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Parent Perspectives on Augmentative and Alternative Communication Integration for

Children with Fragile X Syndrome: It Starts in the Home

Michelle Schladant and Monica Dowling

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This article was based on the primary author's dissertation. I want to convey my deep appreciation to the families and those who assisted me in finding them.

Abstract

Many children with fragile X syndrome (FXS) have complex communication needs and may benefit from augmentative and alternative communication (AAC). This qualitative study explored how four mother–child dyads used AAC in the home. Data were collected using participant observations, open-ended interviews, and record reviews, and analyzed using grounded theory methods. Findings revealed that mothers found AAC to be a useful tool for addressing their children’s complex communication needs, but practical and personal factors impacted its use in the home. This study sheds light on how mothers of children with FXS view and utilize AAC as a way to promote communication at home. Understanding parental perspectives can help to guide professionals in planning appropriate AAC interventions specific to FXS.

Keywords: parent perspectives; augmentative communication; fragile X syndrome; complex communication needs

Parent Perspectives on Augmentative and Alternative Communication Integration for Children with Fragile X Syndrome: It Starts at Home

Fragile X syndrome (FXS) is the most common cause of inherited intellectual disabilities in the United States (Hagerman, 2002). This genetic disorder significantly affects the communication abilities of those diagnosed and, often, family members who may be carriers (Roberts, Chapman, & Warren, 2008). Affected individuals typically exhibit cognitive and behavioral deficits, including intellectual disabilities, attention problems, and anxiety (Huddleston, Visootsak, & Sherman, 2014). Up to 90% of affected males display autism-like features that significantly impact communication (Harris et al., 2008). Females are usually less affected than males because of the presence of a second, normally functioning X chromosome (Hagerman, 2002). The combination of cognitive, behavioral, and autism-like deficits further increases the likelihood that children with FXS will have complex communication needs. Most children with FXS exhibit language impairments across all communication domains, and many, especially boys, remain only minimally verbal (Roberts, Chapman, & Warren, 2008).

Although considerable research has focused on the behavioral FXS phenotype, few studies have addressed communication impairments specific to the disorder (Moskowitz & Jones, 2015). For children with similar disorders, augmentative and alternative communication (AAC) has shown promise as a language intervention. It has been widely documented that AAC (e.g., picture exchange systems, speech-generating devices) improves outcomes for children by supporting their ability to be understood, assisting with conversation maintenance, and increasing social interactions (Light & McNaughton, 2015; Schlosser & Wendt, 2008). Furthermore, parents can use AAC in the home to increase the child's access to communication and participation in important social experiences, especially in the early years (Ronski, Sevcik, Barton-Husley, & Whitmore, 2015).

2 Despite clear benefits, challenges may hinder the use of AAC . One of the main
3 challenges for individuals with disabilities and their families is that skills often targeted in AAC
4 interventions lack real-life contexts and are therefore less applicable to the home environment
5 (Granlund, Bjorck-Akesson, Wilder, & Ylven, 2008; Light & McNaughton, 2015). In their
6 review of thirty years of research in AAC and early intervention, Ronski and colleagues (2015)
7 highlighted a substantial number of papers that discussed issues families face when using AAC.
8 Issues commonly reported by parents and prevalent in more recent research include competing
9 family demands (Goldbart & Marshall, 2004; Mandak, O'Neill, Light, Fosco, 2017), limited
10 professional support (Bailey, Parette, Stoner, Angelo, Carroll, 2006; Meder & Wegner, 2015),
11 and lack of family involvement when professionals make decisions about AAC (Goldbart &
12 Marshall, 2004; Granlund et al., 2008; and Mandak et al., 2017).

13 Few studies have addressed AAC interventions specifically for children with FXS, and
14 even fewer have placed an explicit emphasis on how parents of children with FXS use AAC in
15 naturalistic settings such as the home. To date, there has only been one *empirical* study
16 evaluating the effectiveness of AAC for children with FXS. Stasolla et al. (2014) assessed
17 choice-making in two boys with FXS using AAC supports. Results indicated that choice-making
18 improved and challenging behaviors decreased. This study, however, was conducted in a clinical
19 setting and did not address the potential use of the intervention in the home.

