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The Parent Perspective on Augmentative and Alternative Communication: A Qualitative Study

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NORTHERN ILLINOIS UNIVERSITY

The Parent Perspective on Augmentative and Alternative Communication: A
Qualitative Study

A Capstone Submitted to the

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In Partial Fulfillment of the

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Department Of

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By

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Abstract

Parents are known to be effective communication partners in their child's augmentative and alternative communication (AAC) intervention. This study aimed to better understand the parent perspective in the AAC acquisition, implementation, and handing processes across a range of primary disability labels and ages. Participants engaged in phone interviews to discuss their family's experiences with AAC obtainment and intervention. A qualitative review of their responses developed the following five themes: assessment procedures, external variables that influence device use, barriers to AAC navigation, supports parents have indicated that have helped them, and major takeaways as identified by parents. Further subthemes were also created to better categorize parent responses. Findings support the inclusion of family-centered care for children with complex communication needs who use AAC. Parent responses indicate a greater need for interprofessional communication between members of a child's team and their family to provide comprehensive support. Parents also emphasized a desire to introduce AAC earlier into their family's life.

Keywords: Parent, Augmentative and Alternative Communication, Qualitative inquiry, Supports, Barriers

The Parent Perspective on Augmentative and Alternative Communication: A Qualitative Study

The ability to advocate for oneself, build a meaningful relationship with others, and actively be engaged with the community all rely on an individual's ability to communicate (Andzik et al., 2019), which extends to individuals who use augmentative and alternative communication (AAC). Approximately five million Americans could benefit from using AAC (Beukelman & Light, 2020). However, recent estimates indicate that there are two million individuals with significant expressive language difficulties who use AAC (American Speech-Language-Hearing Association [ASHA], n.d.a). Many caregivers of individuals with complex communication needs report that the use of AAC has positively impacted their child's social and communication skills, independence, and overall ability to be part of their community (Lee & Vega, 2017). Parents and guardians (hereafter, Parents) play a large role in teaching their children communication skills, and research intervention should reflect this role (Fäldt et al., 2020). They have the unique ability to see their child communicate for various purposes across a range of settings, but with this insight comes a set of challenges.

Parents of individuals who use AAC face several barriers. For instance, mothers of individuals who use AAC (specifically speech-generating devices) reported financial burdens, unexpected stress, additional responsibilities, such as time-intensive learning of programming and promoting device use and lacking access to a supportive and knowledgeable resource group (Lee & Vega, 2017). Parents also feel that they can only rely on individualized support from outside resources rather than their speech-language pathologist (Moorcroft et al., 2019). Despite these barriers, parents play a valuable role as communication interventionists for their children. Family activities, such as games or mealtimes, are one area of family life that parents

indicate successful integration of AAC (O'Neil & Wilkinson, 2020). In addition, Walters et al. (2021) found that following a parent-implemented AAC intervention, many participants displayed an emergence of spoken target vocabulary words.

Parent values and goals are a necessary consideration throughout the process of acquiring and implementing AAC. Belonging, social functioning, family, and happiness are reported core values held by parents (Biggs & Hacker, 2021b). Given their instrumental role, parents are vital members of a collaborative team. Families must be recognized for their role as decision-makers, and their knowledge and skills should not be overlooked (ASHA, n.d.b). Recently, Fäldt and colleagues (2020) stressed parents' desire for family-centered therapy, including attending training sessions related to the AAC device and home visits to provide additional support. One group of researchers found that when a speech-language pathologist (SLP) provided group training to multiple family members related to aided language modeling on an AAC device, this allowed for greater communication in the home and connection between the entire family (Douglas et al., 2021). Close collaboration between parents and professionals in the child's life will increase the likelihood of generalization of skills from therapy to the home, easing the stress parents indicate feeling.

Parents are essential to the successful implementation of AAC for their children with complex communication needs. However, little is directly known about the caregivers' perspective on AAC. The perspectives of various professionals, including speech-language pathologists (SLPs; Kovacs, 2021), pediatric nurses (Simmons et al., 2021), school staff (Norburn et al., 2016), and special educators (Andzik et al., 2019), have been investigated, yet only a limited number of studies (e.g., Lee & Vega, 2017; Fäldt et al., 2020) have focused on the perspectives of parents. Much of this literature involves an examination of parent perspectives in

conjunction with other external stakeholders, such as special educators and SLPs. Findings from research have only indicated a few specific supports parents seek (e.g., device training) when implementing AAC with their child. In the current study, participants were asked to share their perspectives across their entire experience with AAC, from the assessment process to the obtainment and implementation stages. We wished to expand upon current literature surrounding the topic by interviewing a larger number of participants across a broader span of backgrounds. The purpose of the present study was to understand parent perspectives on (a) what the assessment procedures look like for individuals who use AAC, (b) the external variables that influence device use (e.g., family, friends, community), (c) the barriers they face when obtaining and navigating AAC use with their child, and (d) the supports they have received or what has worked.

