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L'intersection de la race et du handicap : une analyse critique des inégalités raciales dans les diagnostics d'autisme et de handicap neurodivergent chez les enfants noirs

Safia Abdulle[1]

Abstract

Black children face racial inequities when it comes to autism and neurodevelopmental disability diagnoses. As we know, autism and related neurodevelopmental disabilities have historically been pathologized, stigmatized, and discriminated against. As a result, Autistic self-advocates created the neurodiversity movement, as a direct oppositional force to this historical, and present-day, harm. However, even within the context of this civil rights movement, Black, and other minoritized people have consistently been left at the margins. This marginalization is evident throughout the diagnosis process, where Black children and youth who meet the diagnostic criteria for autism and related neurodevelopmental disabilities face, on average, diagnostic inequities. This includes incorrect diagnoses, later diagnoses, and receiving no diagnoses at all. It is critical to analyze and examine the harmful mechanisms which facilitate the marginalization and inequitable treatment of Black Autistic, neurodevelopmentally disabled youth from a young age.

Keywords

Autism, neurodiversity, neurodevelopmental disability, special education, racial disparity, race, Blackness, disability

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Résumé

Les enfants noirs sont confrontés à des inégalités raciales en ce qui concerne les diagnostics d’autisme et de troubles du développement neurologique. Comme nous le savons, l’autisme et les troubles neurodéveloppementaux connexes ont été historiquement pathologisés, stigmatisés et discriminés. C’est pourquoi les militant·es pour l’autisme ont créé le mouvement de la neurodiversité, en tant que force d’opposition directe à ces préjudices historiques et actuels. Cependant, même dans le contexte de ce mouvement pour les droits civiques, les personnes noires et les autres minorités ont toujours été laissées en marge. Cette marginalisation est évidente tout au long du processus de diagnostic, où les enfants et les jeunes Noir·es qui répondent aux critères de diagnostic de l’autisme et des troubles neurodéveloppementaux connexes sont généralement confrontés à des inégalités en matière d’évaluation : diagnostics, tardifs ou complètement absents. Il est essentiel d’analyser et d’examiner les mécanismes néfastes qui facilitent la marginalisation et le traitement inéquitable des jeunes noir·es autistes ou ayant des troubles neurodéveloppementaux dès leur plus jeune âge.

Mots-clés

Autisme, neurodiversité, handicap neurodéveloppemental, éducation spéciale, disparité raciale, race, noirceur, handicap

Introduction

In a study of over 400 children—all of whom met the diagnostic criteria for Autism—only 58% of Black children received an autism diagnosis, while 72% of White children received an autism diagnosis upon initial visit to a specialized mental health clinic (Mandell et al., 2002). This indicates a clear discrepancy in the diagnosis rates and processes for Black children. The mechanisms and reasonings behind these disparities are complex. Overall, the social understanding of autism and related neurodevelopmental disabilities has vastly changed over time, resulting in a variety of perspectives and social shifts in understanding and existence. However, many of these changes have neglected to fully recognize the intricate considerations of intersectionality, particularly when it comes to race. As a Black clinician working primarily with Autistic and neurodivergent youth, these are complexities I witness regularly. As such, this paper seeks to problematize the ways in which diagnosis processes often pathologize the existence of autism and/or neurodivergence when presented in a racialized, or otherwise 'othered' body.

A Note to Readers

It should be noted that this paper utilizes person-first and identity-first language interchangeably, in solidarity with Autistic (and neurodivergent) self-advocates who have long indicated the importance of using identity-first language (Shakespeare, 2006; Sinclair, 1999; see also Brown, 2011; Pripas-Kapit, 2020), and in opposition to widespread service-provider rhetoric which problematizes its use. Language is an incredibly powerful tool for conveying meaning, concepts, and identity. Person-first language implores individuals to utilize language which emphasizes the individual before the disability (i.e., "a person with a disability") while identity-first language emphasizes language which situates the disability first, as part of the individual's identity (i.e., "Autistic person") (Shakespeare, 2006; Sinclair, 1999; see also Brown, 2011; Pripas-Kapit, 2020). The use of both interchangeably in this paper seeks to recognize the critical importance of analyzing the stigmatization of identity-first language, while recognizing the diverse autonomous perspectives and preferences of disabled people.

