



Portraits of Resistance: Exploring Intra-personal, Social, and Institutional Resistances through the Use of Arts-Based Research among Racialized Parents of Autistic Children and Youth

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ABSTRACT *The lives of children who live at the intersectional nexus between childhood autism and race may be considered as “shadow stories” that have remained silenced in autism literature. We explored the experiences of racialized parents who provide care to autistic children. We drew on a theoretical framework known as DisCrit and decolonizing arts-based methodologies. Racialized parents of autistic children demonstrated resistance along various themes, including fighting the system, protecting my child, and creating cultural communities. We join black girlhood studies, critical race theory, and disabled children’s childhood studies by continuing the journey of decentering Whiteness in childhood disability research. We demonstrate how disabled racialized communities engage in activism and social justice while forming powerful counter-discourses.*

KEYWORDS autism; race; parents; children; youth; arts-based; decolonizing

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We reflect on resistances displayed by the racialized parents of autistic children in Canada,¹ and their role in the generation of counter social-justice movements. We highlight the potential for marginalized communities living at the intersection of childhood disability and race to contribute to cultures of resistance and social justice. Specifically, we contribute novel insights to the burgeoning field of disabled children's childhood studies (Curran & Runswick-Cole, 2013, 2014) through contributions by racialized parents of autistic children. This study also names anti-black racism as part of the health care navigation of parents of autistic children, while opening up new spaces for BIPOC parents to share their experiences.

Specifically, we illuminate resistance work within the racialized child neuro-diverse – or more specifically, autistic – community through the use of narrative and visual data. We purposefully employ both terms. The neurodiversity movement was created in the 1990s by an Australian autistic sociologist, Judy Singer, to promote inclusion among those who have differing neuro-abilities (Leadbitter et al., 2021). It is considered a social justice movement with the aim of increasing inclusion. We also employ the term “autism” because all our participants' children were given this diagnosis. We are deeply attentive to the important autism critiques that scholar Anne McGuire (2016) has made. In her book, McGuire joins autism activists in critiquing the excessive focus on diagnosis.² Here, we consider how autistic people trouble some of the taken-for-granted neoliberal assumptions about the ways that bodies speak, move, communicate, and use time.

Review of the Literature

White supremacy forms the foundation upon which children are constructed. We understand Whiteness not as a biological given but as a social invention that affords some bodies structural privilege (Owen, 2007). We consider Whiteness as normalized, ubiquitous, and invisibilized, with those that occupy these social positions often having the privilege of not having to reflect on race. We recognize that Whiteness has produced violence in contemporary society (Owen, 2007).

Scholars such as Castañeda (2001) suggest that childhood studies and the lives of children have been shaped by colonial thinking, Northern perspectives,

¹ We recognize that language is contentious and often a site of pain. We currently employ the word “racialized” because it considers how power relationships invariably shape what bodies come to be labelled as raced (Ahmed, 2002). The term racialized de-emphasizes race as a biological construct and illuminates the process of racialization as one deeply embedded within power relationships (Ahmed, 2002). We also adopt identity-first (McGuire, p. 93, 2016), rather than person-first, disability language. Person-first language may perpetuate stigma and we see disability as central, rather than secondary, to personhood (Dunn & Andrews, 2015).

² Anne McGuire points out an important distinction between autism activists and autism advocates. Autism activists are autistic people. In contrast, autism advocates are non-autistic people who may be parents.

and White supremacy. Further, the development of race as a concept itself in White society was closely associated with the construction of children as primitive, savage, innocent, and child-like (Castañeda, 2001). Robin Bernstein (2011) also suggests that in dominant Eurocentric traditions, the construction of the child changed in the mid-19th century. Children were no longer regarded as “savage beasts” but were instead thought to be innocent. However, while the notion of childhood innocence is afforded to White children, black children are often excluded from such constructions (Bernstein, 2011). Focusing on carceral states, Erica Meiners (2016) also suggests that black and brown children are not afforded access to dominant scripts of childhood, such as childhood innocence.

Important critiques have also been written about Global North accounts of childhood and how these constructions are undergirded by White supremacy. Global North scholars may often project an illusion onto what the Global South childhood subject is (Abebe et al., 2022). These ideas are not divorced from colonial conquest. The authors call for epistemic and theoretical pluralism when it comes to thinking about childhood in diverse temporal and geographic contexts. In particular, a relational and embodied ontology and epistemology are required when thinking about Global South childhoods in which intergenerational relationships and collective agency are valued (Abebe et al., 2022). Chataika and McKenzie (2013) have emphasized the centrality of the family and community to these disabled children’s lives, while critiquing the inherent individualism that characterizes Global North accounts of disabled childhoods. Similarly, Meekosha’s (2011) scholarship has problematized the universalizing nature of Global North accounts of disability that have served to marginalize Global South narratives.

