The Relationship Between Race, Rural Living Status, and Access to AAC Services

by

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Abstract

Research suggests that rural Black families in the U.S. are less likely to receive equal access to speech-language pathology services. Additionally, Black children may receive less augmentative and alternative communication (AAC) intervention than their otherwise similar white peers. However, limited empirical research has analyzed the effects of both racial and geographical disparities on accessing AAC devices and supports. To fill this gap, the current study consisted of a nationwide survey of caregivers of children 18 and under who use or would benefit from AAC, collecting relevant demographic information and information regarding AAC supports and services. The study addressed the following research questions: 1) How are race and rural living status associated with AAC access for children with disabilities and complex communication needs age 18 and under in the United States?; and (2) How are race and rural living status associated with caregivers' perceptions of the cultural appropriateness and cultural responsiveness of AAC systems and services? Results of regression analyses did not reveal a statistically significant predictive effect of rural living status on either research question, potentially related to the small representation of rural participants in the sample. However, initial correlation analyses did suggest that rural living status may be associated with higher perceptions of culturally responsive services. When investigating the Deep South respondents specifically, Black caregivers reported that their children were significantly less likely to have access to aided AAC than white caregivers. Additional demographic factors were also significantly predictive of access to aided AAC (e.g., income, insurance, child diagnosis) and culturally responsive services (e.g., income, disability type, access to aided AAC). These results suggest that in at least the

Deep South, race may be a unique predictor of access to aided AAC, though other demographic factors are also impactful.

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List of Abbreviations

AAC	Augmentative and Alternative Communication
SLP	Speech-Language Pathologist
ASHA	American Speech Language and Hearing Association
PECS	Picture Exchange Communication System
LAMP	Language Acquisition through Motor Planning
SIGs	Special Interest Groups

Introduction

Augmentative and Alternative Communication

Augmentative and alternative communication (AAC) refers to communication supports that assist individuals with complex communication needs who cannot rely on speech alone to meet their daily communication needs (Beukelman & Light, 2020). AAC encompasses multiple approaches to supplement or replace – either temporarily or permanently – the speech of individuals with complex communication needs (Beukelman & Light, 2020). AAC systems may include aided systems such as communication books, picture exchange systems, single voice output buttons, topic boards, and alphabet boards, as well as computer-based systems (e.g., tablet-based applications with speech output; ASHA, n.d.). AAC systems may also include unaided communication methods such as manual sign, gestures, facial expressions, and body language (ASHA, n.d.). People who benefit from AAC may include those with congenital and acquired disabilities (e.g., autism, cerebral palsy, Down syndrome, aphasia, amyotrophic lateral sclerosis, traumatic brain injury, etc.), and across the lifespan (Beukelman & Light, 2020). Research provides evidence that different types of aided AAC can have positive impacts on communication skills (e.g., Light et al., 2019; Nam et al., 2018). Importantly, AAC does not inhibit speech development but supports it (Millar et al., 2006; White et al., 2021). AAC is critical because it serves as a communication tool for those who have difficulty with speech and/or language. If an individual with complex communication needs does not receive access to AAC supports and services, they will have difficulty communicating their wants and needs in their everyday lives.

Barriers to AAC Services

Estimates suggest that over 5 million people in the U.S. present with complex communication needs and would benefit from AAC (Beukelman & Light, 2020). However, AAC systems and services may be difficult to obtain and implement due to a host of barriers. Some research indicates that only about 40% of students with severe communication disabilities may have access to AAC (Biggs & Hacker, 2021; Towles-Reeves et al., 2012). These data suggest that overall, individuals that can benefit from AAC are not receiving communication supports at the rate they should, affecting speech and language development and how the AAC systems are integrated into their everyday lives.

Additionally, for individuals who do have access to AAC, effective, meaningful integration of AAC supports into everyday communication is often a challenge. Many AAC systems are often underutilized or abandoned after one year or less (Biggs & Hacker, 2021; Johnson et al., 2006). Many preprogrammed AAC systems are also very complex for caregivers to learn and model, potentially impacting AAC use at home (Baxter et al., 2012). Teaching parents and caregivers to support their child's use of their AAC system is important. If proper caregiver training and support is not rendered, it can result in minimal generalization of caregivers supporting their child's communication in everyday life (Donato et al., 2018). Other barriers reducing the access to AAC systems and services include the availability of intervention services and service providers and access to AAC systems and technologies (Donato et al., 2018). Intervention services specifically for AAC systems and service providers knowledgeable in AAC are not always available to every individual who would benefit from AAC supports (Donato et al., 2018). AAC instruction in speech-language pathology (SLP) preservice preparation programs is increasing but is still not included across all programs

(Johnson & Prebor, 2019). Thus, even newly graduated clinicians may not be well-versed in AAC assessment and intervention. In addition, multiple barriers can impact access to AAC systems, including absence of consistent professional guidance and encouragement, lack of SLPs knowledge of AAC system, and financial and funding limitations (Donato et al., 2018). These factors all have a direct effect on whether individuals who would benefit from AAC are able to obtain effective AAC intervention and supports.

However, even though a child may have access to an AAC system and knowledgeable providers, additional barriers to using the system functionally in day-to-day life may still remain, especially for culturally and linguistically diverse populations (Baxter et al., 2012). Preprogrammed AAC systems generally reflect white, middle-class, English-speaking U.S. language and culture, and may require significant modifications to better reflect the language and identity of culturally and linguistically diverse families (Kulkarni & Palmer, 2017). If AAC systems are not adapted/programmed to reflect a family's own language, culture, and identity, this can impact the system's uptake and usefulness in the home and for that child (Baxter et al., 2012). AAC systems need to be culturally appropriate to reflect the child's everyday language. AAC intervention services must also be culturally responsive in order to support optimal outcomes across the diversity of culturally and linguistically different communities within the United States.

Rural Communities

Approximately 20% of U.S. households live in a rural area (Economic Research Service, 2024). Children living in rural communities may experience additional or increased barriers in accessing AAC services. Retaining speech-language pathologists (SLPs) in rural areas has been a rising issue. Many rural schools in the U.S. have switched to contracting SLPs for their special

education programs or using telepractice to ensure their students are able to receive services (Barley & Beesley, 2007). Barley & Beesley (2007) report school shortfalls in activity funding, complexities with teacher collaboration due to scheduling, small tax base, and high numbers on caseloads as key factors of declining SLP retention in rural areas.

Given the difficulties rural education systems have in retaining SLPs, the clinicians who do serve rural communities may have especially large caseloads. This limits the time SLPs can allocate to each student, including providing AAC assessment and intervention services for children with complex communication needs. Large caseloads can pose a difficulty for SLPs when trying to schedule time to collaborate with teachers and other related professionals. Schools in rural areas are at a higher risk of being under-resourced (Barley & Beesly, 2007). Underfunding of rural schools is a critical issue because it contributes to the resources available for both related professionals' salaries and materials and equipment for AAC intervention. Many rural schools are unable to afford an onsite SLP or other related clinical professionals (e.g., physical therapists, occupational therapists, audiologists; Barley & Beesley, 2007). These schools often contract providers outside of their school system for services. Contracted providers often serve an even wider area and thus have less or no time to collaborate with teachers or with each other. Effect AAC assessment and intervention requires a multidisciplinary approach, which is less feasible in underfunded rural schools who more often rely on contracted clinical professionals.

Parents in rural areas report a lack of access to information about AAC, as well as difficulty getting high tech AAC systems funded (O'Callaghan et al., 2005). They often report only having access to stopgap measures to support communication (e.g., free apps), or being limited to gestures, the small amount of words the individual may possess, or a small number of

manual signs (O'Callaghan et al., 2005). Thus, children in rural areas may not have access to AAC systems that meet their communication needs.

If rural areas lack local resources or skilled professionals, families may need to travel significant distances to access services for their children. Research suggests that often rural county residents have to drive over 50 miles to access common healthcare needs such as primary care physicians, hospitals, and clinical specialists – including speech language therapy services (Mendes, 2016). Traveling long distances for services includes the added barriers of fuel costs, access to an available vehicle, and availability of a parent or caregiver to take time off work to travel with their child or family member to appointments.

The SLP shortage that rural areas experience not only places rural citizens who would benefit from AAC at risk of not being able to effectively communicate with their family members and peers but could in fact impact their overall health and safety, potentially resulting in issues that could be life-threatening (Morton et. al, 2022). For instance, an individual may not be able to communicate basic needs such as needing food or water or worse, they may not be able to communicate when they are in pain, distress, etc. Investigating the inequity in access to AAC systems and services in rural areas is critical, in order to guide policy and practice to address these disparities.

Black Communities

Research suggests that Black children and other children of color may face additional challenges in accessing AAC services (Pope et al., 2022). Black children experience disparities in receiving a diagnosis of developmental delay, on average being diagnosed at an older age than their white peers, despite similar presentation (Dababnah et al., 2018). Parents report that delays in diagnosis are partially related to primary care providers ignoring parent concerns and/or

implementing racially biased services (Dababnah et al., 2018). This delay places Black and other children of color at a disadvantage in accessing speech-language therapy and AAC intervention, as clinical and special education services are challenging for families to secure without a diagnosis.

Black et. al (2015) reports that Black and Hispanic children are more likely to receive a communication disorder diagnosis than their white peers but are less likely to receive related clinical services (Davidson et. Al, 2022). Black families share that they have access to less services within the school system and outside the school system compared to their white peers (Taylor & Henninger, 2015; Thomas et al., 2007). Black families also report that the services that are received are less likely to be family-centered and culturally inclusive (Taylor & Henninger, 2015; Montes & Halterman, 2011; Thomas et al., 2007). Additionally, evidence-based practice to support clinical decision making has extensive amounts of research with white children, with little empirical research targeting clinical service delivery for children from culturally and linguistically diverse backgrounds.

