

Access to Quality Caregiver Resources: Assessing the Role of Race and Economic Status in the Personal Experiences of Parents Raising Children with Autism Spectrum Disorders

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Abstract: Raising a child with Autism Spectrum Disorder (ASD) can be extremely difficult. Recent studies have shown that race, ethnicity, and/or having a low income likely affect parents' experiences raising children with ASD. This research utilizes interviews to obtain direct input from a diverse group of parents for the purpose of contributing to Empowering Communities Against Autism and Pervasive Developmental Disorders (EmCAAP), a program in Harrisburg, Pennsylvania. Through interviews, this project seeks to determine correlations between participant responses and demographics. Based on the patterns we discover, this qualitative approach should be useful to many local initiatives dedicated to improving ASD resources.

Introduction

Children with Autism Spectrum Disorder (ASD) are a rapidly growing population in the United States. In contrast with other developmental disabilities such as ADHD and hearing loss, autism diagnoses grew the most (Boyle, Boulet, Schieve, Cohen et al., 2011). Autism Spectrum Disorder (ASD) consists of five pervasive developmental disorders: Autistic Disorder, Asperger's Syndrome, Rett's Syndrome, Child Disintegrative Disorder and Pervasive Developmental Disorder – Not Otherwise Specified (PDD-NOS). Disorders on the autism spectrum impair a person's socialization, communication, and language abilities, as well as create behavioral challenges. Medical practitioners and researchers began utilizing the category ASD to acknowledge the various effects of autism. The degree of autism is adapted to the level of a child's functioning. For example, children with Asperger's syndrome may show some behavioral characteristics of autism while also exhibiting higher level functioning.

Many studies examine how raising a child with ASD affects the lives of parents. However, the majority of these studies focus solely on white families. Black and Hispanic families are rarely included and/or solicited in scholarship on this subject. This can lead people to believe that ASD only affects white families and this is not at all the case. The few studies that discuss racial disparities demonstrate that minority and majority families go through different experiences in raising a child with ASD.

Parents of ASD children are strongly influenced by numerous resources they receive after the child's diagnosis. In particular, black families receiving resources about coping with ASD (e.g. brochures, referrals, newsletters/bulletins) may find that race is missing from depictions of ASD. This project will use focus groups with ASD families for the purposes of discovering the needs of black families from the Harrisburg area that have a child with ASD. The study will investigate these needs by examining the process of receiving a diagnosis, coping strategies for parents, and other aspects. The results from this study will be utilized in the creation of a community initiative called Empowering Communities Against Autism and Other Pervasive Developmental Disorders (EmCAAP).

Literature Review

According to the Autism Society of America, autism is a developmental disability that typically appears during the first three years of life and affects a person's ability to communicate and interact with others (2012). Beginning at an early age, the child may face difficulty with joint attention or elicit atypical responses to human faces and voices (Paul, 2007). They also tend to develop speech at a later time and a slower rate. It can often be seen that they have trouble having reciprocal conversations, and some portray echolalia, which is the repetition of others' vocalizations (Paul, 2007). Few studies have examined the relationship between race and ASD, especially in regards to family experiences with the disability.

Prevalence and Diagnosis of ASD

The current prevalence of ASD is most recently reported to be 1 in 50 (Blumberg et al., 2013) which is a significant increase from the 1 in 88 that it was reported to be in 2007. The rising numbers of children with ASD only reinforces the need for an increase in ASD awareness among the general public. Those diagnosed with ASD exhibit symptoms that typically fall into three areas: social impairment, communication difficulties and repetitive & stereotyped behaviors (NIMH, 2011). Despite having these guidelines, diagnosing ASD is a very complex task because no two children with ASD are the same. There are a number of tools that are typically used to diagnose ASD in different settings. The Autism Diagnostic Observation Schedule (ADOS) is often used to provide opportunities for the child to display their level of socialization (Paul, 2007). For parent interviews, two common tools are the Autism Diagnostic Interview (ADI) and the Childhood Autism Rating Scale (CARS). The CARS consists of 15 items in which parents assign a score of 1-4 to specify their child's social progress. Although brief, it has proved to be reliable and valid (Paul, 2007).

Disparities in ASD Diagnosis

Early diagnosis and intervention are extremely important in ensuring the best possible progress in children with ASD (Reichow & Wolery, 2009). However, there are differences that exist in the diagnostic process when comparing African American children to Caucasian children. One of the main disparities is the age of diagnosis. African American children tend to be diagnosed with autism later than their Caucasian counterparts (Mandell, Wiggins et al., 2009) and are more likely to receive an incorrect

diagnosis before reaching their true autism diagnosis (Mandell et al., 2007). Typically, the first diagnosis is a conduct or adjustment disorder. This is critical because a delay in diagnosis leads to a delay in intervention, which lessens the child's potential developmental progress.

