

# Preface: Autistics of Color: We Exist... We Matter.

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For months it has saddened me that when people learn of our anthology on autism and race/ethnicity, some of their most common responses are confusion and/or bewilderment. Despite a plethora of statistics that document glaring and undeniable disparities that exist between white people and people of color with regard to diagnosis rates, access to critical resources/supports, outcome measures, societal perception, etc. people (white people in particular) frequently wonder, "An anthology about autism and race... why?" And several have remarked something to the effect of: "Autism is autism, right? Does race really make a difference?"

These aren't KKK members asking these questions. These aren't Confederate flag supporters asking these questions. These aren't White supremacists/hate group leaders asking these questions. These are everyday people. Educated people. Upstanding people. People who consider themselves to be progressive and supportive about these matters. They might work with autistic people; they might have an autistic sibling, partner, or child. They frown

down upon overt racial discrimination and might have even sported a "Yes, We Can!" Obama sticker on their vehicle years ago when that was *the thing* to do.

They are our friends. Our colleagues. Our neighbors. They genuinely care for us and for people like us. They want the best for us. And yet their perspectives are so obscured by their own intrinsic privilege with regard to race and ability that they don't understand. Can't understand.

It should be noted, however, that it is not only white people who ask (or think, even if they don't ask) this. It is also something that people of color are unclear about—even some people of color who are autistic. In fact, sometimes especially among people of color who are autistic, many of us have a lot of unlearning to do. Ableism and racism have become deeply ingrained into the collective mindset of humankind. There are so many complex, unspoken, and often contradictory rules about behavior, identity, culture, and society for us to try to comprehend, exacerbated by the reality that (since few of the messages we receive about our neurology or our ethnicity is positive, some, perhaps many, of us internalize those unflattering messages.)

We—the autistics of color—are seldom acknowledged. Our faces, bodies, and voices are conspicuously absent from not only literature and media, but also from much of the discourse surrounding race and that of autism as well. And when we do appear, we are rarely depicted favorably. We are painted as defective, flawed, undesirable, *different*. To be pitied. Not only are we non-white, but we are also disabled too? Uh oh. (Or wahala—o!)

When people finally deign to discuss us, it is often to underscore troubling data about autism, most notably the tremendous *cost/burden* to society autistics are. Typically invisible, we seem to be only dragged into the spotlight as examples when others need to use us to make a point, and even then we are merely reduced to tales of woe and dismal anecdotes. Afterward, we—our plight, our issues, our needs—return to the realm of the ignored, collecting dust until we are needed to serve as unwilling tokens for someone else's cause yet again.

This might sound calloused, but it is the simple truth. We—those of us who exist at the intersection of disability and race—are not treated as if we are "real." Little concern is paid to the innumerable factors present in our lives that impact how we view ourselves and the world, to how we ourselves are viewed by the world, to our strengths, to our needs. This is a grave injustice. Our lives and experiences cannot be splintered or subdivided into neat little categories; race over here, disability over there. We whose lives are greatly impacted by *both* racial and disability matters deserve to be more than tokens one day and non-existent the next.

There was nothing like this anthology in existence for people like me when I was growing up, and that is a shame. I would have cherished something like it because it would have made me feel less alone. Less strange, less weird. Less concerned by the fact that I never fit in.

It's true. I never fit in, anywhere. I was always "different." Never "normal." This is something I was acutely aware of as young as early childhood.

Some differences were obvious, such as how my chocolatey skin, full lips, flared nose, and thick curly hair differed from that of my predominately white classmates. Or the fact that my relatives were spread across three different continents and spoke several languages other than English. Or how my West African last name, which was two syllables and four letters long, apparently defied proper pronunciation by my (white) teachers, but my classmates' Western names didn't (including names like McConaughy, Kowalczyk, Oppenheimer, and Schwarzkopf, which I personally found to be harder to pronounce even if they were "white" names).

But other differences weren't as obvious. I remember helplessly trying to explain to a biracial cousin why I didn't "have it easier" than her merely because I was monoracial. We were both in middle school at the time, and she was frustrated with the endless microaggressions she faced from both people of color and white people about her mixed background. Her concerns were legitimate, as she was never considered "black enough" or "white enough" for some people who unfairly wanted to make her "choose" one over the other. But her assumption that I was "luckier" than she because I looked "black" and she didn't couldn't be more wrong. My experiences were different than hers, but they weren't easier. In some ways they might have even been more difficult.

Because of their racially ambiguous appearance, people weren't as taken aback if my cousin and her siblings didn't understand something in the way that they nearly always were when I didn't understand. However, in my case, because of my dark skin, because of my ethnic features, because I "looked the part," I was *supposed* to automatically understand and be fluent in all these random aspects of life attributed to black American culture. I was expected to speak in a certain way, dress a certain way, listen to a certain type of music, eat certain foods, date certain types of people. If I didn't do these things something was wrong with ME; I wasn't being "black" even though there is no singular way to "be" black.

