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# Divided Communities and Absent Voices: The Search for Autistic BIPOC Parent Blogs

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ABSTRACT *Both autistic adults and families of autistic children rely heavily on blogs and other digital platforms to create community and gain experiential knowledge about autism, but research on autism blogs has failed to distinguish between the perspectives of autistic adults and neurotypical parent bloggers. Furthermore, intersections in the experiences of BIPOC autistics are rarely examined. Using a content analysis with a feminist Critical Disability Studies lens, I explore six autism parent blogs from diverse demographics: a white neurotypical father, a white autistic mother in an interracial relationship, a white neurotypical mother, an Indigenous autistic trans father, a Black autistic nonbinary mother, and a Black neurotypical mother. I examine the attitudes of these bloggers to get a sampling of their opinions on autism, how they parent autistic children, and how their social location, specifically race, impacts their experiences. More intersectional research needs to be done to boost the perspectives of BIPOC autistics and the expertise of autistic parents.*

KEYWORDS autistic; BIPOC; blogging; activism; content analysis

> For some of us, autism isn't a disease but rather something more analogous to being gay or deaf – a condition that, yes, imposes hardships but also helps to make us who we are. (Garcia, 2015)
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> When you have an understanding of yourself you aren't measuring yourself any longer by someone else's criteria. If you are a bird you want to measure yourself by flying not by swimming, because you're not a fish. (Giwa-Onaiwu, quoted in Rozsa, 2017)

In this project, I approach autistic digital community differently than previous studies on autism blogs. I make a distinction between autistic and autism blogs, as McGuire (2016) and Carey et al. (2020) do with respect to advocacy projects. Autistic blogs are written by those who are themselves autistic, while autism blogs are created by non-autistic bloggers who are invested in

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autism, such as neurotypical parents of autistic people. As elaborated in further sections, the goals of (presumably) neurotypical parents of autistic children have often been incompatible with those of autistic adults, and many autistic communities distinguish carefully between the terms used (Bagatell, 2007; Brown, 2011; Carey et al., 2019; Rosqvist et al., 2015; Sinclair, 1993). In my scan of texts on autism blogs, the researchers did not distinguish between the experiences of autistic people (including autistic parents) and neurotypical parents who have autistic children.

In this study I center race in my analysis in order to address what Brown et al. (2017) highlight as an overwhelming whiteness in autism discourse. Moreover, this work is oriented by a Critical Disabilities Studies framework that does not pathologize or dehumanize, and values self-determination of disabled people (Clare, 1999; Davis, 1995; Kafer, 2013; Piepzna-Samarasinha, 2018). Critical Disability Studies (CDS) is an identity-based approach, and this work extends CDS further by developing intersectional experiences of privilege and oppression.

Using a content analysis, I examine six autism blogs by racially diverse parents of autistic children, including parents who are themselves autistic and non-autistic. I illustrate the importance of studying autism/autistic parenting communities online through an intersectional lens. This project is only a snapshot of what a few parents of autistic kids think about autism, how they parent, and how power informs whose voices (blogs) get seen. More and deeper intersectional analyses of autistic experiences is needed.

## Literature Review

### *Online Communities and Blogging*

Digital platforms are important to autistic and autism communities as they facilitate social support, information, and community (Abel et al., 2019; Coppala & Hardy, 2017; Loukisasa & Papoudi, 2016; Newton et al., 2009; Nguyen et al., 2015; Saha & Agarwal, 2015, 2016; Welch et al., 2020). The first autism blog came online in 1991. This blog was created to offer information about autism and emotional support to parents (Abel et al., 2019). The advent of web 2.0 led to an explosion of disability communities online including autism and autistic communities (Ellis & Kent, 2011; Haller, 2010). Existing studies unanimously echo that blogs provide social support to autism and autistic communities (Abel et al., 2019; Coppala & Hardy, 2017; Loukisasa & Papoudi, 2016; Newton et al., 2009; Nguyen et al., 2015; Saha & Agarwal, 2015, 2016; Welch et al., 2020). Parents use these blogs to find information about autism, support for changes in their life, spaces to share their experiences, encouragement from other parents, and to make sense of what it means to have an autistic child (Abel et al., 2019).

Blogs and online communities are also useful to autistic people themselves. It has been posited anecdotally and with some research that autistic people "fit" better online. The asynchronous, incorporeal nature of digital communication aligns with the preferred communication styles of many autistics (Abel et al., 2019). Online, people don't rely so heavily on non-verbal communication and social norms. In many instances, the lack of face-to-face interaction and expectations around it, especially the anticipated timeframe to respond to others, aren't as pressing, which allows autistic people to communicate better with other people (Abel et al., 2019; Newton et al., 2009). Neurotypical norms of communication such as turn taking and eye contact may be absent, thus removing one of the ways autistics are dis-abled and socially excluded by neurotypicals.

Despite the DSM-5 naming autism as a "social deficit," the fact that many autistic people seem to flourish online suggests that autistic people have communication styles at which they excel, and that neurotypical expectations of communication are dis-abling to autistic people. Blogs are one of many kinds of online space that have the potential for autistic people to thrive in. Thousands of autism blogs have been reported to exist; it is unknown how many of them are autistic blogs (written by autistic people), so further research is needed (Saha & Agarwal, 2015). Additionally, an intersectional analysis of autism is largely absent.

Conversations around ethics, consent, and representation are also being had about blogging (Çevik, 2015). I connect these conversations to ethics about memoirs on disabled people (Couser, 2004). Couser problematizes how disabled people are written about in memoirs by their non-disabled family members and how these family members gain prestige or money based on their writing. He argues that disabled people do not have the opportunity to represent themselves or benefit financially from these memoirs about them. Çevik (2015) voices similar critiques when she asks, "where do my parental rights to share my children's photos end and their rights to individual privacy begin?" (Çevik, 2020). She advocates for consent (not coercion) and names the power differential between parent and dependent child. More conversations on ethics are ongoing around who can represent whom and how they may financially benefit.

### *Neurotypical Parents of Autistics*

McGuire (2016) indicates that autism advocacy was first observed in 1962 in the United Kingdom. Neurotypical parents formed a group they named the Autistic Children's Aid Society of North London which would later be renamed the National Autistic Society. At the time, autism was understood as something that developed because of cold, well-educated, working parents, particularly mothers. The psychoanalyst Bruno Bettelheim called these mothers, "refrigerator mothers" (Bettelheim, 1967), based on psychologist

Leo Kanner's thoughts that they lacked maternal warmth. Bettelheim's theory of refrigerator mothers insinuated that the child was neglected or abused by their lack of motherly love. Implicit in Battelheim's theory was that women needed to stay home and care for their children. Thus, subsequent activism by the mothers of autistic children carried an undercurrent that they had to be a "good mother" by doing everything to care for their child. They did this by raising awareness of autism as a disorder that needed support (Carey et al., 2020; Garcia, 2015; McGuire, 2016).

Through decades of activism, apparently neurotypical parent activists have fought for better conditions for their children. They advocated for having their children included in schools, access to services and treatments, and breaking down institutionalization. They fought against stigma, and for legal and policy rights (Carey et al., 2020). Out of the tireless work of neurotypical parent activists, therapies were tried and evaluated (e.g., DIRFloortime®, Sensory Integration Therapy, Treatment and Education of Autistic and related Communications Handicapped Children (TEACCH®), and Applied Behavioural Analysis (ABA)) (Carey et al., 2020).