When it comes to childhood disability and race itself, it is important to note the contributions of scholars in the fields of both education and health care. Within the space of health care, Khanlou and colleagues (2017) found that immigrant mothers of autistic children faced a myriad of access barriers, such as long wait times and limited funding for services, as well as diminished instrumental and emotional support. Beneke et al. (2021) found that mothers parent disabled children through an ethos of care, refusing to engage with limited notions of competence. At the intersection of health care and education, Underwood and colleagues (2019) found that the normative assumptions that underpin early intervention services may not be compatible with Indigenous worldviews, where there may be high regard for difference and disability. Early intervention (EI) services have historically not considered cultural identity or Indigenous world views, or the contributions of colonization toward the production of childhood disability. These EI services may in fact perpetuate harmful colonial practices (Underwood et al., 2019).

Paul Adjei (2018) considers the over-labelling practices that disproportionately serve to cluster black students in special education classrooms. Adjei (2018) offers a novel perspective because he considers the embodiment of blackness as a form of disability in contemporary White

society. Practices such as the over-labelling of black bodies as learning disabled perpetuate all-White educational spaces and prevents the encroachment of racialized students who are often viewed as intruders (Adjei, 2018). Jacqueline Getfield (2022a, 2022b) found that although black mothers lack power in educational and pedagogical settings, they fight back in educational settings by advocating on behalf of their children to ensure access to the Ontario educational curriculum.

Zoebia Ali et al. (2001) are also working on decentering Whiteness in childhood disability research by recognizing the multiple oppressions faced by black disabled people. The voices of ethnic minority disabled children have been virtually absent and a better understanding of the convergence of racism and ableism is needed for racialized disabled children who face “double-discrimination” (Ali et al., 2001, p. 960).

Our study builds on this important work by Beneke et al. (2021), Ali et al. (2001), and Chataika and McKenzie (2013) by focusing specifically on health care and education system navigations among racialized parents of autistic children using arts-based research.

Research Design and Methodology

We adopted a qualitative interpretive study design. The study was approved by the Research Ethics Board at a children’s hospital in Canada in 2020 and funded by two Southern Ontario universities. We used social media advertisements, snowball sampling, and word of mouth to recruit racialized parents of autistic children. Given a long history of breaches of trust in research contexts against marginalized communities, we took our time with the consent process to ensure that participants comprehended the intent and meaning of the study.

Theoretical Insights

We chose DisCrit as an intersectionality-informed theoretical framework (Love & Beneke, 2021) because of its potential to illuminate how racism and ableism, as dual oppressions, uphold discourses of normalcy in health care and educational spaces (Annamma et al., 2018). Even though DisCrit historically has its roots in education, using an educational theory in the context of health care was appropriate because it enabled us to engage in an institutional critique of systems. The work of black feminist scholars, such as Anna Julia Cooper, Kimberlee Crenshaw, and Patricia Hill Collins, were formative to shaping DisCrit and to understanding the operation of interlocking forms of oppression, what it is like to be black in America, and the value of knowledge that emanates from black women (Annamma et al., 2018). Critical race theory was also heavily influential in the development of DisCrit.

The pioneers of DisCrit were also impacted by their anecdotal experiences as special educators. They noticed that youth of colour had worse performance outcomes in comparison to their White counterparts. They also observed that the field of special education remained resistant to engaging with issues of race and that students of colour were over-represented in their classrooms (Annamma et al., 2018; Ferri & Connor, 2005). They recognized that the labelling practices inherent to special education served to only widen race-based disparities. DisCrit scholars have also helped to unpack deeply entrenched normative developmental scripts – that is, theoretical ideas that define how and when normal children develop particular cognitive capacities. These normative developmental scripts are rooted in Whiteness and are disproportionately used to label students of colour as disabled.

Methodology

We employed a hybrid decolonizing and arts-based approach. DisCrit and decolonizing arts-based methodologies are highly compatible because both are devoted to decentering Whiteness. Ushered in by Linda Tuhiwai Smith (1999) in the late 1990s (Barnes, 2018), decolonizing methodologies are rooted in critical, transformative, and Indigenous ways of knowing. Decolonizing methodologies are not a monolith; rather, tremendous nuance characterizes this perspective.

Decolonizing is not a one-time discrete event. Rather, decolonizing is a lifelong process, one that critical black scholar Franz Fanon called “a program of complete disorder” (Fanon, 1963, p. 36, as cited in Thambinathan & Kinsella, 2021, p. 3). Decolonizing researchers aim to give voice to academics who have been historically marginalized within the academy. Decolonizing research is marked by a commitment to centering the voices of the Other through critical self-reflexivity, transformation, and respect for self-determination (Thambinathan & Kinsella, 2021).