Method

Participants

Recruitment for this study was completed through a survey-based study (in-development), which was disseminated through a snowball method, originating through mass email distribution to publicly available email addresses of professionals (e.g., SLPs, principals, applied behavior analysis providers), social media platforms nationwide, and through direct recruitment through the Simons Foundation Powering Autism Research (SPARK) research foundation. To be included in this study, participants had to live in the U.S. and be the parent or guardian of one or more individuals 22 years or younger who used an aided or unaided AAC system to supplement or replace their spoken language. At the end of the survey, participants were asked if they would be willing to complete a follow-up interview. Approximately 120 individuals indicated their interest in a follow-up interview, and approximately 80 were emailed

at random to participate. Twenty-three parents agreed to an interview; however, one participant's responses were not included in the analysis because he could not respond to the questions stating the child's mother knew the answers, and he did not. Twenty-two participant responses were included for analysis.

Participant ages ranged from 32–59 years old ($M = 42$). All participants identified as female; however, one male participant did engage in an interview, but his responses were not included in the analysis because he was unable to answer our questions in detail because his wife was more attuned to the AAC. Most participants ($n = 10$) indicated that a bachelor's degree was their highest degree earned, seven indicated completing high school or some college, three had a master's degree, and two had an associate degree. Only one participant indicated that they had experience with AAC outside of their child's usage, which included working at a daycare with a child who had a device. See Tables 1 and 2 for participant and child demographics. Participants who completed the interview were compensated \$10 via PayPal or Venmo for their time. However, four participants declined the incentive.

Survey Instrument

The semi-structured, open-ended interview questions were developed by all three authors: a doctoral-level special education professor specializing in AAC, an undergraduate researcher majoring in speech-language pathology, and a doctoral-level professor in speech-language pathology specializing in typical and atypical language development and children with autism. The authors developed the interview questions by referring to published literature related to this topic. Once a draft interview protocol was developed, a parent of a child who uses AAC assisted in adjusting and refining interview questions.

Procedures

After obtaining Institutional Board Review (IRB) approval and before beginning each interview, researchers obtained consent to record the interview and use the participant's responses for research. Interviews ranged from 17:59 min to 40:53 min ($M = 25:50$).

Semi-structured interviews were conducted over the phone, with one exception occurring over a video-conferencing platform, and at least one researcher and one parent were present during every interview. The parent that opted to interview over the video-conference platform included her son in the discussion. Researchers first gained information about the demographics of the parent (e.g., gender, highest degree earned) and the child who used AAC (e.g., age, primary disability label). Researchers asked participants to describe their experience with AAC before their child's usage, if any. Then the participants described how they obtained the child's AAC device (e.g., assessment completed) and any funding they received for the device. Researchers also asked about family and friends' acceptance of the device and acceptance by related professionals (e.g., school and/or private therapists). Researchers asked about participants' perceived barriers related to their experience in their child's device acquisition and use (e.g., What factors have been the hardest when getting, implementing, and/or using AAC?) and perceived supports (e.g., What factors have been the most helpful and supportive when getting, implementing, and/or using AAC?). The researchers ended the interview with, "Either now or at the beginning of your journey with AAC, what is something you wish you had/or had gone differently?"

Data Analysis

A phenomenological approach (Creswell, 2013) was used to evaluate parents' experiences when obtaining, learning, and implementing AAC use with their children. We opted to use this approach as phenomenologists often simply report the experiences of those

interviewed. Since the researchers did not have any other data source to develop theories around, we opted against using a grounded theory approach to the data analysis.

The recordings were transcribed by Go Transcript (www.gotranscript.com), and the researchers reviewed each for accuracy. When there was a discrepancy between the written and spoken word, the researchers reviewed the transcript, listened to the audio together, and agreed on what should be included for analysis. Then the researchers reviewed the transcripts in their entirety again to develop a better understanding of the parents' experiences. This process of horizontalization (Moustakas, 1994) paved the way for the researchers to start to develop codes. Then the researchers independently reviewed the transcripts and audio files to quantify which participant experienced each of the 26 possible codes (e.g., child-level barriers within the implementation, where the parent learned how to use the device). Each week, the researchers met to review commonalities among their codes and discussed differences they found within their analysis. This constant comparative method was used throughout the review while researchers repeatedly returned to previous codes to ensure that individual perspectives adequately contributed to the analysis. Finally, researchers considered the quantitative data and collapsed codes into the five major themes discussed in the results section below.

Validation Strategies

The researchers used a variety of approaches when conducting triangulation of the data to maintain a level of trustworthiness and to be confident in our findings (Creswell, 2013). First, the authors had no lived experiences with children who use AAC. Although they reviewed published literature on the topic and did collaborate with SLPs and a parent of a child who used AAC, there was no bias or influence when conducting the interviews. Second, researchers continuously compared participants' responses to one another to identify patterns and trends across the

interviews. This allowed researchers to corroborate findings across participants to ensure a homogeneous group was present before and during the analysis. Third, the researchers performed member checking by emailing each participant the themes that emerged during analysis with the request that they agree or disagree with the findings. Sixteen participants (73%) responded to the inquiry, and those who responded agreed. Finally, the researchers recruited two practicing SLPs to engage in peer debriefing, which included reviewing the initial codes and developing themes that emerged. Each SLP agreed with the findings, stating that they experienced these same trends in their practice.

