



HELPING PARENTS OF CHILDREN WITH ASD FIND APPROPRIATE FAMILY SUPPORT

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— ABSTRACT —

Parents finding out they have a child diagnosed with autism spectrum disorder (ASD) are often frustrated and feel isolated when looking for family support to help them cope. They may come to speech-language pathologists (SLPs) and audiologists for evaluations and therapy, but these professionals often focus their discussions with the parents on the evaluation findings and issues with therapy related to the children. What these professionals miss is discussing where the parents can find support in their communities to be more successful dealing with their children while finding others with whom they can share frustrations and concerns. These interactions cannot only help parents with their children, but also bridge the gap with professionals and the children's caregivers.

This article discusses the lack of support for Black parents who have a child with ASD and the emotional feelings, concerns, and frustrations these parents identify dealing with their child. This will also include misconceptions that are faced by these parents and the negative interactions these parents have with the schools, with medical professionals, and others. The purpose of the article is for SLPs and Audiologists to engage with families and provide appropriate discussions regarding where the families can obtain adequate community support and services.

Key Words: autism spectrum disorder, Black parents, audiologists, speech-language pathologists

Speech-language pathologists (SLPs) and audiologists who deal with children who are diagnosed with autism spectrum disorder (ASD) often engage in evaluating issues with these children as well as providing therapy for these children. They may ask questions of the parents typically focusing on issues related specifically to the child. What these professionals may miss is engaging parents in discussions regarding where these families may find support when they have questions.

What is Available for Parents of Children ASD

In reviewing what is published regarding involvement of SLPs with parents of children diagnosed with ASD, the review indicated that the overwhelming material on the internet where parents may search focuses on what these professionals can provide regarding therapy for their child. The material also discusses how the SLP can work with the parent to help them learn how to support the speech, language, and communication therapy at home that is provided to the child by the SLP. For example, the Autism Speaks website (<https://www.autismspeaks.org/science-blog/speech-language-pathologists-and-autism-learn-how-we-can-help>) discusses “Speech-language pathologists and autism: Learn how we can help focusing on the therapy and communication training for these children with ASD as well as early intervention and early diagnosis of the children’s communication problems.” However, there is nothing regarding where the parents can find community support for any issues or concerns that are affecting the parents and the family as a whole. In an article published in *Focus on Autism and Other Developmental Disabilities* (Beverly & Matthews, 2021) the authors focus their research solely on what SLPs and parents of children with ASD feel about how prepared the SLPs working with the children with ASD are regarding dealing successfully providing speech, language, and communication therapy for these children. There was nothing in their research that discussed the SLP’s interactions with parents regarding support the parents wanted and needed to deal better with their child with ASD as well as support for the parent’s feelings and concerns.

Our national professional association, the American Speech-Language-Hearing Association (ASHA; n.d.) has an online publication regarding Autism (Autism Spectrum Disorder) and the role of the SLP working with such clients. In reviewing this publication, it was noted that the factors discussed are only: information about the definition of Autism (ASD), “Signs and Symptoms” the SLP may see in a child indicating the child may have ASD, the “Causes of

ASD”, what parents and other professionals may need to know regarding “Seeing a Professional” and what the SLP may need to know about other professionals who work with children with ASD, along with “Other Resources”. In the section on “Seeing a Professional”, it was identified that the publication focuses on evaluation/assessments for people with ASD as well as treatments that the SLP may provide for people with ASD. In the section on “Other Resources”, ASHA identifies other places people can check out about information regarding ASD. These places include Autism Navigator, Autism Self-Advocacy Network, Autism Society of America, Autism Speaks, Autism Today, Centers for Disease Control and Prevention, Autism Information Center, and the National Institute of Mental Health Autism Information. Reviewing each of these links in the ASHA publication, the following was identified regarding resources for parents in general versus resources for parents who are Black.