Reflecting upon Smith’s (1999) seminal book, Tuck and Yang (2014) offer particularly nuanced discussions of decolonizing methodologies. Decolonizing methodologies are disruptive of traditional hierarchical relationships between academic researchers and research subjects (Tuck & Yang, 2013). Both authors unpack research as an active site of struggle between the interests of the West and the interests of the Other. Their perspective also exposes research as an enterprise that has historically been used to harm Indigenous people (Tuck, 2013). In particular, Sinclair (2003) suggests that research on Indigenous people has been both predatory and exploitive (Sinclair, 2003; Thambinathan & Kinsella, 2021). Tuck and Yang (2014) also suggest that a triad – including the White settler, the disappearing Indigenous person, and the chattel slave – is what constitutes Whiteness within settler colonizing relationships. Specifically, Tuck and Yang (2014) draw on Sedgwick’s three axioms in research. First, we have tended to document the pain and brokenness of the

Other without a subsequent commitment to also investigating their resilience and regeneration. Indeed, White saviour researchers profit from the inherent voyeurism of such approaches. Tuck and Yang (2014) name the academy as an institution that has furthered settler colonial knowledges. Finally, Tuck and Yang (2014) unpack an underlying assumption of colonial research: that communities require change. Tuck and Yang (2014) propose a framework of refusal in research which shifts the gaze from the violated body back to the violating instrument, that is, colonial research enterprises. Although not utopian, decolonizing work does offer a careful way forward that reduces the risk of re-wounding.

We also drew on arts-based research (ABR). Beth Ferri (2011) suggests that to disrupt dominant disability discourses and to better comprehend ableism and its intersection with other identities, it is important to reflect critically on methods. The use of methods such as film, fiction, popular culture, and narrative contributes to imagining disability differently (Ferri, 2011). Additionally, reflecting on bell hooks' and Audre Lorde's scholarship, Kwan (2019) discusses how, sadly, people of colour have often been the objects of the White colonizer's gaze and have had their bodies represented in particular ways. Thus, visual representation is a site of struggle for many BIPOC people. ABR can also return agency to BIPOC people through control over representational issues and how BIPOC people wish to see themselves. Following Ferri (2011) and Kwan (2019), then, we decided to also take up an ABR approach because of its potential to help us imagine new ways of thinking about disability and other identities as it may engender representational agency for our participants.

Although many arts-based researchers have not utilized the arts in the process of decolonization, it is important to acknowledge those scholars who have utilized ABR to disrupt Whiteness (Mikkonen et al., 2020; Moola, 2020). At the inception of the arts-based research paradigm, some of the most seminal works were undertaken with marginalized communities (Wang & Burris, 1997) and people with HIV/AIDS in Africa (Brett-MacLean, 2009) in an effort to more closely understand their experience of oppression. Specifically, some ABR scholars suggest that the arts can promote decolonization because of its inherent focus on listening to subaltern voices and bearing witness to power relationships (Keifer-Boyd, 2011). Additionally, ABR may promote critical self-reflexivity about privilege and encourage contemplation about oppression from the perspective of those that live outside of dominant power structures (Keifer-Boyd, 2011).

Not all ABR scholars utilize this methodology to consider issues such as embodiment. However, some ABR scholars, such as Keifer-Boyd (2011), also suggest that ABR promotes thinking about social justice because of its focus on embodiment. Keifer-Boyd (2011) suggests that such sensual and multi-sensory methodological approaches are important because they value subjectivity, intuition, and gut feelings. Sadly, Western academia, since the time of Kant, has rejected the arts as a valuable source of knowledge about

embodied experiences (Cooperman, 2018). Because of this, the inherent focus on the body in ABR might also be considered as radical in that it sidesteps the usual binaries of mind over body and reason over emotion that mark contemporary academia (Martikainen et al., 2022). Some scholars, such as Kwan (2019), suggest that when we are engaging with deeply emotional experiences, such as racism and ableism, the arts can provide a compassionate and kind means of engagement.

ABR may also help to decentre the ableism and racism that is part and parcel of traditional research approaches. For those that do not have access to dominant systems, such as non-verbal disabled children or those that do not engage in normative communication, the arts may provide a more inclusive communicative platform (Krøier et al., 2021) to consider that which may live outside of language (Martikainen et al., 2022).

Participants

Eight self-identified racialized parents of autistic children in Canada participated in our study. Participants described their gender and race in the following ways: man, woman, South Asian, Chinese, and Black. One sibling of an autistic child participated as a caregiver, which was approved by the research ethics board. Participants ranged in age from the 20s to 60s and were employed in a variety of occupations, including retail work, engineering, education, technology, and equity work. Our study reflected a broad range of immigrant, refugee, and first-and second-generation experiences. Countries of origin included Sri Lanka, China, Ghana, and Jamaica. Participants resided in the province of Ontario as well as in Eastern Canadian provinces. No participants identified as gender non-conforming. All parents provided care to one or more children who were given a formal diagnosis of autism. Age ranges for children were between two-years old and the mid-20s.