20 Two older studies examined AAC's potential impact for children with FXS, one in a
21 clinical context and one in the home. Mirrett, Roberts, and Price (2003) surveyed 51 speech and
22 language pathologists (SLPs) who provided interventions to increase communication in young
23 boys with FXS. Brady, Skinner, Roberts, and Hennon (2006) conducted the only study involving

2 parents of children with FXS and found that mothers often independently learned how to use
3 AAC without professional support.

4 McDuffie et al.'s (2016) recent research on non-AAC based language interventions was
5 entirely home-based and assessed the effectiveness of a program that taught language
6 interventions to parents of children with FXS. While the children in the study showed moderate
7 increases in prompted communication acts, spontaneous communication acts were more variable.
8 McDuffie and colleagues concluded that intervention efficacy might have been enhanced by
9 incorporating AAC. McDuffie's study was noteworthy as there continues to be a dearth of
10 empirical studies addressing language interventions in the home environment. Furthermore,
11 research investigating AAC use by children with FXS in their home environments is needed to
12 understand how AAC may provide added benefits. The present study examined how mothers and
13 their children with FXS use AAC in the home. This qualitative study provides much-needed
14 information regarding parent perspectives on AAC for children with FXS and how to improve
15 communication outcomes for children with FXS (which may involve AAC). Similar studies that
16 involve more naturalistic language interventions in the home environment are needed in order to
17 better understand how to enhance language development for children with FXS (Light &
18 McNaughton, 2015).

19 **Methods**

20 **Participants and Recruitment**

21 Four mothers of children with FXS participated in the study. Purposeful sampling was
22 used to select parents who: (a) had a child aged 3 to 12 with premutation or full mutation FXS;
23 (b) had a child using some form of AAC (at present or in the past); and (c) agreed to participate.
24 Recruitment methods included distributing approved flyers and contacting organizations serving

2 children with disabilities and their families (e.g., local FXS foundations, research registries,
3 clinics, and schools). As a result, three mothers expressed an interest in participating in the study.
4 Using theoretical sampling (Charmaz, 2006), one out-of-state mother was added to supplement
5 information obtained from home visits with the other three mothers. Two of the three mothers
6 struggled to use AAC at home and one mother had used AAC in the past but was not currently
7 using AAC in home. The information obtained from the fourth mother validated emerging data
8 themes. All four mothers provided informed consent prior to the study. See Table 1 for
9 information about the participants and their children.

10 **Procedures**

11 Using a qualitative approach (Patton, 2002), the first author/primary investigator (PI)
12 conducted 21 home visits with four mother–child dyads ($M = 5$, range: 0 – 8; see table 2). Home
13 visits consisted of interviews, observations, and review of records in order to rigorously examine
14 how mothers and their children with FXS view and use AAC. Semi-structured interviews were
15 used in an effort to capture each mother’s unique perspective. The researchers developed an
16 interview guide that directly related to the family, child, communication, and use of AAC. In the
17 initial interview, the PI asked questions about the child and family history. Subsequent
18 interviews involved more specific questions related to the child’s expressive and receptive
19 language and AAC use. After initial data analysis, the PI conducted a final interview that served
20 as a member check. At that point, the researchers assessed the adequacy of the data and
21 preliminary results, and reviewed emerging ideas for verification, clarity, and elaboration. Each
22 mother participated in three to seven interviews (see Table 2).

23 The PI also observed mother–child dyads during typical, naturally occurring activities.
24 Observation periods ranged from 30 to 90 minutes. The local mother–child dyads were observed

2 three to five times, while the out-of-state mother submitted videotapes of her children using
3 AAC in the home. The PI used a digital recorder to audio record home visits, and a transcription
4 service transcribed the audiotapes verbatim. The PI checked all transcripts for accuracy. During
5 home visits, the PI collected documents and other materials from each mother to be used as data
6 (see Table 2). These included previous evaluations, therapy progress notes, and Individual
7 Education Plans.