Review of Autism Navigator has a specific “link” for parents called “Family Resources”. One of these links is to a “Virtual Community for Families” which focuses on children one to eight years old. This link indicates that the community discussion focuses on information about speech, language, communication, and behavioral issues in children which may indicate ASD, or which may be found in a child identified with ASD. However, the link does not discuss concerns parents may have and frustrations parents may feel and the fact that they can share such issues on this virtual link. While the above link is for parents of children one to eight years of age, there is also a link specifically for parents of children 24 months old and younger. However, this link focuses on the speech, language, and communication factors as well as behavioral issues that may indicate that these young children may have ASD. Thus, there is nothing specifically for parents regarding their personal concerns and where they may find support and help for these issues.

The Autism “Self-Advocacy” link is more for specifics regarding how older children and adolescents and adults can advocate for their needs and issues since they have ASD. It does not focus on families and their specific needs nor on any advocacy they may need.

The Autism Society of America (ASA) provides information regarding local groups that focus on families having children with ASD as well as people with ASD who may be ready for self-learning and advocacy as older adolescents and adults. There may be some support through this Society for families, but they would need to contact their local ASA group to find out.

One concern the authors have identified is the following. One of the authors has a child with ASD and the child's parents went to an ASA meeting. At the meeting there were many families present, but of the nearly 50 families having children with ASD, only two were Black. Thus, would this group of largely White families be able to appropriately reflect on concerns the Black parents have because the group was predominantly White families?

As for the Autism Speaks organization, some of their focus was discussed earlier. However, going to their website what was noticed was that there is a specific link for Parents where they can find some resources. Viewing the resources noted on that link they were mostly regarding information about the person with ASD and that person's specific issues and not issues that parents may have.

The Autism Today link is specifically for parents providing examples of books, videos, and articles about ASD and people, especially children with ASD. There appears to be little focus on where parents of children with ASD can find support for the parents' needs, concerns, emotional frustrations, etc. This led the first author to conduct a comprehensive research study identifying what resources parents have children with ASD find in their communities when the families are Black.

Method

Participants

The researcher developed specific questions and asked them of the parents. These questions involved what resources the parents identified to provide them help when questions or needs arose regarding their child with ASD. Additionally, questions were asked regarding health issues identified by the parents and where they discovered resources to assist them with these problems, and what the parents learned regarding access to community resources and programs.

Consent forms and interview questions were provided to each participant prior to the interviews by email or by mailing them a printed copy. Interviews were conducted either in person or by phone. The researcher did not change her interviewing style between the in person and by phone interviews.

The semi-structured questions were designed for managing the interviews being subdivided into four focus areas, with a set of questions on each of these areas. The four areas were: 1). personal experiences, 2). social support/relationships, 3). community/emotional support, and 4). what needs to be done. Few follow up questions were asked due to the personal

and uncomfortable nature of some of the questions and out of respect to the participants' time and need to spend limited time away from being with their child who has ASD.

For the participants who agreed to meet with the researcher, accommodations were provided by scheduling interviews after church services were completed, due to this being a familiar and similar setting for both the participants and the researcher. The researcher also was sensitive to the limited time available for participants due to parenting responsibilities of a child with ASD. Participants who were interviewed by phone specifically cited attending to the needs of their child as a reason to request an interview that was not conducted in person.

The researcher employed a semi-structured, one-on-one interview methodology to gather rich detail and insight into the daily experiences of families who have children diagnosed with ASD. The researcher focused on asking questions from each of the four categories, but also probed the parent to expand answers provided to better understand their experiences raising a child with ASD.

Phenomenology is the study of experiences from the first-person point of view or centering on that person's experiences while investigating how they communicate with others. Phenomenology describes the common factors identified with several individuals based on their experiences related to a concept or phenomenon. Phenomenological methodologies rely on descriptions of experiences lived to develop an understanding of the meaning of human interactions in everyday life (Schwandt, 2001). By using a phenomenological approach for this research, common or shared experiences of a phenomenon for several individuals can be understood (Creswell & Miller, 2000). This method develops a deeper understanding about the features of the phenomenon (Moustakas, 1994) and provides numerous examples of phenomena that have been identified.

The present research examined the experiences of parents of Black children with ASD employing self-reported data through in-depth interviews. There are three methods used in this study (Elliott, 2005; Pinnegar & Daynes, 2007). First, the sociocultural focus is on cultural considerations which influence the individual parent's experiences. Second, a focus on rich descriptions of the participants' stories about significant issues and their children, are provided. Third, the literary approach is used to complement both the sociocultural focus and the focus on rich description in order to describe experiences adequately (Denzin & Lincoln, 2011).

