mothers used some effective strategies to manage behavior such as using

signs or gestures to cue the child (e.g., "Stop!"), creating routines and structure,

anticipating needs, directing and prompting the child, giving warnings, and planning for

breaks. However, all mothers agreed that maintaining calm and patience was the best

way to manage behaviors. Mothers also reported the need to engineer the environment,

such as placing locks on food cabinets and disabling the computer to prevent compulsive

behaviors. Other strategies such as ignoring, redirecting, and verbal reasoning were

observed to be less effective.

> *Cognitive challenges.* In addition to behavior challenges, there was evidence of

learning challenges that affected the children's communication and use of AAC. All

mothers noted concerns regarding development in one or more areas, such as walking

and/or talking at approximately 2 years of age. Review of educational records revealed a

pattern of a slow rate of learning (see Table 2). All mothers felt that their children knew

more than they could demonstrate. For instance, Beverly shared her thoughts on the

subject:

> The tough part is—you've heard this probably—that in terms of like an IQ test or
> just trying to figure out how smart a kid is, they have fragile X, it's really tough
> because they're not going to respond the same way. The way that you give them
> the test just doesn't work for them. Anyway, so it's hard to really know how
> much your kids understand. And the way that schools work is, they have teachers
> and so forth. They have the set of skills or developmentally what they can do, and
> then you move on after that, after they master that thing.

> While all mothers reported that their children had great visual memories (e.g.,

memorizes books and words, matches letters), they also acknowledged that their children

had poor recall of information and comprehension. For example, most of the children

had trouble answering simple *who, what, where,* and *why* questions. In addition to poor

auditory processing and comprehension, all children showed evidence of neurocognitive deficits in the areas of working memory, recall of information, and executive functioning such as motor planning, organization, inhibition, and attention. Children also exhibited poor reasoning, abstract thinking, and problem-solving skills, which were evidenced by their poor safety awareness, lack of independence, and "acting younger than his age." Beverly described her son's reasoning skills as "little kid thinking: "I can get away with this because she's not going to know."

Review of children's educational records revealed global deficits and learning priorities in the areas of reading, mathematics, written expression, independent functioning, communication, and behavior. All children were described as "concrete learners"; for example, pairing words with pictures and counting with objects. Lastly, mothers gave several accounts that related to poor generalization of concepts learned, such as trouble applying knowledge in day-to-day activities (see Table 2).

Table 2

Cognitive Analysis by Child

Cognitive domain	Tom 4 years old IQ not provided	Greg 6 years old IQ not provided	Gary 8 years old IQ 65	Walter 9 years old IQ 56	Manny 12 years old IQ not provided
Prewriting	-imitates motor actions	-scribbles when drawing a line -beginning to match letters to words	-working on writing and copying sentences	- draws a circle and sun -working on tracing letters, name, and drawing horizontal and circular lines to form letters	-working on writing his name and copy sentencing
Problem-solving and task completion	-uses simple strategies to solve problems	-follows 1-2 step commands -labels pictures and sequences a familiar routine using pictures	-follows 1–2 step commands	-follows simple commands (e.g., give, show, put, bring)	-follows 1-2 step commands
Basic Concepts	-follows and points to object or person to point of disappearance -matches objects from a field of two	-sorts objects by color -classifies objects into 2 familiar categories -counts objects with visual cues up to 3 -rote counts up to 10 with visual cue	-knowledge of basic concepts (numbers, letters, colors); -unable to indicate age when asked	-some knowledge of basic concepts	-knowledge of basic concepts (numbers, letters, colors) - unable to indicate age when asked
Reading comprehension	-attends to a familiar book -imitates words from the story	-attends to a book -answers simple wh- questions about familiar books	-working on pairing vocabulary words with definitions	-identifies words and pictures in a story	-comprehends on a kindergarten level
Reading	-recognizes high interest sight words when presented from a field of 2	-identifies 6/26 letters; -recognizes 10 high interest words and selects from a field of 4 -matches words from a field of 4	-emergent reader reading words paired with pictures -reading skills on a kindergarten level -has difficulties reading words in connected text	-identifies words presented orally from a field of 2 -identifies words presented orally from a familiar book	-reading on a kindergarten, preprimer level -has difficulties reading words in connected text
Mathematics	-matches pictures, colors, objects	-matches and counts 1, 2 sometimes up to 3 -counts up to 5 with visual cues	-counts up to 5 using objects	-matches simple pictures -identifies number 1 to 20	-working on a first grade level

Poor adaptive functioning. Mothers also had trouble managing daily routines due to their children's poor adaptive functioning in self-care and self-direction. Beverly commented on multiple occasions that "daily routines are challenging." All children had difficulty performing age-appropriate daily living skills and independent functioning in dressing, grooming, self-care, feeding, and toileting. All children lacked independence in completing homework and daily tasks appropriate for their age. The frequent need to manage their children's behavior, learning, and adaptive functioning were major concerns for several mothers, contributing to difficulties associated with limited and variable AAC use.

Theme 2: Mothers' Limited and Variable Use of AAC

One of the goals of this research was to understand how mothers used AAC systems with their children in the home. How AAC is used in the home is not widely understood in the AAC literature. Understanding obstacles experienced by mothers in their efforts to use AAC with their children in the context of the home can be an important contribution to improving AAC systems to support the needs of not only children with FXS but also their parents. Interviews with mothers and observations of mother-child interactions in the home revealed limited and variable AAC use.

Strategies used. Perhaps one of the biggest obstacles for the mothers was finding ways to support their children's communication and social interactions. Observations revealed that mothers primarily directed conversational exchanges and used verbal prompts to keep conversations going. These strategies resulted in short and basic communicative exchanges and were inefficient and largely ineffective in creating more elaborate conversations.

To keep conversations going, mothers frequently needed to anticipate, interpret, and mediate communicative exchanges with their children. All mothers reported their children's communication as best when their children were in a calm arousal state and as a result, mothers exerted great effort to keep or get their children calm, engaged, and communicative. Mothers were very skilled at interpreting their children's communicative acts. Rosemary discussed how she plays her son, Walter's, vocalizations and word approximations over and over in her mind to figure out what he was trying to say. Beverly described her strategy to interpret her son's communication as playing a game, "I didn't get it. Tell it to me again."

All mothers used the strategy of asking their children to show/point to interpret messages. Mothers also appeared to assign meaning and purpose to their children's communication and social interactions. For example, Beverly interpreted her son chasing other children around the playground as "playing monster" to describe his social interactions with other children. Other strategies included mothers changing their tone of voice, pacing their child's verbalization through touch, and offering choices.

Mother directed. Although all mothers were remarkably in-tune and responsive to their children, mothers primarily took the lead and directed conversations. Mothers occasionally used some features of child-directed speech, such as following the child's lead and picking up on the child's interests to engage in conversations. For example, the following is a conversational exchange when Beverly and Gary were looking at a book about trucks in an outing to the library:

Beverly: Doesn't that look pretty?

Gary: Yeah.

Beverly: I like seeing all these. What are these?

Gary: inaudible.

Beverly: Yeah. And then what's all this? Thick trees is the...

Gary: Forest.

Beverly: Yeah.

Gary: What is that?

Beverly: Hey, that says it's a train in Alaska. Alaska.

Gary: I'm going there with Daddy.

Beverly: Daddy wants to go there, too. It's true. He wants to see polar bears.

Gary: No.

Beverly: All right. You've got one more minute and then we've got to do some of your homework.

Gary: What!? Oh, look.

Beverly: I'll let you pick what two sheets we do.

Gary: Okay. Okay.

Beverly: This looks like a book that gives you all of the details and drawings of all the components.

Gary: Hey. Hey.

Beverly: All the different parts of the train.

Gary: <inaudible>

Beverly: You're being a little, what do you call it, possessive.

Gary: What's it mean?

Beverly: Of these books that don't even belong to you.

As in this excerpt, mothers primarily directed and redirected conversational exchanges, nominated the topics and used a limited number of visual supports to promote communication. Mothers also frequently determined motivating activities in an attempt

to engage their children in a conversation and used a high degree of verbal prompting to elicit communication.

 Verbal prompting. Mothers used much verbal prompting to promote communication. These strategies appeared to place high demands on both the mothers and their children with the result that the children communicated less. The following is an excerpt of an exchange where Carolina was trying to engage Manny in a conversation:

 Carolina: Huh? What is this on his nose?

 Manny: <Inaudible>.

 Carolina: No? What is that?

 Manny: <Inaudible>.

 Carolina: Manny, you change it too fast, before I say something.

 Manny: <Inaudible>.

 Carolina: What is it?

 Manny: This.

 Carolina: What is this?

 Manny: Hat.

 Carolina: A hat. What else?

 Manny: Red shirt.

 Carolina: Red shirt. Is that a red shirt?

 Manny: Um-hum.

 Carolina: What is he wearing?

 Manny: There no Tia [caretaker]?

 Carolina: No Tia. Well, who—what's that? What kind of animal is that?

 Manny: <Inaudible>.

Beverly described herself as a "walking prompt machine." Observations revealed that verbal prompting was frequently used to engage the children in conversational exchanges. Mothers also asked many questions to keep the conversation going and to reason with the child. The following is an exchange between Rosemary and Walter, age 9 playing a computer game during a home visit:

> Rosemary: Where does that one go, there? (Pointing to picture on the computer screen.) Okay. Good job. That one goes where? Where? (Computer game playing.) Good job, Walter. Uh-uh. Okay. Who checks your teeth? The dentist, the artist, the pilot or the mechanic? (Walter clicking the mouse.) The pilot? No, the pilot doesn't check your teeth, does he? Who checks your teeth? Whose— who checks your teeth? Your teeth? Here, your teeth? Who, who checks your teeth?

> Walter: The guy.

> Rosemary: No, not that guy. He's checking the car. Where's the dentist? Show me the dentist. (Walter clicking on the picture of the dentist.) There we go.

> Walter: That one.

> Rosemary: "That one," yes, that one and don't get upset. (Walter trying to get up and pushing Rosemary.) Uh-uh. No need to be mean. Who cuts hair? (Walter pointing to doctor.) No, not the doctor. Who cuts your hair? Cut hair? There we go, the hairdresser.

AAC forms and functions. Mothers primarily used visual supports and simple VOCAs and felt that when used properly, these tools were effective in increasing their children's communication and comprehension. Mothers also viewed simple AAC systems as effective tools for use at home and in school to control behavior and make simple requests. All mothers reported using simple AAC devices for the purpose of meeting their children's needs.

Simple AAC devices. Mothers reported and were observed to use simple aided AAC devices such as visual aids and VOCAs and that these types of AAC were portable, easy to program, and use. One mother, Carmen, was not observed to be using AAC with

her son currently, but she reported using AAC in the past. All mothers reported using a method called PECS and visual supports such as choice boards, schedules, and token systems and most mothers felt that these tools worked well. For example, when asked how the PECS worked for her son, Rosemary stated,

> Uh ...[PECS worked] pretty easily. I mean, they, they worked well. I, I probably, you know, I was thinking of putting them up recently again but, um, he, he will just go up to them and he'll tap them and he'll show you what he wants.

In addition to aided AAC, all mothers reported using unaided AAC modes such as simple signs and gestures to communicate simple requests. However, these modes were less effective in having back and forth conversations and prolonged communicative exchanges.

Limited purposes. Observations revealed that mothers primarily used AAC for the purpose of making simple requests and comments to meet their children's needs. Mothers also reported using AAC to manage their children's behavior, such as to stay on task and gain attention. Mothers reported using visual aids to help their children learn new words. Rosemary and Kathy used VOCAs in attempting to use the iPod with communication applications to help their sons make simple requests and comments. Mothers used unaided modes for their children to make simple requests; for example, to indicate "more" and to aid in their children's comprehension such as to signal "stop."

Children's response to AAC. Based on observations and interviews, it was apparent that children's response to AAC affected whether or not AAC was used in the home. Three of the five children were not independent in using AAC while the other two children were becoming more independent in their use of AAC. All mothers felt that their children's lack of motivation and engagement affected AAC use. For example, in one observation, Beverly introduced and attempted to use AAC with her son at a horse

stable; it was noted that Greg primarily communicated to get out of situations or activities. Communication breakdowns seemed to occur primarily due to Greg's poor intelligibility and the fact that he was not interested in what his mother was offering.

Beverly attempted to use an AAC system that consisted of a picture board with four icons representing tasks to be completed to augment Greg's comprehension. She also used a token system that consisted of a clipboard with quarters that Greg could earn or trade for a reward such as a piece of cake. The picture board and token system were not effective and Beverly fumbled to use it and to keep Greg engaged and on task. Most importantly, the AAC system was cumbersome and was quickly abandoned. Most of the observations of mothers attempting to use AAC with their children revealed the children's lack of response to the system. For example, the children paid little attention to the AAC and were not engaged in the communication exchange, did not seem to understand the purpose of the system, and were not using the AAC independently in order for the system to be efficient and effective. In fact, it seemed as if the mothers did not understand the system well enough to use it with their children.

