BRINGING FIRE TO THE PEOPLE:
ACTIVIST SCHOLARSHIP, CREATIVE COLLABORATION, & INTERNATIONAL ADVOCACY THROUGH THE LENS OF BLACK DISABILITY STUDIES

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(Artistic rendition of the fire tetrahedron. Created for my thesis by my 11-year-old.)

ABSTRACT

Giwa Onaiwu, M. (2022). *Bringing Fire to the People: Activist Scholarship, Creative Collaboration, & International Advocacy Through the Lens of Black Disability Studies*. University of East Anglia.

This PhD thesis is a distinct contribution to the existing knowledge and practice of inclusive, intersectional stakeholder leadership within key contemporary research advocacy and human rights movements (namely neurodiversity and racial/HIV/gender/disability justice). Moreover, it champions as well as models innovative, transdisciplinary methods and responsive, accessible, culturally affirming techniques to prioritize engagement and equity in scholarship, practice, and pedagogy.

Informed by critical theory produced by Black public intellectuals including bell hooks, Audre Lorde, Patricia Hill Collins, W.E.B. DuBois, Wole Soyinka, Patricia Williams, Sami Schalk, and E. Grollman, among others, this qualitative study is a disability-justice inspired heuristic inquiry. In addition to amplifying the voices of influential historical and contemporary interlocutors of color and disabled activists, the thesis highlights diverse, multimodal strategies (including integrative learning, public digital humanities, narrative theory, participatory and action research, etc.) as tools of public intellectualism, engaged pedagogy, and disability justice that center underrepresented perspectives.

As a framing device, I invoke the fire tetrahedron—fuel, heat, oxygen, and fire—as an analogy for the distinct categories of the selected work (activist scholarship, collaborative practice, and international advocacy). This analogy also elucidates emergent overarching themes including aspects of identity, individual and/or collective action, and burnout. Via the portfolio and exegesis, the narratives and actions of marginalized community leaders of color and/or with disabilities compose anthems of survival, resistance, growth, and progress in the context of disregard, disadvantage, and disenfranchisement, thus illustrating the reality of resistance and resilience. Despite alarming disparities, incessant denial of justice, and systemic inequity, those who—because of race, disability, gender, and/or other intersections—are (mis)perceived as “at risk,” “vulnerable,” or otherwise “impaired” consistently find innovative ways—collectively and individually—to defy the most dismal odds to not only survive, but to even dare to thrive.

Plain language summaries (in Appendix A), lay abstract summaries, images, and other augmentative resources for this thesis are provided in the appendices for the purposes of increasing accessibility of this material as well as paying homage to this topic.

KEYWORDS: Black disability studies, public intellectualism, bell hooks, heuristic inquiry, gender, race, neurodiversity, engaged pedagogy, intellectual activism, Black feminism, disability justice

LAY SUMMARY OF ABSTRACT

Giwa Onaiwu, M. (2022). *Bringing Fire to the People: Activist Scholarship, Creative Collaboration, & International Advocacy Through the Lens of Black Disability Studies.* University of East Anglia.

This PhD thesis helps to explain and extend the way we understand and practice leadership in certain research and human rights fields (such as autism acceptance, neurodiversity, technology, HIV, race, gender, and/or disability), especially when such leaders are members of the most marginalized and/or underserved communities. It provides examples of different creative tools and strategies that can be used by a broad range of people from different backgrounds and are helpful in making sure all are valued and treated fairly.

The study represents the voices of vulnerable, underrepresented groups using "heuristic inquiry," a qualitative research method. Moreover, the study was informed by Black public intellectuals including bell hooks, Audre Lorde, Patricia Hill Collins, W.E.B. DuBois, Wole Soyinka, Patricia Williams, Sami Schalk, and E.A. Grollman. It was also informed by the writings of disability, race, and gender activists, and diverse ideas for learning and research. The study is framed by the research questions: "How has this body of work served as symbols of public intellectualism that represent the voices *of* the people? And how does it gather and share that knowledge *from* the people *to* the people?"

The thesis contains a portfolio and the study in a written summary. The material covered by the study can be broken down into separate groups. Qualities of oxygen, heat, fuel, and fire are used as examples to explain the differences and similarities between the groups.

As part of my commitment to accessibility and public intellectualism, I have included additional helpful information in the appendices: plain language summaries (in Appendix A), images, expanded notes, etc.

KEYWORDS: Black disability studies, public intellectualism, bell hooks, heuristic inquiry, gender, race, neurodiversity, engaged pedagogy, intellectual activism, Black feminism, disability justice

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[1] Several theorists (including K. Crenshaw, B. Cooper, K. Blain, S. Annamma, N. Erevelles, and others) whose contributions are crucial to this work are, sadly, inadequately covered in this thesis due to word count limits. **Recommended readings.* (These were initially in the critical exegesis but were cut due to word count limits.)

DEDICATION

Life Hacks…from the Amazing Jae!

“Leaders aren’t perfect, but neither are the people who are led.”

“We must understand that darkness and light come together. There is no light without darkness. There is no darkness without light.”

“The more rocks are thrown at the main character, the more powerful the resolution.”

“Every day that we live we are developing the plot for our lives.”

“God put me in this particular life for a reason. He knows I’m strong enough to handle it.”

“Media and digital accessibility open up a whole new world.”

“Anything that matters is worth a sacrifice.”

“Like you said, Morénike, instead of focusing on the rain, I need to focus on the rainbow.”

“Our thoughts help determine our lives. If you don’t like your life, change your thoughts.”

“I get the most creative and energetic at night. Why is it then that we have to go to sleep?”

“I wish I could change some of my decisions, but I won’t live in regret.”

“God wants us to move forward in life. Not backward.”

“I was born on an even number day. My family members were all born on odd number days.
No wonder they’re all oddballs.”

“If you ‘ease up’ on others, they will ‘ease up’ on you.”

“Seriously, ‘my Scarlett’ is the sweetest and smartest niece ever!”

“We have to accept that everything changes. Nothing is static or stays the same.”

* * *

This doctoral thesis is dedicated to the author of these quotes. Jae Casper Ross, MA was a global disabled non-binary Jewish human rights and multimedia activist who believed **all** humans have value.

Jae, whose Earth journey ended in May 2021, was many things to many people: child of Rick and Lois; sibling of Brandon and Eric; auncle of Scarlett; artist, writer, organizer, friend, and mentor to multitudes…and now an ancestor, who is both deeply missed and deeply loved on several continents.

If you have the means, please consider a donation to the *Jae Ross Memorial Scholarship* at Jae’s alma mater (CUNY) via the CUNY School of Professional Studies Foundation to support graduate students in need who are committed to positively changing society's view of disabled/marginalized individuals.

Image of Jae Ross and MGO in New York City, February 2020

ACKNOWLEDGEMENTS

First and foremost, immense gratitude to my Creator. Then, the rest of y'all, starting with:

Lucky...my Boaz. My Shining Armor. The eternal Steven to my Connie; the Sapphire to my Ruby; the Jim Holden to my Naomi; the Samwise to my Frodo; the Collins to my Angel; the James Evans to my Flo; the Dwayne to my Whitley; the Gulf of Mexico to my 10,000 Lakes. You have literally as well as figuratively been with me throughout not only this entire endeavor, but in this crazy thing called life. You ALWAYS have my back and I know that none of this would have been possible without you by my side. It means so much to be truly known and loved by you in this lifetime and the next and the next. Honey, you shall forever be my Ride or Die, my "tortora," my "San Padriego," and the lover of my soul. (Intentionally no Bonnie and Clyde comparison; I ain't trynta die like that!)

Mo ni fe re. Te amo. Iru emwen rue. Tienes mi corazón ahora y para siempre.

Next…my PhD chairs Dr. Frederik Byrn Køhlert and Dr. Hilary Emmett. THANK YOU for your advice, support, encouragement, and most of all, your patience with my lengthy, abstract writing! Enormous gratitude to Taiza Pickering for the layperson/plain language translations!

Mom and Dad...though it took me far longer than it should have to take your sage advice, thank you so much for giving it to me anyway, as well as your constant reassurance, support, prayers, and your innumerable sacrifices. You gave everything in your souls to give us a fighting chance in this world.

Sending infinite love to all of my babies (and *yes*, I said "babies." I'm a mom; no matter how old you get; you'll always be my babies). Amina, Anthony, Cherita (and Isaiah and my almost-birthday bonus, Noah); Daniel, Legacy, and Lukas…raising you, without question, has been the greatest honor of my life. I thank God every day for your lives. Like our name (Onaiwu), my love for you is indestructible; it shall never die. You are and will always be the inspiration for all that I am and all that I do.

To the remainder of my family scattered throughout the globe…whether connected by the blood of the covenant, the water of the womb, or chosen/interwoven hands of love, I am thankful for each one of the "525,600 minutes" I am blessed to share with you during each journey around the sun.

Last but never least, I want to acknowledge you - the person(s) reading this. Yes, *you.* I may never know who you are, but I appreciate that you're expending precious time and energy to consider what I have to share. The opportunities I have had to collaborate with, educate, and/or learn alongside amazing people who are trying to grow, be better, and make our world better is a huge privilege, one I do not "take for granted." Please know that this thesis is for *you* too. It's for all of us.

AUTHOR'S NOTE ON CONTENT / TRIGGER WARNING

(Applies to the thesis as a whole)

I have provided a content/trigger warning for this thesis as there is a significant amount of material in this thesis and the appendices that contain descriptions, references, and/or imagery that might create distress. This includes discrimination, abuse, injustice, violence, death, mental health challenges, sexual assault, and manipulation. More specifically, it addresses racism, ableism, intimate partner violence, filicide, homophobia, transphobia, HIV stigma, unethical policies, denial of justice, misogynoir, excessive use of force by authorities/police, suicidal ideation and attempts, harmful cultural practices, betrayal, emotional toxicity, religion, economics, politics, oppression, murder, poverty, sex, etc.

There are also parts of the thesis that do not contain the aforementioned items, but in the spirit of full transparency, it's challenging for me to describe specific parts of the thesis that might be deemed "safer" to read/listen to/view for those who have triggers in one or more of these areas because of the interwoven nature of the thesis. So, while I definitely think that there is much that is (hopefully) affirming, inspiring, and thought-provoking compared to the content that might be triggering, I don't know exactly how to quantify it in a helpful way.

Please prioritize what is best for YOU and your psyche—including opting not to read this thesis if that is a healthier choice for you to make. I am also providing a few optional resources below for support that you might find beneficial; please review, if desired, at your earliest convenience.

Thank you!

- 988 Suicide and Crisis Lifeline (US): https://988LifeLine.org/
- Two pages of tips to help adults with stress and trauma (from the National Center for PTSD [US] & the International Society for Traumatic Stress Studies):

https://istss.org/ISTSS_Main/media/Documents/appendix_e8_tips_for_adults.pdf

- 28-page packet called the "Managing Your Triggers" Toolkit (from Robert Gass & Judith Ankara/The Social Transformation Project on the Mediators Beyond Borders website):

https://MediatorsBeyondBorders.org/wp-content/uploads/2020/01/Managing-Your-Triggers-Toolkit.pdf

- Info about how to text for free help if you are in a crisis (if you live in US, UK, or Canada):

https://www.CrisisTextLine.org/text-us/

AUTHOR'S NOTE ON ACCESSIBILITY

Typically, a note like this would probably be located in the appendices of a dissertation or doctoral thesis. However, I fear that if I place this note back there, many of the people who need to read this never will...because they may never even glance at that section waaay in the back of this doctoral thesis. Thus, I am placing it here, right in the front. I hope that by positioning it in what is figuratively "prime real estate" for such a document, it will increase the chances that it will fulfill its intended purpose.

A thesis is probably one of the least accessible documents one can conceive of. Generally, a thesis is long, wordy, and full of academic jargon. Other than an occasional figure or chart, there's seldom any imagery or multimedia. Because they are expected to be written by "an experienced researcher with academic and/or creative published work in high-quality journals (and/or its equivalent as performance, exhibition, installation, media of various kinds") who can demonstrate "evidence of extensive active research effort…a significant contribution to the development and understanding in one's field," little (if any) priority seems to be given to cognitive accessibility. (UEA, 2021, para 1)

There's a standard that one is expected to follow to produce an "acceptable" doctoral thesis to advance and/or be respected by the "right" people. That's the "formula" for success. But ethically, how can I do that when it contradicts nearly everything that I'm about? I've devoted years of my life advocating for access, acceptance, inclusion; it's a recurring theme throughout much of my work, (including this very document). To disregard that now would, to me, be hypocritical, and I am not comfortable with that. However, as I do want to obtain my doctorate, I have come up with a compromise/workaround that enables me to comply with traditional postgraduate requirements while still making this content available and at least partly accessible to the community at large.

Please go to Appendix A (a section in the back) to read the plain language summaries of this thesis.

Plain language/lay reader summaries in Appendix A primarily developed by T. Pickering.

Appendices (A, B, and C) contain information on accessibility, other versions of the thesis, resources, images, etc.

AUTHOR'S NOTE ON FAIR USAGE & AUTHENTICITY

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The thesis seeks to advance the understanding of race, gender, disability, activist-scholarship, and related topics it addresses. Any/all photos, media, video, articles, posts, figures, quotes, etc. are owned by their respective copyright owner(s). Where possible and/or where ownership is known, attribution is explicitly given throughout the body of the thesis and/or in its appendices (particularly Appendix C).

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Statement of Authenticity

According to Aristotle (Sachs, n.d.), rhetoric has three components: logos, which assesses the logic of the argument, pathos, which focuses on the feelings evoked by the argument, and ethos, which ignores the argument altogether. Ethos is more concerned with the credibility of the storyteller than the story because ultimately our lives are our stories...the story of self.

As this thesis represents over a decade of my work, I have strived to ensure that it is a truthful and accurate portrayal of my life and therefore my story. I urge you, dear reader(s), as you develop the plot of your own life, please be certain that you are crafting a story of self that is true to who you are. If you succeed, your ethos shall be one that is solid and unshakeable indeed.

INTRODUCTION

Background

I was relatively young when I entered the field of human rights; as an undergraduate in my late teens and early 20s, I worked with refugee youth in a housing project and later as a mentor in public schools. I found this work (and the subsequent community outreach I engaged in) highly rewarding, but at the time I assumed this was something that I would only be able to be involved in temporarily.

College, and subsequently, a traditional career (with above-average income and job stability), was the goal. This, I thought, would ensure that I could provide a good life for my hypothetical future family—the quintessential "American Dream."

However, my life took a number of unexpected turns, and as such, the predictable existence I had foreseen never transpired. Instead, I became an activist, which I ultimately came to discover is my true calling.

In retrospect, the primary motivation for my initial foray into activism was pure, unadulterated rage. At times, this fire burned out of control, and I was nearly consumed by it: anger at the injustice that seemed to surround me; anger at how complacent people seemed to be with the unsatisfactory status quo; anger at the sense of helplessness I felt.

Activism provided a channel for me to fuel my anger into action; rather than implode, I could *do* something, and thus at least make things a *little* better for others. It was quite cathartic for me to speak up, act, resist, and engage in what the late Black civil rights icon Congressman John Lewis characterized as "good trouble" as opposed to just accepting the unacceptable. (Ray, 2020, p. 1, para 1)

As I grew as a person, so did my praxis, and thus my scope of work. And in time, even after the anger had long since cooled, I found that activism had, for me, now truly become a way of life.

This thesis is part of my story, which is part of our collective story—the story of humanity.

Activism as Fire

Fire is created when fuel, heat, and oxygen combine. This thesis uses the relationships among these components as its structuring analogy throughout because fire has been one of the most transformative discoveries in the history of humankind. Fire changed the trajectory of our species in ways that still impact us today—thousands of years later. It enabled us to elude predators; allowed us to travel to, explore, and/or live in areas that had once been uninhabitable; helped to diversify what we eat, how we communicate, and how we transport and produce items; etc.

There can be noticeable variation in a fire's intensity, size, and/or spread depending upon the circumstances. Thus, despite being an instrument with significant potential for good, fire has the capacity to enact enormous damage as well. Activism shares a similar dichotomy in that it can both ignite and help sustain changes but can also immolate objects in its path, as stated eloquently by esteemed Black historian W.E.B. Du Bois in *The Souls of Black Folk*: "To stimulate wildly weak and untrained minds is to play with mighty fires." (Du Bois, 1903, p. 2)

Metaphorically as well as literally, fire is a consequence, a natural reaction. We cannot readily observe the development of fire with the naked eye, but the appearance of flames usually alerts us to its presence, as does smoke.

The distinct yet interconnected subcomponents of the fire tetrahedron (fuel, heat, and oxygen) help demonstrate how my work constitutes public intellectualism, utilizes principles of disability justice, and incorporates engaged pedagogy. They also help to describe the impact of my activism on the communities I serve.

Fuel

Fuel is symbolic of my scholarly work as it is the foundation upon which my creative, communal, and activist work is built. The section represented by "Fuel" thus includes my review of existing scholarship and literature in fields relevant to my own scholarship. This section argues that "thought and action can work together in generating theory" and provides an evidence base for the tactics or interventions utilized. (Collins, 1990, p. vi-xiii) Moreover, as fuel is the catalyst that lights the actual fire, it can be perceived as representative of specific enkindling element(s) and/or circumstance(s) that in turn spark or bring forth change.

Heat

It is important to note that just as fuel cannot ignite itself, the mere existence of scholarship influenced by disability justice, engaged pedagogy, and public intellectualism cannot drive change; action is needed. That action is represented here in the form of heat; the scholarly work of editing, collaboration, and anthologisation activates the process of disseminating my work to catalyze action. As a verb, heat exemplifies "doing"—practical application; creative collaboration; collective action. As a noun, it aptly describes an increase in temperature due to a change in current conditions.

Thus, heat can refer to calescent factors in the environment. Such heat transfer can have great impact because "The struggle for justice is larger than any one group, individual, or social movement…it is a collective problem that requires a collective solution." (Collins, 2009b, p. xiii). Moreover, as Black scholar-activist Audre Lorde notes, the future necessitates that we "identify and develop new definitions of power and patterns of relating across difference." (Lorde, 1984, p. 114-223) Complementarity, mutuality, and interdependence are manifested via interaction and joint engagement which facilitate shared understanding, thus figuratively generating heat.

Oxygen

The remaining component required for fire is oxygen. In this thesis, it represents the process of putting my scholarly and collaborative work into practice. In this final step, these two coalesce, emerging in the form of transformative advocacy and global activist work. Oxygen, a necessary component for sustaining human life, is commonly described as a critical ingredient of activism, such as in the frequent admonition to "put on one's own oxygen mask" before that of others to emphasize the importance of activist self-care. (Shepherd, 2018, para 5, 6, 9-15)

Oxygen also symbolizes what Du Bois and Lorde have described as the malleable and intersectional nature of identity. (Du Bois, 1897, para 1, 3; Lorde, 1971, stanza 1; Popova, 2017, para 4) Although it might, in theory, be possible to have a singular identity (technically, it is possible for a single atom of oxygen to exist), this lone form is neither customary nor sustainable in reality. Oxygen, like identity, tends to have multiple components which do not wish for "the older selves to be lost." (Du Bois, 1903a, p. 10-11) Moreover, while identity, like oxygen, might have an inherent or preferred state, it is capable of transforming to—at least temporarily—an alternative (isotope) form if needed, depending upon external factors. This section therefore explores the way my work represents practical application of core concepts in a manner similar to the process of oxidation that brings forth fire.

The Fire Tetrahedron

The fire tetrahedron is fuel + heat + oxygen = fire. Fire is the resulting event. Fire is a process; it is the outcome; a whole that is greater than the sum of its parts. Fire, while hard to contain, can be easily seen and recognized, and has the capacity to dramatically alter its surroundings.

Combining scholarship, community collaborative work, and activism yields a fiery, discernible result as well; one that, embodied in the form of resistance and/or resilience, reveals, as contemporary Black scholar Honoree Jeffers observes of acclaimed poet Phyllis Wheatley Peters in Jesmyn Ward's *The Fire This Time*, the depth of our emotions as well as our thoughts. (Jeffers, 2016, p. 80) And just as fire is born as a reaction to fuel, heat, and oxygen, my work (embodied in the form of activism) born in response to injustice, stigma, and oppression, continues , like fire, to evolve and develop.

CRITICAL FRAMEWORKS

Public Intellectualism

I argue in this thesis that my portfolio constitutes the record of 15 years of public intellectualism. As a public intellectual, my activism is shaped by my commitment to engaged pedagogy, Disability Justice, and Black Disability Studies. In the discussion that follows, I lay out my interlocutors and influences demonstrating the academic and activist work that underpins my practice.

To many, the term “public intellectual” refers to elite, high-profile individuals with near-celebrity status who are publicly considered to be extremely proficient and knowledgeable in a particular field or topic. (Mitchell, 2017, para 2-4) Often hailing from academia, these are the thought leaders and “experts" who are sought out for their perspectives and whose opinions can shape policy and practice. Yet I propose that this definition is a distortion of the concept. The Oxford dictionary’s overly simplistic definition of “an intellectual who expresses views, especially on popular topics, intended to be accessible to a general audience,” is similarly incorrect and fails to capture the complexity of the role of the public intellectual. (Issitt & Jackson, 2013, p. 1-9; Oxford, 2021, definitions)

Ralph Waldo Emerson’s *The American Scholar* presents a description of the “public intellectual” that is much closer to my own definition. The “One Man” Emerson describes simultaneously represents “the farmer, the professor, the engineer, the priest, the scholar, the statesman, the soldier, and the artist.” (Emerson, 1837, para 5) As such, the public intellectual is someone who possesses a broad range of characteristics, potential, knowledge, and actuality, and therefore is symbolic of the totality of all humanity. (Lightman, n.d., para 4) Putting this into practice in the present, Appalachian scholar Katie Trauth Taylor is the founder of Untold Content, an expert technical writing national consultancy that functionalizes public intellectualism through “innovative storytelling.” (Untold Content, n.d., para 3-7) Taylor’s description of public intellectualism as the belief that “all voices should be heard, knowledge should be shared, and that people should have access to information” aligns closely with my values and is manifested in my praxis. (Clark, 2017, para 13-17)

Palestinian American scholar Edward Said’s straightforward yet eloquent writings on public intellectualism emphasize that those of us who are in the public sphere bear significant responsibilities: “The intellectual's role generally is to uncover and elucidate the contest, to challenge and defeat both an imposed silence and the normalized quiet of unseen power, wherever and whenever possible.”

(Said, 2001, p. 19-39) As I also share these sentiments, I make a concerted effort to embody them within my words and actions, and I perceive them as an excellent way to summarize public intellectualism. However, it is in the work of sociologist Patricia Hill Collins that I found public intellectualism outlined in a manner that resonated most deeply with me. Collins' highly acclaimed *Black Feminist Thought* highlights the importance of examining "the complexity of ideas that exist in both scholarly and everyday life," and "presenting those ideas in a way that makes them not less powerful or rigorous, but accessible." (Collins, 1990, p. vii-viii) For me, cognitive accessibility is both a guiding principle and a self-imposed minimum standard. While I recognize that some aspects of accessibility are both variable and individualized, I believe firmly in the concept of collectively embracing and implementing universal design and broad applicability.

Accessibility is more than logistics, i.e., what font type or size you use; inclusion of effective captioning; color contrast; image descriptions—although that's certainly part of it. There is more to accessibility than avoiding walls of text, confusing jargon, buzzwords, and/or unexplained acronyms—although that's also part of it. Accessibility requires more than ensuring compatibility with augmentative tools such as screen readers, text to speech, and/or other tools. It requires all of those things if/when needed, as well as potentially other things.

I believe true accessibility, however, is concerned not only with the medium, but also with the message. Thus, I view my praxis as accessible and translational; making connections and "bridging" gaps between what is theoretical and what is practical; between research and practice; between the researcher, the provider, and the layperson; between the "newbie" and the sage. I maintain that it is not only possible, but it is *critical* that difficult concepts are conveyed in a way that maximizes greater understanding without "dumbing" them down in a manner that dilutes the intended meaning. As such, I agree with Collins (1990, p. vii) that it is "the ideas themselves are important, not the labels we attach to them." Personally, it matters more to me that someone can articulate the way(s) their disability, gender, and/or race may overlap than whether or not the individual in question uses the term "intersectionality" in doing so!

Collins' keen observations in the book *Intellectual Activism* highlight another core aspect of public intellectualism: "My lengthy educational training was designed to equip me to wield the language of power to serve the interests of the gatekeepers who granted me legitimacy," Collins (2013) noted. "My teachers did not consider that I might choose to use the same weapons to challenge much of what I learned." (p. 36-41)

This resonates deeply with me as someone whose educational background (within the academy and outside of it) is extensive given its circuitous route. For—whether I agree with it or not, I have the privilege as well as the capacity to be able to espouse the basic tenets of what is and isn't deemed "acceptable" by (Western) societal standards.

For example, I possess undergraduate and graduate university degrees that are universally accepted in most countries. I can communicate effectively in Standard American English for academic, technical, executive, and/or related purposes via both speaking and writing. I can eloquently convey and defend my perspective, and I typically comprehend concepts at a "high level." I have a general sense of neurotypical social norms/decorum (even if I find much of it nonsensical, unauthentic, obscure, and restrictive).

Seemingly, I have acquired enough "notches" on the figurative belt of what society considers to be "success" that despite my marginalizations, my contributions are seemingly valued. As such, in many instances, people do extend an invitation (though at times fraught with problematic and even potentially tokenistic undertones) for me to have a "seat" at the table. That seat, however, as Collins reveals, comes at a steep moral price, with conditions and/or "strings" attached. Essentially, one learns of the expectation to uphold existing conditions and endorse (implicitly or otherwise) the standards, ideologies, and hierarchical status quo of those already at the table.

Regardless, however, of these (and other) contradictions and complexities, knowledge is still power. Few things can rival its potential to facilitate tremendous change. Sadly, for this reason, while I agree with Collins' (1990, p. vi-ix) assertion that "Theory and intellectual creativity are not the province of a select few but instead emanate from a range of people," this seldom seems true in reality. I must acknowledge that humankind has frequently hoarded, twisted, and/or otherwise weaponized knowledge to subjugate and manipulate others.

To that end, though I have generally found Lorde's (1984, p. 112) oft-repeated quote that "The master's tools will never dismantle the master's house," to be true in many situations, this is not so with public intellectualism. If anything, metaphorically we now possess a previously obscured "blueprint" of the master's toolbox and presumably the tactics the master has been using to do battle. We can then, according to Said, wield it to "alleviate human suffering" and for "speaking truth to power." (Said, 2000, p. 454-469)

Public intellectualism equips us to launch a strategic counterattack—as evident in the work of Nobel prize winning Black author Toni Morrison, who artfully wields the tools of literary criticism to dismantle the edifice of the canon, and in queer autistic scholar Remi Yergeau's use of rhetoric from Aristotle, Zeno of Citium, and musings on culture and narratives to valorize unique aspects of autistic communication. (Morrison, 1992, p. x-xiii, 16-17; Yergeau, 2018, p. 14, 21-23, 32, 34, 40, 45) Public intellectualism's role in enhancing public understanding strengthens the ability of the layperson, if they wish, to critically assess—and potentially act to change—their circumstances. This transmission of knowledge (and therefore power) is a core essence of "bringing fire to the people," ultimately galvanizing them.