8 **Analysis**

9 The researchers analyzed field notes and transcripts using the analytic procedures of
10 grounded theory (Charmaz, 2006), and managed codes using the qualitative data-analysis
11 software program ATLAS.ti, version 6.0. A constant-comparison method (Strauss & Corbin,
12 1998) was used to inductively analyze the data throughout the study, comparing emerging and
13 previous codes until no new ones emerged. The first step involved open coding, whereby the
14 researchers analyzed the field notes line-by-line to conceptualize ideas. This process yielded
15 hundreds of open codes. In the second step, the initial codes were separated, sorted, and
16 synthesized, resulting in 30 refined, distinct open codes. The third step involved grouping the
17 refined codes into 10 conceptual categories. The final step involved integrating the data into four
18 main themes (see Table 3).

19 Using a constructivist approach (Lincoln & Guba, 1981), the researchers established
20 credibility by triangulating three data sources: semi-structured interviews, participant
21 observations, and review of archival records. In addition, two research colleagues independently
22 reviewed the codes, categories, and themes. During these sessions, codes and categories were
23 refined, constructed, and clarified, as needed. Lastly, the researchers checked analytic themes,
24 interpretations, and conclusions with each of the mothers in the study. Altogether, the researchers

2 analyzed data from 16 interviews, 12 observations, and 18 archival records into 30 open codes,
3 12 conceptual categories, and four core themes (see Table 3). Data analysis revealed that, while
4 the mothers viewed AAC as a useful tool for addressing their children's complex communication
5 needs, all encountered practical and personal difficulties in terms of its use.

6 **Findings**

7 **AAC's Usefulness in Addressing Communication Needs**

8 Once mothers decided to implement AAC, they found it useful in addressing their
9 children's communication needs. Four children had a co-morbid diagnosis of autism, and all five
10 exhibited the core communication deficits associated with FXS – minimally verbal, poor
11 intelligibility, limited comprehension, and reduced conversational turn-taking (Reisinger,
12 Shaffer, Pedapati, Dominick, & Erickson, 2019). All mothers reported using a variety of AAC
13 tools, including devices with vocabulary presented on a grid display, Picture Exchange
14 Communication Systems (PECS), and visual supports such as choice boards and schedules.
15 When used properly, these tools effectively improved their children's communication abilities.

16 The mothers reported that these AAC tools were particularly useful in helping their
17 children make simple requests. When asked how the PECS worked for her son, Rosemary,
18 mother of Walter (age 9) stated, “[PECS worked] pretty easily... he will just go up to them and
19 he'll tap them and he'll show you what he wants.” Kathy, mother of Tom (age 4) and Greg (age
20 6), had developed a systematic method for regular AAC use. For example, she often used picture
21 cards, choice boards, a single-message speech-generating device, and picture schedules for
22 segments of the daily routine. Kathy described how she used AAC with Greg at home:

23 I have a board in the kitchen that has icons on it... preferred different items... he'll go
24 and grab a picture and bring it to me, so it might be an iPod or a computer... and he just

2 brings it to me. Another thing that he does... if I'm busy doing something... and he
3 wants to get my attention, I have a BIGmack button that says, "Excuse me, please, I have
4 something to say." And so, he'll push that and then that gets my attention, and I say,
5 "What, Greg?" And then, he'll either try to tell me verbally or he'll pick a picture.

