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Voices of Marginalized Families in Early Intensive Autism Treatment

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ABSTRACT

This is a qualitative, phenomenological study of parents with children with autism who come from non-White backgrounds (N=7). Subjects were interviewed via recorded phone calls, during which they were asked a standard set of questions pertaining to their experiences with in-home family and child treatment. The problem examined in this study was the inequity experienced by families of color who have at least one child with autism and who received in-home early intervention autism services. Parents were interviewed to determine which aspects of treatment were perceived to be effective. The data were coded for emerging themes, with special attention given to opportunities for service amendment, seeking maximal perceived effectiveness. Families benefitted from an individualized approach to treatment that considered the family context, and culture, designed by listening to the family's needs, concerns, and availability. Assuming a one-size-fits-all approach, based on recommendations not made with diverse family backgrounds in mind, was less effective. Future directions in the field should include improved training for psychologists on cultural competence, encourage self-reflections on bias, and training on the development of individualized treatment plans.

KEYWORDS: autism, disparities, early intervention, treatment.

When treated with behavioral interventions such as applied behavior analysis, children with autism make progress in a variety of developmental domains (Zwaigenbaum et al., 2015). However, not all children progress at an equal rate or to an equal degree, and each child requires an individualized method of intervention, tailored to their needs and to the needs of their family (Morgan & Stahmer, 2020). Currently, the field of autism treatment uses a one-size-fits-all approach to treat autistic children and often fails to consider the diversity of the autistic community when addressing the needs of affected families (Zwaigenbaum et al., 2015). Simply put, the current treatment model does not consider the unique needs of each family. It also fails to account for disparities in the field, including the lack of access to diagnosis and treatment for many non-White families.

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Autism affects one in 54 children. Morgan and Stahmer (2020) explained that, although the disorder has been shown to affect all ethnicities equally, it tends to take Black children 1.5 to 5 years longer than their White counterparts to receive a diagnosis, and Black children are often misdiagnosed. Furthermore, they suggested that, regardless of socioeconomic status, Black families with a child who has been diagnosed with autism have less access to behavioral intervention. Those disparities in response to symptom onset indicate a need for evaluation through a critical lens.

Present-day autism treatment often involves multiple professionals entering a family's home for upwards of 40 hours per week. Rogers et al. (2020) found that such an approach often requires at least one adult to be home during treatment sessions, and families unable to meet this requirement risk severely limiting their child's access to treatment. In addition, families are often required to participate in 15 hours of parent training before their child can begin treatment. Rogers and colleagues explained that this training is usually conducted at a community clinic during regular working hours, which make accessing autism treatment challenging for working families, especially those with additional children and numerous responsibilities. Meanwhile, many children can make progress with as few as 12 hours of treatment per week, suggesting that it may not be necessary to burden families with the typical 40-hours-per-week treatment requirements (Rogers et al., 2020).

This research was conducted through the lens of critical race theory (CRT), a transdisciplinary and methodological model that offers a framework through which to examine culture, society, and their relationships with power and race in the United States (Delgado, 2002). This theory was developed in the 1970s and 1980s in American law schools to examine the intersections between dominant and subordinate groups as they relate to issues of race, and how race affects the experiences of Americans. One such idea is that structural racism, in the form of white supremacy, exists and demonstrates power over non-dominate groups (Ford & Airhihenbuwa, 2010). The following research questions guided this study:

1. What are the barriers to receiving early intensive behavior intervention (EIBI) for families from diverse backgrounds?
2. How might the research recommendations for autism EIBI intensity and location need to be adapted to meet the needs of diverse families?
3. What are the lived experiences of EIBI for diverse families?
4. How might early interventions for young children with autism better serve diverse families of color from lower socio-economic households?

Literature Review

For many families, simply knowing what symptoms to look for in their child acts as a barrier to diagnosis (Donohue et al., 2019). To combat the issue of parents needing to know what symptoms to look for in their child and to help children access intervention services as early as possible, screening tools were developed to aid pediatricians in identifying red flags for autism in early childhood. The developmental screening process consists of taking a developmental history, observing the child, identifying factors that protect or put the child at risk, and recording the process (Wallis et al., 2020).