Autism and Neurodiversity

To fully contextualize the racial inequities and disparities which exist in the diagnosis processes of autism and related neurodevelopmental disabilities, it will be important to understand both the historical, and the present-day, accounts of these disabilities.

The Historical Conceptualization of Autism

In 1911, the term ‘autism’ was first coined by a German psychiatrist, Eugen Bleuler, to describe what he theorized was the most ‘severe’ form of childhood schizophrenia (Evans, 2013; Wright, 2019). This theorization of Autism—characterized by “hallucinations” and “extreme detachment” in childhood—remained popular throughout the early 1900s, as did violence against the bodies and minds of Autistic people, including eugenics, institutionalization, and forced sterilization (Evans, 2013; Wright, 2019). Further, it was largely argued that ‘bad mothering’ was the “cause” of autism in children (Waltz, 2020). By the 1940s, Leo Kanner (an Austrian-American psychiatrist) began theorizing that autism was a cognitive and biological “deficit”, rather than a form of mental illness (Jaarsma & Welin, 2012). Kanner proposed the term ‘autistic aloneness’, arguing against the notions of ‘extreme hallucinations’ and suggesting that Autistic individuals were “deficient” and overall, had a lack of consciousness and ability (Jaarsma & Welin, 2012; Waltz, 2020). This new theorization shifted the focus away from ‘bad parenting’ and towards a biological ‘reasoning’ for neurological disability (Jaarsma & Welin, 2012; Waltz, 2020). As a result, however, the social construction of the “normal child” and the “abnormal child” began to gain prominence in society—literature indicates that this type of pathologization, i.e., construction of the ‘normal’ child, has only existed for approximately the past 100 years (Fenton & Krahn, 2007; Waltz, 2020; see also Aries, 1962; Burman, 2007; Foucault, 1965).

By the 1970s and 1980s, a social shift emerged as first-wave disability theorists began to criticize the medical and biomedical fields for applying this type of medical model approach to disabilities (Scully, 2008). Additionally in the 1980s, the deinstitutionalization movement gained momentum, as many so-called ‘mentally disabled’ individuals left institutional facilities, symbolizing another historical social shift in the perspectives around cognitive and neurodevelopmental disabilities. Yet, because of society’s medical model, deficit-based perspectives on disability, people with neurodevelopmental disabilities were still left unsupported, and unable to reintegrate back into communities (Wright, 2019).

Introducing the Neurodiversity Movement

Overall, Autistic and neurodevelopmentally disabled individuals would have been previously labelled as ‘mentally disabled’ or ‘mentally deficient’ throughout history, and as a result, they experienced significant stigma, discrimination, and violence (Acevedo & Nusbaum, 2020; Aries, 1962; Evans, 2013; Fenton & Krahn, 2007; Foucault, 1965; Singer, 1999; Waltz, 2020). Individuals with autism and neurodevelopmental disabilities were viewed as abnormal and were pathologized—seen as a ‘problem’ in society (Jaarsma & Welin, 2012; Waltz, 2020; Wright, 2019). In the 1990s, the neurodiversity movement was created in direct opposition to the historical discrimination and oppression against autism and neurodevelopmental disabled people.

What is Neurodiversity?

Neurodiversity is a term which states that all human brains have neurological variations and thus, all function differently (Kapp, 2020; Singer, 1999; Walker, 2023). The term neurodivergence specifically describes individuals whose minds deviate from the 'expected' neurological make-up society has deemed as "normal" (Rosqvist et al., 2020) and can describe individuals diagnosed with Autism, Attention-Deficit Hyperactivity Disorder (ADHD), and many more. It is important to note that there is currently no clear consensus on the exact parameters of who is included and excluded from a 'neurodivergent' diagnosis or label (Botha & Gillespie-Lynch, 2022; Dekker, 2020; Gillespie-Lynch et al., 2020; Legault et al., 2021; Kapp, 2020; Kapp, 2023; Rosqvist et al., 2020; Russell, 2020; Singer, 1999; Singer, 2017). However, within the context of the medical model and/or using the Diagnostic Manual of Mental Disorders (DSM-5) as a categorization method, neurodivergence largely includes individuals meeting the criteria of a 'Neurodevelopmental Disorder' (which includes Intellectual Disabilities, Communication Disorders, Autism Spectrum Disorders, ADHD, Learning Disorders/Disabilities, and Motor Disorders like Tourette's). Neurodivergent diagnoses can also include individuals meeting criteria for Schizophrenia Disorder, Obsessive-Compulsive Disorder (OCD), and Neurocognitive Disorders as well.