Engaged Pedagogy

Another foundational component of my work is engaged pedagogy, which fosters knowledge through active engagement in a shared learning community. According to its founder, acclaimed scholar bell hooks (1994, p. 13-22), it is not a set of practices, but a calling. Engaged pedagogy rejects the Eurocentric status quo as the "true" or "correct" way to acquire and transmit knowledge. Instead, it requires its practitioners to fully embrace as well as model vulnerability and growth, to strive to become "better, whole human beings," and encourage others to do the same. (hooks, 1994, p. 15-22)

Though philomathy, which refers to an "enjoyment of and passion for learning new facts and acquiring new knowledge" (Dhiman, 2021, para 5), is a term that is seldom used, it is a true phenomenon—and in my case, was an early sign of an intrinsic leaning toward engaged pedagogy prior to having any formal understanding of pedagogical methods. Philomathy is likely my oldest "special" or "circumscribed" interest—an intense focus on a topic that, according to Jordan & Caldwell-Harris (2012, p. 391-402), is present in ~75–95% of autistic people.

Unfortunately, this was complicated by a double standard imposed upon me because of my neurology; this natural proclivity toward an intense desire to learn is unjustly stigmatized because of autism. The same interests that society perceives as favorable "specialized knowledge" when espoused by non-autistic individuals are cited as evidence of the abnormal "restricted, repetitive patterns of autism" when autistic people possess them (Labor-Warren 2021, para 1-7, 20-21), and are seldom positively acknowledged, much less encouraged. Fortunately, I am not easily dissuaded.

I perceive engaged pedagogy as a natural extension of public intellectualism that both shares and builds upon its purpose; but focuses more on depth than breadth. In particular, engaged pedagogy emphasizes the value of living consciously and the importance of personal connections with others. Most significantly, it posits teaching as a powerful instrument of change, correlating with scholar Henri Giroux's cries for educational reform and the need for teachers to embrace transformative processes:

> As radical educators, we can help destroy the myth that education and schooling are the same phenomenon; we can debunk the notion that expertise and academic credentials are the primary qualifications of the 'intellectual.'
>
> Equally important, we can provide, discuss, and learn from historical and contemporary examples in which working-class people and others have come together to create alternative public spheres. (Giroux, 1983, p. 239)

hooks' assertion that all parties bring their valuable knowledge, opinions, etc. into the learning environment in engaged pedagogy builds upon this concept. (hooks, 2009, p. 21) Engaged pedagogy also openly contradicts the Eurocentric notion of "objectivity" and being "free" of values and/or judgments that undergirds much of contemporary academia and research; in reality, the "self" is never completely removed from one's mind as we bring ourselves (our experiences, beliefs, etc.) with us everywhere we go. According to Collins, this phenomenon is part of the learning process; Engaged Pedagogy "doesn't require separation…from our own experiences nor does it require, or assume that it is possible, to separate our thoughts from our feelings." (Collins 1990, p. 258-263)

As an avid practitioner of engaged pedagogy, I acknowledge this reality by cultivating a combination of learned and lived expertise as a distinct hallmark of my work. One example of a method that I utilize is intentionally intertwining personal anecdotes into my work alongside evidence-based empirical data rather than perpetuate the falsehood that the different parts of who we are don't bleed into one another. Instead, I employ dialectical reasoning to identify and strengthen these connections. Such a merger does not dilute the content's rigor or accuracy because critical thinking is explicitly integrated. (hooks, 2000, p. 7-11) My work also embodies engaged pedagogy in the way I incorporate not only my life into my work, but also my work into my (personal and professional) life. As aforementioned, in pursuit of objective "neutrality," mainstream approaches to scholarship and practice admonish us to compartmentalize rather than reconcile our public and private selves. (Lorde, 1984, p. 116-119)

Moreover, I consider the societal belief that one's private and professional life do not intersect a dangerous misconception and denounce the notion that as long as someone can “perform,” it matters little if they are an abusive, deeply wounded hypocrite whose internal life is in shambles. Unfortunately, hooks laments, though contradictory and toxic, in society at large this problematic duality is common. Engaged pedagogy thus vehemently rejects the ideology that what we “do” and who we “are" have nothing to do with one another. The role of an educator is similar to a healer—and a broken healer cannot properly heal others. (hooks, 1994, p. 15) In fact, according to hooks, a practitioner of engaged pedagogy cannot be hailed as a talented “genius” in one sector of their life while wreaking irrevocable havoc and abuse in another. (hooks, 1994, p. 16-17)

Finally, hooks (1994, p. 21) notes that individuals who “embrace the challenge of self-actualization” are more equipped to engage others and offer “ways of knowing that enhance their capacity to live fully and deeply.” An additional factor of engaged pedagogy that resonates with me is the expectation of continual growth. I often self-identify as a “lifelong learner.” Just as fire cannot exist without all the necessary components, earnest pursuit of wholeness is required of all who embrace the engaged pedagogy framework, in order to effectively empower others. As an advocate, I possess an intrinsic, sincere drive to encourage, care about and influence others. (hooks, 1994, p. 15, 19) Whether writing, editing, delivering a keynote address, engaging in activism, or giving a guest lecture, it is never my intention to just “make a point.” I endeavor, in all things, to “make a difference.”

Engaged pedagogy is a holistic philosophy that seeks to help people to thrive in general, not just in one narrow area. The practitioner emphasizes that knowledge is *no*t something that is reserved only for the classroom environment. *All* students bring their own life experiences, which constitute their own form of knowledge as lived expertise. Nurturing and developing this self—which silently accompanies us into the classroom; into the boardroom; into the field; into our research; into the translation and dissemination of information we acquire—has benefits far beyond any academic achievements or accolades and is crucial for simply being in the world. (hooks, 1994, p. 14-15)

Disability Justice

Serving as a practical link between public intellectualism and engaged pedagogy, Disability Justice holds “...a vision born out of collective struggle, drawing upon the legacies of cultural and spiritual resistance within a thousand underground paths, igniting small persistent fires of rebellion in everyday life.” (Projects LETS, 2021; Berne, 2015 para 11-13)

Developed by disability activists Patty Berne, Mia Mingus, Leroy Moore, the late Stacey Park Milbern, Eli Clare, and Sebastian Margaret, Disability Justice contains ten principles: Intersectionality (a term coined by Dr. Kimberle Crenshaw for overlapping marginalized identities [Crenshaw, 1989, p. 140-141]); Leadership of the Most Impacted; Cross-Movement Solidarity; Cross-Disability Solidarity; Recognizing Wholeness; Sustainability, Anti-Capitalism; Interdependence; Collective Liberation; and Collective Access. (Sins Invalid & Berne, 2015, p. 3) These principles challenge the way we understand and address the connection between issues. They also influence how we care for ourselves and others via a culturally sensitive model for affirming collective engagement with one another within safe (or brave) spaces. (Ali & NASPA, 2017, p. 1, 3-4; Collins, 2009a, p. 100-101, 110) Disability Justice emphasizes the need to center people who live at the margins of disability, race, gender, socioeconomic status, sexuality, age, citizenship, and myriad other marginalized identities. (Sins Invalid & Berne, 2015, p. 1-3; Crenshaw, 1989, p. 139)

Mia Mingus, a disabled activist of color, educator, and writer, shared (in a 2010 article about social justice, para 16-18) a key distinction between Disability Justice and the disability rights movement that preceded it. While disability rights focused on “education and advocacy around systems and attitudes" with independence as its cornerstone, Disability Justice emphasizes that while “rights” are things that can be granted or removed by those with authority (i.e., laws), justice represents that which is intangible and cannot be taken from us.” (Disability Activist Collective & Ortiz, 2010, notes)

Disability Justice does not worship at the altar of independence because it acknowledges the reality and the beauty of interdependence. Our bodies, our minds, our past, our circumstances…they are not merely objects to be placed under submission or to be “overcome.” It rejects the binary of medical model of disability on one side and social model of disability on the other, not expecting us to suppress our cultural background, gender identity, or other aspects of ourselves to fully embrace our reality as disabled. It celebrates the personhood and inherent value of every individual without calculating or even caring about “how much” they can contribute.

As an individual who exists at the intersection of numerous identities, some privileged and some marginalized, Disability Justice speaks to my reality…how so many aspects of my life overlap one another. I am Black. I am also Autistic. Both my race and my disability influence one another; I cannot separate them. I am a non-binary woman who was assigned female at birth. I am a parent of disabled children and part of a neurodivergent, serodifferent, multicultural family.

Further, as an "Xennial" (a person who was born as part of the overlapping "microgeneration" within Generation X and the Millennial Generations), I am also an individual who grew up theoretically under the Americans with Disabilities Act's legislative protection, however imperfect it may be.

Disability Justice can be easily likened to the concept of the fire tetrahedron. An outgrowth of the gaps and unmet needs of its forebear (the disability rights movement), rather than preoccupying itself with the movement's (many) past sins, it instead urges us—plaintively—toward reflective action. Disability Justice offers us the instruction guide as well as a rare opportunity: the chance to do things right rather than facing the disastrous self-induced consequences lingering in the horizon. Learning from our past will save us from having to face, as James Baldwin (1963) prophesied solemnly, "The fire next time."

The Disability Justice framework emphasizes numerous ways that ableism is linked to multiple other systems of oppression. Intended to be practiced at the micro, meso, and macro levels, it seeks to dismantle the notion of perceiving and/or engaging disability as a single-issue concern because for many of us, it is not. By "fighting for an interdependence that embraces need and tells the truth," Disability Justice challenges societal beliefs about human value in relation to productivity and vulnerability and highlights ways that society can be far more disabling than any of our diagnoses:

> It's not easy to live with an impairment. There are times when it's not convenient to have a body. But that's not what oppresses us. What oppresses us is living in a system that disregards us, is violent towards us, essentially wants to subjugate our bodies or kill us -- that's oppressive. My body doesn't oppress me. (Berne, 2015; Project LETS, 2021)

Disability Justice pushes against the notions that people's bodies and minds are considered broken, unproductive, abnormal, devalued, etc. It promotes collective access, collective care, collective growth, and collective liberation. According to the late queer disabled BIPoC activist Stacey Park Millbern, "If I'm in a place where my access needs are being met, then my impairment isn't so significant." By encompassing the various parts of who we are, Disability Justice allows us to be our whole selves. (Project LETS, 2021) Though Disability Justice is a distinct entity, given the shared emphasis on fostering community and the inherent individual and collective value of others, I also perceive it as the amalgamation of public intellectualism and Engaged Pedagogy in some ways as well, helping to facilitate justice and inclusion that propels us to care about and work "…with other oppressed groups, educating ourselves, creating solutions and community power can serve everyone." (Disability Justice Collective, 2010 para 1-7; Mingus, 2011, para 1, 3-5, 8-12)

Black Disability Studies

In her seminal book *Black Disability Politics* (2022), Sami Schalk, a disabled Black queer public intellectual, poses the challenging question: “Are you willing to not only do the work, but be transformed by it?” (Schalk, 2022, p. 2). Indeed, as she alludes, activism in the tradition of Black disability studies changes you and requires “breaking some norms of academic research and writing” and “changes in scholarly and activist methods and frameworks.” (Schalk, 2022, p. 2, 5, 6, 8) My work incorporates and advances aspects of both Disability Justice and Black Disability Studies, particularly Black Disability Politics (a subcomponent of Black Disability Studies).

According to Schalk, the characteristics of Black Disability Politics are as follows: 1) It is intersectional, but race-centered; 2) It has a historical and contextualized quality; 3) It does not necessarily require identifying as disabled or embracing disability as one’s identity; and 4) It is holistic and broad. (Schalk, 2022, p. 5-6, 10-17) Crediting various scholars for “merging scholarship, theories, and methods from disability studies, Black studies, postcolonial studies and Black feminist theory,” Schalk celebrates the nascent field of Black Disability Studies that was formed through this blending.

Regarding disability politics specifically, Schalk suggests, it “…actually exists in Black activism and cultural work, but manifests and operates in ways that do not look the same as disability politics in the mainstream movement.” (Schalk, 2022, p. 5-6) Given the “discursively linked” nature of Blackness and disability, Schalk declares, “I cannot get on board with approaches to disability that do not understand it as inherently, inextricably tied to racism and other oppressions.” (Schalk, 2022, p. 2) Schalk’s passion for and commitment to activism infused with Disability Justice and Black Disability Studies resonates deeply with me and highlights a core and recurring theme in my scholarship, my creative collaborations, and also my activism, which is “a labor of love, but labor nonetheless.” (Schalk, 2022, p. 2)

As disability activist and luminary Patty Berne declared brazenly, “There are always going to be people in pain. That’s just the nature of being in a body. But the social body we can change. And I think it requires a power analysis.” (Project LETS, 2021) In what follows, I also engage in analysis as I examine my sole and joint-authored activist scholarship. The next section focuses on my creative collaborations, discussing how they are a form of care work. I also describe collaborative endeavors including co-authorship and multimodal leadership. Finally, years of global advocacy and activism are explored. The conclusion, which encapsulates these points, completes this critical exegesis.


Nothing
about us
without
us
is for
us!

FUEL: ACTIVIST SCHOLARSHIP

Fuel involves the specific enkindling element(s) and/or circumstance(s) - the catalyst - that starts the actual fire. Simply put, fuel is both what starts and what is needed to maintain a fire. Fuel differs from the other components of the fire tetrahedron in that it is considered a "reducing agent;" while others work by making additive changes (increased temperature for heat generation; absorption of electrons for oxidation), fuel becomes combustible by undergoing a process of loss.

Fuel is an excellent analogy for my scholarship, for without this critical layer of firmament—my academic contributions—many of my achievements would likely not exist. There would be no collaborative creative work; there would be no global activism; there would be no "own voices" edited collections; there would be no White House presentations; no addresses at the United Nations. Every one of these things exists because of the groundwork that my scholarly work has cultivated. Similarly, without fuel, it would not be possible for a fire to develop. Further, in an existing fire, if there is not sufficient fuel, the fire cannot be maintained.

Just as renewable energy (wind, solar, hydropower) constitutes a minuscule portion of human fuel usage compared to nonrenewable energy sources (i.e., fossil fuels), scholarship makes up a smaller percentage of my work than the other components. It typically requires substantive uncompensated intellectual labor, so like fuel, my scholarship is also associated with loss. However, it is important to acknowledge that the significance of said scholarship far outweighs its actual size. Without it, would I ever realistically be afforded a platform of this magnitude among renowned investigators, clinicians, and other influential parties to openly challenge the status quo, point out inequities, call for change, and bring awareness to issues relevant to my communities? Quite simply, probably not.

Sole-Authored Publications

There are a few distinct examples of my scholarship that I can single out as powerful catalysts for change. In one sole-authored piece, "'I, Too' Sing Neurodiversity," I deliberately invoke "I, Too," legendary Harlem Renaissance poet Langston Hughes' response to Walt Whitman's "I Hear America Singing" in which Hughes—while acknowledging the inequality that was a hallmark of the lives of the "darker brother" such as himself as a current, persistent, and undesirable reality—asserts his rightful identity as an essential part of the fabric of America. (Giwa Onaiwu, 2020b, p. 58, 66; Funari, 2013, para 6-8)

"'I, Too,' Sing Neurodiversity" highlights the crucial need for anti-racism in the neurodiversity movement via analysis of specific microaggressions directed toward neurodivergent individuals of color. In it, I also encourage White allies to commit to taking concrete action toward dismantling the racism within neurodiversity. (Giwa Onaiwu, 2020b, p. 58-67) It has been identified as one of the top ten most downloaded articles in the peer-reviewed biannual publication in which it appears (ScholarWorks GVSU, 2022, list) and has helped initiate dialogue about meaningful inclusion within neurodiversity circles as well as contemporary literature. (Burton, Carss, & Twumasi, 2022, p. 56)

The article, however, has impacted the nature of the environment in which I work in less favorable ways similar to that of burning fossil fuels. White colleagues have distanced themselves from me professionally and personally since it was published. Noticeably, I have not been re-invited to speak at the summit referenced in the article. Hence, Collins' (1990, p. vii) keen observation that less privileged perspectives are often disregarded unless "we frame our ideas in the language that is familiar to and comfortable for a dominant group" certainly rings true for me. The hypocrisy of these consequences is jarring and demoralizing...the very same individuals who are denouncing ableism not only refuse to acknowledge, much less address, racism in their ranks; they castigate those of us who dare speak of it. Renowned scholar W.E.B Du Bois also warns of this phenomenon, explicitly noting the ironic nature of intersectionality as he muses over the plight of the Black man (person) in America:

> This world...yields him no true self-consciousness, but only lets him see himself through the revelation of the other world. It is a peculiar sensation, this double consciousness, this sense of always looking at one's self through the eyes of others, of measuring one's soul by the tape of a world that looks on in amused contempt and pity. (Du Bois, 1903, p. 194)

I find it particularly hurtful that it is not just non-autistic White allies who have condemned my attempts to mitigate these racial disparities; White autistic individuals, including some with measurable influence, have done so as well. Seemingly, it is preferable to misrepresent my cry for change as divisive and accusatory rather than recognizing my explicit attempts at "autistic joint troubleshooting." Autistic strategist Terra Vance (2021b, section 4) highlights the purpose of joint troubleshooting:

> When autistics confront a violation of values, they expect and anticipate—at least before a lifetime of failed attempts—that others in their shared social intersection will be grateful to them for helping someone to honor their values. Doing that is something an autistic person sees as validating a person's identity.

> For those who think deeply, it (joint troubleshooting) is a social way to process what's on your mind with the input of another person (or people) who may be able to lend their own perspective to the discussion. (Vance, 2021a, section 3)

Given this dynamic, the ostracization from other autistic people—who experience marginalization in the form of ableism on a constant basis throughout their lives—due to being outspoken about race in our community is hard for me to reconcile. Therefore, as I noted in the article, I often feel as though:

> Like in nearly everything else, White is the "default" and everything else is merely Other. White is the foundation upon which neurodiversity rests; White is the standard (that) neurodivergent individuals are measured against; White is the de facto status quo… …Anything that does not perpetually center this toxic Whiteness is perceived as a threat.
>
> (Giwa Onaiwu, 2020b, p. 62-63)

This aligns with an observation that, despite our shared neurology, perhaps the schism exists because White autistics share a similar trait with the White feminists Audre Lorde often referenced in her writings: that they choose to "ignore their built-in privilege of whiteness." In "Age, Race, Class and Sex," Lorde emphasizes the problematic nature of this practice with a chilling comparison:

> Some problems we share...some we do not. You fear your children will grow up to join the patriarchy and testify against you. We fear our children will be dragged from a car and shot down in the street, and you will turn your backs upon the reasons they are dying. (Lorde 1984, p. 119)

Scholarship Addressing Intersectional Dynamics of Race, Disability, and Gender

I offer remedies to this failure of empathy/difference in world view in another important sole-authored publication on the intersection of race and disability. The guest editorial I wrote for *Autism in Adulthood*, an international peer-reviewed journal, "They Don't Know, Don't Show, or Don't Care: Autism's White Privilege Problem" was partly inspired by Black American producer John Singleton's directorial debut, *Boyz N the Hood*. Speaking as a peer as well as a person with lived experience of autism, I urge the reader to "know, to show, and to care" about the pervasive racial disparities in autism research and practice. (Giwa Onaiwu, 2020a, p. 271-272) Outlining concerns about these disparities, I share existing promising practices and practical solutions that investigators and clinicians can consider implementing for measurable changes in their own labs and/or practices.

The editorial has been increasingly cited in recent literature and is consistently ranked as one of *Autism in Adulthood's* most frequently read articles. (Mary Ann Liebert, Inc., 2021, list) Interestingly, though both writings share an intersectional focus, "They Don't Know, Don't Show, or Don't Care: Autism's White Privilege Problem" has been received much more favorably than "'I, Too,' Sing Neurodiversity." I suspect this is because I adopt a different overall tone in the editorial. Though still genuine, in this piece I deploy what Black British scholar Nadena Doharty calls:

> Strategic emotionality…a theoretical concept to explain the conscious decisions Black women (including myself) might make researching under conditions of White supremacy and writing for colour-blind audiences to challenge the monopoly whiteness has on Black women's emotionality of only angry or strong. (Doharty, 2019, p. 4-6, 12-16)

Black disabled scholars Moya Bailey and Izetta Mobley's (2019) poignant, profoundly insightful article "Work in the Intersections: A Black Feminist Disability Framework" examines the paradox faced, historically and contemporarily, by Black women that gives rise to the circumstances which create what Doharty is describing. Bailey and Mobley highlight the ongoing existence of this tension via examples as far back as Harriet Jacobs' confinement-induced impairment in *Incidents in the Life of a Slave Girl* and Harriet Tubman's epileptic seizures. (Bailey & Mobley, 2019, p. 19-40)

Morrison acknowledges a similarly complicated dynamic in her affirmation that "The authenticity of my presence lies in the fact that a very large part of my own literary heritage is the autobiography." (Morrison, 1995, p. 85) She also dissects the quandary faced by former slaves and other Black writers of that era who had to speak in a verifiable way for the self while also demonstrating how their individual experiences were shared by the community:

> Historically, we were seldom invited to participate in the discourse even when we were its topic. In shaping the experience to make it palatable to those who were in a position to alleviate it, these writers were silent about many things, and they 'forgot' many other things. There was a careful selection of the instances that they would record and a careful rendering of those that they chose to describe. (Morrison, 1995, p. 86, 90-91)

Thus, it is fascinating to note that though it was not intentional, my tone in "They Don't Know, Don't Show, or Don't Care: Autism's White Privilege Problem" bears an uncanny similarity to the narratives of Black authors who precede me by many generations in that I have been forced to straddle a dizzying balance in own my work similar to that which Morrison describes.

In order to generate necessary empathy, 21st century activists must often place ourselves, however uncomfortable it might be, under the "spotlight." Somehow, however, we must simultaneously be able to show critical distance to be taken seriously in the academy. I struggle at times with the need to incorporate autobiographical elements into my work for authenticity juxtaposed with having to make the harsh daily realities of the more marginalized palatable for the more privileged. Namely, I worry whether it creates an uneven and/or somewhat detached quality to some of my work—perhaps even in the editorial noted above.

Despite my fears, likely any sense of detachment that might exist is inconsequential; given that I paid the costly Open Access publishing fees for the editorial with funds from my own household budget, I am far from detached. Lacking financial research support from any formal institution at the time, ethically I felt that I had little choice but to absorb the Open Access costs myself despite my meager funds in order to make the editorial publicly available (as opposed to trapped behind a "paywall" and therefore less accessible).

Had I not selected this option, only individuals with institutional access to academic journal subscriptions or the financial means to acquire such would be able to freely read it— simply unacceptable to me. This is one of numerous examples of how, like Collins and other public intellectuals (Black women in particular), my reality is one of being "fully immersed" in the concrete experiences, "ordinary activities," and "everyday actions and ideas" that appear in my scholarly work. (Collins, 1990, p. viii-ix) Logistically (or otherwise), I cannot truly be detached nor alienated from it.

Incorporating the Interpersonal

This phenomenon is affirmed in the writings of Black sociologist and legal scholar Patricia J. Williams, author of *The Alchemy of Rights and Race*, whose work examines intersectional issues without adopting an impersonal, removed perspective. Though praised for her unconventional vulnerability, Williams admits the interconnectedness is both burden and blessing:

> There are moments in my life when I feel as though a part of me is missing. There are days when I feel so invisible that I can't remember what day of the week it is, when I feel so manipulated that I can't remember my own name, when I feel so lost and angry that I can't speak a civil word to the people who love me best. There are times I catch sight of my reflection in store windows, surprised to see a whole person looking back. (Williams, 1992, p. 5-24)

The article "Don't Be Like Me: A Letter to My Daughters" further illustrates the complexity of a life spent contending with these (and other) intersections. Written with poetic prose and in an epistolary style, I use myself as a cautionary tale, indirectly referencing challenges that I have personally experienced. Throughout the short, emotionally charged piece, I admonish my daughters, who share my race, gender, and neurodivergence, to eschew the many pitfalls I have encountered. In doing so, I address complexities including recurring mental health struggles, being discriminated against, having reduced autonomy, and the increased likelihood of experiencing abuse that may occur due to overlapping marginalizations of race, disability, and gender. (Giwa Onaiwu, 2022, p. 50-52) Featured in a family-focused edition of the peer-reviewed journal *Ought*, the sole-authored publication is probably the most overtly autistic of my academic work in terms of form. "Don't Be Like Me: A Letter to My Daughters" employs various autie-ethnographic elements, such as perseverative thought, repetition, and rhyme, to emphasize the significance of living at the intersections and the reality of my experiences, several of which have been as persistent as they have been painful:

> Being me means you will be discarded. Being me means you will be disrespected. Being me means you will be disregarded. Being me is to never be certain of yourself. To never be at ease in known or unfamiliar surroundings. To always struggle to understand things. To trust when you shouldn't, and not to fear when you should. It is complicated, it is draining, it is being too much of some things, yet not nearly enough of others…I don't want your joy depleted and your self-worth deleted…I want you to be free. And that is why you must never | Never, never, never | Never end up like me. (Giwa Onaiwu, 2022, p. 50-51).

For those unfamiliar with autistic forms of expression, autie-ethnography might seem strange. In *Autistic Disturbances'* account of the way autistic discourse is represented in literature, literary and disability studies, scholar Julia Miele Rodas describes how autistic language is "pathologized" and "devalued." (2018, p. 74, 106, 133) Autistic and non-autistic scholars (i.e., Anne McGuire, Robert Rourke, Paul Heilker, and Diana Paulin) concur, adding that much of the criticism that is lobbed against autistic communication is unsubstantiated by data and often has ableist and/or racist implications. (Heilker & King, 2014; Rourke, 2016, Paulin, 2017) Further, autie-ethnographic communication contains key features of literary language that are perceived favorably when non-autistics employ them. (Rodas, 2018) The criticism seems especially charged considering the word autism itself is derived from Greek words meaning "the action or state of 'morbid self-absorption.'" (Rourke, 2016, para 5)

Autistic scholar Damian Milton, developer of the Double Empathy Theory of bi-directional communication challenges, distinguishes autie-ethnography from non-autistic auto-ethnography by noting autie-ethnography tends to be more “fragmented” than the latter, consisting of “snippets of information...formed into ‘rhizomatic’ patterns of shifting meanings.” (Milton, 2018, p. 11, 13) Autistic rhetorician Yergeau also points out autie-ethnography’s “long tradition of employing personal narrative as a means of identifying and collectivizing autistic cultural practices.” (Yergeau, 2015, para 1) In terms of public intellectualism, autie-ethnography enhances autistic representation by centering autistic perspectives via a mechanism that is itself authentically autistic.

Joint-Authored Publications

Because intersectionality is such a core theme in my peer-reviewed scholarly work in my sole-authored pieces, joint authorship, in which myriad perspectives are represented, is fundamental to my scholarly identity. In some pieces, intersectionality is the predominant focus. In “Promoting Well-Being in Autistic Youth and Adults: A Positive Focus on Sexuality and Gender Diversity,” a recent co-authored International Society for Autism Research multinational study, we captured various perspectives of experts (investigators, educators, self-advocates, clinicians, students, parents, other professionals, and allies) from six continents. (de Winter, Giwa Onaiwu, et al, 2022, lay summary) Our team paid close attention to the diversity in experiences, cultural, political, and economic contexts to enfold them into our final recommendations.