6 All mothers found these types of AAC tools useful for supporting their children's
7 communication.

8 The myth that AAC prevents speaking has been thoroughly debunked (i.e., see Schlosser
9 & Wendt, 2008), and it is noteworthy that none of the parents in this study expressed such a
10 concern. In fact, the mothers viewed AAC as a bridge to speaking. Carolina, mother of Manny
11 (age 12), saw AAC's potential to help him learn to talk:

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

20 Carolina understood how the use of AAC at school was helping her son to make notable progress
21 in his communication abilities and, in turn, how this might extend to his skills including speech
22 at home. Although the mothers were supportive of its use and viewed AAC as a valuable tool,
23 they nevertheless experienced many obstacles when trying to use AAC in the home.

24 **Personal Struggles by the Mothers**

2 All mothers experienced personal struggles that impacted their children's AAC use.
3 Many used the phrase "fighting the fact" to describe their degree of acceptance of their child's
4 FXS diagnosis and the impact it had on them and family members. This perspective affected
5 their decisions regarding when and how to introduce AAC. The process of accepting their
6 children's diagnoses, their genetic connection as a premutation carrier to their children's
7 diagnoses, and the implications of family members' subsequent genetic testing impacted when
8 they decided to consider AAC. Kathy shared how she felt when she learned that her eldest son
9 Greg had FXS:

10 And it came back that we should get him a blood test for FXS... And, of course, I look
11 up FXS and so like mentally retarded and all of this and I'm like no, no, no, that not, no. I
12 just couldn't. I was totally in denial.

13 Difficulties accepting a diagnosis of FXS were common among the mothers and often delayed
14 their accessing interventions. For example, Carolina learned that Manny's brother, Robert, had
15 FXS when Manny was just 3 months old, yet she waited two more years before getting Manny
16 tested. When asked why, she replied, "Yeah, I was *fighting the fact* that he might be. I don't want
17 to know."

18 Not only did the mothers struggle with accepting the diagnoses, they also hesitated in
19 introducing AAC. They seemed to prefer a "wait and see if my child talks" approach, seeking
20 medications and other interventions before introducing AAC. Kathy, for example, had waited
21 two years after learning about AAC before using it with her older son, Gary:

22 And so it was two things... actually three things... seeing all the positives that come from
23 it [AAC] and then realizing how long the language was gonna take time to come for my
24 son. And then seeing how to make it [AAC] work... figuring how I could make it work in

2 my house... in our lives. ‘Cause that’s the other piece I think I mentioned, that it takes a
3 while to kinda settle in your brain... that your life’s still gonna be okay if you turn your
4 living space into a preschool because you need to have icons everywhere.

5 Kathy first needed to understand AAC’s benefits, the significance of her son’s language delays,
6 and how to use AAC in her home before she could more fully embrace using it with her sons.

7 All mothers struggled to understand AAC well enough to facilitate in-home use. They
8 tended to overly prompt and direct conversations, resulting in short, basic communicative
9 exchanges rather than more elaborate conversations. While the mothers were in tune and
10 responsive, they anticipated their children’s needs, which impeded their children’s AAC use.

11 Here, Beverly, mother of Gary (age 8), described her struggles to learn to use AAC effectively:

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

15 Kathy had similar difficulties with learning to use AAC:

16 Okay, so once you’re aware of it [AAC], what do you do? How do you know how to set
17 something up? I wouldn’t have had a clue what things to set up first. Since I really
18 believe you have to have someone helping, mentoring, “try this, do this. Try that. How’s
19 that working?” and giving you that support.

20 The mothers’ decisions to use AAC in the home were also impacted by the dynamics of
21 family routines. All mothers had more than one child with FXS, each of whom had individual
22 needs. AAC use was further complicated by the mothers’ frequent need to mediate sibling
23 interactions. Some mothers were less inclined to use AAC in the home because they found it
24 overwhelming, and considered home life to be less structured than the school or community.