I wasn't considered "black" enough for my black American peers; despite our similarities in physical appearance, I had a "funny" name, my family's customs, food, language, religion, and dress weren't the same as theirs, and I was viewed as "too white" in my speech and my mannerisms. But the white world didn't exactly welcome me with open arms either; I was clearly an outsider in that world as well. I was "too Americanized" to be accepted by many in the African community, yet because of my lack of familiarity with certain key aspects of American culture due to my West African heritage, to Americans I wasn't "American" enough.

And then on top of all of that I was a hyperlexic twice-exceptional autistic AND I was a girl; the way I spoke, interacted, moved, and processed things was so very different, which added an additional layer of separation like an invisible barricade. I was a minority group within a minority group within a minority group within a minority

group! There was no place that I belonged, no place where I could find someone who understood me. Even those who accepted me, cared for me, loved me still did not understand me. Having something of my very own, like the anthology, by people and for people who were like me...just as different...would have been inexplicably meaningful.

Moving beyond my youth into adulthood, decades later there was still nothing like this anthology for people like me when my kids were diagnosed as autistic as toddlers—and that was only five years ago. Nor was there anything like this anthology for people like me when I too was diagnosed just a few years ago, as an adult. According to popular opinion, autistic people didn't/don't look like me; autistic people didn't/don't sound like me. Autism = (white male-presenting) toddler wearing a Thomas the Train t-shirt; autism = (white male-presenting) quirky teen gamer; autism = (white male-presenting) geeky computer programmer; autism = (white male-presenting) adult rocking and staring off into space...a ready scapegoat for all of their caregiver's life disappointments; autism = Temple Grandin, puzzle pieces, ABA therapy, and Autism Speaks.

But now people will know better. They will know us, because we are right here, speaking. Speaking through our poems; speaking through our drawings; speaking through our essays; speaking through our art. We are here. We exist, and we matter. And we invite you...frankly, I implore you...to take the time to read this anthology. Take the time to share in our lives, our thoughts, our experiences.

Take the time for us to explain to you all the weight of our dreams.

#### All

(the whole, entire, total amount, quantity, or extent of; every member or part of; the whole number or sum of)

*"We who exist anyway*

*Our selves proof of a revolutionary survival power.*

*We who must keep breathing and breaking bleeding recreating.*

*Revelation."*

(Lee Lyubov, "Revelation")

*"I'm Black. I'm a woman. I'm the child of immigrants. I'm a mother. I'm autistic. And I know there are more people like me somewhere. Try not to be afraid; you're probably not as alone as you think you are."*

(Dee Phair, "Unpacking the Diagnostic TARDIS")

*"We protect the places that protect us, and we are the shelter of places that shelter us. We stand over our mothers' bodies and sin....My children will be wrapped in the love my body has taught me."*

(Jen Meunier (Ghizabaeassigaekwe), "we autistics, we villages, we humanoids")

#### The

(used with a qualifying word or phrase to indicate a particular item as distinct from others; a definite article)

*"Just as I cannot separate my disabled experiences from my racialized identity and experiences, I cannot recognize ableism without recognizing how it is affected by racism, or recognize*

*racism without recognizing how it is affected by ableism. I frequently center my work on disability justice, but the struggle for racial justice is my struggle too. I, too, am racialized."*

(Lydia X. Z. Brown, "I, too, am racialized")

#### Weight

(the amount or quantity of mass or heaviness; the force that gravitation exerts upon an object; a heavy load or burden; the significance or value of an object)

*"I came to this place of assimilation through the sheer will to survive, the sheer will to thrive, the sheer will to be considered alive, a life worth living. I sacrificed my happiness and my health to be the person you see today, the one who can look you in the eye, the one who can walk without a severely non-sequitur gait."*<sup>5</sup>

(Pretty Eyes Ellis, "Blood, Sweat & Tears: On Assimilation")

*"I couldn't save them from their families, couldn't heal their coping mechanisms... I loved them, they loved me, & it breaks my heart that so few other people saw what I saw."*

(Kassiane A. Asasumasu, "Things about working with 'emotionally disturbed' children that will break your heart")

*"But I can say with certainty that it's not mental illness or autism or an interest in violence or being bullied or social awkwardness or violent role playing or violent video games or violent creative writing that lead to mass murder....Ironically, those same assumptions are used to justify real violence against people like me, and often by the people who in theory are supposed to protect us."*

(Lydia X. Z. Brown, "I am autistic, and I am obsessed with violence.")

"...I do not want another kid loathed because the media decided to pin the blame on their brain.... I do not want another child being isolated...I do not want another child to have nightmares like I did... This has got to stop."

(Kassiane A. Asasumasu, "Things about working with 'emotionally disturbed' children that will break your heart.")

"Yeah, I notice.

I notice that I'm different from other blacks because I'm autistic.  
I notice that I'm different from other autistics because I'm black.  
You Think I Don't Notice?"

(COBRA - Confessions of a Black Rhapsodic Aspie)

"... Violence against us happens all the time, both by other people in the community and by government forces."

(Lydia X. Z. Brown, "I am autistic, and I am obsessed with violence.")