Yet as the children of these neurotypical parent activists grew up, tensions arose between neurotypical parents and children on how it was best to understand and support autistic people (Bertilsdotter Rosqvist et al., 2015). Neurotypical parents were more likely to understand autism as, "a pathology of the mind and body; a grueling cost; a life draining epidemic; a dangerous threat; a biological problem necessitating a biomedical solution; an illness needing to be stopped, cured, fixed, eliminated" (McGuire, 2016, p. 19). In stark contrast, their children voiced opinions that normalized autism and viewed it as a positive difference. This division of opinion and activism is what the autism scholar, Michael Orsini coined as "the autism wars" (Orsini, 2009; see also Bertilsdotter Rosqvist et al., 2015).

Some scholars argue that neurotypical parent activism has nuances (Carey et al., 2019, 2020; Neely-Barnes et al., 2011; Sousa, 2011). Their activism has led to many services, laws, and policy changes designed to support autistic children. Neely-Barnes et al. (2011) examine the issues facing neurotypical parents of autistics. Criticizing Kanner's and Bettelheim's traditional mother-blaming theories on autism, Neely-Barnes et al. (2011) note that parents, especially mothers, are frequently blamed for their child's autism, demonstrating the persistent harms of these traditional theories.

Neely-Barnes et al. (2011) further demonstrated that parents of autistics experienced more depression, stress, and lower levels of well-being. The care of children is significantly gendered (Carey et al., 2019, 2020; Fritsch, 2017; Neely-Barnes et al., 2011; Sousa, 2011). Mothers have been blamed for their children's autism by some fathers and their extended families, which has fed into the Refrigerator Mother trope. In order to become a "good mother," these mothers had to shoulder the role of tireless advocate on behalf of their children (Sousa, 2011). This level of activism earned them the term "warrior mom" (Jack, 2014; Sousa, 2011). The growing expectations of mothers of autistics to be warrior moms likely contributes to worsened mental health in parents of autistic children, as they are expected to develop instant mastery in skills such as navigating bureaucracy, law, campaign management, lobbying, education, and more, which is an unrealistic expectation for anyone. Some Black mothers of disabled children used different tactics to get support. They pivoted their Blackness or their children's disability to either play up or downplay those identities in order to try to circumvent the additional layers of racism to the ableist barriers to getting services (Jacobs et al., 2010).

Despite the sometimes hostile relationship between autistic and neurotypical parent activists, there is complexity to parent activism. Parents of autistic people are often victims of systems that provide shoddy support to families and to autistic people. They can also be victims of harassment and sexism, along with any other marginalities they may face. All parents, particularly mothers, deserve compassion, care and support, but not at the expense of their autistic children.

### *Black, Indigenous, People of Colour (BIPOC) Autistics*

> I believe that my experience as an autistic person has definitely been affected by my gender and race. Many characteristics that I possess that are clearly autistic were instead attributed to my race or gender. As a result, not only was I deprived of supports that would have been helpful, I was misunderstood and also, at times, mistreated. *(*Giwa-Onaiwu, 2016)

Giwa-Onaiwu details the experience of working on the anthology, *All the Weight of our Dreams* (Brown et al., 2017). This book is groundbreaking as the only book about BIPOC autistic people's experiences edited and fully written by BIPOC autistic authors themselves (Giwa-Onaiwu, 2020). This anthology had 52 BIPOC autistic people talk about what it means to be a BIPOC autistic person. Giwa-Onaiwu discusses how confused people were that this anthology was even needed. She quoted someone saying, "Autism is autism, right? Does race really make a difference?" (Brown et al., 2017, p. x).

An interview of Giwa-Onaiwu identifies that there is a struggle for visibility and understanding for any autistic who isn't a white cisgender man (Rozsa, 2017). When she goes to autism events, she plays a game of "spot the person of colour" because so few of them are there, even though we know that autism presents itself in all populations (Becerra et al., 2014). This may be because the typical screening tools used for diagnosis are based on the results of white cisgender boys developed in early studies (Kanner, 1943; Martin, 2016; Silberman, 2016; Weddle, 2016), while women, girls, and I would argue trans folks, generally present different traits (Rozsa, 2017). This results in more autistic women, girls, and trans folks having their autism un/misdiagnosed/recognized or diagnosed later in life.

As well, BIPOC children's autism gets misdiagnosed more frequently and instead given labels like ADHD, "mental retardation," or behavioural disorders like Oppositional Defiant Disorder. In the (in)famous 2002 documentary, *Refrigerator Mothers*, Dorothy Groom, a Black mother of an autistic son, spoke about how her son exhibited all the typical autistic traits, but the entire team of doctors at the University of Illinois refused to diagnose him as autistic because he didn't fit the traits of an upper middle class white family. This experience of misdiagnosis was also echoed by Hardwick (2020), who was diagnosed with an emotional disturbance instead of autism. Results in a recent Center for Disease Control (CDC) study show that Black students receive diagnoses an average of two years later than their white counterparts (Constantino, 2020). Additionally, Black families are reported to receive less attention from pediatricians (Silberman, 2016). It is clear that there are biases against Black families (and likely other people of colour) and autism in healthcare.

Even within BIPOC communities, autistics face barriers. Weddle (2016) talks about her experiences being Black and autistic. She describes her communities' view of autism as "a behavioral problem, a set of character flaws, stubbornness, and eccentricity bordering on mental illness" (Weddle, 2016). She talks about the lack of understanding she experienced and how she had to learn to be tough to survive. She wasn't allowed to cry, be a picky eater, or refuse to look people in the eye, which are all common autistic traits. She faced a lot of ostracism for being blunt and truthful to a fault, stimming, and having different interests from her peers. This is not a call to educate Black communities about autism, but to name autism as real and existing in Black and other BIPOC communities, which need to be part of autistic communities too (Weddle, 2016).

In addition to the microaggressions and lateral violence faced by BIPOC autistic people, they also face disproportionate rates of police brutality, arrest, and murder at the hands of police, like all BIPOC people. In a white paper written for the Ruderman Family Foundation on media coverage of police brutality faced by disabled people (Perry & Carter-Long, 2016), the authors claim that from a third to about a half of people murdered by police officers are disabled. It would be helpful to know how many of these disabled people were also BIPOC.

It is important to note that fear of the police transcends educational, career, and professional status for BIPOC autistics. As Eric Garcia (2015, 2016), a Latino autistic journalist notes, despite being employed professionally, well-educated, and living independently, he fears for his life when he encounters law enforcement. He discusses how autistic behaviours such as stimming, sensory processing or overloads, and I would add autistic non-verbal communication, can be read as threats by the police on top of stereotypes associated with BIPOC men (Garcia 2015, 2016; Perry & Carter-Long, 2016). Given the inequities faced by BIPOC autistics, further research is needed to better explore the intersections of autistic/autism parenting communities online, as I address in the examples below.