Results

Following analysis of 22 parent interviews, five major themes relating to our research questions emerged: struggles and triumphs through the assessment procedures, external variables that influence device use (e.g., family, friends, community), barriers identified when navigating AAC, support parents have indicated that have helped them, and major takeaways as identified by parents. Corresponding subthemes were also identified and are explained further below.

What Assessment Procedures Look Like

Assessment

Although all participants indicated that their child used some form of AAC, only 82% of individuals ($n = 18$) shared that there was a formal assessment completed with their child before determining which device the child would be given. Three participants (P10, P17, P18) received more than one assessment completed across multiple providers (e.g., private speech, state agency). Accounting for the three participants who had multiple evaluations, participants cited district SLP ($n = 10$), private SLP ($n = 6$), or a state/agency provider ($n = 6$) as who did the assessment.

Of the four participants whose children did not receive a formal assessment, three had similar remarks about their experience. P6 shared that her son's SLP claimed, "He's 12, he's not going to get much more robust speech, so why don't we try an AAC device." P16 commented that her daughter's SLP simply found an extra school iPad and downloaded TouchChat. When asked if an official assessment was done at the start of her child's AAC use, P11 responded, "Hell, no." When reflecting on her family's assessment experience, P17 noted how an outside evaluation was done because, she said, "In the beginning, the school was resisting any sort of device...we just thought she was ready to move up and they wouldn't do a formal eval."

Trials

Though most participants recalled engaging in a formal assessment, only half of the participants ($n = 11$) indicated that there was a trial process during the acquisition phase. P4 mentioned her child's SLP shared apps that could be downloaded to the device and "got [them] hooked up with a free 60-day trial for it," although she did not have a formal trial period between multiple devices or applications. Other participants (P2, P7, P8, P9, P10) noted access to more apps during a trial period. P8 recalled trying, "maybe two or three different ones," and P7 said they gave her "a bunch of stuff to take home." P2 took data during a trial period for Language Acquisition through Motor Planning (LAMP) and TouchChat, but ultimately chose TouchChat because of the bilingual option. P14 and P22 shared very opposite experiences when trialing eye gaze systems with their children. P22 trialed eye gaze with her child for two years, whereas P14 was only offered a trial for one month.

Early Recommendations for AAC

Although not explicitly asked, all participants ($n = 22$) mentioned, to some degree, who initially recommended AAC to their family (i.e., SLP, their own research, outside person). For

many ($n = 17, 77\%$), the participants identified their SLP or AAC specialist as the driving force. Five participants (P5, P12, P19, P20, P21) said that various outside individuals (e.g., occupational therapist, AAC manufacturer or representative) introduced them to AAC. P5 explained that someone from her church reached out to her on an unrelated matter and just happened to be an occupational therapist, who connected her with a device representative. P21 had a similar by-chance experience when she shared, "One of [his] caregivers through...respite, said at one point, 'I work with another little boy, he has a Dynavox. How come [he] can't have one of those?' We thought, indeed [chuckles], why can't [he] have one of those?" Four participants (P2, P11, 17, 18) responded that they were the ones who approached their SLP to start a conversation about AAC. For example, P18 explained that she acquired the device on her own before her child started school, stating, "It was more me going out and finding that for her...." P11 also shared that she had to advocate for her family after a conversation with an assistive technology specialist who told her, "He's too young. Why are you worried?" With that, she bought an iPad and uploaded an app with yes, no buttons to get her child started.

Payment Source

Participants shared mixed remarks about who paid for the device. Several participants ($n = 8, 36\%$) obtained multiple sources of funding during the acquisition of multiple devices. Twelve participants indicated insurance paid for the device. However, five of those also had to pay out of pocket for a portion of the device or a device to use as a backup or starter system while waiting for insurance funding. Nine participants indicated that some portion of the device was funded through the school district, but five of those individuals also had to find additional funding sources (e.g., self-pay). One participant indicated that a local grant paid for her child's

device. Two other participants indicated that a portion of their device was funded through donations or a non-profit.

Payment for a device equates to who owns the device. A few participants noted wanting to self-pay, so they maintained ownership. P10 said, “we wanted to make sure that we own the device. We didn’t want the school to own the device.” Some participants made remarks about the downside to not owning the device. For example, P16 commented, “[the school has] had it for a week and a half now, which is fine, I understand...but it's like, ‘My kid needs this to communicate with us.’” P14 was motivated to bypass insurance, saying, “We're not going to wait. We have to buy him the device. I don't want to wait any longer. There's no way he can wait six months for a full, complete assessment. Then what if the insurance denies and we have to appeal?” She went on to explain that a Prentke Romich Company-Salttillo (PRC) representative allowed her family to borrow a device for as long as they needed, stating, “...it actually makes me want to cry because I think...that had she not done that, I truly believe that he would not be able to communicate to this day...”