2 **Practical Difficulties with the AAC Devices**

3 The mothers encountered several limitations with the AAC devices themselves. First,
4 they reported that the types of AAC devices used were static, limiting, and ineffective for
5 fostering conversation. For example, Beverly, whose son Gary was using picture cards, voiced
6 concerns about the tool's limitations; she wanted a device that could facilitate more than simple
7 requests: "So the next stage, really, is moving to a back and forth reciprocal conversation, where
8 he can tell you about his day. He can share ideas with you. You can share ideas with him." Kathy
9 expressed the same sentiment:

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

13 All mothers wanted a more dynamic, intuitively designed AAC tool with a robust vocabulary to
14 assist in more prolonged conversations.

15 Second, the mothers reported challenges related to the cost, programming, and
16 maintenance of the devices. They found it burdensome to create and update vocabulary on static
17 boards and devices. Most of them felt that setting up the system required time and planning, yet
18 they still did not know enough to do more than meet basic needs. Moreover, they found
19 manufacturer maintenance to be unsatisfactory; Rosemary stopped using AAC with her son after
20 the device broke:

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

2 Mothers also had concerns about the cost. Even though insurance may cover AAC, Rosemary
3 had trouble getting the \$7,000 device covered and wondered if she could justify its cost:

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

12 Like Rosemary, all of the mothers felt that the cost of AAC limited its practical use.

13 Lastly, the mothers found the actual devices to be cumbersome and not very portable.

14 Rosemary thought it was awkward to carry around a picture book and a small 32-message grid
15 display device for her son Walter to use. Carolina shared her struggles with using AAC with her
16 son Manny:

17 Then when I tried to [use AAC] again... with the help of a teacher many years ago, [who]
18 laminated some [picture cards] with the program specialist... I put them in the car... I'm
19 driving and I'm showing cards, you know? "Don't hit. Don't hit." And he's pulling... It's
20 really very dangerous, it's not safe, it's not effective.

21 Both felt these systems were effective at home, but burdensome and impractical elsewhere.

22 To address these device limitations, some mothers turned to different systems. For
23 example, Rosemary and Kathy were attempting to use an iPad with communication applications,

2 “apps”, to help their sons move beyond simple requests and comments. Kathy explored using the
3 iPad as a more portable, dynamic AAC device:

4 So I have the iPad with the My Talk (application)... So it was really convenient when we
5 were traveling and I was trying to figure out what everybody wanted to eat...So I showed
6 him a bunch of food on there (the iPad), and I let him scroll through the food and he
7 picked “quesadilla.”

8 Rosemary also expressed how a more portable AAC system could assist her son Walter:

9 More independence. That’s one thing I really want for him, [I] mean I’m not going to be
10 around him always, and I want him to be independent... he can drive or take the bus
11 somewhere later on, and then he might not be fully verbal, but he might need AAC just to
12 help him along or if he gets stressed out or he has a panic attack or something he freaks
13 out, he doesn’t know what to say at that moment or how to phrase it. Okay here is, you
14 know, my AAC... I have my iPod and I get in trouble or, you know, I can use this.

15 Both felt a dynamic, portable AAC system would be more helpful outside of the home.

16 **Limited Practitioner Knowledge and Support**

17 Across the board, lack of practitioner AAC knowledge and support for AAC appeared to
18 be the biggest obstacle impacting use. Even Kathy, who developed a basic system for her boys,
19 had trouble finding clinicians with expertise in more sophisticated AAC devices. Practitioners
20 often lacked understanding about FXS as well as about AAC, often providing little information
21 or even misinformation regarding the significant impact of FXS on their children’s language
22 development and when and how to introduce AAC. On receiving the diagnosis, typically from
23 physicians, many of the mothers reported receiving little guidance on intervention. For example,
24 Rosemary remembered after learning that her son Walter had FXS at age 3 and was still not

2 talking, “We had already been doing speech and occupational therapy, and the neurologist told
3 me, ‘There’s nothing else to do. There’s no magic pill... just keep doing what you are doing’.”