Kathy's unique experience with AAC. Kathy, mother of Tom (age 4) and Greg (age 6), who was the only mother to consistently and effectively use AAC in her home, represented a unique case where she had developed a systematic method for AAC use in the home. Although AAC use in the home was similarly limited in the sense that she was using simple AAC tools for the purpose of getting needs met, she had successfully set up a systematic scheme that she used regularly with her boys. For example, she systematically used picture cards, choice boards, a single message VOCA, and picture

schedules for segments of the daily routine. She was also starting to explore more

dynamic AAC systems to expand her sons' communication skills.

On getting started using AAC in the home, Kathy explained how she began using

picture cards:

> We started out doing [AAC] with food, because that's a motivator for the kids.
> So we started out, and I actually have a nice board that says the words "Do you
> want," in squares so that you can tell they're separate, and then there's a Velcro,
> and then a question mark. And so, on the Velcro you put whatever thing it is, so
> broccoli or spinach or pasta or whatever, and then underneath it, there's a "yes"
> and a "no," with Velcro. And so, they actually have to grab the "yes" or grab the
> "no" and hand it to you. And so, then they learn, because if they give you the
> "yes," and you give them the stuff and all act (surprised) "Oh, you meant no." So
> it's definitely something you have to teach them how to use.

Kathy also described using choice boards and a single message VOCA with her

son, Greg. She also indicated her desire to continue the use of AAC even though he was

now verbal.

> So he now, when he's at home, [he] mostly talks now. But I have a board in the
> kitchen that has icons on it, kind of the preferred different items, and so
> sometimes he'll go and he'll grab a picture and bring it to me, so it might be an
> iPod or a computer or a trampoline or whatever, and he just brings it to me.
> Another thing that he does is, this generally happens if I'm busy doing something,
> and or if there are other people here that I'm talking to, and he wants to get my
> attention, I have a Big Mac button that says, "Excuse me, please, I have
> something to say." And so, he'll push that and then that gets my attention, and
> then I say, "What, Greg?" And then, he'll either try to tell me verbally or he'll
> pick a picture.

Interestingly, Kathy felt that behavior problems had been significantly reduced as

a result of AAC. For example, Kathy explained, "I think Tom is less whiney; he's a little

more direct." She also stated that her sons were now beginning to initiate

communication-using AAC, "He comes over and grabs your hand and takes you. And

he'll come over to the board and grab something and bring it to you, a picture."

Kathy's descriptions of the various AAC tools and strategies she used were so vivid that they warrant extensive quotations. One strategy was the "Red Book" which she created for her sons to make choices:

> So finally, I just printed the boards out, and I think I showed that, too, during the presentation, and laminated them and put them in a red book. And so then, you can just tell they were antsy for something or they were whining about something, because it can be that they're bored and they don't know what to do. I would always say, "Go get your red book," and so they would open it. Or they were coming and opening the fridge, any of these cues, I know they want something. So they would get it, and then they would thumb through the pages and find the food page or the find the TV show page or the activities page, and point to the thing they wanted. And then, we were good, so that was huge.

> And the other nice thing is when Grandma would come over or the gal that comes and kind of watches the boys; everybody knows where the red book is kept. And everyone just says, "Get your red book," and they would go get it. And the kids do it, you tell them to get it and then they go get it and they flip through and they show you what they want.

Kathy also portrayed the use of picture schedules as a tool for independence to manage daily routines:

> So anyway, another thing, it just dawned on me, that we use that really has helped with routines, is I kind of have certain times of the day where I care about routines. Otherwise, routines aren't that big for us. So getting dressed in the morning, getting ready to go to school in the morning, and then there's getting ready at night and getting home from school. And it's tough, because there are lots of steps, so you have to figure out how to cut those down so that they're not seeing a million steps on a page. And so the way that I did it is I kind of did three strips on a 8 ½ x 11, I mean it's three strips, excuse me. And so I'm looking right now at my "getting home" strip, and so for Tom, the top strip is backpack off, coat, shoes, shoes away and potty. And then, I fold it. It's laminated with a thinner laminate, and then I fold it, and the next strip is pants down, diaper down, sit down, because he needs that for the potty. The first strip showed "potty," so he knows he needs to get to the potty. Then he needs help with the pants down, diaper down, sit down, whatever. And then folded again, and then there's a third strip. So when he's looking at it, I only have to show him one strip at a time, so it's not as overwhelming.

Kathy attempted to use more dynamic AAC systems:

> So I have the iPod with the My Talk (application), and to be honest with you, I haven't used it a lot. Part of my problem was trying to figure out what it needs to

have on it, like what makes sense to put on it, because at home, we're kind of set. We've got kind of the basic stuff covered. So it was really convenient when we were traveling one time and I was trying to figure out what everybody wanted to eat, and my husband was assuming that Greg wanted to have hamburgers. And so we're trying to ask him, and he's saying "No," which is surprising us. We're thinking maybe he's just saying that, but he is saying "No." and then I showed him, because you can't say, 'Well, then what do you want?' Because it's rarely he might come up with something, but if you give him a choice, then he's going to be more likely. So I showed them I had a bunch of food on there, and I let him scroll through the food and he picked quesadilla. So I think for me at home, we're pretty set as far as icons and all that kind of stuff, but I can't really take it with me. So I think for us, the iPod is going to be more beneficial outside the home.

Kathy also explained how she fits AAC into her daily life with her sons:

Yeah. Really, you kind of have to do the stuff all the time. I guess I kind of pick my battles because if I understand what they're saying in the course of a typical day, I let it go in general. But sometimes I decide, "You know what? We need to work. We need to get some work out of him," and swing is really motivating. And so I choose the swing to get some language out of him.

The implementation of AAC strategies used in conjunction with AAC tools was

an important aspect of Kathy's success with AAC:

As a prompt, yeah, like for Greg, the time that we use it the most is around food again. So we're at the dinner table and he wants more food, and he'll be just kind of whining. He's really whiney. And so this is how I do it. Under my breath kind of, I say, "Mom, Mom, Mom," because I want him to understand he needs to get someone's attention, because sometimes he'll be going, "spaghetti, spaghetti, spaghetti," or whatever. He doesn't really say it like that, but he'll be saying the word, but not to anyone or as a question. And so, under my breath, I'll say, "Mom." Finally, he'll pick up what I'm doing and he'll go "Mom," and then I'll look at him and I'll (say), "What, Greg?" And so he's learning that he needs to get someone's attention. And then, I know what he's wanting.

Overall, strategies included using AAC with highly motivating items or activities, modeling the use of the device, making a big deal when the child uses the device, and setting strict limits on using the device. In other words, not letting the child play with the device so that the child understands that activating the device has a purpose.

Theme 3: Mothers' Internal Struggles

All mothers were determined to understand their children's diagnosis and potential abilities regarding communication and exerted great effort to search for solutions that included the use of AAC. For all mothers, including Kathy, it seemed that AAC use was limited and variable because they did not know enough about AAC in general to develop an effective and efficient AAC system and fully embrace its use in the home. They may have received little information or misinformation from specialists regarding AAC, lacked understanding regarding the impact of FXS on their children's communication development, or developed their own system or ways for communicating with their children.

Mothers also struggled to understand their children's communication needs and to determine how aggressively to pursue AAC. On receiving the diagnosis, many mothers reported receiving very little to no guidance on next steps. For example, Rosemary remembered after learning that her son Walter had FXS,

> We had already been doing speech and occupational therapy, and the neurologist told me, you know, "There's nothing else to do. There's, you know, there's no magic pill. There's nothing in—so, you're just doing what you need to do for him. Just keep doing it."

Mothers' decision to use AAC with their children was influenced by the impact of FXS on their lives, their views regarding AAC, and internal barriers that affected their pursuit and use of AAC.

Impact of FXS. Before mothers pursued AAC, they first had to deal with the impact of FXS on their lives. This included their main concerns regarding their children's development, their coming to terms with and understanding the diagnosis, and their transformed maternal role.

Concerns. Mothers' main concerns regarding their children's development were in one or more of the following areas: communication, behavior, learning, and independence. In addition, mothers expressed a strong desire to seek out specialists/professionals who know about medications and interventions, including the use of AAC systems that work for FXS.

For communication, mothers were particularly concerned with their children's conversation skills. Specific communication goals varied somewhat from child to child, but were not extensive and included having a back and forth conversation and sharing about events of the day. Even Carolina, whose son Manny was verbal, was concerned about communication.

> I mean every year when [his school team] ask me where can you see Manny next year at this time and I hope he'd be talking at Christmas. I hope he's been talking at Christmas. I hope he's fluent in the language. Still this is what I wish for.

Beverly whose son Gary was also verbal expressed concerns regarding his communication abilities, "So the next stage, really, is moving to a back and forth reciprocal conversation, where he can tell you about his day. He can share ideas with you. You can share ideas with him." Mothers were actively seeking to understand their children's communication needs and were receptive to the use of AAC in the home, based on their strong desire for their children to communicate.

Another main concern for 3 of 4 mothers included trying to control and manage behavior. Kathy, who was successfully using AAC in the home, thought that behavior problems were significantly better because her sons were able to communicate more through the use of AAC. For other mothers, as previously stated, specific goals for behavior included reducing aggression to self and others, improving attention and

engagement to tasks, following directions, and complying with requests. Some mothers indicated additional concerns such as eating too much and poor sleep habits.

Mothers were also concerned about learning in all subject areas (e.g., reading, mathematics, and writing) and level of independence. Most mothers were interested in finding ways to stimulate progress and increase their children's rate of development. This was evidenced by comments such as "not wanting him to act like a four year old" and "working so hard to get so little."

The concern about learning was also closely related to their children's independence. Some mothers felt burdened regarding their children's future. When asked about goals for her son's future, Beverly replied, "That he'll be okay. Completely independent from us? Probably never, which is kind of a bummer, too. When I let myself think about that, it's dreaming because it's, like, I never get to retire."

Specific goals for independence included caring for oneself, improving play skills, and developing social skills. Beverly discussed short-term goals such as developing responsibility through teaching her son and daughter to care for a family pet. Mothers also expressed goals for the future such as developing friendships, learning a trade and fitting into society. When asked about future goals for her son, Gary, Beverly answered:

> In my imagination, he is going to graduate, be it a GED. Somehow, he's going to be educated, an educated man. And go to some kind of trade school, kind of, program or an environment where there's a coaching type job, where he would have some kind of mentor onsite with him to help him. Like, the post office or, you know, I don't know, a factory of sorts. A coffee shop that we know of that manufactures the coffee, a roasting house. Things like that I picture him liking. I go with his own interests. He loves trains. So maybe he will work on a train and assist the engineer. I can see him being so fulfilled that way. Or with the guitars, maybe he's going to help bands and set up. And he'll be part of the road crew. I see, as long as there's somebody—he'll always need a team member or

supportive environment. But I see that fulfilling him. And I see a girl in his life. I don't see him ever, maybe, independently working his own finances. But maybe he'll marry that strong girl that's from our generation that's going to be happy to be in charge of the money.

Lastly, mothers were very concerned with trying to find the right combination of medications and interventions that included the possibility of using AAC to support communication, behavior, learning, and independence. Carolina expressed her desire to find the right program for her son, "I wish there was a program that could work more with FXS." When asked if communication was the main priority Kathy replied,

> Yeah, I think it is. I mean, the first goal—well, for Greg—was finding a school environment that I felt comfortable with, that I felt like everyone was supportive and all that. And I feel like I've accomplished that. I really think that this new school that he's at is much better, the teacher is much more supportive in every way, and technology included. I mean even the first day she wrote notes back about how she saw how much he liked the computer and how really good he is at it. So that was the first thing, is finding a place where he could kind of thrive in other ways. And then I—and I also feel really good about where Tom's at, so that's the other thing. So that's kind of the first thing, is that they're at a place that is comfortable for everybody. And then, yeah, I'd say the second thing would be figuring out how to get them the communication what they need, that they want to share, to be able to express what's in there. Because I think that behaviorally, they're pretty good. They don't have too many huge outbursts or anything like that, like some of the other behavior I've seen with FXS. But I think it's got to be frustrating to not be able to tell people what you are thinking, you know? Whether it's a want or a need or a comment or a question or a whatever. I think that people really underestimate what they have to say and just give them the wants and needs and not all the rest that—so anyway.