Methods

We collected data using two qualitative methods, including in-depth interviews and a draw-and-write activity (Moola, 2020). The draw-and-write technique is an arts-based method that has been used for about four decades. Participants draw an image of a health or social issue (Angell et al., 2015) and write a short accompanying narrative. Although the draw-and-write method was developed in an effort to create more inclusive child-centred research methods that do not place excessive language demands on children (Angell et al., 2015), it has been employed with adults for several years (Hartel, 2014). Participants were sent a range of art materials in the mail. Participants engaged in the process of artistic creation in relation to a number of written prompts that they were given. Participants then scheduled their interviews with the research team using a

secure Zoom platform. Interviews lasted approximately 1.5 to 2.5 hours, and during this time, participants also communicated their interpretation of their art. Interviews were conducted by a racially diverse research team to ensure comfort and racial mirroring.

Data Analysis

We employed a thematic and visual analysis. Transcripts were read individually and coded with recurring units of meaning. Then, recurring meaning units across all the transcripts were grouped into provisional categories. These categories were then collapsed into broader themes and theme names refined. We employed Gillian Rose's (2016) framework for visual methodologies and analysis. Rose (2016) posits that there are three "sites" of an image where analysis may occur. First, we evaluated the content and the formal qualities of each composition, such as lines, shapes, forms, colour, and focal points. We also employed a semiological analysis within the site of the image. The semiotic approach aims to understand the meaning of signs (Rose, 2016). Signs are composed of two facets, including the signifier and the signified. The signifier is an image or material that represents an underlying mental concept. In turn, the signified is the mental concept that is evoked in the mind by the signifier. We examined signs relating to disability, care, race, family, and resistance. By finding commonalities between the compositional and symbolic elements of each artwork, we generated three themes in relation to each work among racialized parents of autistic children. These include *fighting and problematizing the system*, *protecting my child*, and *building cultural community support*.

Results

Resistance through Problematizing the System

Problematizing the system was a common thread in participants' narratives and artwork. This refers to the processes whereby racialized parents visibly "call out" the inequities they have faced when navigating both healthcare and education systems. Participant 6 problematizes the healthcare system and the systemic disparities and inequities that exist between the Global North and the Global South. The participant captures the essence of this sentiment by drawing Africa and Europe as separate entities (Figure 1). Importantly, this participant creates a binary between Africa and Europe and it is not clear if she is referring to enslaved Africans brought as slaves or Caribbean people. She explains that African ancestry renders one unseen in medical spaces. In her narrative, she suggests:

There is no communication between them, there is no equality between them. In the eyes of the world, Europe contains all the knowledge, the law, the history, the research (universities), the media power. If you come from Africa, you will not be seen, you will not be listened to. You don't count. (Participant 6)

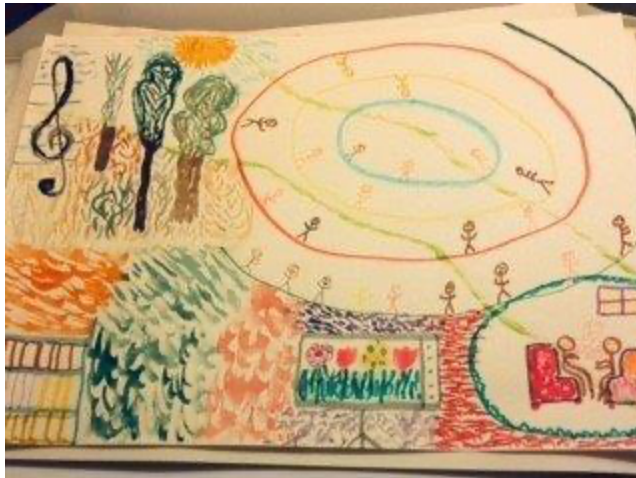


Figure 1. Participant 6's artwork (coloured markers and pencil crayon) depicting Africa and Europe – emphasizing the “huge divide” that exists between the Third World and developed countries.

The same participant also depicts an image whereby an individual is confined to a coffin that does not fit the body (Figure 2). In this haunting image, she explains that if an autistic person does not fit into biomedicine's narrow box, they will not get adequate treatment. She exclaims, “No!” Within the health care system, if you do not fit a given mold, you will not be granted treatment.

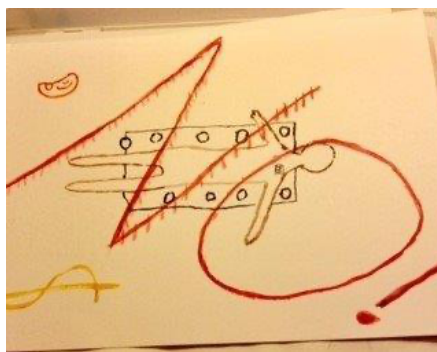


Figure 2. Participant 6's artwork (coloured markers) illustrating an individual in a coffin that is “way too short, way too narrow.” Red bolded letters spelling out “NO!” can be seen across the entirety of the composition.

Participant 7 uses two visual narratives to convey the idea that hurdles (Figure 3) and winding paths (Figure 4) are embedded within the healthcare system, ultimately inhibiting ease of accessibility to treatment that racialized parents are trying to access for their autistic children.