4 Most of the mothers indicated that they had learned how to use AAC with little advice or
5 assistance from knowledgeable practitioners. All mothers reported a lack of SLPs and educators
6 with sufficient AAC training. When asked if AAC was ever formally introduced, Beverly replied
7 sarcastically, “Formally from anyone. Yeah, formally from anyone... It’s strictly been my own
8 hunting and pecking for resources to help.” Beverly further described feeling stuck regarding
9 how to help her son advance his communication: “How do you get the conversation? How do
10 you help him to retrieve events from his day and share with it? That’s where we’re stymied.”
11 Beverly also discussed the lack of continuity and collaboration with interventionists adopting
12 AAC in therapy: “But you have to have the other people involved too and they weren’t.” This
13 lack of knowledge and support impeded the mothers’ use of AAC with their children.

14 Another barrier impacting AAC use was educators lack of experience in AAC use. For
15 example, Carolina felt uncomfortable borrowing a device from the school, and Rosemary and
16 Kathy both sent devices to school but mentioned that teachers were uncomfortable using them.
17 Several mothers stated that the “school requires help,” and weak educational programs described
18 as “not the right fit” and “not suitable” were “holding [the child] back.” The mothers felt that the
19 lack of AAC services in the school was a roadblock for their children’s AAC use.

20 Discussion

21 Limitations

22 Given the limited length of this project (consisting of three to five home visits for each of
23 the local families and spanning less than 8 months), extended observations and outcomes were
24 not possible. However, the researchers used data triangulation, verbatim transcription, and

2 detailed field notes of the observations in order to ensure the saturation of data. As a result, core
3 themes were evident across participants and future needs regarding AAC integration were
4 identified.

5 **Implications for Practice**

6 This U.S. study investigated four mothers' use of AAC in the home with their children
7 with FXS and identified barriers to implementation. Very few studies have specifically examined
8 AAC use by children with FXS. The results of this study highlight the benefits and challenges
9 parents, in particular mothers, may encounter in using AAC to support communication in the
10 home. The investigation exposed three main systemic gaps that may limit the successful
11 integration of AAC in the home: (a) failure to consider unique aspects of the family context; (b)
12 limitations of AAC technologies; and (c) inadequate knowledge of FXS and AAC among
13 practitioners.

14 From diagnosis to treatment, the mothers in this study had great difficulty finding
15 practitioners who were knowledgeable about AAC in particular and FXS in general. The mothers
16 struggled to determine when and how to introduce AAC with their children, doing so mostly as a
17 last resort. All the children demonstrated the language delays and communication deficits
18 characteristic of FXS, but the practitioners the mothers consulted knew little or nothing about
19 AAC's effectiveness in this population. These findings suggest that practitioners working with
20 children who have complex communication needs such as FXS should know, and should inform
21 parents, that AAC is a viable treatment option. Furthermore, practitioners need to know that
22 current recommendations from the broader disability literature suggest that introducing AAC
23 early promotes skills in all communication domains (Light & McNaughton, 2015; Ronski, et al.,
24 2015).

2 Clearly, the development of curricular materials for physicians, SLPs, educators, and
3 other service providers is needed at all levels. Raspa, Wheeler, and Riley (2017) emphasized the
4 importance of pediatricians having up-to-date information to help parents coordinate therapies
5 for children with FXS. Pediatricians may also be called on to support the larger family system
6 because diagnosis can impact many other family members (Raspa et al., 2017). AAC is
7 considered to be a multidisciplinary field, and therefore AAC training is particularly important
8 for SLPs, special educators, and professionals who evaluate children with FXS and related
9 disorders. Costigan and Light (2010) noted that many SLPs and special educators may graduate
10 from preservice training with minimal to no exposure to AAC. According to Baxter and
11 colleagues (2011), the lack of staff training among teachers and speech and language
12 pathologists was reported as a significant barrier to positive AAC outcomes. Professional
13 education across disciplines must ensure that pre- and in-service training programs provide the
14 most current information on using AAC (Light & McNaughton, 2015; Senner & Baud, 2017),
15 ensuring AAC integration.