"Fighting the fact." All mothers indicated the need to come to terms with their children's diagnosis and the implications associated with their children's potential abilities. "Fighting the fact" was also associated with mothers accepting that siblings may also have FXS, their delayed efforts to consider the use of AAC, and extended family members refusing to get tested. Kathy shared how she felt when she learned that her oldest son, Greg had FXS:

And it came back that we should get him a blood test for FXS and then if that's not what it is then some other test, which I don't know. And, of course, I look up FXS and so like mentally retarded and all of this and I'm like no, no, no, that's not, no. I just couldn't—I was totally in denial. And at that time I was working full, I don't remember, I think full time or part time I can't remember, anyway it was either 3 days or full time. And I kind of was just in denial about it and I didn't go have the blood test done. And finally I don't remember what happened but finally it was sort of like okay I've got to do this to figure out—I have to rule this out so I can figure out what else it is and so we finally did the blood test. And our pediatrician called and it was in the evening so I knew something was up. And he said, "Greg" has FXS." And he didn't know much about it. He said he had one or two other kids that he had seen that have it but he was sad. He felt bad and he didn't know what to say and he didn't know much about it which was really tough because here I have a million questions and he didn't have any answers.

Carolina described this process of coming to terms with diagnosis as "fighting the fact." Mothers also seemed to be in disagreement with professionals who labeled their children with intellectual or cognitive impairments. Rosemary explained:

So he, he, he knows more than what he demonstrates, particularly with people that he doesn't know. ... So whenever he's tested, you know, in a new situation, it's hard because I always want to say that he can do that and he knows that. ... And he knows more than that.

All mothers felt that their children understood much more than what they could express. This suggests that some mothers and professionals were unclear about their children's potential abilities.

Mothers also described "fighting the fact" that siblings might have FXS and accepting the fact that more than one child may have FXS. When Manny was 3 months old, Carolina found out that Manny's older brother, Robert had FXS. However, she waited 2 years before getting Manny tested. When asked why she waited, Carolina replied, "Yeah, I was fighting the fact that he might be. I don't want to know."

Mothers also appeared to be "fighting the fact" or delayed in their efforts to consider the use of AAC. For example, Kathy mentioned that she was first introduced to

AAC in her son Gary's toddler class. Yet is was 2 years later when her son was still not talking before she committed in her mind to the idea that AAC was needed to help her son develop communication skills. When asked how she felt when she was first introduced to the idea of AAC:

> I liked the idea. I didn't quite—at the time I didn't fully grasp the big picture of it——of why we needed to do it. I mean—what I mean by that is——I didn't realize how long the language would take. Cause every now and then, they'd throw out a word. And you're like, "Oh, oh. Here it comes then." People—well-meaning regular parents would say, "Oh, and once it starts, it's just gonna come. And it's gonna be——and then you can't shut 'em up." I mean, I can't tell you how many times I've heard that, and <laughter> then that just doesn't happen. <laughter> They might have one word for a while and that's it. It just takes so much longer than the typical. So back at that time, I didn't realize how important it would be—how much the lack of language affects other things——behavior and I don't know. There's so many other things that I'm sure are going on in their head that is negatively affected 'cause they can't communicate. But I mean and then the other piece, too, is the negatives for the parents and the people around them that don't understand what's happening. So at the time—that first—if anything, that's where the switch happened when my friend explained it to me and gave me real-life examples with her son. It was like, "Oh, now I see." And I had seen that a couple years later, he still didn't have language. Greg didn't have much language——much useful—that was gonna get us anywhere.

Some mothers expressed the feeling of stress associated with family members who were "fighting the fact" of a FXS diagnosis and not wanting to get tested. When asked why extended family members resisted getting tested for FXS, Beverly explained:

> Nobody wants to know that they've got a retardation gene. My brother when he did get and then the poor guy finds out not only that he's a carrier but he's got it, killed him. He started calling himself the X man, but he got depressed. Who wants to invite that into their lives, there's no benefit really. And now even for my nieces who are likely carriers, they haven't been tested yet. My sister in-law had asked me a few questions and felt it more, but I just tell her the positive stuff and she's a progressive lady so she's comfortable with the science for in vitro and stuff like that.

Motherhood transformed. Mothers also discussed how the impact of FXS transformed their maternal role. Beverly described her transformed maternal role as "morphed" and being thrown into another career:

It's like I got thrown into a new career. A lot of people—I can't imagine. My perspective is very skewed, because when I think about being a mom, I knew I was going to enjoy it. But I guess I, kind of, also, pictured I was going to be in a traditional—well, no. I don't know. I never—as a mom, I was always, like, the coach and the cheerleader, and just really, like a playmate. I just loved every minute of every phase of being with that child. It was a drug for me. We just fed off each other, and things were so wonderful. And then, when the preschool things hit, I was taking time before I knew about FXS. Mary, [Gary's older sister with FXS] was 3. I just learned that she was going to be a different learner. But I'm making friends and learning how to be a better parent for my child. But I was always so much more into that and being the best mom I could be, than feeling like I was missing out on my own social life or something. So it's almost like it's natural circumstances for me to have morphed into needing to use technology and figure out how to teach my kids. Because it's a continuation of what was so wonderful at the beginning. So I never had an opinion. I just would sometimes sit back when I'm looking at other moms and thinking, you know, I can't relate to you. You know, sitting back quietly thinking, I don't get those problems. My kids go to sleep at night. You know, they're having a different set of problems that I can identify with.

When asked how the diagnosis changed her as a mother, Carolina replied:

Receiving the news is, it's just terrible—terrible. Denial, I, you know, did not want to hear it, I fought it as far as accepting it. How it changed me, just get me more involved. I'm no longer as a mom, I'm the advocate, made me really feel guilty that I did not do much for Robert when I—because I did not find out for Robert 'till he was 14, so it—it made me feel guilty as far as Robert but a better advocate for Manny. Not to go through what I did not for Robert. So I gave Manny and I'm still giving—well now it's for both of them, but at that point, as far as FXS, I give Manny my full attention more than I did with Robert, not knowing what is FXS. It just made me a better advocate.

Mothers described their many different roles such as caretaker and timekeeper. Mothers also took on the responsibility to coordinate therapies and school and to facilitate collaboration with professionals providing educational and therapeutic services. Beverly described her job as, "Asking the right questions, knowing what my resources are, and then, making sure that they're being used. And that's the hardest part." With regard to treatment, mothers took on duties such as tutor, therapist, and expert on FXS. Kathy and Beverly indicated a desire to get certified to teach special education to not only help their children but also to work with other children with special needs. Mothers

also described being the coach and cheerleader; advocate, speaking up for the child; and

teacher/therapist assistant for their children. Carolina described her role with her son's

school:

> In the beginning before when I started with Robert [Manny's older brother with
> FXS], I did not know anything. It was I didn't understand all of the language.
> But the more I get involved, you know, ever. I know some parents do. Now I
> question and I question and I write down with my note with me. I make note. I
> prepare myself. I know what they're saying. I understand. If not, I ask them to
> repeat it in a different way if I don't understand. And I ask for copies and they do
> give me copies. But I ask. And the things what I don't like if I don't get an
> answer back, especially from principal or program specialist. I'm not sure they
> like me and I don't care. I really don't care. If I don't speak for Manny, who
> would? Yes, he is in a good setting. I'm not complaining. They're very
> protected. He is where he's supposed to be. I wish there was a program that
> could work more with FXS, I really do, but at this time, I have to take what
> [inaudible] in the best setting.

Mothers described their role as a mother, paradoxically, the same yet different.

For example, Beverly stated, "Like everyone, I have struggles I realized that are just

different." Rosemary described her motherhood transformation like this, "It changes

everything ... goals, perspectives, future planning, on daily life. It's just a lot of different

changes." Yet she described her role as a mother being the same: "I mean, it's still

probably the same, like, you know, your—just your way of doing things changes, and

sometimes your priorities change, and things that you thought were important are no

longer important."

Views on AAC. As mothers gained clarity regarding their children's diagnosis,

communication needs, potential ability to talk, and their maternal role, mothers sought

the use of interventions that included AAC to help their children talk. Kathy explained

how she came to the decision to use AAC with her two sons, Gary and Tom:

> And so it was kinda two things. So it was one—seeing the real world—seeing
> how it really can work and how you can—well, actually three things. So—okay,
> so seeing it—seeing all the positives that come from it and then realizing how

long the language was gonna take time to come for my son. And then also seeing how to make it work—figuring out how I could make it work in my house—in our lives. 'Cause that's the other piece I think I mentioned, that it takes a while to kinda settle that in your brain and in your—that it's gonna be—that you're gonna <laughter> that your life's still gonna be okay if you turn your living space into a preschool because you need to have icons everywhere.

Mothers' views regarding AAC were based on their past and current experiences with AAC and their future ideas.

Past and current experience with AAC. Interestingly, all mothers had positive views regarding their past and present experiences with simple AAC systems and felt that these tools were effective in helping their children make simple requests and manage their behavior. Beverly described her first impression of AAC when his preschool teacher introduced it to Gary when he was 3 years old,

> To me, it was like a light went on ... because it seemed so simple, in that sense, and so powerful. … And to see the light, the bright eyes of my child, as a response to it [AAC], just reinforced that it was all good.

In addition, all mothers considered AAC use as a bridge to build language and improve communication and social interactions. For instance, Carolina described the first time she heard about her son using AAC at preschool:

> Yeah, so when I go pick him up, [the teacher said,] "come on Mommy, see what Manny learned"… But she had this one [device], I think it has I think four or six pictures, but it had a few pictures. … So she said he understand, he knows. … So it was [a] really a good tool by that [I mean] giving me—giving me an understanding that Manny knew more than what he could communicate. So that gave me hope that the next time hopefully we could replace that [device] with sound that he could make. And ultimately it did, it led to that. So I give credit to the equipment, I give a credit to the teacher and the way that she present it, and use it, it had a lot of things so it really gave me hope. … I know from that point that Manny's going to talk.

Future ideas. All mothers envisioned an AAC system that was more dynamic and portable ("can be used on the fly"), such that their children would have access to a robust vocabulary for the purpose of moving beyond simple requests to having a back and forth

conversation and recalling past events. Mothers also had ideas about AAC assisting with

independent functioning and processing language. Lastly, mothers discussed the use of

the iPod with communication applications as a dynamic and portable system.

When asked whether she would like to find a way to help her son move to the

next level in communication, Beverly answered,

> Yeah, I most definitely would. Something that empowers him and isn't
> intimidating to him. Like, the simplicity of PECS—of the augmentative device
> with the pictures. It's just such a simple act that gave him such a wealth of
> control and got what he wanted. So now, we have to figure out something in the
> augmentative world that allows him to have that conversation. Figure out how he
> can answer back. Keep his interest, and give him the answers he wants, and it's
> some how fun for him. I don't know.

Kathy expressed the same sentiment:

> Definitely I want to find that device that is going to grow with them, and at any
> point in time that the device has more language on it than they have used so far,
> so that they have the opportunity to use more.

Mothers' ideas for AAC use involved not only improving communication, but

also using AAC to improve their children's independent functioning. For example,

Rosemary expressed her ideas on how AAC could assist her son:

> More independence. That's one thing I really want for him. I mean I'm not going
> to be around him always, you know, and I want him to be able to be independent
> and, you know, if being independent and he can drive or he can take a bus
> somewhere later on, you know, and then he might not be fully verbal, but he
> might need the AAC just to help him along or if he gets stressed out or he has a
> panic attack or something he freaks out, he doesn't know what to say at that
> moment or how to phrase it. Okay here is, you know, my AAC, I know I can rely
> on this, you know, and maybe he might not need it, but right now he needs the
> crutch so to speak, to be able to keep moving along because I do see progress but
> he's not quite there yet. If that ever became, like I said a source of, it is a source
> of stress for him so if he has something that he may not need it, but just knowing
> that okay, well, you know, I have my iPod and if I get in trouble or, you know, I
> can, I can use this.

Beverly also believed AAC could help with social skills:

I wish that they had the social piece though, social stories that they could interact with and get rewarded for having a proper response; have a chance to say something over. Let's say if it didn't come out right or if they had like a panic attack, because now, all of a sudden, three people are looking at them and listening. And instead of getting really silly because the words all just disappear, I don't know, that there somehow be a reinforcer in there to settle [his sister] down—Gary, too for that matter; both of them—and let them stay in an exercise of learning how to play a game with a peer, having table manners and having dinner conversation. I don't know. That's a huge, huge piece that has to be done with other kids, but typical kids and special kids don't mix well without an adult there helping. So maybe the assistive technology could form that ... gel it together.

Rosemary and Beverly were also interested in AAC to help with skills associated with processing language such as working memory, auditory comprehension, and motor planning.