### *Tying It All Together*

I focus on online communities, parent experiences, and BIPOC autistics to draw attention to why we need intersectional autism research that centers the needs of autistic people while simultaneously supporting parents. The needs of BIPOC autistics and other intersectional groups differ from the white, middle class, cisgender heterosexual male autistic that Kanner constructed through early diagnostic criteria. The solutions to support everyone associated with autism need to be complex and nuanced to address multiplicity and conflicting needs. Online communities and blogs demonstrate the resourcefulness of families and autistics in organizing and sharing knowledge and experience in the face of insurmountable systemic ableism. This research focused on the intersections of BIPOC autistic/autism parenting communities to address the following questions. How do the struggles and needs expressed by parents in blogs differ based on factors of intersectionality? What omissions do we see when we look at most autism parenting blogs? Although the following examples are not representative, they provide a starting place for further research that centers diverse populations when thinking about autism and parenting communities online.

## Methodology

Blogs are a publicly available and easily accessible form of media for most people with the privilege of basic internet connection. Blogs allow "disabled people, their parents, and disability organizations [to take] control of the information about disability available to the general public" (Haller, 2010, p. 1). Mainstream media may not cover points that are important to disabled people and their families. Blogs allow ordinary people to represent themselves and share their experiences with others (Haller, 2010).

Informed by Critical Disability Studies and its emphasis on the importance of agency and bodily autonomy of disabled people (Clare, 1999), I scoped the internet for blogs written by parents of autistics from diverse backgrounds. Influenced by Patricia Leavy (2007), I developed a methodology in line with feminist disability content analysis. Leavy (2007) describes feminist content analysis as a tool to ask different (i.e., identity-based) questions about norms, values, and other indicators of culture. According to Leavy, applying a feminist lens brings up issues relevant to feminists, such as equality, power dynamics, and gender norms in a culture. I adapt this feminist lens, focusing on race, disability, and gender, paying attention to social location to point out how systemic oppression impacts people's lives and what needs to be done to address it. For this reason, I used a scoping sampling method to get an idea of what different representatives from different social locations experienced and thought (Arksey & O'Malley, 2005). I name my own social location as a mixed race, autistic, queer, disabled, trans scholar who is not a parent. This puts me in a position where more intersectional, autistic-centered research would be directly beneficial to my interests and life.

By focusing on the words parents have said on public domain blogs I infer how different identity groups view autism and parenting. My content analysis process first sampled blogs using inclusion and exclusion criteria outlined further below. Next, I selected posts for analysis. Third, I coded for pre-determined themes. Finally, I analyzed posts for content related to autistic/autism parenting experiences and their intersections with race.

I analyzed two posts each from six separate blogs. I selected blogs based on the blogger's social location. Because this is an exploratory paper, my aim was to demonstrate a breadth of different experiences through diverse social locations across race, gender, and neurotype. This resulted in a white neurotypical mother, a white neurotypical father, a white autistic mother, a black autistic nonbinary mother, an Indigenous autistic trans father, and a black neurotypical mother.

I excluded blogs if they were not clearly authored by a parent, such as those run by an organization. I also excluded microblogs on platforms like Facebook or Twitter because the brevity of their posts made it challenging to compare them to the long style posts on individual blog sites. I began my search for autism/autistic blogs with a Google search and immediately found a top autism blogs list; their top parent blogs were a white neurotypical father and a white neurotypical mother (Cherney, 2020). There were no BIPOC parent blogs on this list so I had to make a more concerted effort to find them. My Google search terms were "BIPOC" "POC," "Black," "Asian," "racialized," "Indigenous," "Native American," "Latino," AND/OR "autistic," "ASD," "autism parent blog". I could not identify any BIPOC parent blogs using the search criteria listed above (perhaps because of the limitations of Google algorithms), but results did yield a white autistic mother through this search.

Because I did not identify any BIPOC parent of autistic blogs through my first searches, I asked my friend, Lydia Brown (L. Brown, personal communication, June 11, 2020), a well-connected autistic activist in BIPOC circles, for blogs that fit my inclusion criteria. They provided me with a few names of BIPOC autistic parents who might have blogs. Searching for these parents' names led me to find two BIPOC autistic parent blogs. Additionally, I identified the Black neurotypical mother's blog in an article for my literature review (Giwa-Onaiwu, 2020).

I selected blog posts through searching for keywords based on themes from my literature review. I searched for "parenting," "education," and "ABA." The latter represents service provision, because until 2019 it was the only autism service funded by Ontario (Janse van Rensburg, 2021). ABA is also a highly divisive topic internationally that elicits strong feelings from many parties invested in supporting autistics. Focusing on ABA allowed me to explore some of the complexities of autism/autistic parenting.

I created a coding key of questions based on predetermined ideas and themes taken from the literature review (Autistic Self Advocacy Network, 2009; Brown, 2011; Carter & Hyde, 2015; Coppala & Hardy, 2017; Garcia, 2015; Glenn, 2004; McGuire, 2016). These themes included pathologizing autism; police brutality; negative views on autism; lack of personhood; silencing; self-determination; language used; and filicide. Using inductive and deductive approaches to coding, I was surprised to see how many presumptions I made. Therefore, codes were revised with the consultation of a friend from A4A and I performed a second round of analysis.[1]

## Sample

### *Rob Gorski*

Rob Gorski is a white, neurotypical father whose blog is called the *Autism Dad*. He's a single father with three autistic boys aged pre-teen to young adult. He names all his children in his posts and often talks about what is going on in his and their lives. He characterizes his blog as transparent, open and honest about the ups and downs of their lives on his About page. According to his Revolver Maps widget, his blog has received 537,805 hits from August 18, 2019 to January 25, 2022 and he's been featured on news stations such as BBC Worldwide and CNN. His blog has some income generated through autism product reviews, sponsorships, and PayPal donations. He doesn't write about whiteness, privilege, or his social location, and there was no evidence of connection to autistic peers or autistic organizations. The blog posts analyzed were, "This is how I know I let my kids down and it breaks my heart" [809 words] (Gorski 2020b), and "A Break Down of Autism Behavioural Analysis (ABA) Therapy For Parents" [663 words] (Gorski, 2020a).

### *Meghan Ashburn*

Meghan Ashburn is a white, autistic mother whose blog is called *Not an Autism Mom: Parenting… With a Dash of Awareness*. She is in an interracial marriage with two mid-childhood autistic sons and two neurotypical teenage sons. She does not name her children on the blog, but there are some images of them. She writes a bit about them, but her focus is more on her experiences

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[1] A4A or Autistics4Autistics is an autistic advocacy group in Ontario fighting for autistic rights and self-determination through activism. Their website is https://a4aontario.com/

as an autistic parent, giving advice to other parents. Her blog is based on the fact she is #actuallyautistic, a mother, and the education work she's doing. She's developed a community through her book club and by interviewing prominent autistics and autism service providers. She has published on five other blogs including *Neuroclastic* and *The Mighty*. She has some income generated from an ad banner, Patreon, an Etsy shop, and consultations. Despite having mixed-race Black children, Ashburn's focus is not generally on whiteness, but more on being autistic and motherhood. The blog posts I studied were, "Autism Didn't Ruin That Event. My Own Expectations Did" [737 words] (Ashburn, 2019b), and "Before You Start Grieving for Your Autistic Child…" [1405 words] (Ashburn, 2019a).