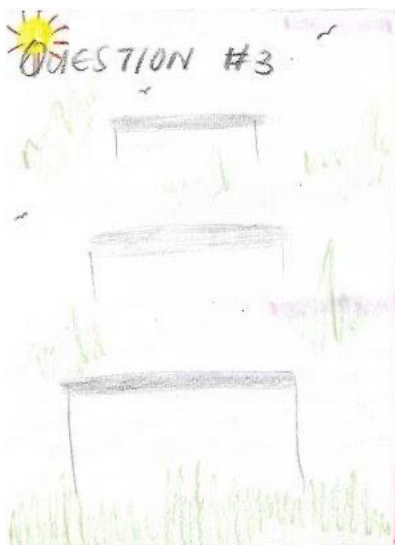


Figure 3. Participant 7’s artwork (pencil crayon) exhibiting a sunny day with the promise of “joy” in receiving treatment for her son. In the foreground, hurdles represent the barriers one experiences in accessing care.

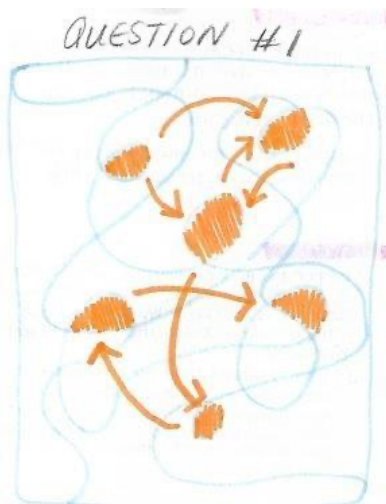


Figure 4. Participant 7’s artwork (coloured markers) depicting yellow “hoops” one must go through to get “services and help.”

In a rather chilling narrative, a black parent of an autistic child (participant 6) shares experiences of anti-black racism in hospital spaces. She now questions what White staff are thinking and is “always on her toes.” The first part of the narrative pertains to a White medical resident telling the concerned racialized parent that the reason her newborn baby is so dark in complexion is because of the “black blood” that runs through the mother’s body. The notion of black blood conjures up biological determinism, or the notion that certain traits, like “blood,” can be rooted in biological bodies (Mason, 1994). Fanon regarded biological determinism as part and parcel of colonial dominance (Kane, 2007).

I have two experiences that I always think about; they never left me. The first one is when my daughter was born, she was born and was very purple, really, really dark when she was born. I was really struck by that. I kept asking staff if that was normal, if there was not an issue about that, and I was very preoccupied with that ... At one point there was a pediatric student, I asked her the question, like, “Are babies born that dark, that purple? Could that be a sign of any health issues?” And she told me, and she didn’t know me, she didn’t ask me any questions. She said that because I had some black blood in me, sometimes children are born with a blue tinge and I couldn’t believe it. I said, “Is this real? Is she really telling me that?” And since then, each time I had the opportunity to ask that question to a specialist, I asked it, and they’ve never heard this story. So that was one thing. Right from the start I thought, “Holy moly, what’s going on in her mind?” So that was the first warning for me – that I have to be on my toes and be careful. (Brianna)

In the next narrative, the same racialized mother experiences anti-black racism in a hospital space again. This time, it is directed at her appearance and choice of clothing attire. The mother also questions whether all parents (i.e., White parents) are also told how to dress on a cold winter’s day.

Then there was another example, when my daughter had her first surgery at Sick Kids. At the time, my hair was all matted because my mother would come and stay with us and she would do my hair. So I think it was more obvious that I was black or had some black origin in me. So I was at Sick Kids and my daughter had her surgery; she was doing better and we were going home. My husband went home to get some stuff or get the car and I was alone with the pediatrician on the ward. I was dressed, I don’t know, it was very hot in the hospital, so I had a t-shirt and maybe I don’t remember, but she looked at me and said, “Do you know it’s winter outside and it’s really cold, and you need to dress up? You have a daughter who’s going to have a lot of health appointments and you’re going to have to be really serious and focused about it.” And I thought, “Holy moly, what does she think?” I thought, “Does she say that to every parent?” And I just thought that she’d waited a moment for when I was going to be alone, when my husband was not there, to tell me that, as if she needed to “put some sense” into me. (Brianna)

Another black parent shares her encounter with institutional racism in the education system. In particular, her autistic son had been “accidentally” locked outside of the school on several occasions because he was unable to notice

when recess was over, and the other children were going inside. The mother shares her experience of being racialized and dismissed by the school principal in relation to her efforts to advocate on behalf of her autistic son. She also alludes to the microaggression of being told that “you speak so intelligently.”