External Variables that Influence Device Access

Use with Family

The extent to which the child has access to and can use the device depends on various external variables, such as buy-in from family and friends. Fourteen participants (64%) responded that their child used their device to communicate with family members and siblings. For example, P5, P6, P10 noted having the child’s siblings use the device to communicate with them at home. P14 shared how impactful a day camp was for her children, stating, “My eight-year-old son has gone to camp with his brother, and that’s been really good because he learned more modeling and things like that with seeing other siblings.” She also noted that her children

naturally use partner-assisted scanning at home. Some ($n = 7$) participants shared that extended family members use the device to communicate with the child consistently. P4 expressed that the child's grandmother was not against the device but was still figuring out how to use it. Another participant, P12, made a similar comment, saying, "The younger ones, like my nieces, are much better at using it with her than my mother- and father-in-law."

Some parents ($n = 6$) noted feelings of isolation when in a home without other experienced communication partners. P9 reflected, "Other than myself, there's nobody modeling. My husband doesn't. My son doesn't." P13 shared a similar response when asked if her husband was able to navigate their children's device, stating the following response: "He likes the idea, but I would say he probably considers it my project with the boys, but he's not against it...Actually, he wouldn't know what to do with it if I handed it to him." Fortunately, P5 expressed that the whole family has embraced the device as she explained that she "never felt weary or alone in the process."

Although about 60% of participants reported that their child used the device with family and friends, less than half ($n = 10$, 45%) shared that the device was the primary communication method for their child while at home. P3 acknowledged that the device was most often used at home and school but said one of their family's goals is to "make it more a part of everything that [they] do, at least at home." Other participants did not place as much stress on using the device in the home. P13 summarized this sentiment by stating, "We don't really need it to have them communicate to us because we understand them." One participant with a child who uses an eye gaze system (P22) noted that they used the device less at home than in other locations due to the set-up at home being "more burdensome than helpful."

Community Use

Fifteen participants noted that implementing the device in the community proved difficult. Two participants (P4, P19) mentioned that using the device in community settings became more difficult because of COVID-19, and P2 and P13 commented that community use was a goal they have recently started working towards. P10 shared an example of why the device isn't used in public when she asked, "Do you put it in a plastic bag and try to get into the hospital or leave it in the car?" Participants also mentioned times when they could effectively incorporate AAC into their community. For example, P13 noted that device use at home had become more centered on teaching how to use AAC in the community. Of the seven participants who did not indicate that using a device in public was difficult, four participants (P6, P12, P15, P21) specifically referenced scenarios in the community that involved restaurants. P6 said that her son would use his device to order food when her family went out to eat. Similarly, P12 shared, "We intentionally take her to places to use it. When we go to restaurants and stuff, we give her the menu, we give her talker and we have her tell us what she wants." P1 would ask communication partners in the community to slow down; she coined this as "everything's a teachable moment."

Child Buy-in and Physical Access

Child buy-in, general motivation, and overall knowledge or awareness of the device were factors pertaining to a child's overall access to their device. Eight participants (36%) said that child-level barriers were a big issue in their families. P4 commented that having her son focus on the device, particularly when he feels distressed, could be difficult. P8 also acknowledged that the device could be challenging to implement during times of anxiety, and she added that one of their goals was to teach him that the device is "not for entertainment, we're doing it to help him expand his vocabulary..." Participants noted that it was harder to encourage device use when their child did not fully accept the device, as P4 commented that one of the biggest challenges of

AAC was “just getting [him] to embrace it.” Not every participant commented on child buy-in in this manner. P5, for example, explained that her daughter was “very motivated to use her device. She uses it a lot.” P21 shared a similar sentiment, saying that “it’s just his device, and he’s very protective of it.”

Limitations in physical access were a source of difficulty for some participants ($n = 10$). Three individuals (P3, P10, P14) noted that carrying the device and corresponding accessories was difficult for both the child and the parent, limiting complete access in some situations. P14 noted that her child had access to his device only when he was in his wheelchair and indoors, given the nature of his eye gaze device. P3 emphasized that taking her son’s walker and trachea equipment with her family when they left the house could be daunting, stating, “it does make it very difficult just having lots of things....” A similar comment was made by P6, who also discussed the visual limitations of smaller, more portable devices. Motor control was an area identified by two participants (P18, P22). P18 commented that her daughter struggled when isolating her finger to select the correct button, even with keyguard support. P22 noted fine motor control as a limitation in her child’s AAC use, stating, “I think if it were easier for him, he would definitely do it more.”

