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African American Parents' Perceptions of Diagnosis and Services for Children with Autism

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Abstract: The identification of children with autism spectrum disorder (ASD) during the first two years of life has become more promising; however, the probability of early ASD diagnoses does not always extend to African American children. This disparity has decreased the likelihood that African American children will benefit from early intervention services. This qualitative inquiry explored, via semi-structured interviews, the perceived factors that facilitate and impede early diagnoses and access to services among African American parents of young children with ASD. A constant comparative approach was employed and 15 themes related to diagnoses, services, and recommendations emerged (e.g., parent knowledge of ASD as a facilitator to diagnosis, "aggressive advocacy" as a barrier to accessing services, and parent education as a recommendation for addressing identified barriers). Parent advocacy and partnerships with professionals were overarching themes in this study. Implications for parent training related to knowledge of ASD, parent advocacy, and partnerships with professionals are discussed.

Recent findings have indicated that the prevalence of ASD is 1 in 68 children (CDC, 2016). Over the past several years, the increased prevalence of ASD has heightened the need for more educational and therapeutic services and interventions for individuals with ASD (Wong et al., 2014). The early childhood years are critical for children with ASD because early identification is associated with increased benefits from interventions and services (Bruder, 2010; Irvin, McBee, Boyd, Hume, & Odom, 2012). Although the identification of ASD in children younger than two years has become more promising in recent years (Boyd, Odom, Humphreys, & Sam, 2010), this likelihood of early ASD diagnoses is not consistent among African American children. African American children are often diagnosed months or even years after the onset of symptoms and can go undiagnosed until school age or later (Hilton et al., 2010; Mandell et al., 2009).

Access to Services

Across racial and ethnic backgrounds, services for individuals with ASD have been described as limited, inaccessible, and costly (Dymond, Gilson, & Myran, 2007; Irvin et al., 2012). Among families of color however, access to appropriate services is further compounded by factors such as socioeconomic status and living environment (Reichard, Sacco, & Turnbull, 2004). Some of the work around the intersection of culture, race and disability has highlighted the challenges that families of color face when seeking access to services. For example, Blanchett, Klinger, and Harry (2009) argue that minority families of children with disabilities face barriers to accessing services such as: (a) differing cultural perspectives of disability, (b) limited access and unfamiliarity with available service delivery options, and (c) service providers' lack of understanding of factors such as race, social class, cultural values, and experiences. Blanchett et al. (2009) suggest that when families of color seek services for children with developmental disabilities, they are likely to face systems and structures

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This research was supported in part by funding from the Office of Special Education Programs, U.S. Department of Education: Project LEAD (H325D100062). The views or opinions presented in this manuscript are solely those of the authors and do not necessarily represent those of the funding agency. Correspondence concerning this article should be addressed to Jamie Pearson, 2310 Stinson Drive, Campus Box 7801, Raleigh, NC 27695. E-mail: jnpearso@ncsu.edu (e.g., human and community services, special education system) that are not adequately prepared to help them navigate services. In many cases, this results in families of color receiving culturally unresponsive and inappropriate services and interventions.

Other researchers argue that healthcare providers' (HCP) knowledge and perceptions of African American families impedes access to services for these children (Gourdine, Baffour, & Teasley, 2011; Liptak et al., 2008; Mandell, Listerud, Levy, & Pinto-Martin, 2002; Thomas et al., 2007). For example, Reichard et al. (2004) found that many families of children with developmental disabilities from minority backgrounds reported difficulties finding competent and trustworthy practitioners who were empathetic and understanding of their concerns. On the other hand, Gourdine et al. (2011) purported that African American parents are less likely to view certain treatment methods as helpful for their children because of the history of stereotyping, discrimination, and racism that they have experienced when seeking mental health services in the past.

Barriers to Diagnoses for African American Children

Among African American children in particular, the three primary categories that contribute to the disparate access to diagnoses and services include: differential diagnoses, socioeconomic status, and cultural divergence (Pearson, 2015). Previous researchers (e.g., Blanchett et al., 2009) have described similar barriers and challenges related to children of color with ASD.

Differential diagnoses. Differential diagnoses among African American children are defined as rates and timing of diagnoses of ASD that are less than or more delayed than those of European American children (Pearson, 2015). Access to services for African American parents of children with ASD is a common barrier to obtaining accurate and timely diagnoses. In their work, Mandell et al. (2002) found that on average, African American children were 7.9 years old when they first received a diagnosis. Mandell and colleagues also found that 50% of the European American children in their sample received an ASD diagnosis by the age of 5.5 while less than 30% of African American children received a diagnosis of ASD by age 5.5.

Socioeconomic status. Socioeconomic status (SES) is viewed as a barrier when financial resources inhibit access to services for this population. Low SES, however, does not account for the under diagnosis and misdiagnosis of ASD in African American children. Low SES impacts families across racial and ethnic backgrounds (Irvin et al., 2011); however, given the disproportionate number of African American children under 18 living in poverty (DeNavas-Walt, & Proctor, 2015), it is believed that low SES further exacerbates delayed diagnoses and access to services among this population (Pearson, 2015). For example, Liptak et al. (2008) found that families living in poverty had decreased access in getting care from a specialist, having a personal physician, getting acute care, and receiving preventative care for their children.

Cultural divergence. "Cultural divergence is the idea that there exists a disconnection between parents of color and the medical professionals who treat their children" (Pearson, 2015, p. 54). Cultural divergence is a barrier described as cultural phenomenon that impacts access to services for African American families of children with ASD. As a result, many African American families face culturally unresponsive and untimely access to early intervention.