Screening Tools

A variety of screening tools exist; however, no single tool comes with a recommendation meant to universally apply to all pediatricians or practices (Wallis et al., 2020). The screening tool should be selected based on what the screening is for, how well it fits into practice, and how easily participants complete it. Screening tools exist both in hard copy format, to be completed by hand, and as electronic tools to be completed online (Wallis et al., 2020). One problem with the current use of screening tools is that clinicians often rely on parents to report concerns prior to using a screening tool. This means that if a family is unaware that behavior is concerning and should be reported to a doctor, the concerning behavior could go unnoticed and delay the beginning of services. Reduced reporting of symptoms of ASD by Black parents could be a contributing factor in providers' disproportionate failure to identify ASD symptoms in Black children (Donohue et al., 2019).

Screening Families of Color

Inclusive screening tools that are user-friendly for diverse families improve the equality of opportunity to identify autism. Children from low-income or minority parents face additional challenges during the screening phase, which delays their ability to initiate care (Wallis et al., 2020). One contributor to these delays is the limited availability of screening tools in languages other than English (Stahmer et al, 2019). As few as 29% of pediatricians offer developmental screening in general in Spanish, and as few as 10% offer autism-specific screening in Spanish. This challenge also greatly affects Korean Americans. Few Korean-speaking specialists are able to offer screenings to families from Korea, making the completion of parent-reported screening tools inaccessible to them (Kang-Yi et al., 2013). Providers who serve large numbers of low-income, Spanish-speaking, Spanish-speaking children report not having sufficient time to complete screenings for these children. For Spanish-speaking children with ASD, most community assessment reports have not specified the language used for the child's assessment, which could mean that doctors are avoiding reporting that they did not properly screen that child (Angell et al., 2018).

Wallis et al. (2020) found that even after screening was completed, Black and Asian children were still less likely to be receiving ASD treatment services. Guthrie et al. (2019) found that, when screening tools missed children, the missed children were more likely to be children of color, from lower-income households, receiving care in an urban clinic, receiving public care, and being exposed to a language other than English. Angell et al. (2018) found that primary care providers perceive ASD screening tools to be less useful when used with Spanish-speaking parents or parents with low literacy levels. Due to this perception, families often fail to receive proper screening, or their child misses their deserved opportunity for screening due to provider perception rather than data or research (Angell et al., 2018). Eisenhower et al. (2021) found that early intervention providers were less likely to return first-stage screening packets for non-English-speaking children.

Guthrie et al. (2019) argued that the age of diagnosis disparities for children of color with ASD is likely preceded by disparities in screening rates and accuracy of screening tools for children from diverse backgrounds. Children whose families do not have health insurance are less likely to attend a well-child visit, which could lead them to miss an early screening opportunity in that setting (Rea et al., 2019). When screening tools are consistently used, reliance on clinician judgment alone markedly decreases, which is known to show bias and omit certain racial groups. Nonetheless, clinicians remain hesitant to use these tools (Rea et al. 2019).

A child who screens positive for autism empirically benefits from a follow-up interview to confirm the positive screening. If confirmed from the follow-up, the child should then receive a referral for additional follow-up diagnostic appointments (Rea et al., 2019, Wallis et al. 2020). Rea et al. (2019) found little consistency in the referral process. Furthermore, the majority of the children screened, primarily children from Black and Spanish-speaking backgrounds, did not receive the appropriate follow-up and referrals to better ensure proper care. These differences in the referral process may reflect clinician preferences, which are inherently problematic and omit some of the most vulnerable children (Rea et al., 2019).

Evidence has also shown that existing ASD screeners could create an abundance of false positives for Spanish-speaking children (Rea et al., 2019, Wallis et al. 2020). In Rea et al.'s (2019) study, a significant proportion of the Spanish-speaking participants screened positive for ASD—at a rate higher than the national average. This higher rate of ASD diagnosis could be due to a lack of culturally sensitive screening tools for Spanish-speaking families (Rea et al., 2019). Since Spanish-speaking families are already less likely to understand the symptoms of ASD and more likely to meet culturally insensitive treatment providers, this could be affecting outcomes for children during the screening phase (Rea et al., 2019, Wallis et al., 2020). Moreover, some children from immigrant families face additional challenges, such as less exposure to English, trauma, and challenges regarding immigration that physicians might not be paying close enough attention to. These unique challenges could be causing false positive screenings for ASD (Rea et al., 2019).

Diagnosis

The first challenge parents face when they suspect that something might be different about their child is attaining a diagnosis. This often involves seeking a clinician who is experienced in identifying autism (Stahmer et al., 2019a). This step alone can pose challenges for many families—they can have difficulty accepting that something is different about their child, pursuing or attaining the resources to meet with a clinician, and confidently, objectively evaluating whether the diagnosis is accurate (Lovelace et al., 2018, Rea et al. 2019). Diverse families face many inequities at this stage alone (Stahmer et al., 2019b).

