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Breaking Me Down and Lifting Me Up: An Autoethnography of Being a Black Autistic Woman Online

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Cover Page Footnote

I would like to extend special thanks to Jinx Mylo for invaluable support and guidance throughout the entire process of writing this essay.

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Morgan Harper-Nichols

When I was 13, I was thrown against a wall by a classmate for being in her way. I was rendered nonverbal and was unable to participate in class for the rest of the day. I expected to be bullied by kids who didn't look like me, but in this incident my bully was a Black girl my own age. I hadn't seen it coming. I was used to bullying by different groups, but this confused my understanding of bullying and social dynamics. I didn't know how to pinpoint what was wrong with me that was leading to these situations. I didn't know which parts of my identity were making me "weird." I knew I was different but didn't know why.

This began my journey of turning both inward and toward the internet, in search of a new way to connect to the world. Driven by the potential for anonymity, I realized I could create a universe where no one had to know I was a Black girl or any of the other things that made me different, even if I still didn't know what those were. In spite of some unpleasant lessons along the way, this led me to create 20 years' worth of tangled webs of web sites, blogs, and social media accounts.

As it turned out, one of the things that made me different was that I was autistic. Being on the web created opportunities for me to become a self-employed artist, but it also gave me the courage to pursue an autism diagnosis. Families of Black children face additional challenges when trying to seek diagnosis for their children (Weitlauf et al., 2023), and I had been turned down for a referral years before by my doctor. It wasn't until seeing Tiktok videos of late-diagnosed autistic people that I began the diagnostic process in 2020. I received my diagnosis in 2021, and as other late-diagnosed adults have expressed, finding out that I was autistic was by far the most pivotal point in my life (Arnold et al., 2020). From that point on, I had a new way to look at my experiences with a more thorough understanding of the intersectional forces that have shaped my life online.

Media researcher Henry Jenkins and his co-researchers (2015) define participatory culture as having “low barriers to artistic expression and civic engagement,” but what does it look like for a Black autistic woman? My story is largely one of encountering these “low barriers” as “high barriers” when it comes to the racial and social aspects of being online. I do not speak for all Black autistic women, but this autoethnography provides insight into what I experienced online from 2003-2023 and seeks to highlight the Black autistic woman’s perspective, so often left out of autism research, in the study of internet culture.

Early Explorations: Forums, Fandom, and GeoCities

One of my first internet searches (at age 13) to find more people like me led to a message board dedicated to teen writers who wanted to share their work. I was eager to become a member of the club and to connect with fellow young writers. Unsure of how to present myself online and offline, I spent my early days on the internet testing the waters, figuring out what version of myself I needed to be. There was no way to upload a profile photo back then, and when you signed up, it just asked you to create a username and nothing else, so I made a conscious decision to be vague about my identity as a Black girl.

Within days of joining the one-page forum, I encountered racist jokes about Black girls and sexist complaints in a discussion of gender stereotypes in *Lord of the Rings*. My naive approach to participating online started to wear off after encountering the “ghetto” jokes and the Gandalf gatekeeping, and I discovered that if you were Black or a girl, you could very quickly be considered as “other” or less than (Gatson & Reid, 2012). The only way I could be there was by being cautious about if, when, and where I would reveal that I was a Black girl. It eventually got to me and I started building my own site on GeoCities, hoping to establish a community of my own. While my first Geocities site was small and short-lived, other sites like MySpace, Open Diary, LiveJournal, and Xanga would soon become key places for sharing my creativity and forming connections online. However, with each site, it was only a matter of time before I would encounter coded language or direct racism.

Although I wouldn’t meet them until much later, I was joining a worldwide community of Black people who sought to be part of fandoms and create

their own narratives, despite facing racism in every space from fiction to comic book conventions. When Black people participate in fandom, they also face the reality that by being the minority, their way of expressing their fandom may not be accepted (Stanfill, 2018). I was a young *Lord of the Rings* fan who did not see myself represented in the films that were being released in the early 2000s, but having learned on the forums that it wasn't even tolerable to imagine a woman version of Gandalf, there was no way that I could speak about Black elves or fairies without pushback. So I decided to be as vague as possible in my fan fiction character descriptions, describing them as having "curly hair" and being "people of the sun." While I didn't know the term yet, my fan fiction was a part of a multicultural fandom practice called "racebending," a way that non-white fans of popular culture can imagine themselves in stories that didn't include characters that looked like them (McCracken et al., 2020).

