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## “A Dream Deferred” No Longer: Backstory of the First Autism and Race Anthology

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The way I perceive things, my involvement as one of the editors of the first-ever anthology on race and autism, *All the Weight of Our Dreams: On Living Racialized Autism* [1], was by pure accident.

An extremely fortunate accident that I will eternally be grateful for, but an accident nonetheless.

The anthology itself was conceived in the mind of Lydia X. Z. Brown, an Autistic disability rights activist with whom I serve on the Board of Directors of the Autistic Women and Nonbinary Network (AWN Network, a grassroots Autistic-led nonprofit for gender minorities that was founded in 2009), and AWN Network enthusiastically agreed to partner with Lydia to bring the project, announced in summer 2014, to fruition.

Having learned about the idea early in its development, I, like many others, embraced and helped to promote it. Community support for the anthology was vital for a variety of reasons—fundraising being one of them. Though AWN Network had successfully secured a small amount

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of grant funding and sponsorships for the anthology, in order for it to become a reality a lot more money was going to be needed...and as none of us had much money, it was clear that we were going to have to rely upon crowdfunding to obtain the rest. However, to get people to donate, we knew it was crucial for us to make a convincing case for why this anthology needed to be published. So in the beginning, when the anthology was just a creative idea, a lot of the focus was on finding the means to make it happen. To justify a reason for its existence.

Ultimately, the most compelling reason we could come up with, and the one that successfully enabled us to reach our \$10,000 fundraising goal in approximately one year (\$6712 from 143 different supporters, \$2000 from a state Developmental Disabilities Council, \$1000 from the Autistic Self Advocacy Network, and the rest from in-kind donations) was simply the truth. And that truth is one that Autistic people of color like myself, Lydia, E. Ashkenazy (a Deaf multiracial Autistic woman who is also one of the editors of the anthology), and the more than 60 different individuals who would later become contributors to our anthology share: that the existing public discourse about autism is glaringly incomplete.

The experiences, stories, and images of people of color on the autism spectrum are conspicuously absent both in the public view and sadly even within the sphere of disability. The glaring lack of visibility of people of color within the disability community which prompted Vilissa Thompson, a Black disabled writer and social worker, to coin a phrase that became a viral hashtag (#DisabilityTooWhite) clearly exists within the autism realm as well. In fact, it might be an even greater problem.

Sharing that simple yet profound truth over and over was successful. Our plight resonated with people and they supported us both in word and in coin. And eventually there was a sufficient amount of money to begin the actual work of creating the anthology.

Initially, the plan was for Lydia to serve as the Lead Editor of the project and E. Ashkenazy as Project Manager. However, as a result of the overwhelming response to the call for submissions (submissions were pouring in from various countries across the globe), it became apparent that another member of the primary editorial team would be needed and I was selected. So although I had not originally planned to be involved with the anthology beyond providing general external support for the idea,

things changed, and when approached to join the team I happily accepted. At the time I was not fully aware of the depth of the task we had before us nor could I grasp its overall significance; I was just excited, but it would later dawn on me.

We were quite an eclectic team, and we had a lot to learn. We were all Autistic. We were all people of color: Lydia is East Asian; E. is multiracial; I am Black. All of us loved to write and had even had some previous work published, but none of us considered ourselves professional writers. None of us had an educational nor work background in journalism; none of us had ever worked for a magazine, book publisher, or newspaper. None of us had ever been involved in a project quite like this. In addition, we all had major time constraints due to our busy lives and numerous responsibilities. Lydia was enrolled in law school at the time; E. was running a professional skating and dance company; I was teaching. E. and I had eight kids between the two of us. All three of us had various advocacy commitments we were engaged in that required time and energy, and we all had different work schedules. Furthermore, we all lived in different parts of the US: E. lived on the West Coast, Lydia on the East Coast, and I was in the South.