And it was about a month after that, we were notified by one of his daycare teachers that there were some major problems at the school. She had actually found him locked outside on the school grounds by himself because it was at a lunchtime and when they had made the children line up at the front door to go back into the school, [child’s name], being the typical kid he was, he probably was looking at the sky, looking all around, didn’t see the lineup proceeding into the school, and whoever was responsible for the children going in, didn’t notice that [child] was left outside and they locked him outside. And if his daycare teacher hadn’t been worried, she wouldn’t have been hiding behind the fence watching and that’s how he ended up safe ... So I had to approach the principal first, who was giving me nothing. That school had a very bad reputation of stereotyping parents and treating them in discriminatory ways. You know, racializing parents, judging them by their economic status, so I was getting all these judgements on me because nobody knew me or who I was or what I did. Once the principal started to do that passive-aggressive, “Sorry, there’s nothing we can do,” I wrote a very threatening letter to everybody from the principal to all the way up to the Minister of Education because I was preparing a human rights complaint against them ... She (the principal) assumed a lot of things about me, but what really made me upset was I knew other parents from the community who were low income, who might not have had a high education. Why do their children not deserve services? Why do they deserve to be disrespected because of those things? I was even given the compliment of “I speak so intelligently.” That’s not a compliment. (Maria)

Protecting my Child

Through an ethos of protectionism, racialized parents sought to protect their disabled children from many sources of harm, including the medical system, patronizing doctors, and the education system, to name a few. Participant 3 depicts herself with her “hands up” to “block” any harm that may come to her child, who is seen playing with toy cars in the background (Figure 5, right side). This participant used to rely on her husband to protect her child. Now, however, she explicitly states that “when it comes to cultural stigma, I am the one that now defends my son.” Participant 1 also tries to protect her child through engagement in spiritual practices like prayer (Figure 6). When she is praying for her child, in an effort to protect them, she specifically prays for her child to experience “betterment in his health, school situation, and behavioural incidents.”

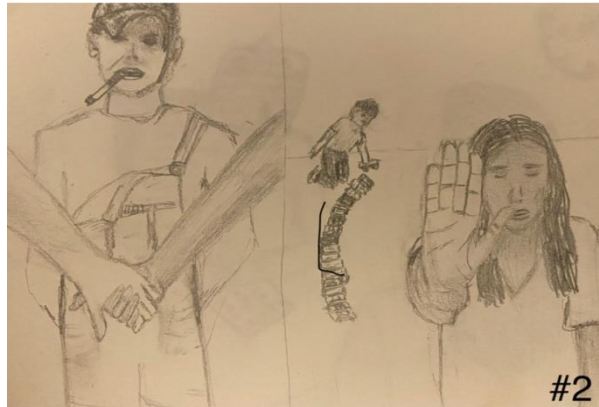


Figure 5. Participant 3's drawing (pencil). On the left, the participant is holding hands with her husband, on whom, she states, she used to be dependant. On the right, the participant is seen with her hand up, independently protecting her son, seen in the background.

Participant 1A, the child's older sibling, shares:

Yeah it [spiritual practice] definitely does, because it influences our moral and ethical code for sure. We grew up based on those beliefs and especially for my brother it plays a big role in his life because he prays a lot, like he prays regularly. So, he will get up in the morning and then brush his teeth whatever, and then he will go straight to the "Swami room," the prayer room, and he'll pray and he will do the same thing in the evening and [he] sings like certain mantras like twice a week, things like that so he has a regular routine because of his prayers.

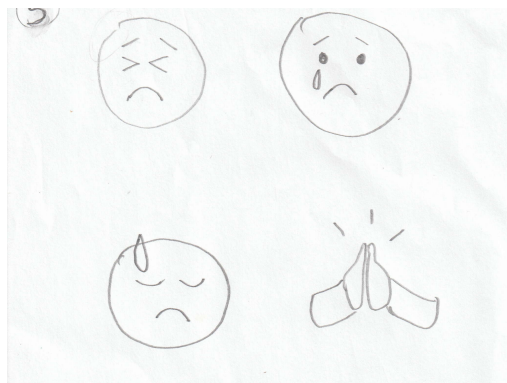


Figure 6. Participant 1's drawing (pencil) illustrating how they cope with stressful situations related to their son, using various symbols emphasizing emotions such as being overwhelmed, praying, crying, and becoming frustrated.

Lastly, participant 5 depicts resistance in the form of a protective and empowered mother, whom she refers to as the “Black Autism Mom.”

Her heart is almost bursting out of her chest with love for her children. Her roots represent her trying to stay grounded or else she cannot grow and continue to care for her children. The red background represents the angry, hateful world that she and her children exist. With all of that going on she still stands strong with her arms open to embrace and receive love, kindness, help, and hope in which she will then provide to her children. (Participant 5)

The image itself (Figure 7) contains references to the empowered mother, as she is depicted with roots stemming from the earth and stands in a tall stance with her arms open toward the sky. She appears as if she is wearing the autism logo as a badge of honour and source of pride, as it is central in the composition and displayed on her chest.



Figure 7. Participant 5 artwork (painting) exhibiting the “Black Autism Mom.”

