Autism Spectrum Disorder: Disparities in Access Across Communities

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How can living with a diagnosed disability be a positive? Ask the millions of Americans who do not have the option to get an accurate or timely diagnosis, and they will have an answer. Being stopped by systemic racism, a healthcare system that favors the wealthy, or geographic discrimination, many are left to face this challenge on their own. Disparities in access to healthcare for autism spectrum disorder (ASD) exist within every step of the diagnostic and treatment processes, with significant increases in difficulty for certain marginalized populations. The intersectionality between race, socioeconomic status, and location of residence are three of the leading factors in prejudice against children with ASD, along with their parents who advocate for them. Privileges associated with skin color, financial stability, and where someone lives determine the quality of life for those affected by ASD—before, during, and after a diagnosis.

The differences in healthcare access between privileged and marginalized groups is unfortunately an age-old story, and the disparities with ASD deserve their own chapter. The first issue lies within the recognition of the very prevalent and complex spectrum of disorders. Autism was first introduced on a global scale when Austrian physician and psychiatrist, Leo Kanner, published an article about it in 1943. While comparing it to the symptoms of schizophrenia, he “suggested that children with autism also live in their own world, cut off from normal intercourse” (Goldstein et al., 2009, p. 4). Although the connection between schizophrenia and ASD has since been disproven, the idea of children being isolated from the outside world remains true. A more inclusive society would provide opportunities for children with ASD, from all walks of life, to receive the help they need. Instead, they are still seen as separate and stigmatized. Attempts at treatment for ASD began twenty years after that first publishment, with an "early successful use of applied behavioral analysis (ABA)" (Donvan & Zucker, 2016, p. 555). This study was done on a child whose parents were middle-class, which begs the question if a lower income child would have gotten the same opportunity at that time. This too still applies today, as economic status in this country is related to quality of care. Furthermore, it was only 1980 when the disorder was "listed as a mental disorder for the first time in the *DSM (Diagnostic and Statistical Manual of Mental Disorders)*" (Donvan & Zucker, 2016, p. 557). Being that 1980 was only forty-three years ago, there is much more room for improvement in modernizing diagnostic and treatment processes to fit our modern, racially, ethnically, and geographically diverse country.

Racism within Autism

Specifically at-risk for the injustices related to misunderstanding and misrepresentation of ASD are mothers and children of color and Latina mothers and their children. These injustices lie from anywhere between disregard from healthcare professionals, biased treatment, or lack of resources altogether, simply because of their skin color or ethnic origin. The first disadvantage for these women and children is the ways that the system has blocked their access to health education on ASD. Whether it be from a lack of representative examples in the media or schools, or simply bias against helping a certain group of people, the outcome of the child is inevitably altered.

Thus, without key information on ASD, parents are left powerless and unable to act on behalf of their children, for reasons they cannot control. Although it may seem obvious that a mother would know if something was 'wrong' with their child in terms of development, this is not always the case. If a person does not know or was not taught what is considered normal or abnormal development, how would they know when to seek help? The problem does not lie in parenting, but in the prejudiced way in which parents, and specifically mothers of color, are addressed and informed by physicians. This awareness, or lack thereof, of ASD symptoms is one of the first of many boxes that must be checked to receive healthcare services for a child with suspected ASD. One study suggested that the parents who have had success in the process of caring for their children "have a higher level of health literacy to recognize atypical child development" (Aylward et al., 2021, p. 683). As with many things in our society, gaining an advantage comes with a price tag. In this case, health literacy may have been taught in colleges or secondary education, something that not everyone is lucky enough to receive. Furthermore, it is easier to understand the signs if they are seen or represented in someone of the same race, which has historically been an issue for non-white Americans. Adding on to this point, another study found that "White mothers had significantly more sources of knowledge than Latino mothers" (Magana et al., 2013, p. 147). An African American mother who was trying to break the barriers of lack of education said that "somebody could have said something" (Pearson & Meadan, 2018, p. 24), in regard to helping her navigate this confusing process. It's true, there should be someone, or many people, changing the ways in which education systems report disabilities in minority groups, but that has unfortunately not been made a nationwide initiative yet.