Diagnostic Barriers

Some aspects of receiving the diagnosis of autism are universally challenging. Makino et al. (2021) explained that not all professionals agree on the appropriate diagnostic tools, resulting that, across systems and practices, the way a child receives a diagnosis varies. Furthermore, they found that several barriers exist for professionals tasked with making the diagnosis as well; these range from a lack of training, issues around disclosing the diagnosis to the family, and the complexity of the assessment tool and the variability of ASD characteristics. Zuckerman et al. (2017) found that, particularly for Spanish-speaking families, understanding and navigating the medical systems was a barrier to accessing a diagnosis for a child.

Makino et al. (2021) found other significant barriers. For instance, parents have reported that the major challenges to receiving a diagnosis for their child include being told that there is nothing to worry about or having their concerns dismissed completely. Another barrier is the lack of experience and expertise of many clinicians making these diagnoses. In addition, not all clinicians are trained to recognize autism symptoms. Consequently, when a child comes to them for an assessment, clinicians might need to request a second opinion or ask the child to return for another assessment. A lack of awareness of signs and symptoms of ASD, or with nuanced variability of symptoms, is another frequent barrier (Makino et al., 2021, Zuckerman et al., 2017).

Families are often unaware of what to look for or how to recognize that something is different about their child. Some families describe their child as shy or attribute differences that their child displays as matters of temperament, leaving them unlikely to seek help (Zeleke et al., 2019). Finally, wait times to see a clinician further complicate the acquisition of services (Makino et al., 2019).

Parents report of the assessment process itself is polarized, with some viewing it positively and others reporting an exceedingly negative experience (Makino et al, 2021). Some families feel that the assessment is too rigorous for their child, while others felt it is overly casual (Makino et al., 2021). Zuckerman et al. (2017) found that parents report high levels of stress during the diagnostic process. Overall, parents in that study reported a desire for information upfront about what to expect, how to prepare, and how to support their child. Parents showed a preference for being involved and collaborating (Makino, et al., 2021). Overwhelmingly, parents report the experience of receiving an autism diagnosis as intense, emotional, and heavy (Makino et al., 2021, Zuckerman et al., 2017). Some parents have called the experience a “trauma” and used words like “shocking” and “painful” (Stahmer et al., 2019b).

Disparities in Diagnosis

According to the literature, a primary disparity in autism diagnosis is that Black children with autism are diagnosed later than their White peers and are more likely to be misdiagnosed (Dababnah et al., 2018). Despite Black and White parents bringing developmental concerns to their pediatricians at about the same stage of development, Black children are diagnosed at later stages and are less likely to receive a developmental evaluation before the age of three (Dababnah et al., 2018, Stahmer et al., 2019a). Morgan and Stahmer (2020) found that Black children are often identified after the window for early intervention closes. The average number of visits to a pediatrician it takes for a Black family to receive a referral for an evaluation is approximately three times more than for White children. Black families also experience a longer period between initial contact with their pediatrician to their diagnosis (Dababnah et al., 2018). Furthermore, it takes three times more visits to the doctor to receive a diagnosis for Black children than their White counterparts (Mandell et al., 2002).

Black children are more likely to be diagnosed with more severe forms of ASD than other children, which suggests an underrepresentation of children with milder forms of ASD (Dababnah et al., 2018). They are also more likely to receive fewer evaluations overall and less likely to be identified with ASD despite displaying similar symptoms (Stahmer et al., 2019b). Furthermore, Black children have a higher chance of being misdiagnosed and being given labels for disorders such as oppositional defiant disorder, conduct disorders, or an adjustment disorder at rates much higher than White children (Mandell et al. 2002; Williams et al., 2020). Black children were found to be 5.1 times more likely than White children to receive a diagnosis of an adjustment disorder than attention deficit hyperactivity disorder (ADHD) or ASD and 2.4 times more likely to be given a diagnosis of a conduct disorder other than ADHD (Mandell et al., 2007). Black children showing non-compliance behaviors, which is common in ASD, are more likely to be diagnosed with the oppositional defiant disorder than White children with similar non-compliance challenges (Mandell et al., 2007). Black children also spent 8 months longer in mental health treatment than White children prior to receiving an ASD diagnosis (Donohue et al., 2019). Furthermore, Black children were more likely than White children (44% versus 22%) to be given a co-morbid autism diagnosis with an intellectual disability, suggesting that Black children are seen as having a more severe display of symptoms (Baio et al., 2018).