The Neurodiversity Movement as Revolution

The term 'neurodiversity' seems to have first been used in literature in 1999 by sociologist Judy Singer, while the neurodiversity movement itself is understood to have begun in the 1990s by autistic self-advocates from prominent online Autism rights groups (Dekker, 2020; Gillespie-Lynch et al., 2020; Kapp, 2020; Rosqvist et al., 2020; Singer, 1999;

Singer, 2017). Online autistic self-advocacy groups began having discussions about how the acceptance of neurological difference should be understood as a new paradigm of thought, asserting that neurological diversity should be treated as biological diversity—natural and essential to human life (Dekker, 2020; Kapp, 2020; Singer, 1999; Singer, 2017). As a social justice movement, the neurodiversity movement asserts that neurodivergence is not a 'defect' and should be reconceptualized as a natural, non-pathological part of human diversity (Leadbitter et al., 2021; O'Dell et al., 2016). Judy Singer (1999) then arguably popularized these revolutionary conversations and the term 'neurodiversity' in her highly influential essay titled "Why Can't You Be Normal for Once In Your Life?" where she spoke of the politics of neurodiversity and further challenged the disability rights movement to better include autistic [and neurodivergent] people. Moreover, around this time in 1999, Jim Sinclair published an essay titled, "Why I Dislike Person-First Language" and highlighted the problematic nature of person-first language as a dehumanizing, deficit-based perspective—further changing the landscape of the neurodiversity rights movement. Sinclair (1999) is noted as one of the first to reject person-first language and advocate for an identity-first stance (see also Brown, 2011; Pripas-Kapit, 2020). Overarchingly, the neurodiversity movement was revolutionary in asserting the rights and humanity of Autistic and neurodevelopmentally disabled (hereby referred to as neurodivergent) peoples.

Critical Analysis of the Neurodiversity Movement

Overall, the neurodiversity movement has been radical and groundbreaking in starting to shift discourse around autism and neurodivergent disabilities. It has begun to change societal understanding, and arguably the acceptance, of neurological, brain-based differences.

An important critique of this movement is outlined by Gillespie-Lynch et al. (2020) as they indicate that while “attributing autism to brain difference can lead to non-pathologized forms of identity and community, it can also conceal intersectional complexities of personhood” (p. 7). As such, even within this revolutionary social justice movement, much of the discourse and research on Autism and neurodiversity has failed to include intersectionality (Botha & Gillespie-Lynch, 2022; Davis et al., 2022). Neurodiversity research, and the neurodiversity movement overall, has largely focused on non-racialized and male bodies, leading to a limited understanding of the presentation of neurodivergence—one that marginalizes identities like race and gender. Often, popularized media or social depictions of Autistic or neurodivergent people include individuals who are White and male. Consequently, I argue that this movement has specifically, albeit inadvertently, left individuals with intersectional identities at the margins, and this can clearly be showcased through the racial disparities which still exist in the diagnosis of autism and neurodivergent disabilities.