Yes, I think that would definitely help him with his communication and his independence, and it's got everything to do, I guess, with his working memory. So if he had a tool like that, then the words that I say would just disappear into space. He'd have a guideline.

Carmen, Rosemary, and Kathy felt that a VOCA would offer a way for their sons to hear how to say a word correctly. None of the mothers were concerned that AAC would prevent their children from talking and did not see AAC as something permanent, but as a tool to help their children be comfortable when they are unable to verbalize or "get the words out." When asked if she thought AAC would help more with receptive or expressive communication, Rosemary replied,

I think it helps him more in his expression, in like the comfort, like "I don't have to go through the hard time to say what I want to say." Like he had trouble telling me the other day what he wanted to say, because like the "come" was "cooooome," and then "went"—I mean, and he was even using the correct tense. It's not like, you know, "How come went here" or, you know. He was trying really hard to put the sentence in the tense and in the way that he wanted to say it, which is why it took so long. But the "went" was like "wwwweeeent," you know, so he was—it took him a hard time. So if he had the thing, he probably would've just tapped it and told me, you know. But then again, he can't put that type of thought together with PECS.

Kathy, Beverly, and Rosemary had ideas for using an iPod with communication applications as having the potential to be a dynamic, portable system. Rosemary and Kathy expressed an interest in using the iPod as an AAC device based on the idea that "everyone has it" and "it's cool," suggesting mothers may be concerned about stigma associated with using an AAC device in public. Rosemary was trying to use the iPod with a communication application to give her son an alternative way to communicate to help manage his behavior:

> But at that point, it's just like he can't [verbalize]. So I want to be able to offer him that alternative and get him more comfortable so that if he gets stuck, we don't have to have him throwing himself on the floor, hitting his head, biting, scratching, you know, especially if we're in a public place.

Internal barriers. Despite the many positive experiences with AAC and constructive ideas for AAC use in the future, mothers encountered internal barriers that contributed to their limited and variable use of AAC in the home. When asked what was the biggest barrier to using AAC with her son, Gary, Beverly replied, "I'm the biggest barrier." Most mothers lacked sufficient knowledge of AAC to effectively implement it in the home and some mothers were less comfortable with using more sophisticated AAC devices. Also, mothers found less of a need to use AAC in the home because they had developed their own ways for communicating with their children.

Rosemary indicated the struggles she was having with AAC:

> It's just actually getting it rolling. You know, sometimes you start and you reach, like, a stumbling point, and then you kind of stop and then it doesn't get picked up again. It just hasn't been, I guess, the right thing for him, because had it been, it would have been something that would have just kind of taken its own life, you know, like its own course.

Mothers' knowledge of AAC. All mothers including Kathy, reported struggles to understand AAC well enough to fully embrace its use in the home. When asked about some of the barriers that parents may have toward AAC, Kathy explained:

> Well, I think the first one is not knowing, just not being aware of it. I think that's the basic one, is not being aware that there's something out there. There's also the idea of "he'll talk at some point." Then there's the idea that—okay, so once they're aware of it, what do they do? How do you know how to set something up? I wouldn't have had a clue what things to set up first. Since I really believe you have to have someone helping, mentoring, "Try this, do this. Try that. How's that working?" and giving you that support.

Beverly also described her struggles to understand AAC well enough to use it effectively:

> I don't see any output. And, probably, it falls—the onus falls on me. So now I have a book of all of these stories I could use for my augmentative training with him, but I don't know how. How do I make that fun and not tedious? I don't know.

Most mothers indicated that for the most part they learned how to use AAC on their own without the help of professionals who were knowledgeable about AAC. Mothers also found it difficult to come up with and keep up with the vocabulary on static boards and devices. Most felt that setting up AAC takes time and planning and most felt that they did not know enough to use it beyond getting basic needs met. Overall, mothers happen to stumble on the idea of using AAC. When asked if AAC was ever formally introduced, Beverly replied sarcastically, "Formally from anyone. Yeah, formally from anyone. ... It's strictly been my own hunting and pecking for resources to help." Kathy was first introduced to AAC informally while her son, Gary, was attending an early intervention program where it was being used in his toddler class. His teacher showed Kathy how it was being used in the class and gave her some ideas for how she could use some of the methods at home. However, she reported that she did not fully understand

the purpose or importance for using it. Kathy's experience is not unique; the other

mothers had similar experiences. Beverly and Carolina got the idea of using AAC

through their sons' preschool teachers who were using VOCAs and picture boards as part

of daily activities with all of their students. Rosemary learned about AAC from other

mothers and her son's preschool teacher. However, like the other mothers, AAC was

never really explained to her: "Speaking to some other moms at, at therapy. Um, they

had recommended it at early intervention but they didn't really tell me what it was for."

She added, "Well, they were using PECS in the classroom. He was in the Pre-K ESE

program, so they had PECS and they labeled everything, and so we decided to do the

same things at home."

     Mothers' comfort level with AAC system. Most mothers found AAC use in the

home cumbersome and overwhelming. Some mothers felt uncomfortable using AAC

devices. For example, when asked how comfortable she was with the technology,

Beverly replied:

> I just don't know how to do it, I feel like it's an intensive yearlong exercise to
> learn the technology, apply the technology for myself, teach Gary the technology
> and apply it independently, spontaneously. You might as well be asking us to
> learn to walk again.

     Rosemary found it awkward to carry around and use a picture book and a small

32-message device with her son, Walter. When asked why she had stopped using AAC,

Beverly replied, "But I think I stopped using this [AAC] because Gary and I couldn't use

it independent[ly]." She also explained how she developed her own AAC system based

on her comfort level:

> I think the teacher must've, or the autistic coach. ... I never used it well—at least,
> not their version. I put my own together, like I said, with pictures. But it wasn't
> really used in order to get what he needed at the time. It was used to help him
> build his vocabulary in a quiet moment, break time, sitting and waiting in a

doctor's office. Whenever we had that free moment, we would use it. You know, "Let's do this and then, we'll play some games, or you get to watch TV," or something.

Carolina shared her struggles with trying to implement an AAC system in the home with her son, Manny:

> Then when I tried to do it again with the help of a teacher many years ago, laminated some with the program specialist, like the head, pulling hair while I'm driving in the car, I put them in the car. But then again, remember, I can't have this very influence or a good part of, you know, making sure the message is delivered correctly. I'm driving and I'm showing cards, you know? "Don't hit. Don't hit." And he's pulling, "Don't, don't," you know? It's really very dangerous, it's not safe, it's not effective.

> ***Mothers developed their own system for communication.*** All mothers felt less of a need to use AAC in the home and most did not fully understand the reason or benefit of using AAC in the home. This was partly due to the fact that mothers were so in-tune with their children that they understood their needs intuitively. Kathy described the struggle of using AAC consistently in the home:

> It's tough to be the one that has to do it all, because what I find is it's easy— especially at home—we understand a lot of what he says, although I know I've seen glimpses of there's way more in there, even at home, that he could say, but he doesn't have the means. But it's easy to get complacent, because life happens, you know? Because you're busy with life stuff. And so it's good to talk to you because it kind of reminds me that I need to keep pushing ahead. Because, I mean, I think Tom especially has a ton to say, and it's just sad that he can't. At least Greg at this point can say a lot of things. But poor Tom just is stuck with— he only has a few words. And he's so cute, because he'll try to say things. He'll sort of just mumble at you and you know he's trying to tell you something, but I have no idea what it is, because he's very intentional.

While all mothers felt it critical to use AAC at school and in the community with unfamiliar people, mothers felt less of need to use it at home. For example, Beverly explained,

> For me, I didn't need [AAC], because I had other—I had his confidence. He was secure with me. So I didn't need that. For the school, it was critical. For the school he loved it. He'd sit there, and he'd do what he was supposed to. And

he'd reach—and again, there's motion involved, movement. And it kept him engaged, and he liked it. So if I had been the teacher of the group I would've used it.

Some mothers reported difficulty using AAC systems at home because home life is more relaxed, less structured, and dynamic (i.e., many things going on at once). For example, Carolina explained,

He would not follow. Here we are loose. Here there is no structure. Here he's not the only one in the house. Here there is a lot of interruption. You remember there's two of them [with] the same priority. And it's almost like I can't do this with Robert [Manny's brother who also has FXS] because he's more higher functioning, you know? But Robert interfered with Manny's schedule. It's just the nature how they are and they are together. I also didn't have so much time to put emphasis on it. When I thought it was not working, I just gave up.

Theme 4: External Barriers: "Roadblocks and Stymied Progress"

As previously discussed, AAC use in the home was limited and variable, yet mothers viewed AAC as a positive influence in helping their children's communication and behavior. Despite their positive experiences, mothers encountered internal struggles related to understanding their children's diagnosis, communication abilities, and use of AAC. These struggles included the process of understanding their children's condition, the search for interventions to address their concerns, their limited experiences with AAC, and the challenges associated with setting up a functional AAC system in the home. As a result, most mothers expressed feelings of uncertainty in their pursuit of AAC.

After learning about FXS, mothers actively sought interventions that included the use of AAC to address their many concerns. The decision to use AAC was an informal process and most mothers reported learning about AAC systems "on their own" without guidance from professionals. In spite of mothers actively seeking support and building connections, mothers reported numerous "roadblocks" and "stymied" progress.

As more and more children are being identified with FXS and other genetic disorders in infancy and in some cases sooner, through newborn screening, it would seem likely that through surveillance and early intervention services, children with FXS would acquire language sooner rather than later. However, despite the fact that these children were diagnosed early, prior to the age of 4 and all received early intervention services, progress was still slow, especially in the area of communication. In addition, although all children were introduced to AAC prior to the age of 5, mothers were delayed in their efforts to implement AAC use in the home. Furthermore, mothers encountered a multitude of stressors in their efforts to seek support and access AAC interventions to help their children. These external barriers included limited supports and services, financial and family issues, and struggles with school.

The need for support. All mothers noted the importance of having support and building connections for the successful implementation of AAC in the home. For example, Kathy, who represented a unique experience with AAC, stated, "I've been the type of person that makes things happen. I figure out who to call, I call. I figure out what I need to do, I do it. ... I make things happen." Later on in the interview Kathy emphasized the importance of having support:

> I think one of the biggest things that you could ever do for anyone, for any parent that has kids with special needs, is empower them to feel like what they think, that they want the best for their child, and just to feel empowered to do something about it, that it's okay to ask questions, that it's okay to push the envelope. It's okay to ask for more, and to look around and find out what more might look like. That's what I'm finding, that parents just need that supportive push and that feeling of, "Okay, so and so is an expert or another mom that's gotten this done, or whatever, and she's telling me that it's okay for me to do this, so I'm going to do it." I think that is a huge piece. Again, it's such a weird, isolating, you kind of feel bad and guilty and all kinds of weird things. So if someone comes along and says, "No, you're doing fine. Let me give you some resources on how to push

more and this and that," I think that's huge. And then they can work towards all the other little pieces like AAC.

Across the board it appeared that the biggest obstacle affecting AAC use was the lack of support. Even Kathy, who had developed a low tech AAC system for her boys, was having trouble finding support to help her use more sophisticated AAC technologies to expand her boys' use of AAC.

Seeking support. Mothers discussed seeking professional/programmatic support services primarily through word of mouth from other mothers, the National FXS Association, and FXS mailing-list servers and expressed the need for support to implement interventions at home. Beverly described how she found her son's speech therapist: "I happened to get acquainted with her because I had, as a parent, been going to different programs to educate myself on different learning systems." She went on to explain, "I had a very strong leader in the speech person, took us under her wing, came to my home, helped me with the picture system that you see that I haven't integrated yet."

Beyond accessing professional support services such as quality SLPs and other specialists who know about FXS and Medicaid Waiver and respite services, mothers talked about needing different types of support. First, mothers talked about needing the physical support of having someone to help develop the home-based AAC system. Beverly cleverly contacted community programs such as Kiwanis and Boys Town to get volunteers to help her make choice boards and other visual supports to use in the home. Kathy talked about the importance of having AAC support:

> And the other thing is, I believe you really have to have someone who's supporting you, because I had actually a gal whose son has pretty severe autism and she has been kind of a local pioneer of this stuff. I think she knows more about AAC than pretty much anybody else I know, and that includes us, speech and language therapist, or anybody. And so she would come over and help me get stuff set up and give me ideas, because her son is not verbal at all. And now,

he's reading. They told her that he was one of the lowest functioning kids with autism they had ever seen, and now, he reads at grade level because of what she's done. So it's just totally motivating. When you hear about and see results, you're so much more motivated to do it yourself, because it can kind of be overwhelming, like, "Oh, gosh, do I really do need to do this?"