Procedures

The researcher met socially and privately with participating parents and took notes. The in-depth questions developed by the researcher (i.e., the first author) were presented to get concrete information regarding whether Black parents received or found support for their concerns about their child diagnosed with ASD, and input regarding from whom this information was obtained and what, specifically, was told to them. Additionally, general discussions were held to expand on what the parents said and clarify issues that they presented.

The researcher took notes and, later, reviewed the notes focusing on themes that were identified as common among the 12 participating families. The study employed one-on-one interviews to obtain information and perceptions of Black families of children with ASD. The one-on-one interviews provided the opportunity to better understand the experiences of raising a child with ASD in a Black family and how emotional, social, and caregiving support can affect that experience.

Data collection in phenomenological studies often consists of in-depth interviews with participants, although sometimes data is collected as part of a focus group (Polkinghorne, 1989). Using in-depth interviews establishes a cohesive partnership between the researcher and the participants. Denzin and Lincoln (2011) suggest conducting qualitative research which leads to empowering individuals to share their stories and have their voices heard. Qualitative research also functions to minimize the power differential in relationships that often exist between a researcher and the participants in a study.

Phenomenology is the study of what the individual experiences and how the experience is received and explained both internally and personally when presented to others (Moustakas, 1994). Phenomenology was used to describe the experiences of these Black parents of children with ASD. A phenomenological study attempts to set aside biases and preconceived assumptions of human experiences, feelings, and responses to a particular situation. Phenomenological research refers to researching how an individual perceives the meaning of an event, as opposed to how the event exists beyond the perception of people through a descriptive passage that discusses the essence of the experience for individuals. Moustakas (1994) argues that the experiences of individuals and how they have both subjective experiences of the phenomenon and objective experiences of something in common with other people are important. This research form endeavors to understand what a group of people felt during a phenomenon. Perceptions, perspectives, and understanding are all going to be analyzed and then used to create an understanding

of what it is like to experience autism within a Black family. Within interdisciplinary fields of study, phenomenology attempts to bring pure, untainted data from those who have experienced the phenomena. Deeply rooted in philosophy, this form of research certainly has its benefits, including a unique perspective to the experience, an intimate understanding of how the family's experiences are different, but at the same time, the similar, and rich data explaining daily, lived experiences (Maxwell, 2013).

The fundamental goal of the approach is to arrive at a description of the nature of the particular phenomenon that is rich in detail (Creswell, 2013). In-depth interviews with Black parents who have first-hand knowledge of autism as they are raising their children with ASD provide a rich description of this lived experience. The interviews answer broad questions (Moustakas, 1994) related to what is experienced in terms of the phenomenon and what contexts or situations typically influence the experiences of the phenomenon being studied (Creswell, 2013). Through this process the researcher asks the study participants to explain their daily, life experiences and arrive at a shared understanding of the phenomenon.

Results

The interview data from Black parents raising children with ASD provides voice to their daily experiences of the challenges and difficulties of parenting a child with special needs. Many different themes, especially Major/Primary Themes (see Table 1), arose from the interview data, using the parents' explanations of how they met the challenges and difficulties of raising a child with ASD and how they seek support or encouragement in dealing with the frustrations of parenting, additional stress of rearing a child with ASD, and what support they wish was provided for them from the medical community, including SLPs and Audiologists, within their family and from "friends groups" at their places of religious worship.

Results from the input provided by these Black parents of children diagnosed with ASD revealed high stress levels with these parents negatively affected by significant disparities when seeking and receiving healthcare. Black families with children with ASD cite the significance of religion, community, and family involvement as important providers of emotional support. They rely on many people for emotional and spiritual support, including their families, church members, and friends.

One significant factor identified was how these Black parents have come to accept or be stigmatized having a child with ASD. Parents and caregivers of children with ASD feel they need continued social

and spiritual support and information about autism. The support and information they seek can be provided by family and friends, faith communities, and healthcare providers, including SLPs and audiologists.

Specifically, the themes or categories of data identified from the interviews included inequalities in the diagnosis and treatment of Black children with ASD and disparities across all services provided to the children which was a constant theme.