ASD has also been described as a non-discriminatory disorder, meaning that it does not affect any race more or less than another. Given this information, it is expected that the numbers of children within the school system that have an autism diagnosis are relatively equal across all races. However, African American, Native American, and Latino children are underrepresented within schools while Caucasians and Asian/Pacific Islanders are overrepresented (Morrier and Hess, 2012). Along the same lines, Mandell et al. (2009) conducted a study to see how many students that fit the criteria actually had a documented diagnosis of autism. By abstracting records from educational and clinical sources, they found that African American children were less likely to have been diagnosed with ASD than Caucasian students.

Another important part of diagnosis is the professional providing the evaluation. Lack of coursework and experience dealing with autism during their careers can leave pediatricians feeling uncomfortable when providing an ASD diagnosis (Finke et al., 2010). Similarly, speech-language pathologists (SLPs) lack education of and exposure to children with ASD. A majority of SLPs have only had a week of training in ASD throughout their undergraduate careers (Schwartz & Drager, 2008). Since a team of professionals can be involved in observing a child to provide an ASD diagnosis, it is important that they have a fluid knowledge of at least the related symptoms. However, it seems that most professionals are lacking in knowledge, and those that do have a basic competency, obtain it through the reading of journals, not from their education (Finke et al., 2010).

Family Experiences with ASD

Raising a child with ASD can cause parents added stress and pressure. Parents need to balance all of their daily demands and continue to be available for all of their child's needs. This requires them to live moment to moment, making it difficult to follow a routine schedule (DeGrace, 2004). Their child's needs tend to take priority over most things, sometimes other family members. If there is another child in the household that is typically developing, they may be slightly neglected because their sibling with ASD requires so much attention (Glazzard & Overall, 2012).

Aside from managing their families internally, parents may also face judgment from strangers. Some children with ASD demonstrate tantrums or other problematic behaviors, and when these occur in public, those that are unaware of the child's diagnosis deem the child disobedient and the parent inadequate (Glazzard & Overall, 2012).

Looking for outside support to care for the child can also prove difficult. Whereas parents of typically developing children can call on a babysitter fairly easily in order to have a night out, most babysitters are not equipped to handle a child with ASD (DeGrace, 2004). And knowing how difficult it can be, parents tend to refrain from calling on extended family members unless it is absolutely necessary (DeGrace, 2004). In regards to resources to help the parents cope, some parents may turn to focus groups to spend time with others who understand what it is like to raise a child with ASD. However, it seems that African American parents are less likely to take part in these

groups (Mandell & Salzer, 2007). This may indicate a lack of available resources or a lack of knowledge of these resources.

Interactions between Parents and Professionals

When looking at the quality of care given to families by their health care professionals, researchers tend to use the measurement of family-centered care. This can be broken down into five categories: spending enough time with the child, listening carefully to the child and family, sensitivity to the family's customs and values, giving the family needed specific information and making the parents feel like partners in the care of the child (Montes & Halterman, 2011). Parents of children with ASD are less likely to report receiving family-centered care when compared to parents of children with other special health care needs. Even further, black parents of children with ASD are less likely to receive enough time with or culturally sensitive care from their health professional. This speaks to both the training of the professionals and the lesser quality of care that black families are receiving.

Costs of Having a Child with ASD

With the number of interventions implemented with a child who has ASD, it is no surprise that having a child with autism is more expensive than having a child who is typically developing. There are numerous services that can be used to help a child with autism, the most popular including a case manager and speech therapy (Kohler, 1999) and unfortunately, not all are covered by insurance, which leaves families to pay out-of-pocket. On average, approximately 14% of a family's income goes toward care for their child with ASD (Montes & Halterman, 2008) and when a family's annual household income was reported to be less than \$40,000, they were likely to struggle more (Sharpe & Baker, 2007). It is worthwhile to look into this struggle and address the affect it has on the child's ability to utilize the necessary interventions.

Methodology

Participants

Participants were recruited with the use of flyers posted around popular Harrisburg locations as well as announcements made at local events. A television ad was also created and played on a local Harrisburg network. Participants were both parents/caregivers of children with ASD from the Harrisburg area. One participant was the mother of a 4 year old with autism. The other was a 50 year old woman and the primary caregiver for her 44 year old, nonverbal brother with autism. This allowed us to gather information regarding growing up with a sibling with autism as well as being a primary caregiver. For the purpose of maintaining confidentiality, the mother and 4 year old will be referred to as Allison and Jackson respectively. The woman and her brother that she takes care of will be referred to as Jennifer and Michael respectively.