Similarly, in the co-authored article “An Expert Discussion on Autism in the COVID-19 Pandemic,” I deliberately incorporate race and disability into the facilitated discourse about issues impacting our community. (Cassidy et al, 2020, p. 106-117) “Racial/Ethnic Differences in Psychiatric and Medical Diagnoses Among Autistic Adults,” another co-authored publication, examines health vulnerabilities, diagnostic disparities, and measurable differences in healthcare quality, rates of utilization, and outcomes (including morbidity and mortality) according to race and disability status in autistic and non-autistic adults in a large integrated health system over an extended period of time. (Ames, Morgan, Giwa Onaiwu, 2022) Race, disability, and other factors are similarly interwoven into the co-authored “Ethics of HIV Cure Research: An Unfinished Agenda” (Dube et al, 2021) and “Centering the Inner Experience of Autism: Development of the Self-Assessment of Autistic Traits.” (Ratto et al, 2022) Both of these peer-reviewed articles highlight the value of incorporating intersectionality into community-engaged research practices.

This intersectional lens is also present in my additional scholarly endeavors, which include further research; delivering keynote addresses and guest lectures throughout the US; serving several terms as an institutional review member for one of the state's largest divisions of public health; reviewing abstracts for a municipal HIV planning body and for HIV national conferences as well as FASD symposia; and volunteer efforts as an anonymous peer reviewer for several journals, including Journal of Racial and Ethnic Health Disparities, Feminist Review, and Journal of Leadership Studies. Moreover, it is evident in specific activist scholarship endeavors that tend to be lean more heavily on the "activism" side, such as my individual and collaborative work in the Justice for Kayleb campaign.

According to an investigation conducted by the Center for Public Integrity (2015), a disproportionate percentage of disabled and BIPoC youth "graduate" from the special education system to prison in what is known as the "school to prison pipeline" due to schools referring behavioral incidents that happened on campus to law enforcement. Though sadly, such a pipeline exists in several countries, within the US it is particularly egregious. The state of Virginia is America's worst offender, referring students to law enforcement at three times the (already astonishingly high) national rate. The problem with Virginia was highlighted when Kayleb Moon-Robinson, a Black autistic 11-year-old, kicked a trash can out of frustration the first week of school, a school police officer then physically restrained and arrested the sixth grader, charging him with "felony assault." (Center for Public Integrity, 2015)

Learning of Kayleb's plight online, I was outraged. Though he was a stranger living across the country, I launched a global campaign and a petition to exonerate Kayleb in partnership with autistic colleague Lei Wiley-Mydske. I also maximized my position as a scholar to address the problem. Utilizing Kayleb's debacle as a teaching tool, I facilitated guest lectures and other acts of public pedagogy at Hofstra University, University of South Florida, Brooklyn Public Library, Springfield Public Library, McGovern Medical School at the University of Texas, and the Rainard School to call attention to this issue as well as equip schools, universities, etc. with information to help mitigate these disparities.

Our petition went viral, garnering international attention and 150,000+ signatures. Days before the sentencing, I traveled to Virginia to deliver the petition to the prosecutor's office with Kayleb and his mother, accompanied by the media—and ALL charges were dropped! I was honored to be selected as that year's recipient of the Autistic Self Advocacy Network's annual "Service to the Self-Advocacy Community" Award for my Kayleb-related activist scholarship. (Change.org, 2015-2016; Autistic Self Advocacy Network, 2015)

Disabled people of color face risks within the legal system that are beyond the school to prison pipeline. Thus, I have also engaged in other forms of activist scholarship related to the intersection of race and disability. Of note, I served on the small national steering committee that coordinated the historic Million Moms March against police brutality in Washington, DC; a disproportionate percent of individuals who are racially profiled by authorities are disabled as well as Black or Brown.

The Million Moms March was led by several "Mothers of the [Black Lives Matter] Movement" and captured international media attention. With thousands of supporters from around the country, we swarmed the nation's capital on Mother's Day to declare that:

> We march in solidarity with mothers who have lost their children to police and vigilante violence. We demand justice and demand answers. We march against the culture of silence that allows these types of atrocities to occur. We are marching for our lives, our children's lives, and for a better tomorrow. (Giwa Onaiwu, 2015, para 8)

Prior to being invited to join the national march planning team, I was keenly aware of the heightened risk of police brutality among disabled BIPoC. This is due in part to the pre-existing "legacy of disability justice" within Black liberation work. (Schalk, 2022, p. 6) However, as I'd previously participated in as well as helped to coordinate smaller local rallies, Black Lives Matter demonstrations, and related events, it was also knowledge I obtained "with the privilege of my position as an academic and with the risks of my positions as an activist." (Schalk, 2022, p. 8, 22)

Using my dual identities as a scholar who is also an activist, I co-developed an anti-racism curriculum and supplementary resources to be used by allies, educators, parents, etc. The material included lesson plans, discussion questions, recommended reading and activities, etc. Though I initially became involved as a volunteer content expert experienced with academic and program design, it soon became much more. Things were shifting externally as discontent grew within the community over one killing after another at the hands of police.

Things were shifting internally, within my own life, as well:

> There were more unarmed individuals whose lives were cut short with no criminal charges or indictments afterward…more meetings, vigils, protests, die-ins…
>
> We held hands…people recited poetry, shared sobering statistics, read lists of victims' names, sang songs…

> The stack of protest signs in my trunk grew larger and larger – until one day my three-year-old son told me that he was tired of going; that he was tired of "marching because someone died."
>
> My heart was ablaze with emotions I couldn't describe…
>
> They say wisdom comes out of the mouths of babes. My son is tired of marching because someone died, and I agree with him. I am tired of marching because someone died too.
>
> I'm tired of the injustice, of the callous disregard for life, of fearing for my children as they get older and begin to resemble black men more than black boys. I'm tired of questionable court findings and victim slandering.
>
> I'm tired of video and photo footage of grief and anguish.
>
> I'm tired. (Giwa Onaiwu, 2015, para 2-6)

As a freelance, unconventional, non-tenured, disabled Black scholar-activist, my role is somewhat unusual. Though less constrained than my tenure-track peers in terms of what actions I can take, what causes I can champion openly, and which individuals and/or organizations I choose to collaborate with, I also lack the level of financial stability they possess and therefore fall short in most measures of "success" according to traditional scholarly standards.

Nonetheless, I am fully aware of the enormous privilege that I have compared to many of my colleagues *and* my mentors (heroes), particularly grassroots community members engaging in the very important and too-seldom applauded service of public intellectualism, mutual aid, direct and indirect activism, and other critical acts of public pedagogy that has paved the way for me and many others. Though they often feel tenuous and at times have seemed largely honorific, my institutional affiliations and related connections to academia lend me, however precariously, greater access to spaces and potentially a veneer of "legitimacy" also, whether I am deserving or not.

Therefore, it is my responsibility to be both a conduit *and* a liaison whenever possible to help make the type of progress that Black queer intellectual activist E. Grollman encourages, seeking to "raise consciousness about injustice…supports marginalized perspectives" with the goal of "making academia a more equitable and humane place" to create "more space to serve our communities and speak truth to people." (Grollman, 2015, para 3, 6, 8-14) Other influential contemporary Black scholar activists, including Brittney Cooper and Susana Morris (co-founders of the Crunk Feminist Collective, 2010-2021), express similar sentiments in their work as well by highlighting the contributions of individual BIPoC feminists as well as Black women's organizations – including longstanding membership groups including the Order of Eastern Star and legacy sororities from the "Divine Nine" to uplift their communities. However, others, including Black historian Keisha Blain, concentrate on distinct, broad-reaching mobilization and academic/social media crowdsourcing initiatives (such as the widely read #CharlestonSyllabus and Trump Syllabus 2.0 Blain co-edited), which "speak truth" by addressing racial injustice. (Blain, 2022, Public Writing)

The late Archbishop Desmond Tutu once stated: "Language is very powerful. Language does not just describe reality. Language creates the reality it describes." (Moyers, 1999) Due to my pedantic speech, hyperlexia, and giftedness, as an autistic child growing up, I was often referred to (sometimes affectionately; other times exasperatedly) by others as a "little professor" (a [potentially problematic] phrase that Hans Asperger, 1944) coined.

Perhaps, as Bishop Tutu notes, that nickname served as a type of foreshadowing for adulthood as I have spent many years of my life educating others in my work, occupying roles that have included years as a full-time college faculty member, former K-12 educator, federal disability appointee, and global network liaison partnering with world renowned universities and research consortiums centers. It is the activist scholarship analyzed in this section that provides the fuel undergirding all those roles and provides a solid platform for the creative collaborations developed over the years as well as my international advocacy and activism, which are among the most visible components of my work.

HEAT: CREATIVE COLLABORATION

Heat refers to thermal energy that has been transferred from one entity, body, or system to another and is a critical item necessary for the development of fire. (Zimmerman Jones, 2018, para 1) For fire to exist, temperature (which is a measure of thermal energy) in the surrounding environment must increase enough so that when added to fuel, there will be sufficient heat to react once in the presence of oxygen. Heat, however, should not be perceived as merely a passive byproduct. Though primarily influenced by calescent factors in the environment, it can also be generated.

In the context of this thesis, heat represents the trajectory of how critical, but often unseen and/or minimally regarded collaborative care work (such as the editorial work and various parenting, disability, and digital health projects within my selected body of work, many of which are related, to but distinct from one another) contribute measurably to a change in current conditions, thus resulting in an increase in temperature. Sometimes a seemingly slight change might be all that needs to happen for heat to develop.

Humans are accustomed to utilizing temperature as a gauge for the presence or absence of heat. However, for a variety of reasons, temperature is an unreliable source for determining how much heat is present. For one, although temperature itself can theoretically be considered an objective measure, generally it is described in a subjective manner—typically, in relation to perceived thermal comfort. (Cho et al, 2020, p. 258-268)

Another reason is that it can be misleading. The temperature of an item might be so low it may appear devoid of heat when it is not. (Callen, 1985, p. 8-9) Because it is generated by kinetic (movement) energy, there is some measure of thermal energy – heat – in all forms of matter as all matter contains subatomic particles that are in constant motion. Even if it’s small, whether we are cognizant of its presence or not, it’s there.

In a similar sense, building on the momentum (acquired by the activist scholarship that has served as a source of fuel for my work), I have successfully utilized various forms of creative collaboration as care work to figuratively generate heat. (That heat, in turn, helps to facilitate movement-building that will eventually oxidize into a critical mass: international advocacy and activism which, like oxygen, can absorb the surrounding negative energy, thus enabling our survival.)

Understanding Creative Collaboration as a Form of Care Work

The Care Collective Manifesto (2020) encapsulates what I strive to do in my creative collaborations:

> To put care centre stage…elaborating a feminist, queer, antiracist, and eco-socialist perspective as an organising principle as broadly as possible… Care is our individual and common ability to provide the political, social, material, and emotional conditions active across every distinct scale of life…for the vast majority of people and living creatures on this planet - along with the planet itself - to thrive. By multiplying our circles of care, we can achieve the psychic infrastructures necessary to build a caring society that has universal care as its ideal…an ethic and social capacity that proliferates outwards to redefine caring relations from the most intimate to the most distant: kinship groups, communities, states, and planet. (p. 5-8, 19-22)

I was unaware of the term “universal care” until recently, but it aligns almost seamlessly with what I do, why and how I do it, and who I do it with. The methods I employ all stem from the principles that I have internalized as well as operationalized in various forms and mirror the volitional mandate of universal care for us to prioritize our fellow human as much as we do ourselves and “our own.”

> The goal is…recognising and embracing our mutual interdependencies and the intrinsic value of all life…to ensure that the whole of society shares care's multiple joys and burdens. This does not mean that “everyone has to do everything.” But it does mean cultivating and prioritising the social, institutional, and political facilities that enable and enhance our capacities to care for each other and to restore and nurture rather than pillage the natural world…all manifestations of care in all spheres. (Care Collective, 2020, p. 26, 33-34, 40-41)

Led by an intrinsic conceptual framework of universal care, I collaborate in a multitude of ways with colleagues, peers, allies, and the community at large via a range of creative mechanisms. The work is collaborative in nature, creative in method, and serves in both a practical and a philosophical sense as care work in its application. It exists in several forms, including non-academic co-authorship, co-editing; developing community-centered principles and practices; and displaying through my work the importance of integrity and authentically prioritizing creativity and co-contributions. I seek to demonstrate, through the topics, tools, and teams I select, the inherent value of care via creative techniques that incorporate and promote collaboration.

Co-Authorship

I have engaged in myriad forms of creative collaborative care work. This work is primarily writing-related: editing, co-authorship, etc. Anthologizing in particular is a crucial component of my work. Per my commitment to the role of anthologies and related communal projects in amplifying individual and collective perspectives simultaneously, I have authored chapters in several non-fiction anthologies:

- The Foreword in *I Will Die on This Hill: Autistic Adults, Autism Parents, and the Children Who Deserve a Better World* from Jessica Kingsley Publishing
- “Am I Mom Enough? Contending with the Voices in My Head” in *For the Love of Autism: Stories of Love, Awareness and Acceptance on the Spectrum* from Fig Factor Media
- “I Don't Really Wanna Fight No More” in *From Hurt to Hope: Stories of Mental Health, Mental Illness, and Being Autistic* from Jessica Kingsley Publishing
- “The Lady on the Plane” in *Dazzling Colours of Calm* from Heady Mix
- "‘A Dream Deferred’ No Longer: Backstory of the First Autism and Race Anthology” in *Autistic Community and the Neurodiversity Movement: Stories from the Frontline* from Springer/Palgrave Macmillan
- “All of Me: How Do I Know Where Blackness Ends and Neurodivergence Begins?” in *Knowing Why: Adult-Diagnosed Autistic People on Life and Autism* from Autistic Press
- “Why I Don't Like All of Those ‘Get Off of Social Media and into the Real World’ Posts” in *The Real Experts: Readings for Parents of Autistic Children* from Autonomous Press

In addition to contributing these chapters, I have served in a leading role in several edited collections. I am the sole editor of the forthcoming book *Neurodiversity en Noir* from Jessica Kingsley Publishing highlighting the lived experiences of Black neurodivergent individuals and their families. I am a co-author of an upcoming non-fiction cross-disability monograph, *At the Intersection of Parenting, Race, and Disability throughout the Diaspora: Black Motherhood and the Journey Beyond Diagnosis*. I am a co-editor of *All the Weight of Our Dreams: On Living Racialized Autism* and *Sincerely, Your Autistic Child: What People on the Autism Spectrum Wish Their Parents Knew About Growing Up, Acceptance, and Identity* from Beacon Press (which earned a starred review from the Library Journal!). My work also appears in *Respectfully Connected: Journeys in Autism, Parenting, and Neurodiversity*.

Autie-Ethnography

I enjoy how artfully autie-ethnography, a methodology that I frequently deploy in my writing, can be enfolded into collaborative writing work. In terms of heat formation, autie-ethnography can be likened to convection due to its natural, expansive, and spontaneous flow that hovers above traditional communication. Unique and eclectic, it can be formal and/or informal; technical and/or artistic; evocative and/or obscure. Despite its importance, it is often misperceived by outsiders, an unpleasant reality I have unfortunately encountered personally. Autistic scholar Robert Rourke (2016) explains that the "poetry, disjointed narrative, and other forms of expressive writing" common in autie-ethnography are seldom respected. Ironically, as Rodas points out, those same literary elements, when written by non-autistic people, are praised. (Rodas, 2018, Preface) Unfortunately, autie-ethnography is not considered legitimate even though it truly is a functional, intrinsic form of autistic communication. (Rourke, 2016, para 5-6; Rodas, 2018)

The legacy of the late disability activist Mel Baggs, a primarily nonspeaking queer white autistic writer who was a pioneer in the neurodiversity movement, is laden with autie-ethnography. Notable examples include Baggs' internationally acclaimed video *In My Language* (2007) and Baggs' blog Ballastexistenz, "a historical term that means 'ballast existence' or 'ballast life', that was applied to disabled people in order to make us seem like useless eaters, lives unworthy of life." (Baggs, 2012, para 2) Similarly, in the highly acclaimed book *Authoring Autism: On Rhetoric and Neurological Queerness*, Yergeau, an influential autistic scholar, utilizes nonlinear, emotive writing to illustrate the "idiosyncratic, self-focused, ephemeral" nature of autie-ethnographic narratives. (Yergeau, 2018)

Writing poignantly yet explicitly about the inaccurate and stereotypical manner autistic people are perceived by society (especially by non-autistic professional autism "experts"), Yergeau highlights the contradictory dilemma posed by the concept of autie-ethnography: theoretically, how can such a thing exist? After all, due to autistic people's "impaired Theory of Mind" and "lack of empathy," we apparently lack the emotional capacity or understanding for such complex rhetorical expression as autie-ethnography. (Yergeau, 2018, p. 7-9)

Sarcasm aside, there is a significant ethical concern (both present and historical) in relation to autie-ethnographic narratives collectively. Despite its merit as a tool to give voice to those who are often unfairly silenced, autie-ethnography has, to date, largely failed to meaningfully include the accounts of many BIPoC autistics. We are erased; at best, the particularities of our experiences are crudely subsumed into a singular (white) "autistic perspective." At worst, we are simply rendered invisible.

This (sad) reality is a primary motivator for my own autie-ethnographic work. My utilization of autie-ethnography allows me to act as a herald of sorts for those like me in the community as I am able, through my words, to generate much-needed attention to this erasure. It also, however, offers me an opportunity to do my part (however small or large that might be) to help mitigate said issue by holding space for those like me in the community.

Though a sizeable percent of autie-ethnography certainly disregards and/or otherwise omits BIPoC autistics, there are a few notable exceptions. One example is Ly (also known as Lydia) Brown. Brown, a prominent Asian American queer autistic attorney, is generally acknowledged by the autistic community for their intersectional labor, which includes actively campaigning against the controversial graduated electric shock "treatment" at the notorious Judge Rotenberg Center in Massachusetts for over a decade as well as their varied disability justice work. (Brown, 2011-2021, Repository)

Another exception can be found in the Autistic Archive, activist Ira Eidle's extensive grassroots neurodiversity archival efforts. (Eidle, 2021-2022) In addition to covering the "usual suspects" associated with the movement, Eidle openly recognizes less "mainstream" but equally significant autistic elders who have profoundly impacted the community: Cal Montgomery, Anita Cameron, Kassiane Asasumasu, Oswin Latimer. (Eidle, 2021, Chapters 2-4) Respected BIPoC disability leaders Mrs. Kerima Cevik (2010-2022), Riah Person, Diane J. Wright (2018-2021), Anna Perng, Ly Brown, Alice Wong, and Jules Edwards have paid homage to underrepresented BIPoC autistics as well.

Other than the above examples, however, BIPoC autistics have been overwhelmingly missing in the discourse surrounding autie-ethnography. Currently (~three decades later), we still are. As such, in my creative collaborative care work, I deliberately use autie-ethnographic writing—principally within anthologies/edited collections—to articulate and amplify the BIPoC autistic perspective.

The most visible example of this is my work as a co-editor of a grassroots, self- and crowdfunded literary project. When *All the Weight of Our Dreams: On Living Racialized Autism* was published in 2017, it was groundbreaking. There was nothing remotely similar in existence. Intended to be the first-ever anthology entirely by autistic people of color, the widely read book featured numerous autie-ethnographic works, including "poetry, essays, short fiction, photography, paintings, and drawings of 61 contributors" from various countries who are predominantly "Black, Brown, Latinx, Indigenous, Multiracial, and other racialized people of color" addressing issues of "marginality, intersectionality, and liberation." (Brown et al, 2017)

All the Weight of Our Dreams is in circulation at over 100 public libraries in several countries. (WorldCat, 2022, Listings 1-2) Moreover, it has been utilized extensively as a teaching tool; from 2017-2021, more than twenty undergraduate and graduate university course syllabi listed it as required reading. It is also referenced in various training curricula, in literature, book clubs, etc. Unfortunately, there were some disturbing discoveries related to our anthology and some of its contributors in 2021. It became apparent that a small number of contributors were not autistic people of color, and that there were some elements of the book that caused harm. After conferring with one another, AWN's board and executive director, and other trusted advisors, our editorial team made the painful but ethical decision to discontinue publication of *All the Weight of Our Dreams*.

Integrity

How this situation was handled exemplifies another aspect of my creative collaborative care work, one that, in terms of heat, is best categorized as a form of convection. We chose to be accountable to our community. Publicly, we accepted responsibility, apologized, and outlined plans to try to rectify the hurt we'd caused. In addition to ceasing printing of the book in its current form, we committed to supporting a republication of the book with new contributors. This included identifying an entirely new editorial team, implementing a robust community and cultural sensitivity peer review process, and a financial donation to select BIPoC organizations (namely programs supporting Indigenous communities and Jewish people of color) as reparations. (Autism and Race, 2021, para 1)

I have been told throughout my life that I have an extraordinary vocabulary, but even now, over a year since the aftermath, I lack the capacity to adequately convey in words the depth of the devastation this incident created within me. In addition to trying to navigate complicated feelings of disappointment, loss, and betrayal, I had to work arduously not to be overcome by anger. Some days my efforts failed…such as the morning I wrote a scathing social media post, part of which declared the following:

> Really, white autistic folx? Really?!?! Y'all already have everything; everything. You couldn't allow autistic PoC to have ONE thing for ourselves? Just one thing? You just *had* to have this too? How dare you utter a word about 'internalized ableism' and autistic masking when you have no qualms with blackfishing people who naively trusted you. Y'all disgust me. You've destroyed what little was left of my faith in humans; hope it was worth it.

Fortunately, I was able to gain my composure and selected “Save as draft,” instead of posting the angry accusation publicly. Though I believe my frustration is justified, handling it in that way wouldn’t have solved anything, and would have only created more hurt and further polarized the autistic community. Instead, I have chosen to allow that anger to serve as a source of heat for me, almost like solar energy, because in the end, what I want is change. Rather than hiding in shame, cowering in fear, or imploding with rage over these—and other—circumstances that I cannot control, I have instead chosen to transfer that energy into my work itself. My thoughts mirror those of author Chimamanda Ngozi Adichie:

> I am angry. We should all be angry. Anger has a long history of bringing about positive change. But I am also hopeful, because I believe deeply in the ability of human beings to remake themselves for the better.” (Adichie, 2013, TEDx Euston)

Community-Centered Principles

My creative collaborative care work helps to enact change in existing conditions, therefore generating heat. In the years since we developed *All the Weight of Our Dreams,* I have chosen to “lean in” to what I learned throughout that process. Those lessons have proven themselves to be invaluable for me:

> Our process was going to look and feel different in several ways and was going to be both non-linear and nontraditional. Because of this, we weren’t going to have a formal framework, “blueprint”, or set of instructions that we would be able to rely on. Where there was no precedent, we had to be ready to trust one another and forge our own way—and we did. (Giwa Onaiwu, 2020, p. 246)

The principles that were developed during that period are the same ones that guide much of my creative collaborative care work: 1) Nothing About Us Without Us, 2) Everybody Gets Paid, 3) You Define You, 4) It’s Not a Term Paper, 5) Real Transparency, and 6) We’ve Only Just Begun. These names were never formally chosen; this is just what comes to mind when I think about the philosophy as well as the actions that steer me. The intentional incorporation of these principles into my creative collaborative care work can be compared to generating heat via conduction in that it is movement or transfer through direct contact or directly through a connected channel or passage. Direct application of these concepts allows for meaningful involvement, facilitates connection, honors differences, and strengthens the community. Together, we are able to create something much more beautiful than what any of us could create alone!

These principles keep me (figuratively) grounded and help preserve the integrity of my creative collaboration care work. It is essential that I maintain my perspective because while in theory, the concept of the anthology—whose very name is derived from a Greek phrase meaning "a gathering or collection of flowers"—is praised for the diversity of thought it presents (MasterClass, 2022, para 1-3; Brown, 2016, para 4), in reality editing, anthologization, and related tasks aren't universally regarded with the respect they deserve. Sarah Blackwood, a professor and editor, notes that though editing and related care work "nurtures talent and creates common spaces in which individuals can thrive" when done well, due to its gendered and "relatively undertheorized" nature, it "erases itself." Given this dynamic, Blackwood ponders the merits of creating a standard of ethics to protect the "often invisible" scholar who engages in editorial labor from exploitation. (Blackwood, 2014, para 1, 5, 7-9)

Blackwood's thoughts about gender bias in care work, which are similar to the Care Collective's, certainly have merit. However, I suspect there is an ableist component to the invisibilizing Blackwood alludes to as well. Prominent recommendations for editing anthologies emphasize "consistency" and "added value" and other radical changes that, to me, strip away the core characteristics that make them unique. (Davis & Blossey, 2011, p. 247-248) I vehemently reject incorporating this approach to my creative collaborative care work, as I desire for it to be exactly that: creative, collaborative, and caring.

Community-Centered Practices

I opt for a different method. It doesn't even have a name, but it is a hallmark of my creative collaboration work, and in a sense, it is antithetical to the editing advice offered by traditional "experts." It's a bit difficult to define. It is a combination of intuition, flexibility, defiance, inclusion, and in terms of heat can be most accurately attributed to the final form of heat generation/transfer, which is radiation. Radiation generates heat via multiple rapid waves, rays, or particles that are emitted from a source radiating outward in all directions. It varies widely in form, intensity, and stability.

Generating heat figuratively via radioactive means is simply my refusal to confine myself or my collaborators to restrictive standards—standards that are often arbitrary, classist, and/or ableist. Editors are explicitly admonished to strive for uniformity in "substance as well as style, context, and content." Further, they are urged to adopt a singular system for format, tone, referencing, length, etc. across different chapters and contributors to be considered "a worthwhile purchase" rather than perceived as a "redundant" collection of "more stuff to read" or a "mis-mash" with "little significant value." (Davis & Blossey, 2011, p. 247-250; McGill-Queen University Press, 2022, p. 168)

I am not unwilling to compromise, within reason, on select non-essential matters, as I do realize that there are valid reasons certain rules exist. For example, I am fine with adhering to certain customs in my creative collaborative work, including concepts such as identifying and integrating themes in order to synthesize the whole. After all, as Patricia Hill Collins states, “It is possible to be both centered in one’s own experiences and engaged in coalitions with others.” (Collins, 2000, p. ix-x, 228)

However, as I believe that this can and should be done while preserving the unique (and at time, if warranted, even the disparate) elements within the work, I employ an unconventional approach to editing. In this regard, there is some overlap with the six guiding principles, but it’s broader because it applies to more than spelling, grammar, and other mechanical conventions of writing. It’s about typography, and spacing, and intended meaning; terminology, tone, and even topic.

One example of this can be found in *Respectfully Connected: Journeys in Autism, Parenting, and Neurodiversity."* There is a chapter in this anthology entitled, “Attachment Parenting While Black and Autistic” in which I share an exchange between myself and a security guard regarding my children. In the chapter, there is a part toward the end where the security guard “code-switches” in mid-conversation. Though she was originally conversing with me using “Standard American English,” she soon changes her speech pattern to “African American Vernacular English” in what appeared to be an act of displaying camaraderie. For accuracy and visibility, I capture her unique timbre, spelling, etc.