Emerson et al. (2016) found that additional barriers to diagnosis include that minority children are less likely to have recently had a physician visit or a medical care home, which means they are less likely to have a consistent source of care. Health insurance also plays an important role in a child’s ability to receive a diagnosis; thus, children without insurance are less likely to have care available to them or to have recently seen a physician. Among the Spanish-speaking community, in particular, Zuckerman et al. (2017) found that trust in local community medical providers was a barrier to getting a child diagnosed. Angell et al. (2018) found that clinician bias, whether explicit or implicit, may play a role in the under-diagnosis of and delayed diagnosis of children from ethnic and racial minority groups. Black families have reported a distrust in the system at this stage in the process and have often wondered if doctors are misreading their children’s needs. Asian families have reported experiencing great deals of shame during the diagnostic process and have found the healthcare system to be unsupportive of their needs (Zeleke et al., 2019).

In Magana et al.’s (2012) study, parents of Black children with autism were more likely than parents of White children with ASD to report not having access to a personal doctor or nurse, not having a doctor who spends a significant amount of time with their child, and not having a doctor who listens carefully to their concerns. Black families also reported not having a doctor or medical provider sensitive about family values or customs and one who makes parents feel like a partner (Magana et al., 2012, Magana et al., 2015). In addition, Black parents felt that they did not receive enough information from their doctors and that their doctors did not spend considerable time discussing their concerns (Magana et al., 2015). In another study, parents of Black children described feeling like they did not have the same access as White families to coordinated or family-centered care (Doshi et al., 2017). In Stahmer et al. (2019a), Black families noted that there is little information about autism and the diagnostic process that is specific to children of color.

Stahmer et al. (2019a) indicated that when Black families shared concerns with their providers, they often felt dismissed and as though their worries were invalid. Providers would tell Black families to “wait and see” if the behavior improves. In the same study, the authors found that caregivers expressed concern about the dismissal of their child’s abnormal behavior and did not feel heard by their health provider. Many Black and Spanish-speaking families felt that this dismissal was largely due to ethnic stereotypes (Stahmer et al., 2019b). Mothers felt invalidated for sharing their concerns, which in turn delayed a diagnosis by forcing subsequent visits. This in turn led parents to question what they were seeing in their children (Dababnah et al., 2018).

Treatment

After receiving a diagnosis of autism, the next step for a parent is to enroll their child in treatment. Treatment for autism often involves a variety of professionals entering the family’s home to work one-on-one with the child and provide training to the parent. At times, it also involves visits to a clinic for assessment, coaching, or generalization (Rivard et al., 2020). Treatment often requires at least one family member to be present while the child is receiving therapy. The child might receive upwards of 30 hours of therapy in a week, requiring someone to be present for that entire time (Rivard et al., 2020). The goal of therapy is to improve the child’s overall functioning in pivotal areas of development, including communication skills, social functioning, adaptive skills, challenging behavior reduction, and the building of new skills (Breik et al., 2018).

Barriers to Accessing Treatment

Accessing early intervention services within the first few months of diagnosis plays a crucial role in producing long-term positive outcomes for those with autism and their families (Lord et al., 2020). A delay in starting intervention services could limit a child's capacities later in life (Luelmo et al., 2020). Despite that the literature has clearly documented this outcome, many families, particularly those from diverse backgrounds, still face insurmountable challenges when attempting to access intervention services for their children (Luelmo et al., 2020).

The cost of treatment can be a limiting factor for many families. While treatment is usually covered by the state, the time commitment required for early intervention can be intense and is not possible for every family (Zeleke et al., 2019). Stahmer et al. (2019a) indicated that some caregivers have had to give up their jobs to manage their children's services and the multitude of appointments children with autism often must attend; however, forgoing work is simply not available to all families, especially single parents, or parents from low socio-economic backgrounds. Nonetheless, unwilling to give up work, the parents who were able felt it a necessary sacrifice to make for the benefit of their child (Stahmer et al., 2019a). However, doing so can also lead to feelings of guilt, shame, frustration, and incompetence for parents who do not have this luxury (Zeleke et al., 2019).