Doctors express implicit and explicit bias towards people of color and women whether it be intentional or not. If a parent catches onto the signs that their child may be delayed in some way or possibly on the autism spectrum, their next step would be to visit the doctor for an evaluation. Once they secure an appointment, under the assumption they even have access to healthcare coverage, parents who are both Hispanic and African American have complained of "confusion and frustration… and provider dismissal of parental concerns" (Wiggins et al., 2020, p. 8).

Microaggressions like these violate the Hippocratic oath, which has doctors swear to do no harm to their patients. What could be more harmful than refusing to treat someone based on their skin color? An interesting study detailed the firsthand struggles experienced by African American mothers of children with ASD, from their point of view. Having that dialogue from mothers who have personally went through the battle for equal treatment shows the real-life effect of that these injustices cause. One finding from this study explained that a "barrier to obtaining diagnoses for African American children with ASD occurred when HCP [Healthcare Providers] ignored parental concerns" (Pearson & Meadan, 2018, p. 25). This again, shows the bias faced by women of color at the doctor's office. One mother was discussing how she had to research everything about ASD from square one, even saying she "did it all by myself" (Pearson & Meadan, 2018, p. 24). Without the resources and expertise of healthcare professionals, this process can become very lengthy. Through researching, it has become clear, however, that the stereotypes run both ways. Doctors have shown that they inappropriately treat or lack the knowledge of how to treat children of color. Consequently, parents then fail to trust the healthcare system as a whole. A parent could then refuse to even consider taking their child who may have ASD to see a professional, under the fear that they will be discriminated against. This cycle of mistrust will only elongate the process of receiving help and treatment for marginalized children.

There is no obvious or easy cure-all for systemic issues on lack of reporting and educating diversity in healthcare, but there are ways in which strides can be made. The first one is receiving a diagnosis of ASD. While it may seem like a rather simple goal, this milestone is not frequently or quickly reached for racially and ethnically marginalized groups of children with ASD. Without a diagnosis of ASD, insurance may not cover, or a child may not even be eligible for life-changing therapies. Being told that a child has autism, while it may be a tough conversation, it is one that everyone is entitled to, but not granted.

In an ideal world, the next step after a doctor's visit would be finally getting a diagnosis. This opinion is not unanimous, though. Some mothers of color or Latina mothers may not even want to get the diagnosis for their child, as in certain cultures the child may be seen as less or weak. Other cultures may handle misbehavior differently, and the behavioral aspects of ASD could be misinterpreted as typical child behavior. From the perspective of a mother of color, a child may face enough discrimination from their skin color, and adding a labeled disability will only worsen it. ASD itself has been plagued with a largely negative stigma in the media. False reporting in the news led millions to think that it was caused by vaccines, leading to widespread dangerous misassumptions. Additionally, it has been inaccurately portrayed in movies by actors that do not even have ASD itself. Calling someone "autistic" is used as a derogatory joke by some, only increasing the stigma against the very prevalent disorder. Despite these reasons that a diagnosis may negatively affect a person's life, without one a child with ASD may not be able to receive life-changing therapies that will improve their quality of life.

This problem involving receiving a diagnosis of ASD is disproportionately faced by African American parents and their children. For instance, it was found that "African American children with ASD whose parents participated in this study were diagnosed on average, at 3.5 years old" (Pearson & Meadan, 2018, p. 29). Seems young enough, right? Wrong. The issue here is that "at age 3, young children age out of early intervention services" (Pearson & Meadan, 2018, p. 29). This means that by the time a diagnosis is achieved, these African American children may have already missed the crucial time period of receiving beneficial early intervention treatment. To receive a diagnosis after some of the treatments would be helpful may be seen as worse than not getting the diagnosis at all. Having to fight to even get their feet in the door of the doctor's office, mothers, and children of color with ASD are, yet again, faced with a disadvantage due to skin color. Becoming a caretaker for a child with special needs, on top of working to support the child are two, separate but coexisting full-time jobs. Trying to do either of these without support from society, the financial, or geographical resources, will not only impact the health of the mothers, but of their children as well.