### *Kate Swenson*

Kate Swenson is a white, neurotypical mother whose blog is called, *Finding [redacted]'s Voice.*[2] She's a married professional with one mid-childhood autistic and two neurotypical sons and an early childhood daughter. Her children are named in the blog and their lives are documented explicitly. Her autistic son's name is even in the title of the blog itself. She defines her blog as a safe, honest, caring space. Swenson has a huge following of 600,000 people on Facebook, and numerous guest contributors. Of all the bloggers I sampled, she seems to have the most sources of income, with two advertisement banners with active ads in them, a subscription service to her own community group, a t-shirt store, a memoire, and Amazon affiliates. She also runs a donation service to fund caregivers for three sessions of therapy. She does not talk about whiteness or her social location and there do not appear to be any connections to autistic peers or organizations. The blog posts studied were, "The Secret World of Finding [redacted]'s Voice" [1387 words] (Swenson, 2017), and "Sometimes I Forget" [576 words] (Swenson, 2019).

### *Oswin Latimer*

Oswin Latimer is an Indigenous, autistic trans father, and his blog is called, *Autistic Spectrum Parenting*. He is married and has multiple autistic and neurodivergent children who are probably teens. Latimer doesn't talk much about his children in his most recent entries, but digging through his archives, he refers to them by initials; it is only further back that one can find their names. His goal in this blog is to make space for autistic parents. There are no banners or organization affiliations, but he did start his own autism service

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[2] I redact her son's name in order to at least give him a semblance of privacy from having a blog about him with his name in the title.

run by autistics. His only sources of income from the blog are consultation or workshop fees. I did not find any articles where he talked about being Indigenous or trans, but he talks often about being autistic and his connections to other autistic organizers. The blog posts I looked at were, "Preparing for the Future" [668 words] (Latimer, 2017b), and "Beyond Awareness – Perceptions and Informed Parenting" [830 words] (Latimer, 2017a).

### *Morénike Giwa Onaiwu*

Morénike Giwa Onaiwu is a Black autistic nonbinary mother whose blog is called, *Just Being Me…Who Needs 'Normalcy' Anyway?* She's married and identifies her family as multicultural, serodifferent, and neurodiverse. She has multiple children from middle childhood to teenage, some of whom are autistic. I didn't find any of her children's names, just their initials or nicknames for them. Her blog is part of her website which documents her work in multiple sectors. She is very well-published, has connections to 38 organizations, and had been featured in 149 news articles at the time of data collection (June 2020). She generates income from consultations, trainings, talks, and likely some of her writing contributions. Her blog posts often weave together the complexities of being Black, autistic, and a parent. Blog posts by Giwa-Onaiwu that I studied were, "Don't Pray My Autism Away" [1,465 words] (Giwa-Onaiwu, 2015), and "All of Me: How do I Know Where Blackness Ends and Neurodivergence Begins?" [3,739 words] (Giwa-Onaiwu, 2016).

### *Mrs. Kerima Çevik*

Mrs. Kerima Çevik is a Black, neurotypical mother and her blog is titled, "The Autism Wars."[3] She's married to a Turkish man and has an adult neurotypical daughter and teenage autistic son. Her son is named throughout the blog, but she has written about only posting references to and images of him on the blog with his consent (Çevik, 2020). Her blog is an extension of her work as a human rights activist and is primarily devoted to BIPOC autistics who have been murdered by parents or the police. Her blog does not have any social affiliations, but she frequently refers to other BIPOC or autistic people and organizations as well as intersectional issues affecting BIPOC and autistic folks. She does not seem to make any money off of the blog. The blog posts I examined were, "Autism, Accommodation for

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[3] She prefers being referred to as Mrs. because of some peoples' racist assumptions that Black women like her all had children out of wedlock (see http://theautismwars.blogspot.com/p/blog-page.html).

Disability, and Traumatic Normalization” [1,282 words] (Çevik, 2017a), and “Hobson's Choice, Nonverbal Autism, Technology, And The Myth Of No Future” [2,409 words] (Çevik, 2017b).

## Discussion

From my observations, there is a clear schism of attitudes on autism and parenting based on the communities to which the parents studied in this research had access. Gorski and Swenson did not seem to find support from adult autistic communities, judging by the absence of autistic people or autistic-led organizations; these were present in all the other blogs. Nor did I readily find intersectional content that was cognizant of power and privilege. These two blogs were also the only ones in the sample that were found using a simple Google search for autism blogs. All the other bloggers, by contrast, had a fairly consistent, affirmational view of autistic ways of existing and mentioned autistic adults and autistic-led organizations without the need to search for them. Their levels of explicitly intersectional content varied. I was only able to get some indicators of popularity for the white bloggers. Swenson has over 600,000 Facebook followers, Gorski has over 500,000 hits, and Ashburn has over 200,000 hits. None of the BIPOC bloggers had any widgets or counters that reported number of hits.

### *Social Location*

Only Gorski and Swenson failed to discuss their social locations. What is more interesting is that Ashburn additionally doesn’t name herself as white despite having mixed-race kids. These observations are in line with how whiteness is non-raced or made invisible (Dyer, 2013). For those with privilege such as whiteness or being abled, it is made the default. Privilege is invisible, yet it is carried like an invisible backpack (McIntosh, 1989). In practice, this means that neurotypical and white people are less likely to acknowledge the ways society treats them with respect and dignity due to that facet of their social location, or knowingly use their privilege to support their autistic or BIPOC children. For example, Ashburn has a recommended book list on autism and has sections for autistic authors, non-speaking autistic authors, parents and educators, women and trans folks, books in Spanish, queer folks, a general section, picture books, kids, and teens. Despite a good intersectional list, there is no list on BIPOC autistics (Ashburn, 2020). There are some BIPOC authors on these lists, but there is no list for them specifically. Despite many areas where Ashburn uses her privilege, race is glaringly absent.

Çevik was unique in how she deploys her neurotypicality in her blog. Under her tab, “Why I Blog”, she says, “My intent is to stand by my son and his neurodivergent peers and work with them to improve my son's quality of life by helping improve the quality of the lives of everyone in the Autism community” (Çevik, n.d.).

### *Monetization*

Monetization can be an indicator of success or privilege. Only the white bloggers, both autistic and non-autistic, had their blogs monetized directly. Latimer and Giwa-Onaiwu only advertise they can be hired for consultations and Çevik doesn’t seem to make any money off her blog. This may point towards the effects of white privilege. Ashburn, despite being autistic, has a large enough following (273,444 visitors on January 25th, 2022) to warrant a Patreon, an Etsy shop,[4] a spot for an ad banner (not occupied), and she too offers consultations. Gorski’s blog includes autism product reviews, sponsorships, and donations through PayPal. Swenson has two active ad banners, a subscription service to her paid group, a t-shirt store, Amazon affiliates, a memoire, and she runs a donation service to fund caregivers for three sessions of therapy. Exact incomes could not be found, but it appears that Swenson may have the highest income from her blog judging by the number of advertisements, sponsorships, and different sources of income in comparison to everyone else.