Also, in Stahmer et al.'s (2019b) study, Black parents described frustration with the lack of evidence of the effectiveness of interventions for their children specifically. Black parents from lower socioeconomic households were also less likely to know about evidence-based intervention options for their families, which differed from what middle-class families reported, suggesting that class plays a role in awareness. Coming from a family of color and living in a lower SES household has been correlated with parents having lower expectations for the benefits of therapy, engaging in services less, and believing more strongly that their child's condition is a mystery (Zuckerman et al., 2015). Families from lower SES backgrounds use fewer resources than other families, which could be a reason for the reduction in awareness. Other explanations exist as well; for example, treatment schedules can be intensive and require a parent to be home multiple hours per week (Stahmer et al., 2019b). This can be challenging for families who must work multiple jobs and are struggling to meet basic food and housing needs. Treatment providers have shared that it can be challenging to engage families coping with many additional life stressors such as poverty and multiple people living in one household (Pickard et al., 2016).

Research Method and Design

This qualitative phenomenology included data collected from interviews with diverse families who had their child in EIBI treatment to learn what modifications would benefit them and to understand how to improve the quality of autism treatment. The methodology was chosen because qualitative phenomenology was best suited for this type of research (Gill, 2008). The responses received were coded for common themes, which allowed the researcher to develop a universally meaningful and profound understanding of the complex problem in question (Maxwell, 2013). A primary aim of the study was to identify systemic and hegemonic obstacles, which typically necessitate a qualitative approach (Apuke, 2017).

Participants

The participants for this study included parents of children with autism who were from diverse (non-White) backgrounds and who have had at least one child participate in early intervention autism treatment. All participants had participated in a prior study conducted by the UC Davis MIND Institute titled “Connecting the Dots,” which took place in Sacramento, California, and its surrounding areas (within a 20-mile radius of Sacramento). For this study, families were consented and asked if they would be willing to participate in future research. UC Davis had an IRB for human research study, which these families were all a part of. If families were willing, participation occurred in-person in their homes. When this was a limiting factor, interviews were conducted over the phone or through a web-based video conferencing tool such as Skype or Zoom.

Families were selected for potential participation if they were from non-White and low SES backgrounds. Sacramento County defines low income for a family of four as an annual salary of $72,500 (State of California Department of Housing, 2021). Since the study only contained around 15 such families, they were all asked if they were willing to participate in order to reach enough participants to draw conclusions and themes based on their interviews. Since at least six participants are required to draw themes, it was the minimum participant requirement for this study (Saunders et al., 2018). Up to 15 participants were allowed.

Gender was not a factor in determining participation. The primary factor in participation was race/ethnicity. Participants who identified as Black, Spanish-speaking, Asian American, Pacific Islander, or other non-White ethnicities were asked if they were interested in participating. Maternal and paternal ages were not factors either. Although the age of the children was not a limitation, their mean age was 5 years old. Participants were also screened based on their socioeconomic status to learn more about the experiences of early intervention for low-income families.

Procedure

The interview questions were generated to formulate a series of open-ended questions that would elicit a response from the participants about their experiences with autism treatment. The questions were designed to engage the interviewee in a discussion about barriers and facilitators related to their experience. The overarching question is to gain an understanding of the lived experiences of families engaging in intervention, so this feedback could be mapped onto what the research supports to guide changes in autism treatment for the population being interviewed.

The interview guide was field tested with three colleagues who have been at the UC Davis MIND Institute for a minimum of nine years. They all have extensive experience working with families from diverse backgrounds with children diagnosed with ASD. All three felt that the removed question about parent coaching should be reinserted. According to them, this information would be useful when learning about the challenges families face since it is a requirement of intervention and a challenge to attend for many families. One of the field testers mentioned, though, that the question regarding the referral process would need clarification. The families, they argued, might not readily identify that as the referral process and would need prompts to know what the researcher is referring to. The requested changes were made to the instrument.

Semi-structured interview questions were used to collect data on the experiences, behaviors, and opinions of the families from diverse backgrounds who had participated in early intervention autism treatment. Most of the interview questions were open-ended, although some close-ended follow-up questions were asked based on the first answers received. All families were asked the same set of initial questions. The interviews were conducted with participants and later transcribed and coded for themes and a saturation point using the transcription software NVivo. The interviews lasted around 20 minutes depending on the individual and how much information they shared. These discussions occurred over the computer or phone based on the individual's preference. The interview questions were written out and asked in the same way to everyone. The only potential changes to the questions were based on each person's response. Some participants were asked additional questions to seek further information or to follow up on something they had shared during the interview. Study replication would involve asking the same list of questions to another group of individuals with lived experiences similar to those interviewed in this study.

Data Analysis

Interviews were audio recorded and transcribed in Microsoft Word. The qualitative software NVivo was used to help analyze the data and find themes. Along with NVivo, a codebook was developed based on the research questions, which guided the coding of the transcripts. Line-by-line coding was used to assign categories to sentences, phrases, or paragraphs. Multiple categories were assigned at the same time, if appropriate, to capture what was shared in the interviews. Categories and subcategories were developed to assist with coding and theme capturing.