Barriers Caregivers Face when Navigating AAC use with their Child

Parent Comfort

Most participants ($n = 16, 73\%$) responded that they felt comfortable navigating, implementing, and/or programming their child’s AAC device. When asked how comfortable she was with the device, P14 stated, “Very, very, very comfortable. I’ve made it my melon.” Similarly, P9 described herself as “AAC obsessed.” Some participants (P8, P17, P18) did not have an extensive amount of comfort but indicated that they were in the process of learning more

about the device. Six participants (P2, P3, P10, P12, P16, P21) responded in a way to indicate that they did not feel particularly comfortable navigating their child's AAC device. These participants replied that they were still learning the device's full capabilities, with P3 noting that their device was currently used only for communicating common words used every day. Two participants (P10, P21) whose children had been using AAC for fourteen years and twelve years, respectively, commented that their difficulty using the device stemmed from not remembering everything. P10 commented that she would need to look up how to program the device again; P21 made a similar statement, reflecting how "you don't do it for a while, and then you forget." P15 was very honest when she shared that her child knew the device better than her, and P11 boasted that she was just as good with the device representative.

Parent Training

Parents shared the varying types of training they received to be prepared to work with their child's device and to promote its use. Although all the participants mentioned some level of self-training, only eight participants described going through a more formal training process. Fourteen respondents indicated they were self-taught with no formal training. Although many parents described trial and error, some mentioned only being able to work with the device once their child was asleep. A popular source of help was online videos. For example, P18 commented, "I have YouTubed a lot of TouchChat videos on how to navigate through [the device]." P2 simply stated that she learned by "Just doing it." Those who did get training did so through their child's SLP or AAC specialist, the device representative, or their own efforts (e.g., attending a conference). One participant (P17) mentioned her school district's SLP as a source of training, saying, "...they had this qualified person who was always willing to train parents if they wanted it." P1 and P3 mentioned a PRC training and a Tobii Dynavox training, respectively, as a

source of formal instruction on their child's device. P6, P9, and P14 discussed parent coaching and mentoring, and P14 reflected on taking a workshop from the SLP that was "like AAC 101 for parents."

Public School Support

In some cases, parents indicated that their child was homeschooled because their public school was not meeting all their child's needs. P5 mentioned that she does not "ever see putting her back in public school," and P11 noted that her child started to use his device as his full-time voice after the decision to homeschool. Pulling a child from public school due to the lack of support or access to an expert in AAC is a hard decision for parents, but P14 described attempting public school during the pandemic with the following statement: "I always knew that he really wasn't getting the support that he needed in school, but when the pandemic hit, we just decided he deserves to be homeschooled." P10 noted a similar experience, expressing that her son's public school was not challenging him. The one participant who had not taken up homeschooling but was considering it (P15) shared that her experience with the school district was a contributing factor in deciding. When thinking about her child starting kindergarten, P15 expressed that she was unsure if she should continue with public education or switch to homeschooling because she "was not impressed with [her] district at all."

Supports Parents Received, What Works

Access to Expert (For the Parent)

Eighteen participants (82%) responded that they had access to an appropriate expert to help with their child's AAC instruction and use. P1 reflected that her family has been "blessed with great providers." However, four parents (P9, P11, P13, P17) expressed difficulty finding access to an SLP in their children's school district. P9's daughter started with her eleventh SLP;

she is only in 8th grade. These issues were so significant that P11 decided to homeschool her child. One participant, P13, felt that neither her private nor district SLPs were accessible resources for her family, and she commented that “the speech device almost needs its own little support corner.”

Aside from access to valuable device experts, most families described their children receiving services from various providers (e.g., Applied Behavior Analysis [ABA], private or self-pay SLP), and only seven described quality collaboration between their providers. P6, P7, and P18 noted good collaboration between their child’s private SLP and district SLP. When referencing the two providers, P6 commented that “they’re all linked up,” and she explained that the two SLPs were in contact with one another more frequently than the paraprofessionals. Though seven participants mentioned effective collaboration between providers, most respondents ($n = 13$) had either poor collaboration or no collaboration. P14 believed there was limited communication between her child’s district and private SLP, commenting, “We don’t get much out of school-based speech therapy.” The remaining two participants did not mention collaboration between providers in any capacity.

External Supports

Over half of participants ($n = 12$, 55%) indicated that they referred to social media and/or instructional videos online as a source of support. P8, for example, mentioned that she was a member of a Facebook group composed of other parents who had children with complex communication needs that provided her with emotional bonds. Other participants used social media and video resources to learn more about specific aspects of their child’s AAC device in an academic sense. P22 noted, “then I found YouTube videos, like when I wasn’t sure how to do something on the device, and I didn’t want to ask.” Four participants (P1, P2, P9, P14) said they

were members of various parent support groups, with P1 explaining that she ran a support group for parents of children with autism. P2 explained that her membership in an organization for families with Down syndrome was what allowed her to learn about potential high-tech AAC devices for her son. Four participants (P3, P6, P9, P14) also mentioned other sources of support, from additional private organizations to mentor support. P9 shared that her family has utilized an advocate from the state to support her family during times of challenge with the school district.

Parents Go-To Person

Participants were asked whom their go-to person was, meaning, if their device were to stop working, who was the first person they would reach out to for assistance. There was some variation within responses, and some participants responded with multiple answers, but many individuals ($n = 17$) responded that they would contact their SLP and/or AAC specialist. P2 mentioned her son's AAC specialist as her family's biggest supporter, saying that without her, their family "would have had to fight harder" for a device. Eight individuals noted that their primary assistance came from an outside provider (e.g., an ABA therapist or device representative). P9 mentioned that despite being in-between representatives at the time, she still felt that she could reach out to PRC for assistance if an issue with the device occurred. Two participants (P1, P5) said they would first turn to their husbands for support.