Cultural divergence also highlights the notion that HCP knowledge and perceptions of African American families impedes diagnoses and access to services (Liptak et al., 2008). For example, in their case study, Gourdine et al. (2011) found that a two-parent, college-educated, middle-class African American family faced many challenges obtaining an initial diagnosis and subsequent access to services. During their first clinical visit, HCPs assumed the parents were uneducated and immediately recommended placing their son in an institution. Reichard, Sacco, and Turnbull (2004) found that culturally and linguistically diverse families of children with developmental disabilities reported difficulties finding competent and trustworthy practitioners and wanted them to show more concern. Zuckerman et al. (2013) identified disparate diagnoses and referrals for Latino and African American children with ASD based on the cultural perceptions of the medical professionals who treated them. Their findings indicated that HCP perceptions of families of children with ASD suggested that Latino and African American children had less knowledge of ASD than parents of European American children. The HCPs also suggested that, as practitioners, they faced more difficulty in recognizing the characteristics of ASD in Latino and African American children, as compared to European American children (Zuckerman et al., 2013).

There is a dearth of literature around diagnosis and misdiagnosis of ASD in the African American community (Mandell et al., 2002). Despite the availability of evidence-based, early intervention services for children with ASD, African American children continue to go undiagnosed and misdiagnosed at alarming rates. These findings reflect a need to explore the reasons why late diagnoses and disproportionate access to services are, as indicated throughout the literature, unique to this ethnic minority population. Therefore, the purpose of this study was to explore the perceived notions that facilitate and impede early diagnoses and access to services for children with ASD in grades K-5, by interviewing African American parents about their experiences. This study was guided by the following research questions: (1) What are the reported experiences of African American parents of children with ASD in grades K-5 when obtaining an initial diagnosis? (2) What are the reported experiences of African American parents in gaining access to services? and (3) What recommendations do African American parents have for educators, service providers, and healthcare providers to better serve the needs of African American children with ASD and their families?

Method

Participants

Semi-structured interviews were conducted with 11 African American mothers of children ages 4–11 with ASD living in a midwestern state. The inclusionary criteria were: (a) a parent or caregiver of a child with a primary diagnosis of ASD who qualified for special education and related services in a public school, (b) *both* parents/guardians and the child were African-American and resided in the state, and (c) the child was between grades K-5 at the time of the study. All caregivers (including fathers) were eligible and invited to participate; mothers, however, were the only respondents.

After receiving Institutional Review Board approval, efforts were made to reach families who resided in all regions of the state, including urban, rural, and remote communities. Participants were recruited through a local autism program, Parent Training and Information Centers, Easter Seals, and various local community agencies using emails, newsletters, and flyer announcements. Thirteen parents expressed their interest in the study after receiving a flyer from the researchers or from participants who had already completed the study (i.e., snowball sampling). Of the 13 parents who expressed interest, 11 met inclusion criteria to participate in the study. Data were collected from 11 African American mothers in urban and rural areas whose children (boys, n = 9; girls, n =3) were 4–11 years old (mean age = 7.92 years) at the time of the study. The mother's ages ranged from 31 to 48 years (mean age = 38.9 years). Six mothers were single, three were married, and two were living with their partners. Annual family income ranged from $8,700 to $90,000 (mean Annual Family Income = $48,600). Two participants were mothers of two children with ASD who met inclusion criteria; therefore, child data is representative of 13 children (see Table 1).

Data Collection

To explore the experiences of African American parents of children with ASD, participants completed a family background questionnaire and participated in semi-structured interviews.

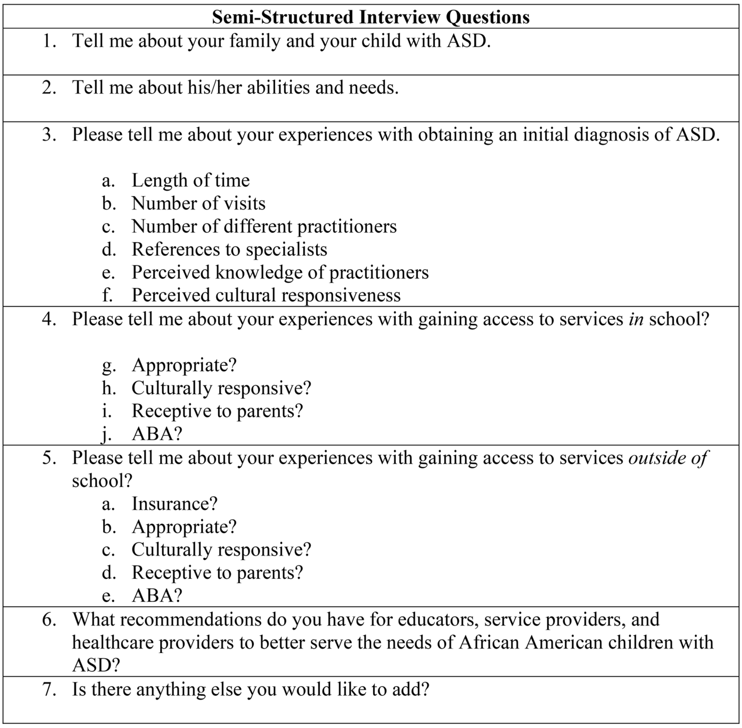
Family information questionnaire. The Family Information Questionnaire was developed by the authors and was administered to collect demographic information about the parents and the types of services that their children with ASD received. The questionnaire included 15 items and took 5–10 minutes to complete. The questionnaire included demographic questions such as parent's age, gender, marital status, level of education, employment status, family income, and child information. The questionnaire also included questions about the types