Procedure

The two interviews were conducted via phone or Skype and recorded. The conversation was led by the researcher with a list of interview questions designed to gather the desired information. Each participant signed an informed consent form and

filled out a demographic questionnaire prior to the interview. For background information, questions included asked about age, location of residency, race, gender, and number of children.

Each interview started with the researcher greeting the participants and thanking them for their participation. The researcher then gave another brief overview of the purpose of the study and got into the main focus group questions that were designed to elicit responses pertaining to their experiences raising a child with ASD and how they were affected by their living situation. We were particularly interested in discovering where they encountered struggles, if and how they overcame them, and what could have helped them in the process. Questions inquired about the process of receiving a diagnosis, services utilized by their child, financing these services and their everyday lives.

Data Analysis

Interviews were recorded and transcribed. The researcher then listened to the interviews multiple times and extracted the main themes and points throughout.

Results

Lots of valuable information was collected from these two interviews. The interview with Jennifer revealed a lot of information pertaining to the adaptation of behaviors done by her and her siblings and how times have changed regarding the attitude toward caring for a child with autism. Jennifer told the researcher that Michael did not receive an official diagnosis until he was a teenager, however they always knew that there was something special about him given his behavior. Two things that he seemed obsessed with were pouring out liquids and floating items in the toilet. Therefore, Jennifer and her other three siblings adjusted by making sure that their doors were locked and their belongings were out of Michael's reach. This prevented anyone from finding a bottle of perfume empty or one of his or her shoes in the toilet. Despite these changes that were made, Jennifer said that none of this really seemed difficult or out of the ordinary. It was all that her family knew; it was their normal.

Although Michael received a diagnosis as a teenager, he was not enrolled in any interventions. He was assigned a case coordinator with his diagnosis but his parents had a different approach to taking care of their son. "They had a 'this is my child and I'll take care of him' mindset (Jennifer). As a result of this, Michael spent all of his time either at school or at home and did not really interact with anyone outside of family. This resulted in the inability for them to have complete family outings. When they would go out to dinner or a movie, someone would have to stay home with Michael.

Four years ago, Jennifer became Michael's primary caregiver. When that transition occurred, Jennifer and Michael's care coordinator got him a behavior support specialist and speech therapist. As a result, Michael has made serious improvements in Michael's communication and behavior. Being nonverbal, he cannot communicate with traditional language, however he is still able to tell people what he wants, needs and how he feels. He is also better being out in public, being patient waiting in line or for food. He is also more involved around the house, doing things such as folding clothes and making snacks for himself. Jennifer says that he has been doing so well that she is going

to transition him into a group home soon, which is something she never would have imagined happening just a few years ago. This will be extremely beneficial because he will be around people who are trained to care for him and can help with the difficulties he still faces with things such as brushing his teeth and maintaining personal cleanliness. He also has health issues caused by his hypersensitivity to stimuli. He cannot get a shot at the doctor or go to the dentist without being sedated. The staff at the group home will be able to maintain his health and further his progress.

Discussion

This interview is a prime example of how times have changed and how critical it is to provide intervention for people with autism. A few decades ago, when the knowledge about autism was limited, parents relied on themselves to care for their children. The thought was not to get their child evaluated or enroll them in programs. The progress that Michael showed within the past four years is a prime example of the efficacy and importance of interventions for people with autism. Jennifer believes that his improvements would be even greater had he started earlier.

But these resources are not always available which leaves a lot of children undiagnosed with no interventions. When asked what she wanted for her brother, Jennifer said that she wanted Michael to have a good quality of life however he would define it. That is exactly the purpose of interventions, to allow the individual to communicate effectively which can increase happiness.

Limitations and Future Plans

The two main limitations for this study were time and recruitment. Given that the researcher only had 9 weeks to complete the project, she was not able to go as in-depth and she would have liked. Along the way, it was also realized how difficult it is to make connections with people from the targeted population. It remains even more difficult to find a time where the caregiver is completely free to engage in an interview given the hectic schedule associated with raising a child with ASD.

In the future, we plan to put in more time in order to conduct the focus groups we originally desired. After gaining information about what resources are lacking, we will work with Empowering Communities Against Autism and Pervasive Developmental Disorders (EmCAAP) to provide the necessary resources and raise awareness about autism altogether.

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