Intersections of Race and Disability

To begin, intersectionality is a term coined by Kimberlé Crenshaw which recognizes how social identities, such as race, disability status, class, or gender, are interconnected and intersect with one another, leading to various experiences of oppression and privilege in society (Crenshaw, 1991; Crenshaw, 2018). Intersectionality can be a powerful tool; it is a theoretical perspective which highlights the complexities of the human experience and can be utilized to better understand how disabled people with marginalized identities face unique experiences, barriers, and challenges (Crenshaw, 1991). It can be significant in specifically recognizing how autism and neurodivergence manifest differently across gender identity, sexual orientation, class, race, ethnicity, and various other social identity categories (Davis et al., 2022). However, dominant literature on race and neurodivergence showcases an emergent gap in the intersections between the two concepts. Neurodiversity research has largely over-looked Black individuals by focusing on non-marginalized (primarily White male) bodies which facilitates a narrow societal understanding of neurodivergence—one that, as previously indicated, discounts identities such as race (Davis et al., 2022; Haney, 2018; Rosqvist et al., 2020). The failure to recognize the existence of the intersectional identities of Autistic and neurodivergent people is a problematic and dangerous one, and can lead to outcomes including dehumanization, criminalization, and increased risks of violence (Coles & Powell, 2020; Dumas & Nelson, 2016; Goff et al., 2014; Skiba & Williams, 2014).

As clearly exemplified through the historical account of the treatment of Autistic and neurodevelopmentally disabled people, neurodivergent individuals face stigma, discrimination, pathologization, and consequently, harmful and negative consequences of existence. I argue that the neurodiversity movement has arguably begun to act as a “social shield” against some of this pathologization through conversations of societal acceptance of neurological, brain-based differences. However, the failure to consider the realities of racialized, gendered, and otherwise ‘othered’ bodies within the context of autism and neurodivergence results in this “social shield” not extending to cover all individuals—

meaning that these individuals are, yet again, more susceptible to the consequences of pathologization and discrimination.

Racial Inequities in Autism and Neurodivergent Diagnoses

As previously indicated, the consequences of the marginalization of neurodivergent, racialized can clearly be showcased through the racial disparities which still exist in diagnosis. Autism and neurodevelopmentally disabled children who also identify as Black or racialized receive inequitable rates of appropriate, accurate diagnoses when compared to their non-Black or non-racialized peers (Cameron & Guterman, 2007; Fadus et al., 2020; Mandell et al., 2007; Mandell et al., 2002; Mandell et al., 2009). While the following analysis will primarily focus on Black children and youth, a few diagnostic disparities centering other racialized youth populations will additionally be highlighted.

Inequitable Diagnosis of Black and Racialized Children

Literature consistently showcases that the bodies, brains, and behaviours of Black Autistic and neurodivergent children are extremely misunderstood. When compared to their White peers, Black children who are Autistic and/or neurodivergent are at higher risks of receiving late diagnoses, incorrect diagnoses, and no diagnoses at all (Mandell et al., 2007; Mandell et al., 2002; Mandell et al., 2009). In multiple studies analyzing this phenomenon, researchers reviewed data which analyzed Autistic and neurodivergent children’s interactions with the mental health system. In these studies, all of the children met the criteria for an autism diagnosis or a neurodevelopmental disability diagnosis (like ADHD or

Dyslexia). Importantly, this meant that all children in these studies should have been considered for, and received, an autism and neurodevelopmental disability diagnosis.

Mandell et al. (2009), in their study of over 2500 children who all met diagnostic criteria for autism, found that Black children were consistently 4% less likely than White children to have a documented diagnosis of autism on their records. These disparities are further expanded upon in the following studies. It was additionally found that, upon a child's initial visit to a specialized mental health clinic setting, White children received the appropriate diagnoses of Autism 72% of the time, while Black children received the appropriate diagnoses of autism only 58% of the time, meaning Black children were 14% less likely to receive a proper diagnosis (Mandell et al., 2002). Moreover, Black children are additionally over 2.5 times more likely to receive no diagnosis at all, during their first visit to a mental health or psychiatric clinic in comparison to White children (Mandell et al., 2007). Even more, Black children are at higher jeopardy of receiving later diagnoses, with Black children on average receiving appropriate autism diagnoses over 2 years later than White children—which is often about 3 years after parents' first attempt to receive supports (Aylward et al., 2021; Mandell et al., 2002; Mandell et al., 2009). Similarly, Mandell et al. (2002) also recognized that Latino children were similarly at-risk of receiving later diagnoses and receive their appropriate Autism diagnosis 3 years later than White children. Mandell et al. (2002) assert that Black children (in comparison to White children) must access mental health and psychiatric settings 3 times as often, over a period 3 times as long, to finally receive their appropriate diagnosis. Even after receiving an autism diagnosis, some disparities in service access continue, as Black children are over 5 times less likely to receive out-patient autism related services (Bilaver et al., 2020; Losen et al., 2014).