While Ashburn derives income through her blog, it’s Gorski and especially Swenson who have significant sources of income through their blogs. This may indicate the effects of whose voices are privileged over others because Ashburn, despite being a well-credentialed white autistic parent, has significantly fewer hits and sources of income than her neurotypical counterparts. It concerns me that these two neurotypical parents make money off of their children’s lived experiences. If their children weren’t autistic, would they have gone viral in the first place? If they talked less openly about their child’s tantrums, would their blogs get nearly as much support and validation? If Gorski’s children weren’t autistic, would companies ask him to review their products? And if their children weren't autistic, would this style of blogging be considered exploitative?

What qualifications do Gorski and Swenson have to warrant people giving them money for their expertise on autism when compared with autistic and BIPOC parents of autistic children? There was no indication of degrees related to autism or years of experience working with autistic people anywhere on their blogs. By contrast, Ashburn is an educational consultant and former teacher, Çevik has worked for autistic organizations, completed research studies, worked with legislators, and she’s a contributing author to

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[4] Patreon is a website for content creators and artists to solicit money from fans through monthly membership fees. The members gain perks like extra content or direct conversations with the creator. Etsy is an online marketplace where individuals can sell handmade or vintage products.

multiple blogs. Both Giwa-Onaiwu and Latimer are highly qualified autistic professionals. Yet none of these qualifications held by BIPOC and autistic parents of autistic children seem to warrant the plethora of followers and monetization enjoyed by white autism parents Gorski and Swenson. Further research needs to be done on algorithm bias, racism, and blog revenue.

### *Confidentiality*

Another important theme emerging in the blogs that relates back to my literature review (Çevik, 2015; Couser, 2004), were conversations about ethics around autism blogs. Some of that discussion relates to monetization as discussed previously, as well as privacy concerns. While Çevik brought up confidentiality for children on her own blog, all the neurotypicals including Çevik revealed their children's (apparently real) names in their blogs. Swenson went so far as to put her autistic son's name in the title of her blog. In contrast, autistic bloggers studied in this sample, regardless of race, generally referred to their children by initials, nicknames, or a descriptor such as, "my eldest/youngest," or "the twins." It is interesting to note Latimer and Ashburn named their children earlier in their blogging history, but have not recently (Ashburn, 2017a; Latimer, 2014). This may indicate they held different perspectives on privacy or did not think as much about it when they first began blogging. Çevik calls for better consent yet explicitly names her son in her blog (Çevik 2015). She says she obtains consent before posting any photos or telling stories about him, but it is unclear if she had conversations with him about if he wanted his name disclosed on the world wide web, or the possible consequences of no longer being anonymous online (Gay Family Values, 2011).

By contrast, blogs like Gay Family Values (2011) offered their children opportunities to make their own informed decisions by talking with them about difficult topics related to public profiles, and treat their children like they are human beings with their own thoughts, feelings, and decisions to make. This is something I find lacking in Swenson's, and to a lesser degree Gorski's, blogs. The following quote demonstrates how Swenson feels about keeping the details of her son's life confidential after receiving ABA therapy:

> No meltdowns.
> No off the wall behaviors.
> It's sleeping through the night.
> No fighting over food or pants or swimming.
> No hitting. No screaming. No self injuring.
> Suddenly, I am smiling more. I am sitting and watching my children in my living room. All three of them. (Swenson, 2019)

If her son read those publicly accessible words about his behaviour and struggles, how might he feel? If he had friends who read the blog, how would they react to his mother’s words? With a reach of at least tens of thousands of viewers, how will her son be seen by her readership?

Gorski may not have kept details about his children’s lives confidential, but he did not reveal potentially harmful details about them:

> I sat him down and talked to him for a little while about how grown-up stress isn’t his fault and that it’s something I need to better manage. I told him that yes, he can drive me crazy but that’s what kids do. I know I drove my parents crazy and he was simply granting their wish that someday I would know what it’s like to be a parent driven crazy by their children. (Gorski, 2020b)

From this discussion, the ethics of confidentiality run a gamut of experiences. Giwa-Onaiwu, Latimer, and Ashburn, as autistics, speak to their own experiences of autism and of parenting independently of their children and kept their children’s names confidential, at least in the more recent posts on their blogs. It was only when I went diving through their archive that I found their children’s names. On the other hand, Swenson’s blog exemplifies why I have concerns about the ethics of blogging about one’s child as it openly discusses their children’s struggles and shows no sign of informed consent. Gorski and Çevik occupy a middle space where I don’t know if they get informed consent from their children about what they’re posting, but it seems that Çevik is more explicit about discussing informed consent.

### *Attitudes Towards Autism*

I began the discussion section by noting that the bloggers who talked about autistic adults and autistic organizations were the ones who had a uniformly positive understanding of autism. All of them name the negative feelings some parents have towards autism as the real barrier: “Your child is the same amazing, lovable, caring, goofy, courageous child they were before getting an autism diagnosis. You get to decide how you feel about it” (Ashburn, 2019b).

As this group was mostly comprised of autistic people who are parents themselves, they have the unique position of having lived experience growing up autistic (even if their autism was not recognized/diagnosed) and raising autistic children of their own. Çevik is the exception as a neurotypical mother who passes on the lessons she has learned from the autistic people with whom she is associated, as evidenced on her blog. Ashburn and Çevik give parenting advice and encourage neurotypical parents to learn to accept their autistic child as normal just as they are. They simultaneously propose supportive ways to parent:

> It is a question of supporting decision making, educating your children about the scope of their disability and how to keep their mental health intact by using accommodations and assistive technology to support their processing and navigating a world not built for them. (Çevik, 2017a)

Giwa-Onaiwu's approach is to discuss many of her experiences and those of her children and how other people stereotype them. For example, she wrote about an old church lady who wanted to pray both her and her daughter's autism away (Giwa-Onaiwu, 2015). In another incident in a department store, her child was infantilized by a worker while trying to pick out new clothes (Giwa-Onaiwu, 2016).

Latimer takes up a more academic approach in his blog articles naming issues such as pathologizing autism, autism as an epidemic, autism cure narratives, and pseudoscience (Latimer, 2017a, 2017b). He is concerned less with the everyday experience of being a parent and more with evaluating support services or discursive issues that autistic people and parents may face, for example, what it means to have a generation of kids coming of age who grew up with internalized ableism from autism "treatments."

> This is about what we as an autistic community are about to face. A generation of autistic people that have been told that autism is bad. A generation of autistic people that have been taught how to not be autistic. A generation of autistic people who have been forced medical interventions, diets, and pseudoscientific treatments. (Latimer, 2017a)

Gorski and Swenson expressed more negative or stigmatizing values towards autism. They expressed views of autism as a disorder, and a medical condition that needs treatment. In one of Gorski's blog posts, he praises his understanding of ABA and doesn't even take into consideration what the child would want out of autism services. Nowhere does he explain the importance of why a behaviour or a skill is necessary.

> According to the chosen goal for your child, successfully learning a skill rewards them with a meaningful present, praise, or activity. Over time, this activity leads to a change in behavior as the positive reinforcement encourages your child to repeat success. (Gorski, 2020a)

Gorski seems to have a discrepancy in his understanding of the competence and agency of autistic people. When interacting with his own children, he is willing to apologize for mistakes he makes and explain what he did wrong (Gorski, 2020b). He also refutes the "eternal child" stereotype when he talks about his children growing up (Gorski, 2020a). In another blog post, (Gorski, 2020c), his eldest son expressed interest in moving out and into a living situation with people his own age and support needs. While I applaud Gorski's positive language and unconditional support for his son, he focuses more on his son's lack of readiness (O'Brien & O'Brien, 1998) instead of how to work alongside his son to ensure he's able to thrive outside the home.