To improve trustworthiness, one research assistant from the UC Davis MIND Institute was trained in the transcription process. The assistant checked the transcription and noted any edits or differences found. The researcher then reviewed and made necessary edits. The research assistant was also trained in how to use the codebook. Once the codebook guidelines were developed, both the primary researcher and the research assistant independently coded two transcripts to check for inter-rater reliability.

Results

The results of the data analysis included themes to determine what kept families who have autistic children from accessing treatment. The data were analyzed using thematic analysis, a method used for coding qualitative data that is typically employed when analyzing interviews (Braun & Clarke, 2006). The process of conducting a thematic analysis typically follows six steps: familiarizing, coding, generating themes, reviewing themes, defining, and naming themes, and reporting the findings (Braun & Clarke, 2006). This study used Braun and Clarke's (2006 analysis strategy. The following outlined steps were taken in the analysis. Familiarization involves transcribing the audio, reading the transcripts, and becoming familiar with the information (Braun & Clarke, 2006). Coding involves reviewing the text and highlighting words, sentences, or phrases and giving them "codes" to describe their content (Braun & Clarke, 2006). Generating themes entails analyzing the codes and identifying their patterns and themes (Braun & Clarke, 2006). When reviewing the themes, the researcher checks the data and codes to ensure that they seem appropriate and changing them if required (Braun & Clarke, 2006). Defining the themes means specifying what each theme is and giving it a short and understandable name (Braun & Clarke, 2006). Finally, all this information was recorded so that the gathered information could be shared (Braun & Clarke, 2006). The themes are outlined below.

Challenges with Service Systems

Families described their experiences with community treatment either before or after participating in the research study. Their descriptions reflected barriers to accessing services and countered the areas they felt went well in the project. Families discussed the challenges they experienced with nearly every service system they had to navigate, including school, regional centers, ABA companies, and their insurance. One of the primary barriers to beginning treatment was waitlists. Families were put on wait lists to start services, which generally lasted for months with little communication on when they were going to be able to begin treatment. Five out of seven families (71%) indicated that COVID exacerbated the problem, as some treatment centers lost staff or were unable to provide services due to health concerns. Families indicated that they waited not only for ABA treatment but for other critical treatments as well, such as speech and occupational therapy. Participant one described her own experience with community services:

> *We have [Regional Center] but they won't provide us with any services. And the school district won't provide anything. The school district sucks, it really sucks. And our insurance has been really reluctant to work with us on providing any sort of support, so now we kind of don't have any help with him.*

Families with children who have transitioned into school shared their frustrations with school services. In particular, participants reported a lack of communication, disregard for their concerns, an inability to hold meetings when requested, and incompetent teaching. They also expressed frustration when speaking about the service systems, such as the regional center and personal insurance companies, as participant three did when discussing her regional center:

> *I wasn't getting responses back from individuals. I was being passed on from one person to another. Finally, I had just had enough and started doing everything on my own. And then when [the regional center], which was absolutely no benefit or help, said they were stepping in to help me, I was passed around from everybody from there. I felt like I was doing more than I should have been doing.*

The need to advocate and a desire to commandeer their child's treatment were repeatedly articulated throughout the interviews. Parents reported a perception that the service systems did not have the time, care, or respect to meet their needs; they had to call multiple times, reach out to multiple people, and manage many frustrations to have their needs met. Five out of seven families also shared feeling extremely lost throughout the process. Even when people did come to their homes, they were not always sure who the home providers were. Families felt the need for greater clarity and transparency throughout the process of navigating the autism treatment service system from diagnosis to treatment.

Currently, research recommendations have not been scaled or adapted depending on the family. They are general and broad recommendations that do not consider family context, daily life, or hardships. This question was designed to understand what family life considerations were made when making recommendations on treatment hours and location. These ranged from needing support traveling to a clinic, reducing the number of hours a family must work, increasing flexibility with providers, offering treatment in the home or in other locations at which the child spends time, and providing treatment outside of usual business hours to accommodate working parents.