I could have easily written it in the “standard” way, but community-centered practices require me to be “true” and “real” in my creative collaborations regardless of what society thinks. I value authenticity above conformity. Plus, having one universal “standard” that is imposed upon everyone defeats the overall purpose of creative collaboration in my opinion. Why even incorporate others at all if you’re going to shroud their voices?

I believe that cultivators of creative collaboration must ensure that collectively and individually, our stories are “told and preserved in narrative form and not ‘torn apart in analysis.’” (Collins, 2000, p. 258) To me, paying homage to diverse perspectives and/or presentations “in name only” is dishonest if one truly believes that **“**Theory and intellectual creativity are not the province of a select few but instead emanate from a range of people.” (Collins, 1990, p. viii) As such, I include collaborators from different backgrounds, disciplines, and perspectives, drawing upon Collins’ insight on collective work:

> I came to see my work as being part of a larger process, as one voice in a dialogue among people who have been silenced. My hope is that others who were formerly and are currently silenced will find their voices. I, for one, certainly want to hear what they have to say. (Collins, 1990, p. ix)

This is not limited to just my editing. As Collins emphasizes that "the struggle for justice is larger than any one group, individual, or social movement," I seek to lead by example. (Collins, 2000, p. xiii) I try to embody this philosophy in the way I conduct myself within my collaborations as well. It has become evident that when a person of a certain "status" is appointed to executive, advanced, and/or senior roles such as several of those that I occupy, they attempt to give you preferential treatment that is not afforded to one's colleagues who are perceived as more junior level and/or less "accomplished." However, for me, it's important to feel that I am "carrying my weight" due to the caliber of my work, not just because of my reputation. I thus choose to be actively involved as much as possible as opposed to moonlighting as some sort of elite VIP. This also aligns with being "true" and "real" in my work.

Most of the time, I still develop and offer a unique contribution for consideration/possible inclusion to the final product anyway. This is my choice despite not being obligated to do so as I do not understand what is gained by me being "exempted" from partaking in the activities of my peers simply because of presumably having reached a particular "higher" level or status. I don't perceive laboring alongside my peers as something that's supposed to be "beneath" me merely because of my achievements; I am part of this community too! After all, as W.E.B. DuBois stated frankly, "Need I add that I who speak here am bone of the bone and flesh of the flesh of them that live within the Veil?" (DuBois, 1903)

Prioritizing Creativity and Collaboration

A final core element of my creative collaborative work is the purpose of the work itself, and two individuals whose work has inspired me in this area are Wole Soyinka and E. Grollman. Considered "one of Africa's most creative artists," Wole Soyinka, an internationally recognized Nigerian playwright and activist and first African Nobel Prize in Literature winner, has published a significant number of literary works, including drama, poetry, novels, short stories, memoirs, and essays. (Lindfors, 1994, p. 25-26) Using satire, theatre, poetry, fiction, etc., the 88-year-old has used his platform for decades to speak out sharply against human rights abuses—even using his Nobel Prize acceptance speech to condemn apartheid. Soyinka, who has endured arrests, detention, exile, and attempts to take his life (Munshi, 2021; Ogunyemi, 2021), endorses living one's life with meaning:

> You cannot live a normal existence if you haven't taken care of a problem that affects your life and affects the lives of others, values that you hold which in fact define your very existence… I don't know any other way to live but to wake up every day armed with my convictions, not yielding them to the threat of danger and to the power and force of people who might despise me." (Akinyoade, 2020)

Black, queer, non-binary social justice advocate, researcher, and educator E. Grollman is significantly younger than Soyinka, but the self-described "activist gone academic" has utilized their platform, usually via collaborative public digital humanities, as a mechanism for "necessarily challenging injustice." While Soyinka's creative collaborations address broad community concerns, Grollman has intentionally focused on higher education—specifically, connecting and supporting marginalized scholars in an effort to help make academia more equitable and humane. Similar to a sentiment that Collins has expressed, Grollman chooses to engage in work that is caring and collaborative rather than being "objective, detached, and apolitical." (Grollman, 2015, para 15-16; 2016, para 8-12, 14, 16-17)

I love to choose words based upon not just what they mean, but also how they sound when I say them aloud and how vivid an image they might conjure up in my head when I think of them. I find them to be quite "stimmy" (self-stimulatory) for me. They form a "shifting mosaic" whose "disjunctures" both connect different parts and help "distinguish them from one another." (Collins, 1990, p. ix) There is often an element of artful repetition. It might seem intentional, but it isn't always; sometimes it is subconscious.

"No-poo," for example, comes from "All of Me," my chapter in *Knowing Why*. It's a Black natural hair care reference/play on the phrase, "Rinse, lather, repeat." In recent years, it has become known that several of the ingredients in many hair care products are damaging for individuals—like myself —whose hair texture naturally grows in a tight, coarse curl pattern. The texture is like that of an afro (even if not worn/styled in that way) and is often referred to as 4B and/or 4C hair. As one especially problematic ingredient can be found in shampoos, people with this hair have discovered that if we solely use conditioner to wash our hair, it still gets clean, but it is much softer and healthier. Skipping shampoo results in less dryness and breakage, allowing for more optimal growth; we call it "no poo." Substituting with "Rinse, no poo, repeat," allow me to still convey the meaning of a common, applicable cliché without erasing myself as a Black person who no longer "lathers," but *does* no-poo!

Music is a very powerful tool for expression too. Thus, I often incorporate song lyrics into my creative collaboration work, akin to how DuBois (1903) mentioned that in his writing “Before each chapter, as now printed, stands a bar of some echo of haunting melody from the only American music which welled up from black souls in the dark past.” Sometimes I’ll use a portion of a song or a poem as the title of a chapter or an article, i.e., in “I Don’t Really Wanna Fight No More,” which is derived from an old Tina Turner song (from the soundtrack of her autobiographical film *What’s Love Got To Do With It?*) and in “‘I Too,’ Sing Neurodiversity,” which is inspired by a W.E.B. Du Bois poem. The chapter title “Time After Time” (featured in in the global collaborative *Respectfully Connected* writing project as well as in *A Neurodiversity and Gentle Parenting Journey…in Color*) is also from an old song from a former pop icon from decades ago, Cyndi Lauper.

At times, I also tend to write in a “stream of consciousness” manner similar to that of a journal entry and just pour out my thoughts. In those instances, because the reader is privy to everything that I am even if others featured in the writing are not, there’s an element of “breaking the fourth wall.” I liken it to Patricia Hill Collins’ keen observations about public intellectualism as literature and music:

> Books, stories, and poetry allowed oppressed people to communicate one with another and to produce a sense of shared identity. Such cultural expressions have historically given voice to the voiceless. Those who were denied political or academic power could express their ideas and experiences through story and poetry. As long as the political majority could read these as “fictions,” as long as they weren’t faced with the facts of oppression, blacks were allowed these cultural outlets in “race markets.” (Collins, 2000, p. 100-106)

Multimodal Leadership and Allyship as Creative Collaborative Care Work

Additionally, there are manifestations of my creative collaboration that are not centered on writing, such as my work as a leader and/or ally in various spaces. I have had the opportunity to co-facilitate of a national learning lab focused on Black disability feminism; moderate several international panels; serve as an appointee on various executive and advisory boards; participate in numerous global constituency advocacy, research, health, policy, and education groups; accept the role(s) of global community liaison and rapporteur for various conferences, symposia, and meetings; and assist with a plethora of collaborative projects and care work virtually as well as in-person. Select examples can be reviewed in the corresponding portion of the portfolio.

Guided by Collins' assertion that theory allows me to "see all of these associations with fresh eyes, while concrete experiences challenged the worldviews that are offered by theory," (Collins, 2000, p. 35), I strive to develop creative collaborative work that stimulates positive change, pairing facts and feelings in my work so that the material is grounded in data but does not feel sterile and impersonal. Revisions might be made as needed, but its core essence generally remains unchanged. For me, it needs to feel "right," or I cannot proceed. And as my creative collaborative care work and my global advocacy and activism are the largest manifestations of my work overall, this is critical. Ultimately, I combine subjectivity and objectivity, to demonstrate authenticity that radiates powerfully enough to warm he mind and the heart while retaining the core of who I am.


work with
one for all
network
liberate
contribute
team up
offer thanks
be accountable
collaborate
support others
all for one
listen well
notice others
side by side
exchange
be part of
join in
partake in
tolerate
empower
care about
participate
teamwork
respect all
unite
educate
show up
support others
all for one
be of service
link together
exchange
serve others
be generous
give attention
welcome all
network
take a role
co-operate
interact
encourage
engage with
care for
collaborate

OXYGEN: ADVOCACY AND ACTIVISM ACROSS CAUSES, CONTEXTS, AND CONTINENTS

There's an oft-quoted idiom about oxygen that people mention when discussing activist self-care: "Put your own oxygen mask on first before helping others." Oxygen, the final component needed to create fire, is an oxidizing agent and an essential element that exists in abundance on Earth. Oxygen is responsible for producing energy and is vital to the existence of nearly all living organisms—so much so, that being deprived of it for even a short period can prove debilitating and even fatal.

Advocacy and activism often serve as the pulse and the lifeblood of community action—indeed, as essential to our lives as oxygen. I have engaged in many different forms of activism and advocacy over the last decade and a half, including various speaking engagements. As one key example, some years ago I served as an expert panelist at the White House Inaugural Forum on Civil Rights of Parents with Disabilities. Although I didn't have my speech nor my notes present as a result of having to hurriedly evacuate the hotel in the wee hours because of a bomb threat, I gave a talk identifying and addressing common barriers families encounter as they attempt to navigate the complexities of various systems (i.e., disability services, schools, medical care, etc.) for themselves and/or their children. Although the forum was by invitation only, the content was shared in part on the White House official media broadcast, YouTube channel and website.

I returned to the White House a second time when I was invited to the White House Forum on the LGBT and Disability Issues, held on National HIV/AIDS Testing Day. Along with my colleague Angel Hernandez, a queer disabled Puerto Rican activist, I officially represented the Global Community Advisory Board of multinational AIDS Clinical Trials Group. The Forum highlighted various community led efforts focused on LGBTQIAP+ people with disabilities and hosted a moderated discussion on best practices to promote inclusion. (White House, archive; ACTG, n.d., About)

I have also engaged in advocacy work with the United Nations, including consultation as an invited expert (in conjunction with Erich Kofmel of Autistic Minority International), for the United Nations Programme on Disability. I have participated in think tanks convened by the Joint United Nations Programme on HIV/AIDS and the United Nations Global Communications. Moreover, I contributed to a written supplement for a report to the United Nations Special Rapporteur on Violence Against Women.

A few years prior, I'd also had the honor of being an invited presenter at the United Nations Headquarters for the annual observance of World Autism Awareness Day. (UN WebTV, n.d.) In my World Autism Day United Nations address, I spoke about the unique and intersectional challenges of autistic people with multiple marginalizations, including race, serostatus, gender, and sexuality.

I also emphasized the importance of empowerment and meaningful involvement and representation in education, health, policy development, and decision making. (This year [2022], I was also invited by the United Nations Messenger of Peace Programme to submit a brief on inclusive education access for their virtual observance of World Autism Awareness Day in April but was unable to due to illness.)

To Make Change, One Must Be the Change

Writing is my native language, but I also engage in activism in addition to and outside of my writing. The #JusticeForKayleb campaign discussed earlier in the thesis also had a photo-visual component. As the hearing date approached, I requested for supporters to submit images of frogs and the Justice League (Kayleb's special interests) using his hashtag as a show of solidarity and to encourage his family. Since the Change.org petition I'd launched to have the unjust felony charges dropped against Kayleb had 151,000+ signatories from all over the world, happily, he received a LOT of images!

POSITIVE EXPOSURE was founded by award-winning photographer Rick Guidotti to challenge "traditional ideas of beauty through the beauty and richness of human diversity to promote a more inclusive world." (Guidotti, n.d., About) Reel Abilities is "the largest festival in the US dedicated to promoting awareness and appreciation of the lives, stories and artistic expressions of people with different disabilities." (Reel Abilities, n.d., About) In partnership with POSITIVE EXPOSURE and Reel Abilities, I was part of a photo-visual activism campaign about disabled families. My portrait and name were prominently displayed during the ten-day disability festival and then subsequently in art galleries as part of a traveling exhibit.

This campaign was the first time I publicly declared my identity as a disabled person as opposed to only referring to myself a "parent of children with disabilities" like I'd done previously. As shared earlier, Black disability policy does not require a disability-centric identity as it might not match the reality of many in the Black community. Further, for a multitude of reasons, some Black people might not identify themselves as having a disability or being disabled at various parts of their lives (or ever). Schalk provides important context about this in the introduction of her book *Black Disability Politics.*

"The whiteness and racism of the disability rights movement and disability studies as a field…often excludes or alienates Black disabled people and…Black activism and cultural work." (Schalk, 2022, p. 6) There is also the harsh reality of the "cost" of being recognized as a disabled parent of color, including the potential of loss of custody of one's child(ren) to the family legal system. (Powell, 2021, para 4-14) For these and other reasons, I do not vilify those who consider it unsafe and/or unnecessary to identify as disabled.

Moreover, due to what I have learned through the years, particularly through my activism, I advise my disabled peers to carefully consider the potential long-term effects of the choices they make regarding disclosure—something I was previously ignorant of. Nevertheless, proclaiming myself openly as "unapologetically Black and disabled" liberated something inside of me.

These opportunities have also enabled me, someone with "hidden" disability, to demonstrate solidarity with peers whose disabilities are more readily apparent than mine. I fully agree with Schalk's refusal "…to act as if I am separate from the communities I write about, live within, and learn from every day." (Schalk, 2022, p. 2) Though, as stated previously, I am marginalized in several ways, I am also extremely privileged in distinct ways as well. Like Soyinka, I choose to use that privilege, when possible, to advance the collective interests of the community rather than merely to further my own interests.

This has propelled me into continued activism of this type, including collaborative visual projects utilizing photography and/or a variety of multimedia in which I have intentionally "oxidized" my role, position, and/or identities for the greater good. I participated in the "We are HERO" photo-visual campaign as a form of legislative activism intended to garner support for a proposed citywide anti-discrimination bill. The Houston Equal Rights Ordinance, or HERO for short, sought to impose a ban on discrimination and/or unequal treatment of various Houstonians. Essentially, one could not discriminate, refuse to serve, and/or otherwise mistreat someone anyone on the basis of "protected characteristics," namely: "sexual orientation, gender identity, sex, race, color, ethnicity, national origin, age, religion, disability, pregnancy, genetic information, family, marital, and military status." If the ordinance became law, it would apply to all privately and publicly owned accommodations, businesses, services, places of employment, amusement, etc. with 25 or more employees within the city limits. (City of Houston, 2014, p. 1-36)

Although only local residents were eligible to cast a vote, HERO generated international interest and was endorsed by many: various Chamber of Commerce committees, civic organizations, advocacy groups, progressive faith leaders, universities, non-elected community leaders, LGBTQIAP+ activists, celebrities, and more. It was, however, also disavowed by many individuals and organizations as well, including influential local and nationwide conservative and religious leaders, who disparagingly referred to it as the "UnEqual Rights Ordinance." Because of that, several local progressive allies collaborated to develop strategies we could use to try to counter the "bathroom bill" hysteria being perpetuated by HERO's transphobic opponents. "We are HERO" was one of those strategies.

Published in local print media and online, "We are HERO" featured portraits and stories of individuals and families (including mine) from each of 15 groups whose municipal civil rights HERO would protect. Giving the ordinance a human face seemed to work with voters. It is believed that HERO passed and become law in part due to our activism—although, unfortunately, our success was very "short-lived" as HERO was targeted by conservatives and repealed the following year. (Ura, 2015)

"My Life-Changing Autism Diagnosis" is an episode that was featured on a weekly BBC podcast hosted by journalist Kim Chakanetsa. In it, I and another guest, British author Sara Gibbs, discuss our experiences as women who were diagnosed with autism in adulthood. This segment aired on BBC World Service, BBC News, and more than 1,400+ affiliated stations in ~39 languages. (BBC, 2022, About) Given the large disparities in autism diagnosis rates across the gender spectrum, my singular goal in this multimedia activist project was to get the attention of clinicians as well as the public; too many individuals go mis- or undiagnosed for years because of stereotypical presumptions about autism that aren't necessarily reflective of some of us, especially racial and gender minorities.

I also contributed, along with several colleagues, to several additional autism-related photovisual and multimedia activism projects. For example, I joined autistic colleague (and event host) Ly Brown, Dr. Temple Grandin, and personnel affiliated with the Matthew Reardon Center for Autism for an annual anti-filicide vigil held in the state of Georgia. The event was captured by photojournalist Lynne Turner for a special feature on autism sponsored by *National Geographic*. Created by autistic activist Zoe Gross, the "International Disability Day of Mourning" is an annual vigil held on March 1st in many cities, states, and some countries to mourn the loss of disabled people of all ages who have been murdered by family members and/or caregivers.

The purpose of highlighting these tragedies (outside of commemorating these lost lives) is to counter misconceptions as these murderous acts are frequently portrayed in the media as “mercy” killings. An additional objective of the vigil is to demand justice and adequate protection under the law for all disabled individuals who utilize caregivers.

I have coordinated other commemorative vigils as well, including an evening of remembrance for the tragic, too frequent murders of those who face a disproportionate burden of violence, including cisgender and transgender women living with HIV, transgender women of color, and North American indigenous women and girls.

Later, I collaborated with Condé Nast, a “premier global media company” that produces many influential brands, i.e., Vogue, Vanity Fair, Glamour, Brides, Self, and GQ (Condé Nast, 2022, About), to co-develop “What Women with Autism Want You to Know.” Featuring several other autistic women and femmes in addition to me, the ten-minute viral video aimed to dispel autism myths, obtaining over 3.6 million views in its initial year.

I was also invited to participate in a print media initiative “focused on innovative autism storytelling to change perceptions and end the stigma of autism.” *Zoom Magazine* hosted a special issue about women with disabilities. I was a featured guest along with actress Alyssa Milano, activist Mia Ives-Rubee, founding AWN executive director Sharon daVanport, ASAN executive director Julia Bascom, and US Senator Tammy Duckworth. My contribution, “From Feeling Powerless to Owning My Own Power” sought to encourage other people with disabilities and allies to work collaboratively to eradicate ableism and empower one another.

Unlike the other campaigns I have described—which were intentional, pre-determined demonstrations of art and practice-based activism—the extent of my involvement with the “A Day with HIV” global campaign was completely unplanned! Since 2010, Positively Aware Magazine has set aside a day in September each year to coordinate “a single 24-hour period in the lives of people affected by HIV,” attracting participants from all over the world. (Positively Aware, n.d.) Throughout the day, photos (of people who are living with HIV and people who are not) appear on the campaign’s website and on social media with the hashtag #ADayWithHIV. The images include family members, self-advocates, researchers, educators, married couples, activists, health care providers, etc. (Positively Aware, n.d.)

When I posted an image of my family wearing our matching “NO Shame About HIV” AIDS Walk t-shirts, it was simply an act of community solidarity. Though we hadn’t before possessed a photo of this type, I had supported A Day With HIV in various other capacities for several consecutive years. I never anticipated that our (unfiltered!) image would actually be chosen for publication! But it was. I was contacted and asked to consent to our photo being featured in forthcoming print and digital magazine issues, which I did. Although HIV impacts my family personally as we are a serodifferent household, it is, like COVID-19, an intersectional issue that should be everyone’s concern. Furthermore, HIV is not a crime nor a sin; it’s a manageable chronic condition; a disability. My hope was that by showing our family—real people living our real lives—we could eradicate some of the misinformation and stigma surrounding HIV, and hopefully inspire others to consider doing the same.

Global advocacy and activism of various types, both traditional and nontraditional, constitute my largest body of work. They have provided individual and collective opportunities to build upon my activist scholarship and to implement integral aspects of my creative collaborative care work. The predominant ones, some of which are featured in the portfolio, bear similarities in various ways to the work of Black luminaries such as Sojourner Truth, the aforementioned Sami Schalk, Wole Soyinka, and E. Grollman, and others.

As the examples described here are far from a sufficient depiction of the size, scope, and significance of my global advocacy and activism, additional information has been included in the portfolio in an attempt to augment what has been briefly noted in this section. It is also discussed in the appendices (specifically, the latter part of Appendix B) as well.

One can envision several connections regarding oxygen in the fire tetrahedron and practical application of the principles my activism and advocacy is aligned with and influenced by. It can also be likened to the life-sustaining role of oxygen in nature overall. This is important to note because I truly seek to embody the aforementioned concepts as an advocate and an activist. As such, I must lead by example, not just by words.

I recognize that throughout this thesis, I have drawn inferences between myself and individuals who, when compared to me, are more akin to role models than peers, i.e., Audre Lorde, bell hooks, Wole Soyinka, Patricia Hill Collins, Sojourner Truth. However, that is intentional; my standards are high. I am not content with merely “standing” on “the shoulders of giants;” I have instead opted, while standing there, to emulate them.

Burnout: The Risks and the Rewards of Fire

Earlier I mentioned that fire enabled humankind the ability to develop new forms of transportation and communication and to engage in various forms of work. Life as we know it would not be possible without fire. It has been, and continues to be, a vital component of our lives. However, despite the many merits of fire, there are also problematic aspects associated with fire. A few of those can be attributed to fire itself, i.e., burning and/or burnout. Burning can occur spontaneously in nature, such as in the case of wildfires, lightning strikes, or volcanic activity; it can also be induced, as in the case of industrial conflagrations, arson, and structure or urban fires. Enormous damage can occur if a fire burns unexpectedly and/or out of control, though fire prevention and protection efforts can help to avoid and/or mitigate this.

Interestingly, however, the greatest hazard humans face from fire isn't from its flames. Most of the harm comes from the unhealthy conditions the combustion causes. Harmful particles and gases are released from fire as waste—the equivalent of humans excreting sweat, urine, and feces from our bodies. These unwanted byproducts, smoke and/or carbon monoxide, are the primary causes of human fire-related injury and death. Smoke inhalation and/or carbon monoxide poisoning cause extensive damage to the respiratory tract and tissues, resulting in lowered levels of oxygen. This impedes breathing, causes disorientation, and can facilitate systemic toxicity resulting in organ failure.

Unlike burns, which are immediately obvious, signs of smoke and/or carbon monoxide inhalation might have a delayed onset and therefore be missed. Carbon monoxide in particular poses a significant risk because it has no odor, color, or taste and can potentially linger in the atmosphere for one to two months. It is imperative to assess someone thoroughly if they might have potentially inhaled fumes; though they might appear to be relatively unharmed, they could be on the verge of death!

As someone who believes deeply in authenticity, I want to note that though my work—my fire—has indeed had an extraordinary impact in many positive ways, there have also been numerous toxic effects too, at times potentially akin to exposure to smoke and/or carbon monoxide. You typically cannot have rainbows without rain nor roses without thorns.

It hasn't all been love, light, peace, and solidarity. The burden, at times, is almost too much to bear. There have been (many) tears. There has been disillusionment. There has been rage; there has been pain. In a very raw 2021 online essay, entitled "Shattered Beyond Repair," I pour out my emotions:

> I have been burned over and over again. Sometimes directly – things being done to harm me. Sometimes indirectly, in the millions of little micro aggressions and bigoted words and actions. Either way, it's too frequent and it's too much.
>
> I am so very tired of having malcontent ascribed to my genuine and heartfelt actions. So tired of being punished for wanting better.
>
> I don't know how much more I can reasonably be expected to take. I'm destroyed…every part of me. (Giwa Onaiwu, 2021a, para 7-10; Giwa Onaiwu, 2021, para 6-7)

Quite frankly, this work has taken its toll, literally and figuratively, on my well-being and that of my loved ones. It requires a nearly insatiable amount of time, effort, emotional and intellectual labor as well as resources (i.e., money, since a lot of my work is pro bono and unfunded) of which I have little to spare. It has obliterated a lot of my innocence and naivete time and time again as I have discovered that many things weren't what I'd perceived them to be and as people and/or organizations that I had deeply admired disappointed me and/or fell from grace.

> I keep trying. Keep speaking out; keep trying to believe; keep trying to make change. Only to be consistently and callously immolated by people who don't like what I have to say. If the truth hurts, they're going to make sure *you* hurt for the crime of uttering said truth as opposed to fawning over the non-existent garment being flaunted by the emperor.
>
> The price for refusing to imbibe the enticing blue pill of falsehood is a very, very steep one. Maybe one day I will learn. (Giwa Onaiwu, 2021, para 4-5)

It has caused me to lose relationships with people as well as entities that I cared about because of philosophical and/or political irreconcilability. It has forced me at times to make impossible decisions when the needs and/or perspectives of the different communities I am part of and/or work with conflict with one another. It has cost me precious memories with my family. It has impacted my mental health.

> Stupid, stupid, stupid Morénike. When will you learn? No one *truly* wants all these things we all talk about…you know, justice, equity, inclusion, acceptance. Those are just pretty buzzwords. The only fool who actually believes in these concepts is you. You're not supposed to *really* want it to happen. I was so hopeful and so energetic that together we were all going actually to change this world, make it a more accepting and inclusive place. I honestly believed that. I don't now. (Giwa Onaiwu, 2021, para 18)

Activist and Autistic Burnout

I don't quit. But it has caused me to slow down, and, at times, contemplate just giving up entirely. (Several times, in fact.) I bear the telltale scars, internally and externally, of habitual "spoon" depletion as well as burnout, including diminished performance, low energy, overwhelming exhaustion, chronic malaise, reduced cognitive capacity, challenges with functioning, etc. Running out of spoons and combatting burnout are unpleasant but unfortunately common phenomena for individuals like me, and while I have made some progress rationing, replenishing, and preserving my spoons, I've had much less success dealing with the Cerberus-like inferno of community kyriarchy, activist fatigue, and autistic burnout (I will refer to this sordid trio collectively as "burnout" in this thesis for brevity).

> Truthfully, this hasn't felt like a community to me in a long time now, but I just couldn't put down the "hopium" pipe.
>
> There is no "us."
>
> There never was; I just believed the Wizard behind the curtain was real. (Giwa Onaiwu, 2021a, para 6-8; middle and end sections)

Burnout, like smoke and carbon monoxide, is a familiar and unwanted byproduct of fire, one that tends to "come with the territory" and is difficult to contend with. There are various reasons why I, and others like me, are prone to burnout. Equity scholar Paul Gorski, who has done commendable research examining social justice and human rights activists, educators, and other key individuals and groups in various activist movements (including anti-racism, climate change/environment, peacekeeping, multicultural education, etc.), noted that activist burnout research bears explicit similarity to vocational burnout findings. (Gorski, 2019) According to Gorski and colleagues (Gorski, 2019; Chen & Gorski, 2015), activist burnout, defined as the combination of "debilitating deterioration of physical health," "debilitating deterioration of psychological or emotional health," and "debilitating deterioration of hope," typically has four core causes.