Swenson's views of autism in contrast are uniformly negative: "I'll forget that it's autism. I'll think maybe it's better now" (Swenson, 2019). She refers to her son's disability as confusing without any evident concern about what her son may be going through (Swenson, 2017). She doesn't see that her child *is* autistic with potentially different desires and life trajectory than what she expected and all this feeds into a number of autism stereotypes, such as "autism holding their child hostage" and "subhuman/incapable of making decisions" (Autistic Self Advocacy Network, 2009). By contrast, Swenson focuses on her own struggles as the mother of an autistic child with a very public profile. For example:

> On average I have to ban 10 people a week who say things to me like…I'm a terrible mother, I am ugly, my kid is brat, my kid is ugly, I should just die, I should just shut up, and my personal favorite…autistic kids are a product of the devil. (Swenson, 2017)

### *Race and Autism*

Out of all the blogs, only those by Giwa-Onaiwu and Çevik overtly engaged intersectional issues. While it is great that all the autistic bloggers talk extensively and critically about autism, I combed through multiple pages of each blog looking for references to intersectional issues related to race, gender, sexual orientation, or class and only managed to find short references in Ashburn's blog. However, this related to her older children, who are not autistic, and autism was not referenced. Ashburn talks about how she fears her sons will experience police brutality in this political climate with more visible and violent racists (Ashburn, 2017b).

Latimer wrote about white fragility, but explicitly stated that this post had nothing to do with being autistic or having autistic kids (Latimer, 2018). I could not find any posts where he talked about being Indigenous or included racism in his discussions about autism or parenting. Nor did I find anything about how his transness and queer relationship speak to his experiences of being an autistic parent.

Contrast this with Giwa-Onaiwu who did an excellent job discussing the tensions and difficulties of both herself and her family navigating being Black and autistic and various other disabilities. For example:

> It is unclear to me which characteristic was the driving factor behind an assumption by "professionals" of intellectual impairment in the absence of evidence or formal testing. They had written her off without even verifying if their hypothesis was right or wrong. (Giwa-Onaiwu, 2016)

The lack of race-based analysis, let alone other intersections, demonstrates how much work needs to be done in order to support diverse autistic populations. There are very few works that talk about BIPOC autistic experience or issues, particularly that have breached the ceiling of peer reviewed, academic publications.

## Limitations

This study relies on a very small sample size, and has yielded preliminary research meant to encourage other researchers to pick up from where I end. More research is needed on the differences between different populations' attitudes towards autism and their lived experiences and barriers with autism and interacting with the world. More work needs to be done that focuses on BIPOC autistics. More support needs to be given for BIPOC autistics to be published in academic journals and books. This study only looked at people who are parents. There are BIPOC autistic bloggers that are relatively easy to find through Google. There could also be a study on microblogs, on platforms such as Facebook or Tiktok. Sexual orientation and gender identity were not addressed in this paper partly because these were not topics discussed explicitly by the bloggers in their posts, nor did I have the space to delve into the literature.

As a scholar trained in feminist, queer and disability theory, I prefer theorizing about power and oppression over other ways to analyze the texts. I chose to examine sample populations of bloggers in order to curate diverse perspectives on autism parenting. As an autistic person, I have biases against neurotypical autism parents because of the things I brought up in this paper. There were not many texts that dealt with specifically BIPOC autistic people, let alone by BIPOC autistic people published in an academic journal. The lack of racial diversity among BIPOC people included in the study is because that was what was available.

## Conclusions and Recommendations

Autistic parents need to be at the center of knowledge produced and services created for autistic people. Autism needs to be de-associated with suffering, being a burden, and autistics needs to be presumed competent people who desire self-determination. We also need to integrate diverse, intersectional autistic experiences and perspectives into services created, knowledge produced, and knowledge published.

In the process of conducting this research, it was challenging to find any BIPOC autism parent blogs, although blogs by white neurotypical parents abound. It did not take more than a few Google searches to find a white autistic mother. But I only found BIPOC people through personal connections and through my literature review. It is remarkable that Çevik, Giwa-Onaiwu, and Latimer are not as easily found with Google searches given the importance of their perspectives and expertise; they should be at the top of autism blogs lists. The fact that a United Nations-recognized, well-published, well-connected, smart person like Giwa-Onaiwu is not more well-known suggests the influences of ableism and racism. She deserves the fame of Temple Grandin.

I would like to see a breadth of BIPOC experiences across different populations represented across different platforms. Future research should explore important questions that arise with intersectional research, for example, what differences are there between Black, Tamil, and white passing mixed Japanese people's experience of autism services? How is autism understood in the Mohawk nation and is it different from Coast Salish? Where are the studies looking at racial biases in ABA practitioners? Where is Planned Parenthood campaigning to voice how BIPOC autistics face higher levels of sexual violence? Where is the commission to investigate the harassment of Chinese autistics during the COVID pandemic? The lack of research delving into the nuances of different racial groups and their experiences of autism is another indicator of how racism is alive and well. It is a challenge for BIPOC and other marginalized peoples to get into positions of power or produce knowledge recognized by decision makers as valid (such as an essay like this). When Latimer didn't bring up much intersectional content in his blog posts, I was disappointed, but I cannot blame him. The pressure to be a multiply marginalized role model is strong, as is the pressure to produce perfectly intersectional texts all the time. What really disappoints me is when white bloggers never overtly address whiteness. This absence is what resounds loudest (Glenn, 2004).

The divide between autistic adults and neurotypical parents needs to be addressed and healed, and one step in doing this is to critically examine intersectional experiences in parenting autistic children. Without neurotypical parent activists, there would be even fewer autistic services than there already are. However, as is clear from this study, differences in positionality mean differences in need and priorities. Future research and policy must be nuanced and take into consideration the needs of both autistic people and their families, keeping intersectional considerations like race a priority.

I would like to suggest for neurotypical parents to seek autistics, especially autistic parents, from which to get advice. They should also find the support they need, and learn to accept their autistic child.

I imagine a future group like PFLAG (Parents and Friends of Lesbians and Gays), where neurotypical parents can learn from each other, with autistic people leading with some valuable insider knowledge. The amount of work that needs to be done is astronomical. We autistic people cannot do this alone. We need all people interested in making a world better for autistic people, including the neurotypical parent bloggers.

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## References

Abel, S., Machin, T., & Brownlow, C. (2019). Support, socialise and advocate: An exploration of the stated purposes of Facebook autism groups. *Research in Autism Spectrum Disorders*, *61*, 10-21.

Arksey, H., & O'Malley, L. (2005). Scoping studies: Towards a methodological framework. *International Journal of Social Research Methodology, 8*(1), 19-32.