The disparities in access to ASD healthcare do not end with the African American population, as members of the Latino/a community are also affected disproportionately. Where racism was seen to interfere with the healthcare of African Americans, the anti-immigrant sentiment against Latino/a women and children has lingering effects, too. A study was done that goes into detail of the experiences of Latina mothers and their struggle with trying to receive help for their children with ASD. After comparing testimonies and data from both White and non-White Latina mothers, it discovered that "White children were significantly more likely to be diagnosed with ASD almost one year earlier than Latino children" (Magana et al., 2013, p. 146). Considering the data which stated the age that early intervention therapies work more efficiently, this data is troubling. Thus lies a similarity between the Latino/a and African American children; that, on average, they received the life-changing diagnosis later than the White children. A year later is definitely a long time, but in terms of childhood development, those twelve months could be the difference between breakthroughs and breakdowns. The data does not lie, which is why the truth of the inequalities must be made apparent to everyone.

The Trials and Tribulations of Treatments

After having received a diagnosis of ASD, the next step in the process would be to place a child into some form of therapy or special education. The tiring campaign of receiving a diagnosis is unfortunately not the end of the tunnel. Parents must immediately prepare themselves again for the battle of obtaining services for their children with special needs. To understand how exactly the later diagnoses are impacting the development of the disregarded children, the efficacy of treatment must also be looked at. One of the earliest treatment options offered for children who have been diagnosed with ASD is early intervention therapies. These services can range anywhere from receiving speech, occupational, or physical therapies during infanthood or toddlerhood. Getting that first step into treatment at such a young age will allow the children to have better chances at a typical development. Specifically, communication and skills are necessary for children to express their needs as they age. If a child with ASD is nonverbal, this lack of language skills can result in behavioral issues that increase throughout their life. Thus, without language skills, the behavior and development of the child may remain stagnant or even decline. One longitudinal study found that "early age of entry in EIBI [early intensive behavioral intervention] to significantly predict a better language trajectory, especially for expressive language, and a better educational placement outcome" (Frazier et al., 2021, p. 4546). Now, consider this data with the previously discussed information that African American and Latino/a children receive later diagnoses, and that a child would not be eligible for early intervention without that diagnosis. The preciseness of when early intervention works best, specifically with "the strongest gains occurring within the first 12 months" (Frazier et al., 2021, p. 4542) proves the necessity for swiftness in diagnosing all children, regardless of skin color or ethnicity, with ASD. Without these services, a child's disabilities will develop with them as they age, because autism grows within the child as they do. The older a child gets, the more detrimental the developmental delays will be in altering their ability to function and live independently.

Once children age out of the early intervention period, whether or not they were able to reap its benefits, the next step might be special education. The lack of access to key intervention during younger years leaves marginalized groups to being almost inevitably placed in some form of special education. School-provided special education services may include individualized education plans (IEPs) and other therapies like applied behavioral analysis (ABA) therapy, speech therapy, occupational therapy, or physical therapy. Research concluded that “African American and Hispanic students are more likely to be in special education than white students” (Pitney, 2015, p. 67). Even using the term “special education” adds another label onto children who are discriminated against enough for their skin color or ethnicity. So, taking that information with the knowledge that these children make up a lot of special education services, the discrimination doubles. The data presented in the study makes sense with the other corroborating information that the underprivileged communities, intersecting with race and ethnicity, have less access to intervention. Whereas, white children, who on average have more access to services, may have developed in a more ‘typical’ way, leaving their counterparts all but destined for a disability attached to them throughout school years. Increased steps in the developmental process could see a child with autism in general education classes with an IEP or aide, but again, the chances of this happening are greatly improved by early intervention and having fair skin tone.