One primary cause of activist burnout is the intensity of internal stressors activists face due to self-induced pressure for social change. This often occurs because of a strong commitment to the cause; activists tend to be deeply emotionally invested. Recognition of the magnitude of the problems they are addressing also contributes to internal stress. Activists are keenly aware of the many structural systemic barriers that uphold oppression and inhibit change; examination of the reality one exists under can be discouraging. (Gorski, 2019; Chen & Gorski, 2015)

A second cause is external stressors. The external component consists of societal resistance and/or retaliation, inadequate financial and logistical support for the work, and safety concerns because of one's heightened risk and/or likelihood of being a target for actual or potential threats. (Gorski, 2019) External threats vary from bullying, slander, and character assassination to arrest, harassment, and/or physical violence. These external stressors are often paired with the third cause, psychosocial stressors. Human rights and social justice activists, especially those who are BIPoC, often hail from communities similar to those whom they are laboring for/with. As a result (particularly in conjunction with the nature of their activism), they might be predisposed to various circumstances and social determinants of health including higher risk of economic instability, health challenges, ongoing discrimination., etc. (Gorski, 2019)

Given these psychosocial aspects, it is not surprising that Gorski and colleagues noted the majority of BIPoC activists studied (over 70%) reported distinct behavioral indicators of depression, including fatigue, hypersomnia or insomnia, reduced interest in activities, and reduced interactions with one's partner and/or children. (Chen & Gorski, 2015) Moreover, it may result in financial vulnerability as well; the impact of the aforementioned second and third causes can mar one's reputation, thus reducing opportunities; and/or exacerbating battle fatigue…impeding one's ability to successfully do the work. (Gorski, 2019)

These three factors are also detrimental to one's physical health, as observed by Gorski and colleagues (Chen & Gorski, 2015), and the average life expectancy for autistic adults is already shorter than our non-autistic peers. If we are still alive by our late 30's, we've beaten the odds. You start to become numb when you repeatedly have to pay respects to this person or that person whose lives have ended, in their 20's, 30's, and 40's, before they have even had much of an opportunity to live. This doesn't even factor in the vast number of people who are fortunately still living, but have been repeatedly hospitalized, are fighting for their lives, and/or have struggled with recurring suicidal ideation and/or mental health crises, sometimes resulting in (involuntary) psychiatric hospitalization. (Gardiner, 2022)

Despite clear, credible data confirming these devastating disparities, a vocal fringe group of anti-neurodiversity critics conjure up and parrot various falsehoods about the "minimal" challenges faced by the supposedly "high functioning" individuals of the "activist class." (Escher, 2022) Having been closely involved with various social justice communities which contain a plethora of activists from marginalized backgrounds, for nearly all my adult life, I would beg to differ.

The fourth cause of activist burnout uncovered from Gorski's research, in-movement stress, is the most damaging. It is heavily psychosocial, but it occurs with such frequency that it merits its own category as opposed to being embedded within the third cause. Activists, especially activists of color, are persistently burdened with specific in-movement stressors. A predominant one is the overt and covert pressure to embrace a martyr-like "culture of selflessness" which has been associated with burnout and other negative mental health outcomes. (Gorski, 2019) This implicit expectation asserts that those who are genuinely committed to the movement must willingly and continuously invest copious amounts of emotional labor regardless of the toll it might take on one's life. (Chen & Gorski, 2015)

According to Gorski and colleagues (2015), other reasons for in-movement stress include activists discriminating against one another and activist "infighting, backbiting, and struggles for power." Gorski's findings align well with BIPoC queer autistic organizer Ly X.Z. Brown's observations about trauma that is perpetuated by the autistic community. First, Brown noted that small insular communities such as the autistic community often develop "cult-like" dynamics. Next, in addition to being small, Brown explains that the (autistic) movement is also quite young; the newness of the movement and its members' unprecedented familiarity with one another (until very recently) likely contribute to poor relations as well. (Brown, 2022, February 5th Twitter thread)

The final two factors Brown mentioned are "It's a giant trauma fest!" and "artificial scarcity." Due to the lives most autistic adults have lived, many have experienced trauma that might not be sufficiently addressed and therefore inflict trauma on others because "hurt people tend to hurt people." Similarly, the false sense of scarcity results in a toxic, recurring cycle that Brown describes as "Tall Poppy/ Hitler or Jesus Syndrome" in which activists are initially placed on a pedestal only to viciously torn down from it for their lack of perfection and/or others' jealousy:

> Activists and organizers have gone back and forth for decades and decades about whether our movements should recognize charismatic leaders or not, whether we should highlight individual people's work or instead focus on orgs/collectives' work and not recognize individuals. And there's really good arguments to be made that we need both, because not recognizing individuals can fuel erasure and exploitation of multiply marginalized people, especially poor, disabled, queer, trans, women, [people] of color, etc., and…also focusing too much on "celebrities" disempowers mass movements and creates a top-down structure that's easy for the state/corporations to sabotage by taking down/out one leader. (Brown, 2022, February 5th Twitter thread)

Autistic physician, advocate, and parent Mary Doherty (@AutisticDoctor) suggests a fifth component to the trauma induced nature that seems to mesh well with Brown's observations: the fact that within the autistic community there is an "inability to resolve interpersonal conflict. Minor disagreements lead to irrevocable splits. People go from colleagues/friends to enemies in an instant." (Doherty, M., 2022 in Brown, 2022, February 5th Twitter thread) Doherty's speculation is especially poignant in consideration of the finding that social justice and human rights activists in general are seldom equipped with any formal training, mentoring, or resources to prepare them for in-movement stress, according to Gorski and Chen. (2015) The absence of such support is generally the norm rather than the exception--despite an attrition rate among activists estimated to be as high as 60%.

Finally, one must take autistic burnout into account. The Academic Autism Spectrum Partnership in Research and Education (AASPIRE) defines it as follows:

> Autistic burnout is a syndrome conceptualized as resulting from chronic life stress and a mismatch of expectations and abilities without adequate supports. It is characterized by pervasive, long-term (typically 3+ months) exhaustion, loss of function, and reduced tolerance to stimulus. (Raymaker et al, 2020, p. 132)

The exhaustion experienced in autistic burnout is more than just "standard" fatigue. Rather, it is a severe depletion of energy that occurs because of having to overextend oneself in daily life. Loss of function can range from a decline in one's skills, emotional regulation, communication, and/or cognitive ability to being unable to instrumental activities of daily living. Reduced stimuli tolerance can cause someone to be more sensitive than usual to their environment and/or less capable of tuning things out, which can increase meltdowns, shutdowns, and stimulus avoidance. (Raymaker et al, 2020) Data also suggests that the practice of autistic camouflaging, also referred to as "masking," plays a significant role in autistic burnout. Several studies have discovered correlations between masking and depressive disorder as well as anxiety; other studies show an association between masking and suicide risk. (Raymaker et al, 2020, p. 132-143)

Danquah, Lopez, Wade, and Castillo (2021, p.526-529) make several recommendations for combatting burnout that are specific to BIPoC women and femme activists in the US. One is that activists should learn the signs of burnout to be able to recognize its manifestation. They should also strive to develop an individualized self-care plan in advance if/when burnout occurs. Conducting whole body scans, deep breathing, and gentle stretching can help reduce tension in the body.

Moreover, this can decrease blood pressure and stabilize heart rate. This is of particular importance in this population as evidence indicates that women of color tend to experience psychosomatic manifestations of stress and burnout. Mindfulness and relaxation techniques can help, as well as rest, addressing negative emotions, taking some time to "recharge" for a while, and seeking peer support and/or mental health services as needed. (Danquah et al, 2021, p. 527-528)

Autistic activist Brown also shares how they have coped with the dynamics of the autistic community:

> I have been sick + tired of these dynamics for most of the last decade, and I have chosen to focus on building community with people who are also willing to talk through trauma who care less about "activism clout" and more about what we are doing to care for each other. Many of those people have happened to be autistic. But I haven't really been part of the "autistic community" in years since being functionally pushed out by various factions/people engaged in a smear campaign/character assassination campaign against me, and I'm okay with that. My mental and physical health are better for it. (Brown, 2022, February 5th Twitter thread)

These and other helpful strategies can be implemented as a protective (and, if necessary, a restorative) burnout tool, similar to methods that may be used for combustion prevention and/or firefighting and fire management. The specific techniques one might find effective vary. However, whether it is cultivating meaningful supports and accommodations, engaging in mindfulness and/or relaxation, developing intentional community, etc., incorporating Audre Lorde's sage advice in doing so is critical:

> I had to examine, in my dreams as well as in my immune-function tests, the devastating effects of overextension. Overextending myself is not stretching myself. I had to accept how difficult it is to monitor the difference. Crucial. Physically. Psychically. Caring for myself is not self-indulgence, it is self-preservation, and that is an act of political warfare. (Lorde, 1988, p. 130)

It should be noted, however, that figuratively as well as literally, preventing burnout isn't always possible nor ideal. Sometimes those engaging in fire management and firefighting find that *not* extinguishing a fire might be useful. In certain circumstances (including power plants and various "cool" or "prescribed" fires), it is beneficial to permit "hazard reduction," "controlled," or "patch" burning to occur. In some cases, it is assumed that when "managing" the masses is a goal, sacrificing a few outliers—regardless of how painful—is deemed acceptable (maybe even necessary) by the powers that be.

Hypothetically, however, such situations should be rare. The onus should not fall solely upon me and people like me to have to repeatedly endure the flames nor to unilaterally fix what society has broken. We should *all* be undertaking that task, together.

Collectively, society at large, and namely, our allies, can take active measures to transform the status quo and therefore also work to combat burnout. There are numerous possibilities for facilitating this. Some points to consider are outlined succinctly in the recommendations I gave at the end of my *Autism in Adulthood* editorial as well as inferred in several of the assorted quotes below about fire:

> Commit to doing the work to know what is happening. Make concerted efforts to show these important concepts to others so they can be more informed. And, through practical and consistent action, show that you do, indeed, care. It will require some innovation and some patience on your part, but it can be done. Seek opportunities to make progress, even if seemingly small or unconventional. (Giwa Onaiwu, 2020, p. 272)

Quotes Pertaining to Fire

> "You cannot, you cannot use someone else's fire. You can only use your own. And in order to do that, you must first be willing to believe that you have it." - Audre Lorde
>
> "Light up the fire of love inside and blaze the thoughts away." - Rumi
>
> "...the poet is actually a thief of Fire!" - Arthur Rimbaud
>
> "Don't set yourself on fire trying to keep others warm." - Penny Reid
>
> "The mind is not a vessel to be taught. It is a fire to be kindled." - Plutarch
>
> "How you walk through the fire says a lot about you." - Mohadesa Najumi
>
> "I burn, and I hope." - Jesmyn Ward
>
> "It is not light that we need, but fire; it is not the gentle shower, but thunder." – Frederick Douglass
>
> "...The light of love is always within us, no matter how cold the flame. It is always present, waiting for the spark to ignite, waiting for the heart to awaken…" - bell hooks

Combatting Burnout with Camaraderie, Support, and Self-Growth

Initially, I had ended this chapter right after the quote above. But weeks later, I've come back to it as it just didn't feel right to me. It didn't feel complete, nor did it feel balanced. It isn't that what I have shared is untrue, but there's more to know about fire than just its risks and preventing it from killing you. To culminate the chapter on fire the way I almost did…in such a utilitarian and abrupt manner after everything that I have shared in this thesis…feels not only unfinished, but, frankly, wrong. Therefore, I continue this chapter to discuss some of fire's rewards as well.

Instinctively, I start to envision the faces of the people whom I labor to change the world the most for: Cherita, Noah, Isaiah, Daniel, Amina, Anthony, Legacy, Lukas; DeJonte, Lola, Kam, Preston, Ezra, Londyn. My babies, as well as my nieces, nephews, niblings. How do I find the words to adequately convey my intense love for them and how much their existence motivates me daily to keep going, to keep trying? How do I place my husband and biggest supporter, Lucky, in context, and demonstrate the instrumental role he has played in all my achievements given that much of what I have accomplished has been because of his unwavering love and support?

And how exactly do I discuss my loved ones properly in relation to fire? My family, my friends, my communities…numerous unseen, unheard people who have supported me over the years in so many ways that I am unable to recall (much less name) them all?

My mom's daily prayers and words of encouragement were "food to my soul." My dad's sacrifices throughout the years gave me a chance to venture out into the world and discover myself. Kay and Erica loaned me money even though I had a poor track record of paying them back, and they always showed my family so much love. Link and Andrea kept me grounded. Cherry and Bruce were always "down for whatever." My mother-in-law's patience and unconditional love were a lifeline. Monique always kept us in her thoughts. My father-in-law offered pragmatic advice, love, and thoughtfulness.

Outside of my family, the support of various individuals and organizations also enveloped me in warmth. AWN sent my family funds for meals and transportation and created numerous opportunities for me. Leslie maintained close contact; helped solve various dilemmas, gave countless rides; covered us with prayer. Mrs. Judy scrambled out of bed on many an early morning to help me with morning school drop-off on days where I was running behind…simply out of kindness. April always lent an ear and/or a shoulder. FDM offered me growth, stability, and friendship. Gabby, Terra, Bryan, Claudia, Nicole, Marta, Wayne, and Deanna had my back at work. The IEC sent me flowers (and wine too!)

Kind Theory sent me chocolates. Anna, Shaun, Caren, Ly, Jane, and my church family fought tirelessly for my children. Bev, Daman, Jules, Heather, and others sent me money that I know they don't have to spare. The HIV Clinical Trials Networks, especially my beloved ACTG, IMPAACT, and HPTN families as well as HANC, mentored, supported, and embraced me. So many have been there for me.

Yes, there are significant risks associated with fire, including burnout, smoke inhalation, and getting burned. It is important to acknowledge, prevent, prepare for, and when applicable address these very real risks. But we cannot perseverate on the risks of fire while disregarding its rewards, for indeed there are many. The sense of community one can gain in this work is invaluable, even amidst the pain. Even more importantly, there are valuable lessons you will come to uncover and to teach yourself. Burnout is a reality, but it doesn't have to be the end of your story. You have to fight to keep that flame lit!

When oxygen, heat, and fuel combine, fire is born. Fire is the resulting event; it is a process; it is the "oeuvre" of the previous three steps. Fire is the consequence; fire is a reaction. Similarly, advocacy, activism, and resistance are often born in response to injustice, stigma, and oppression.

A fire first begins with an initial spark, surge, or flame of brightness and heat. Fiery and passionate, it might blaze intensely at a very high heat; it might intensify as a result of an accelerant and/or an additional fuel source; it might exhaust its fuel source and fizzle out quickly; it might have one of the three necessary elements (oxygen, heat, and fuel) blocked and thus will be extinguished.

Alternatively, the fire, like social movements, may evolve. Rather than surging wildly or dying out, fire can transform, achieving a balance that provides equilibrium. Such a change occasionally happens spontaneously in nature, but the majority of the time, it will not happen without intentional effort. If we put forth the necessary time, work, and resources, we can cultivate a controlled, steady fire. Such a fire evokes a sense of security. It provides light and warmth, but in a contained manner that does not destroy everything in its path. It is a fire of life; a fire of change that lasts. Reminiscent of a hearth or a fireplace, it offers stability, fulfilling multiple purposes and thus meeting multiple needs.

We maintain controlled fire via ongoing efforts to acknowledge and appreciate having proximity to this critical resource (fire) and therefore prioritizing its sustenance by maintaining the desired ratio of the elements of its tetrahedron. This is an active process, for fire is not stagnant; it is ever-evolving, as are we. We will always have needs to meet; things to learn; things to do. Though there will be change, growth, and loss as we travel life's winding paths, we can—we *must*—still celebrate the journey itself.

Additional Resources for Combatting Burnout

Throughout this section, I share several different challenges and struggles as well as people and/or entities that have been, for me, a lifeline. Although it isn't possible for me to provide an exhaustive list, I do think it's important for me to share some resources for combatting burnout that might be of benefit to anyone for whom the examples might feel familiar. I cannot formally endorse, recommend, and/or otherwise vouch for any items listed here, but please review the list below as needed/desired.

This Poem Will Change Your Life | Rudy Francisco – Short Video: Complainers:
https://www.youtube.com/watch?v=1E3Wr2AoEho

Mind (Mental Health Integration & Navigation Database): https://mindapps.org/Home

Programs - Mental Health First Aid: https://www.mentalhealthfirstaid.org/programs

Tools for Transformation: https://atctools.org/tools-for-transformation/

International Society for Traumatic Stress Studies - Public Resources: https://istss.org/public-resources

National Center for PTSD: https://www.ptsd.va.gov/index.asp

Text for Humanity: https://www.textforhumanity.com/

Resource Library - Green Mountain Self-Advocates: https://gmsavt.org/resource-library

Resources - Self Advocacy Resource & Technical Assistance Center:
https://www.selfadvocacyinfo.org/resources/

US Bureau of Primary Health Care (public health clinics): https://bphc.hrsa.gov/

Local Help | Workforce/Employment Service – Career One Stop:
https://www.careeronestop.org/LocalHelp/local-help.aspx

Crisis Text Line: https://www.crisistextline.org/

Disaster & Emergency Resources | Ready.gov: https://www.ready.gov/resources

Mood Tools: https://www.moodtools.org

Index Of Articles & Advice About Mental Health | Better Help: https://www.betterhelp.com/advice/

Portia Jackson-Preston: The Missing Ingredient in Self Care | TED Talk:
https://www.ted.com/talks/portia_jackson_preston_the_missing_ingredient_in_self_care

Sangu Delle: There's No Shame in Taking Care of Your Mental Health | TED Talk: https://www.ted.com/talks/sangu_delle_there_s_no_shame_in_taking_care_of_your_mental_health?language=en

Travis Heath: Self Care to Communities of Care | TED Talk: https://www.ted.com/talks/travis_heath_self_care_to_communities_of_care

(Research) Article about Life Crafting to Find Purpose and Meaning in Life: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6923189/

(Research) Article: Existential Positive Psychology and Integrative Meaning Therapy: https://www.tandfonline.com/doi/full/10.1080/09540261.2020.1814703

Weave Silk Online Interactive Generative Art: http://weavesilk.com/

Online Sketchpad: https://sketch.io/sketchpad/

The Trevor Project (Support for LGBTQIAP+ Youth): https://www.thetrevorproject.org/

National Domestic Violence Hotline: https://www.thehotline.org/

Nature Relaxation Films: https://www.youtube.com/c/dhuting/videos

Josu Relax Videos: https://www.youtube.com/c/JosuRelax/videos

Bjorn's Chill & Relax Visual Effects Videos: https://www.youtube.com/c/ChillRelaxwithVisualEffects/videos

Calm Videos, etc. (from Calm App): https://www.youtube.com/c/calm/videos

CONCLUSION

This doctoral thesis examines my intersectional research, activism, public speaking, writing, and practice over the past decade and a half, framed by the analogy of the fire tetrahedron. It includes published and creative outputs (chapters, articles, digital humanities, and other public pedagogy) and is structured as a qualitative study. (Moustakas, 1994, 21-27) Most of this work has sought to illustrate and center the perspectives of those who, like myself, occupy overlapping marginalized identities within the broad human spectrum of social groups whose characteristics determine privilege and oppression. (Williams, 1994, p. 93-118; Yep, 2015, para 1-4)

Activism, by nature, has an element of unpredictability and thus demands that we become proficient at adapting, continuously increasing our capacity to think and act critically across multiple contexts, including when potentially under-resourced and/or in duress. Moreover, authenticity, camaraderie, and connection are often critical components of successful public and engaged pedagogy as well as developing and maintaining community.

The principles I have shared shape and inform my work; the strategies I have shared grant me a sense of autonomy along with a welcome balance of predictability and spontaneity in circumstances in which I generally have little control. The holistic nature of my private and public self is a hallmark of all my activist-scholarship, creative collaborations, and global advocacy and activism endeavors. When combined, all these factors ultimately help to make me "me."

My work is eclectic and sincere, fueled by my lived and learned experiences, my various identities, and the communities that I am part of. Words are my craft, born from something deep within. It's like you just have to go with it...heed its call to make, to create, to speak, to act…or your soul will not be at rest. It is transformative and at times, potentially even disruptive—a powerful, almost visceral experience. I have long stopped resisting it; now I completely yield myself to it.

The selections offered are a diverse combination of publications, multimedia, speaking engagements, critical narrativism, collaborative advocacy, and expressive art derived from several established disciplines, including cultural studies (namely Black Public Intellectualism and Black Disability Studies), public digital humanities, pedagogy, sociology, etc. Emerging and hybridized fields such as ethnomediaology, equity literacy, engaged research, and related subgenres (including "autie-ethnography") are also represented among the submissions.

The augmentative resources in the appendices supplement both the selections shared and the critical exegesis. By offering crucial context, particularly a sobering yet transparent overview of the devastating disparities that persist at the overlap of disability, race, gender, and other identities as well as helpful background and other relevant content, these auxiliary material further highlight the important themes I address in both my individual and collaborative published and creative work.

Embodying core principles of Public Intellectualism, engaged pedagogy, and Disability Justice/Black Disability Studies, this work symbolizes over a decade of earnest efforts; mistakes made; lessons learned; "blood, sweat, and tears" shed that has informed practice, augmented curriculum, influenced policy, and inspired many. Paired with the critical analysis, the material—which promotes activist scholarship and creative collaboration on an international level—makes a substantive contribution to the knowledge and understanding of the lived experiences of underrepresented perspectives, particularly in the tradition of Black Disability Studies. Moreover, it unapologetically calls for further inquiry into as well as massive reform of procedural standards, legislation, terminology, and societal worldviews.

As a portion of my "life's work," it is also my lifeline in that it contains my essence as part of my life story. In telling that story—as well as that of the various communities of which I am a part—this thesis documents the reality and the necessity of resilience, challenges, triumphs, and hope throughout our ongoing quest for the acceptance, equity, justice, and empowerment that, as humans, is our birthright.

We who reside at the intersections of oppressed identities have learned hard lessons from life. However, though our existence is marked by struggle, it is not unilaterally defined by it; we rebel and resist, but we simultaneously live, learn, and love.

Our arduously acquired knowledge has granted us the ability to consistently convert our pain into platforms for growth; our regrets into resourcefulness; our crying into creativity. Thus, collectively, those of us whom society has deemed as "other" make space for, uplift, and replenish one another - all while laboring to usher in a tomorrow we realize that many of us will likely never live to see.

As those of us at the margins of the margins, for whom intersectionality is our lived reality, continue to strive-—through scholarship, collaboration, activism, research, practice, art, policy, mutual aid, technology, advocacy, and various other means—to bring fire to the people, may the glow from that fire eternally light the way to progress, hope, and a just world that honors and celebrates us all.

PORTFOLIO

(Hyperlinked as well as enclosed)

PORTFOLIO: FUEL

Activist Scholarship

Sole-Authored Publications

Fuel 1: "'I Too,' Sing Neurodiversity" (article)

Fuel 2: "They Don't Know, Don't Show, or Don't Care: Autism's White Privilege Problem" (editorial)

Fuel 3: "Don't Be Like Me: A Letter to My Daughters" (article)

Co-Authored Publications

Fuel 4: "An Expert Discussion on Autism in the COVID-19 Pandemic" (roundtable)

Fuel 5: "Promoting Well-Being in Autistic Youth and Adults: A Positive Focus on Sexuality and Gender Diversity" (relevant documents enclosed in lieu of embargoed policy brief)

Fuel 6: "Ethics of HIV Cure Research: An Unfinished Agenda" (article)

Fuel 7: "Racial/Ethnic Differences in Psychiatric & Medical Diagnoses Among Autistic Adults" (article)

Fuel 8: "Centering the Inner Experience of Autism: Development of the Self-Assessment of Autistic Traits" (article)

Fuel 9: **"**Autism Intervention Research Network-Physical Health Autistic Researchers Review Board" (article)

Other Activist Scholarship

Fuel 10a: Justice For Kayleb (relevant images & miscellaneous in lieu of embargoed curriculum)

Fuel 10b: Million Moms March (relevant images & miscellaneous in lieu of embargoed curriculum)

Select other examples enclosed in portfolio.

PORTFOLIO: HEAT

Creative Collaboration

Heat 1: Preface - *All the Weight of Our Dreams: On Living Racialized Autism* (excerpt)

Heat 2: Letter from the Editors - *Sincerely, Your Autistic Child: What People on the Autism Spectrum Wish Their Parents Knew About Growing Up, Acceptance, and Identity* (excerpt)

Heat 3: Recalling "D" Day - *At the Intersection of Parenting, Race, and Disability throughout the Diaspora* (excerpt)

Heat 4: Foreword - *I Will Die on This Hill: Autistic Adults, Autism Parents, and the Children Who Deserve a Better World* (excerpt)

Heat 5: Am I Mom Enough? Contending with the Voices in My Head - *For the Love of Autism: Stories of Love, Awareness and Acceptance on the Spectrum* (excerpt)

Heat 6: I Don't Really Wanna Fight No More - *From Hurt to Hope: Stories of Mental Health, Mental Illness, and Being Autistic* (excerpt)

Heat 7: The Lady on the Plane - *Dazzling Colours of Calm* (excerpt)

Heat 8: Finding Me: The Journey to Acceptance - *Sincerely, Your Autistic Child: What People on the Autism Spectrum Wish Their Parents Knew About Growing Up, Acceptance, & Identity* (excerpt)

Heat 9: "A Dream Deferred" No Longer: Backstory of the First Autism and Race Anthology - *Autistic Community & the Neurodiversity Movement: Stories from the Frontline* (Open Access link)

Heat 10: All of Me: How Do I Know Where Blackness Ends and Neurodivergence Begins? - *Knowing Why: Adult-Diagnosed Autistic People on Life and Autism* (excerpt)

Heat 11: Why I Don't Like All of Those "Get Off Social Media and into the Real World" Posts - *The Real Experts: Readings for Parents of Autistic Children* (excerpt)

Heat 12a: Various chapters - *All the Weight of Our Dreams: On Living Racialized Autism* (excerpts)

Heat 12b: Various chapters - *A Family's Neurodiversity & Gentle Parenting Journey…in Color* and *Respectfully Connected: Journeys in Autism, Parenting, and Neurodiversity* (excerpts)

Select other examples enclosed in portfolio.

PORTFOLIO: OXYGEN

Advocacy & Activism Across Causes, Contexts, & Continents

Oxygen 1: The White House (video, images/assorted documents of relevance)

Oxygen 2: The United Nations (video, images/assorted documents of relevance)

Oxygen 3: Justice For Kayleb (petition link; updates, and related items of relevance)

Oxygen 4: POSITIVE EXPOSURE & Reel Abilities (images, link, link, link)

Oxygen 5: “We are HERO” (images, link, and assorted documents of relevance)

Oxygen 6: “A Day With HIV” (images/assorted items of relevance)

Oxygen 7: “My Life-Changing Autism Diagnosis” (audio podcast link, images, etc., BBC World)

Oxygen 8: “International Disability Day of Mourning” (images and link of relevance)

Oxygen 9: “Powerful Women: Become Them, Know Them, Raise Them” (article, Zoom Magazine Issue 15)

Oxygen 10: “What Women with Autism Want You to Know” (video link and images, Conde Nast)

Select other examples and video(s) enclosed in portfolio and/or linked on this page.