The Health Belief Model (HBM) helps explain the frustrations of Black parents who seek medical treatment and services for their children with ASD. HBM identifies perceptions of those studied being important predictors of whether the person will seek treatment and how motivated these people are to change their behaviors. For the present study, the perceptions of severity and susceptibility and the concerns about barriers to receiving treatment were identified as very important. Black parents of children with ASD face many barriers when trying to get their children diagnosed with ASD, and after strong advocacy to obtain appropriate assessments, they must continue to forcefully request services and treatments for their children. HBM also identifies perceived benefits of behavior change as impacting whether changes are made. Parents of Black children with ASD are typically very motivated to pursue medical and other interventions for their children as they believe there are benefits from such interventions. Medical professionals, including Speech-Language Pathologists and Audiologists, need to understand the gravity of health disparities Black families face when seeking medical care and treatments, especially for ASD-related issues, and help remove these barriers which prevent access to beneficial services.

Parents interviewed for this study also mentioned many times their frustrations with the process of getting their child properly diagnosed with ASD and their desire that medical professionals would be more proactive in observing changes in their children which would indicate a possible ASD diagnosis. Following the diagnosis, Black parents in this study recommend and request that medical professionals including SLPs and audiologists proactively provide information about autism and how to access services for their children, especially since the ASD diagnosis itself is life changing and usually prompts feelings of helplessness and uncertainty for parents.

The theory of intersectionality also helps explain this disparity in receiving diagnosis for ASD and treatment for young Black children. This study provides the phenomenological daily experiences of mothers who are raising a child with ASD. As intersectionality reveals intersections of oppression,

health disparities can be better understood. Intersectionality shows that women seeking healthcare services for their Black children with ASD can experience health disparities because of their many layers of identity, including race, gender, age, socioeconomic status, etc. Concerns raised by women with medical professionals are more likely to be dismissed without appropriate testing or treatment. There is a longstanding history of healthcare segregation based on race. When a Black mother of a child with ASD advocates for her child with medical professionals, including SLP and Audiologists, her concerns are likely ignored. Black fathers of children with ASD are also likely to have their concerns dismissed or minimized by such professionals. Although men are not typically burdened by their gender, they, too, can experience multiple intersections of oppression. Regardless of profession or socioeconomic status, Black men also face discrimination from medical professionals and are less likely to have their concerns addressed, tested, or treated than their middle-class White peers.

The parents of Black children with ASD interviewed for this study constantly mention community support as being an important need for them to adequately reduce their own stresses and provide a loving home for their children. Community support in this study can be defined as any support outside of the family unit. Extended family, friends, community groups, and church groups are all entities from which support is desired by parents of Black children with ASD.

Lack of resources is a continual concern for these parents. Geographically, resources may not be readily available for Black children with ASD. Additionally, parents of children with autism may not even be informed by medical professionals or government agencies that resources are or should be available for their children. Healthcare practitioners may neglect to tell Black parents of children with autism about resources or where to seek them because they believe the parent will not be motivated to seek this assistance. Thus, medical and health professionals, including SLP and Audiologists, may be a barrier as identified in the HBM to better healthcare due to their beliefs about their patients or their patients' caregivers. Because Blacks are often stigmatized by medical professionals and experience health disparities because of these stigmatizations, their healthcare is substandard.

Many of the Black parents of children with autism interviewed for this study believe media messages about autism are typically positive, but not necessarily realistic. Because people with ASD are depicted. Parents of children with ASD would prefer that persons with autism are depicted in the media as having abilities and skills across the autism spectrum.