When considering SLP services specifically, preschool- and kindergarten-age Black children are less likely to receive SLP intervention, as compared to white children with similar skills and needs (Morgan et al., 2016; Davidson et. al, 2022). As a result, young Black children have a lower likelihood of accessing or being referred for AAC services during these critical early language learning years. For Black children who are successful in receiving AAC services in earlier development, evidence suggests that these children likely receive significantly less targeted AAC intervention than their white peers (Pope et. al, 2022).

Culturally Responsive AAC Services

Social, cultural, and economic factors can influence how healthcare needs are prioritized by individuals in diverse communities (Strickland & Strickland, 1996). For communities that face significant barriers to accessing even basic services (e.g., medical care, education, basic resources), the process of obtaining AAC services for their child may be perceived as an additional barrier (Strickland & Strickland, 1996). Rural areas especially have a substantially smaller amount of medical infrastructure than urban areas, placing even greater access barriers on these communities (Strickland & Strickland, 1996).

Families are a critical piece in children learning how to utilize AAC systems, as it is with their family that children first build meaningful, relative communicative interactions (Soto, 2012). Cultural norms and expectations may impact how families perceive the role of AAC systems in their child's communication and language development (Kulkarni & Parmar, 2017). Cultural perceptions about their child's disability can also impact how families may implement suggested therapy ideas and incorporate AAC supports into their child's daily life (Kulkarni & Parmar, 2017). It is critical that SLPs practice cultural humility and engage in culturally responsive practice to ensure that families and their children remain at the center of intervention decisions, to ensure that intervention practices align with their cultural values.

Thus, even when individuals and families can access AAC systems and services, AAC systems and intervention services also need to be culturally appropriate and responsive to be meaningfully integrated into everyday life (Kulkarni & Parmar, 2017; Soto, 2012). AAC systems should reflect the language that the child encounters on a day-to-day basis, have voice output that sounds similar to theirs if not their own voice, and have symbols and vocabulary that reflect the child and family's cultural identity. AAC intervention services that are culturally responsive

support optimal outcomes across the diversity of cultural and linguistic communities within the United States (Kulkarni & Parmar, 2017: Soto, 2012). This means understanding how the family communicates, including family members as an equal part of the team, and providing appropriate supports to assist the family with integrating AAC into their family and community environment (Soto, 2012).

Implications for AAC Services in Rural Black Communities

Considering the combination of these factors, residing in a rural Black community may place Black children at an especially high disadvantage when accessing AAC resources. Strickland and Strickland (1996) identified many barriers that rural Black communities face in accessing healthcare services generally, such as ability to pay, service availability, accessibility of services, and the perception of racism. Living in a rural community poses challenges in terms of accessing service providers (Barley & Beesley, 2007). In addition, Black children are less likely to receive SLP services (Black, 2015; Morgan et al., 2016; Davidson et. al, 2022), including AAC intervention specifically (Pope et al., 2022).

Both rural schools and schools within any Black community are also more likely to be underfunded (Darling-Hammond, 2013), impacting the available resources to support AAC access. Research also suggests that Black families have less access to services both within and outside of the school system, compared to their white peers (Taylor & Henninger, 2015; Thomas et al., 2007), which is likely exacerbated by a rural setting. Even if children do get access to AAC systems and services, Black families report that services are less likely to be family-centered and culturally inclusive (Taylor & Henninger, 2015; Montes & Halterman, 2011; Thomas et al., 2007). AAC systems are also unlikely to reflect the cultural and linguistic features of rural Black families without adaptation (Kulkarni & Parmar, 2017; Soto, 2012). Given the

compounded potential barriers to AAC intervention for children with complex communication needs living in rural Black communities, it is critical to better conceptualize what access to AAC systems and services looks like for this population.

The Current Study

Minimal research exists addressing inequities in access to AAC, and no published studies focus on inequities in access to AAC supports and services based on the intersection of race and geographic location. To fill this gap, the current study aims to investigate whether race and geographical location are associated with AAC access. A nationwide electronic survey was used to collect relevant demographic information and information regarding AAC supports and services for children with complex communication needs age 18 and under in the United States. The goal of this research is to identify disparities that are affecting AAC access for populations based on race and geographical location and identify potential next steps that can assist members of underrepresented communities in accessing critical AAC supports and services to promote equitable communication outcomes.

The current study addressed the following research questions: 1) How are race and rural living status associated with AAC access for children with disabilities and complex communication needs age 18 and under in the United States?; and (2) How are race and rural living status associated with caregivers' perceptions of the cultural appropriateness and cultural responsiveness of AAC systems and services?

It is hypothesized that Black[1] families residing in rural areas will have the most difficulty accessing AAC systems and services for their children with complex communication needs. Across all respondents, those living in rural areas are expected to report more difficulty

[1] Black or African American was a choice given in the demographics section of the survey. Black will be used to refer to all participants who selected this identity category throughout the manuscript.

accessing AAC supports (regardless of race), and those identifying as Black/African American are also expected to report greater challenges (regardless of rural living status). It is also hypothesized that rural Black participants will be the most likely to report that their child's AAC systems and services are not culturally appropriate or responsive. Similarly, Black families across geographic locations are expected to report less culturally appropriate and responsive AAC, as well as rural living participants across racial groups.

Figure 1 The Literature Puzzle

Methods

Participants

After receiving Institutional Review Board approval, caregivers and parents of children who use AAC or could benefit from AAC supports were recruited from across the United States. To be eligible, caregivers needed to meet the following inclusion criteria: (a) be a primary caregiver of a child who uses AAC supports or could benefit from AAC supports; (b) 18 years of age or older; (c) English language skills to participate in a written survey; (d) access to a mobile device or computer and internet connection to complete the online survey; (e) living in the United States. Children of participating caregivers were: (a) 18 years of age or younger and (b) had a developmental or acquired disability (e.g., autism, cerebral palsy, Down syndrome, a genetic disorder, a traumatic brain injury, etc.) that impacted their ability to meet all of their communication needs via speech. Caregivers were allowed to participate even if their child did not have access to an AAC system but could benefit from one. Exclusionary criteria included: (a) caregivers of Deaf children who did not also have a developmental/acquired disability and (b) caregivers who lived outside of the United States. To address the specific research questions, survey response data was extracted only for participants who identified as either white or Black.

Procedures

Participating caregivers were recruited through various methods. Recruitment flyers were distributed electronically with QR Codes and direct links to the survey. The survey was distributed through online caregiver forums that focused on populations who may have benefited from AAC (e.g., autism parent forums, Down syndrome parent forums), with permission from group moderators. The survey was also distributed to professionals via relevant American Speech-Language-Hearing Association (ASHA) Special Interest Groups (SIGs), with the aim of

redistribution to caregivers. The survey was accessible online through a secure survey system (Qualtrics), accessible through a QR Code or direct link. No identifiable information was collected, only basic demographic information describing participating caregivers and their child, and their child's communication needs and journey.

Survey data were extracted for participants that reported to be Black or African American or white. Participants' survey responses from Qualtrics were converted to an excel spreadsheet and saved on a secured drive. Black participants were considered to be participants who selected Black or African American only for their own or their child's racial/ethnic identity, or who selected Black or African American and up to one additional racial/ethnic category for their own or their child's racial/ethnic identity, indicating that they and/or their child is/are biracial (including Black or African American identity). The only exclusion was participants who selected both Black or African American and white (these participants were not included in analyses). White participants were participants that selected white only for both their child's racial/ethnic identity and their own racial/ethnic identity. Participant racial identity was operationalized in this manner to account for how the lived experience of either the caregiver and/or the child in each participant dyad might have impacted access to AAC services or perceived cultural appropriateness of AAC systems or services.

Next, each participant from the subset of Black and white participants was classified as urban or rural. Each participant's self-reported zip code was entered into the *Am I Rural?* federal database (https://www.ruralhealthinfo.org/am-i-rural) to indicate whether they resided in a rural or urban area. Information from the section, *Core Based Statistical Areas (CBSAs), 2023* on the *Am I Rural?* database served as the determiner of whether the participant resided in a rural or urban area. This section provided the most up to date (2023) rural living status data and had a

distinguisher system to determine whether the zip code was in an urban or rural area – *Micropolitan* and *Metropolitan* were each considered urban areas while *Rural* only meant rural. Only a few discrepancies (<5) were noted when comparing the *Am I Rural?* classifications to self-reported data of participants regarding whether they considered themselves to live in an urban or rural area (Areas with fewer than 5,000 residents), suggesting self-report data may be a viable method for classifying rural living status. Incomplete survey responses (i.e. incomplete demographics) were removed from the overall data as well as irrelevant responses (i.e. spam). Two graduate students in the Speech, Language, and Hearing Sciences Department reviewed all survey responses from the extracted subset of Black and white participants, confirmed by the primary researcher.

Materials

The target survey was developed for this study to address the specific research questions (see Appendix A). Survey questions were organized into six separate sections. Section 1 collected demographic information about the caregiver ("Information about you"). Section 2 collected demographic information about the child/children who currently use or would benefit from AAC ("Information about the child who uses/would benefit from communication supports"). Section 3 collected information about the child's/children's current communication, including AAC supports ("Information about the child's communication supports"). Section 4 collected information about the steps taken to obtain the child's AAC system ("Information about obtaining the child's communication supports"). Lastly, Section 5 included open ended questions that aimed to collect information about barriers and facilitators for accessing AAC supports for their child/children, and whether they were successful in obtaining an AAC system. Prior to broad dissemination, feedback on the survey was obtained from research partners with

expertise in survey development for rural and culturally and linguistically diverse populations. The survey was also piloted with a group of caregivers from the local rural community. Feedback from both groups was used to make adjustments to survey questions or structure. Feedback included changes to some of the verbiage of the questions, inclusion and placement of the graphics, and comments regarding the open-ended questions at the end of the survey.