PLEASE VIEW PORTFOLIO CONTENT

(Fuel, Heat, and Oxygen: select links/enclosures; attachment. Please note that some content has been redacted to adhere to copyright laws.)

APPENDICES

(Appendix A; Appendix B; Appendix C)

Bringing Fire to the People: Activist Scholarship, Creative Collaboration, & International Advocacy Through the Lens of Black Disability Studies

M. Giwa Onaiwu | University of East Anglia Doctoral Thesis | 2022

Contents of Appendices

Appendix A: Plain language summaries of the thesis

Appendix B: Augmentative content and images

Appendix C: Copyright/fair usage, authorship, submission statements; final thoughts; sources

Appendix A Summaries (29,715 words)

These summaries were mostly written by Taiza Pickering.

Welcome Note for Plain Language Summaries

Hi! THANK YOU for reading my thesis (that's the name of reports like this one. The college I go to calls it a "thesis." Some other people, and other colleges call it a "dissertation." Both mean almost the same thing: a long report with a lot of details). I'm going to call it a "report" in this note, not a thesis.

It is important to me that different people who want to read what I've written have the same chance to understand as anyone else. That's why even though it took a very long time and a lot of work to finish the original version of my report, I wanted to include another version - the one you are reading now. (Confession: I like both, but this one is my favorite out of the two!)

This report using what is called "plain" or "lay" language. (They call it that because it uses plain, everyday language many people can understand. "Lay" stands for "layperson" - which just means a regular person, not a research scientist or a person who teaches classes in colleges.)

This report is just as important as the original one. It explains **all the same things** as the original one (plus some cool extra information that is only in *this* one). It tries to explain things in a clearer way than the original one because it uses regular, everyday language instead of a lot of long, technical words that only make sense to some people (probably less people). Because of these things, *this* report may be more important and helpful than the original one!

There are some ideas that are hard to explain even when you try to use simpler words. I tried to make things more understandable, but I know some things might still be confusing. I'm sorry about that, but I hope you still try to read what you can, and I hope you learn something from this report.

Every day I learn so much from the different experiences I have living in this world. I also learn from reading, asking questions, and trying to think about things in different ways. Even if you don't learn anything new from this report, I hope that reading it will be useful or helpful to you. Thank you once again!

Respectfully, MGO

BRINGING FIRE TO THE PEOPLE:

ACTIVIST SCHOLARSHIP, CREATIVE COLLABORATION, & INTERNATIONAL ADVOCACY THROUGH THE LENS OF BLACK DISABILITY STUDIES

A Plain Language/Layperson Version of the Doctoral Thesis (report)

Presented to

University of East Anglia

(Research and Teaching in Arts, Media, and American Studies)

For the Degree of

Doctor of Philosophy (PhD)

---

by

Morénike Sheri Giwa Onaiwu

2022

BRINGING FIRE TO THE PEOPLE:

ACTIVIST SCHOLARSHIP, CREATIVE COLLABORATION, & INTERNATIONAL ADVOCACY THROUGH THE LENS OF BLACK DISABILITY STUDIES

by

Morénike Sheri Giwa Onaiwu

A Plain Language Version of the original report by Morénike Giwa Onaiwu
Summaries of published and creative work included for:
University of East Anglia
Doctor of Philosophy (PhD)
Art, Media, and American Studies
(Arts and Humanities Program)
England.
2022.

Bringing Fire to the People: Activist Scholarship, Creative Collaboration, & International Advocacy Through the Lens of Black Disability Studies

M. Giwa Onaiwu | University of East Anglia Doctoral Thesis | 2022

List of things inside this section (Appendix A, B, & C)

Appendix A: Plain language/layperson summaries of the thesis

Appendix B: Helpful materials and images

Appendix C: Things that I have included that are required by the rules of my university

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Contents of Appendix A (everything in this section is in plain language)

A1. Welcome Note
(Welcome/greetings and some helpful information you should know.)

A2. Title & Copyright Pages
(The report's name and the rules [copyright] about who owns it [me] and how to share it)

A3. Appendix A Table of Contents & Helpful Tools
(This gives the order of the report and what is in each part. There are also optional links for more help.)

A4. Summary (Abstract)
(Abstracts are like a preview, "teaser," or "trailer," but in writing. This abstract explains this report.)

A5. Author's Note
(This explains a little more about why my report is different from other reports [For example, I have more than one version of my report so that I can use plain language and include more images].)

A6. Trigger Warning *(Written by L. Giwa – my beautiful niece!)*
(This explains that you need to know before you read this that some of the things that I write about in this report might cause you to feel strong emotions like sadness, anger, or fear. I talk about hurt, abuse, and other bad things that have happened to me or others [or could happen].)

A7. Summaries *(Written by T. Pickering)*
(This explains the content of this report in a clearer way so that more people can have a chance to read it. If a person chooses to, they can read Appendix A only instead of the whole report and still understand all the same information that is in the original report.)

HELPFUL TOOLS

Links

- Text to Voice Software Choices
  - Natural Reader: https://www.naturalreaders.com/
  - WordTalk: https://www.wordtalk.org.uk/
  - iSpeech: https://www.ispeech.org/
  - ReadSpeaker: https://www.readspeaker.com/
- About the Easy Reading Project: https://www.easyreading.eu/the-project/
- Access the Easy Reading Software Tool: https://www.easyreading.eu/

Copies of the Reports

Other versions (copies) of the thesis (report) that will hopefully be made available in 2023:

- A text-only PDF version of *both versions* of the thesis: https://MorenikeGO.com/resources/thesis
- A text-only PDF version of this *plain language version* of the thesis: https://MorenikeGO.com/resources/thesis/plain
- A web-based version of *both versions* of the thesis: https://sites.google.com/morenikego.com/thesis
- A web-based version of this *plain language version* of the thesis: https://sites.google.com/morenikego.com/thesis-plain

***Plain Language** Summary of ABSTRACT*

Giwa Onaiwu, M. (2022). *Bringing Fire To the People: Activist Scholarship, Creative Collaboration, & International Advocacy Through the Lens of Black Disability Studies.* University of East Anglia.

*(**FYI**: An abstract [what is on this page] is a shortened way to help explain what a report is about. If someone reads an abstract, they can learn helpful information about the report in a quicker way. This saves the person time and energy, so they don't have to wait until they have read a whole, long report to know what it's about. In that way, an abstract is a little bit like a "movie trailer," you can think of it as similar to the summary on the back cover (or inside) of a book. Or maybe like a preview of a show. Most reports have abstracts because after reading one, a person can decide whether they are interested in reading more of the report or not.*

I have written the abstracts and the reports that go with them because that is required for me to get my PhD degree from this university. I have gotten other college degrees before this one and they are both good. But years after that, I made the choice to spend more time and money to do more work to get the PhD too. Getting any college degree is a choice. There's no rule that people have to get a college degree or go to college at all. There are lots of different ways to learn things and lots of different places to learn. College is one of the ways that I chose. Getting one or more college degrees requires a lot of time, hard work, and money. This degree is important to me because it is the highest degree that I can ever earn; I want to do it right.)

There is an important saying that is used often by different groups of people who care about human rights, disabilities, and other important issues: "Nothing About Us Without Us!" (Sometimes it is written as "Nothing About Us Without Us is For Us!") This report is inspired by the ideas that helped to develop that saying: helping to explain different ways that people can serve as leaders to improve and change things in our world to make life better, fairer, and safer for every person.

I cover important topics in the report, many that I can deeply relate to because they are a part of my life such as disabilities, race, and gender issues. I describe the value of meaningfully including people from different backgrounds (some with learned experience; others with lived experience) to guide and inform research, advocacy, education, etc. I share thoughts developed by past and present leaders, especially from writers and advocates of color and with disabilities like bell hooks, Audre Lorde, W.E.B. DuBois, and Mel Baggs, using the example of how fire is made to describe how creative ideas are helpful in making sure all are valued and treated fairly. I also combine research, writing, and lived experience to use a method called "heuristic inquiry" to explore, understand, and explain the unique ways that knowledge can be formed and shared in our communities.

I divided this report into different parts so that more people can have a chance to read it. Appendix A is another version of the original report. It is written in plain language. Appendix B has extra information that is different from everything else that might be interesting to read to learn more. It is not written in plain language. Appendix C has different pages with signatures and information required by my college. It is not written in plain language.

APPENDIX A: Author's Note

I've decided to place a note in the front of the thesis (report). People who create notes like this usually put them in the back, not in front like I'm doing. (But I did something different this time because I actually want people to read it. I think more people will notice it in the front).

A thesis is usually a very long report with many pages. It often has complicated words most people don't really use in regular communication. Truthfully, many people don't even understand some of those words. Most of the time, when people write a thesis, they aren't writing it for everyday people because they think people will not be interested in reading it. They also think that even if people might be interested, many people probably wouldn't be able to understand it anyway. Because of that, they just write it for the small number of people they think will both care and understand.

But I do **not** want *my* thesis to be like that. For years, I have been trying to do and say things to help make the world a place that is more accepting. That's what this whole thesis is about: All people deserve to be included and accepted. To me, if I really believe acceptance is important, it can't just be something I talk about. I need to be a good example in the way I behave. That includes the way I write. I want many different kinds of people to be able to read and understand what I write.

There are some people, especially people who work in colleges, who think there is a certain "best" way to write reports like this thesis (using a lot of complex words and ideas that might not be clear to many people). I don't like the idea of only a few people being able to understand things, and I don't think it's good to write something in only one way if that way doesn't make sense to many others. I like writing things in a way (or in a few different ways) that many people can understand.

Even though I feel this way, since I am a college student, I do need to follow the rules of the college. (One of the rules requires a thesis to be written using complicated words.) I have followed these rules, but I also asked the college if it was okay for me to do something else too. I asked for permission to write a second type of report. I explained that my second report would be about all the same important things that I included in the longer report with more complicated words. However, the second, shorter version would be written with regular language to make it easier for most people to understand. They agreed; that second type of report is what you're reading right now!

****All of Appendix A is written in plain language.***

Most of the plain language summaries were written by Taiza Pickering.

APPENDIX A: ***Trigger Warning*** *(Translated by Lola Reese Green Giwa)*

I made a trigger warning for the entire thesis (report) because it has graphic descriptions that may make you uncomfortable. A trigger is something that can cause someone to have a feeling or memory that is a lot like something that has happened in the past (often something that wasn't good). The triggering content includes the following: treating or viewing someone worse than others because of race, disability age, sex, etc.; hurting someone you're in a relationship with; death; problems with mental health; and making someone do things they don't want to.

There is also information about: sex, unfair rules or people refusing to be fair, treating people in the LGBTQIA+ community unfairly, parents who hurt or kill their children, treating people with HIV unfairly, treating Black women unfairly, police officers or other people in charge being too rough or using too much force compared to the crime, having thoughts about killing yourself, trying to kill yourself, being treated badly because someone thinks you are different from them, getting badly hurt or even killed, negative emotions, religion, money, politics, being poor, etc.

There are also parts of the thesis that don't have triggering items, but honestly, it's hard to explain the "safer" parts of the thesis without talking about the graphic parts because they're very connected. Even though I think there are inspiring and positive things here compared to the triggering information, I don't know how to present it in a different way.

Do what is best for you and your sanity, even if that means not reading the thesis. Below I put some links that offer support and may help you. Thank you!

- *988 Suicide and Crisis Lifeline* (in the US; formerly the National Suicide Prevention Lifeline)
    - https://988lifeline.org/
- *Two pages of tips to help adults with stress and trauma* (from the National Center for PTSD [US] & the International Society for Traumatic Stress Studies)
    - https://istss.org/ISTSS_Main/media/Documents/appendix_e8_tips_for_adults.pdf
- *28-page packet called the "Managing Your Triggers" Toolkit* (from Robert Gass & Judith Ankara/The Social Transformation Project. Posted on the Mediators Beyond Borders website)
    - https://mediatorsbeyondborders.org/wp-content/uploads/2020/01/managing-your-triggers-toolkit.pdf
- *Info about how to text for free help if you are in a crisis* (if you live in US, UK, or Canada)
    - https://www.CrisisTextLine.org/text-us/

APPENDIX A: INTRODUCTION

Background

When I was young, I entered the field of human rights. It was rewarding, but I thought it was temporary. I had planned to get a college education, so I could get a high paying job and enjoy a high standard of living. Life is unpredictable, and it led me down a different road than what I expected. I became an activist, which is my true calling.

I got into activism because I felt like I was overflowing with anger. As I saw and learned about injustice and how it didn't always seem like it was an important issue to other people, I felt helpless and angry. I used my anger as useful energy for activism and tried to help people and to fight for important changes. Before he died, Black civil rights leader Congressman John Lewis encouraged people to cause "good trouble" to help make our world better. (Ray, 2020, p. 1, para 1). I tried to do that instead of thinking that the problems in the world would never be fixed and that we had to just accept things that weren't right.

As I grew and changed, the anger I felt cooled off, but I still cared about activism. It became a way of life for me, and it has deeply influenced my college education, career, and lifestyle.

This thesis is part of my story. which is part of our collective story—the story of humanity.

APPENDIX A: STRUCTURE

Activism as Fire

To understand the structure of this thesis, think of three triangles. One triangle represents fuel, another heat, and the last oxygen. When you put the three triangles together in a three-dimensional way (like a three-sided pyramid), you form something new that is the combination of them all. In this case, what forms is the three-sided pyramid, which represents fire. A tetrahedron is a three-sided pyramid. This metaphor of the tetrahedron of fire is used as an example to build this thesis.

I chose fire for comparison (as an analogy) because of the way fire has transformed human history and way of life. Fire allowed humans to travel, live in harsh climates, cook food that would otherwise be toxic, avoid predators, helped change how we communicate, how we transport and produce items, etc. But even with all the benefits fire has given humanity, it can still be very dangerous. The risk of possible danger and damage caused by fire can be compared to activism too. Once a fire has started, it can create permanent change and/or burn everything in its path to the ground. Activism can work the same way, as stated over 100 years ago by W.E.B. Du Bois in *The Souls of Black Folk*: “To stimulate wildly weak and untrained minds is to play with mighty fires.” (Du Bois, 1903, p. 2)

Fire Tetrahedron

Fire can be hard to observe directly. This applies to the three-sided pyramid analogy mentioned above as well. Explaining the three triangles that make up the pyramid—fuel, heat, and oxygen—and what they represent will help the analogy make more sense.

Fuel is a symbol for my scholarly work. In other words, my academic (educational) pursuits (research, writing, etc.) fuel my activism. I have studied theories, thoughts, and ideas that influence the world we live in; but I have also learned tips that are useful for life in general and especially for activism. (Collins, 1990, p. vi-xiii). Think of all of the learning required to get a doctorate, and then think of that as kindling for the fire. But it’s important to understand that knowing something does not cause anything to change by itself, just as fuel does not start itself on fire. Studying important topics such as disability justice, engaged pedagogy, and public intellectualism doesn’t do anything by itself. Action is still needed.

That takes us to the next triangle. Heat.

Heat has two parts. First, as a verb it is a symbol for working together. The focus is "we" instead of "me." As sociologist Patricia Hill Collins states in the second version of her groundbreaking book *Black Feminist Thought*, "The struggle for justice is larger than any one group, individual, or social movement…it is a collective problem that requires a collective solution." (Collins, 2009b, p. xiii) Second, heat as a noun is a symbol for a temperature increase. Temperatures can rise when there's a change in outside circumstance. In this way, heat can be compared to social pressures in life that "heat things up" and what that might cause. As an example, if society were an oven, the baking elements causing a heat transfer would have an impact on anything within that oven. As Black scholar-activist Audre Lorde states, the future requires us to "identify and develop new definitions of power and patterns of relating across difference." (Lorde, 1984, p. 114-223)

Oxygen is the final triangle making up the third side of the pyramid of fire. It is a symbol for knowledge and action working together in a practical (useful) way within the lived human experience. Oxygen works well a symbol because it (oxygen) is necessary for life. Also, oxygen has been described as an ingredient of activism. We've all heard the expression "put on one's own oxygen mask" before that of others as an example for activist self-care (Connely, L.A. & Hubbard, R. 2022, 3:52-7:32; Shepherd, 2018, para 5, 6, 9-15). There's also an expression, or cliché, about someone "putting on airs" that points to how people identify and show themselves to others. I carry this over to the symbol of oxygen as a symbol for a person's identity. Du Bois and Lorde described the nature of identity: 1. It can change, and 2. Different parts of a person's identity can overlap (Du Bois, 1897, para 1, 3; Lorde, 1971, stanza 1; Popova, 2017, para 4). It's possible for one oxygen atom to exist by itself, but that's not very likely. Oxygen atoms are usually grouped together with other oxygen atoms or grouped with other molecules. How oxygen presents itself depends a lot on what it's around. It's the same for identity, which has many parts and doesn't want "the older selves to be lost." (Du Bois, 1903a, p. 10-11) Also, identity and oxygen can both change—at least temporarily—into a different state (an isotope) under stress.

The fire tetrahedron is fuel + heat + oxygen = fire. Fire is the resulting event. Fire is a process; it is the outcome; a whole that is greater than the sum of its parts. Fire, while hard to control, can be easily seen and recognized, and it can change its surroundings dramatically. Combining scholarship, community collaborative work, and activism can also create huge, dramatic changes. And when those changes show up in the form of resistance or resilience often seen in activism, it becomes clear how deep our thoughts and emotions can be, a lot like how Phyllis Wheatley Peters (who wrote very powerful poetry) is described in Jesmyn Ward's *The Fire This Time*. (Jeffers, 2016, p. 80)

APPENDIX A: RESEARCH METHODS (Bonus Content)

Research Methods

This doctoral thesis looks at many resources from different subject areas, and most of them would probably not be grouped together. It also tries to explore the experience of being human from the perspective of a human. I considered several research options and decided to go with a specific approach that is not widely used but does exist and has research to prove that it is effective. (Moustakas, 1990, p. 9, 47). It uses autobiography and is considered a "social constructivist" approach.

In a paper like this, there are three main type of research people often use: a) autoethnography, b) interpretative phenomenological analysis; and c) grounded theory. I found none of these methodologies were the best choice for the ground I wanted to cover in this thesis. Phenomenology focuses on the past and I wanted to focus on past and present. Grounded theory searches for one main theme and because it is heavily data-focused it can be hard to make it work in research that explores the experiences of people who are marginalized. It's also hard to make it work with research topics that are based on feelings and opinion and/or are more human-centered. (Sultan, 2019, p. 9) So I didn't choose either of those methods.

Autoethnography is a method for understanding how a topic has been experienced by "one" self—the researcher. I wanted my research to focus on more universal experience. (Throne, 2019, p. 66-67) I didn't choose autoethnography because it wouldn't have helped me study the bigger picture of lived experiences of marginalization related to race, gender, sexuality, disability, serostatus, ethnicity, household, etc.

Heuristic Inquiry

Heuristic Inquiry is a method of research that expands upon heuristics and takes part of its name from the Greek word *heuriskein*, meaning "an internal search for knowledge" (Moustakas, 1990, p. 9). Heuristics relies on experiencing life as a human being, exploring relationships and interactions between the human being and their experiences. According to heuristics, the idea of "being human" is built on a person's invisible and internal thoughts and how we process them to solve problems. The problem-solving skills involve obtaining crucial information, and making complicated decisions (Chen & Wohlner, 2021).

At first glance, Heuristic Inquiry might seem simplistic, but it is a very detailed research method that describes qualities and characteristics that was developed by American psychologist Clark Moustakas, who was a leader in humanistic psychology. Heuristic inquiry is based on content, data, and investigation and uses heuristics as described above to conduct research. (Throne, 2019, p. 66-67; Moustakas, 1990, p. 9; 27; 39-40) with a six-phase process: *initial engagement* (experience/idea), *immersion* (exploration), *incubation* (reflection and/or brainstorming), *illumination* (discovery), *explication,* and *creative synthesis* (Sultan, 2019, p. 10-18; Moustakas, 1990, p. 27-33, 39-40).

Heuristic Inquiry uses a system, but it is non-linear, meaning it does not go smoothly from one stage to another like points on a line. Because it is non-linear, the scientific researcher can be blended in with the scientific inquiry (only if it relates to the study). The goal of Heuristic Inquiry is to create a unified story of human experience that is both unique and universal (Sultan, 2019, p. 13-15, 21-22; Moustakas, 1990, p. 130). Researchers attempt to look beyond their own biases while trying to understand what is actively happening. Heuristic Inquiry uses tools such as creative expression (art, images, music, journaling), interviewing, and exploring processes and items that belong to a specific group (or to specific groups) with the goal of a shared inquiry in mind.

Literature Review Search Strategy

The approach and structure of this thesis made it impossible to use limit my sources just to "traditional" data because that would not have allowed to answer the study's research questions. Instead, this thesis reviews a mix of information (literature). I selected what to review took place over time, not all at once, and there were several searches. The early searches helped make it clearer in later searches what information should be searched for and be included.

It is very important to me that my communities are able to understand and see themselves in this work. Because of this, including their voices was of utmost importance. In searching, I included both scholarly (traditional academic) and "gray" literature (information that does not come from "peer-reviewed" books and journal articles). I also used known sources. (Grollman, 2013, p. 7-10; Diaz et al, 2021, para 1, 4-5) I wanted to go beyond academic material to include nontraditional sources and show that they are valuable, they are many, and they are legitimate, especially information from BIPoC and/or disabled activists. This also fits with a growing call for the world to expand the idea of Public Intellectualism. It shouldn't have to be connected with a university to be worthwhile. (Fraser & Griffin 2020, p. 1005-1031)

It’s also really important to recognize and understand that even though the role of the Black Public Intellectual and the Black woman has been powerful, both are often ignored and/treated unfairly, both in academia and activism. (Collins,1990, p. vi, vii; Fraser & Umouren, 2022. p. 1-5) Sadly, disabled people also mistreat other disabled people at times. Using Heuristic Inquiry as my approach has allowed me to bring attention to all of this erasure and mistreatment. Heuristic Inquiry is a form of inclusion, as I reject the idea that “I must alienate myself from my communities, my family, and even my own self in order to produce credible intellectual work (Collins, 1990, p. ix).” Heuristic Inquiry allows me to meet the scholarly requirements for my thesis while also including my communities.

Research Questions

Reflecting on years of experiences and knowledge, my thesis seeks to answer these questions:

1. How much do the collected works reflect, discuss, and inform about the lived experience of people living with multiple marginalizations?
2. How does this body of work encourage dialogue and teaching moments in the tradition of Black disability studies?

Overview of Thesis Structure; Content

I am including this introductory section and sharing a breakdown of the structure to make the overall thesis easier to understand, beginning with my background as an activist. Next, I talk about the use of fire as a metaphor and the three-sided pyramid to describe structure, and then stating my research methods.

The next sections review literature which explores the three major themes that I discovered through Heuristic Inquiry. Those themes are public intellectualism, engaged pedagogy, and disability justice, and will be explained in detail along with information about important experts (primarily BIPoC and disabled) and their thoughts and ideas.

The material after that helps analyze years of creative and published work. They also address scholarly topics, activism, and how the two them can work together well in daily life. Those topics include activist scholarship, creative collaboration and care work, international advocacy efforts, burnout, etc. The conclusion, ties everything together. Then, there is a portfolio that contains some examples of the work (chapters, articles, etc.) and closes out the thesis.

Outside of the required information before and after the thesis (called “front” matter and “back” matter, such as the abstract, references, etc.), the rest of the thesis is optional/not required. It is information that I wanted to have as part of my thesis even though I did not have to include any of them. There are three appendices (Appendix A, B, and C) that are special sections after the “official” part of the thesis ends. Appendix A, which offers detailed summaries (translated by Taiza Pickering) written plainly for the everyday human (layperson). These summaries cover the content in the thesis. They can be used as a substitute version of the thesis, or they can be used to help with the thesis. The thesis also has trigger/content warnings, a note on accessibility, images, image descriptions, etc.

Using the Heuristic Inquiry research method, this doctoral thesis explores important information, using symbols, themes, etc. to understand the material. I review published and creative work created over a period of time. The goal of the study is to highlight the perspectives and experiences of people with marginalized identities as their lives do not receive enough focus and attention. The study mainly highlights people who are disabled, gender diverse, and/or communities of color.

APPENDIX A: CRITICAL FRAMEWORKS (IDEAS)

Public Intellectualism

Something called Public Intellectualism is important in my work. To some people, Public Intellectualism means the opinions of highly educated experts that guide public opinion. (Mitchell, 2017, para 2-4) An example many people will know of is Doctor Anthony Fauci. His guidance through the coronavirus pandemic is an example of Public Intellectualism according to this definition.

However, I think the definition of only considering the highly educated people to be public intellectuals is limited. The Oxford dictionary defines Public Intellectualism as "…an intellectual who expresses views, especially on popular topics, intended to be accessible to a general audience," and to me, that is also too simplified. (Issitt & Jackson, 2013, p. 1-9; Oxford, 2021, definitions)

Ralph Waldo Emerson's *The American Scholar* presents a description of the "public intellectual" that is closer to how I define the word. The "One Man" Emerson describes represents "the farmer, the professor, the engineer, the priest, the scholar, the statesman, the soldier, and the artist." (Emerson, 1837, para 5) This means the idea of who is a public intellectual includes far more than just people who are seen as experts because they have college degrees. Public intellectuals don't always have a college education. They can be experts because of life experience and knowledge of the real world, and not just the theories that many intellectuals are experts in. Taking it a step further, the public intellectual represents all humanity. (Lightman, n.d., para 4)

Appalachian scholar Katie Trauth Taylor created a writing and mentoring company, Untold Content. This company uses "innovative storytelling" to create public intellectualism. (Untold Content, n.d., para 3-7) Taylor's description of public intellectualism as the belief that "all voices should be heard, knowledge should be shared, and that people should have access to information" matches up with my focus and values as an advocate. (Clark, 2017, para 13-17)

Edward Said, a Palestinian American scholar, wrote about public intellectualism in a way that lines up with my beliefs. Said explains that those of us who are in the public eye have a huge responsibility: "The intellectual's role generally is to uncover and elucidate the contest, to challenge and defeat both an imposed silence and the normalized quiet of unseen power, wherever and whenever possible." (Said, 2001, p. 19-39) I share these feelings, and I try hard to live them within my words and actions.

The work of the sociologist Patricia Hill Collins, whom I've mentioned before, outlined public intellectualism in a way that I agree with most. Her amazing book *Black Feminist Thought* stresses the importance of examining "the complexity of ideas that exist in both scholarly and everyday life," and "presenting those ideas in a way that makes them not less powerful or rigorous, but accessible." (Collins, 1990, p. vii-viii) For me, making ideas understandable and inclusive is both my minimum standard and a core value of the work I do. I recognize that making something so absolutely everyone can understand it may not be possible; however, I believe in making the best efforts in trying to do so.

Next, let's look at what accessibility is, and what it means to make a message accessible. Font type and size, captioning, color contrast, image descriptions etc. all make messages more accessible. Avoiding blocks of text, jargon, buzzwords, and unexplained acronyms also makes information more accessible. Making sure material can work with screen readers, text to speech, and other tools also makes information accessible. All these things help make information accessible, but more is required.