However, she was having difficulty getting continued AAC support to develop a more dynamic AAC system:

She's been really out of the loop too. She's been gone all summer and I haven't—I heard she might be back for fall, but not conclusively. So she might not be available at all. I've tried to e-mail her a few times and call her. I've talked to other people too, and no one has gotten in touch with her. So I'm not sure what's going on. So I might be on my [own] now.

Beverly also discussed the importance of having physical support:

There was a 9-month spread where I wasn't doing a lot of volunteering. I wasn't working. And so I would get things in order, plan the things that I wanted to cover with the kids. And then, this gal came and would help for 2 to 5-hour periods. And we kept a journal, and it was just—my life was beautiful. I was making progress with the kids. They were reading. She was reading. We were doing the chores. It was 9 months out of a decade.

When asked what happened she stated, "She went off to help another friend with a different job. And then, ultimately went to New York to be an Art major." Carolina shared a similar experience: her son's speech therapist had moved away and now she was having trouble communicating with her son:

[The use of gestures] is not working but I have no other way to work with him now. I need also, too, to learn how to deal with certain things. He had a wonderful speech therapist that was coming to the house; the most wonderful I ever met. However, all the good ones leave. He was contracted by an agency to be in the school system, but he is originally from Madison, Wisconsin and he got fed up with the system.

Despite having therapists and teachers who were receptive to the idea of using AAC, Rosemary commented on the lack of AAC experts:

No. I don't think I would say an expert. … Comfortable using it, yes. Willing to try, everybody. Everybody's willing to try, but like, now also with, like, the iTouch, which is small, portable, you know, it's got its positives and its negatives.

But then again, you know, I'm doing a lot of the research, you know, and they're learning with their kids at the same time because it's something that's fairly new. You know, one parent uses one program, and it works for one kid, then they find one that works for another kid. So it's kind of, everybody's trying to find what works best on that device, because there are so many options available.

Next, mothers addressed the need for emotional support. Mothers gained emotional support from various sources. Kathy talked about gaining emotional support through her faith:

So the one piece I haven't talked to you about really is my faith. And I firmly believe that all of this is God-planned. ... When God's involved you step out but then you just kind of ride the wave. ... So the whole thing, like I say, I feel like I'm just kind of—I mean I'm doing the work but I'm not stressed about it. I'm not anxious about it. I'm just going along.

Mothers also found emotional support through the encouragement of friends. Kathy shared her experience:

I mean I guess I would think that there's also another level of support which is just people around you saying—like just yesterday I talked to a gal that's in my small group and I kind told her about some stuff going on. And she said, "Oh you're my hero. I just am amazed at what you've done with your kids and how you've made it such a positive thing." And so just having your friends around that you can talk to and say, "I'm having a rough time" or "Listen to this great thing that's happening," or that kind of thing too.

Carolina also talked about having a strong support network of friends:

In fact, I think there is maybe a dozen [friends]. I have friends enough in Florida. They understand. I have my friend, the neighbor down the street. She has an autistic daughter and she has a gifted child, which is 3 months younger than Manny in the same school as Manny. You know what? I don't know what it feels like to be normal because I don't have a normal child, so it's different for me to understand. It's friends. It's a circle of friends. Maybe clients and their family who I service. That's another source. You can share. You can be comfortable.

Two mothers drew strength from their strong family support system. For example, Rosemary stated,

I mean my family's support has allowed me to do a lot of the things that I do. I don't think that without the family support I could, you know, do all the research studies or volunteer and, you know, try to raise money to, to help and, you know,

help Walter in school. It just—it wouldn't, it wouldn't be possible. Like right now my mom, I wanted—I had wanted to put him in [Confraternity of Christian Doctrine] CCD for his first communion. ... My Mom and I are going to take turns, she told me; I'll take him every Saturday and I'll sit with him and give him the support that he needs you know, so that he can do his communion. It will probably take him, not the 2 years but 3 years, but you know with the help I can do it, since I have Abigail [Walter's baby sister], who I also have to—you know, she's small. She has a lot of needs, so even though my husband helps out, it's an extra comfort and peace of mind knowing that it's not all on me.

Networking. In addition to getting physical and emotional support, mothers discussed the importance of "building connections"; in other words, networking with people in the community. For example, Beverly explained,

And the long and short of it is we're still here and probably will be now forever because the kids, for me, we require the consistency and the connections. I mean much like why we're speaking is because of Jennifer who was my daughter's 3-year-old teacher so that goes 7 years ago.

Carolina noted the importance of building a network of supportive medical professionals and the need for understanding and tolerant people in their community. Some mothers found it stressful to deal with doctors who do not know about FXS and to take their children out in public for fear of public scrutiny. Carolina shared the difficulties involved with taking her son Manny to the doctor:

I get nervous ahead of time as far as Manny when there's a doctor's appointment because I know what's going to happen. But at the doctor appointment they all understand and made clear that this is a special-need child. Not to open the door bigger for him, but they understand there is a tolerance. I don't expect it from the parents or the patients in there, but the staff. ... So they are aware and that make things easier for me. ... I still do my job, I still control Manny and bring him with me with a lot of tools to distract him, and I bring my husband, I couldn't go to the doctor without him. Because not about restraining Manny but it's about distracting him in different ways.

Mothers also talked about the importance of establishing rapport and networking with professionals and parents through the National FXS Association. All mothers discussed the importance of joining FXS mailing-list servers and sharing experiences

with other parents of children with FXS. Beverly talked about the importance of

connecting with FXS experts at the Medical Investigation of Neurodevelopmental

Disorders (MIND) Institute in California:

> And it would have been a huge detriment if I hadn't known and didn't get to get plugged in with the folks [at the MIND Institute] ... brought me complete organization and peace of mind and I just wish I had more of these experts because we talked about the nuggets of people and some I don't even know personally but I need to have them in my life because it's a unique thing that you try to find, a person that genuinely cares about your child and connects with them and is skilled, super skilled and those are rare finds.

> Kathy discussed the importance of networking with other parents who use AAC.

However, most mothers had difficulty networking with people in the community who are

knowledgeable about AAC. Kathy was fortunate to find an AAC expert through a family

support network in her community to initially set up an AAC system in her home. She

also talked about networking with others through the Internet to make interactive

communication boards using a program called Boardmaker:

> This class that I'm taking on technology has been really fantastic and really talking about how the Internet can really help with collaboration and teachers learning from other teachers and parents and whatever. My plan is to get more invested in that, and try to learn from other—I am certain, I know there are other people that know more about Boardmaker than I do and have done some of these cool boards that I want to be able to do. And in fact, I e-mailed—on the Boardmaker Share, you can actually contact people, and so I sent out a discussion thing, I think, and I said, "Hey, I want to know how to do this." Someone responded and she didn't actually tell me how to do it, but she sent me a basic board that I can use to do it. So at some point, I'm going to try to go into that even further. And then I actually put up my [inaudible] the boards that I created, up onto the Share website for other people.

"Lack of choices." In addition to limited support, all mothers were faced with

the challenge of locating and maintaining effective behavioral interventions that included

the use of AAC and medical treatments to help their children not only develop

communication, but also to manage their behavior and to support learning. Beverly

described her struggles to find appropriate interventions as a "lack of choices." In

general, mothers reported a lack of FXS-specific resources and discussed seeking out

interventions for similar disorders such as apraxia and autism. In addition, mothers

lacked choices regarding finding SLPs trained in the use of AAC. Beverly further

described feeling stuck with regard to how to help her son advance in his communication

development by stating, "How do you get the conversation? How do you help him to

retrieve events from his day and share with it? That's where we're stymied."

Use of interventions. Overall, mothers described therapists using an "eclectic

approach" to interventions with a focus on working on skills in isolation in therapy.

Mothers felt there was much trial and error involved in finding interventions that were

going to work for their children. Mothers noted the importance of speech and language

therapy and their struggles to access appropriate speech and language services. Kathy

shared her struggles with finding an SLP to work with her son:

> So when I was—I talked with people at the FXS Foundation when Greg was still
> in pre-K and I mean, I think, he was probably 4 or 5. And they said to me, "you
> need to get a speech language pathologist" because he didn't have one at the time.
> ... So I talked with the early intervention program and said, "Look, we need an
> SLP." ... They kind of brushed me off. And I pushed it farther because, well, I
> figured that he needed it. And not really fully understanding what an SLP does or
> is supposed to do. But so what ended up happening is that the early intervention
> program they had an SLP come and evaluate him and she said there's no point in
> working with him [because] he doesn't have enough language.

After researching more about speech and language therapy services, Kathy shared

her thoughts regarding why she was having difficulties finding an SLP to work with her

son:

> What I kind of figured out through the whole thing is that there [are] some SLPs
> in the world whose theory is that their job is only to work on articulation, and
> until the child has language there's no point. So then the other group of SLPs,
> they actually think that language is their job also, not just the speech. And so they
> believe it's their job to have games and tricks and toys and activities and whatever

to try to get the language out. And so that was a huge—that was a big deal to figure out. I mean it was such a struggle to get an SLP and we finally got the SLP but it's the one that believes in articulation only. And so she did a few things like flash card kinds of things to get him to say things but I'm sure it wasn't highly effective because that wasn't—she didn't feel that was her job to entertain him or, I mean, to motivate him to talk.

Most children had received speech and language therapy primarily focused on speech production using a variety of methods geared toward apraxia such as PROMPTs for Restructuring Oral Muscular Phonetic Targets techniques, oral-motor exercises, modeling, verbal rehearsal, and drill and practice with picture cards to develop vocabulary. Beverly discussed her experience with an apraxia specialist who was working with her son, Gary:

> The sign language at the beginning using an [applied behavior analysis] kind of approach, like ... "Arm up," you're making his arm go up because he wasn't doing it, you're making his arm go up and you're giving him his cheerio. And that was kind of the first thing that got him, I don't know, woken up to the whole communication concept; this is at 2. And that's when I told you we started using signs, "Drink," okay, drink, where he's got the sign for drink and he's flipping it up, got his drink. ... All of a sudden he was a different kid and was doing it all day, "Help. Help." And then we started having the word come out. Words didn't actually come out until we got the apraxia tended to which was through a speech pathologist in Boca. In 10 minutes with that touch, the PROMPT therapy is the technique that works with apraxic kids like magic. In 10 minutes he was saying the words that he'd been signing. And I just sat back floored.

While these techniques were somewhat helpful in improving oral-motor functions and speech production, these interventions were less effective in developing language and conversational skills. Beverly felt that his communication skills were still "stymied" because he was still not able to have a back and forth conversation.

Mothers also discussed seeking out interventions from autism-specific resources. Interventions included ABA and related programs designed for ASD such as discrete trial, verbal-behavior therapy, functional-communication training, the Strategies for Teaching Based on Autism Research curriculum, PECS, Treatment and Education

of Autistic and Communication Related Handicapped Children methods, and social-skills

training. Kathy shared her thoughts regarding methods designed for children with ASD:

> But you know, I would also just want to throw this out. I'm not sure if I told you this before. At the beginning, I was really frustrated by people who kept lumping my boys into the autism category. And then I finally realized that it's actually a positive thing, because it seems like there's so much more research on behaviors and the sensory needs and all of that stuff for autism. So you can benefit from that, because in fact our kids tend to respond to those things. So I found, I think I told you, getting involved in groups, I mean, I'm involved in groups that are mostly kids with autism, but those parents are more on top of stuff and doing things and making stuff happen and helping each other, that that has turned out to be a really positive piece for me, when in fact at the beginning, I was really opposed to and irritated with people who put my kids in that category.

Beverly also discussed the lack of continuity and collaboration with

interventionists adopting the use of AAC in therapy, "But you have to have the other

people involved too and they weren't." Regarding speech and language interventions,

mothers were not explicitly introduced to AAC as a way to get their young children

talking. For most mothers, their children's speech and language therapist did not

recommend AAC. In addition, very few specialists used AAC as part of their children's

interventions. In fact, none of the children's SLPs was using AAC methods beyond the

use of simple signs and picture cards to communicate basic needs. Although, Kathy

mentioned that she was working with an SLP therapist to get her son a communication

device through her insurance company, the therapist was not working directly with her

son.

> Beverly believed professionals have different opinions regarding the use of AAC.

> So the teacher connected me with the ABA person. I'm trying to remember if the speech person had told me about any of these things [AAC]. And I cannot remember a speech person talking about the augmentative devices. In fact, there was a weird discipline bias, I guess, that they didn't want crutches. They wanted—the kid has to talk. They didn't like sign language, even. I was getting a lot of flack, or hearing flack, from that. And I would just be quiet, because it was so effective with me. So I wasn't going to jump in on that argument. And they

could say whatever they wanted, but I knew it worked. And so I remember hearing stuff like that from the private sector specialist for speech. And he didn't have that much [AAC] before we were in school.