Resistances through Cultural Community Support

Participants also demonstrated resistance by building an extensive network of racialized friends and family members in an effort to aid them in their parenting experience. This is a form of resistance in that it requires one to actively stand with others in recognition that there is a shared struggle and need for support.

Participant 1 depicts a familial and community-based network in Figure 8, where she illustrates her child's aunts, uncles, cousins, and organizations such as Surrey Place – all of which she claims are her “biggest support system” and source of “amazing guidance.” Her vast network of friends, family, and cousins are very supportive of her autistic son:

So they've been very supportive, um they always they always try to whenever they come and see him, they always try to talk to him and actually have conversations with him, and get him stimulated and uh they've also been very supportive of his musical career as well, like they come to all the shows, his performances, even for his last birthday they pitched in money together and got him a piano for his birthday. Yeah, they do things like that, so we have a very supportive cousin system. And also our aunts and uncles they've also been very encouraging, they have also tried to cause you know sometimes he's like our little son, so then we tend to sometimes spoil him; um they're always like “no no, you guys have to make him independent, he has to do all these things alone.” So like they always have a supportive eye on him. (Participant 1)

Participant 1 also depicts the South Asian Autism Awareness Centre (SAAAC).

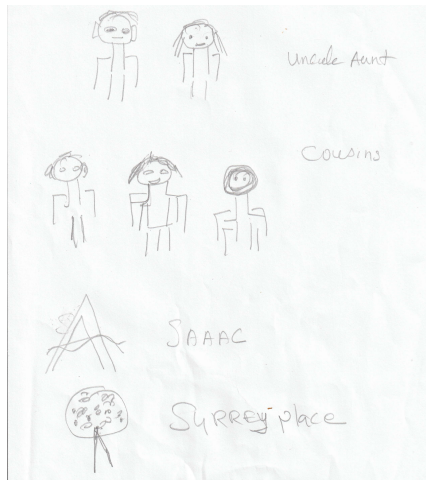


Figure 8. Participant 1's drawing (pencil) depicting the various people and organizations who have supported her and her family.

Participant 2 similarly illustrated a familial network of various individuals in Figure 9, which is accompanied by text stating “family members help him and me.”

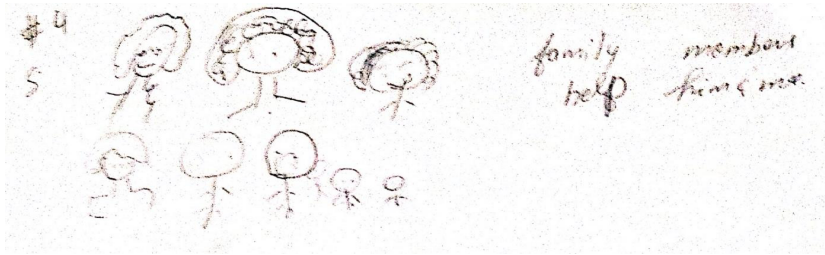


Figure 9. Participant 2’s drawing (pencil) depicting support received from familial networks.

Like participant 1, participant 2 also finds the South Asian Autism Service to be extremely beneficial, given the shared cultural systems of meaning and understanding.

Yeah like really, the SAAAC [South Asian Autism Service] group, because I think of our culture, [child’s name] is more quick to pick up things, perform at events, and helps with communication. I’ve tried different agencies as well, but you don’t have a connection because of culture. But with SAAAC we get the parents’ connection, outside of the agency as well. Like with the SAAAC moms, we go for dinner, for eating, and then for also other things.

Many parents also demonstrated resistance via establishing online social connections across the globe using platforms such as Facebook. Specifically, participant 3 refers to garnering support from a communal network in the realm of social media. The participant indicates that their drawing depicts “the autism community on Facebook,” including “self-advocates and other parents” (Figure 10). In this way, resistance is formed through the active seeking of like-minded individuals across the globe who are united through their desire to advocate for disabled children.

Lastly, participant 6 refers to communal support in the form of people and shared narratives about “the human element.” They depict a human stick figure with the head of a novel, which appears to be spreading information from its pages (Figure 11). They state how they can always turn to the collective “stories of the world” in the form of “music, nature, screens, novels, research.”

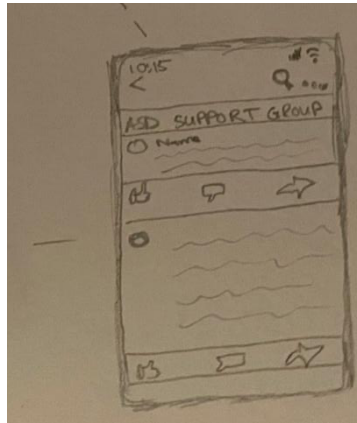


Figure 10. Participant 3's drawing (pencil) depicting the use of Facebook to represent the wider autism community, consisting of advocates and parents across the globe.