TABLE 1

Participant Demographic Information

Mother	*Name*	*Mother Age*	*Marital Status*	*Education*	*Employment*	*Family Income*	*Total # of Children*	*Other Children with Disabilities*	*Child Gender*	*Child Age*	*Age of Diagnosis*
1	Jennifer	46	Single	Some College	Phone Operator	$24,000	2	No	Male	10	4
2	Laura	33	Single	Bachelor of Arts	Salon Manager	$31,000	3	No	Male	10	3
3	Meghan	31	Married	Bachelor of Arts	Youth Counselor	$33,500	2	Yes	Male	9	1.5
4	Tiffany	35	Married	Masters of Science	Instructor	$55,000	4	No	Female	8	4
5	Michelle	36	Divorced	Bachelor of Arts	Correctional Officer	$58,000	2	No	Male	4	2
6	Linda	40	Single	High School	Not employed	$8,652	4	No	Female	8	3
7	Tameka	40	Single	Some College	Information Technology	$65,000	2	Yes	Male	6	3
7	Tameka	40	Single	Some College	Information Technology	$65,000	2	Yes	Male	5	2
8	Lynette	43	Divorced	Masters of Science	Not employed	$60,000	2	Yes	Male	11	5
8	Lynette	43	Divorced	Masters of Science	Not employed	$60,000	2	Yes	Female	9	6
9	Ebony	43	Married	Masters of Arts	Program Coordinator	$42,000	2	No	Male	7	3
10	Deborah	48	Single	Bachelor of Arts	Supervisor	$67,500	1	No	Female	7	6
11	Donna	33	Single	Associate of Arts	House Manager	$90,000	1	No	Male	9	3

* Participants 7 and 8 reported experiences based on *two* children with ASD.



Semi-Structured Interview Questions
1. Tell me about your family and your child with ASD.
2. Tell me about his/her abilities and needs.
3. Please tell me about your experiences with obtaining an initial diagnosis of ASD. a. Length of time b. Number of visits c. Number of different practitioners d. References to specialists e. Perceived knowledge of practitioners f. Perceived cultural responsiveness
4. Please tell me about your experiences with gaining access to services *in* school? g. Appropriate? h. Culturally responsive? i. Receptive to parents? j. ABA?
5. Please tell me about your experiences with gaining access to services *outside of* school? a. Insurance? b. Appropriate? c. Culturally responsive? d. Receptive to parents? e. ABA?
6. What recommendations do you have for educators, service providers, and healthcare providers to better serve the needs of African American children with ASD?
7. Is there anything else you would like to add?

Figure 1. Interview Protocol.

and amount of services their child with ASD received.

Interviews. The first author conducted semi-structured interviews with each participant. The interview protocol was piloted with a single mother of a 10-year-old child with ASD. The pilot participant confirmed that the interview questions were clear and expressed that the questions were developed well enough to capture the experiences of African American parents of children with ASD. The final protocol included seven open-ended questions (see Figure 1). The main areas of inquiry that were addressed include: (a) experiences of African American parents of children with ASD obtaining diagnoses, (b) experiences gaining access to services, and (c) recommendations for healthcare providers, service providers, and educators to better meet the needs of African American children with ASD. During each interview, the researcher followed up when necessary, with additional probes based on information that parents provided in the family information questionnaire. The interviews were conducted at a time and place that was most convenient for the participants (e.g., public library, homes). Each interview was audio-recorded, field notes were collected, and interviews were transcribed verbatim. Ten out of 11 interviews lasted between 42 and 73 minutes, and one interview lasted 10 minutes (average = 53 minutes).

Data Analysis

Data from the Family Information Questionnaire were analyzed to provide descriptive information about the participants (see Table 1). The questionnaire data were compared to the interview data to provide support for data triangulation (e.g., number and types of services). A constant comparative method (Corbin & Strauss, 2008) was used to analyze the interview data and data analysis was conducted in four phases. First, the researchers each read, independently, one transcript at a time to identify and label significant pieces of text that emerged from the data (i.e., open coding). Next, the researchers met to reach a consensus on significant text and develop categories based on their line-by-line coding. Third, the researchers compared the categories to their previously identified categories to ensure consistency. Finally, the first author reviewed all of the transcripts to ensure the categories were applied uniformly, and together, the authors developed the final emergent themes.

Credibility and trustworthiness. To select appropriate participants the researchers recruited from a number of community agencies, social networks, and schools across the state. Participants were screened prior to scheduling the interview to verify that they met criteria for the study. Furthermore, the researcher employed a snowball sampling technique such that each participant was given recruitment flyers and was encouraged to share them with other families who met criteria. Each of these measures was taken to ensure that the sample was purposely identified, effectively recruited, adequate in number, and representative (Brantlinger, Jimenez, Pugach, & Richardson, 2005).

To ensure that the data were credible and trustworthy the researchers employed data triangulation (i.e., questionnaire and semi-structured interview) and researcher reflexivity (i.e., the first author was forthright about her position and perspectives within the context of this research by monitoring her possible biases through field notes, memos, and regular debriefings). Additionally, level two member checks were employed to confirm the accuracy and inaccuracy of the transcript summaries, and to gain support for the researchers' conclusions. Ten out of 11 parents participated in the member checks (i.e., reviewed summaries). Feedback from eight participants confirmed the validity of the researcher's interpretation of the responses. Feedback from two mothers provided clarifications related to diagnoses. For example, one mother's clarifying response was, "The school [early education center] diagnosed her with autism at that time; she was 2 1/2. She did not receive a medical diagnosis from a health care provider until she was 6." Finally, the first author worked collaboratively, with a culturally and ethnically diverse research team with expertise in both content and methodology during data analysis. The team verified transcripts, reviewed and verified summaries, and assisted in coding (Brantlinger et al., 2005).

Findings

After analyzing the data, seven themes emerged as they were related to experiences obtaining diagnoses: (a) navigation, (b) concerns initiated by others, (c) referrals, (d) extended family views, (e) parent knowledge of development and disability, (f) HCP knowledge of ASD, and (g) HCP response to parent concerns. Additionally, seven themes were categorized as experiences related to accessing services: (a) advocacy, (b) partnerships with HCPs, service providers, and educators, (c) sources of support, (d) healthcare coverage and costs, (e) employment, (f) geographical location, and (g) family life events. Finally, three themes were identified in the mother's recommendations for HCPs, service providers, educators, and other parents. These themes include: training, education, and experience. Figure 2 illustrates themes and sub themes related to diagnoses, access to services, and recommendations for practice.