Culturally Responsive Services Scale

A four-question scale was developed as a part of the survey, addressing caregivers' perceptions of the cultural appropriateness of their child's AAC system, as well as whether they receive culturally responsive services. These four questions were combined into a total score from 0-8, with 0 representing low cultural appropriateness/responsiveness, and 8 reflecting high cultural appropriateness/responsiveness of AAC systems and services. The first two questions (Provider Subscale) addressed caregivers' perceptions of the cultural responsiveness of service provision: (1) How well do you feel like your child's service providers consider your culture and beliefs?; (2) How well do you feel like your child's service providers listen to your needs and concerns about your child's communication?. The second two questions addressed caregivers' perceptions of the cultural appropriateness of their child's AAC system: (3) How well does the vocabulary included in the child's communication device/support(s) reflect what you and the family talk about at home?; (4) Do you feel like the communication device/support(s) is a good reflection of yourself and/or your child? All participants answered questions 1 and 2. Only caregivers who reported that their child had access to aided AAC answered questions 3 and 4, in addition.

Data Analyses

Descriptive data were reported for participants' survey responses, broken down by race (white or Black) and geographic location (rural or urban). Given the overwhelming representation of respondents from the Deep South (Alabama, Louisiana, and Georgia), all research questions (and thus associated statistical analyses) described below were explored in both (a) the national dataset, as well (b) the subset of respondents from the Deep South. The Deep South is a southeastern region of the United States characterized by disparities such as lower socioeconomic status and limited access to healthcare, resulting in poorer health outcomes (Pisu et al., 2022). According to Pisu et al. (2022), this region comprises Alabama, Georgia, Louisiana, Mississippi, and South Carolina. Knuckey (2016) argues that eastern Texas and the Florida Panhandle should also be included; however, Pisu et al. (2022) emphasize that the aforementioned states exhibit characteristics most associated with the Deep South's historical and socioeconomic reputation. For analysis, survey responses from Alabama, Louisiana, and Georgia were used to construct a Deep South dataset (there were no survey responses from Mississippi or South Carolina). Research Question 1 (How are race and rural living status associated with AAC access for children with disabilities and complex communication needs age 18 and under in the United States?) was addressed using two separate analyses. First, logistic regression was used to look at the impact of geographic location (rural vs. urban) and race (Black vs. white) on whether or not children had access to a high tech AAC system and/or a low tech AAC system. From those participants whose child did have access to an aided AAC system, a separate multiple linear regression model investigated the impact of geographic location and race on age of first getting an aided AAC system. Additional predictor variables that may impact AAC access were also included in each model: insurance, income, education, and child

diagnosis. In addition to these regression analyses, Spearman's rank-order correlation analyses were conducted to explore the relationships between the predictor variables and AAC access outcomes, with particular attention to the roles of race and rural living status.

Research Question 2 (How are race and rural living status associated with caregivers' perceptions of the cultural appropriateness and cultural responsiveness of AAC systems and service?) was also addressed using two separate analyses – one that included only those participants who reported that their child had either a high-tech or low-tech AAC system (i.e., some form of aided AAC), and one that included all participants. Multiple linear regression analyses were used to address the predictive value of race and geographic location on caregiver's perceptions of the cultural appropriateness and cultural responsiveness of AAC systems and services. All participating caregivers answered questions 1 and 2 (Provider Subscale). A multiple linear regression analysis was run that included only participants who answered all four questions of the Culturally Responsive Services Scale (i.e., only those caregivers whose children had access to aided AAC), with the summed scale score as the outcome variable, and race, geographic location, insurance, income, education, and child diagnosis as predictor variables. A separate multiple linear regression analysis was run that included all participants for the Provider Subscale (questions 1 and 2 on the scale), with the scores for this subscale as the outcome variable, and race, geographic location, insurance, income, education, child diagnosis, and access to aided AAC as predictor variables. In addition, Spearman's rank-order correlation analyses were conducted to explore any relationships between predictor variables and caregiver-reported perceptions of cultural appropriateness and responsiveness of AAC systems and services, with particular focus on the roles of race and rural living status.

Results

A total of 499 caregivers completed the online study survey. The survey was disseminated through various channels, including Facebook Groups targeting SLPs and caregivers, ASHA Special Interest Groups (SIGs), email, word-of-mouth, and printed flyers. Among these methods, Facebook Groups proved to be the most effective, allowing the survey to reach hundreds of individuals simultaneously, particularly those engaged in discussions related to AAC, specific diagnoses, and targeted recruitment efforts. This conclusion is supported by participant responses indicating how they learned about the survey. Of those 499 participants, 418 were categorized as white or Black child-caregiver dyads. Of those 418 respondents, 116 were removed as a result of being either incomplete (only demographic information included) or showing evidence of not being valid survey responses (e.g., fill-in-the-blank questions were random number or letter strings). The remaining 302 survey responses from Black or white caregiver-child dyads were included in the following analyses. Table 1 includes demographic information of all caregivers of the national data set who completed the survey, and Table 2 includes demographic information of their children of the national data set who would benefit from AAC. Table 3 includes demographic information of all caregivers of the Deep South data set, and Table 4 includes demographic information of the children in the Deep South data set. Figure 1 represents the distribution of participants across the United States.

The main predictor variables of interest in this study were race and rural living status. However, additional variables collected from survey respondents were also considered to have possible predictive value related to access to aided AAC, age of first aided AAC system, and/or degree of culturally responsive services, and thus were also included in regression models (e.g., income, education, insurance, child diagnosis).

Rural living status did not have any significant predictive power related to access to aided AAC, and age of first AAC supports in the regression model; however, Spearman correlational analyses indicated that rural living status may be associated with higher perceptions of culturally responsive services. Race emerged as a significant predictor in the Deep South data subset, with Black caregivers reporting significantly less access to aided AAC for their children than white caregivers. The following sections address results of statistical analyses related to each research question.

Table 1

National Dataset Caregiver Demographics

	Race	
	Black (32)	White (270)
Rural Living Status		
Urban	24 (75%)	242 (90%)
Rural	8 (25%)	28 (10%)
Education		
High School	6 (19%)	8 (30%)
Some College	8 (25%)	52 (19%)
Bachelors	8 (25%)	93 (34%)
Graduate	10 (31%)	115 (43%)
Income		
Less than $30,000	5 (16%)	11 (4%)
$30,000-$65,000	12 (38%)	41 (15%)
$65,001-$85,000	5 (16%)	141 (52%)
$85,001-$100,000	3 (9%)	50 (19%)
Greater than $100,000	7 (22%)	26 (10%)
Access to AAC		
Yes	23 (72%)	217 (80%)
No	9 (28%)	53(20%)

Table 2

National Dataset Child Demographics

	Race	
	Black (32)	White (270)
Age		
1 to 5	15 (47%)	76 (28%)
6 to 10	8 (25%)	108 (40%)
11 to 15	4 (13%)	68 (25%)
15 to 18	3 (9%)	18 (7%)
Diagnosis		
Autism	19 (59%)	148 (55%)
Cerebral Palsy	3 (9%)	15 (6%)
Down Syndrome	2 (6%)	9 (3%)
Genetic	0 (0%)	8 (3%)
Multiple Disabilities	2 (6%)	17 (6%)
Traumatic Brain Injury	0 (0%)	8 (3%)
General Developmental Disability/Delay	0 (0%)	8 (3%)
Access to Aided AAC		
Yes	23 (72%)	217 (80%)
No	9 (28%)	53 (20%)
Age of First Aided AAC		
1 to 5	10 (31%)	101 (34%)
6 to 10	4 (13%)	93 (34%)
11 to 15	1 (3%)	12 (4%)
15 to 18	2 (6%)	12 (4%)

Table 3

Deep South Caregiver Demographics

	Race	
	Black (10)	White (186)
Rural Living Status		
Urban	7 (70%)	169 (90%)
Rural	3 (30%)	17 (10%)
Education		
High School	1 (11%)	2 (1%)
Some College	4 (44%)	16 (9%)
Bachelors	1 (11%)	66 (36%)
Graduate	4 (33%)	100 (55%)
Income		
Less than $30,000	2(20%)	4 (2%)
$30,000-$65,000	3 (30%)	27 (15%)
$65,001-$85,000	2 (20%)	117 (63%)
$85,001-$100,000	2 (20%)	30 (16%)
Greater than $100,000	0 (0%)	7 (4%)
Access to AAC		
Yes	23 (72%)	217 (80%)
No	9 (28%)	53(20%)

Table 4

Deep South Child Demographics

	Race	
	Black (10)	White (186)
Age		
1 to 5	6 (60%)	44 (24%)
6 to 10	2 (20%)	82 (44%)
11 to 15	1 (10%)	45 (24%)
15 to 18	1 (10%)	14 (8%)
Diagnosis		
Autism	8 (80%)	106 (57%)
Cerebral Palsy	0 (0%)	14 (8%)
Down Syndrome	0 (0%)	7 (4%)
Genetic	0 (0%)	5 (3%)
Multiple Disabilities	0 (0%)	17 (9%)
Traumatic Brain Injury	0 (0%)	6 (3%)
General Developmental Disability/Delay	0 (0%)	8 (4%)
Access to Aided AAC		
Yes	4 (40%)	149 (80%)
No	5 (50%)	36 (19%)
Age of First Aided AAC		
1 to 5	3 (30%)	63 (34%)
6 to 10	0 (0%)	74 (40%)
11 to 15	0 (0%)	7 (4%)
15 to 18	0 (0%)	4 (2%)