Flexibility

Families also described flexibility as a major source of support in their ability to consistently access services. Like being accommodating, every family indicated that flexibility was a key to their family's successful treatment regarding both treatment hours and location. Participant six discussed this, stating,

> *And just the convenience of it. The staff were very flexible, and like, for them to provide the therapy, but then also to adjust to the family's needs and schedules, not to mention coming over to the house, that is just such a great help.*

Families preferred having staff come to their homes rather than travel themselves to the clinic. They appreciated the flexibility of having either as an option in case one was occasionally not viable for some reason. Some families mentioned distance from the clinic as a barrier, and that the drive and traffic could have been a barrier. Consequently, they discussed, they appreciated the ability to move a clinic visit to the home when needed. Conversely, some families at times needed to have a session outside their home due to grandparents staying over, an unclean home, and other factors. The majority of interviewees indicated a desire to come to the clinic when and if their home was not ideal or possible.

None of the families were receiving the standard dose of treatment (40 hours per week) and cited the flexibility with and consideration for their family life and needs as beneficial. Had the staff forced the typical 40 hours of treatment, they would not have been able to continue the services. Families received 12–15 hours per week of treatment, and six out of seven families described this amount as "perfect" for them. In particular, participant three described her experience with a community provider with whom she did not see as a good fit and who was not flexible with her schedule:

> *It was horrible. It was absolutely horrible. I, so this is where I got frustrated with this company. She told us that they needed a minimum of him to do like 30 hours a week or something like that. She said it was some astronomical number. I said that's like a full-time job. And he's only what, three, four years old. So no, that's just, that's not an option.*

Other parents described appreciating the flexibility of topics that arose throughout treatment and the chance to receive support for a variety of different concerns. At the start of treatment, many of the families thought they were only going to be allowed to discuss issues related to behavioral challenges, so they were gratified by the broad support they were given when needed. Participant two shared that:

> *[Our supervisor] helped us set up a plan for how to transition our son from our room into his own room. How to get him off a bottle, how to get him off a pacifier, how to set up a plan for potty training. You know, these were all things that I didn't, I didn't really think that was, that was part of the, uh, that was part of the service, you know?*

Consideration of Family Needs

An additional theme that emerged was the consideration of family needs. This related primarily to listening and responding to the family when they had a concern. Five out of the seven families discussed a time when the staff member working with their child did not seem like a good fit for their child or family. Those who mentioned this all wanted to highlight that they were a good person and a fine worker, but that they simply did not work well with their child or fit with their family. Participant two discussed their experience with this, noting that:

> *One of the things I really noticed that that helped [child] thrive was when he got paired with a therapist, um, that he was really comfortable with and that he was, he was really able to, um, work really well with. There were times where, I mean, we, we talked about like different therapists that he was a little bit more comfortable or that he just basically he would escape if he didn't like the person, he literally would run-away. And we had our house pinned up at one point, I think I counted at least five different gates trying to lock him into like a small space. And he still was managing to escape. Like we had the living room, like across the belly of the living room. There was a gate, every doorway had a gate. And he was still trying to escape this person and, and we're like, oh, it's just not a good fit. So, I think that would be, um, that's something that, you know, should be kind of taken into consideration. It's not, it's not the therapist, it's not the kid. It's just, sometimes you learn better with someone else that you're able to resonate with.*

Another parent shared similar concerns with a therapist who was working in her home, and the mother eventually asked for a change in staff. Participant one stated:

> *I think there was like a little bit of growing pains in the beginning. We started with one, um, behavioral technician who, you know, wasn't, wasn't good, I don't want to say anything bad about her. She was fine, but like, she wasn't familiar with a particular type of treatment. Like once we got past that, and then we got to, um, have the technician who had been to those trainings and was way more familiar with how, uh, you know, the structure of the treatment it was much better much. And from that point on, it was very smooth and very helpful.*

Much previous research has been predominantly focused on the experiences of white families who have received services for their children with autism. While this input is a necessary guide for treatment, it is not reflective of all types of families that receive autism therapies. The objective was to understand what the system currently works for families and what does not. This information can guide possible future changes. Themes related primarily to what worked well, which was when treatment fit with the family structure, when treatment was dynamic, and when the treatment team listened to the family with respect.

Resources

Another theme that emerged was how helpful families found it when treatment providers shared resources with them. The families also expressed gratitude for having someone help them actually use the resources rather than simply leaving the family to navigate them alone. Furthermore, the families found it beneficial when the staff members themselves acted as resources and were available for families to call or e-mail for any additional support. Participant seven observed her clinical director that "She was always there for me, always giving me more resources, always." Participant one spoke of her experience with a company that gave resources without explanation:

> *She tried really hard, I think. Um, I just wish there was more of a component of education for parents, like earlier on, um, I think that kind of got lost in translation because we would do these meetings with the checklists, from the book and everything. It just, I don't know, like some of it got lost in translation. Um, almost like it was like third hand information.*

She described feeling lost and confused when given books and checklists without explanation or orientation. In a later experience, when someone was able to walk her through those materials, she felt that she "could finally look up from it all" and "make sense" of what she had been given. Six of the seven parents noted that the ability to call or e-mail their program supervisors when a question arose was a way the staff acted as a valuable resource for the family. Words like "team," "reliable," and "she was our greatest resource" were common throughout the interviews.