I created different versions of myself based on who I thought I should be in a particular space, based on my perceptions of the expectations in each environment. Today I am able to connect with Black artists and writers with all kinds of interests, but as a teenager just trying to learn how to use the internet in accordance with my parents' restrictions, my barriers to entry were higher, even when I was sharing anonymously. This would only become more challenging as the 2000s social networking landscape began to change with the rise of MySpace.

MySpace

Launched in 2003, MySpace provided users with the ability to create personalized profiles, connect with friends, and share music, photos, and videos. As a Black girl, I was grappling with finding my place in the world, both online and offline, while trying to fit in with my peers. As MySpace became increasingly popular, I learned friends I'd met in real life were different online. They were nice to me in person, but some of their customized online profiles revealed glittery Confederate flag gifs and "southern heritage" borders. We all lived in Georgia, where the Confederate flag was a part of the state flag until the early 2000s, so I was used to seeing these flags in various contexts. This made me question my ability to have friends and trust what people told me, and was the first part of MySpace becoming a little less of a fun escape for me than I'd hoped.

Another MySpace feature was a drag-and-drop hierarchical ranking system called the “Top 8,” which would allow you to display a list of your friends on your profile and tell the world which people were the most important in your life (Reid, 2017). A typical “Top 8” might include best friends, significant others, family members, or even bands and music groups (Thelwall, 2008). Even though the drag-and-drop feature could be viewed as advantageous for some people who took pride in displaying close friends, younger users on the platform had a more complicated relationship with the feature. One described the management of your Top 8 list as psychological warfare, while others described the power plays involved in taking people off the list or changing the order of appearance (boyd, 2006).

I had a strong aversion toward the Top 8 from the beginning. Creating a highly visible structure around high school relationships felt like an impossible feat to me. As I started to add my new real-life friends online, I couldn’t help but notice that after putting them in my Top 8, I never made it onto theirs. This became a constant reminder of my low social ranking—now proven to be even lower than I thought it was. Between not understanding the rules and not enjoying the outcome of the Top 8, I chose to turn my attention elsewhere on the platform, and created a MySpace music profile for myself where in my Top 8, I displayed my favorite bands instead of people.

To this day, I struggle with “friending” and its close friend “following” in places like Facebook, Instagram, and Twitter, where I have historically followed and followed back lots of people to cover up my struggle with making and keeping friends. Years after MySpace, the complexities of social media navigation, from who’s allowed to see your Instagram Story (Kreling et al., 2021) to monitoring one’s follower count as a form of social acceptance (Sciara et al., 2021), continue to confuse and impact users’ self-esteem, self-expression, and the capacity to establish connections and build community in a complex manner.

YouTube

In the early days, YouTube for its wide array of amateur videos. Like many others, I watched lonelygirl15, a popular YouTube personality who would later be revealed to be a fictional character produced by a group of filmmakers. The series felt like it was a new template for how to be online.

Around the same time a young musician named Wade Johnson started uploading cover songs to YouTube and creating a community of followers. I was certain that I could do something like this—at least, a Black girl version.

I was in high school struggling with a variety of issues, including academic challenges, so I launched a YouTube channel, appearing on camera with a guitar as a protective barrier for comfort. I hoped that developing a public persona on camera would help me acquire real-world, socially acceptable skills that could enhance my college and career aspects. Live music performances were challenging for me due to complex social dynamics, so YouTube offered me a platform to experiment with cover songs.

I set up my Nikon Coolpix digital camera on the edge of my desk in my bedroom, took a few steps back, and played my heart out with my guitar as between me and the camera. The window behind my head created such a big glow that you could hardly see me, and the audio quality was so poor that you could hardly hear me, but if lonelygirl15 and so many others could hop in front of the camera and be praised and accepted, then surely I could, too. I started uploading videos of myself playing guitar and singing along to songs like “Blackbird” by the Beatles and “Folsom Prison Blues” by Johnny Cash, which were popular on guitar tab websites where I learned how to play. These kinds of songs were the highest ranking as cover songs online. As a result, I began to hyper-fixate on learning this instrument with a mission of uploading songs to YouTube.

By now I knew to proceed with caution and prepare for negative feedback, but I vastly underestimated the racist comments I would receive. I would upload a video and a few hours later, return to my computer to find comments calling me the “n” word, and others saying that Johnny Cash would be rolling over in his grave if he saw this. Comments were significantly harder to moderate back then, with no easy filters to turn on. My moderation system was waiting for comments to appear so I could delete them, and managing the racist comments became overwhelming. Johnston recalled experiencing both positive and negative reactions to the popular cover songs he was sharing on YouTube (Cayari, 2011), but this white male teenager’s experiences were very different than my own as a Black girl on the platform, where both my gender and my race contributed to more severe harassment (Sengupta & Chaudhuri, 2011; Wotanis & McMillan, 2014). I decided to focus on creating

original music, and thankfully that worked to avoid some of the negative comments. Getting to make and share music without having to be on a stage with bright lights and loud sounds just made me feel more alive.