However, all three of us were devoted to the project and willing to "learn on the job" and challenge ourselves to make things work. We all possessed a strong work ethic, an enormous amount of enthusiasm, the ability to "think outside the box" which helped us to grasp new things quickly, and the ability to hyperfocus. We had different working styles: one of us was a planner who liked to make lists and preferred to stay ahead of deadlines; another was a perfectionist and procrastinator who would have periods of inactivity/dormancy and then become infused with a creative burst of energy that enabled rapid completion of a voluminous amount of work at the very last moment; the other person was a combination of these two types.

Our differences worked in our favor as we all brought unique strengths to the team and were able to support one another well if we faltered because we didn't all share the same weaknesses. We were united in our belief in the importance of the anthology and in our respect for one another. Over the years we maintained regular (sometimes multiple times daily) communication via email, message, and other electronic means. Together,

along with several other dedicated individuals, we built something real, something monumental, something beautiful.

From the very beginning, it was important to us that the anthology remained true to Lydia's original vision (which was one that we shared). It was also important that we created something that we believed in and could be proud of. We realized early on that many established "best practices" that are utilized in the development of publishing a book of this volume, while generally helpful and useful for others, were not going to necessarily work for us. Our process was going to look and feel different in several ways, and was going to be both non-linear and nontraditional. Because of this, we weren't going to have a formal framework, "blueprint", or set of instructions that we would be able to rely on. Where there was no precedent, we had to be ready to trust one another and forge our own way—and we did.

We developed and agreed upon several guiding principles throughout the process of birthing the anthology. Some of them include:

**Nothing About Us Without Us.** Every member of the (lead) editorial team, which consisted of the three of us, had to be an Autistic person of color (PoC), and we needed to have full autonomy over our work.

We did allow Autistic people who were not PoC to assist with the project itself, and many did, including Shain Neumeier and Clare Barber-Stetson (White Autistic colleagues who assisted with reviewing submissions and providing feedback on any necessary revisions), Amanda Gaul (White Autistic colleague who provided legal and financial assistance), Melanie Yergeau (White Autistic colleague who completed most of the formatting [along with Tracy Garza who is an Autistic PoC]), and Lori Berkowitz (White Autistic colleague who provided web and technical support). We also had a number of White allies in the community help with generating interest and media attention for the anthology. Solidarity is important, and we appreciate the efforts made by the many people who supported this project.

However, it needed to be **our** project. "Our" meaning Autistic PoC. Led by us, coordinated by us. Not by White people—no matter how supportive and like-minded they might be. It was imperative that we did not perpetuate the false notion that people who do not have the lived experience of being a PoC are somehow able to effectively represent us.

**Every** key decision about the anthology had to be made by and approved by us—period.

In that vein, we strived to have as many Autistic people, and especially Autistic PoC, involved in various aspects of the project as possible. The only contributors we accepted for publication were from among those who identified as Autistic PoC. We also intentionally sought out a graphic designer who was an Autistic PoC (Finn Gardner) for the cover art of the anthology. Although not a formal part of the anthology, another Autistic PoC, Sharon daVanport (AWN Executive Director), provided logistical support throughout the entire process. Moreover, we set aside funds to hire an Autistic PoC after the anthology was published to assist with a social media and marketing campaign.

We welcomed, and still do welcome, any and every person to read the anthology—regardless of what race they are and whether they are Autistic or not. It is not something that is only FOR us. But it had to be only BY us—and only us, and that was non-negotiable.

**Everybody Gets Paid** was another guiding principle that we felt strongly about and one that we will never compromise on.

Far too often the labor of marginalized people is minimized and treated as if it were of little value; meanwhile, those with vastly more privilege go on to profit enormously from the resources they have derived from those same seemingly “less valuable” people. Academics and professionals amass a plethora of publications, enhanced research portfolios, and career advancements on the backs of stakeholders whose only acknowledgment is a gift card and a contrived one line “thank you” written in small print at the end of their abstract or on their last presentation slide (or begrudgingly acknowledged in public decades later after numerous lawsuits, as in the case of the family of Henrietta Lacks).