True accessibility includes the message itself. One way to do this is by making connections and finding ways to bridge the gap between theory and real life. The gap between newbie and expert also needs to be bridged. Basically, it is *critical* that difficult concepts are clearly communicated without oversimplifying or giving up the intended meaning. I agree with Collins (1990, p. vii) that it is "the ideas themselves are important, not the labels we attach to them." Personally, it matters more to me that someone can express the way(s) their disability, gender, and/or race may overlap than whether or not the individual in question knows to use the term "intersectionality" in doing so!

In her book *Intellectual Activism*, Collins points to another aspect of public intellectualism that I use in my work: "My lengthy educational training was designed to equip me to wield the language of power to serve the interests of the gatekeepers who granted me legitimacy," Collins (2013) shared. "My teachers did not consider that I might choose to use the same weapons to challenge much of what I learned." (p. 36-41) I relate to this because my educational background (inside traditional "schools" and outside of it) is extensive, and I took a *very* scenic route to get to where I am now. This helps me understand what much of the world think is and isn't "acceptable" and gives me privilege others may not have. For example, I have college degrees. I can write using academic, technical, and business styles. I understand difficult concepts easily. I can argue and defend my point of view when needed. I can often find ways to deal with social situations that others with a neurodivergence might find difficult even if I am also uncomfortable in those situations.

Basically, I have jumped through enough hoops that I am considered “successful” by much of the world’s rules. So even though there are parts of me that might not be respected, people look past those things and still value what I think or say. Because of this, I often have a “seat” at the table to help make decisions or share my ideas. I deserve the seat, but it can be stressful having it. Since people like me aren’t usually given a seat, there are people who do it but don’t like doing having me there. Also, that seat comes with hidden “strings” attached. There’s an unspoken expectation that I should be grateful to have a seat. They think instead of trying to get more people seats at the table I should not rock the boat, so to speak. They believe that I should maintain the status quo of the people already at the table.

Moving through the maze of systems, where I have a seat at the table, is hard, but knowledge is still very powerful. Few things can challenge the power knowledge has to create tremendous change. I agree with Collins’ (1990, p. vi-ix) saying that “Theory and intellectual creativity are not the province of a select few but instead emanate from a range of people.” Sadly, this doesn’t seem true in real life. For most of human history, knowledge has been guarded and withheld by those with power to harm and deny rights to those with less power.

In too many situations, the quote “The master’s tools will never dismantle the master’s house,” something Lorde said (1984, p. 112), is true. The quote means while a person can learn how the powerful keep their power, the person can’t use that learning to change the systems in place. That doesn’t have to be the case with public intellectualism. If anything, to play on Lorde’s quote, we now possess the “blueprint” of the master’s house, the toolbox, and even the tactics the master has been using to do battle. We can then, according to Said, use them to “alleviate human suffering” and for “speaking truth to power.” (Said, 2000, p. 454-469)

Public intellectualism helps us plan strategies and launch a counterattack against those who try to use knowledge against us. For example, legendary Black author Toni Morrison challenges the established literary community using literary criticism–one of their own tools! Another example is queer autistic scholar Remi Yergeau. Yergeau uses rhetoric from Aristotle and Zeno of Citium in written reflections to show the value of autistic communication. (Morrison, 1992, p. x-xiii, 16-17; Yergeau, 2018, p. 14, 21-23, 32, 34, 40, 45) By expanding who is considered a public intellectual, and granting their work the status of Public Intellectualism, everyday people have access to knowledge that gives them the ability to evaluate–and change–their circumstances. Making knowledge available, and the power it brings, is at the heart of “bringing fire to the people,” in order to empower them.

Engaged Pedagogy

As a very brief description, Engaged Pedagogy is a collective philosophy that wants to see all people thrive in life. It values living consciously and the importance of personal connections with others. It stimulates learning through active participation in a shared learning community. With Engaged Pedagogy, learning doesn't happen in a vacuum, and the learner is not a neutral participant removed from their environment. The learner, the teacher, and the environment are all a part of the system of learning taking place. These all have value and responsibility in the system of exchanging of ideas and learning.

The concept of Engaged Pedagogy is central to my work. This concept was founded by the celebrated bell hooks (1994, p. 13-22), who stated it is not a set of practices, but a calling. Engaged Pedagogy disagrees that the traditional ways of teaching and learning are the "correct" way. Instead, it focuses on embracing and modeling vulnerability and growth, while including the idea of being "better, whole human beings," and to encourage others to do the same. All of this considered part of getting an education. (hooks, 1994, p. 15-22)

Next, I want to look at philomathy, which refers to an "enjoyment of and passion for learning new facts and acquiring new knowledge." (Dhiman, 2021, para 5) This term is rarely used, but I use it to point to something specific. In my case, this was an early sign of a natural impulse towards Engaged Pedagogy before I even knew what pedagogical methods were.

Philomathy is likely my oldest "special" interest—an intense focus on a topic that, according to Jordan & Caldwell-Harris (2012, p. 391-402), is common in many autistic people. There's a frustrating double-standard, though, when a child has a passionate focus in learning one topic. The world approves of intellectuals having "specialized knowledge," but when an autistic person single-handedly pursues learning a topic, it's seen as abnormal – "restricted, repetitive patterns of autism." (Labor-Warren 2021, para 1-7, 20-21)

The way I see it, Engaged Pedagogy is an extension of Public Intellectualism. As mentioned earlier, Public Intellectualism is about using the knowledge and expertise of others to learn, evaluate, and make good decisions for change. Engaged Pedagogy is the learning environment to make that happen, in a system that values living consciously and valuing connection to other people. As far as education goes, this helps to position teaching as a powerful tool for change.

North American scholar Henri Giroux says as much, with the quote below:

> As radical educators, we can help destroy the myth that education and schooling are the same phenomenon; we can debunk the notion that expertise and academic credentials are the primary qualifications of the 'intellectual,' and, equally important, we can provide, discuss, and learn from historical and contemporary examples in which working-class people and others have come together to create alternative public spheres. (Giroux, 1983, p. 239)

hooks believed all people have valuable knowledge and opinions, and that everyone should have a seat at that metaphorical table mentioned earlier. (hooks, 2009, p. 21) Current learning systems claim to be "objective" and neutral. So does most of academia. This discourages personal judgments and opinions about material being learned. Engaged Pedagogy challenges this idea. The "self" can never really be taken out of the picture. According to Collins, this is part of the learning process. Engaged Pedagogy "doesn't require separation…from our own experiences nor does it require, or assume that it is possible, to separate our thoughts from our feelings." (Collins 1990, p. 258-263)

As a fan of Engaged Pedagogy, I've created a combination of learned and lived expertise as a signature of my work. I purposely mix personal stories with data. Different parts of who we are bleed into one another, so I identify and strengthen these connections. Critical thinking is used in combining the scholarly and personal, so this approach does not weaken the content. (hooks, 2000, p. 7-11)

Engaged Pedagogy shows up in my professional work as well as my personal life, and that's a big part of what Engaged Pedagogy *is*. Intellectuals are often taught to separate their professional and personal lives. (Lorde, 1984, p. 116-119) Engaged Pedagogy, however, strongly rejects the idea that what we "do" is different from who we "are." According to hooks, the role of an educator is like a healer—and a broken healer cannot properly heal others. With Engaged Pedagogy you cannot be seen as a talented "genius" in one part of life while causing damage and abuse in another. (hooks, 1994, p. 15-17)

As actions speak louder than words, I strive to live what I teach. My opinion on this issue is similar Engaged Pedagogy's view. I think the belief that one's private and professional life don't affect each other is dangerous and wrong. Unfortunately, hooks explains, this duality is common in our society despite being hypocritical and toxic. There have been, however, hopeful signs of change. The Me, Too Movement and Mute R. Kelly campaigns suggest the public is pushing back against the falsehood that our harmful private actions have nothing to do with our public selves. (Tsioulcas, 2021, para 6-9)

Finally, hooks (1994, p. 21) states that individuals who "embrace the challenge of self-actualization" work better with others and offer "ways of knowing that enhance their capacity to live fully and deeply." Continual growth is another value of Engaged Pedagogy. I often self-identify as a "lifelong learner." Just as fire cannot exist without heat, fuel, and oxygen, for those who embrace the Engaged Pedagogy framework, working for wholeness is necessary to be a powerful leader. As an advocate, I want to encourage, care about and influence others. (hooks, 1994, p. 15, 19) Whether writing, editing, delivering a keynote address, engaging in activism, or giving a guest lecture, it is never my intention to just "make a point." I aim, in all things, to "make a difference."

Engaged Pedagogy is a thought-system that seeks to help people to thrive in general, not just in one narrow area. Knowledge is *no*t something that happens only in a classroom environment. *All* students bring their own life experiences, which adds up to their own knowledge as lived expertise. Nurturing and developing this self—which comes with us into the classroom; into the boardroom; into the field; into our research; into our relationship with Public Intellectualism—has benefits far beyond any academic achievements is crucial for simply being in the world. (hooks, 1994, p. 14-15)

Disability Justice

Disability Justice is a framework and concept that forms a major part of my work. It serves as the real-world link between public intellectualism and engaged pedagogy. Disability Justice holds "...a vision born out of collective struggle, drawing upon the legacies of cultural and spiritual resistance within a thousand underground paths, igniting small persistent fires of rebellion in everyday life," according to disability activists Patty Berne, Mia Mingus, Leroy Moore, the late Stacey Park Milbern, Eli Clare, and Sebastian Margaret. (Projects LETS, 2021; Berne, 2015 para 11-13)

Disability Justice has ten main principles: Intersectionality; Leadership of the Most Impacted; Cross-Movement Solidarity; Cross-Disability Solidarity; Recognizing Wholeness; Sustainability, Anti-Capitalism; Interdependence; Collective Liberation; and Collective Access (Sins Invalid & Berne, 2015, p. 3). These principles change the way we look at connection between issues. They also influence how we interact and engage with one another in safe (or brave) spaces (Ali & NASPA, 2017, p. 1, 3-4); Collins, 2009a, p. 100-101, 110). Disability Justice focuses on people who live in the margins of disability, race, gender, socioeconomic status, sexuality, age, citizenship, and other marginalized identities. (Sins Invalid & Berne, 2015, p. 1-3)

There is an important difference between Disability Justice and the disability rights movement that preceded it according to Mia Mingus, a disabled activist of color, educator, and writer (in a 2010 article about social justice, para 16-18). Disability rights focused on independence in "education and advocacy around systems and attitudes." Disability Justice makes a point that "rights" are granted or taken away by those in authority, but justice is intangible that cannot be taken away. (Disability Activist Collective & Ortiz, 2010, notes).

Disability Justice believes people have value just because they exist. Independence is not highly valued because Disability Justice accepts the reality and the beauty of interdependence. Our bodies, our minds, our past, our circumstances…they are not merely things that must be forced or "overcome." Social standards and medical standards of disability are often seen as two separate things; Disability Justice doesn't see it that way. It does not expect us to try to hide our cultural background, gender identity, or other parts of ourselves to also accept our reality as disabled. It celebrates the value of every person without caring about their contributions.

Disability Justice reflects my life experience as an individual with many identities, some privileged and some marginalized. Many parts of my life overlap one another. I am Black. I am also Autistic. I am a non-binary woman who was assigned female at birth. I am a parent of disabled children and part of a neurodivergent, serodifferent, multicultural family. I'm an "Xennial" (born between the Generation X and millennial generations) who grew up under the protection of the Americans with Disabilities Act, however imperfect it may be. These all influence one another; I cannot separate them.

Disability Justice can be easily compared to the fire tetrahedron. The disability rights movement that came before Disability Justice developed for a good reason. But it left gaps and unmet needs. Knowledge of these gaps can fuel change. The heat of collective action can force people to realize there is a need for change. People working together, breathing life into something that corrects those gaps, is oxygen to the fire.

We shouldn't waste time and energy worrying what the disability rights movement got wrong, Disability Justice instead urges us to be reflective while taking action. Disability Justice offers us the chance, together, to do things right instead of dealing with the fallout of what didn't work. If we can learn from our past and make the right choices now, it will save us from having to face, as James Baldwin (1963) predicted, "The fire next time."

The Disability Justice framework shows how ableism is linked to other systems of oppression. Disability Justice seeks to change how we see disability as a single, isolated issue of concern, when for many of us, it is not. Because of this, Disability Justice involves looking at small details, the big picture, and everything in between. By "fighting for an interdependence that embraces need and tells the truth," Disability Justice challenges beliefs about vulnerability, what being "productive" means, and about our value as humans:

> It's not easy to live with an impairment. There are times when it's not convenient to have a body. But that's not what oppresses us. What oppresses us is living in a system that disregards us, is violent towards us, essentially wants to subjugate our bodies or kill us -- that's oppressive. My body doesn't oppress me. (Berne, 2015; Project LETS, 2021)

Disability Justice pushes against the idea that people's bodies and minds are considered broken, unproductive, abnormal, devalued, etc. It promotes collective access, collective care, collective growth, and collective liberation. According to the late queer disabled BIPoC activist Stacey Park Millbern, "If I'm in a place where my access needs are being met, then my impairment isn't so significant." By accepting the different parts of who we are, Disability Justice allows us to be our whole selves.

As disability activist and luminary Patty Berne bravely declared, "There are always going to be people in pain. That's just the nature of being in a body. But the social body we can change. And I think it requires a power analysis." (Project LETS, 2021)

With that in mind, to me Disability Justice is Public Intellectualism and Engaged Pedagogy combined! But that's not all—I also consider it justice that moves us to care about and work "…with other oppressed groups, educating ourselves, creating solutions and community power can serve everyone." (Disability Justice Collective, 2010 para 1-7; Mingus, 2011, para 1, 3-5, 8-12)

Black Disability Studies

"Are you willing to not only do the work, but be transformed by it?" (Schalk, 2022, p. 2) In her book *Black Disability* Politics (2022), Sami Schalk, a disabled Black queer public intellectual, asks this question. Getting involved in activism in the tradition of Black disability studies truly changes you. But it does, Schalk warns, require "breaking some norms of academic research and writing" and "changes in scholarly and activist methods and frameworks." (Schalk, 2022, p. 2-8)

Schalk also explains that Black disability politics is a subtopic of Black disability studies. Black disability politics has four characteristics. I am listing them here: 1) It is intersectional, but race-centered; 2) It looks at history and at context; 3) It does not necessarily require identifying as disabled; and 4) It looks at the whole picture and has a broad range. (Schalk, 2022, p. 5-6, 10-17)

Schalk credits different scholars, and celebrates this new, budding field of Black disability studies. The field was formed through blending “scholarship, theories, and methods from disability studies, Black studies, postcolonial studies and Black feminist theory.” Schalk suggests disability politics “…actually exists in Black activism and cultural work, but manifests and operates in ways that do not look the same as disability politics in the mainstream movement.” (Schalk, 2022, p. 5-6) This mean the essence of Black disability studies exists in Black activism, even if it is not visible in mainstream activism.

Blackness and disability are areas of marginalization that often get sidelined together, what Schalk calls the “discursively linked” nature of Blackness and disability. Schalk declares, “I cannot get on board with approaches to disability that do not understand it as inherently, inextricably tied to racism and other oppressions.” (Schalk, 2022, p. 2)

I deeply relate to Schalk’s passion and commitment to activism where Disability Justice and Black Disability Studies combine. This connects to a main idea in my work: intersectionality. This idea is so important that it shows up repeatedly in my work–scholarly papers, collaborations, and activism. My activism is “a labor of love, but labor nonetheless.” (Schalk, 2022, p. 2)

APPENDIX A: FUEL - ACTIVIST SCHOLARSHIP

Fuel is what starts and is needed to keep a fire going; without fuel a fire cannot burn. Fuel is different from the other parts of the fire pyramid because it is a "reducing agent." That means that fuel undergoes a process of loss. (The other parts of the fire pyramid–heat and oxygen–are changes made from a process of adding. Heat needs added temperature; oxygen involves adding electrons in the chemical process of oxidation.) As fuel burns, it loses energy, so it has less energy than it started with. It can never get this energy back. In fact, with some fuels, like natural gas and oil, it's possible to burn through the entire source of the fuel on the planet. (Heron, 2018, para 1-8) These sources are nonrenewable.

The US Geological Survey found that in America, almost all energy that is used comes from nonrenewable fuels—a total of 85% overall. 99% of US vehicles run on gasoline or diesel oils and 70% of US homes use natural gas for cooking, heating, and drying clothing. Even making electricity uses nonrenewable fuel, because burning coal is how more than 50% of US homes get their electrical power. (Heron, 2018, para 4) While fossil fuels, including natural gas, oil, and coal are useful, burning them has negative consequences. These commonly used fuels have ruined our environment. (Johnson, 2017, para 3-4) Drilling, mining, and other ways of getting these fossil fuels from the earth destroy natural areas, killing plants and wildlife, and creating toxic waste. Also, burning these fuels creates carbon dioxide. (Heron, 2018, para 1-6) This changes the pressure in the atmosphere and causes climate changes that cannot be undone. Fossil fuels also create air pollution as carbon monoxide, nitrogen oxides, sulfur dioxide and particulates are released upon burning. (Lee, 2017, para 1-7)

In comparison, less than a tenth of US electricity US comes from renewable fuel sources. Renewable fuels include wood fuels, wind energy that comes from windmills, moving water through dams–hydroelectric power, and using heat from the earth's core–geothermal energy. (Heron, 2018, para 7-8) All of these renewable fuels are great alternatives to consider as energy sources. Aside from being practical, abundant, and replaceable, they don't destroy the environment the way fossil fuels do. (Johnson, 2017, para 1, 4)

Fuel is an excellent comparison for my academic studies. Without this important part of my life's journey—my academic contributions—many of my other achievements would not exist. It's allowed me to collaborate creatively, be a global activist, create "own voices" edited collections, present at the White House, and address the United Nations. Every one of these events happened because of my scholarly work.

I can compare my scholarly work to the renewable energy above, which makes up a small percentage of the total amount. That being said, the significance of my academic work far outweighs its actual size. Realistically, without it, would I be given the platform I have– among world-leading investigators, health professionals, and other influential people to openly challenge the status quo and call for change for issues affecting my communities?

Quite simply, probably not.

Sole-Authored Publications (written only by me)

There are a few specific examples of my scholarly work that powerfully call for change. In one piece I wrote, "'I, Too' Sing Neurodiversity," I refer to another work "I, Too," written by legendary poet Langston Hughes, which in turn, Hughes wrote in response to Walt Whitman's "I Hear America Singing." In the face of racism, Hugh insists on his rightful identity as an essential part of America (Giwa Onaiwu, 2020b, p. 58, 66; Funari, 2013, para 6-8). The article I wrote explains the need for anti-racism in the neurodiversity movement. This is done by pointing out microaggressions–subtle behavior and interactions that disfavor a specific group of people–specifically, neurodivergent people of color. In it, I also encourage White allies to take measurable steps in addressing racism within neurodiversity. (Giwa Onaiwu, 2020b, p. 58-67)

"'I, Too,' Sing Neurodiversity" is one of the top ten most downloaded articles in the publication it appears in (ScholarWorks GVSU, 2022, list). The article initiated important conversations about including people within neurodiversity communities, and also literature. (Burton, Carss, & Twumasi, 2022, p. 56) Like fuel, I underwent a process of loss after writing the article. White colleagues have distanced themselves from me professionally and personally since it was published. Also, I have not been asked to speak again at the summit referenced in the article. I discovered that challenging the perspective of a dominant group can lead to dismissal. As Collins pointed out, (1990, p. vii) "we frame our ideas in the language that is familiar to and comfortable for a dominant group" certainly rings true for me.

The hypocrisy is both upsetting and crushing...that the very same individuals who are fighting against ableism are unwilling to face the racism in their own ranks; they cast out those of us who speak up. Like Collins, the famous Black scholar W.E.B Du Bois also warns about this happening, as he reflects on the difficulty of the Black man (person) in America:

> This world...yields him no true self-consciousness, but only lets him see himself through the revelation of the other world. It is a peculiar sensation, this double consciousness, this sense of always looking at one's self through the eyes of others, of measuring one's soul by the tape of a world that looks on in amused contempt and pity. (Du Bois, 1903, p. 194)

I am disappointed. It's not just non-autistic White allies who have condemned me for trying to challenge racism; some leading White autistic individuals have done so as well. Instead of seeing my efforts as "autistic joint troubleshooting," I have been accused of creating conflict in the neurodivergent community. Autistic strategist Terra Vance (2021b, section 4), of the autistic-led nonprofit NeuroClastic, helps to explain what autistic joint troubleshooting is and its overall purpose:

> When autistics confront a violation of values, they expect and anticipate that others in their shared social intersection will be grateful to them for helping someone to honor their values. Doing that is something an autistic person sees as validating a person's identity. For those who think deeply, it (joint troubleshooting) is a social way to process what's on your mind with the input of another person (or people) who may be able to lend their own perspective to the discussion. (Vance, 2021a, section 3)

What that quote says in more plain terms is that, when autistics notice something is wrong, they point it out because they generally expect the person(s) they are pointing it out to will be glad that someone made them aware of it and will be motivated to fix it. Autistics seek a respectful conversation that works towards a win-win solution and equal problem solving. They aren't bringing the issue up because they want to cause problems; this is often how we try to fix it. Autistic people constantly experience marginalization in the form of ableism, so I was shocked when my concerns about racism showing up in our community were dismissed. I thought we'd be able to problem-solve the issue; instead, I received a cold-shoulder. I often feel as though:

> Like in nearly everything else, White is the "default" and everything else is merely Other. White is the foundation upon which neurodiversity rests; White is the standard (that) neurodivergent individuals are measured against; White is the de facto status quo. …Anything that does not perpetually center this toxic Whiteness is perceived as a threat. (Giwa Onaiwu, 2020b, p. 62-63)

Although we share similar brain-wiring, perhaps White autistics have more in common with those White feminists who choose to "ignore their built-in privilege of whiteness," as described by the writer, Audre Lorde. Case in point, Lorde (1984) reveals the truth of this situation with a disturbing image she describes in her "Age, Race, Class and Sex" writing:

> Some problems we share...some we do not. You fear your children will grow up to join the patriarchy and testify against you. We fear our children will be dragged from a car and shot down in the street, and you will turn your backs upon the reasons they are dying. p. 119)

When Race, Disability, and Gender Overlap

I talk about the meeting of race and disability and offer solutions to the mess mentioned above–the lack of empathy and difference in world view–in another of my pieces of writing, "They Don't Know, Don't Show, or Don't Care: Autism's White Privilege Problem," I wrote it as a guest editorial for *Autism in Adulthood*. This was partly inspired by *Boyz N tha Hood* by Black American producer John Singleton. As autistics often find themselves in the same boat, not forgetting I am also a person in that boat, I urge the reader to "know, to show, and to care" about the gaps in care and research and people receive, where the difference in quality comes down to race. (Giwa Onaiwu, 2020a, p. 272) I outline concerns about these gaps, and I provide examples of solutions that work. Healthcare providers can make changes, and measure their success, in their own labs and practices (Giwa Onaiwu, 2020a, p. 271)**.**

That editorial has been often referenced in other people's writings and is ranked as one of *Autism in Adulthood's* most frequently read articles (Mary Ann Liebert, Inc., 2021, list). Both pieces of writing share an intersectional focus, but "They Don't Know, Don't Show, or Don't Care: Autism's White Privilege Problem" has been received much more favorably than "'I, Too,' Sing Neurodiversity." I suspect this was the tone I used in the editorial. Tone plays a surprisingly important role in a message's ability to be heard by White ears. According to Black British scholar Nadena Doharty, a change in tone like that represents:

> Strategic emotionality…a theoretical concept to explain the conscious decisions Black women (including myself) might make researching under conditions of White supremacy and writing for colour-blind audiences to challenge the monopoly whiteness has on Black women's emotionality of only angry or strong. (Doharty, 2019, p. 4-6, 12-16)

Black disabled scholars Moya Bailey and Izetta Mobley (2019) wrote a thought-provoking article titled "Work in the Intersections: A Black Feminist Disability Framework." The article gives different examples, both modern-day and going as far back as Harriet Jacobs' disability caused by her confinement in *Incidents in the Life of a Slave Girl* and Harriet Tubman's epileptic seizures. (Bailey & Mobley, 2019, p. 19-40)

Author Toni Morrison mentions similar difficulties she faced when she wrote, "The authenticity of my presence lies in the fact that a very large part of my own literary heritage is the autobiography." (Morrison, 1995, p. 85) Basically, she was able to have a wider range of emotion because she was writing about herself, otherwise what would have been considered "acceptable" topics for her to write about would have been far more limited.

She also speaks about the challenges faced by former slaves and other Black writers of that era who had to speak to the truth of their own experience, while also representing their shared experiences:

> Historically, we were seldom invited to participate in the discourse even when we were its topic. In shaping the experience to make it palatable to those who were in a position to alleviate it, these writers were silent about many things, and they 'forgot' many other things. There was a careful selection of the instances that they would record and a careful rendering of those that they chose to describe. (Morrison, 1995, p. 86, 90-91)

It's fascinating and unintentional, but my tone in "They Don't Know, Don't Show, or Don't Care: Autism's White Privilege Problem" shares an alarming similarity to the writing approaches of Black authors who came before me, by many generations. I have been forced to find that delicate balance that Morrison talks about– in my own modern work. No matter how uncomfortable or humiliating, 21st century activists are often required to share deeply personal details about our lives for people to empathize with our situations.

At the same time, we must be able to show neutrality—to our own vulnerable experience—for scholars to take us seriously. I struggle at times with the need to include my own life experience, while also playing down the daily suffering of marginalized people—just to avoid making people with privilege uncomfortable.

I sometimes worry whether it creates an uneven or removed quality to some of my work—perhaps even in the widely read editorial noted above. That is not something I want to happen at all!

Despite my fears, I am far from detached. I paid costly Open Access publishing fees for the editorial with funds from my own cash-strapped pocket. I was lacking financial research support from any formal institution at the time, and ethically I wanted to make the editorial available to everyone. If I had not paid the Open Access publishing fees, the editorial could only be read by people with academic journal subscriptions or those who could pay to gain access to it. This is simply unacceptable to me, and just one of numerous examples of how, like Collins and other public intellectuals (Black women in particular), I am "fully immersed" in the concrete experiences, "ordinary activities," and "everyday actions and ideas" that appear in my scholarly work. (Collins, 1990, p. viii-ix) I cannot be detached and removed from it.

Interpersonal Issues

Patricia J. Williams' work talks about intersectional issues related to race, gender, and class without using an impersonal, removed point of view. Williams is a Black sociologist and legal scholar, as well as the author of *The Alchemy of Rights and Race*. She's praised for her vulnerable style, but Williams admits it can be both a burden and a blessing:

> There are moments in my life when I feel as though a part of me is missing. There are days when I feel so invisible that I can't remember what day of the week it is, when I feel so manipulated that I can't remember my own name, when I feel so lost and angry that I can't speak a civil word to the people who love me best. There are times I catch sight of my reflection in store windows, surprised to see a whole person looking back. (Williams 1992, p. 5-24)

My article "Don't Be Like Me: A Letter to My Daughters" portrays the lifelong struggle I've spent handling these (and other) intersections. Published in a peer-reviewed international journal, it is written as a poetic letter with a serious tone, I use myself as a cautionary tale referring to many challenges that I have personally experienced. Throughout the short, emotional piece, I advise my daughters (who share my race, gender, and neurodivergence) to avoid mistakes I have made. In doing so, I mention mental health struggles, being discriminated against, having my independence challenged, and danger of abuse that may happen due to the vulnerabilities of race, disability, and gender. (Giwa Onaiwu, 2022, p. 50-52) The article was featured in the journal *Ought,* in a family-themed, special edition. Of all my academic work, it is probably the most plainly and openly autistic in terms of form. It uses autie-ethnographic elements (for reference, autie-ethnographic was mentioned in the Introduction, under Research Methods), including repetition and rhyme.