This comment was affirmed during an observation of Gary in a therapy session where his speech therapist believed AAC would actually deter Gary from speaking and developing listening-comprehension skills. Kathy also shared a similar situation where the school speech therapist assessed that Greg was not ready to use an AAC device due to the fact that he had not learned enough vocabulary to use an AAC system in school, despite the fact that he was successfully using an AAC system at home. Kathy also learned through her research that graduate students in speech and language pathology at a local university are not getting much training in AAC in their graduate programs:

> The graduate student was only—that was just this summer and all it was is that I found out that she's becoming an SLP and I just asked her what she knew about aug-com and she said pretty much nothing. She didn't know—I mean she would only have a topic of that during her schooling for like 2 weeks or something. Like it's just a very minor piece of what she learns.

Lastly, mothers also reported many obstacles that prevented them from continuing with the interventions and contributed to their "lack of choices." Most mothers expressed frustration over their children's lack of generalization in acquired skills and slow progress. In fact, some mothers were not really sure programs were effective because their children's response to interventions varied day by day. This was the case for Beverly who stated, "I make these connections because I struggle, but everyday is always something a little bit different." Additional obstacles included implementing the interventions at home, fitting therapies into an already busy schedule, therapist moving away, cost of therapies, and long wait list for skilled therapists.

"Medication ebbs and flows." Several mothers reported seeking medical treatments such as the use of medications to regulate their children's behavior. These

mothers discussed exploring the use of medications at some point with their children and that sometimes the medications had a positive effect on helping regulate their children's behavior such as improving attention and focus and to keep them "calm," which in turn helped their children be more verbal. Mothers reported at some point using many different types and combinations of medications such as antipsychotics and mood stabilizers to decrease aggression, (e.g., Abilify, risperdone, Seoquel), clonidine for sleeplessness (e.g., Tenex,), selective serotonin reuptake inhibitors (antidepressants) for the treatment of anxiety and obsessive-compulsive behaviors (e.g., Prozac, Celexa, sertraline), and stimulants to address attention problems (e.g., Focalin, Concerta, Strattera, Daytrana, Buspar). Several mothers also explored vitamin supplements such as folic acid and omega fatty acids (3, 6, 9). Two mothers explained that their children were more verbal while on medication. For example, Beverly explained:

> Yes. It's been hit or miss. There's a couple that have been slam-dunks that I continue to use. But the [inaudible] medication is what really—And a small dose of it is what settled him down, organized him, made him seem typical. We kind of noticed it right away really strong and then it flatlined a little bit. But I felt like I got sentences out and things much more independently and spontaneous. When I added the attention drug, I thought I got more alertness and staying on task longer.

 However, she reported "glitches" with the medication:

> Medication has it's ebbs and flows in the system I guess. So he has his fall back days. But I'm trying to stay and be very disciplined at maintaining the medicine. I was at some point, given information by reputable people that you can take like the child off of the stimulants for instance, because the stimulant only works in the child's system the day you're on it. But there was definitely some kind of aggression or emotional side effects when he wasn't on it that would hit 2 days later, just as we were going back to school. So if I wanted to take him off on the weekends let's say, to budget out the prescription or to just not have his system have to be on it, because of the risks that are associated with some of these meds, it just seemed, I was causing more aggravation and damage. He was falling back to having bathroom accidents and stuff.

However, this may be due to the fact that some mothers appeared to be managing the medication on their own without consulting with their children's physician first. Beverly was actually finding it difficult to find a local physician to help with medication management:

> It's hard to get to see the local pediatric neurologist who writes the scripts for me. ... [The doctor from the MIND Institute] is my anchor for all things medicine and she sets the path. My local doctor obliges me. And then since I can't always see him, I've made some tweaking and done some things on my own until I can get in. And now we're at the crossroads. He doesn't take our new insurance so I have to start over.

Carolina reported concerns about possible side effects and not wanting to medicate her son even though she had used medication with her son in the past.

> I do often think about the future and his size and medication and I'm fearing to put him back on medication, I'm just hoping—I don't like medication, I know what it can do for you, and I deal with client that they take a bunch of medication and I see what it can do for them, I want him to be the person they are, that they could function on their own. It's really a very hard call to put him on medication, but when I see things that could benefit ... I have to be very, very ... eagle watching any changes, because I'm really concerned about Manny. I was telling [my husband], oh my god, we've got this year, next year he's in high school, that's scary. I'm scared if I have—need to put him on medication that always scares me, so his size, his behavior is a big, big issue.

Stressors. Lastly, mothers encountered numerous stressors that contributed to "roadblocks" and "stymied" progress with regard to AAC use in the home. For example, Rosemary summarized the challenges associated with AAC use like this:

> Well, first of all cost. You know, I mean, some of them, I mean, you look at them and you think, is it really worth that kind of money? So you have to see before you invest in something like that whether it's something that is really going to work for your child, because I don't mind spending a thousand dollars if the thousand dollars are going to be the, you know, the best thing for him. But then you think, well, I spent a thousand dollars, it didn't work, it's sitting gathering dust, you know. So you kind of get a little discouraged sometimes when you're doing these things. But, you know, cost, portability, whether it can be used at home and at school, when you're out—because ideally, you want him to use the same thing. You know, you don't want him to learn how to use Technology A at home and then use Technology B at school. And then, the things are not the

same. So when he gets to school, it's got one procedure. And then he's trying to teach me something, he's trying something at home from school, and they just don't match because we have different systems. You know, it's got to be something that gets to be used across the board.

Beverly shared her thoughts on barriers affecting AAC use in the home:

Yeah, well the biggest barrier is having—I need more people in my life to help me every day. And that would be the time—the money part and time part because my friends that are successfully doing this are on Craig's List all the time putting in their ads. Just on ABA alone, on her two children, she's paying $30,000 a year on the ABA, just that component and there's tons more than that. So I know that it takes the money and the time and being organized. So I often wish that I had some kind of manager for me to put me on track and then hold me accountable and then show up. And together we're doing things like my kids, I just need the visual, I need to physically go through it in order for me to master it and then be able to use it on the fly.

Stressors that interfered with AAC use in the home included challenges associated with the AAC system, "bartering for therapy," struggles with schools, siblings with and without FXS, and dealing with extended family members.

AAC system challenges. AAC use in the home was also complicated as a result of challenges associated with the actual AAC system. Mothers reported problems with portability and maintenance of the system. Some mothers who developed AAC systems in the home reported that the system was not portable to use outside of the home. Rosemary stopped using AAC with her son after the device broke.

But what happened was, I had to send it back ... to get it fixed. And then by the time it came back, it was about 3 months later, almost 4 months later. ... And then, so, to get him to use it again, he just wasn't really fond of using it."

"Bartering for therapy." Another obstacle experienced by mothers that contributed to roadblocks in AAC use was cost for AAC devices and support. Many mothers had issues with the cost of the device, and even though AAC is sometimes covered by insurance, one mother was having difficulties getting her insurance company to cover a $7,000 device. Mothers reported having to budget for therapies. Some

mothers reported having to put therapies on hold because they could not afford to keep up with the interventions. Some mothers sought out grants, scholarships, volunteers, and free resources to cover the cost of devices and support. Beverly discussed "bartering for therapy" by working at her son's therapy office once a week to pay for her son's speech and language therapy.

Struggles with school. Lack of home–school collaboration was another huge barrier that contributed to limited and variable AAC use for some of the mothers. For example, Kathy felt that she had to push for AAC at her son, Gary's school.

> I feel like I have to kind of stand on this rock of "I know what I'm doing," because it feels like if I back down at all, saying, "Oh, well what do you think is better?" that then they're going to drop down again to this <inaudible>—you know what I mean? Like that sort of idea of, "Oh, well, then if you're not pushing, then we're going to just say we're just going to do this little thing."

She went on to say that she was struggling with the school to even consider the use of AAC at school:

> And they indicated that I would need to demonstrate that he could do the things that use the technology. So it's definitely a step ahead, because I have to actually use it, show them—have him use it and show them he can use it before they're going to believe me that he could do it, which is very frustrating. And so, I mean, I'm hopeful—a little bit; I have a little bit of hope—that when we have our first meeting—because we're going to have an aug-comm meeting to do the whole [Student, Environment, Tasks, and Tools] thing—so that is coming up—I don't know—probably within a month, ish. We'll see. I mean, maybe because I've told them all the things he can say—and he did seem a little bit excited about that, the aug-comm guy—maybe that helped enough that they will step up a little bit. I don't know.

Other school barriers included transferring the device from school to home and vice versa. For example, Carolina felt uncomfortable borrowing a device from the school and Rosemary and Kathy, who sent AAC devices to school, mentioned that the schools were uncomfortable using the device.

Several mothers stated that the "school requires help," and weak educational programs described as "not the right fit" and "not suitable," were "holding [the child] back." Mothers often felt forced to settle for a "better option ... not optimal" program due to limited choices regarding educational programming and search for schools in the community. For example, Beverly explained her reason for transferring her son from a public school to a private school. Although not optimal she felt it was a better option for him:

> Well, the big reason was because he can go all the way to high school and in my exhausted mind I'm thinking I am so tired of retraining teachers every year. I had a very strong leader in the speech person, took us under her wing, came to my home, helped me with the picture system that you see that I haven't integrated yet and yet the teachers were young and I don't know, inefficient. I can't explain it. Why else was he being held back? He never had homework. Now he's got homework all the time. These people at the school will learn every facet of my child and I don't have to retrain them every year. We'll get to build finally on something. How does this child learn? What are the resources we have? Let's learn the resources all the way to high school.

Rosemary made the decision to transfer her son to a private special-needs school stating,

> They [public school team] were missing it. And so then he wasn't motivated to even try. ... I just had a lot of issues with his teacher and she wasn't really motivated, I think, to, to get him to do certain things.

Mothers reported that most teachers were not knowledgeable about FXS or AAC and were reportedly not effectively using AAC. When asked if AAC was consistently being used at school Beverly replied,

> The consistent thing, that's where your question started at the beginning, was that it was put to the sidelines because even when I brought it up at school and I knew what to ask for at the school, it wasn't delivered. Because the teachers likewise are in a very dynamic environment and to give that one student who needs that device, which I recognize from talking to you and what I've learned, it would help all the kids from the savants to just the typical genius kid down to the kid that's struggling with reading or past tenses. I don't know you'd have great tool[s] that they could use as part of their curriculum and they just don't, the school system

does not do it, the therapists don't use it in therapy sessions; nowhere have I been exposed to it.

Mothers felt that lack of communication and collaboration, power struggles, and lack of parental involvement contributed to struggles in school and mothers oftentimes did not feel part of the school team. In addition, lack of speech services and AAC specialists contributed to roadblocks in accessing AAC resources in the school. Beverly and Kathy discussed the importance of having someone attend school meetings to help them advocate for their children. In fact, all mothers discussed the need to advocate at school meetings programs and services that would help their children, and many felt that they were working against people or systems that were providing care or services for their children. For example, during an observation at a school meeting lasting 5-hours, Carolina was caught off guard when the school proposed to reduce the amount of speech and language therapy her son was receiving in school. Despite her concern about her son's progress in speech and language, the school apparently made the decision to reduce the amount of speech therapy without first consulting with Carolina. She felt that her input was not considered prior to the school team making the decision.

Siblings with and without FXS. Mothers' decision to use AAC in the home was a challenge because of the dynamic nature of family routines, such as trying to meet the needs of other siblings with and without FXS. All mothers had more than one child and all mothers had more than one child with FXS. Mothers talked about siblings with and without FXS and that they each have their own set of needs. Carolina had an older son in his 20s with FXS, Rosemary had a younger daughter who was unaffected and an infant who recently tested positive for FXS, Beverly had an older daughter age 11 with FXS, and Kathy had two young sons both affected. All mothers reported positive sibling

relationships, however, mothers reported difficulties with interactions, especially if the child's sibling had FXS. AAC use in the home was also complicated by mothers' frequent need to mediate sibling interactions and mothers were often burdened with caring for the needs of multiple children with FXS. Rosemary's younger daughter, Allison, who was unaffected, oftentimes took on the caretaker role to help manage her brother's behavior and help care for her infant sister. Kathy and Carolina benefited from having an older sibling with FXS in that they were able to provide surveillance for Tom and Manny's development, which resulted in them being diagnosed sooner.