Big Takeaway

At the end of every interview, the researcher asked participants if there was anything they would change about their experience or if they could go back and do something different, and what that might be. A majority ($n = 16, 72\%$) of participants mentioned, in some capacity, that they wished they had started the AAC path for their child sooner. P21 highlighted, "I would do it from as early on as you possibly could have." Several participants ($n = 6$) indicated that they

would not change the time their family started AAC because of circumstances that would have likely made it impossible to have started sooner. For example, P5 started her child with AAC support immediately after adopting her, and in another case, P12 noted that “technology really just started to come out.” P11 felt that her family found AAC at just the right time, stating, “I believe that when you’re given a child with some complex stuff, sometimes you’re not ready to consider that that’s going to be the only way.”

A few participants ($n = 3$; P13, P15, P22) commented that although they did wish they started AAC sooner, they did not because of concerns regarding how it would affect their child’s vocal speech development. P13 mentioned that she knew the current research showed that introducing a device would not hurt the child’s speech, but she still felt as if there were times when she was going backward by using the device. P15 shared a similar hesitation in introducing AAC but said that her son has “blossomed” since he started with AAC. When thinking about how her son started AAC, P22 reflected that she did not start early because she was unaware of how his condition would manifest, and she had thoughts that “maybe he could still catch up.”

A small number of participants ($n = 3$) expressed that they wished they had tried harder during their child’s AAC acquisition or training. In this regard, all three participants (P1, P3, P19) felt that there was something they could have been working on more consistently. For example, when reflecting on her family’s AAC journey, P19 commented, “I would have trialed different programs for longer before settling on LAMP.” Both P1 and P3 mentioned that they wish they had their child use AAC more frequently and followed recommendations from professionals more often, with P1 stating that her bad days are when she feels like she “could’ve pushed communication a little bit more.”

Discussion

Twenty-two parents shared varying responses about their experiences with the acquisition of AAC for their child, the training they had received, the professionals in their lives involved with supporting their family, and the ongoing struggles and successes around the implementation of AAC for their children. Although most participants' children did receive a formal AAC assessment, only half were provided devices to trial before selecting their system. Participants also described various external variables that either promoted AAC use or acted as a barrier, including family use, community use, child buy-in, and physical access to the device. Specific barriers (e.g., parent level of comfort, public school support) and supports (e.g., access to a reliable expert, parent support groups) were mentioned by participants, wherein they explained the most helpful or burdensome aspects in their navigation of AAC. When asked what they wish had gone differently, most parents indicated that they wished they had started AAC sooner in their child's life. However, some expressed concerns about AAC hurting vocal speech development and feelings that, as parents, they could have tried harder during some point of their family's AAC journey. The parent perspective must be included in AAC research to implement feasible therapy techniques to achieve generalization across all environments.

The present study sought to expand upon existing research by analyzing the parent perspective on integrating AAC into an individual's daily life. By including individuals with a wide range of disorders (e.g., autism spectrum disorder, Down syndrome, cerebral palsy), our research directly responded to O'Neil's and Wilkinson's (2020) call for including the perspectives parents of children who have disabilities beyond one diagnosis (i.e., cerebral palsy) and beyond the young children that were the focus of their inquiry. Similarly, the current study explored changes in needs and preferences over the lifespan, with participants reporting their children's ages to be between 3 years and 22 years old. Our larger participant pool allowed us to

feature a wider range of perspectives than other studies which interviewed a smaller sample (12, Park, 2020; 10, Lee & Vega, 2017; 8, O'Neil & Wilkinson, 2020). We found that parent responses complemented findings from other studies involving the parent perspective. For example, limited training and support from qualified professionals was a previously noted barrier (Moorcroft, 2019; Kulkarni & Parmar, 2017). Also, Biggs and Hacker found multiple child-related factors like physical access and child buy-in to be barriers (2021a). The work of the current authors sought to build upon noted supports and challenges of AAC by including perspectives on the assessment, obtainment, and implementation processes across multiple disability labels and ages of individuals who use AAC. Parent perspectives found in previous studies were echoed, and findings from this interview-based study provide a greater outlook on the parent's perspective on AAC by including a more comprehensive range of eligible participants.

Implications for Practice

Several clinical implications can be drawn from a parent's perspective. To start, family-centered practice should be considered when making an intervention plan for individuals with complex communication needs. Several studies have already highlighted parent's role as goal-makers and interventionists in their child's AAC use (Biggs & Hacker, 2021b; Walters et al., 2021). Knowing this, it is important to listen to parents when they describe the realities and challenges of incorporating AAC use into their family and encouraging child buy-in. It is also necessary to consider the education and training professionals receive related to AAC. Although ASHA requires SLPs to demonstrate knowledge of AAC, many universities only offer courses covering this content as electives or optional certificates. More formal training should be

required for SLPs and special educators alike to better serve their clients and families that use AAC.