Research Question 1: Experiences Obtaining Initial Diagnoses

The age at diagnosis for the 13 children whose parents participated in this study ranged from 1.5 years to 6 years. The average age at diagnosis was 3.5 years. Five (38.5%) children were not diagnosed with ASD until they were 4 years or older. In regards to their experiences accessing EI services, three of the four mothers who had access to EI often discussed challenges with receiving EI for their children such as inflexible work schedules. The seven mothers who did not have EI services for their children, acknowledged the benefits, and often expressed a desire to have had the opportunity for those services for their children at a young age. During the interviews, mothers were asked to share their experiences related to obtaining an initial diagnosis of ASD. A number of categories and subcategories emerged in their responses to this question that act as facilitators or barriers to obtaining diagnoses for African American children with ASD (see Figure 2).

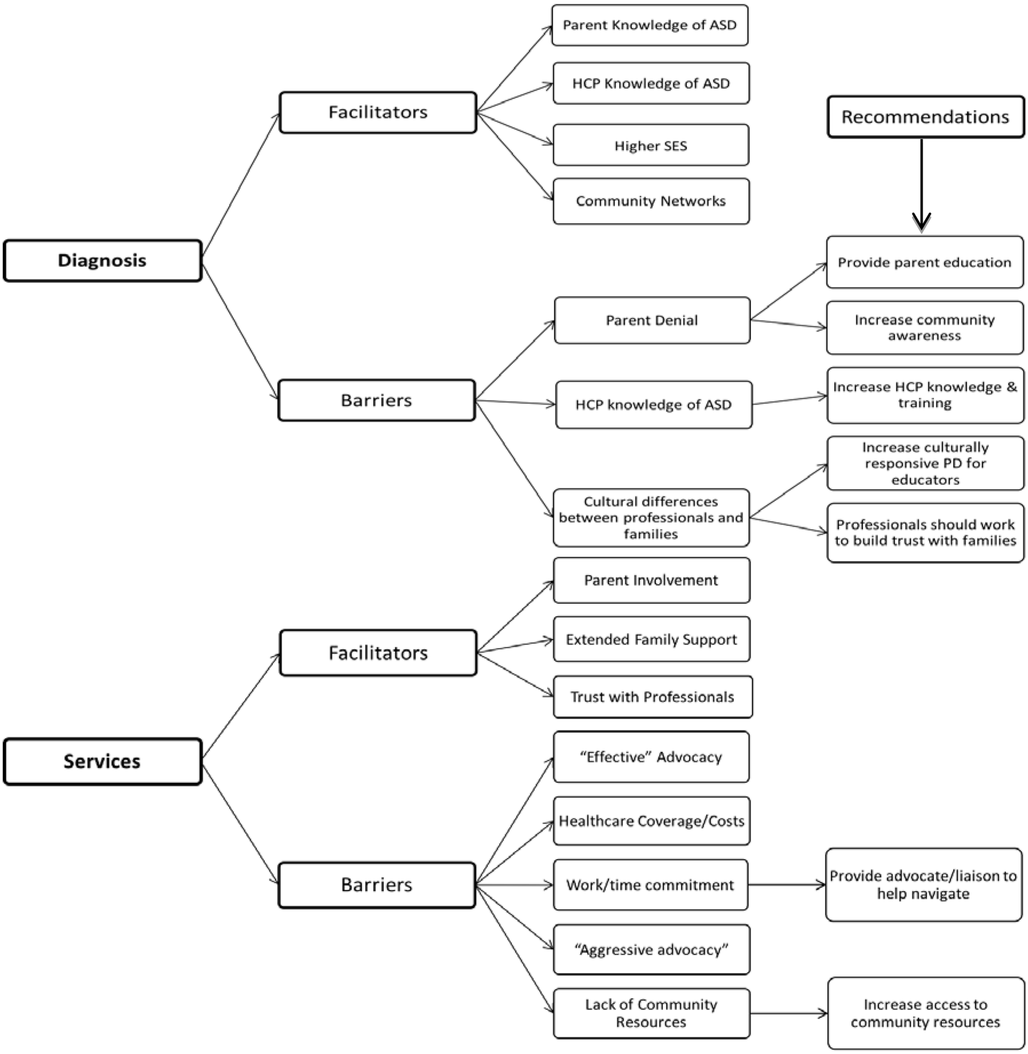


Figure 2. Emergent Categories, Themes, and Recommendations.

Facilitators. During the interviews, a few mothers identified specific factors that helped them obtain diagnoses for their children. These emergent themes referred to as facilitators include: navigation, concerns initiated by others, and referrals.

Navigating the service delivery system. Four participants shared their experiences with navigating the service system when seeking a diagnosis for their child. In instances when they were not able to get immediate attention and services, mothers sought other avenues. For example, Jennifer said:

> Because it took so long to get in to see Dr. M [developmental pediatrician], I went through [community organization] and I was able to get in to see one of their therapists and she was the one who diagnosed him.

In two cases, participants discussed how news and media helped them with navigation related to obtaining a diagnoses and services. Meghan explained:

> I felt like I was frustrated with the doctor because at that time I knew nothing about

> autism. And it just so happened that at that time I think Toni Braxton was coming out and Jenny McCarthy was coming out and I am like oh my gosh, he does that. And, so, I just think that like, if I didn't watch that or see them on Good Morning America, you know, I wouldn't have known anything either. So when it came time to go to the doctor and I filled out his general check-up, I am like, well he doesn't do this. I felt like those are red flags. So, I am like, somebody could have said something. You all could have told me to go here or, you know, but I did it all by myself.