Instagram and Associates

As a millennial college graduate, I was experimenting with everything from Flickr to Pinterest, trying to find work while still wanting to connect with people on the internet. The economic uncertainty of the late 2000s led me, (and many others) to explore the digital gig economy. Struggling to secure a steady living, Instagram and Etsy were platforms where I could experiment with dozens of accounts, sharing and selling my interests and creative output without showing my face, all from the convenience of my phone.

Both sites provided aesthetically beautiful and friendly settings that made me feel safe to create there. In contrast to the old forums, MySpace, and YouTube, being on Instagram felt like finally having the credentials to be featured in a fancy magazine. Being on Etsy felt like finally being able to shop in a sleek, high-end boutique. Not only did I feel welcome, but I felt like the earlier experiences I'd had with social media as a means of escaping my regular life were now accepted by the mainstream as the new path to success (Duffy, 2022). At this point, I was still just trying to survive, never mind becoming a success, but it inspired me to feel like I could have my own counter in the fancy store and sell my art to earn a living.

Over the years, I've had more than 25 Etsy shops, where I experimented with selling everything from hand-knitted bracelets made from craft store materials to photography printed at Walmart. Most of the time, I chose not to put my face on the accounts because I felt that I needed to look "professional." This meant needing to straighten my hair, which I didn't want to do because it was painful, a common experience of Black women in the workplace. (Johnson & Bankhead, 2014)

During this time, I also became more active on Twitter as a way of communicating with others through direct messages (DMs) and replies to other people's tweets. I chose not to share very much there; racism and harassment were a regular part of the Twitter experience for Black users in the 2010s, especially as issues related to the police killings of Black

people and Black Lives Matter became a part of public discourse (Ince et al., 2017). In addition, the design of the app made it difficult for me to follow the conversation threads of people I followed, and I struggled to share or respond with the same speed others could.

I was trying to find a way to move through the world and feel like I actually belonged. I realized that many people were dealing with things similar to what I had been struggling with over the years, and this led to the art and poetry that I share today. I was able to try out different ways of connecting with people. For example, my diet largely consisted of pizza and tacos, and I struggled with finding ways to expand it. I didn't want to eat other things, but I absolutely detested the textures of salads. I made an anonymous Instagram account sharing beautiful salads I had no intention of eating, tagging the creators and obtaining several thousand followers. I tried things like starting my own copyright-free photo-sharing account. I would upload my mediocre photographs of road trip landscapes and flowers and add #creativecommonszero to it. I had an account where I did illustrations of YouTubers and would tag them in the posts. I had another one where I would use colors in order of the color spectrum with color-related poems in the captions. All those Instagram profiles helped me make sense of the world and who I was in it, without needing to show my face. Black girls having secondary, private Instagram accounts called "Finstas" (fake Instagrams) is a way to express themselves outside of the gaze on their public account (Williams, 2022).

After George Floyd's tragic murder, I was one of many Black creators posting about the Black Lives Matter movement and frequently being mentioned in posts as a "Black person to follow." By this point, I had been sharing my art and poetry since 2017 and had amassed over 1 million followers on Instagram, but the summer of 2020 led to an even larger influx of new followers. I experienced racist harassment in my DMs like never before, and I was mentioned in a post belittling my work with a derogatory comparison to "The Help," a racially insensitive period drama set in the 1960s. I was feeling the strain of this new level of aggression that came with being a Black woman on social media at that time. Black creators as a whole have expressed the emotional and mental toll of 2020, which resulted in many leaving the platforms altogether (Casula et al., 2021). I developed a practice of taking breaks on the platform, especially as it related to opening up my DMs.