Ashburn, M. (2017a, June 20). *Don't fight an autism diagnosis. Fight for it!* Not An Autism Mom. https://notanautismmom.com/2017/06/20/dont-fight-an-autism-diagnosis-fight-for-it/

Ashburn, M. (2017b, July 18). *Teaching my kids to survive in 'merica.* Not an Autism Mom. https://notanautismmom.com/2017/07/18/teaching-my-kids-to-survive-in-merica/

Ashburn, M. (2019a, October 24). *Before you start grieving for your autistic child.* Not an Autism Mom. https://notanautismmom.com/2019/10/24/grieving-autism/

Ashburn, M. (2019b, May 29). *Autism didn't ruin that event. My own expectations did*. Not an Autism Mom. https://notanautismmom.com/2019/05/29/events-one/

Ashburn, M. (2020, July 20). *100-ish books on autism and neurodiversity.* Not an Autism Mom. https://notanautismmom.com/2020/07/20/autism-books/

Autistic Self Advocacy Network. (2009, September 23). *Horrific autism speaks "I am autism" ad transcript.* https://autisticadvocacy.org/2009/09/horrific-autism-speaks-i-am-autism-ad-transcript/

Bagatell, N. (2007). *Orchestrating voices: Autism, identity and the power of discourse*. *Disability and Society*, *22*(4), 413-426.

Bascom, J. (2012). *Loud hands: Autistic people, speaking.* Autistic Self Advocacy Network.

Becerra, T. A., von Ehrenstein, O. S., Heck, J. E., Olsen, J., Arah, O. A., Jeste, S. S., Rodriguez, M., & Ritz, B. (2014). Autism spectrum disorders and race, ethnicity, and nativity: A population-based study. *Pediatrics, 134*(1), e63-e71. https://doi.org/10.1542/peds.2013-3928

Beitleheim, B. (1967). *Empty fortress: Infantile autism and the birth of the self.* Free Press

Bertilsdotter Rosqvist, H., O'Dell, L., & Brownlow, C. (2015). "An Association for all" - Notions of the meaning of autistic self-advocacy politics within a parent-dominated autistic movement. *Journal of Community & Applied Social Psychology*, *25*(3), 219-231

Brown, L. X. Z., Ashkenazy, E., & Giwa Onaiwu, M. (2017). *All the weight of our dreams: On living racialized autism.* DragonBee Press.

Brown, L. (2011). *The significance of semantics: Person-first language: Why it matters*. Autistic Hoya. https://www.autistichoya.com/2011/08/significance-of-semantics-person-first.html

Carey, A., Block, P., & Scotch, R. (2019) Sometimes allies: Parent-led disability organizations and social movements. *Disability Studies Quarterly*, *39*(1). http://dx.doi.org/10.18061/dsq.v39i1.6281

Carey, A., Block, P., & Scotch, R. (2020). *Allies and obstacles: Disability activism and parents of children with disabilities.* Temple University Press.

Carter, E., & Hyde, J. (2015). Designing autism research for maximum impact. In B. Begole, J. Kim, K. Inkpen & W. Woo (Eds.), *Proceedings of the 33rd annual ACM Conference on Human Factors in Computing Systems* (pp. 2801-2804). Association for Computing Machinery.

Çevik, K. (n.d.). *Why I blog.* The Autism Wars. http://theautismwars.blogspot.com/p/the-reason-i-blog.html

Çevik, K. (2015, March 8). *On digital exhibitionism by autism parents: Why parents live tweeting their disabled children's worst moments is red flag that should concern everyone.* The Autism Wars. http://theautismwars.blogspot.com/2015/03/on-digital-exhibitionism-by-autism.html

Çevik, K. (2017a, May 12). *Autism, accommodation for disability, and traumatic normalization.* The Autism Wars. http://theautismwars.blogspot.com/2017/05/autism-accommodation-for-disability-and.html

Çevik, K. (2017b, May 21). *Hobson's choice, nonverbal autism, technology, and the myth of no future.* The Autism Wars. http://theautismwars.blogspot.com/2017/05/hobsons-choice-nonverbal-autism.html

Çevik, K. (2020, January 1). *Power, disability, and the realities of consent.* The Autism Wars. http://theautismwars.blogspot.com/2020/01/power-disability-and-realities-of.html

Cherney, K. (2020) *The best autism blogs of 2020.* Healthline. https://www.healthline.com/health/autism/best-blogs-of-the-year#1

Clare, E. (1999). *Exile and pride: Disability, queerness, and liberation.* South End Press.

Constantino, J. N., Abbacchi, A. M., Saulnier, C., Klaiman, C., Mandell, D. S., Zhang, Y., Hawks, Z., Bates, J., Klin, A., Shattuck, P., Molholm, S., Fitzgerald, R., Roux, A., Lowe, J. K., & Geschwind, D. H. (2020). Timing of the diagnosis of autism in African American children. *Pediatrics, 146*(3), e20193629. https://doi.org/10.1542/peds.2019-3629

Coppala, A. C., & Hardy, J. A. (2017). Attitudes toward autism of parents raising autistic children: Evidence from "Mom" and "Dad" blogs. In E. Friginal (Eds.), *Studies in corpus-based sociolinguistics* (pp. 236-252). Routledge.

Couser, G. T. (2004). *Vulnerable subjects: Ethics and life writing.* Cornell University Press.

Davis, L. J. (1995). *Enforcing normalcy: Disability, deafness, and the body.* Verso Books.

Dyer, R. (2013). *White: Essays on race and culture.* Taylor & Francis.

Ellis, K., & Kent, M. (2011). *Disability and new media.* Routledge.

Frederick, A., & Shifrer, D. (2018). *Race and disability: From analogy to intersectionality. Sociology of Race and Ethnicity*, *5*(2), 200-214

Fritsch, K. (2017). Contesting the neoliberal affects of disabled parenting: Toward a relational emergence of disability. In M. Rembis (Ed.), *Disabling domesticity* (pp. 243-267). Palgrave Macmillan

Garcia, E. (2015, December 4). I'm not broken: What this Washington reporter with autism wants you to understand*. The Atlantic*. https://www.theatlantic.com/politics/archive/2015/12/im-not-broken/446550/

Garcia, E. (2016). *What it feels like to be an autistic person of color in the eyes of the police.* The Daily Beast. https://www.thedailybeast.com/what-it-feels-like-to-be-an-autistic-person-of-color-in-the-eyes-of-the-police

Gay Family Values (2011, November 5). *The trouble with quibbles or...why we put our kids on the net*. http://gayfamilyvalues.blogspot.com/2011/11/trouble-with-quibbles-orwhy-we-put-our.html#more

Giwa-Onaiwu, M. (2015). *Don't pray my autism away.* https://morenikego.com/dont-pray-my-autism-away/

Giwa-Onaiwu, M. (2016). *All of me: How do I know where blackness ends and neurodivergence begins?* https://morenikego.com/all-of-me-how-do-i-know-where-blackness-ends-and-neurodivergence-begins/

Giwa-Onaiwu, M. (2020). "A dream deferred" no longer: Backstory of the first autism and race anthology. In S. K. Kapp (Ed.), *Autistic community and the neurodiversity movement stories from the frontline* (pp. 243-252). Palgrave MacMillan.

Glenn, C. (2004). *Unspoken: A rhetoric of silence.* Southern Illinois University Press.