Figure 2

Map of Survey Participants

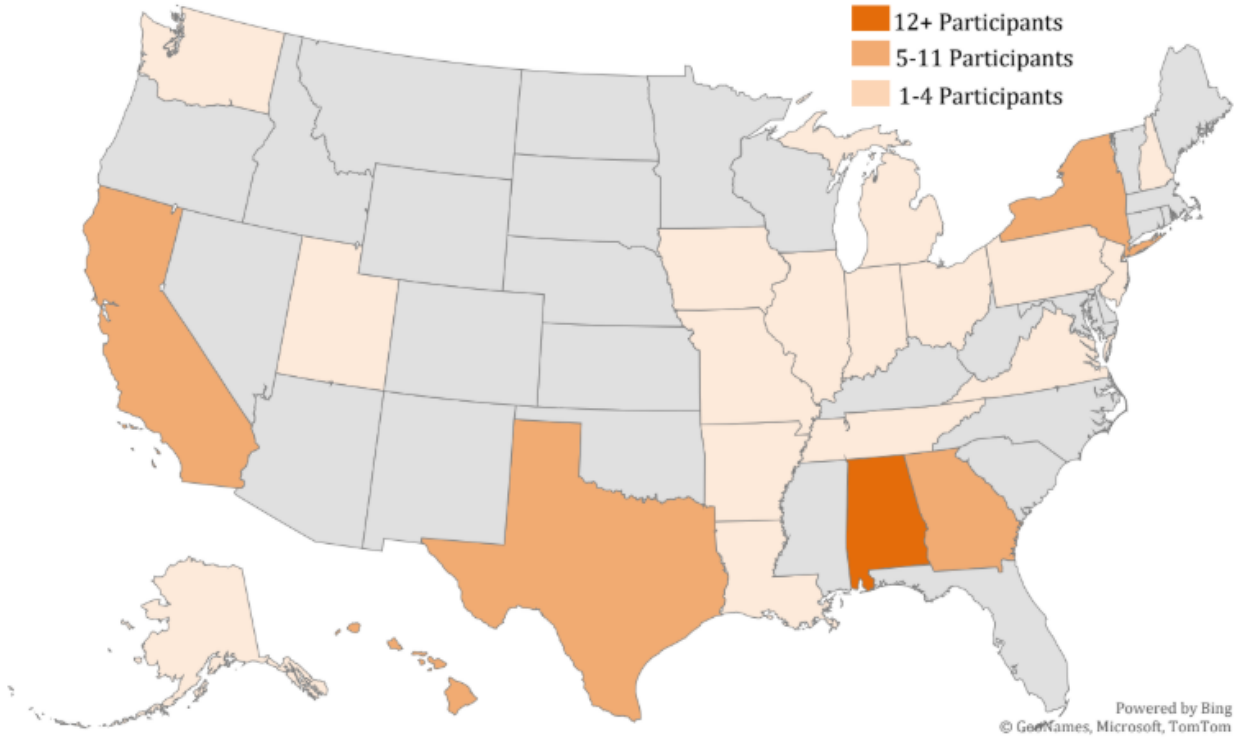

Table 5

Number of Participating Caregivers by State

State	Number of Participants
Alabama	168
Arkansas	1
Alaska	1
Florida	2
Georgia	12
Illinois	2
Indiana	3
Iowa	1
Kansas	1
Kentucky	1
Louisiana	2
Maryland	2
Michigan	1
Minnesota	1
Missouri	4
New York	15
North Carolina	3
Ohio	3
Pennsylvania	4
Tennessee	4
Texas	9
Utah	1
Virginia	6
Washington	6
West Virginia	2
Wyoming	1

Correlation Results

Spearman rank correlations were run to explore any relationships between the following variables in both the national dataset and Deep South data subset: race, rural living status, income, education level, insurance, child diagnosis, child access to aided AAC, and culturally responsive providers and overall services.

National Dataset

In the national dataset, race was correlated with: (1) education level, with Black participants being more likely than white participants to have a terminal high school degree ($r_s(300) = .231$, $p < 0.000$); and (2) health insurance, with Black participants being more likely than white participants to have private only health insurance ($r_s(300) = .134$, $p = 0.020$). Thus, Black participants were more likely to be less educated than white participants, and to rely solely on private health insurance.

Rural living status was correlated with: (1) education level, with rural participants being more likely than urban participants to have a terminal high school degree ($r_s(300) = .14$, $p = 0.017$) or some college ($r_s(300) = .2$, $p = 0.007$), and urban participants being more likely to have a graduate degree ($r_s(300) = -.1$, $p = 0.042$); (2) diagnosis, with rural participants' children being more likely to have a general developmental disorder/delay than urban participants' children ($r_s(299) = .2$, $p = 0.005$); and (3) culturally responsive services, with rural participants being more likely to report culturally responsive providers ($r_s(296) = .2$, $p = 0.008$) and overall service provision ($r_s(238) = .15$, $p = 0.021$) than urban participants. Similar to Black participants generally, rural participants were also more likely to be less educated, compared to urban participants. Rural children were also more likely to have received a less specific diagnosis (e.g., general developmental disorder) than urban children. However, rural participants perceived their

children's services and service providers to be more culturally responsive than urban participants.

Culturally responsive services was correlated with: (1) income, with higher income participants reporting more culturally responsive providers ($r_s(295) = .2$, $p = 0.003$) and overall services ($r_s(237) = .2$, $p = 0.008$) than lower income participants; (2) education, with participants with terminal high school degrees being more likely to report culturally responsive providers ($r_s(296) = .12$, $p = 0.041$); (3) diagnosis, with participants whose children had TBIs reporting more culturally responsive providers ($r_s(295) = .2$, $p = 0.008$) and overall services ($r_s(238) = .16$, $p = 0.013$); and (4) access to any AAC, with participants whose children had access to AAC reporting more culturally responsive providers than those whose children did not have access to AAC ($r_s(296) = .193$, $p = 0.001$). Higher income participants and participants with a terminal high school degree indicated a higher perception of culturally responsive providers. Individuals with TBI reported greater cultural responsiveness from both providers and services. Additionally, caregivers of children with access to AAC systems reported more culturally responsive providers compared to those without AAC access.

Participants' children having access to any form of aided AAC was correlated with: (1) education, with children of participants with a graduate degree being more likely to have access to AAC ($r_s(296) = .16$, $p = 0.007$); (2) insurance coverage, with the children of participants with both private and government insurance being more likely to have access to AAC ($r_s(296) = .13$, $p = 0.02$); and (3) diagnosis, with children on the autism spectrum being more likely to have access to AAC ($r_s(295) = .140$, $p = 0.010$) and children with a general developmental disorder/delay being less likely to have access to AAC ($r_s(295) = -.15$, $p = 0.012$). The children of caregivers who were more educated, held multiple forms of insurance coverage, and whose children had a

diagnosis of autism was more likely to have access to AAC systems and supports. However, the opposite was true for participants' children that had a general developmental disorder/delay, where they were less likely to receive supports.

Deep South Data Subset

In the Deep South subset of the dataset, race was correlated with: (1) education level, with Black participants being more likely than white participants to have a terminal high school degree ($r_s(195) = .150$, $p = 0.035$) or some college ($r_s(195) = .22$, $p = 0.002$) ; and (2) access to any AAC, with children of Black participants being less likely than children of white participants to have access to any AAC supports ($r_s(193) = -.165$, $p = 0.021$). The analysis indicated that Black participants were more likely to have a high school degree or some college experience. As for access to AAC, the correlation analysis revealed that Black participants are less likely to have any access to AAC supports.

Rural living status was correlated with: (1) diagnosis, with rural participants' children being less likely to have an autism diagnosis than urban participants' children ($r_s(195) = .165$, $p = 0.020$) and more likely to have a diagnosis of general developmental disability/delay ($r_s(195) = .205$, $p = 0.004$) ; and (3) culturally responsive services, with rural participants being more likely to report culturally responsive providers ($r_s(193) = .172$, $p = 0.016$) than urban participants. Rural living status significantly correlated with child diagnosis, with rural children being less likely to have a specific diagnosis such as autism and more likely to have a less specific diagnosis such as a general developmental disability/delay. Rural participants were also more likely to report culturally responsive providers.

Culturally responsive services was also correlated with: (1) income, with higher income participants reporting more culturally responsive providers ($r_s192) = .178$, $p = 0.013$) and overall

services ($r_s(151) = .214$, $p = 0.008$) than lower income participants; (2) education, with participants with terminal high school degrees ($r_s(193) = .161$, $p = 0.024$) and some college ($r_s(193) = .153$, $p = 0.032$) being more likely to report culturally responsive providers, and participants with bachelors degrees being less likely to report culturally responsive providers ($r_s(193) = -.188$, $p = 0.008$) ; (3) diagnosis, with participants whose children had CP reporting less culturally responsive providers ($r_s(193) = -.171$, $p = 0.017$), Down syndrome less culturally responsive services overall ($r_s(193) = -.161$, $p = 0.046$), and TBI reporting more culturally responsive providers ($r_s(193) = .201$, $p = 0.005$) and overall services ($r_s(193) = .216$, $p = 0.007$); and (4) access to any AAC, with participants whose children had access to AAC reporting more culturally responsive providers than those whose children did not have access to AAC ($r_s(193) = .188$, $p = 0.008$). Culturally responsiveness correlated with a higher income indicating a higher rating of culturally responsive providers. Similar to rural living status, participants with a high school degree versus other schooling and training reported culturally responsive providers. As for diagnosis, diagnoses like CP and Down syndrome reported less culturally responsive. TBI revealed more culturally responsive providers. Lastly, children with any AAC reported more culturally responsive providers than those without access to AAC.