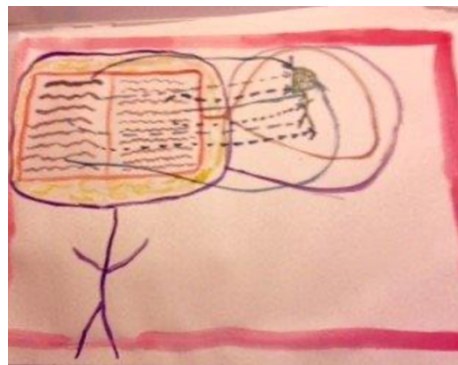


Figure 11. Participant 6's artwork (coloured markers) illustrating a human stick figure with a novel on its head, representing how one can always find comfort in communal stories and narratives.

Our findings are discussed below in the context of the research.

Discussion and Recommendations

Parents engaged in “fighting back” against health care and educational systems. Parents’ resistance to the education system was thought to limit their child’s opportunities and choices. A similar finding was also reported in a study by Beneke and colleagues (2021) where racialized parents did not accept the limited educational opportunities prescribed for their children. Our study builds on this literature by also documenting how parents fight against the

health care system. Parents named the system as decidedly anti-African in nature and described it as laden with hurdles. Parents criticized the system for not treating anyone who does not fit the confines of a narrow diagnostic box. Parents' critiques of anti-Africanism are underscored by the scholarship of Chataika and McKenzie (2013). Parents were extremely vocal about the injustices they faced in the health care system and called out these injustices. To our knowledge, racialized parents' fight against the Canadian health care system in an effort to protect their children is a novel finding. Importantly, "fighting the system" was not always an outward process. In some cases, "fighting back" was demonstrated as an internal shift in which parents recognized that, because of racism, it was necessary for them to always "be on guard." Parents also spoke to experiences of anti-black racism in hospital spaces through derogatory commentary about "black blood, black hair," or assuming that a black parent did not know how to dress herself or her child for the cold Canadian winters. While anti-black racism in autism care is acknowledged as a significant problem (Straiton & Sridhar, 2021), there is a lack of empirical data on this experience.

Clinicians and researchers should be aware that racialized parents both internally and externally "fight" the system. Clinicians should also be aware that dealing with microaggressions is often perceived as exhausting for the victim (Nadal et al., 2017). Anti-racist and cultural competency training – including on the harms of anti-black racism in hospital spaces – must be conducted to reduce these adverse experiences for racialized parents of disabled children.

Racialized parents cultivated an ethos of "protectionism" and care for their disabled children and also engaged in prayer. Prayer was used to protect children from behavioural problems, and simultaneously as an avenue of communication. Prayer was also utilized as a way to ensure better outcomes for their children. Racialized parents tried to protect their children by remaining grounded and open to love, care, and help, despite the racist and hateful worlds racialized autistic families had to navigate. Protectionism for the disabled has mostly been thought of in paternalizing ways (Starke et al., 2016). However, authors Nishida (2022) and Piepzna-Samarasinha (2018) propose radical revisions to the concepts of disability care that are highly relevant to the discussion here. As demonstrated in our study, care work may also be considered as a deeply relational endeavour that builds connection and love (Nishida, 2022). In our study, protectionism and care seemed to be a stance that parents took to keep their children safe. The complex ways that racialized parents protect their disabled children has not been demonstrated in the literature, and, in this way, these are novel findings. Health care providers should be aware of the complex ways that racialized parents protect disabled children, including their awareness of their resilience. Reducing racism and cultural blunders in medical spaces may reduce parents' constant need to protect their children from harm (Broder-Fingert et al., 2020).

Racialized parents demonstrated resistance by forging a vast network of social connections with friends, family, and community-based organizations. Facebook and other online social forums were utilized while seeking connection and comfort. Health care providers and researchers should be aware of how cultural practices may be a protective factor in autism care for racialized families. This has been reported in the First Nations suicide literature (Chandler & Lalonde, 2008). Best practice principles for culturally sensitive care should be implemented in autism centres. More culturally-specific autism organizations should be created to enhance opportunities for cultural connectivity. The social support benefits of the digital age (Clifford & Minnes, 2013) should be recognized as well to better support these families.

Contributions

Our study has opened a space for BIPOC parents of autistic children to share their experiences navigating the health care system. This study has contributed to recognizing anti-black racism in health care and education while also capturing individual narratives of resistance from parents. Despite the importance of these individual resistance narratives, to dismantle these ableist and racist systems there is also a need for collective resistance. A disability justice framework may pave the way toward collective social solidarity. In addition to illustrating what it is like to parent under oppressive conditions, a disability justice approach underpins the need for collective resistance.

Author Esi Edugyan (2021) suggests that there is a greater need to pay attention to “stories in the shadows,” that is, those stories that live outside of the centre, in the periphery of mainstream social life. We explored the “shadow” stories and art of racialized parents who care for autistic children and live in the space between racism, childism, and ableism. Parents demonstrated intrapersonal, social, and institutionalized resistances. Our paper also underscores how the arts and arts-based research can help us on the long and tedious journey of decolonizing childhood disability research and care.

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