The Price of Progress

Under the assumption that a child has been lucky enough to receive evaluations and a diagnosis of ASD, what if their parents cannot afford treatment? Does all of the hard work in advocating for their child’s care go to waste? Unfortunately, the answer may be yes for low-income families or single parents. Financially insecure families are often forced to make impossible sacrifices to help afford the treatments for their children. With that being said, besides being white in America, another privilege is having insurance. Coverage for ASD related doctor's visits or therapy appointments adds another struggle onto the minds of the parents who simply want the best for their child, but due to the greed in society, cannot give it.

For those families or parents who do not make enough to pay for private insurance, they may be eligible for Medicaid. Medicaid is insurance provided to those less fortunate by the government, granted they meet the requirements. However, just because it is provided by the government does not mean it is free of expenses. For instance, five years ago, "Analyses of nationwide Medicaid claims data reported mean expenditures of roughly $11,000 to $30,000 for children with ASD" (Zuvekas et al., 2021, p. 2956). This number of course, has probably increased within the last five years, especially with the inflation that the American economy currently finds itself in. Even still, that range of money could be more than a parent makes in a year, and if they did not have Medicaid, how could they begin to think about paying for ASD treatments. At first, this may seem promising to get governmental insurance, but satisfying the needs to qualify for Medicaid comes with further discrimination. These requirements include, but are not limited to, "meeting a disability listing according to SSA [Social Security Act] rules; having received a diagnostic evaluation by a qualified clinician stating the child has a diagnosis of autism… the child being under eight years old, and the family must locate a provider who will provide treatment when funding becomes available" (Magana et al., 2013, p. 142,143). To break this down, the difficulty of obtaining a diagnosis from a racial standpoint has already been made clear. Some people, however, may not be able to get that diagnosis of ASD because they cannot afford the copays that come from evaluations and follow ups. On another note, they may not be able to afford transportation to and from a doctor or be able to take time off work. Additionally, the age of the child is important, considering the later diagnoses that minority children will get, on average compared to White children. Trying to find a provider that takes Medicaid can be difficult as well, because many doctors will want to make the most they can and take private insurance. These three requirements alone serve as roadblocks in the way of the path to progress for children with ASD. The government's attempt at helping is at most, an attempt, being that qualifying for Medicaid is another struggle for underrepresented groups of people.

The difficulty in finding coverage does not end with Medicaid, as there is a gray area that lies between what is covered in private insurance plans and what is not. Varying levels of income are affected by insufficient coverage, showing that although lower income families are disproportionately disadvantaged in accessing services, the system itself is flawed for everyone. For example, when interviewed, some mothers of children with ASD said, "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 insurance" (Pearson & Meadan, 2018, p. 27). In this situation, the parents would either have to sacrifice their current job position and make less than what they deserve or work even harder than they already are. Taking care of a child while working, whether it is a single parent or dual income household, is also a challenge for anyone. In addition, some therapy approaches involve including the parents in applying behavioral techniques at home. This is not an option for one, parents who cannot afford private therapies, and two, for those who do not work the expected nine-to-five. Parents who have coverage under their employer, which is known as self-funded in the insurance world, also face a crossroads when it is time to pay the bills. Their dilemma is that "the great majority of workers in self-funded plans do not have access to autism coverage" (Pitney, 2015, p. 98). The child or their parents may need insurance to cover for other medical or dental issues but are left stranded and stigmatized against when it comes to ASD.

A final issue that may not even cross the radar of issues for the wealthy is finding legal advice. Believe it or not, this applies to the disparities in ASD access as well. It has been said that “Attorneys have become major figures in the world of autism, because people often need legal counsel to get services from school districts and other government agencies” (Pitney, 2015, p. 10). The speed at which the justice system works can cause even the wealthiest to lose a big chunk of their money in legal fees, so this may not even be an option for lower income families. It must also be remembered that in this country, the more money you have is correlated with the better representation you can afford, which results in better outcomes. Imagine how difficult it would be for a family to accept defeat when there is someone out there who can help their child, but at too high of a cost. The fact that lawyers are even needed in the first place to fight for services that should be given to all children with ASD in the first place is upsetting by itself. Despite the increasing prevalence of ASD diagnoses in American children, healthcare coverage and related costs clearly continues to remain at these disappointing and unfair rates.