Participants' children having access to any form of aided AAC was also correlated with: (1) education, with children of participants with a bachelor's degree being less likely to have access to AAC ($r_s(193) = -.145$, $p = 0.044$), while children of participants with a graduate degree were more likely to have access to AAC ($r_s(193) = .168$, $p = 0.019$); and (2) diagnosis, with children on the autism spectrum being more likely to have access to AAC (rs193) = .198, $p = 0.006$) and children with CP being less likely to have access to AAC ($r_s(193) = -.295$, $p < 0.001$). Access to aided AAC was correlated with education and diagnosis. Children of participants with

graduate degrees were more likely to have AAC access, while those whose parents held bachelor's degrees were less likely. Additionally, children on the autism spectrum had greater AAC access, whereas children with CP were less likely to have access. Children of caregivers with graduate degrees were more likely to have AAC access, whereas those whose caregivers held bachelor's degrees were less likely. Additionally, children diagnosed with autism were more likely to have access to AAC, while those with cerebral palsy were less likely to have such access.

Regression Results

Access to Aided AAC

A binary logistic regression model was run to determine whether the following factors predicted access to aided AAC: race, rural living status, insurance, income, education, and child diagnosis. VIF values indicated no indication of multicollinearity between predictor variables. The overall model was statistically significant ($\chi 2$ (18) = 38.7, p = 0.003) and explained 20% of the variation of access to aided AAC (Nagelkerke R^2), correctly predicting 80.5% of cases. However, only child diagnosis was statistically significant, with children on the autism spectrum being 3.14 times more likely to have an aided AAC system than children with general developmental disabilities/delay (p = 0.003).

The same analysis was replicated in the Deep South data subset to determine whether the following factors significantly predicted access to aided AAC: race, rural living status, income, education, and child diagnosis. VIF values indicated no indication of multicollinearity between predictor variables. The overall model was statistically significant ($\chi 2$ (18) = 50.97, p < 0.001) and explained 36% of the variation of access to aided AAC (Nagelkerke R^2), correctly predicting 78.9% of cases. Race was statistically significant, with Black children being slightly less likely

(0.18 times less likely) to have access to an aided AAC system (p = 0.047). Child diagnosis was also statistically significant, with children on the autism spectrum being 6.3 times more likely to have an aided AAC system than children with general developmental disabilities/delay (p < 0.001), and children with cerebral palsy being less likely than children with general developmental disabilities/delay to have access to aided AAC (p = 0.027).

Table 6

Access to Aided AAC

National Dataset						
	B	Wald	p-value	Exp(B)	95% CI	
Autism	1.145	9.135	.003	3.142	1.495	6.601
Deep South Data Subset	B	Wald	p-value		95% CI	
Race	-1.737	3.953	.047	.176	.032	.976
Autism	1.840	11.949	<.001	6.298	2.218	17.880
Cerebral Palsy	-1.586	4.875	.027	.205	.050	.837

Age of First Aided AAC Supports

A multiple linear regression model was run in the national dataset to determine whether the following factors significantly predicted age of first aided AAC supports: race, rural living status, insurance, income, education, and child diagnosis. The age of first aided AAC supports was the age that participating caregiver reported that their child was initially provided with an aided AAC system (e.g., 3 years old), measured as a continuous variable. VIF values indicated no indication of multicollinearity between predictor variables. The overall model was statistically significant, F (15, 209) = 2.62, p < 0.001, R2 = 0.16. Higher income (t = -2.95, p = 0.004) and having any type of insurance (private: t = -2.26, p = 0.025; government: t = -2.44, p = 0.016; private and government: t = -1.95, p = 0.053) were associated with an earlier age of initial access to aided AAC supports. Child diagnosis was also statistically significant, with children with general developmental disability/delay associated with an earlier age of initial access to aided

AAC supports than children with TBI ($t = 3.0$, $p = 0.003$) or multiple disabilities ($t = 2.06$, $p = 0.04$). Education level was also associated with age of first aided AAC supports, with a higher education level related to later access to aided AAC (all compared to high school education level - some college: $t = 2.61$, $p = 0.01$; bachelor's degree: $t = 2.47$, $p = 0.014$; graduate degree: $t = 3.18$, $p = 0.002$).

The same analysis was replicated in the Deep South data subset to determine whether the following factors significantly predicted age of first aided AAC supports: race, rural living status, insurance, income, education, and child diagnosis. VIF values indicated no indication of multicollinearity between predictor variables. The overall model was statistically significant, $F(15, 135) = 3.12$, $p < 0.001$, $R2 = 0.26$, with similar patterns in the predictor variables. Having any type of insurance (private: $t = -2.6$, $p = 0.01$; government: $t = -2.81$, $p = 0.16$; private and government: $t = -2.55$, $p = 0.012$) was associated with an earlier age of initial access to aided AAC supports. Child diagnosis was also statistically significant, with children with TBI having later initial access to aided AAC supports than children with autism ($t = -2.4$, $p = 0.018$), Down syndrome ($t = -3.89$, $p < 0.001$), or general developmental disability/delay ($t = -2.82$, $p = 0.006$). Higher income and education level approached significance, again with higher income associated with earlier access to aided AAC ($t = -2.95$, $p = 0.004$) but higher education associated with later access to aided AAC (compared to high school education level - graduate degree: $t = 1.85$, $p = 0.068$).

Table 7

Age of First AAC Supports

National Dataset					
	B	t	p-value	95 % CI	
Income	-.672	-2.951	.004	-1.121	-.223
Some College	3.207	2.612	.010	.787	5.627
Bachelors	3.038	2.472	.014	.615	5.460
Graduate	3.853	3.176	.002	1.462	6.245
Private Only	-2.785	-2.264	.025	-5.210	-.360
Government Only	-2.880	-2.437	.016	-5.210	-.551
Private + Government	-2.302	-1.945	.053[+]	-4.634	.031
Multiple Disabilities	2.543	2.064	.040	.114	4.972
TBI	3.549	2.999	.003	1.217	5.882
Deep South Data Subset	B	t	p-value	95 % CI	
Income	-.577	-1.836	.068[+]	-1.199	.044
Graduate	3.301	1.852	.066[+]	-.223	6.825
Private Only	-8.461	-2.603	.010	-14.889	-2.033
Government Only	-9.109	-2.809	.006	-15.521	-2.697
Private + Government	-8.309	-2.550	.012	-14.752	-1.865

[+]Approaching statistical significance at alpha = 0.05

Culturally Responsive Services Scale

A multiple linear regression model was run in the national dataset to determine whether the following factors significantly predicted caregiver's reported access to culturally responsive services: race, rural living status, insurance, income, education, and child diagnosis. VIF values indicated no indication of multicollinearity between predictor variables. The overall model was statistically significant, F (16, 222) = 1.72, p = 0.045, R2 = 0.11. Higher income was associated with reporting more culturally responsive services (t = 2.48, p = 0.014), whereas higher education was associated with less culturally responsive services (all compared to high school education level - bachelor's: t = -2.46, p = 0.015; graduate: t = -1.93, p = 0.055). Child diagnosis was also statistically significant, with caregivers of children with TBI reporting more culturally responsive services than caregivers of children with cerebral palsy (t = -2.34, p = 0.02), Down

syndrome ($t = -2.79$, $p = 0.006$), general developmental disability/delay ($t = -2.36$, $p = 0.019$), and on the autism spectrum ($t = -2.91$, $p = 0.004$).

Only caregivers whose children had access to aided AAC completed all sections of the culturally responsive services scale, as the full scale included questions about the cultural appropriateness of their child's aided AAC system's symbol representation and vocabulary. However, all participating caregivers were able to complete the service provider subscale of the culturally responsive services scale. The same model was run with just the culturally responsive services – provider subscale as the outcome variable, with the addition of access to aided AAC as another predictor variable. VIF values indicated no indication of multicollinearity between predictor variables.

The overall model was statistically significant, $F(15, 280) = 3.3$, $p < 0.001$, $R2 = 0.15$, with similar patterns in terms of significant predictors. Higher income was associated with reporting more culturally responsive providers ($t = 2.94$, $p = 0.004$), whereas higher education was associated with less culturally responsive providers (all compared to high school education level - some college: $t = -2.38$, $p = 0.018$; bachelor's: $t = -4.22$, $p < 0.001$; graduate: $t = -3.26$, $p = 0.001$). Child diagnosis was also statistically significant, with caregivers of children with TBI reporting more culturally responsive services than caregivers of children with cerebral palsy ($t = -3.59$, $p < 0.001$), Down syndrome ($t = -3.43$, $p < 0.001$), general developmental disability/delay ($t = -3.65$, $p < 0.001$), genetic disorders ($t = -2.01$, $p = 0.045$), multiple disabilities ($t = -3.05$, $p = 0.003$), or on the autism spectrum ($t = -3.51$, $p < 0.001$). Access to aided AAC was an additional significant predictor of caregivers' perspectives on culturally responsive providers, with access to an aided AAC system associated with greater perceptions of providers' culturally responsive practice ($t = 2.93$, $p = 0.004$).

The same analyses were replicated in the Deep South data subset to determine whether the following factors significantly predicted caregiver's reported access to culturally responsive services: race, rural living status, insurance, income, education, and child diagnosis. VIF values indicated no indication of multicollinearity between predictor variables. The overall model was statistically significant, $F(16, 136) = 2.04$, $p = 0.015$, $R2 = 0.19$, with similar patterns in the predictor variables. Higher income was associated with reporting more culturally responsive services ($t = 2.48$, $p = 0.014$). Child diagnosis was also statistically significant, with caregivers of children with TBI reporting more culturally responsive services than caregivers of children with general developmental disability/delay ($t = 2.44$, $p = 0.016$).