Concerns initiated by others. In two cases, mothers mentioned that someone else (e.g., educators, service providers, friends) brought to their attention that their child's communication, socialization, and/or behaviors were possibly indicative of a disability. For example, during a weekend retreat, Deborah was sharing her concerns about her son's development with a group of friends and expressed that she was not familiar with ASD. She said, "The special ed teacher [friend] said, 'have you ever heard about autism?' I said, 'I heard of it, but I didn't know what it was.' She said, 'well look into that. It could be that.'" Similarly, Laura shared, "He was very busy and that was an issue for me. He wouldn't sit still. And someone [friend] had mentioned to me that he should be checked out. She said, 'you know he might be delayed.'"

Referrals. Deborah explained that it was her friend's referral that helped her obtain a diagnosis for her son. She said,

> There was a lady that worked with me. She works with special needs children.
>
> She asked me to bring him with me. She said, let me just observe him. So, when she was doing a little observing just for me, she said, you know what, it does seem like your friend is right. So, she told me to go through what is called Easter Seals.

Similarly, Linda said, "I watch TV, you know; things tell the signs so I took her to the doctor and let her pediatrician know. She referred me to Dr. M [doctor's name] and he diagnosed her."

Barriers. During the interviews, mothers also discussed a number of factors that created difficulty when they were seeking to obtain diagnoses for their children. These emergent themes referred to as barriers include: extended family members' views, parent knowledge of development and disability, HCPs knowledge of ASD, and HCP responses to parent concerns.

Extended family views. Five participants in this study discussed the ways in which their extended family members' perceptions of their child delayed the process when they were trying to obtain a diagnosis. In some instances, family members noticed characteristics and behaviors that were indicative of a possible disability, but they viewed them as typical behaviors. For example, Meghan shared a story about how her father's views of her son's behaviors conflicted with her own instincts. She said, "He [child] would have those tantrums and I was like, oh my gosh, what is going on. My dad is like, 'he is just a boy.'"

In other instances, participants and family members were more passive in their responses to observed behaviors and characteristics of ASD. That is, they were aware of the problem behaviors, but did not always address them. Laura shared her frustration about her mother's views of her son:

> My mama was a daycare provider and I was like, 'did you really overlook all of this?' I felt like she should have been the first one, but that is her grandbaby so there is nothing wrong with my grandbaby.

Similarly, Lynette said:

> They [her extended family] just kind of avoided it and it became very clear to me that they really were not going to take it serious when they [her children] were showing different behaviors and things–there was a strict intolerance to it.

Parent knowledge of development and disability. Another primary theme related to obtaining diagnoses was parent's general knowledge of child development and disability. In two cases, mothers admitted that they knew little about development and disability, and discussed the role it played in their decisions to seek a diagnosis. In other words, some mothers knew something was different about their child, but they were not exactly confident in their knowledge of the characteristics of disability. Jennifer said, "So that is why I waited a year. It wasn't because I was being naïve about it. It was more so I wanted the school to tell me that they see a problem. Confirm what I already knew."

Other mother's indicated that their knowledge of child development in general, was limited because their child with ASD was also their first child. For example, Deborah shared, "being she is my only child, I was a teacher but I worked with kids five and up. So, if they are walking and talking I could handle that. I wasn't familiar with babies."

HCP knowledge of ASD. One mother who participated in this study indicated that her child's primary HCP lacked the knowledge and/or training to provide timely diagnoses and support. On a number of occasions the doctor actually expressed that she was not familiar with ASD. Lynette explained,

> The first pediatrician we had, she was just a general practitioner. She is like, 'I really don't know anything about it [autism]'. I would come to her and tell her different things and she was just like, 'I really don't know anything about it.'

In other cases, HCPs' knowledge of ASD was reflected in their responses to parents' concerns about their children's development. The fact that HCP's ignored characteristics of ASD in addition to parent concerns appeared to be associated with their actual knowledge of ASD. This phenomenon is described in more detail below.

HCP response to parent concerns. In this study, a frequently mentioned barrier to obtaining diagnoses for African American children with ASD occurred when HCPs ignored parental concerns. Even when mothers brought forth their concerns of a potential delay or disability, they were often challenged by the responses they faced from their child's healthcare provider. Of the 11 mothers who participated in this study, five shared similar experiences. Meghan said:

> So I brought him to the doctor and I am like, 'well he is not pointing. He doesn't wave.' And she said, 'oh you know he is just, he has a delay he will be fine. No need to do anything.' So the next time I went to the doctor I told her, I said, 'he is still not pointing. He is not doing any nonverbal' and she said, 'well you know, some kids, they just have a delay.' So at the next appointment–same thing. I said, 'now he is having like these tantrums.' She said, 'at that age that is normal.' So I took it upon myself, I am like I need to call somebody else because obviously she is not listening to me. So I kept telling her I said, 'well I am seeing more and more about autism' and I started doing the research and I am like, 'can you test him for autism?' and she said at the time, 'well I don't really think he has autism.' And I said, 'well I still want him tested.'

Overall, the most frequently mentioned facilitator for obtaining diagnoses was having the knowledge and resources for swift and effective navigation of services. Two of the most frequently mentioned barriers included HCP response to parent concerns and extended family views of disability.

Research Question 2: Experiences Accessing Services

In terms of experiences with services in school and community environments, mothers reported a number of facilitators and barriers for gaining access to services (see Figure 2). Positive experiences with educators, administrators, and service providers were often facilitated by factors such as advocacy and partnership. Perceived barriers associated with services in schools included teacher training and experiences.