16 Another struggle for the mothers in this study was limitations in the AAC technologies.
17 All mothers discussed difficulties with the AAC device's, particularly limited vocabulary, poor
18 navigation, high cost, and portability issues. Newer AAC technology designs need to support a
19 broader range of language concepts and communicative functions other than requesting (Light,
20 McNaughton, Caron, 2019). In addition, most AAC technologies use a grid layout where
21 symbols are decontextualized and presented in isolation making navigation difficult (McCarthy,
22 Benigno, Broach, Boster, & Wright, 2018). Visual scene displays are one research based option
23 that has untapped potential, providing social and visual context that may be more motivating and
24 meaningful to children learning to use AAC (Light et al., 2019). Mobile technologies are also

2 emerging as a desirable option for families because they are ever present in society and more
3 affordable, portable, and appealing to children (Ganz, 2015). Therrien and Light's (2016) study
4 points to the potential of using the iPad with an AAC app programmed with a visual scene
5 displays may be effective in increasing communicative turns to support social communication.

6 Most importantly, while all mothers recognized that AAC held promise to support their
7 children's communication development, at the same time, all mothers described struggles they
8 and their family members experienced in their attempts to integrate AAC use in the home.

9 Access to devices did not ensure successful AAC integration in the home. Too often, AAC
10 interventions are narrowly focused on teaching communication skills in decontextualized
11 settings, removed from the natural environment rather than targeting those skills in real world
12 circumstances (Granlund et al., 2008; Light & McNaughton, 2015; Snell et al., 2010). AAC
13 interventions must be family centered and consider the family context (Mandak, et al., 2016).
14 Clinical practices to support family-centered AAC interventions need to recognize the family as
15 expert and establish collaborative relationships, be sensitive to the family's unique needs,
16 integrate AAC into existing family routines, and involve all relevant family members (Mandak,
17 et al., 2016).

18 Practitioners must also be cognizant that FXS is a multigenerational genetic disorder and
19 mothers, in particular, may need additional support (Wheeler, Raspa, Hagerman, Mailick, &
20 Riley, 2017) to effectively integrate AAC in the home. AAC use can be a challenging process,
21 and communication partner training is crucial (Granlund, et al., 2008; Light et al., 2019; Meder
22 & Wegner, 2015). Strong evidence suggests that parents can be taught to use AAC and that
23 communication partner instruction has positive effects on children's communication (Kent-
24 Walsh et al., 2015; Light, et al., 2019). With increased knowledge (Senner & Baud, 2017) and

2 newer technologies designed to support the family system (Mandak et al., 2017) and children's
3 language learning (Therrien & Light, 2016)), practitioners can introduce AAC as a viable option;
4 SLPs and educators can integrate AAC into real world contexts; and parents will have the
5 necessary skills to seamlessly integrate AAC into all aspects of life.

6 **Future Directions**

7 More rigorous research is needed on targeted AAC treatments for children with FXS.
8 Because of the high co-morbidity of FXS and ASD, literature on AAC interventions for children
9 with ASD is useful (Moskowitz & Jones, 2015). However, children with FXS may need different
10 interventions due to the FXS phenotype (Kasari, 2015). Raspa et al. (2017) noted a shortage of
11 evidence regarding behavioral treatments for individuals with FXS.

12 In addition, AAC experts and technology developers can capitalize on emerging
13 technologies to improve accessibility and ease of use. Experts with knowledge in vocabulary
14 development and human computer interaction designers could develop apps using just-in-time
15 programming that allow AAC users to scan a scene and spontaneously adjust the vocabulary
16 (Holyfield, Drager, Light, Caron, 2017; Schlosser, et al., 2016). Technology developers and
17 AAC experts can potentially develop easier-to-use technologies adaptable for a wide range of
18 cognitive and communication disorders (Caron, Light, & Drager, 2016).