The model was also significant when considering only the provider subscale of the culturally responsive services scale, $F(17, 176) = 3.61$, $p < 0.001$, $R2 = 0.26$, with VIF values indicating no indication of multicollinearity between predictor variables. Again, higher income was associated with reporting more culturally responsive providers ($t = 2.26$, $p = 0.025$), whereas higher education was associated with less culturally responsive providers (all compared to high school education level - some college: $t = -2.31$, $p = 0.022$; bachelor's degree: $t = -4.11$, $p < 0.001$; graduate degree: $t = -3.79$, $p < 0.001$). Child diagnosis was also statistically significant, with caregivers of children with TBI reporting more culturally responsive services than caregivers of children with cerebral palsy ($t = -3.18$, $p = 002$), Down syndrome ($t = -3.21$, $p = 0.002$), multiple disabilities ($t = -3.31$, $p = 0.001$), general developmental disability/delay ($t = -3.55$, $p < 0.001$), or on the autism spectrum ($t = -3.84$, $p < 0.001$). Access to aided AAC trended in the same direction as in the national sample, with children with access to aided AAC trending toward their caregivers reporting significantly greater culturally responsive providers ($t = 1.71$, $p = 0.09$).

Table 8

Culturally Responsive Services Scale

National Dataset					
	B	t	p-value	95 % CI	
Income	.247	2.476	.014	.050	.444
Bachelors	-1.174	-2.458	.015	-2.115	-.233
Graduate	-.907	-1.928	.055[+]	-1.834	.020
Cerebral Palsy	-1.602	-2.337	.020	-2.952	-.251
Down Syndrome	-1.830	-2.788	.006	-3.123	-.537
General Dev. Disability	-1.221	-2.363	.019	-2.240	-.203
Autism	-1.434	-2.909	.004	-2.406	-.463
Provider Subscale					
Access to Aided AAC	.747	2.928	.004	.245	1.249
Income	.161	2.942	.004	.053	.268
Some College	-.602	-2.380	.018	-1.099	-.104
Bachelors	-1.049	-4.217	<.001	-1.538	-.559
Graduate	-.801	-3.255	.001	-1.285	-.316
Cerebral Palsy	-1.187	-3.589	<.001	-1.838	-.536
Down Syndrome	-1.266	-3.430	<.001	-1.993	-.539
General Dev. Disability	-1.015	-3.651	<.001	-1.562	-.468
Autism	-.946	-3.506	<.001	-1.478	-.415
Genetic Disorders	-.676	-2.009	.045	-1.337	-.014
Multiple Disabilities	-1.207	-3.046	.003	-1.987	-.427
Deep South Data Subset	B	t	p-value	95 % CI	
Income	.370	2.534	.012	.081	.658
TBI	1.253	2.439	.016	.237	2.269
Provider Subscale					
Income	.167	2.264	.025	.021	.312
Some College	-.917	-2.312	.022	-1.699	-.134
Bachelors	-1.56	-4.113	<.001	-2.31	-.81
Graduate	-1.43	-3.79	<.001	-2.18	-.69
Cerebral Palsy	-1.021	-3.176	.002	-1.655	-.386
Down Syndrome	-1.180	-3.209	.002	-1.905	-.454
General Dev. Disability	-.909	-3.545	<.001	-1.415	-.403
Autism	-.925	-3.840	<.001	-1.401	-.450
Multiple Disabilities	-1.533	-3.314	.001	-2.447	-.620

[+]Approaching statistical significance at alpha = 0.05

Discussion

Much of the existing research examining the intersection of demographic factors, such as race and rural living status, with access to clinical services was conducted over a decade ago, highlighting a significant gap in the literature. Additionally, this appears to be the first study to examine both race and rural living status in relation to AAC access specifically. The study also provides a unique contribution by assessing how families perceived the cultural relevance of the services they received, as well as the extent to which their children's AAC systems reflected their cultural background, lived experiences, and daily needs.

The current study hypothesized that Black families living in rural areas would face the greatest challenges in accessing AAC systems and services and would also be more likely to perceive AAC systems and services as lacking cultural appropriateness and responsiveness. The results of this survey indicated that in the full national dataset and the Deep South data subset, rural living status was correlated with higher perceptions of culturally responsive services compared to urban participants, though rural living status was not a significant predictor of perceptions of culturally responsive services in the regression model. It is possible that if service providers in rural areas were also members of the same cultural communities as participating caregivers, they may have been more likely to have shared cultural norms, whereas in an urban area there may be more instances of service providers and families from different cultural groups. However, the current study did not collect data to directly address this possibility. There was no significant effect of rural living status on access to aided AAC or age of first aided AAC supports.

In the national dataset, there were no significant effects of race on access to aided AAC, age of first aided AAC supports, or culturally responsive services. Applying the same statistical

analyses to a Deep South subset of the data including the three represented Deep South states (Alabama, Georgia, and Louisiana) indicated that race was also not a significant predictor of perceptions of culturally responsive practice or the cultural appropriateness of aided AAC systems.

Unlike in the national dataset, Black families in the Deep South subset of the data were significantly less likely to report that their children had access to aided AAC than white families. As research and resources progress, it is still reported that despite some improvements, Black families in the U.S. continuously experience disparities in access to healthcare and receive lower-quality care, particularly in areas such as care coordination and person-centered care (Mendes, 2016). These disparities have also been noted in access to AAC intervention services specifically (Pope et al., 2022). Factors that contribute to this ongoing trend of events are social factors such as emotional and instrumental support, institutional factors such as funding for health care providers, healthcare programs, insurance, etc., and medical hesitation in the Black community due to mistrust and the fear of the unknown risks (Mendes, 2016).

Black Families and Disparities in the Deep South

These factors may be intensified in the Deep South. Overall child health is significantly poorer in the Deep South as compared to the U.S. at large, and research suggests that these health disparities are exacerbated in Black communities (Davidson et. Al, 2022; Goldhagen et al., 2005) Black residents in rural areas of the Deep South identify barriers to their health at multiple levels (individual, interpersonal, environmental, structural) that align with the social determinants of health, or the environments in which people work and live (Scott & Wilson, 2011). Lack of access to healthy foods and well-paying jobs, difficulty engaging in preventative health activities, educational systems that discourage advanced education, difficulty accessing quality

healthcare and implicit racism in health service provision have all been identified as substantial barriers to health in rural Black communities (Scott & Wilson, 2011).

Racial disparities for Black communities in the Deep South may be more compounded than in other parts of the U.S. in part as a result of the legacy of slavery (Reece & O'Connell, 2016). For example, educational disparities based on race at the county level in the Deep South have been tied to the history of slavery in those counties, and disinvestment in the public education system that disenfranchises Black students (Reece & O'Connell, 2016). Systemic racism in the U.S. is prevalent across domains that affect the social determinants of health, including healthcare access, housing, law enforcement, child welfare, etc. (Hayes-Greene & Love, 2018). Given the unique historical context of the Deep South, disparities across domains tied to systemic racism may be greater than in other areas of the U.S. – including in access to aided AAC. However, it is also important to note that the Deep South was disproportionately represented within the national dataset in this study, compared to other regions of the U.S. It is possible that variation in overall healthcare and education access across regions in the U.S. may have obscured similar trends in race-based inequity of access to aided AAC within other subregions of the U.S.

Autism and Access to AAC

The significant impact of other included predictor variables on access to aided AAC generally aligns with other expected disparities in healthcare more generally. Firstly, the results of this study indicated that children on the autism spectrum yielded a greater rate of access to aided AAC than children with other diagnoses that were self-reported within the survey. This is likely due in part to both provider perceptions and awareness related to AAC for children on the autism spectrum, as well as expanded health insurance benefits families of children on the autism

spectrum may be able to receive once a diagnosis is obtained (Donato et al., 2018). SLPs may be less knowledgeable about AAC and how it can be used for diagnoses other than autism since many AAC intervention programs are structured for children on the autism spectrum specifically, such as the Picture Exchange Communication System (PECS) or Language Acquisition through Motor Planning (LAMP). Children with a diagnosis of autism may have greater access to insurance coverage for therapeutic services than children with other disabilities, due to targeted state insurance mandates (Barry et al., 2017). Insurance plays a critical role by providing financial support for diagnostic evaluations and covering the costs of therapy sessions that may be recommended following a diagnosis. Insurance is also a key factor that offsets some of the cost to obtain aided AAC. Thus, an autism diagnosis may facilitate quicker access to aided AAC supports, as the benefits of these systems can be more readily substantiated to insurance providers. In contrast, children with other diagnoses may require more extensive documentation or face challenges due to less clarity about the benefits related to AAC assessment, intervention, and aided AAC device access, from the perspective of insurance companies.

Healthcare and education providers may also be more likely to consider AAC systems for children on the autism spectrum, due to how well the efficacy of aided AAC for this population is documented in the research (e.g., Ganz et al., 2012), as well as in family and provider-oriented organizations focused on autism. This relatively large body of research conducted to support why an AAC system would be beneficial for children on the autism spectrum likely provides heightened awareness amongst providers and insurance companies. Given the identified discrepancy, future research is critical to continue to document the benefits of aided AAC systems for a broader range of disabilities, as well as advocating for policy changes to improve access to all children who would benefit from aided AAC.

Income and Access to AAC and Culturally Responsive Services

Findings from this survey also demonstrated that families with higher income levels tended to access initial aided AAC supports at earlier ages for their children. This is also an unsurprising result. Being able to afford more comprehensive insurance plans to cover more of the costs such as an evaluation for an AAC system, transportation, speech-language services to start the process, etc., likely expedites the process to receiving an AAC system. In fact, participating caregivers with any form of insurance also reported significantly earlier access to aided AAC supports for their children than those without insurance coverage.