Facilitators for accessing services. Participants discussed a number of facilitators that positively shaped their experiences with gaining access to services. Parent advocacy was a primary theme that was echoed throughout a number of interviews as a strategy to impact action and attention to their child's needs. Other themes that were identified as facilitators of service provision include: (a) partnerships with educators, service providers, and HCPs, (b) general satisfaction with services, and (c) sources of support (see Figure 2).

Advocacy. One of the most fundamental ways that mothers were able to gain access to services for their children was through advocacy. During the interviews, nine out of 11 mothers explained how they have often advocated for the rights and services of their children. Tiffany explained:

> We were able to advocate to get her [aide] to continue to be with our daughter and we even had to be specific in what we wanted to put in her IEP. They didn't want to put personal aide. They wanted to put classroom aide and we had to say, 'I am sorry, we weren't born yesterday. We know the difference and we want a personal aide who is specifically for our daughter not somebody that you can pool and do whatever you need.'

Pursuit of knowledge. Another facilitator that aided in parents' ability to access timely and appropriate services for their children was the pursuit of knowledge- a subcategory of parent advocacy. Four mothers discussed the efforts they made to increase both their general knowledge about ASD, and their knowledge of the services that were available for their children. For example, Tameka shared, "It's just me taking advantage and going to the classes and trying to learn stuff."

Similarly, Lynette shared, "I had to go for parental classes. So, they could teach us how to work with the children in therapy. I think it was like four or five sessions of that for myself."

Dissemination of knowledge. A second subcategory of parent advocacy was dissemination of knowledge. During the interviews, three mothers who discussed their efforts to gain knowledge, also shared the knowledge they had acquired, with family members, friends, and other individuals in their communities. Meghan said, "'cause I would educate anybody in a minute. I take them to the side, 'don't judge him. He has autism.'" Deborah said, "I put it on my social networks. I try to talk to parents in the school and let them know, hey they are offering this for the kids."

Partnerships. Another facilitator for accessing services was the development of collaborative partnerships between the parents (primarily mothers) and the educators, service providers, and healthcare providers. Moreover, some of these partnerships were with individuals in the community who connected the families to the appropriate administrator or service provider (i.e., external partnership). Of the 11 mothers who participated in this study, six of them discussed the partnerships they developed and the impact that these partnerships had on their experiences. Meghan shared her experiences with a teacher who did not have any previous experience teaching children with ASD. Over time however, she was able to develop a partnership with him that led to more collaboration and positive outcomes. She said:

> The teacher went to different seminars about autism. So, he was trying to educate himself. He tried his best . . . He would text me all the time and I would text him. And, when J [child's name] forgets his homework he takes a picture of it and texts it to me.

Sources of support. During the interviews, several mothers expressed how they were able to cope with the challenges, frustrations, and barriers they often faced when seeking access to services for their children. They often relied on their sources of support as avenues of encouragement, strength, and perseverance to continue to advocate for services for their children. The two primary sources of support that the mothers referenced were faith and family.

Faith. Five mothers in this study referenced their faith as source of support. Tiffany said, "Our family has done amazing, I would say, by God's grace." Similarly, Ebony said, "The first 4 and a half months of her life it was very dire financially. It was really just the grace of God. It [faith] has kept me sane."

Family. During the diagnosis process, mothers often described many of their family members' perceptions of disability (ASD in particular) as a challenge, or barrier. Once mothers were seeking or obtaining access to services however, they described more positive dynamics of their relationships with their family members. For example, Tameka explained,

> Blessedly we had his [child's father] mom because she was babysitting for us. The early intervention really sucks if you are not the one at home. So she became our stay at home parent. The services were happening in her house and she was very good.

Tiffany acknowledged how pivotal it was to have the support of her husband as she coped with the experiences and challenges of parenting a child with ASD. She said, "I am fortunate to have a husband. How many of these kids, particularly African American children, are in single-family homes, particularly single moms, who don't have the emotional support as they are going through the stages of grief."

Barriers. When asked about their experiences accessing services, participants also discussed a number of factors that inhibited their access to services, or created challenges with service delivery. The emergent categories of barriers included: healthcare coverage and costs, employment, geographical location, and family life events.

Healthcare Coverage and Costs. Five participants discussed the impact that private healthcare coverage in particular, has had on their ability to access services. These mothers explained that they were better able to access services when their children were covered under state plans as opposed to private insurance. Tiffany shared,

> It is unbelievable how much it would cost and not only just meeting deductibles. For example, The Autism Center was $200 per semester; $200 to some people is a lot, and others it's like okay. But they are actually changing and they are going to be billing insurance in the spring. And because it is the beginning of the New Year, guess what that means? You have to meet your deductible all over again, so you are going to be paying thousands of dollars out of pocket to get services from somebody who doesn't even have their master's degree yet. Therefore, my daughter will not be able to continue services there.

Lynette explained a common experience that families who have private insurance often face, "I think where parents run into problems with insurance is when you have private insurance because they won't cover a lot of things." Three other mothers echoed experiences where they make too much to qualify for state coverage, and too little to afford the co-pays and out of pocket expenses associated with private coverage.

Employment. For a few parents, particularly single, working moms, employment was in some ways, a barrier to service delivery. For example, Tameka said, "If you are a working parent it [EI] doesn't work as well." She went on to say:

> I really hate that I have to work. Not to say that it would be so much easier if I wasn't working; at least I could devote more time and energy to it [accessing services] if I wasn't working. The only time you can truly focus on it [implementing strategies] is on the weekend because once you get home from work it is just like, feed them, go to bed.

Geographical location. The three mothers who live in rural areas expressed a number of challenges related to the accessibility of services due to their geographical location. Tiffany shared how her location has been a barrier for accessing services for her daughter. She explained,

> There are limited resources in southern [state] altogether, and being able to get ABA therapy specifically; we haven't been able to do that. We tried to get ABA therapy and the closest place is like 45 minutes away and I would have to go up there a couple days a week. Driving 45 minutes to get therapy and having [three] other children is ridiculous.