Gorski, R. (2020a, September 18). *A break down of autism behavioural analysis (ABA) therapy for parents*. The Autism Dad. https://www.theautismdad.com/2020/09/18/a-break-down-of-autism-behavioural-analysis-aba-therapy-for-parents/

Gorski, R. (2020b, December 5). *This is how I know I let my kids down and it breaks my heart*. The Autism Dad. https://www.theautismdad.com/2020/12/05/this-is-how-i-know-i-let-my-kids-down-and-it-breaks-my-heart/

Gorski, R. (2020c, December 12). *My #autistic son gave himself a haircut today.* The Autism Dad. https://www.theautismdad.com/2020/12/12/my-autistic-son-gave-himself-a-haircut-today/

Gruson-Wood, J. (2016). Autism, expert discourses, and subjectification: A critical examination of applied behavioural therapies. *Studies in Social Justice, 10*(1), 38-58.

Haller, B. A. (2010). *Representing disability in an ableist world: Essays on mass media.* The Avocado Press.

Hardwick, L. (2020, June 23). *Cultural bias and disability: We have to do better with children of folor.* The Art of Autism. https://the-art-of-autism.com/cultural-bias-and-disability-we-have-to-do-better-with-children-of-color/

Jack, J. (2014). *Autism and gender: From refrigerator mothers to computer geeks.* University of Illinois Press.

Jacobs, L., Lawlor, M., & Mattingly, C. (2011). I/we narratives among African American families raising children with special needs. *Culture, Medicine & Psychiatry, 35*(1), 3-25.

Janse van Rensburg, M. (2021*).* Centering autistic persons' perspectives in autism social policy: A qualitative study. *Perspectives on Social Work, 16*(2), 47-60.

Kafer, A. (2013). *Feminist, queer, crip*. Indiana University Press.

Kanner, L. (1943). Autistic disturbances of affective contact. *Nervous Child*, *2*, 217-250.

Latimer, O. (2014, December 30). *A tween among us*. Autistic Spectrum Parenting. https://www.asparenting.com/a-tween-among-us/

Latimer, O. (2017a, July 13). *Beyond awareness – perceptions and informed parenting*. Autistic Spectrum Parenting. https://www.asparenting.com/beyond-awareness-perceptions-and-informed-parenting/

Latimer, O. (2017b, April 25). *Preparing for the future.* Autistic Spectrum Parenting. https://www.asparenting.com/preparing-for-the-future/

Latimer, O. (2018, January 5). *On white fragility, nonpologies and mommy culture.* Autistic Spectrum Parenting. https://www.asparenting.com/on-white-fragility-nonpologies-and-mommy-culture/

Leavy, P. (2007). The feminist practice of content analysis. In S. N. Hesse-Biber & P. Leavy (Eds.), *Feminist research practice* (pp. 222-248). SAGE.

Loukisasa, T., & Papoudi, L. (2016). Mothers' experiences of children in the autistic spectrum in Greece: Narratives of development, education and disability across their blogs. *International Journal of Disability, Development and Education*, *63*(1), 64-78.

Martin, M. (2016, February 21). *African-Americans with autism face additional challenges.* NPR. https://www.npr.org/2016/02/21/467582515/african-americans-with-autism-face-additional-challenges.

McGuire, A. (2016). *War on autism: On the cultural logic of normative violence.* University of Michigan Press.

McIntosh, P. (1989). *White privilege: Unpacking the invisible knapsack.* University of Maryland. https://psychology.umbc.edu/files/2016/10/White-Privilege_McIntosh-1989.pdf

Neely-Barnes, S., Hall, H., Roberts, R., & Graff, C. (2011). Parenting a child with an autism spectrum disorder: Public perceptions and parental conceptualizations*. Journal of Family Social Work*, *14*(3), 208-225.

Newton, T., Kramer, A., & McIntosh, D. (2009). Autism online: A comparison of word usage in bloggers with and without autism spectrum disorders. *CHI '09: proceedings of the SIGCHI conference on human factors in computing systems* (pp. 463-466). Association for Computing Machinery. https://doi.org/10.1145/1518701.1518775

Nguyen, T. Duong, T., Venkatesh, S., & Phung, D. (2015). Autism blogs: Expressed emotion, language styles and concerns in personal and community settings. *IEEE Transactions on Affective Computing, 6*(3), 312-323. doi: 10.1109/TAFFC.2015.2400912.

O'Brien, J., & O'Brien, C. (1998). *A little book about person centered planning*. Inclusion Press.

Orsini, M. (2009). Contesting the autistic subject: Biological citizenship and the autism/autistic movement. In S. J. Murray & D. Holmes (Eds.), *Critical interventions in the ethics of healthcare. Challenging the principle of autonomy in bioethics* (pp. 115-130). Farnham.

Perry, D. M., & Carter-Long, L. (2016). *The ruderman white paper on media coverage of law enforcement use of force and disability: A media study (2013-2015) and overview.* Ruderman Family Foundation. https://rudermanfoundation.org/wp-content/uploads/2017/08/MediaStudy-PoliceDisability_final-final.pdf

Piepzna-Samarasinha, L. L. (2018). *Care work: Dreaming disability justice.* Arsenal Pulp Press.

Rozsa, M. (2017, March 15). *Listen: Black, female and autistic — hiding in plain sight.* Salon. https://www.salon.com/2017/03/15/listen-black-female-and-autistic-hiding-in-plain-sight/

Saha A., & Agarwal, N. (2015) Social support and stress in autism blogging community on twitter. In N. Agarwal, K. Xu & N. Osgood (Eds.), *Social computing, behavioral-cultural modeling, and prediction* [SBP 2015. Lecture notes in computer science, vol 9021]. Springer. https://doi.org/10.1007/978-3-319-16268-3_53

Saha, A., & Agarwal, N. (2016). Modeling social support in autism community on social media. *Network Modeling Analysis in Health Informatics and Bioinformatics, 5*(8). https://doi-org.ezproxy.library.yorku.ca/10.1007/s13721-016-0115-8

Silberman, S. (2016, May 17). *The invisibility of black autism: Why generations of clearly autistic black children have been diagnosed with ADHD or even "mental retardation" instead.* Undark. https://undark.org/2016/05/17/invisibility-black-autism/

Sinclair, J. (1993). *Don't mourn for us*. Autreat. https://www.autreat.com/dont_mourn.html

Sousa, A. (2011). From refrigerator mothers to warrior-heroes: The cultural identity transformation of mothers raising children with intellectual disabilities. *Symbolic Interaction*, *34*(2), 220-243.

Swenson, K. (2017, June 29). *The secret world of finding Cooper's voice*. Finding Cooper's Voice. https://www.findingcoopersvoice.com/2017/06/29/the-world-of-finding-coopers-voice/

Swenson, K. (2019, July 23). *Sometimes I forget*. Finding Cooper's Voice. https://www.findingcoopersvoice.com/2019/07/23/sometimes-forget-2/

Weddle, A. (2016, February 28). *The autism shift: The visibly invisible – autistic people of color.* The Art of Autism. https://the-art-of-autism.com/the-autism-shift-the-visibly-invisible-autistic-people-of-color/?fbclid=IwAR2Kto9Xz2uvsj3nBId0HQuQLSvyaRQphlNmNaFQPpobkzjnARqhAWdP4F4

Welch, C., Cameron, D., Fitch, M., & Polatajko, H. (2020). From "since" to "if": using blogs to explore an insider-informed framing of autism. *Disability & Society*. https://doi.org/10.1080/09687599.2020.1836479