Additionally, higher income may also equip families with the power to pay out-of-pocket costs for evaluations, AAC devices, and related therapies if the insurance happens to be delayed or limited. Due to access to increased resources, families with higher incomes may also have higher levels of health literacy and awareness about AAC options, empowering them with the tools to advocate for their child at an earlier age. Partially to the aim of this study, higher levels of income may also enable families to reside in urban areas with greater access to healthcare services along with SLPs that specialize in AAC, which might be difficult for families residing in rural areas. Overall, the data from the current survey indicated that both higher income and any form of insurance provided families and their children with earlier access to initial AAC supports. Without insurance and/or additional financial resources, AAC systems may be more difficult to obtain.

These results suggest that SLPs and other service providers (e.g., pediatricians, social workers, special educators) may benefit from providing extra support and education about AAC to assist families with lower levels of income and/or without insurance coverage to receive the same care. At the school district, county, state, or federal level, specific funding sources and

policies are urgently needed to help provide targeted funding or streamlined processes for obtaining AAC devices for families in lower income brackets or without insurance. Additionally, SLPs can assist families in accessing low- or no-cost aided AAC supports (e.g., free or discounted communication applications, paper-based or "low-tech" aided AAC supports), either in lieu of or while waiting for access to more expensive AAC options (as applicable).

Higher income families also reported that they received more culturally responsive services from their providers. Caregivers with more income may have access to more (or better) resources to ensure that their child's AAC system and service provision reflects their culture and may also be privy to a better understanding of the AAC system and how it can benefit their child's communication. The specialists that higher income families can access may be more knowledgeable and well-resourced, which can better ensure prioritizing cultural responsiveness in service delivery and AAC system design. The knowledge of where and how to search for such specialists may be related to higher levels of health literacy, which equips families to advocate for culturally responsive services. The greater ability and opportunity to choose their children's providers allows families the flexibility to change providers if their needs are not being met, encouraging competition and the emphasis and higher standards of culturally responsive practices.

Interestingly, families whose children had access to aided AAC also reported interacting with more culturally responsive service providers than those whose children did not have access to aided AAC. All participating caregivers in this survey indicated that their child could benefit from communication supports. Thus, the very fact of getting access to aided AAC may reflect that those providers are more effectively considering the caregivers' perspectives on their children's communication needs than the providers of families whose children did not have

access to aided AAC. Families who have successfully secured AAC systems for their children may also be those who have the resources and health literacy to advocate for more culturally responsive services and providers. Or, conversely, some families may be elated that their child has access to some form of communication at all and may be less likely to question whether the AAC service providers considered their culture and beliefs more broadly.

Interestingly, a follow-up analysis indicated that caregivers of children with access to high-tech AAC may be more likely to report less culturally responsive services than those with low-tech AAC systems ($p = 0.071$). High-tech AAC systems are often complex, requiring more technical training and operational skill, and generally come pre-programmed with vocabulary. As a result, the technical aspects of using the device may become more of the focus, overshadowing the need to tailor and personalize the device for the individual's needs from a cultural standpoint. Given the complexity of (most) high-tech AAC systems, they may be less approachable for families to learn and navigate. High-tech systems may also be perceived to lack flexibility to cultural nuances such as language variations, dialects, or communication styles compared to low-tech systems, which are often easier to customize, and do not include voice output.

AAC manufacturers can continue to reflect on how they design high-tech AAC systems to be more user friendly and better reflect numerous cultural and linguistic backgrounds. One route may be increasing the inclusion of more culturally diverse staff and designers on the teams that create AAC systems, as well as ensuring that manufacturers pilot new systems with diverse groups. However, regardless of how a high-tech AAC system may be initially pre-programmed, it is critical that SLPs collaborate with the individual and their family to ensure that the AAC

system is personalized to reflect the identity and culture of that person and their family and community.

Education Level and Culturally Responsive Services

In contrast to the study results related to income, surprisingly, caregivers with more advanced higher education degrees were less likely to report receiving culturally responsive services than caregivers with high school degrees and also reported later access to aided AAC for their children. It is possible that caregivers with higher levels of education may have higher expectations for service quality, making them more aware of the cultural gaps in service provision, and thus their identification of their children's services being less culturally responsive. This perception of less culturally responsive service provision may result in a delay in access to aided AAC supports, if these families are less satisfied with their service providers and their recommendations, seeking out additional opinions. However, it is unclear within the current study what the exact mechanism might be for the observed relationship of more educated families reporting receiving less culturally responsive services and later access to aided AAC.

TBI and Culturally Responsive Services

Another unexpected finding was that families of children with TBIs were more likely to report receiving culturally responsive services than all other disability populations. Interestingly, TBI was the only acquired disorder explicitly included in the survey options for type of disability. These results are very preliminary, and there was no intended comparison between acquired and developmental disorders in the current survey results. However, these results may imply a potential difference in caregiver perspectives, service provider perspectives, and/or AAC system provision for children with acquired vs. developmental disabilities. One potential explanation could be that providers' services might differ based on implicit biases related to a

person's disability type, and whether intervention is focusing on habilitative (e.g., for children with developmental disabilities) or rehabilitative (e.g., for children with acquired disabilities) services. However, additional research is needed to more directly explore this question. To provide equitable care, it is critical that individuals such as healthcare providers, SLPs, special educators, etc. seek out continuing education to maintain or build their cultural responsiveness and ensure that they provide effective person- and family-centered care to all individuals and families. For SLPs, it is their duty based on the American Speech-Language-Hearing Association's (ASHA) Code of Ethics to provide equitable services (ASHA, 2016), which may include continued self-reflection on the part of the SLP, providing family-centered and culturally responsive care, identifying underlying factors of AAC service inequities in that community, and collaboration with other professionals and families to address identified inequities (Pope et al., 2022).

Pre-service preparation programs should also ensure that their curriculum addressing culturally responsive services covers multiple aspects of identity, focusing not only race and ethnicity but also ability status, geographic location, socioeconomic status, education level, and other identity characteristics (e.g., gender identity, religion, home language(s), etc.). Additionally, preservice preparation programs would benefit from increased recruitment and retention of both students and faculty from culturally and linguistically diverse backgrounds to diversify both the preservice preparation program experiences as well as the demographics of future SLP service providers.

Limitations and Future Directions

To the best of the researcher's knowledge, this study is the first to analyze the intersection of race and rural living status in relation to AAC access. Additionally, it is among

the few studies that explored caregivers' perspectives of the cultural appropriateness and responsiveness of AAC systems and services, especially in a national sample. However, this research is preliminary, and several important limitations should be acknowledged.

Only caregivers who reported themselves or their child to be white or Black were included in these analyses. This excluded possible participants that may have contributed to sample size and any other racial disparities that may have been experienced from their cultural and linguistic perspective. Future research should investigate the experiences of other underrepresented racial, ethnic, and linguistic groups in relation to AAC access.

Black participants were significantly underrepresented in the dataset compared to white participants. However, of the 302 survey participants, 11% identified as Black. In comparison, the U.S. Census estimates that approximately 13.7% of the population identifies as Black or African American. While there is a slight underrepresentation of Black participants in this study compared to Census data, the sample remains relatively reflective of national demographic trends.

Rural participants were also significantly less represented than urban participants, especially Black rural participants. The smaller sample sizes of Black and rural participants may limit the generalizability of these results and also limited the statistical power of the analyses. These discrepancies may have been related in part to the recruitment methods. Family and caregiver support groups on social media (e.g., *Facebook*) were by far the most successful recruitment methods overall for study participation. However, these social media groups may not have had similar levels of participation from Black caregivers or rural caregivers, compared to urban and white caregivers. Future research to more directly investigate the experiences of Black rural caregivers of children who would benefit from AAC should put an emphasis on venturing

into communities, visiting community centers and churches, etc. where Black rural participants may be more likely to frequent, to build rapport and trust to gain their participation in the study.

The overall sample size was a respectable number, but there were not equal numbers of participants from the multiple states reported, which contributed to the sample not being the most representative in the national data set. Contrastingly, the Deep South was overrepresented in the sample, which may have been one factor as to why the impact of race on access to aided AAC was observed in that data subset only.

Future research is vital to analyze inequities and barriers in AAC access within more representative samples, and for other underrepresented demographics. Qualitative research with Black rural caregivers and other underrepresented and underserved populations is critical to addressing inequities in AAC service delivery in this population directly. This type of future research can address specific barriers and potential supports via primary accounts by Black rural caregivers and allow for a deeper analysis. In addition, research investigating the type and frequency of therapy services children have access to is also critical. Future additional research exploring inequities in AAC services along all points of service delivery is essential to provide the American Speech-Language-Hearing Association (ASHA), SLPs, AAC manufacturers, and preservice preparation programs with a better understanding of the barriers that families experience related to AAC service delivery, which may help to reveal pertinent supports and expedite the process for families receiving supports.

Conclusion

This study was the first to examine the impact of the intersectionality of race and rural living status on AAC access and caregivers' perspectives on the cultural responsiveness of intervention services. Results from correlation analyses indicated that rural living status was associated with higher perceptions of culturally responsive services – though rural living status was not a significant predictor of perceptions of culturally response services in regression analyses. There was no significant impact of race within the national data set; however, analysis of a Deep South data subset of Alabama, Georgia, and Louisiana revealed that Black families were less likely to receive aided AAC for their children compared to their white peers. In addition, other significant demographic factors (e.g., income, insurance, child diagnosis, education level) on both access to aided AAC and culturally responsive services suggest the critical need to address a variety of barriers to AAC intervention.

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Appendix

Survey

This survey is for family members/caregivers/parents who have **children 18 years old or younger who use communication supports or would benefit from communication supports**, related to having a developmental or acquired disability (e.g., autism, cerebral palsy, Down syndrome, a genetic disorder, a traumatic brain injury, etc.).