After 20 years of experiencing these kinds of things and becoming a full-time artist as a result of my internet activities, I am still surprised by the new ways these platforms break you down when you least expect it. As a part of an initiative to organize my art and poetry files, I recently downloaded all of my data from Instagram, which included thousands of DMs that were sent to me in 2020 that I had never seen. Downloading every racist message—including actual photos of lynchings—to my computer felt like a violation. There is a lot of talk about users having access to their data, but this made me question, “Do I even want to have that data?” I had encountered racist messages before, and if I was going to be talking about Black lives in any specific way, I wouldn’t open DMs for at least the next 24 hours, but this was something else. I pressed “Command+A” and deleted everything inside of the folder

Another thing that I first encountered on Instagram was the prevalence of misattribution and content theft. I have dealt with this multiple times, from A-List celebrities sharing my poetry and art without attribution and/or rebranded as their own to accounts that used my art to rebrand Q-Anon messages with an Instagram aesthetic. Across different media channels, from articles to poetry, Black women’s work is taken and not properly attributed, leading to movements such as #CiteBlackWomen by Christen A. Smith (Smith, n.d.).

At age 29, I finally made my own website through Shopify to sell art prints and stickers, and I sent it out to a mailing list of people who had been following my art and poetry on Instagram. This was the first time I began to see income that was steady enough not to have to worry every single moment. After 7 years of nonstop experimentation on platforms where I was the product, running my own site store provided me with enough financial support to be confident that I could continue to earn a more steady income, and allowed me to loosen to the tight grip of self-censorship that I had cultivated for years online.

TikTok

I’ve been on TikTok since its musical.ly days, and while the platform has its share of issues, it’s had a huge impact on my life. When I was 30, watching Tiktok videos of late-diagnosed autistic individuals and recognizing myself gave me the courage to pursue an autism diagnosis. I had been discouraged

by a previous doctor's denial of a specialist referral. Seeing these videos helped me understand the value of seeking out a specialist with experience in autism in women. As a result, I was formally diagnosed with autism, ADHD, and a sensory processing disorder in 2021, and since then I've connected with other Black autistics on TikTok who share experiences like mine.

There are still issues. The TikTok algorithm shows me related content, but it also distributes videos with strobing lights that negatively affect me. Unfortunately, there's no way to prevent these videos from appearing, especially if they're part of a popular trend. My videos have also been used in "stitch" or "duet" videos, which has led to some people reposting my content and mocking it. Despite these irritations, I've also made genuine connections and received meaningful comments, and have been able to connect with more like-minded people on this platform than any other in my 20 years of sharing online. I've discovered new special interests and communities of people who love them as much as I do.

These experiences on TikTok in many ways just feel like amplifications of experiences on other platforms. As I get older, I still limit what I share with my name and face attached, but I also still enjoy experimenting and exploring these apps. For instance, I have an anonymous TikTok account with 3 followers where I post videos of potatoes. It's the small things like this that allow me to enjoy the internet in spite of the negative aspects that never seem to go away.

Looking Back with an Autistic Eye

Since my diagnosis, I've realized how much of my past online existence has been an intersectional experience of being Black, autistic, and a woman. When I was being bullied at 13, doctors had told my parents that I was just a bit "quirky" and would grow out of it. This is an experience shared by many autistic women, who were told they were quirky or weird (Bumiller, 2008; Kelly et al., 2021). Many autistic adolescents have been observed to socialize differently than their peers, making them outcasts even when they do not want to be (Cresswell et al., 2019). Most of the time, no matter how hard I tried, I couldn't mask my autistic traits well enough to appear "normal" and be accepted by my peers, and like other autistic people, I used camouflaging strategies to (unsuccessfully) mimic the behaviors of people around me

(Perry et al., 2022). While it may help one “blend in” to varying degrees, it has been shown to have a negative impact on mental health from an early age, as it did with me (Chapman et al., 2022). Like many autistic teen girls, I wanted to fit in with my peers in an era when popular media *Teen Vogue* and MTV targeted teen girls to fit a mold (Tierney et al., 2016). I even tried imitating the girl rocker aesthetic of Fefe Dobson and Avril Lavigne, but it didn’t lead to social acceptance. The sheer sensory overload of trying to straighten my hair or wear nail polish that was nauseating to me drove me to look for other ways to participate.

When I think back to my participation in online forums, I can see that what I thought were just hobbies and curiosities in fantasy were actually special interests—which many autistic people use to express themselves, cope, or socialize and connect with others (Jordan & Caldwell-Harris, 2012). Participating in fandom digitally can help to promote and foster social interaction for autistic adolescents (Leyman, 2022). Fan activities, like cosplay, play a vital role in modern culture and identity, especially for disempowered groups such as autistic youth, who may find a more accepting community in fandom (Leyman, 2022). The more I’ve learned about the connection between autistic people and fandom activity, the more I’ve been able to make sense of why I kept participating in the community, even though I usually felt that Black girls like me weren’t welcome.