Dealing with extended family members. Another source of stress for some mothers was the fact that extended family members were not always supportive. Beverly and Carolina shared that many extended family members refused to get tested or were "fighting the fact" that FXS is a genetic disorder passed on by relatives. When asked why her extended family was resistant to getting tested, Beverly replied, "Nobody wants to know that they've got a retardation gene." Hence, visits with family members were often stressful as mothers exerted great effort to make sure that their children were on their best behavior. Carolina shared the instance when she first brought up the idea of getting tested to her brother:

> Because I presented to my brother about—he is PhD in engineering, that this intelligent, because he has a daughter. I brought him the booklet from the National FXS Foundation. It's free. And I remember he was sitting here and as they leave, they went in a hotel in Miami Beach, he left it. I say, "You forgot it." And then at some point he told his daughter that we are not going to do anything. If you in the future get married, have kids, we will think about it then.

Conclusion

The study revealed numerous obstacles for mothers of children with FXS and their experience with AAC. These challenges contributed to limited and variable AAC

use in the home, inadequate understanding of AAC, and lack of AAC resources and

support. The final chapter will discuss the implications of these challenges.

Chapter 5: Discussion

Four mothers of five children with FXS participated in this study on their experiences with AAC systems in the context of the home and how they communicate with their children. Most of the mothers shared similar experiences and perspectives regarding AAC. However, one mother, Kathy, was able to overcome many of the obstacles experienced by the other mothers and successfully implement AAC in her home with her two young sons with FXS. Kathy had developed an efficient and systematic AAC system in her home to allow her sons to communicate basic needs. As a result, behavior problems were minimal and her sons had begun to initiate and generalize the use of AAC across environments. The themes and core finding of this study assist in highlighting the many challenges faced by these mothers regarding communication and use of AAC in the home, as well as offering an explanation of barriers that interfere with their decisions and abilities to use AAC with their children.

As previously discussed in the findings, the themes that developed through the analysis of data led to one core finding and four themes that exemplify the complex nature of AAC use in these homes: For children with FXS, the interplay of children's complex developmental challenges, mothers' internal struggles, and the absence of external supports, led to limited and variable use of AAC in the home. This section will reflect on the implications of the core finding and four themes.

Implications of the Complex Nature of AAC Use in the Home

The complex nature of AAC use in the home is a difficult process that leads to limited and variable use, which has implications for how these children develop communication skills. Interviews with the mothers, observations of AAC use in the

home, and review of educational records revealed (a) that AAC was greatly underused in the home, (b) most children had developed little to no functional communication skills, and (c) most mothers were ineffective communication partners. A review of research on the use of AAC systems in young children by Light and Drager (2007) found that AAC systems had positive effects on children's communication skills and that research investigating parent perspectives on AAC use and AAC interventions with parents as communication partners are limited. This study offers insight into the nature of AAC use by mothers in the home, and reveals the need for portable and dynamic AAC systems and targeted AAC interventions that are specific to the needs of children with FXS to support the use of AAC in the home, to increase children's functional-communication skills, and to improve mothers' effectiveness as their communication partners.

The Use of AAC in Light of Children with FXS

Results of this study revealed that all mothers believed that their children understood much more than they could express verbally. However, finding ways to help their children communicate posed a serious challenge for them. Research has shown that AAC interventions increase speech production, decrease behavior challenges, and improve communication skills in similar developmental conditions. In spite of the fact that all mothers in the present study believed that AAC was a bridge to verbal communication, AAC use was highly underused. One explanation for this may be that children with FXS present with significant complexities such as limited to no speech, behavior challenges, and poor communication skills that make AAC use difficult.

The behavioral and cognitive challenges associated with FXS significantly impacted the children's response to AAC and posed a serious challenge for mothers to

effectively implement AAC use in the home. Roberts and colleagues (2008) outlined the behavioral and neurocognitive features associated with FXS. These include (a) mild to profound cognitive impairments, (b) impulsivity, (c) executive functioning impairments, (d) overreactivity to stimuli, (e) anxiety, (f) autism characteristics, and (g) mood instability. These developmental challenges further impede communication development. Therefore, speech and language interventions that focus on speech production alone will be inefficient in maximizing these children's potential abilities to communicate and socialize with others. Most children in the study had developed little or no functional-communication skill in spite of years of speech and language therapy.

All mothers in the study stated that improving their children's communication skills was a priority. Romski and Sevcik (2005) stated that the inability to communicate effectively with others places children at risk for decreased social interactions, communication breakdowns, and learning and behavior problems in a multitude of contexts, particularly in the home. Many of the children in this study have started to experience these consequences and are a substantial risk for future dependency, social isolation, and lack of independence. Hence, these children would benefit from targeted AAC interventions that involve specific and structured AAC training by a trained AAC expert to develop their communication skills.

In addition, behavioral interventions that do not address the communication challenges experienced by children with FXS will likely be ineffective. Many behavior problems observed in this study appeared to be as a result of the children's inability to communicate even on a basic level. Therefore, parents and professionals need to understand how underlying conditions such as FXS impact communication and how

AAC systems and targeted AAC interventions can help support communication, behavior, and cognition.

The Need for Parent Training to Maximize AAC Interventions in the Home

Mothers are key communication partners because they can provide important social experiences and opportunities to practice using AAC to facilitate their children's development of communication skills. However, the use of an AAC system for communication differs from the usual expectations for communication with one's child. Therefore, parent training in AAC systems is essential. Starble and colleagues (2005) discussed the importance of training parents to be effective communication partners to support their children's language development as well as AAC use in the home. The present study was the first to investigate the perspectives of mothers of children with FXS who use AAC systems in the home. Although mothers were in-tune and responsive to their children's needs, most mothers felt that they were minimally effective in setting the stage for meaningful communication exchanges to occur. Stephenson and Dowrick (2005) discussed the importance of responsive parents to the behaviors of their children as critical elements for children's development of strong communication skills. However, the observations of the mothers communicating with their children in the present study revealed the difficulties involved in managing the complex nature of their children's communication needs and challenges associated with FXS. Most mothers relied on talking and prompting and struggled to support their children's development of communication skills. Most children in the study were highly dependent on their mothers as the primary mediator of conversations and interactions. Therefore, targeted AAC

interventions need to include training communication partners to communicate more effectively with their children.

Another possible explanation for the underuse of AAC was problems with the AAC system itself. The use of AAC appeared unnatural and mothers felt burdened by its use in the home. The central concern expressed by all mothers was the need for a more portable and less cumbersome AAC system. While all mothers reported some positive experiences with AAC use, the AAC systems they used were inefficient and minimally effective. In other words, the AAC systems were limited and not conducive to supporting interactive conversations, sharing about and recalling events of the day. This was also the case for Kathy, who was successfully using simple AAC systems with her sons. All mothers expressed their desire to find a more dynamic AAC device that would grow with their children and help them expand their language.

While all mothers stated that they felt that AAC use had helped their children be more communicative, all mothers in this study were struggling to use AAC. This supports the early work of Parette and Angelo (1996), who found that there is a high degree of abandonment such that parents start to use AAC, but give up and underuse it; parents do not know enough about AAC to fully embrace its use. This was certainly the case with the mothers in this study. Most mothers had at some point started to use AAC with their children but stopped, and all mothers felt that they did not know enough to fully embrace its use in the home.

Mothers Have Internal Struggles That Require Attention

Even if children do have the potential to improve communication through the use of AAC, and training is provided for both the child and parent, mothers have internal

struggles that need to be overcome. Mothers' internal struggles about their children's diagnosis, communication abilities, and AAC suggest that mothers are unclear as to how aggressively they should pursue AAC. Most mothers in this study waited for their children to talk and introduced AAC as a last resort and not as a first step toward helping their children to talk. All mothers struggled to understand and accept their children's diagnosis, as well as struggling to understand their children's communication needs. As a result, all mothers experienced a period when they were unsure about their children's potential ability to talk and were unclear as to how aggressively they should pursue AAC. Brady and colleagues (2006) suggested that parents often question professionals and other parents about expected development for their children; and D. B. Bailey and colleagues (2009) added that parents might be hesitant to introduce interventions without access to accurate and understandable information. The mothers in the present study struggled to determine when and how to introduce AAC with their children. Therefore, parents need access to accurate and understandable information soon after receiving the diagnosis, to increase their knowledge of AAC and make informed decisions regarding when to start AAC interventions.

External AAC Supports are Essential

In light of the complex needs of children with FXS, the difficulties inherent in AAC systems and mothers' own struggles, external supports are essential. A recurring problem experienced by all mothers was the profound lack of professional support regarding the use of AAC in the home. Schlosser and Wendt (2008) found that even though there are a multitude of AAC approaches available, many families, as well as SLPs and service providers alike, are concerned that the use of AAC may hinder the

child's natural speech production. This was the case with Beverly who reported that her son's speech and language therapist was not using AAC because she felt that it would prevent him from speaking and using language to communicate. Kathy reported that her son's SLP at school was reluctant to use AAC because he had not demonstrated enough language to benefit from AAC.

Societal stressors such as lack of preservice and inservice training in the area of AAC and home–school collaboration are issues that many of the mothers indicated as problematic. Kathy was surprised to learn that graduate students in speech and language pathology at a local university received very little preservice training in AAC. Ratcliff et al. (2008) noted the lack of preservice training in AAC for graduate students in speech and language pathology and special education, and identified the critical need for more academic and clinical preparation in AAC. Beukelman and Miranda (2005) indicated that individuals who provide service delivery for those who use AAC are required to understand a multitude of strategies, techniques, technologies, as well as characteristics of communication partners and other professionals. Most mothers were having problems collaborating with the school regarding the use of AAC. While AAC is considered a multidisciplinary field, training in the area of AAC is particularly important for SLPs and special educators.

Mothers also had difficulties locating trained experts in FXS and interventions specifically designed for FXS. As a result, many children were receiving interventions designed for children with ASD, and mothers reported accessing support through autism networks. Roberts and colleague (2008) stated that FXS is a model for autism based on the fact that as many as 30% of children with FXS have autism and 2 to 6% of children

with autism have FXS. Both disorders have similar behavioral phenotypes such as social impairments, stereotypic behaviors, language delays, anxiety, and attention problems. Although mothers reported a lack of services and support geared for FXS, many felt that ASD interventions were working. There is a growing body of research on AAC and autism, which presents an opportunity to expand on that research as it applies to FXS. In addition, new advances in newborn screening of FXS present a unique opportunity to understand how early intervention using AAC can promote positive outcomes for emerging language development that may also be applicable to children with ASD.

In addition, family influences are contributing factors that affect mothers' decisions to use AAC effectively and efficiently in the home. Ratcliff et al. (2008) noted the increased demands and responsibilities of families, in particular mothers, in the implementation of AAC use in the home. R. L. Bailey and colleagues (2006) found that ease of device use, home–school collaboration, and limitations of the AAC device affected AAC use in school. However, R. L. Bailey et al. did not study limitations of AAC use in the home.

The present study investigating AAC use in the home revealed that AAC use is also influenced by family stressors such as siblings with and without FXS, financial resources, and family values/beliefs. It appeared that all mothers in the study were hard working, educated, and persistent. However, the present study raised concerns as to the impact of social status and culture on parents' decisions to use AAC and their support of AAC use in the home. Harry and colleagues (1995) argued that families from different cultures may perceive AAC systems as unnatural and stigmatizing and professionals need to be aware of parents' preferences regarding AAC. McCord and Soto (2004) stressed

the importance of understanding the cultural context of the child and family that will likely influence the effectiveness of the AAC recommendations. Furthermore, there may be cultural beliefs in which families may not expect to be decision makers or collaborators in planning the child's intervention. Kalyanpur and Harry (1999) recommended a four-step process leading toward a posture of cultural reciprocity that can be used to make decisions when working with families regarding AAC: (a) identifying the values of families related to AAC, (b) determining if family values differ from those of professionals, (c) acknowledging respect for any cultural differences and fully explaining the cultural basis of professional assumptions, and (d) determining most effective ways to adapt professional recommendations to family's values (as cited in Parette & Brotherson, 2004).

Recommendations for Practice

This study helped to identify the many obstacles and challenges that need to be addressed to increase the use of AAC in the homes of parents with children with FXS and related disorders. Although the obstacles are great, tackling the challenges can likely improve the communication outcomes for these children, as well as improve parent outcomes.

One mother, Kathy, presented a more optimistic vision of AAC use and presented several suggestions for guiding and supporting parents in their decision to use AAC and for increasing the use of AAC in the homes of parents with children with FXS and related disorders. She proposed ensuring that professionals know which AAC resources are available and when to give out information to parents. She put forth that when parents first receive the diagnosis of FXS, parents get overwhelmed when professionals provide

too many resources and recommendations. Rather, she felt that it is better to give parents

a contact for where they can access information on resources when they are ready to

receive information, such as contacting the local 211 directory for health and community

services. She also suggested including AAC information in IEP workshops and meetings

so that parents could learn about their rights and the services that are available through

the public school. She also emphasized the importance of professionals empowering

parents to trust that they know what's best for their children, to know that it is all right for

them to ask questions and push the envelope. She went on to say that professionals need

to help parents find out what "more" might look like and that parents need the supportive

"push" to do something. Parents need to feel that they are on the right track and

supported along the way.