19 Increased access to funding sources for AAC devices, including mobile devices with web
20 access are also needed. While all of the major AAC manufacturers have funding support teams to
21 assist SLPs and parents, securing funding in the U.S. can be a lengthy and time-consuming
22 process (Goldman, 2016). In addition, under previous Medicare policy, insurance companies
23 would only fund devices that were strictly dedicated for the purpose of speech and that they
24 could not be connected to the Internet. While Medicare AAC policy has expanded device

2 coverage to include internet access and written and phone messages, there are still exclusions to
3 fund mobile devices (Satterfield, 2015). Stakeholders and policy makers need to continue to
4 advocate for policies to simplify the funding process and expand insurance coverage to include
5 mobile devices that allow for other types of communication.

6 The findings from this study highlight a number of challenges that must be addressed to
7 increase the effective integration of AAC in the homes of children with FXS and related
8 disorders. Based on the difficulties experienced by mothers and children with FXS, practitioners
9 and parents (in particular premutation and full mutation mothers) need explicit training to
10 effectively use AAC. Having access to knowledgeable practitioners who can provide ongoing
11 guidance and support from diagnosis to treatment and beyond is critical.

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Table 1

Family Demographics

<u>Mother</u>	<u>Residence</u>	<u>Mothers' FXS status</u>	<u>Race/Ethnicity</u>	<u>Mothers' marital status</u>	<u>Child</u>	<u>Child's age in years</u>	<u>Child's FXS status</u>	<u>Child's age of DXS in years</u>	<u>Siblings</u>	<u>Sibling's age</u>	<u>Sibling's FXS status</u>
Beverly	South Florida	Premutation Carrier	White/Non-Hispanic	Married	Gary	8	*Full-mutation	2.0	Mary	11	Full-mutation
Carolina	South Florida	Premutation Carrier	White, Hispanic	Married	Manny	12	*Full-mutation	2.0	Robert	26	Full-mutation
Kathy	Oregon	Premutation Carrier	White, Non-Hispanic	Married	Greg	6	*Full-mutation	2.5	Tom	4	Full-mutation
					Tom	4	Full-mutation	4	Greg	6	*Full-mutation
Rosemary	South Florida	Premutation Carrier	White, Hispanic	Married	Walter	9	*Full-mutation	3.0	Allison Abigail	7 1	Premutation Full-mutation

Family Demographics of mothers and their children. *indicates child has co-morbid ASD diagnosis

Table 2

Sources of Data

<u>Mother</u>	<u>Interviews</u>	<u>Observations</u>	<u>Home Visits</u>	<u>Review Records</u>
Beverly	3	3	6	Therapy notes
Carolina	3	4	7	Individual Education Plan
Rosemary	3	5	8	Psychological reports; therapy notes; Individual Education Plan
Kathy	7	0	0	Videos; school notes; therapy notes
Total	15	12	21	18

Data sources for each participant in the study.

Table 3

Data Analysis Map

<u>Themes</u>	<u>Conceptual categories</u>	<u>Open coding</u>
AAC Usefulness in Addressing Communication Needs	Complex communication needs	- Expressive skills; receptive skills; oral motor and motor planning; social skills
	Challenges associated with Fragile X syndrome	- Behavior; cognition, adaptive functioning
	Kathy's unique experience	-Kathy's experiences
	Augmentative communication forms and functions	-Simple augmentative devices; limited purposes; children's responses
Personal Difficulties Experienced by the Mothers	Impact of Fragile X	- Concerns;" fighting the fact"; motherhood transformed
	Strategies used	-Mother directed; verbal prompting
	Knowledge, attitude, beliefs	-Mothers' knowledge; mothers' comfort level; mothers developed their own system
Practical Difficulties with AAC system	Experiences with AAC	-Past and current experiences with AAC; AAC challenges; future ideas
	Stressors	-Siblings with and without Fragile X syndrome; dealing with extended family members
Limited Practitioner Knowledge and Support	Need for support	-Seeking support; networking
	"Lack of choices"	-Use of interventions; medical treatments; "bartering for therapy"
	School issues	-Struggles with school