Family life events. Four mothers discussed a number family life events that sometimes either impacted their ability to access services, interrupted services, or created a need for additional services for their children. Some examples of these family life events include unstable housing (i.e., moving to and from a number of shelters), relocating, divorce, child abuse and trauma, illness of a spouse, and the death of a loved one. Laura explained how it was often difficult for her to focus on getting services for her son because she had to prioritize the immediate needs of her family. She said, "My mom was ill. He was diagnosed while she was ill. It was just so much. There was just so much going on at the time." When discussing the challenges of finances as a single parent mother, Deborah explained the following,

> Every month I am behind I'm constantly juggling the car note and rent, making do and I shouldn't have to. I am a supervisor, I

> make decent money. I think I make more money than I have ever made in my life. I should not, you know be needing the child support. I wouldn't have to work overtime. I would have more time to spend with her, to do things, you know, so that is the reality. And, I think the other reality is a lot of people don't want to hear it. Or they don't accept, I think it is just assumed well, you are a single parent, you have to do two jobs. Well I don't want to have to do that.

More than one third of the mothers who participated in this study experienced family life events that impacted their ability to obtain or maintain services for their children with ASD. As such, these experiences were not only stressors, but also external barriers that affected their ability to access services for their children.

Research Question 3: Mothers' Recommendations

At the end of each interview, mothers were asked, *What recommendations do you have for educators, service providers, and healthcare providers to better serve the needs of African American children with ASD?* Their recommendations are discussed below (see Figure 2).

Educators. The primary category that emerged for educators was specialized training and experience in autism. Ebony said,

> I think teachers should be specialized in what they teach. Her teacher has a special education certification, not a certification in autism, and there is a difference. She has had teachers that are specialized in autism and I could see the difference immediately.

Other recommendations for educators include expansion of after school services and better communication with parents.

Healthcare providers. When participants were asked about their recommendations for healthcare providers, the primary category that emerged was knowledge and training for HCPs. For example, Laura said, "they just have to seek experience because doctors are not going to say I don't know. You know, just 'cause you have years of experience, don't mean you have years of good experience." Similarly, Meghan said:

> I feel like maybe because of lack of knowledge and education, they should be more, what is the word? Not focus—but you know. Like I feel like I got turned away so many times. You know, and if I didn't go on there and Google or read he probably still wouldn't be diagnosed.

Lynette also discussed the importance of training for HCPs, "I think medical professionals, they definitely need to teach this in the schools because it doesn't make any sense for a parent to get a diagnosis and go back to their pediatrician and they can't help them."

Interestingly, Ebony provided a suggestion that would play on the strengths of HCPs specialties. She said:

> If a pediatrician has a patient with autism, I think the appointment should be tag teamed with a developmental pediatrician. Once a year it should be a team appointment; general and developmental pediatricians and then maybe they can take a video or something. They would get a better idea of what was going on developmentally.

In addition to recommendations related to training, education, and areas of specialty, participants recommended that HCPs be more responsive to parents' concerns. Tiffany said,

> I recommend that educators, health professionals, and other service providers really listen to the parents. I think everybody is so busy and time is so limited that, you know, things fall between the cracks. Because in our case, I think our daughter should have been diagnosed a whole lot sooner than she was.

Finally, one parent provided a recommendation for healthcare providers that would help parents navigate the service system. Tameka said,

> It would be nice if upon discovery there was more than just some print out that they were handing you–if there was an actual person that they could hand you. Like the social services person– have that person you can call.

Parents. Many recommendations provided by participants were actually for other parents.

The primary emergent theme was a need for parent education and support. Tiffany said, "Parents not only need to know the resources that are available and how to access them, but they need training themselves." Similarly, Michelle shared:

> For me, the biggest thing is to help me to understand or help me to help him; not the generic class, but maybe what your particular child might need. More parent education as far as, how to navigate these systems.

Discussion

The purpose of this study was to explore the perceived factors that facilitate and impede early diagnoses for African American children with ASD in grades K-5 by investigating parents' experiences gaining access to services. Overall, participants in this study indicated that (a) there is a need for more parent education and training around ASD for African American families, (b) HCPs should be more responsive to the concerns of African American parents of children with ASD, and (c) HCPs should be more knowledgeable of ASD diagnostic criteria. The participants also recommended specialized training and experience in ASD for educators. The following section is organized by the research questions that guided this investigation.

Obtaining Diagnoses

Previous research findings have indicated that the early childhood years are critical for children with ASD because the earlier a child is identified, the greater the likelihood that he or she will benefit from interventions and services designed to address his or her needs (Bruder, 2010; Irvin et al., 2011). African American children with ASD whose parents participated in this study were diagnosed on average, at 3.5 years old. At age 3, young children age out of early intervention services; moreover, these families and children have likely not had any exposure to parenting programs, community programs, or support groups, for example.

Overall, findings from this study indicate that mothers' perceptions of facilitators for obtaining diagnoses for African American children with ASD include navigation, concerns initiated by others, and referrals. Previous studies have not highlighted facilitators for obtaining diagnoses; therefore, this study extends the current literature in this domain. Furthermore, factors described by other researchers as barriers to obtaining diagnoses for African American children with ASD include extended family members' views (Gourdine et al., 2011), parent knowledge of development and disability, HCP knowledge of ASD (Mandell, Ittenbach, Levy, & Pinto-Martin, 2007; Zuckerman et al., 2013), and HCP responses to parent concerns (Reichard et al., 2004). These findings not only support previous work, but also extend the literature around barriers to access for African American families of children with ASD in two ways. First, the current study includes in-depth interviews with 11 African American mothers of children with ASD; the only other qualitative study to address the experiences of African American parents of children with ASD was a single-family case study (Gourdine et al., 2011). Second, unlike many of the quantitative studies that have been conducted around ASD and African American children, the qualitative data from this study highlight specific experiences of African American families and provide examples of both barriers and facilitators for obtaining diagnoses and gaining access to services.