Table 1*Major/Primary Themes Identified from the Interviews with Black Parents of Children with ASD*

Theme	Description	Sample Quotes (when appropriate)
High Levels of Stress	Parents felt that there were many challenges and difficulties raising a child with ASD that caused parental stress.	
Lack of Resources	Parents felt they did not have appropriate support to help them overcome the challenges and difficulties. (This includes services by SLPs and Audiologists.)	<i>“Practitioners should have information to share with families, schools should have a person available to reach out to families, provide seminars and information packets, institutions should provide fair and adequate resources and funding to all families.”</i>
Access to Healthcare and Limited Services	Stress was made worse because of problems obtaining appropriate healthcare and services their child with ASD needed.	
Problems Obtaining Information Regarding Their Children with ASD.		<i>“Many of us are not in environments where information is easily accessible and, as a result, some of our children get diagnosed much later and get services or help later than other ethnic groups.”</i>
Being Stigmatized Having a Child with ASD	Many Parents felt that people and the media view ASD in very negative ways which stigmatized them, their families and, especially, their child.	
Significant Healthcare Disparities for Black Families	There are many barriers that Black Families may face when seeking appropriate services for their children, especially a child with ASD, including SLP and Audiology services.	
Obtaining Appropriate Diagnosis for Their Child with ASD	Often the child with ASD was diagnosed with some other emotional or behavioral disorder which was later found to be inappropriate. (This is very important for SLPs and Audiologists to consider.)	
Obtaining Appropriate Treatment for Their Child with ASD	Schools often provided inappropriate IEPs for their children, or a lack of appropriate services and Parents often did not know where to go for appropriate services. (This is very important for SLPs and Audiologists.)	
Media Messages about Autism	Autism is often viewed negatively in the media.	<i>“The message that I receive from media is that autism is a cookie cutter disability, and it is not. I am constantly amazed at the things that my child and my students achieve and develop as they grow.”</i>

Unfortunately, media still provides very negative depictions of ASD as well, portraying children as well as adults as awkward and unpredictable which further stigmatizes and makes others hesitant to interact with children with ASD.

Lack of awareness of autism in the United States is an ongoing problem for Black parents raising children with ASD. Because autism is still viewed as different or exotic, and those beliefs are furthered by negative media images, autism and children with ASD are negatively stigmatized. Parents interviewed for this study prefer that people approach them personally and ask questions about autism so they can help others become aware of autism and how children are affected by the spectrum both with their abilities and limitations. The need to bring more awareness to ASD is also believed to be important, so that society as a whole must make an effort to build awareness of autism and not just rely upon persons with ASD or their caregiving parents to inform others about autism and how it impacts their Black families.

Conclusion

As a Black parent of a child with ASD, there are many challenges in daily life. One of the large challenges is communicating with one's child with ASD who may have varying abilities to understand verbal and nonverbal communication and may be severely limited in communicating to others both verbally and nonverbally. Caregiving for someone who has difficulty communicating is a challenge and adds stress to parents of Black children with ASD. This stress of communicating can be reduced somewhat as parents identify how to best communicate with their child with ASD and how the child's abilities can be utilized to communicate effectively. The stress of all those identified in interviews involved in the present study is addressed solely by those who have experience working with persons with ASD, such as medical professionals, educators, and SLP and Audiologists. Additionally, parents of children with ASD who are willing to help and mentor other parents of children with ASD can be an important part of supporting and helping these other parents, especially Black parents.

The responsibilities of caring for a child with ASD are great and can be alleviated somewhat by the nurturing social support of others. Limited social support was mentioned many times by the Black parents of children with ASD interviewed for this study. Social support can be provided by friends, family members, and members of church groups, etc. Listening to the parent of a child with ASD, being willing to listen to venting about frustrations and stresses of

raising such a child and providing opportunities to do something other than caregiving are all welcome ways for professionals, such as SLP and Audiologists to provide social support to parents of Black children with ASD. Table 2 outlines some of the support parents identified they found, which SLPs and Audiologists can share with Black families having a child with ASD.

Raising a child is a stressful experience. However, raising a child with ASD is additionally stressful due to special needs that children with autism have. The Black parents of children with autism interviewed for this study also talked about the heavy stresses the entire family faces when raising a child with ASD. In this phenomenological study of daily lived experiences of Black parents of children with autism, it is important to highlight the many stresses experienced when caregiving for such a child.

Receiving the information that a child has been diagnosed with ASD is almost a universally devastating experience for the Black parents as identified by the parents interviewed for the present study. The initial finding was negative experiences and feelings of hopelessness and helplessness which were common among these parents. However, some of the parents were able to quickly reframe their frustration and grief into recognizing that parenting a Black child with ASD is a blessing to them and their families. Because of the religious and spiritual beliefs of the parents interviewed, some of them are able to realize the blessings of learning from their children with ASD and appreciating the perspective that a child with ASD provides the Black parents and their families.