Thinking back to MySpace, I can see now that my aversion toward the social hierarchy of “Top 8” is connected to my autistic preference for low-pressure socializing with a more open, rhizomatic way of connecting with others. Trying to navigate social hierarchies and status cues can be more difficult for autistic people and can lead to challenges with being socially accepted (Koski et al., 2015).

With YouTube, I recognize that my desire to keep sharing my music, despite the harassment, was largely rooted in fearing I could not live up to society’s expectation that teens do well on standardized tests and possess discernible skills to secure college and career opportunities. In my case, I struggled with standardized tests in high school, which is why I went on YouTube, thinking that being a singer was the only way I could have a career. But, when my educational environment changed and I had smaller classes in settings with less sensory stimulation, I found that I did just fine on most tests. I’ve

learned, though, that even when given accommodations, autistic students may still struggle when it comes to performing well on standardized tests, which also increases the possibility of not accurately measuring their abilities or evaluating their intelligence (Eigsti, 2023; Wood & Happe, 2020).

Looking back on my time with Instagram, I know that although I enjoyed using the platform to share art and connect with others, so much of the early motivation to post came from trying to figure out how I could get enough gigs to survive while trying to keep my mask on and hide behind the my art. In addition to Instagram supporting another round of my special interests, I think about my food issues and the salad account I created to try and make sense of them. Finding out that being highly selective about food and having nutritional inadequacies is an autistic trait that is experienced by many on the spectrum (Molina-López et al., 2021) makes me feel more normal.

On TikTok, even before I knew the term “autistic burnout” I saw people like me describing the internal battle I was experiencing, leading me toward the moment when I realized I might be autistic. When the strobe effect on Tiktok caused sensory overload, it was Reddit that helped me find space to read about autistic experiences on a simple dark-mode screen. And if I didn’t have words to add, I could just contribute via a small upvote.

In addition to the stories I’ve shared here, other platforms have places on my journey. When the stories I was writing on the picnic benches at summer camp in high school made me the subject of mockery, it was LiveJournal, Xanga, and Teen Open Diary that made me feel like my stories could have a place. When the kids who had bullied me were coming onto MySpace and Facebook, it was Flickr, Purevolume, Blogspot, and Pinterest where I ran to share my poetry, art, and music.

I stood in the back of the room on game night in college, not because I wanted to, but because I couldn’t find the words to speak that night, it was the language learning blog I’d created on WordPress that helped me feel like maybe there was a still a way to meet people around the globe. Just as I didn’t realize my individual participation in fandom aligned with a bigger trend among Black fans, I now realize that my language blog was part of a long tradition of autistic people using the internet to connect with others who share their special interests. Kind comments on my blog from people with

extensive linguistic knowledge made me feel like it was okay to share what I was curious about, even when I didn't really know much.

GeoCities, Matmice, Angelfire, Tripod, Xanga, Yahoo! Groups, Open Diary, LiveJournal, phpBB forums, Teen Open Diary, Deviantart, Hi5, Last.fm, Blogspot, WordPress, Flickr, Facebook, YouTube, Vimeo, Reddit, Keek, Purevolume, Twitter, Tumblr, Behance, WattPad, Soundcloud, Ello, Dribbble, We Heart It, Purevolume, Quora, Foursquare, Instagram, Pinterest, Google+, Snapchat, Vine, Periscope, Discord, LinkedIn, VSCO, GoodReads, TikTok, Bereal, Substack, Lemon8, Mastodon, Nostr.

Over and over again, I explored the internet landscape to find my own way of communicating, connecting, and creating. For all of the issues the internet has, if I need to ask Google something, I don't have to practice speaking sentences out loud like I do when I walk up to a reception desk at the office. I've always had to do this kind of social scripting, but until I found out I was autistic, I never knew this had a name, and is common among autistic people (Jordan, 2017).

It's not that the internet is the perfect or only place for someone like me—autistic, Black, and female—to find belonging. Instead, it is that, in a world that often places neurotypical expectations on autistic people (Lawson, 2010) and often expects Black women to fit a stereotype from Mammy to the Magical Negro (Burke, 2019), the internet has been a place to experiment with when, where, and how I might be able to be me. I hit wall after wall of racism, exclusion, and harassment. However, unlike the halls of the school where I couldn't escape the bullies, at least here on the internet, when I sign up for a new account, no one knows who I am, and the game resets. When I look back on my 20 years as a Black autistic woman creating and connecting online, I see why, despite all of the issues and imperfections I've found here, I keep coming back. Because in a world that often operates through an unspoken language and code of conduct that is hard for me to understand, at least, on the internet, to some degree, I can finally see the code.

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