While it can be argued that these diagnostic differences could exist for a multitude of reasons, including sociocultural differences in help-seeking, socioeconomic barriers, and/or systemic racial injustices, it should still be noted that these inequities exist and persist. Moreover, even further complicating these disparities, Black Autistic and neurodivergent children face even more troublesome statistics. More specifically demonstrating the link of these diagnostic discrepancies to race, Black children are not only more likely to receive no diagnoses and later diagnoses, but Black children are also more likely than White children to receive an incorrect diagnosis.

Mandell et al. (2007) further examined rates of misdiagnosis for children who met the diagnostic criteria for autism. Their study, including over 400 children, found that children were most commonly misdiagnosed with ADHD, with approximately 21% of children getting an incorrect ADHD diagnosis prior to receiving the appropriate autism diagnosis. This statistic remained consistent across races (Mandell et al., 2007). However, it was further identified that Black children were more likely to receive incorrect diagnoses of adjustment disorder and conduct disorder, when compared to White children. Specifically, Mandell et al. (2007) found that Black children were approximately 2 times more likely than White children to receive a diagnosis of conduct disorder, with approximately 15% of Black children receiving an incorrect conduct disorder diagnosis, and about 6% of White children receiving an incorrect conduct disorder diagnosis. Even further, Black children were about 5 times more likely to receive an incorrect diagnosis of adjustment disorder when compared to White children, with over 12% of Black children being misdiagnosed with adjustment disorder, compared to just over 2% of White children being misdiagnosed with adjustment disorder (Mandell et al., 2007).

These research findings were echoed in other studies which showcased similar racial disparities existing for other racialized children and youth. When investigating the implications of conduct disorder diagnoses on children and youth, a study by Cameron & Guterman (2007) found that Hispanic children were most likely to be assigned with a conduct disorder diagnosis, with Black children second most likely to receive the diagnosis, and White children least likely to be assigned the diagnosis (43.3%, 34.4%, and 24.4%, respectively). Importantly, it was recognized that all these children, irrespective of race, displayed similar levels of behavioural aggressiveness. This indicates that Black and Hispanic children's behaviours may overall be viewed as more 'clinically aggressive' than White children's behaviours—even when those behaviours externally present similarly (Cameron & Guterman, 2007). Interestingly, Fadus et al. (2020) highlight that Black and Hispanic children who display these so-called 'aggressive' behaviours are often diagnosed with conduct disorder or oppositional defiant disorder, while White children who display similar behaviours are often diagnosed with anxiety or mood disorders.

Racialized children—in this case namely Black, Latino, and Hispanic children—who are Autistic and/or neurodivergent are being misdiagnosed. Importantly, these disorders are categorized as behavioural disorders, which interestingly enough can present similarly to developmental disabilities, but carry different, more problematic societal connotations. To understand the implications of these incorrect diagnoses more fully, we need to more closely examine how these diagnoses are conceptualized in the medical model, through the Diagnostic and Statistical Manual of Mental Disorders (alternatively known as the 'DSM'). Adjustment disorder is classified in the DSM as an emotional and/or behavioural disorder, given to individuals who display unhealthy or extreme reactions to changes in one's life

(American Psychiatric Association, 2013). Conduct disorder is classified in the DSM as a behavioural disorder, given to individuals who display anti-social behaviours, who violate others, and/or who do not follow social norms, laws, or behaviours (American Psychiatric Association, 2013). Oppositional defiant disorder is classified in the DSM as a behavioural disorder, given specifically to children who display patterns of behaviour that are considered hostile, defiant, combative or disruptive (American Psychiatric Association, 2013). It is critical to recognize the implications of these incorrect diagnoses. In all instances of aforementioned misdiagnosis, it is evident that Black, Hispanic, and Latino Autistic and neurodivergent children are problematized, pathologized, and understood within a context of deviance, disruptiveness, and/or defiance.