Black women have traditionally taken the primary caregiving role for children and housekeeping tasks within Black households. Mothering a child with ASD becomes an all-consuming task for many of the women interviewed for this study based on the experiences of the Black families with a child with ASD interviewed. Although each parent has many identities, the mothers in this study say that their experiences parenting a child with ASD shaped their identity as a mother to the child with ASD first and all other identities, including spouse, employee, friend, or even parent to other children became secondary. While focusing on a child with ASD is important and providing excellent care to the child is necessary, parents can find relief from their parenting stresses by taking breaks from the caregiving by focusing on their other identities and relationships they have that are defined by their other identities.

Raising a child with ASD can make many parents feel socially isolated. The feelings of isolation are felt personally as a parent of a child with autism

Table 2*Where Black Parents of Children with ASD Found Support*

Religious Community	Many parents found minimal support from church members including Pastors and other families whether these families did or did not have a child with ASD. SLPs and Audiologists may find it helpful to present to church members on autism awareness.
Withing the Family	Support was often found by members of the family such as the spouse or other children who would help the parent deal with their child with ASD.
Friends	Parents of children with ASD found turning to close friends was helpful to share the parents' concerns as well as express their problems which reduced stress many times. SLPs and Audiologists may find it helpful to present to communities on autism awareness.
ASD Organizations	There are a number of special ASD organizations which have websites (many cited in this article) and community meetings. However, as reported, these organizations may not have many Black families involved so SLPs and Audiologists should check out these organizations to see which, if any in the family's community, have other Black families involved.
Providing Appropriate Information	Many concerns the Black families raised were a lack of appropriate information regarding ASD including treatments and daily needs. SLPs and Audiologists should discuss with all families having a child with ASD appropriate and comprehensive information that the families can understand. This is especially important for Black families having a child with ASD.

may not have friends or family members they can rely on to assist physically with the child or even listen to their frustrations. A parent of a child with ASD who feels isolated can also further isolate the entire family from vital relationships and interactions. Fears of how a child with ASD will behave or react to new people or new situations and settings sometimes makes it difficult to interact with the family and other people. However, parents raising children with ASD crave opportunities to not feel so isolated and appreciate the efforts of others to include them and their children with ASD in activities and programs.

Access to programs and resources benefiting children with ASD is an important need for Black parents of children with ASD. Knowledge of which programs and resources exist is the first thing that needs to be provided to such parents. This information can be provided by the Speech-Language Pathologist and Audiologist. Unfortunately, the access to information about programs and resources for children with ASD is unevenly provided. If information about such programs is provided, access to those programs and resources is usually not easily attained and Black parents of children with ASD must repeatedly advocate to receive benefits for their children.

Parents of Black children with autism also reported that they believe society needs to provide education about autism to everyone. This education could be in the form of classes or programming, or even through the media. These parents know that their children and families are stigmatized due to their child having ASD, and they realize the stigmatization will only be reduced when all are educated about autism and the special needs and abilities of children who have ASD. The responsibility of providing education about autism should be assumed by everyone, including Speech-Language Pathologists and Audiologists, especially since there are more diagnoses of autism each year.

Results from the present study indicate that sources of support for Black parents of children with ASD can be provided by many different people. Family, friends, church members, members of organizations for families involved with ASD are all important sources for reducing parental stress when raising a child with autism. Speech-Language Pathologists and Audiologists working with these children also need to provide support through listening and consultation with these parents to help them with their concerns and guide them to places where they can get what they need.

The Black parents with children with ASD interviewed for this study hope for greater acceptance of ASD and their children in society. They believe children need to be taught from a young age to accept

everyone, regardless of their limitations or abilities, and provide a welcoming experience for all children. Too often children with ASD and their families still face discrimination in all realms of life because autism is not readily understood nor accepted. By educating and encouraging everyone to embrace and accept children with ASD, raising a child with autism will be an easier experience for Black parents, all their children, and their entire families. Speech-Language Pathologists and Audiologists can be a significant supporting part to make these experiences more positive for these families.

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