Based on the perspectives of these mothers who presented their firsthand

experiences with the many difficulties they faced, the following recommendations

warrant attention:

- Parents and professionals need access to accurate and understandable
  information through disability-related resource portals such as 211 to
  increase their knowledge of AAC and to help them make informed
  decisions regarding AAC interventions.

- AAC parent mentors are needed to empower and support parents through
  the process of making the decision to use AAC.

- Community-based workshops for parents and professionals on targeted
  AAC interventions should include training parents on how to be effective

communication partners to support the use of AAC in the home and to increase children's functional-communication skills.

- AAC coaches are needed to guide parents in setting up AAC systems and training them to be effective communication-partner coaches in the home, as well as to provide support to professionals in using AAC across environments (home, school, and therapy).

- Systematic AAC interventions for children with FXS should be designed to include the home environment and mothers as communication partner, as well as promoting positive behavior and cognitive development.

- SLPs and special-education teachers need more inservice and preservice training in AAC interventions to incorporate AAC tools and strategies into therapeutic and educational programs.

Future Investigations

After completion of this study, several new questions were raised. Future studies should investigate the following:

- Parent coaching in AAC implementations on parent outcomes such as parental stress and quality of life.

- Effects of AAC intervention on child outcomes such as improving communication skills and reducing of behavior problems.

- A longitudinal study measuring language acquisition of young children with FXS who receive AAC intervention prior to the age of 2 (prelinguistic stage) and literacy development in later years.

- SLPs and special-education teachers' experiences with AAC, surveying preservice and inservice training.

- The influence of culture and social status on use of AAC in the home.

Methodological Dilemmas

Every effort was made throughout the study to ensure that the guidelines and requirements of the Institutional Review Board were met. The following procedures were used to strengthen validity and reliability, establish credibility, and minimize researcher bias:

1. Triangulation: Data were analyzed from more than one data source and included semistructured interviews, limited participant observations, and review of archival records.

2. Reflexivity is a process whereby researchers scrutinizes their assumptions, interpretations, and decisions that influence the study. Reflective memos captured subjective experiences and were recorded throughout the data collection and analysis.

3. Peer debriefings were conducted in which a research colleague who was not associated with the study reviewed the coded field notes and thematic analysis.

4. Member checks involved checking analytic themes, interpretations, and conclusions with the participants in the study. After each home visit the data were analyzed and member checks occurred with all mothers.

Despite these measures, several methodological challenges were still evident.

Prolonged engagement and persistent observation. Qualitative researchers place a high value on prolonged engagement and persistent observation, which refer to the investment of sufficient time to learn about the desired phenomenon or to build trust. The length of the project was relatively short and spanned less than 8 months from March to November. In addition, I conducted a minimum of four home visits consisting of observations and interviews for each family and additional home visits were scheduled as needed. Each family received between four to six home visits that consisted of observations and interviews. Therefore, due to the relatively short amount of time in each home and limited length of time needed to complete the study, true prolonged engagement and persistent observation was not achieved. I addressed this issue by transcribing the interviews verbatim and writing detailed field notes of the observations. I spent considerable time systematically coding the data by crosschecking my notes and codes, and by cross-validating sources during my fieldwork. Through this process, saturation of data was achieved, as core themes were evident across participants. Therefore, I am confident that my analysis is supported in the data collected.

Self-awareness and role as a researcher. Because of my extensive background in the area of AAC and my work as a clinician, I had concerns about my own personal distortions of the analysis. I addressed this by creating written memos and reflections that were coded and analyzed. I would have also liked to spend more time in the home collecting data to verify the information I gathered, to safeguard against any personal distortions and misinformation. At times, I found it very difficult to remain neutral and to detach myself from wanting to help and offer guidance to the mothers who were all struggling to make AAC work in their homes. I had to remind myself that my role as a

researcher was that of observer, learning about the mothers' experiences with AAC and how they communicate with their children with FXS. I addressed this conflict at the end of the study by offering each family the opportunity to ask me questions about AAC and AAC resources and information to help them. Lincoln (1995) noted the importance of reciprocity, which involves recognizing and validating the relationships between the researcher and participants, which are reciprocal in nature.

Conclusion

The findings from this study assist in highlighting the many challenges faced by these mothers regarding communication and use of AAC in the home, as well as offering an explanation of barriers that interfere with their decisions and abilities to use AAC with their children. Children with FXS present with significant complexities such as limited to no speech, behavior challenges, and poor communication skills that make AAC use difficult. Although AAC use is unnatural and cumbersome, making it extremely difficult for mothers to use, research has shown that AAC can significantly increase speech production, decrease behavior challenges, and improve communication in children with similar developmental disorders, suggesting that AAC will work for FXS. Mothers also have internal struggles that need to be addressed and overcome before they can embrace its use. Despite these challenges, this study suggests that the use of AAC that is specific to the needs of FXS may be a viable treatment option for children with FXS to increase speech production, decrease challenging behaviors, and improve communication skills, as well as promote positive parent outcomes.

This study helped identify the many obstacles and challenges that need to be addressed to increase the use of AAC in the homes of parents with children with FXS and

related disorders. Although the obstacles are great, tackling the challenges will likely improve the communication outcomes for these children, as well as improve parent outcomes. Based on difficulties experienced by mothers and children with FXS, mothers need help to make AAC work. Therefore, external supports are critical. Designing AAC systems that are portable and dynamic and target interventions for children with FXS that include the home environment, and training mothers to be effective communication partners are essential. In addition, professionals, in particular, SLPs and special-education teachers need more training in AAC interventions and need to also understand cultural influences when planning and developing AAC interventions for families in the context of the home.

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Appendix A: Family Demographics

Mother	Residence	Mothers' FXS status	Mothers' occupation	Mothers' marital status	Child	Child's age in years	Child's FXS status	Child's age of FXS in years	Siblings	Sibling's age	Sibling's FXS status
Beverly	Broward	Premutation Carrier	Home-Maker	Married	Gary	8	Full-mutation	2.0	Mary	11	Full-mutation
Carolina	Dade	Premutation Carrier	Part-time Vocational Rehabilitation Counselor	Married	Manny	12	Full-mutation	2.0	Robert	26	Full-mutation
Kathy	Oregon	Premutation Carrier	Part-time Aerobics Instructor	Married	Greg	6	Full-mutation	2.5	Tom	4	Full-mutation
Rosemary	Dade	Premutation Carrier	Home-Maker	Married	Walter	9	Full-mutation	3.0	Allison Abigail	7 1	Premutation Full-mutation

Appendix B: Semistructured Interview Protocol

Introduction: To make sure that I accurately capture your responses, I would like to audio tape our conversation today. For your information, only researchers on the project will have access to the recordings, which will be eventually destroyed after they are transcribed. I would like to remind you that, (1) all information will be held confidential, (2) your participation is voluntary and you may stop at any time if you feel uncomfortable, and (3) I do not intend to inflict any harm. Thank you again for your agreeing to participate in this study.

I have planned this interview to last no longer than 60 minutes. Whatever we don't cover today, we can pick back up the next time we meet. During this time, I am interested to hear more about what (name of child) is like, your expectations, hopes, and concerns related to (name of child)'s communication and use of augmentative and alternative communication (AAC). AAC includes the use of external tools such as communication books or boards with photographs, pictures, and words or recordable/programmable devices that produce voice output and/or written output. These tools allow the child to use picture symbols, letters, and/or words and phrases that stand for what the child wants to express. AAC can also involve the use signs, gestures, and facial expressions that a child may use to express him/herself. I would also like you to tell me about the strategies you use as a parent to communicate with (name of child) and how you have been involved with professionals regarding making the decision to use AAC with (name of child).

There are no right or wrong answers to these questions. Every family's experiences and adaptations are different. I want to understand and document these different experiences and adaptations as part of this study in hopes of making this process easier and more productive for families and their children.

To the best of your ability, please answer all of the questions. You may choose not to answer any of the questions.

I.   ABOUT THE FAMILY

     a.   Tell me about your family structure.

     b.   Tell me how your children get along?

     c.   Tell me about the roles and responsibilities of the members of your family?

II.   ABOUT THE CHILD

     a.   Tell me about (name of child)'s birth?

     b.   Describe (name of child) as infant.

    c.   Tell me about when did you find out that (name of child) had

             fragile X?

    d.   Tell me about school.

    e.   Tell me about (child).

    f.   What are your biggest concerns regarding (name of child)?

III.   COMMUNICATION AND USE OF AAC

    a.   Tell me how (name of child) communicates.

    b.   Tell me about the AAC system that (name of child).

IV.   ABOUT THE AAC-DECISION MAKING PROCESS

    a.   Tell me about the time when you were first introduced to the idea

             of using AAC?

    b.   How were you involved in the decision to use AAC?

    c.   Who else was involved in the decision to use AAC?

    d.   Tell me how you have learned to use the AAC system with (name

             of child).

    e.   Explain how AAC has affected your child's ability to express

             him/herself and your ability to understand him/her. Others?

V.   ABOUT PARENTAL EXPECTATIONS AND STRATEGIES

    a.   Overall, what expectations and goals do you have for (child) now?

    b.   How is AAC helping, or not helping to meet these goals and

             expectations?

    c.   Probe: What other things are you doing with (name of child) to

             help meet these goals?

d.   Are there things you do to help (name of child) learn to use the AAC system?

e.   In general, what do you consider to be your roles and responsibilities in relation to (name of child) and his/her use of AAC?

f.   What do you consider to be the roles and responsibilities of professionals in relation to (name of child) and his or her use of AAC?

g.   Tell me about your concerns, challenges, and frustrations regarding (name of child)'s use of AAC to communicate.

h.   How have professionals involved in the process addressed your concerns, challenges, and frustrations?

Appendix C: Observational Guide

1. Describe the setting and physical environment.

    a. What is arrangement of the room and/space?

    b. How are the individuals positioned in the room?

    c. Where is the AAC device? Other tools?

2. Describe the social environment.

    a. Who is part of the social interactions?

    b. What are the patterns of interaction?

    c. How are they interacting?

    d. How is the social interaction being directed? (e.g., child-directed)

3. Describe the communication.

    a. How is the caregiver communicating? For what purposes?

    b. How is the child communicating? For what purposes?

    c. Describe communication breakdowns and what strategies are being used to repair and by whom.

    d. How is the child using AAC and for what purposes?

    e. How is the parent using AAC and what strategies are being used to promote the use?

Appendix D: Follow-Up Interview Protocol

Introduction: To make sure that I accurately capture your responses, I would like to audio tape our conversation today. For your information, only researchers on the project will have access to the recordings, which will be eventually destroyed after they are transcribed. I would like to remind you that, (1) all information will be held confidential, (2) your participation is voluntary and you may stop at any time if you feel uncomfortable, and (3) I do not intend to inflict any harm. Thank you again for your agreeing to participate in this study.

I have planned this interview to last no longer than 30 minutes. I'd like to pick up where we left off (refer to semistructured interview guide). During this time, I am interested to hear if there have been any changes regarding (name of child)'s communication and use of AAC.

As a reminder, there are no right or wrong answers to these questions. Every family's experiences and adaptations are different. I want to understand and document these different experiences and adaptations as part of this study in hopes of making this process easier and more productive for families and their children.

To the best of your ability, please answer all of the questions. You may choose not to answer any of the questions.

I.   ABOUT THE FAMILY

a.   Have there been any changes to your family since the last time we

met? If so, please explain.

II.   ABOUT THE CHILD

a.   Have there been any changes with (name of child) since the last

time we met? If so, please explain.

b.   Have your concerns and challenges regarding (name of child)

changed since the last time we met? If so, please explain.

III. COMMUNICATION AND USE OF AAC

a.   Tell me how it is going with (name of child)'s communication and

use of AAC?

b. Have there been any changes with (name of child)'s AAC system? If so, explain.

IV. ABOUT THE AAC-DECISION MAKING PROCESS

a. Have there been any recent AAC- decision making related developments? If so, please explain.

b. Have there been any changes to the support you are receiving regarding the decision to use AAC with (name of child)? If so, please explain.

V. ABOUT PARENTAL EXPECTATIONS AND STRATEGIES

a. Have your expectations and goals changed related to AAC? If so, please explain.

b. Have your roles and responsibilities and the roles of professionals in relation to (name of child) and his/her use of AAC changed? If so, please explain.

c. Are there new challenges, concerns, and frustrations regarding (name of child)'s use of AAC to communicate? If so, please explain.

d. How have professionals involved in the process addressed these new concerns, challenges, and frustrations?