Gaining Access to Services

Positive experiences with educators, administrators, and service providers in the school were often facilitated by factors such as advocacy and partnership. Perceived barriers associated with services in schools included limited teacher training and experience. Three out of 11 mothers who participated in this study were receiving various types of home and community-based services for their children (e.g., play therapy, ABA therapy, social skills group), on average, for three hours per week. The primary service these families received in the community was social skills groups. In addition, those mothers of children with ASD who live in rural areas of the state expressed more difficulties with accessing community services than those who live in urban areas.

Recommendations

The participants provided various recommendations for educators, healthcare providers, and parents to better address the needs of families of children with ASD. Their primary recommendations suggest that educators and healthcare providers need more training and experiences specific to ASD. Mothers emphasized the point that learning about ASD is not enough and experience is crucial. Moreover, the mothers suggested that parents need more training and support. These recommendations support the previous work of Gourdine and colleagues (2011) that suggests that African American parents need more opportunities to access information on ASD, and HCPs need more training (Zuckerman et al., 2013).

Finally, mothers suggested that all service providers be more receptive to the voices and concerns of African American parents of children with ASD. The recent work of Zuckerman and colleagues (2015) based on their nationally representative sample of children with ASD, indicates that diagnosis is delayed by as much as three years after the first parental conversation with the healthcare provider. The findings from the current study corroborate previous work that suggests that (a) many families of children with ASD and other developmental disabilities from minority and nonminority backgrounds face difficulties finding competent and trustworthy practitioners and want them to show more concern (Reichard, et al. 2004; Zuckerman, Lindly, & Sinche, 2015), and (b) there is a need for more support for HCPs to be better prepared to provide earlier diagnoses that will help young children with ASD and their families gain access to early intervention.

Limitations and Implications

Limitations. The primary limitation in this study was that participants were all mothers, and not representative of the SES and marital status of African American families overall. Future studies should aim to recruit more representative families. Moreover, this study was based solely on mother's reports, which may have influenced the accuracy of results (e.g., the number of services received in school). A review of IEPs and other school documents might be helpful in addressing this limitation in future studies. Finally, this study focused specifically on the experiences of African American mother's of children with ASD. The interviews from this study provide rich information about the lived experiences specific to these families. Therefore, comparisons cannot be drawn about the differences in diagnoses and access to services between African American families of children with ASD, and families from other racial backgrounds. It does, however, elucidate the voice of African American parents of children with ASD, little of which has been done in the literature to date.

Implications for research. Given these limitations, future research in this domain should: (a) include a larger sample of African American parents of children with ASD from various locations across the country, (b) include interviews with African American fathers of children with ASD, (c) explore pliant barriers and facilitators (i.e., those barriers in some families, that may be facilitators for others), and (d) include interviews with educators, HCPs, and service providers to gain their perspective on providing services for African American children with ASD and their families. Future research might also employ additional sources of information such as IEP or teacher reports.

Participants in this study identified a number of facilitators for accessing services and coping with challenges (e.g., advocacy, collaborative partnerships with professionals, and identifying and tapping into sources of support). Future intervention research should aim to develop and examine the effectiveness of parent-advocacy trainings that (a) embed empowerment practices as a component of the intervention, (b) emphasize advocacy, partnerships with professionals, and knowledge of ASD (e.g., social communication strategies) as tools for gaining access to services, and (c) rely on a sociocultural theoretical approach whereupon African American families can engage with each other, share knowledge of resources, share experiences, help brainstorm, and troubleshoot challenges related to their experiences as parents of children with ASD through critical reflection and discussion (Baumgartner, 2001).

Implications for practice. First, the findings from this study indicate that there is a need for more positive partnerships between healthcare providers and African American parents. Second, African American parents and extended family members should receive more training and education to increase (a) their knowledge and awareness of ASD, (b) their knowledge of available services for children with ASD, and (c) their knowledge and skillset for effective advocacy. ASD occurs once in every 68 children (CDC, 2016) and, although the prevalence is consistent across racial and ethnic backgrounds, the reported incidence of ASD is not. Participants in this study indicated that they and their family members were sometimes unfamiliar with ASD and didn't realize the frequency with which it occurs in the African American community. Therefore, news and media sources should aim to be more representative by showing the faces and sharing the voices and experiences of African American families of children with ASD. It is plausible that this exposure will not only increase awareness, but also enable family members to feel more empowered and able to advocate for their children, even when healthcare providers fail to provide timely and accurate diagnoses.

This study extends the research on ASD in African American children by elaborating on the findings from correlational designs and highlighting the lived experiences of these families. In addition, unlike previous research in this domain, this study highlights facilitators, in addition to barriers to obtaining diagnoses and gaining access to services. Having better knowledge of both facilitators and barriers alike could potentially shape future practices.

Conclusion. The findings from this study support previous research that suggests that African American parents face difficulties with healthcare providers who either have limited knowledge of ASD (Zuckerman et al., 2013) or are not responsive to parental concerns related to ASD or disability (Zuckerman et al., 2015). This points to the need for more HCP training not only specific to the characteristics of ASD, but training that also better prepares providers to respond appropriately to parental concerns. The findings from this study also add to existing literature by sharing the voices and untold experiences of 11 African American mothers of children with ASD. Future practice around diagnoses and services for children with ASD should aim to prepare (a) knowledgeable (in regards to ASD) and responsive healthcare providers, (b) experienced and responsive educators and service providers, and (c) strong parent advocates, who together, can address the needs specific to African American children with ASD and their families.

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