Many SLPs have concerns that parents may not be receptive to integrating AAC into their family's life because they feel it will hinder speech development, despite the wealth of research that shows the benefits of AAC for individuals with complex communication needs (Branson & Demchak, 2009; Gevarter et al., 2021; Naguib Bedwani et al., 2015). Parents interviewed in this study self-reported their wish to have started AAC sooner. The few participants who specifically mentioned that they did not start earlier because of their concern surrounding speech development reported some regret once they saw their child's capabilities in using AAC. With this information, SLPs can share parental experiences and additional resources on the validity of AAC with their clients who might be hesitating to start AAC. It is also important to note that greater public awareness of AAC may help parents become more informed about devices before their child acquires one, making them more comfortable integrating AAC into their family's life when they make that decision.

Additionally, findings indicate that SLPs should consider therapy outside the home or school for AAC intervention, as seen by our participants' comments on the difficulties of incorporating AAC into the community. SLPs can push for AAC use across environments to encourage clients and families to fully utilize their devices in their communities. In addition to expanding treatment locations, SLPs should also promote increased family presence in sessions. Participants in the current study commented on their appreciation of training and camps specifically designed to increase the use and acceptance of a child's device with their siblings. Douglas et al. (2021) provided tele practice-based training and modeling to the family members

of a child who uses AAC, and their results showed an increased rate of AAC use. Rethinking AAC therapy could promote overall AAC use and family buy-in.

Interprofessional collaboration is another parent-perceived area for improved clinical implementation. Parents noted difficulties in gross and fine motor skills as a barrier regarding their child's AAC access and use. Collaboration between SLPs and occupational therapists (OTs) can ease some of the difficulties of AAC use. Having an awareness and understanding of the two disciplines can provide greater insight into AAC assessment and intervention (Wallace & Benson, 2018; Lewis et al., 2017). Furthermore, the collaboration between these two professionals can also be shared with parents to discuss practical ways to incorporate skills learned in therapy in the home, community, and school environments. Better communication between all members of an individual's team (e.g., SLPs, OTs, teachers, ABA providers, family members) can help to provide more comprehensive and effective services. By following ASHA's (n.d.c) recommendations regarding interprofessional practice, parents may feel more supported in all aspects of their child's AAC intervention. When considering parent comments regarding motor control and AAC implementation, SLPs and OTs should work together to provide the most support to ensure the greatest fluent and functional use of an individual's device.

Limitations

Interviews were designed to be as inclusive of a family's AAC assessment and intervention journey as possible to uncover the full range of successes and challenges regarding AAC. However, there are limitations noted within this study that can be expanded upon in future research. For one, all participants identified as female and categorized their relationship to their child as a mother; no male participants were included in our analysis who identified as the father, so their perspective was not represented in our study. A somewhat limited range of geographic

locations can also be noted within our study. Participants reported living in the northeast, southeast, and western regions of the United States, but we did not interview any participants from the southwest region. Future studies can include more participants to reflect the geographical factors that influence AAC use and the growing diversity in the United States.

Upon review of the limitations of the present study, recommendations for future research can be made. A more comprehensive understanding of AAC can be understood with research that expands the inclusion criteria of a family; future research studies may include interviews involving the child who uses AAC, siblings, and all other individuals directly involved in a child's life (e.g., grandparents, other caregivers). Further researchers may also include longitudinal studies to better understand how a family's perception and implementation of AAC changes over time.

Conclusion

The authors of this study reported on the perspectives of 22 parents of children who use AAC, specifically regarding their experiences with assessment, external variables that influence their child's device use, barriers, supports, and using AAC in general. Parents reported on their child's assessment to acquire a device and various obstacles related to funding their child's device. They also provided information on their level of comfort navigating their child's device, their family's ability to integrate the device into both home and community settings, and the sources they turn to when they need support. Future research should include a broader family perspective to capture a more accurate image of AAC integration outside of therapeutic settings. From there, professionals on a multidisciplinary team can be better equipped to support clients and their families.

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Table 1
Participant Demographics

Participant	State	Gender	Age	Language	Highest education	Race
1	OH	Female	34	ENGL	AA	White
2	CA	Female	43	SPN, ENGL	Current PhD, completed MA	White, Hispanic
3	TN	Female	35	ENGL	Some college	White
4	WA	Female	37	ENGL	Some college	White, Hispanic
5	OH	Female	41	ENGL	BA	White
6	OH	Female	55	ENGL	MA	Pacific Islander
7	WI	Female	32	ENGL	AA	White
8	WA	Female	33	ENGL, PIGE	BA	Mexican American
9	CT	Female	46	ENGL	Some college; technical degree	White
10	IN	Female	51	ENGL	BA	White
11	NC	Female	42	ENGL	Current MA, completed BA	White
12	PA	Female	45	ENGL	BA	White
13	WI	Female	51	ENGL	BA	White
14	CA	Female	40	ENGL	BA	White
15	OH	Female	37	ENGL	HS diploma	White
16	NC	Female	45	ENGL	HS diploma	White
17	IL	Female	51	ENGL	BA	White
18	CA	Female	38	ENGL	Some college	White
19	VA	Female	34	ENGL	BA	White
20	GA	Female	40	ENGL	BA	Black
21	IL	Female	59	ENGL	MA	White
22	IN	Female	37	ENGL	Some college	White