"Once you experience anxiety to the depth that I do, then you know it will stay with you; it doesn't hide away, or leave temporarily—it's there for a lifetime."

(Keara Farnan, "A Struggle Within Itself")

"Autistic students need to be given more positive visibility, more of a voice.... the intragroup diversity within this population ought to be included..."

(Joseph "Joey" Juarez, "Understanding the Challenges Facing Autistic Students in Higher Education")

"I grew up learning that Passing was Necessary. I grew up hating that I had to try to Pass."

xviii

(Jane Strauss, "Passing—and Passing")

"If my children are autistic or mentally ill or both, I don't want them to grow up in a world where their humanity is questioned every single day, or where police brutality based on their disability status could end their lives."

(Lydia X. Z. Brown, "I am autistic, and I am obsessed with violence.")

Of

(indicating connection, association, possession, or specific identity; pertaining to)

"Today I remembered from your graves and bones that I am kin to you,

and you were loved, and therefore

I, too, am worthy of love."

(Kajajii Gomez Wick, "Viva La Lebensunwertes Leben")

Our

(items those which belong to us; indicating we have possession of one or more objects)

"You are order, you are chaos, you are electric words like stim and echolalia,

words that hum and buzz

and loit around on the tongue... You are me, and I am you."

(Kajajii Gomez Wick, "Love Letter To My Autism")

"My love for my community is my shield and my strength... I am standing for love..."

This is for those who I will know in the

future. Who I love without having met yet. For those I know now,

xix

and love with such ferocity there are not words for it."  
(Kassiane A. Asasumasu, "Litany Against Fear/Litany for Love")

"Neurodiversity is part of a new scope of sight that needs to reach even deeper than social models of disability which retain the white colonial privilege of that delusion. Autistics of colour are among those who fall first and hardest to the violence against us that punctuates that delusion, and so our voices need to be heard across the movements that are rising today..."

(Jen Meunier (Gzhibaeassigaekwe), "we autistics, we villages, we humanoids")

#### Dreams

(a succession of images, thoughts, or emotions passing through the mind during sleep; aspirations; goals; aims; hopes)

"Learning to cope. Learning to stand. Learning to embrace oneself. Learning to live....Being human. Being accepted. Being loved.

Being free....A growing community. Hope. Change. Faith. Surrounded by the love and support that strengthens us."

(Morénike Giwa Onaiwu, "Autism Defined")

"I worked hard to rebel against the labels placed on me, to be authentic. I am not a walking stereotype. Nor am I defined by diagnosis. I do not fit into the boxes others try to put me in. I am me. I am no longer an outsider."

(Stephan B., "My Experience")

"I am also happy to be comfortable being me, with all my quirks and routines."

(Jennifer Msumba, "All Kinds of Different")

"I'm not a 'freak'—there are lots of other people who are different in the same ways. I don't have to keep trying to meet societal expectations and pass as 'normal,' because there is nothing wrong with how I am. I can't always speak, but that doesn't mean I will be silenced. I am free to take off the invisibility cloak."

(Shane Bentley, "The Silencing Invisibility Cloak")

"I want to believe in peace. I want to believe we can unlearn violence & affirm our interdependency. I dream of a community of lovers, who navigate pain, joy, laughter and grief together, collectively & with care; experiencing endless beauty. I think I am dreaming of a modern day heaven, or perhaps I am dreaming of the good we were meant to be."

(Ki'tay Davidson, "Why I Quit Philanthropy")

#### All the Weight of Our Dreams: On Living Racialized Autism.

What does autism have to do with race? It seems simple, but it is extremely complicated. I urge you to read this anthology and explore this in depth as you dive into the hearts of the authors. They are yellow, brown, red, black, and multi-hued; they are young and old; they share their purpose, their passion, and their pain. But before you embark upon this journey, I have a "spoiler."

On every page, in every account, from every contributor you will find one profound, universal theme threaded silently and artfully throughout the entire anthology. Again and again, you will find that the answer to the aforementioned question, now unspoken, "What does

autism have to do with race?" is a gentle, but resounding,  
"Everything."

# Foreword: On Autism and Race

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## E. Ashkenazy

White. Japanese. Mongolian. Black. Cherokee. Indonesian.  
Multiracial. American. Autistic. Married. Parent of an  
autistic child. Deaf. Bilingual. Jewish. Female. Welcome to  
my world.

As a person of color, I face a multitude of personal and  
collective challenges as I strive to define my unique  
experiences and to have my voice heard. The autistic  
community also shares this truth. The experiences of  
people of color, and of autistic people, are distinct, yet as a  
whole we demand respect. It is our right to determine  
how we wish to identify ourselves, both within our  
communities and within society.

This essay begins with a discussion on race and identity,  
which is in and of itself worthy of rich detailed dialogue,  
before I merge it with the equally diverse and multifaceted  
world of autism.

The human brain is wired to sort and classify what we  
take in via our senses. Though our brains are eager to  
work efficiently, it is a precious courtesy awarded when a  
conscientious person recognizes, understands, and