Respect

The final theme related to how treatment can better serve families of color was the perceived measure of respect given to clients. Every family mentioned respect either as an aspect of treatment that was working well or as an area that was important enough that it should be at the forefront of the minds of any individual working with children with autism. Families wanted staff to respect their struggle, specifically how much they might have been juggling. Some parents had multiple children with special needs, some were working full-time and were in school, and some were raising their children without help. The families mentioned that respecting where they are coming from assists in their commitment to the process. Respecting family time was another way respect arose in the discussions. Participant three shared her experience with starting treatment:

> *I think surely having an understanding of what mom is already doing and trying to work around my schedule and that aspect 'cause Dad wasn't here, he was working, he wasn't available. And he definitely wasn't even in the same state, so just being respectful of the time this is what I can offer you. I even made it very, very clear before we even got involved in the study that I am a full-time student and I still work full-time. So, the time that I do have, and I make available, please respect that and do what you can with that. And if that doesn't work for you to let me know, we can make other arrangements.*

The theme of perceived respect permeated discussions of the service systems as well. While families appeared to appreciate and acknowledge the benefits of parent coaching, four out of seven felt that parent coaching should not be a mandate from regional centers or insurance companies and that it should be more fluid and occur as needed. One parent who had a second child with autism observed that “this isn’t my first rodeo” and felt that her insurance did not respect her time or knowledge by mandating parent coaching for her child.

Discussion

Findings from this study were consistent with the literature on barriers faced by families, ways to improve treatment access, necessary strategies for support and resources, and necessary training. Findings were also consistent with the application of CRT as the lens through which to view these challenges. Families from White backgrounds are benefitting from systemic support in ways that marginalized families are not. The literature showed that families from marginalized backgrounds face more challenges when receiving autism interventions than their White counterparts. These families have more often been misdiagnosed, delayed, questioned, passed around, and ignored than White families, a finding that families in this study reflected as well. Families from non-White backgrounds often had to work harder to attain the same services, which results in a loss of time in treatment at a crucial moment in the child’s development. These findings are consistent with what is seen in critical race theory in regard to disparities.

The future of autism treatment can act to rectify these challenges and ensure that all families receiving treatment can do so equitably. Future work might also ensure that non-White families become research participants to shape the field to better meet their needs. Resources must be disseminated and shared with these families, and trust must be built; it is crucial that they feel comfortable and confident coming to a research center or clinic. Information about autism treatment should be more broadly disseminated to locations that these families are likely to encounter like daycares and pediatric offices, to make the information more likely to reach them. This information also needs to be available in a variety of languages and be culturally appropriate for different types of families.

Conclusion

Companies that provide ABA treatment will greatly benefit from improvements to the training of staff. This would function both to retain them for longer periods and to better equip them to work with families from a variety of cultures and backgrounds. Staff would receive training in how to support parents and families, how to work in a culturally competent manner, and how to approach treatment from a place of understanding and compassion. Treatment companies must find creative ways to better support families waiting for treatment, possibly by offering telehealth appointments or parent coaching until in-person treatment is available. Treatments should be flexible and consider the needs of the family rather than try to make the same treatment format work for everyone. Furthermore, companies must improve their staff hiring practices to reflect the cultures of the families they work with. Families have reported feeling better about treatment when the staff working with their child had a similar background. Furthermore, a similar background can improve family alliance and trust in the treatment (Rivard et al., 2020).

Autism treatment requires an individualized approach rather than a one-size-fits-all method. Providers should hold conversations with families prior to beginning treatment to determine the type of treatment that has been researched for children and what types are available to determine the optimal fit for the family based on hours and approach. The family alliance can additionally be improved by understanding families' expectations for treatment and their beliefs about in-home treatment efficacy. Best practices must be in place to ensure that families feel respected. Providers should develop and express an understanding that the parents are the experts on their child, and that treatment is simply adding to their already-broad knowledge base. In summary, services must work to align with families rather than present solutions that families must either fight against or work tirelessly to gain access to.

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