Note. State abbreviations are representative of each state; ENGL = English; SPN = Spanish; PIGE = Pigeon; HS = High School AA = Associate Degree; BA = Bachelor's Degree; MA = Master's Degree; PhD = Doctor of Philosophy

Table 2.
Child Demographics

Participant	Age	Gender	Disability	Race	How long AAC	AAC System, platform	Communicative competence of their AAC use
1	7	Male	Autism	White	3.5 years	LAMP, Accent 1,000	Mostly requesting. High motivation; independent use. 10-20 verbal words (familiar listener), gestures.
2	5	Male	Down syndrome	Hispanic	7 months	TouchChat, iPad	Uses AAC to repair communication. Has some vocal speech. Pointing, gestures, modeling with body.
3	5	Male	Genetic disorder	White	2 years	Tobii Dynavox Snap Core Plus, iPad	Exploring AAC; not always purposeful communication. Uses AAC for nonfamiliar listeners. Multiple modes: gestures vocalization, sign (30-40 signs).
4	5.5	Male	Autism	White	4 months	Tobii Dynavox Snap, iPad	Uses AAC when stressed or dysregulated. Sign independently, AAC requires prompting. Highly verbal.
5	14	Female	Autism	White	5.5 years	LAMP, Accent 800	Primarily uses device; not in full sentences (1-3 words). Minor sign; modeling with body.
6	17	Male	Autism	Pacific Islander / White	5 years	TouchChat, iPad	Uses device for identification and requesting. Can echo but doesn't produce speech unprompted. Mostly independent AAC use. Will grab/lead before AAC.
7	3	Male	Autism	White	10 months	Core board	Primarily uses verbal speech; uses device only when not understood. Says 3-4-word phrases.
8	4	Male	Autism	Filipino-Asian	1 year	NovaChat 8	Verbal speech understandable sometimes to familiar listeners. Signs, uses device, directs to specific items.

9	13	Female	Autism, genetic disorder	White	7 years	Accent 800, Unity language	Uses device to clarify. Multimodal (Sign Language, verbal). Independent but still requires modeling.
10	17	Male	Autism	White	14 years	LAMP, iPad	Nonverbal; mostly device with some signs and gestures. Uses mostly when prompted but sometimes independently.
11	13	Male	Cerebral palsy	White	11.5 years	NuEye Gaze, PRC Accent 1400	The primary mode is an eye gaze device, modified sign with a few vocalizations. Uses device when prompted and independently. Modified sign/gesture for unfamiliar listeners.
12	14	Female	Autism, genetic disorder	White	10 years	Touch Chat, iPad	Uses daily at school, independently and prompted. Gestures to get attention.
13	11	Male	Down syndrome	White	1.5 years	Tobii Dynavox Snap, Tobii Dynavox	Uses device at school, during some parts of the day; not used at home. Needs prompting.
14	12	Male	Cerebral palsy	White	6 years	PRC Accent 1400 with eye gaze	Facial gesture for yes/no; device access only indoors with wheelchair. Uses partner assisted scanning. Engages with family or friends with a device.
15	5	Male	Cerebral palsy, epilepsy	White	1.5 years	Snap Core on I-110, Tobii Dynavox	Verbal words for “mom” and “dad”; repetition of “baba” for some things or first syllable of some words. Gestures and points in conjunction with device. Uses independently.
16	9	Female	Genetic disorder	White	2 years	TouchChat, iPad	Limited verbal speech; small amount of sign. Uses device at school and home. Uses independently and prompted.
17	21	Female	Down syndrome, autism	White	19 years	TouchChat, Samsung Tablet	Does not use verbal language; AAC is primary mode. Uses combination of pointing and confirming with gestures, independently and prompted.

18	5	Female	Genetic disorder	White / Hispanic	1 year	Touch Chat, iPad	Uses a lot of gestures and vocalizations; still learning AAC device. Needs prompting.
19	5	Male	Autism	White	2.5 years	LAMP Language for Life, PRiO	Everything is prompted. Uses PECS at home.
20	6	Female	Autism	Black	3 years	Touch Chat, iPad	Primary used at school and therapy. Will use device independently and unprompted.
21	22	Male	Genetic disorder	White	18.5 years	ProloQuo2Go, iPad	Uses device for concrete needs and basic interactions. Multiple modes: gesture, guiding, inconsistent vocalizations.
22	10	Male	Cerebral palsy	White / Asian	7 years	Help Me Grow, Accent 1400	Mainly uses device at school. Will use when prompted. Uses vocalizations, touching, and pointing.

Note. AAC = Augmentative and alternative communication; LAMP = Language Acquisition through Motor Planning; PRC = Prentke Romich Company-Salttillo; PECS = Picture Exchange Communication System