We refused to be like that. We were not going to ask, nor expect Autistic PoC to contribute to an anthology and not get fair market value for their work. Marginalized people are frequently expected to possess a sense of altruism that is not expected of more privileged people; we are guilted into doing hordes of unpaid work to “help” our people, and/or told that we are getting “exposure” in lieu of paid wages. Well, you can’t eat exposure. Your landlord won’t accept exposure in place of a rent payment. Exposure doesn’t buy diapers and milk. Meanwhile, others are paid for their time

and effort. We respect and value the work of our people and if they could not get paid then we were not going to go through with the anthology. We researched market rates to determine what would be fair compensation and we made sure that every single person—from the contributors to the formatters to the attorney to the graphic designer, etc.—received payment for their involvement with the anthology.

We were warned by several external parties that this was not “sound business practice” and that our decision to do this was not recommended. We were told that this would not be profitable. We chose to reject their warnings as we believe in people over profit. Knowing the high rate of unemployment and underemployment among Autistic adults and the many challenges our community faces, how could we even conceive of taking advantage of our own people and cheating them out of what they deserve?

**You Define You** was a third guiding principle. Race is complicated and messy. So is neurology. Although our requirement that **all** contributors whose work was accepted for publication had to be Autistic PoC, we were adamantly against “policing” people’s identities with regard to race and being Autistic. Phenotype does not always equal genotype; we refused to define race in a narrow, binary manner. ALL Autistic PoC, including biracial, multiracial and “White passing but PoC identified” individuals were welcome.

Additionally, Autistic PoC from any part of the spectrum were included, regardless of whether a person had a “PDD-NOS” diagnosis, an “Autism Spectrum Disorder” diagnosis, whether the person had self-diagnosed, etc. We did not require any of our contributors to have to conjure up “proof” that they were enough of this category or that category. You define YOU. We recognize that many barriers exist for Autistic PoC to obtain formal diagnoses should they choose to do so and also acknowledge that for some of our people it is neither advisable nor safe to do so.

For the anthology, we opted to accept the validity of people’s self-identification as stated.

**It’s Not a Term Paper** was another guiding principle of ours, and one that we have found to be somewhat controversial. We made the decision that we were not going to edit our contributors’ pieces to death. Too often rigorous, elitist Western standards are applied to PoC, especially

disabled ones, when they are inappropriate for the context. We felt that this would have been an instance where "standard" editing procedures would have created more harm than good. Autism is, among other things, a social communication disability; it is to be expected that there may and likely are some differences in how things are communicated—and that's without taking cultural factors (because all of the contributors are PoC) into account.

We preferred to prioritize retaining the true essence of what our contributors were trying to say over chopping up and "white-washing" their words for the purposes of ensuring they had perfect grammar, punctuation, and spelling. Especially since the accepted pieces come from contributors from a range of ages (one as young as five years old!), countries (including countries where English is not a commonly spoken language), backgrounds, and levels of schooling (from very little formal education to graduate school). Unless there was a pressing need to make grammatical corrections, we chose for the most part to capture our contributors' intended meaning AND original wording as is.

This guiding principle applied to us as well, not just to the contributors; if you review my own preface to the anthology carefully, you might see a word repeated twice accidentally. Other places in the anthology you might find various colloquialisms, ethnic slang, misspellings, etc. Yes, we saw them all—and yes, we left them there. Humans do not write perfectly; why pretend that we do? Why create a written version of a heavily "PhotoShopped" image that barely looks like the real thing when we have an opportunity to be authentic in our presentation? For us, there was no valid reason why and were plenty of reasons not to.

**Real Transparency** was another guiding principle of ours in putting together the anthology. We viewed this project as one that belonged to the community. For before the anthology even had a name, before we had even a single contributor, when it was just a dream floating around in the cosmos that we were trying to make tangible...our community backed us. It was they who provided the bulk of the money for us to pay everyone involved. It was they who encouraged us when we hit snags in the process (which happened more than we had anticipated, unfortunately). It was they who shared with their friends, family, and coworkers about the anthology that was underway to help us to get buyers.