Children who would benefit from communication supports are unable to communicate like typical children their same age using speech (e.g., they may be nonverbal, have minimal speech, have speech that is very hard to understand for unfamiliar people, only be able to communicate a small number of words/phrases using speech).

This survey is **NOT** intended for family members/caregivers/parents of Deaf children *without* developmental/acquired disabilities who communicate using sign language.

Examples of communication supports (your child's communication supports may look **different**)



Information about YOU (person completing this survey)

1. How old are you?
   a. (open response box)
2. Which category or categories describe you? (Check All that Apply)
   a. American Indian or Alaska Native
   b. Asian
   c. Black or African American
   d. Hispanic, Latino, or Spanish Origin
   e. Middle Eastern or North African
   f. Native Hawaiian or Pacific Islander
   g. White
   h. Multiethnic
   i. Other

3. What state do you live in?
    a. (drop down menu of all state names)
4. What is your zip code?
    a. (open response box)
5. How would you describe the area you live in?
    a. rural (Areas with fewer than 5,000 residents)
    b. urban (Areas with 5,000+ residents)
6. What is the average yearly income of your household?
    a. Less than $30,000
    b. $30,000$-65,000
    c. $65,001-$85,000
    d. $85,001-$100,000
    e. Greater than $100,000
7. What is your current occupation?
    a. (open response box)
8. What is your highest level of education or level of school you have completed?
    a. Less than high school diploma
    b. High school diploma or GED
    c. Some college, but no degree
    d. Associates Degree (eg. AA, AS)
    e. Bachelor's Degree (eg. BA, BBA,BS, etc.)
    f. Master's Degree (eg. MA, MS, etc.)
    g. Professional Degree (eg. MD, DDS, JD)
    h. Doctorate (eg. PhD, EdD, etc.)
9. What type of insurance do you have? (Check All that Apply)
    a. Private insurance (e.g., Blue Cross/ Blue Shield, UnitedHealthCare, Aetna)
    b. Medicaid
    c. Medicare
    d. Other government insurance (e.g., TriCare, VHA)
    e. None
    f. Other (open response box)
10. Who lives at home as a part of the family?
    a. Mother
    b. Father
    c. Sister
    d. Brother
    e. Grandparent/Grandparents
    f. Cousins
    g. Aunt/ Uncle
    h. Friends

i. Other (open response box)

11. How many children are there in the home?
    a. 1
    b. 2
    c. 3
    d. 4
    e. 5+
12. How many children in your household use/would benefit from communication supports?
    a. 1
    b. 2
    c. 3
    d. 4

Information about the CHILD WHO USES/WOULD BENEFIT FROM COMMUNICATION SUPPORTS

1. What is your relationship to the child who uses/would benefit from communication supports?
    a. Parent
    b. Grandparent
    c. Sibling
    d. Foster parent
    e. Legal guardian
    f. Other (open response box)
2. How old is the child?
    a. (open response box)
3. Which category or categories describe the child? (Check All that Apply)
    a. American Indian or Alaska Native
    b. Asian
    c. Black or African American
    d. Hispanic, Latino, or Spanish Origin
    e. Middle Eastern or North African
    f. Native Hawaiian or Pacific Islander
    g. White
    h. Multiethnic
    i. Other
4. What is the diagnosis of the child? (select more than one if applicable)
    a. Autism
    b. Down syndrome
    c. Cerebral Palsy
    d. General developmental disability/delay (unrelated to another diagnosis)

    e. Genetic disorder
    f. Traumatic brain injury
    g. Other (open response box)
5. At what age did the child receive this diagnosis?
    a. (open response box)
6. Does the child have any visual impairments? (Check All that Apply)
    a. No visual impairments
    b. Low vision
    c. Blind
    d. Cortical visual impairment (CVI)
    e. Other (open response box)
7. Does the child have any hearing impairments?
    a. No hearing impairments
    b. Hard of hearing
    c. Deaf
    d. Other (open response box)
8. Does the child use any mobility supports because of motor impairments? (Check All that Apply)
    a. No motor impairments
    b. Wheelchair
    c. Stander
    d. Other (open response box)
9. What are the current services the child receives?
    a. Speech-Language Therapy
    b. Occupational Therapy
    c. Physical Therapy
    d. ABA/RBT
    e. Other (open response box)
10. Where does the child receive [Speech-Language Therapy?] (Check All that Apply)
    a. Early Intervention
        i. How much time does it take to travel here? (open response box)
    b. School
        i. How much time does it take to travel here? (open response box)
    c. Private therapy clinic
        i. How much time does it take to travel here? (open response box)
    d. Telepractice
        i. How much time does it take to travel here? (open response box)
    e. Other (open response box)
        i. How much time does it take to travel here? (open response box)

11. How often does the child receive [Speech-Language Therapy?]
    a. (open response box)

Information about the CHILD'S COMMUNICATION

1. How does the child **typically** communicate with you at HOME? (Check All that Apply)
    a. Speech/vocalizations
    b. Gestures/sign language/facial expressions
    c. Communication device (e.g., iPad app, AAC device, LAMP, Proloquo2Go, TouchChat, TD Snap, a Tobii, a "talker")
    d. Other communication supports (e.g., PECS, PODD books, topic boards, single buttons that speak a message, GoTalks)
    e. Other (open response box)
2. To the best of your knowledge, how does the child **typically** communicate at SCHOOL? (Check All that Apply)
    a. The same as at home
    b. Speech/vocalizations
    c. Gestures/sign language/facial expressions
    d. Communication device (e.g., iPad app, AAC device, LAMP, Proloquo2Go, TouchChat, TD Snap, a Tobii, a "talker")
    e. Other communication supports (e.g., PECS, PODD books, topic boards, single buttons that speak a message, GoTalks)
    f. Other (open response box)

Communication supports refers to both technology-based *communication devices* like iPad apps (e.g., a "talker," AAC device, LAMP, Proloquo2Go, TouchChat, TD Snap, a Tobii), as well as other, non-technology *communication supports* (e.g., PECS, PODD books, topic boards, single buttons that speak a message, GoTalks).

<u>Examples</u> of communication supports (your child's communication supports may look **different**)


1. Does the child use a technology-based communication device? (e.g., iPad app, AAC device, LAMP, Proloquo2Go, TouchChat, TD Snap, a Tobii, a "talker")
    a. Yes
    b. No
2. What is the name of the app/device (if you know)?
    a. (open response box)
3. Does the child use other communication supports (not technology based)? (e.g., PECS, PODD books, topic boards, single buttons that speak a message, GoTalks)
    a. Yes
    b. No
4. What type of other communication supports does the child use (if you know)? (e.g., PECS, PODD books, topic boards, single buttons that speak a message, GoTalks)
    a. (open response box)
5. How often does the child use the communication device/supports to communicate at HOME?
    a. Most of the time or always
    b. Some of the time
    c. Rarely or never
6. To your knowledge, how often does the child use the communication device/supports to communicate at SCHOOL?
    a. Most of the time or always
    b. Some of the time
    c. Rarely or never
7. How well do you feel like your child's service providers consider your culture and beliefs?
    a. Very well
    b. Somewhat well
    c. Not very well
8. How well do you feel like your child's service providers listen to your needs and concerns about your child's communication?
    a. Very Well
    b. Somewhat well
    c. Not very well
9. How well does the vocabulary included in the child's communication device/support(s) reflect what you and the family talk about at home?
    a. Very well
    b. Somewhat well
    c. Not very well
    d. Not applicable – the child does not have communication supports

10. Do you feel like the communication device/support(s) is a good reflection of yourself and/or your child?
    a. Yes
    b. Somewhat
    c. No
    d. Not applicable – the child does not have communication supports

Information about OBTAINING THE CHILD'S COMMUNICATION SUPPORTS

1. Did the child receive an evaluation for a communication device/communication supports?
    a. Yes
    b. No
2. Who referred you for the communication device/supports evaluation?
    a. Primary Care Physician
    b. Speech-Language Pathologist
    c. Classroom Teacher
    d. Other (open response box)
3. Who completed the evaluation for the communication device/supports?
    a. The child's regular Speech-Language Pathologist
    b. A Speech-Language Pathologist who specializes in communication supports (e.g., AAC specialist, AT specialist)
    c. Other (open response box)
4. At what age did the child receive their **first** communication device/supports?
    a. (open response box)
    b. Not applicable (the child does not have access to communication supports)
5. At what age did the child receive their **first** technology-based communication device? (e.g., iPad app, AAC device, LAMP, Proloquo2Go, TouchChat, TD Snap, a Tobii, a "talker")
    a. (open response box)
    b. Not applicable (the child does not have access to a technology-based communication device)
6. How long did it take until you successfully received communication supports for the child, after beginning the process?
    a. (open response box)
    b. Not applicable (the child does not have access to communication supports)
7. What factors were HELPFUL in obtaining the child's communication device/supports? (Check All that Apply)
    a. Insurance
    b. Other funding sources
    c. Access to knowledgeable professionals (e.g., Speech-Language Pathologists, AAC/AT specialist)

    d. Other
8. Please describe how the factor(s) you indicated, or others, were HELPFUL in trying to obtain AAC supports for the child.
    a. (open response box)
9. What factors were CHALLENGES in obtaining the child's communication device/supports? (Check All that Apply)
    a. Insurance
    b. Other funding sources
    c. Access to knowledgeable professionals (e.g., Speech-Language Pathologists, AAC/AT specialist)
    d. Other (open response box)
10. Please describe how the factor(s) you indicated, or others, were CHALLENGES in trying to obtain AAC supports for the child.
    a. (open response box)
11. Where did you hear about this survey?
    a. Online support group
    b. Assistive technology manufacturer
    c. Professional (e.g., the child's speech-language pathologist or teacher)
    d. Other (open response box)