Finding ASD Services on the GPS

Hypothetically, if all of the racial, ethnic, and socioeconomic odds are in the favor of a child with ASD, they may still be systematically denied services for their disability. Research has shown a surprising difference in the amount of access to care in urban and rural areas within various parts of the United States. Rural areas have been found to be deserts in the map of finding therapists and special education services for children with ASD. For instance, one mother had an experience where she “tried to get ABA therapy and the closest place was 45 minutes away” (Pearson & Meadan, 2018, p. 27). The distance of the therapy location, coupled with the possibility that a family may not have their own transportation, or time to spend driving there, dims the light at the end of the tunnel. Interestingly enough, one study examined the discrepancies between rural and urban areas that consisted of mostly Caucasian children. Again, showing that although minorities are affected by this lack of access to healthcare for autism, it is still a widespread issue on the front of geography. The results showed a “gap in availability of behavior management services and speech language therapy services for rural vs. urban areas” (Murphy & Ruble, 2012, p. 4). Along with the importance of therapy services in language development and behavioral improvements, children living in rural areas are visibly at a setback.

Employment shortages in the helping profession also undoubtedly impact the outcome of children with ASD, if they are limited to which, if any, therapies they can go to locally. There is currently an issue in hiring more trained professionals and special education teachers to work in the more rural areas of the country. Being that therapists have “higher caseloads and lower pay” (Murphy & Ruble, 2012, p. 10), it is understandable why more isolated areas might have less attraction for new employees. A person could have the purest intentions at heart of helping children who are in need but may not want to sacrifice job security for lower pay and more work. Another barrier that exists for trying to locate help is the fact that “Although there is a national organization that credentials behavior analysts (the Behavior Analyst Certification Board), only nineteen states have laws providing for their licensing and certification in their own right” (Pitney, 2015, p. 99)”. Again, the government has not accommodated their policies to apply to all American children with ASD. Upon further research, since the publication of the article eight years ago, more states do have ABA licensing laws, but it is still not nationwide. As a result, children with ASD in the remaining states are left missing out on a form of care that has been proven to help regulate behavioral issues.

Something else to consider is the resources that are available in certain geographic areas compared to others. For example, urban areas are more likely to have state of the art technology that can be used to serve patients, than rural areas that are miles away from the nearest hospital. A study researching the geographic differences in the availability of ASD outpatient facilities mentioned that “We suspect that better-resourced facilities are more likely to offer telehealth and have the ability to treat children with ASD” (Cantor et al., 2022, p. 175). In the time of the pandemic, families had to take on the role of not only the caregiver but therapists when their children could not go to therapy in person. A smaller, more isolated therapy or outpatient center for children with ASD may not have the technological resources needed to keep up with virtual sessions. Another intersectionality lies here with poverty, since clients who are less fortunate may not have the devices needed for the essential telehealth appointments, or even access to the internet. It was also found that “counties in the highest quartile of poverty rate had fewer outpatient facilities with mental health care for children with ASD” (Cantor et al., 2022, p. 172). With a significant difference between county lines in the amount of access to ASD facilities accessible, more people are forced to try to help their children on their own.

The intersectionality between race, financial stability, and location of residence when trying to access care for ASD runs deep within society. A person who is labeled as disabled may be lucky if that is they only other label they receive in life. Getting to the point of receiving a diagnosis and treatment for ASD is a privilege that every child deserves to have. However, as with many other chronic racial and socioeconomic issues that exist in our country, this one will continue to get pushed to the backburner, leaving families and children continuing to struggle. By highlighting some of these pressing disparities in access to autism related diagnoses and care, privilege may become more understood. Hopefully, it can then be used to help those who have been systemically suppressed, or in a perfect world, these groups would not face inequality any longer.

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