Moreover, and notably consequential, it was shown that Black children are particularly vulnerable to receiving lower diagnosis rates of ‘mild-moderate’ autism, and are more likely to be diagnosed with ‘severe’ (otherwise harmfully known as “low-functioning”) autism. It can be argued that this indicates a racial bias, as Black children are seemingly over-represented and over-labelled as intellectually disabled, yet under-diagnosed as non-intellectually, neurologically disabled (Coles & Powell, 2020; Dumas, 2014; Gibson et al., 2014; Losen & Orfield, 2002; Ratto et al., 2016).

Literature further indicates that Black youth are not only under-represented and misdiagnosed with autism and neurodevelopmental disabilities, but they are additionally excluded from equitable education through an over-representation in special education classes (Coles & Powell, 2020; Dumas, 2014; Dyches et al., 2004; Gibson et al., 2014; Fadus et al., 2020; Losen & Orfield, 2002; Parrish, 2002; Reschly, 1997; Skiba et al., 2002; Wilt, 2021). In the 1970s, Black students constituted only 16% of children enrolled in school, yet made up 38% of students placed in special education/classes for the intellectually disabled (Losen & Orfield, 2002). In comparison, White children constituted 63% of students enrolled (47% more enrollment than Black students) yet made up 54% of students in special education classes (only a 16% higher rate of placement than Black students), and even further, were 76% of those considered intellectually gifted or talented (Losen & Orfield, 2002). Only 8% of all Black children were seen as intellectually gifted or talented (Coles & Powell, 2020; Dumas, 2014; Gibson et al., 2014; Losen & Orfield, 2002). Similar trends of Black student over-representation continue to appear today, as Black children are primarily most over-represented in the classification of emotional and behavioural disorders, and intellectual disability, as exemplified above (Parrish, 2002; Wilt, 2021).

Implications and Calls to Action

While the exact reasons behind these misdiagnoses and inequitable diagnoses are yet to be determined, and while the literature on Black Autistic and neurodivergent people is still limited, it remains clear that these discrepancies exist. Even more, the implications of these discrepancies are clear as well. Black youth, as well as Hispanic and Latino youth, are being incorrectly over-categorized as “bad” or “the problem kids” while simultaneously being over-represented within special education classrooms, leading to these youth not getting the appropriate care and supports they need. These rates of incorrect diagnoses further make invisible (i.e., ‘less common’) the existence of Black Autistic and neurodivergent people, further exacerbating the problem at its source.

As indicated by Goff et al. (2014), Black children are left vulnerable in today’s society, and Black youth, specifically Black boys, are seen as “less innocent…than their

White same-age peers" (p. 526) resulting in a dangerous dehumanization process. This dehumanization process is a key factor in the misidentification of Black youth behaviours as misconduct or deviance, rather than as indicators of needs or developmental disability. It is evident that Black children and youth are being unjustly mischaracterized, resulting in a lack of appropriate mental health, and developmental disability, diagnoses. The dehumanization of Black Autistic and neurodivergent youth results in the experience of harsher realities. Black children are 18 times more likely than White children to be sentenced as adults and represent 58% of children sentenced to adult facilities (Goff et al., 2014). Black children, and specifically boys, are seen as less childlike and less innocent than White children and White boys. Consequently, Black children are dehumanized, not given the privilege of innocence, are less likely to have the characteristics of childhood applied to them and are more likely to be held responsible for their actions. In the context of autism and neurodivergence, if Black children are less likely to be afforded the privileges associated with childhood, their behaviours are more likely to be pathologized and dehumanized, rather than supported—leading to lower rates of accurate diagnoses.

This dehumanization process fundamentally strips Black children and youth from the necessary and just considerations afforded to non-Black (primarily White) children and youth—the safe and supportive learning environments needed for children to thrive—and consequently violates the rights and needs of children to be understood, nurtured and protected (Gibson et al., 2014; Goff et al., 2014). These issues, in my view, start and stem from the diagnosis process. More research is needed to fully understand and contextualize the racial disparities evident in autism and neurodivergent disability diagnoses. It is pivotal to critically analyze how racialized children, youth, and families experience the diagnosis process. Further, we need to reimagine how we recognize ‘difference’, and how we conceptualize what autism and neurodivergence ‘look like’—particularly when existing in a non-marginalized young body.

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