On our [AutismAndRace.com](http://AutismAndRace.com) website as well as on social media and in other places we were open about timelines that we struggled with (not surprising given that this was a new undertaking for all of us, we are all Autistic people who struggle with executive functioning, and that we were juggling this project among a number of other responsibilities). We were forthright about delays, but also about successes and exciting developments that occurred along the way. We also regularly expressed our gratitude for the support and encouragement we were receiving. Good or bad, promising or disappointing, pretty or ugly...we kept it 100% real with our followers the whole way through.

**We've Only Just Begun** is probably my very favorite of all of the guiding principles of our anthology. Before the ink was dry on the first draft paperback copy of the anthology, we were already making plans for what we wanted to see happen next. The anthology alone was never intended to be the "end" of this journey; it was our beginning.

This is NOT in any way to diminish the significance of the anthology. *All the Weight of Our Dreams* is the first-ever anthology about and by Autistic people of color; quite literally, it made history. It was an important start, a groundbreaking milestone and we remain extremely proud of it. But there is so much more that we want to do to with and for Autistic people of color; the anthology helped us to realize that and to begin dreaming yet again.

It's hard not to feel heartbroken when you mail a contributor's copy to one of the brilliant writers in the anthology—and that copy comes back to you in the mail undelivered because that writer, that amazing, talented Autistic PoC, is now homeless. It's hard not to feel frustrated when you see yet another link to a fundraiser for an Autistic PoC who has been fired from their job again due to racism and ableism and now they are struggling to pay their rent. There are so many stories; there is so much need; there are so many voices still unheard.

We've succeeded in capturing a snapshot of our reality as part of the global community of Autistic PoC. One of its central themes is an illustration of intersectionality. Not in the way it is frequently misunderstood and misused, but as Dr. Kimberle Crenshaw, the Black scholar, attorney,



and womanist (among her many honorifics) who is the creator of the term [2], intended: a way of describing the overlapping effect of existing with multiple oppressions/marginalizations—like Autistic PoC do. It’s never “just” autism for us, and it’s never “just” race. Intersectionality, for us, isn’t an intriguing concept to have philosophical debates about; it’s our real lives.

And in these real lives, we face unique challenges, but also have unique strengths. It is our hope to be able to impact individuals as well as our community in a meaningful way through this anthology. We have already started to do so, in fact: with a portion of the proceeds we have earned from sales of the anthology as well as an external grant, in summer 2018 on the one-year anniversary of our anthology’s publication date, we have launched the first-ever Fund for Community Reparations for Autistic People of Color’s Interdependence, Survival, and Empowerment (<https://autismandrace.com/autistic-people-of-color-fund/>). The fund, which is operated by AWN Network and managed by the anthology editorial leadership team, provides direct financial support to Autistic people of color through individual microgrants of amounts between \$100 and \$500. We have assisted individuals in purchasing medicine, food, assistive technology, educational workshops, housing costs, legal fees, and more.

We also have plans to develop a few special editions of the anthology in the future, including an audiobook version in as many of our own voices (for speaking contributors) as possible and a version with full-color artwork from the anthology. Additionally, we hope to be able to obtain funding to help support Autistic PoC with scholarships, to help defray the costs of presenting at conferences, and in other endeavors.

The more that I think about it, my involvement with the anthology was no true accident. It was supposed to be this way, and everything is unfolding the way it was designed. Just as I could not foresee becoming part of it, now I can’t envision a future where I am not a part of this life-changing project. It isn’t just a book; it’s truly a dream come true that has the potential to change hearts, change minds, and hopefully continue to change lives.

## References

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2. Crenshaw, K. (1989). Demarginalizing the intersection of race and sex: A black feminist critique of antidiscrimination doctrine, feminist theory and antiracist politics. *University of Chicago Legal Forum*, 139, 139–167.

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