The article portrays living at the intersections and the reality of my experiences, several of which have been as persistent as they have been painful:

> Being me means you will be discarded. Being me means you will be disrespected. Being me means you will be disregarded. Being me is to never be certain of yourself. To never be at ease in known or unfamiliar surroundings. To always struggle to understand things. To trust when you shouldn't, and not to fear when you should. It is complicated, it is draining, it is being too much of some things, yet not nearly enough of others…I don't want your joy depleted and your self-worth deleted…I want you to be free. And that is why you must never | Never, never, never | Never end up like me. (Giwa Onaiwu, 2022, p. 50-51).

For those unfamiliar with autistic forms of expression, autie-ethnography might seem strange. In *Autistic Disturbances*, author Rodas describes how autistic language is "pathologized" and "devalued." (2018, p. 74, 106, 133) Autistic and non-autistic scholars (i.e., Anne McGuire, Robert Rourke, Paul Heilker, and Diana Paulin) agree, adding that much of the criticism often has ableist and/or racist undertones. (Heilker & King, 2014; Rourke, 2016, Paulin, 2017) When non-autistics use features and language found in autie-ethnographic communication, they are often seen favorably. (Rodas, 2018) Even the word autism comes from Greek words meaning "the action or state of 'morbid self-absorption.'" (Rourke, 2016, para 5) Autistic scholar Damian Milton developed the Double Empathy Theory of bi-directional communication challenges. He says autie-ethnography has "snippets of information" and "patterns of shifting meanings. (Milton, 2018, p. 11-13) Autistic rhetorician Remi Yergeau also points out autie-ethnography's "long tradition of employing personal narrative as a means of identifying and collectivizing autistic cultural practices." (Yergeau, 2015, para 1)

Joint-Authored Publications (written by two or more people, not only me)

Intersectionality is a major theme of my writing. This is true as much for the pieces I write myself as those I write with other authors. In some cases, it is the primary topic. In "Promoting Well-Being in Autistic Youth and Adults: A Positive Focus on Sexuality and Gender Diversity," a recent co-authored International Society for Autism Research multinational study, we rounded up experts' opinions from six continents. The experts included investigators, educators, self-advocates, health professionals, students, parents, other professionals, and allies. (de Winter, Giwa Onaiwu, et al, 2022, lay summary) Our team paid close attention to the diversity in experiences, being sure to represent different cultural, political, and economic situations.

Similarly, in the co-authored article “An Expert Discussion on Autism in the COVID-19 Pandemic,” I purposely included race and disability in the conversations about issues facing our community. (Cassidy et al, 2020, p. 106-117) Intersectionality is threaded throughout the co-authored “Ethics of HIV Cure Research: An Unfinished Agenda” as well as a recent study funded by the Working for Inclusive and Transformative Healthcare Foundation. That study examined health vulnerabilities, differences in healthcare quality, and gaps in accurate diagnosing when race and disability status were presented. The study looked at ~1500 autistic and ~15000 non-autistic adults in a large, diverse healthcare system. (Ames, Morgan, Giwa Onaiwu, 2022, abstract)

This intersectional lens is present in my other scholarly work too, which include different research roles: peer, community, and co-investigator. Here’s a laundry list of other academic work where my focus on intersectional topics also shows delivering keynote addresses and guest lectures throughout the US; serving as a reviewer for one of the nation’s largest divisions of public health; reviewing writings for a municipal HIV planning group and an HIV research conference; and volunteer efforts as an anonymous peer reviewer for several journals.

My role as a disabled Black scholar-activist not connected full-time to a university or other research organization is unusual. I don’t have to worry in the same exact way about the fall out that could happen. I don’t have the stress of a university limiting the causes I support or having to think whether they won’t approve who I choose to work with. My associates who are tied to a particular college or university are limited in this way. But at the same time, there are negative parts of it too. Being “freelance,” I don’t have the financial stability they have. So, I don’t publish as much as they do and might be seen as less of a “success” according to what most people with my level of education expect. But I still have a lot of privilege compared to many of my colleagues *and* my mentors (heroes).

This feels particularly true when it comes to grassroots community members who are often overlooked or dismissed, but make giant contributions to public intellectualism, mutual aid, direct and indirect activism, and other critical acts of public improvement. These people have paved the way for me and many others. My academic journey has given me specific “legitimacy” and influence, whether I am deserving or not. I need to use that privilege to be a “go-between” whenever possible. As Black queer intellectual activist E. Grollman encourages, I seek to “raise consciousness about injustice…supports marginalized perspectives” with the goal of “making academia a more equitable and humane place” to create “more space to serve our communities and speak truth to people.” (Grollman, 2015, para 3, 6, 8-14)

The late Archbishop Desmond Tutu once said: “Language is very powerful. Language does not just describe reality. Language creates the reality it describes.” (Moyers, 1999). As a child, I was sometimes called a “little professor” due to my perfectionist approach to language, and giftedness, as an autistic child with hyperlexia. This term was created by Hans Asperger (1944). Perhaps, as Bishop Tutu notes, that nickname predicted my adulthood. I have spent years of my life educating myself and others. I’ve also served as a global networking partner with world famous universities, research teams, and health centers. All my scholarly work reviewed here provides the fuel for all those roles. It also provides a solid platform for the creative collaborations I’ve developed over the years. These creative collaborations and the international advocacy that will be discussed later are the most visible portions of my work.

APPENDIX A: HEAT - CREATIVE COLLABORATION

Heat happens when something with a high temperature transfers some of its hotness to something with a lower temperature and is necessary for fire. (Zimmerman Jones, 2018, para 1) In fact, for fire to exist, temperature must increase enough for fuel to ignite when oxygen is added. Although heat exists naturally in the environment, it can also be created. Sometimes a slight change might be all that is needed for that heat to develop.

This thesis compares heat to collaborative care work, which I will explain in a moment. First, I just want to mention collaborative care work is often unseen, just like we generally don't see heat. Humans use temperature as a way to measure heat, or the lack of it. We go with how hot something feels because we can't really see heat itself. (Cho et al, 2020, p. 258-268). But even though we do this, temperature isn't the best way to figure out how hot something actually is. Just think of how 70 degrees Fahrenheit (21 degrees Celsius) in the summer feels cool, but in the winter, it is hot.

There's also a scientific reason why what we "feel" doesn't measure heat properly. Technically, heat is caused by a type of energy called thermal energy. When something is really, really cold, humans might think it has no heat at all because that's how it might feel to us. (Callen, 1985, p. 8-9). But even in items that are very, very cold, there is still some thermal energy and – heat – there. This is because inside, different atoms and molecules are moving around. So even when something seems to be so cold that it has no heat, that's not true. There's still heat in it, even if it's a very small amount.

Creative collaboration is "a process of working with others toward a shared goal in creative way." (CROOW, n.d.) Most of my collaborative care work is done through my writing. I cover many different topics: parenting, disability, digital health, etc. They all work together to challenge current situations. In a similar sense, I have used creative collaboration to create heat. Working together as one body, my writings increase the temperature, helping us recognize that things in our lives are really heating up!

Of course, the heat is a metaphor, and it ties directly to the energy of fuel mentioned earlier. The pieces of the three-sided fire pyramid (fuel, heat, and oxygen) build on each other. The last section focused on fuel; this one focuses on heat. The two build into each other for the future topic of oxygen and the verb *to oxidize.* The long-term goal is a movement to create real change, with worldwide advocacy and activism. (To continue the analogy, oxygen will absorb negative energy and real change will be created.).

Co-Authorship

A lot of my work is a form of creative collaboration and care work. This work is mostly writing-related: editing, co-authorship, etc. Anthologies are a big part of my work. (An anthology is a book or collection of writings with a specific theme in mind. They often have the writing of different authors combined together.) I think anthologies are very valuable because they share individual voices and group voices at the same time. I have written chapters in many non-fiction anthologies:

- The Foreword in *I Will Die on This Hill: Autistic Adults, Autism Parents, and the Children Who Deserve a Better World* from Jessica Kingsley Publishing
- "Am I Mom Enough? Contending with the Voices in My Head" in *For the Love of Autism: Stories of Love, Awareness and Acceptance on the Spectrum* from Fig Factor Media
- "I Don't Really Wanna Fight No More" in *From Hurt to Hope: Stories of Mental Health, Mental Illness, and Being Autistic*
- "The Lady on the Plane" in *Dazzling Colours of Calm* from Heady Mix
- "'A Dream Deferred' No Longer: Backstory of the First Autism and Race Anthology" in *Autistic Community and the Neurodiversity Movement: Stories from the Frontline* from Springer/Palgrave Macmillan
- "All of Me: How Do I Know Where Blackness Ends and Neurodivergence Begins?" in *Knowing Why: Adult-Diagnosed Autistic People on Life and Autism* from Autistic Press
- "Why I Don't Like All of Those 'Get Off of Social Media and into the Real World' Posts" in *The Real Experts: Readings for Parents of Autistic Children* from Autonomous Press

Besides writing the chapters mentioned above, I have helped organize and edit anthologies too. (The editor is whoever is in charge of putting everything together in an anthology. If there is more than one editor, they split up the work as co-editors.) I am the editor of the upcoming anthology *Neurodiversity en Noir*. Jessica Kingsley Publishing International is the publisher. This book is about Black families from different countries where one or more people are neurodivergent (with different types of brains).

I am a co-author of a nonfiction anthology about family life with different disabilities as well. It’s called *At the Intersection of Parenting, Race, and Disability throughout the Diaspora: Black Motherhood and the Journey Beyond Diagnosis*. Plus, I am a co-editor of three other anthologies. One is *All the Weight of Our Dreams: On Living Racialized Autism*. Another is *Sincerely, Your Autistic Child: What People on the Autism Spectrum Wish Their Parents Knew About Growing Up, Acceptance, and Identity* from Beacon Press. (The Library Journal gave this anthology a starred review! This is one of the companies that helps rate whether a book is good or not. A starred review means they think it is really good.) I’m also co-editor of *Respectfully Connected: One Family’s Autism and Neurodiversity Journey…in Color.*

Autie-Ethnography

I’ve mentioned autie-ethnography in this thesis. It's a writing style I use a lot. I enjoy how autie-ethnography can be used in collaborative writing work almost like a form of art. In terms of heat, autie-ethnography can be compared to an oven and how an oven heats things up. The heating elements get hot, which warms up the air in the oven. The hot air then bakes or cooks whatever is inside the oven. Autie-ethnography is like that. It enhances the words inside it.

Sadly, this writing style is often misunderstood, something I’ve mentioned in the earlier sections. Autistic writer Robert Rourke explains in a 2016 article that the “poetry, disjointed narrative, and other forms of expressive writing” style that autie-ethnography uses isn’t appreciated. This is annoying because when non-autistic people write that way, it is considered to be an amazing and creative style. A professor named Julia Miele Rodas points out this double standard. (Rodas, 2018, Preface) All this said, many non-autistic people don’t think of autie-ethnography as “real” writing or speaking even though it’s the way autistics naturally communicate. (Rourke, 2016, para 5-6; Rodas, 2018)

Mel Baggs, who was primarily nonspeaking, was a writer who used autie-ethnography. Mel Baggs was a queer white autistic and disability activist. Baggs was important to the neurodiversity movement. Some well-known examples of Baggs’ work include the internationally praised video *In My Language* (2007) and Baggs’ blog Ballastexistenz, “a historical term that means ‘ballast existence’ or ‘ballast life’, that was applied to disabled people in order to make us seem like useless eaters, lives unworthy of life.” (Baggs, 2012, para 2) Both of these used autie-ethnography.

Remi Yergeau, an autistic professor I have written about before, uses autie-ethnography also. Yergeau disagrees with many of the negative statements made about autistic people, especially by non-autistic professionals who are supposed to be autism "experts." Yergeau explores autie-ethnography in their book *Authoring Autism: On Rhetoric and Neurological Queerness.* Yergeau writes in a way that is truthful and has a lot of spirit to show the "idiosyncratic, self-focused, ephemeral" nature of autie-ethnographies. (Yergeau, 2018) Yergeau says the idea of autie-ethnography might seem confusing to non-autistic people because it supposedly doesn't make sense. In a sarcastic way, Yergeau asks, "How can autie-ethnography even exist at all?" It shouldn't because non-autistic "experts" say autistic people have a so-called "impaired Theory of Mind." They also say we don't have empathy. So if all that's true, writing autie-ethnography should be too complicated to even exist, right? (Yergeau, 2018, p. 7-9) (The last sentence has sarcasm in it.)

Autie-ethnography helps tell the stories of many people who are often silenced, which is good. But a lot of autie-ethnographic writing has ignored the life experiences of different races, and that's bad. The voices of autistic people of color just get swallowed into an "autistic perspective" that's truer for white autistics than for others. And that's a problem. There are a few exceptions to this rule, though. One example is Ly X.Z. Brown, who is an Asian American queer autistic attorney. For over a decade, Brown has fought against the abusive electric shock "treatment" at a live-in program in Massachusetts called the Judge Rotenberg Center. Brown is also recognized for their disability justice work across different marginalized groups within the autistic community. (Brown, 2011-2021, Repository)

Another exception can be found in the huge amount of documentary-like work by autistic activist Ira Eidle (2021, 2022). Eidle writes about topics related to autistic communities, including a topic that is often left out–contributions and impacts made by autistics of the past. Eidle specifically mentions Cal Montgomery as well as Anita Cameron. (Eidle, 2021-2022, Chapters 2-4; Noncompliant Podcast, 2019a)

Respected BIPoC (Black, Indigenous, and people of color) disability leaders Mrs. Kerima Cevik (2010-2022), Riah Person (2020), Diane J. Wright (2018-2021), Anna Perng, and Jules Edwards (2017) have paid tribute to marginalized BIPoC autistics as well. Outside of these exceptions, BIPoC autistics have mostly been left out of a lot of autie-ethnography. And we are still left out a lot now even though it's been over thirty years!

In order to bring light to this, I try to focus on autie-ethnographies, especially if I can bring many writers together in order to increase the voices of BIPoC autistics and share their stories and life experiences. The most visible example of this is *All the Weight of Our Dreams: On Living Racialized Autism.* I was a co-editor of the project, which was crowdfunded. The work was published in 2017, and it was groundbreaking. Nothing like it existed.

All the Weight of Our Dreams was supposed to be the first-ever anthology completely by autistic people of color. The book was widely read. It had a lot of autie-ethnography. It included "poetry, essays, short fiction, photography, paintings, and drawings of 61 contributors" from all over the world. They were mostly "Black, Brown, Latinx, Indigenous, Multiracial, and other racialized people of color" writing about issues of "marginality, intersectionality, and liberation." (Brown et al, 2017) *All the Weight of Our Dreams* can be checked out at more than 100 public libraries in several countries. (WorldCat, 2022, Listings 1-2) From 2017-2021, more than twenty university classes used the book as required reading.

Unfortunately, in 2021, we discovered some of the contributors were not actually autistic people of color. Also, some elements of the book caused harm. Because of that, our team made the painful decision to discontinue *All the Weight of Our Dreams*.

Integrity

We chose to be accountable to our community and stopped publishing *All the Weight of Our Dreams*. Publicly, we accepted responsibility, apologized, and made plans to correct the harm that was caused by the book. We also made plans to re-publish the book with new contributors. The plans we made included making a new editorial team and strongly focusing on sensitivity in the review process. This would help us avoid future books from causing harm.

Also, to try to make amends for the harm that was done, we donated money to programs for Indigenous groups and Jewish people of color. (Autism and Race, 2021, para 1) All of this is the creative collaborative care part of my work. And we hope the integrity we show transfers to our community, just as the heating element of an oven warms the air and meal inside of it.

I know a lot of big words, but I still cannot express how bad I felt about how this project went. In addition, I had to deal with other people's disappointment and betrayal, without getting angry. Some days I failed…such as the morning I wrote this for social media:

> Really, white autistic folx? Really?!?! Y'all already have everything; everything. You couldn't allow autistic PoC to have ONE thing for ourselves? Just one thing? You just *had* to have this too? How dare you utter a word about 'internalized ableism' and autistic masking when you have no qualms with blackfishing people who were naive and trusted you. Y'all disgust me. You've destroyed what little was left of my faith in humans; hope it was worth it.

However, this was just a draft. I didn't actually post it. Though my frustrations were justified, posting that would not have helped my long-term goals for the autistic community. Instead, I let that anger warm me up and motivate me, almost like a solar energy charging station. In the end, I want change. When I face situations that I cannot control, I channel that energy into my work itself instead of hiding in shame, cowering in fear, or exploding with rage. My thoughts reflect those of author Chimamanda Ngozi Adichie:

> I am angry. We should all be angry. Anger has a long history of bringing about positive change. But I am also hopeful, because I believe deeply in the ability of human beings to remake themselves for the better." (Adichie, 2013, TEDx Euston)

Community-Centered Principles

There's an expression of "warming up the audience" during performances. In a sense, my creative collaborative care work helps warm up the autistic communities as we face our everyday challenges and motivates action. This is like generating heat. I chose to take to heart the lessons that I learned in the years since we developed *All the Weight of Our Dreams*. Those lessons have been very valuable:

> Our process was going to look and feel different in several ways and was going to be both non-linear and nontraditional. Because of this, we weren't going to have a formal framework, "blueprint", or set of instructions that we would be able to rely on. Where there was no precedent, we had to be ready to trust one another and forge our own way—and we did. (Giwa Onaiwu, 2020, p. 246)

I developed six community-centered principles that guide most of my creative collaborative care work. They are: 1) Nothing About Us Without Us, 2) Everybody Gets Paid, 3) You Define You, 4) It's Not a Term Paper, 5) Real Transparency, and 6) We've Only Just Begun. I didn't plan on creating any of these principles in advance. They just seemed to form naturally over the years, and I committed to them. Applying these principles gives us a way to combine our warmth together, which creates heat!

These principles keep me grounded so my creative collaboration care work stays lined up with my beliefs. I do it even though many times, anthology work gets overlooked. It also builds connection and involvement, honors differences, strengthening and centering the community. Together we can create something much more beautiful than we could create alone!

Anthology comes from a Greek phrase meaning “a gathering or collection of flowers." In a perfect world, anthologies would be seen as valuable for the collection of perspectives they have. (MasterClass, 2022, para 1-3; Brown, 2016, para 4) But that’s not how it really is. Creating and editing an anthology doesn’t get the credit it deserves. A professor and editor named Sarah Blackwood, says that care work “nurtures talent and creates common spaces in which individuals can thrive” when it is done well. Basically, because of this and its “relatively undertheorized” nature, it “erases itself.” Blackwood suggests that there needs to be ways to make the efforts of editors more obvious, as their work is “often invisible.” (Blackwood, 2014, para 1, 5, 7-9) She also explains that editing and other care work is overlooked because of gender discrimination. There are many people who consider many forms of care work to fall under so-called “women’s work.”

I agree with Blackwood. However, I suspect it’s not just gender, though. Ableism makes people invisible in the same way. Plus, the “best standards” for anthologies push for editing to make all the writing “consistent” to give it “added value.” (Davis & Blossey, 2011, p. 247-248) Basically, they want you to change all the different writing styles in an anthology so that everything in it pretty much sounds the same.

This brings me to my next method. I use it instead of going with “best standards” because I think those standards strip away what makes each voice unique. I refuse to use that approach for my creative collaborative care work because I actually want my work to be what it is supposed to be: creative, collaborative, and caring.

Community-Centered Practices

I go for different methods. There isn’t really a name for them. But they are centered in the community and are part of all my creative collaboration work. It’s hard to define because it’s a mix of different things. It feels like something that comes from inside of me. There’s a stubbornness in it (because I refuse to do something experts say is “right” when I know it’s wrong). It’s also flexible and it is inclusive, centered on the communities I collaborate with.

In terms of heat, it can be compared to radiation or radiating energy. This is a way of generating heat where rays of energy move outward and heat up everything around them. Radiating energy can vary greatly in form, intensity, and stability. Refusing to restrict myself or my collaborators is like generating heat with radioactive energy. The restrictive standards I refuse to use are often random and can be classist and ableist. According to "expert" advice, editors are supposed to try to make their "substance, style, context, and content" the same. They are supposed to pick a single tone, format, and length for contributors to use. If you don't follow these rules, "experts" will think of your anthology as a "redundant" collection of "more stuff to read" or a "mis-mash" with "little significant value" that is not a "worthwhile purchase." (Davis & Blossey, 2011, p. 247-250; McGill-Queen University Press, 2022, p. 168)

Basically, I pretty much do the opposite of what the "experts" say and use community-centered practices in my editing instead. Let me try to explain why because I'm not the kind of person who just breaks rules for no good reason. I try to follow rules when I can, especially important ones. For example, I follow some of the "expert" anthology standards, like identifying key ideas that glue the whole anthology together. This is like something Patricia Hill Collins, who I mentioned earlier, says: "It is possible to be both centered in one's own experiences and engaged in coalitions with others." (Collins, 2000, p. ix-x, 228) I agree, and I believe this should be done in a way that keeps the unique elements in the work, too. I don't think anthologies need to be like "clones."

Some of this approach to editing anthologies overlaps with the six community-centered principles to my creative collaboration I wrote about in the last section. But it's so much more than how I deal with people's spelling and grammar. It's also about how the work looks and feels: font, spacing, words used, writing tone, and even topic. An example of this is in a chapter of an anthology in which I depicted a person who spoke differently depending upon who she was communicating with. In the chapter, the person changes in mid-conversation and starts talking very differently than she was at first.

I need to be "true" to with myself in my creative collaborations, regardless of what the world thinks. I'd rather my work be real than "acceptable." Having one universal "standard" that is imposed upon everyone defeats the purpose of creative collaboration in my opinion. Why involve others anyway if you're just going to strip away their voices? We should be sure that our unique and shared stories are "told and preserved in narrative form and not 'torn apart in analysis.'" (Collins, 2000, p. 258)

I don't think it's honest to value individual voices "in name only." Collins once said, **"**Theory and intellectual creativity are not the province of a select few but instead emanate from a range of people," and I believe that. (Collins, 1990, p. viii) Because of this, I include collaborators from different backgrounds, fields, ages, and points-of-view, like Collins described:

> I came to see my work as being part of a larger process, as one voice in a dialogue among people who have been silenced. My hope is that others who were formerly and are currently silenced will find their voices. I, for one, certainly want to hear what they have to say. (Collins, 1990, p. ix)

I do this both in my editing and in other ways also. Collins states that "the struggle for justice is larger than any one group, individual, or social movement." (Collins, 2000, p. xiii) This lines up with being "true" to and "real" with myself in my work. I agree with this, so I try to lead by example in the way I collaborate. As an editor, I have seen how status influences how people are treated. Junior colleagues usually receive less respect. The more "accomplished" people get special treatment. However, I don't agree with this. I don't think I should be treated as if I'm better than the people I am working with! And I do not want to "rest on my laurels" either. I want to be "carrying my weight" with the quality of my work, not just my reputation.

I choose to be actively involved as much as possible instead of just slapping my name on a project for the sake of status. I don't consider myself above the nitty-gritty part of work. In fact, I usually write pieces to be considered in anthologies I help edit. I do not consider anything "beneath" me merely because of my achievements. After all, I am part of this community too! Like W.E.B. DuBois said, "Need I add that I who speak here am bone of the bone and flesh of the flesh of them that live within the Veil?" (DuBois, 1903)

The Value of Creativity and Collaboration

A final important part of my creative collaborative work is the purpose of the work itself. Adichie says, "Many stories matter. Stories have been used to dispossess and to malign. But stories can also be used to empower, and to humanize. Stories can break the dignity of a people. But stories can also repair that broken dignity." (Facing History and Ourselves, 2022, Chapter 1, Reading 2) I feel similarly. I focus on human experiences, so I do collaborative projects instead of just working alone. This is a way of using stories to empower people and repair broken dignity like Adichie wrote.

Also, I choose the specific creative methods I use on purpose. I know what the world standards are for a “superior” anthology or edited collection. Meeting those standards gets more attention and makes more money. If I did those things, I could make more money and have a lot more opportunities. I limit my market with some of the choices I make. However, I don’t care. I prefer to do creative collaborations instead of work that centers on me.

I’ll explain more about the creative methods. My work is diverse. I mix-it-up on purpose and use a range of styles. Here is a list of some of the styles I use: critical essays, autie-ethnographic narratives, poetry, interviews, etc. I cover many topics and write works of different lengths. Sometimes it is raw, emotional, with no filter and has the feel/sound/energy of an artist’s demo or “mixtape.” Sometimes I use quotes from tv or movie scenes or other pop culture. I might mention something important that happened in the past or something that’s going on now. Sometimes I will add something about race, gender, or my generation. My writing style is honest and informal and shows a “slice of life. I describe what’s happening along with my thoughts and feelings at that moment. My beloved children often appear in my work. I also include conversations I have with people around me. I might even include conversations I have with myself, in which I try to “make sense” of the situations around me.

I use many different forms of expression in my work. I include acronyms (such as “BTW” for “By the way” and PoC for people of color. I also use made-up words (for example, “ginormous” or “gazillion”). I like to repeat words, use slang, and play with words by repeating or rhyming. I will use words that have a specific meaning within certain groups. I play around with punctuation marks and language markers, like dashes, dots, and stars. Sometimes, I type in all caps, mess with spacing, or break other grammar rules. I do this to change topics, make a point, or raise a question, etc.

I don’t just choose words because of what they mean. I might use certain words because I like how they sound out aloud. Or maybe a bright image comes to mind when I think of some word. For me, playing with words is quite “stimmy” (self-stimulatory). It gives me satisfaction. One example comes from “All of Me,” my chapter in *Knowing Why*. In it, I use the phrase “no-poo.” It plays on the phrase “Rinse, lather, repeat.” I instead say, “Rinse, no-poo, repeat,” to refer to Black natural hair. There’s an ingredient in most shampoos that ruins hair textures that naturally grow in a tight, coarse curl pattern (called 4B and/or 4C hair). People with this hair can skip shampoo and instead use conditioner to wash their hair to keep it softer and healthier. We call it “no poo” (short for no shampoo). Saying “Rinse, no poo, repeat,” allows me to refer to a common saying, but in a way that doesn’t erase me as a Black person who no longer “lathers,” but definitely does no-poo!

Music is another powerful way to communicate, so I use song lyrics in my creative collaboration work too. W.E.B DuBois does this as well. He mentioned that in his writing "before each chapter, as now printed, stands a bar of some echo of haunting melody from the only American music which welled up from black souls in the dark past." (DuBois, 1903) Sometimes I take part of a song or poem and use it as the title of a chapter or an article. For example, "I Don't Really Wanna Fight No More," is from a Tina Turner song. "'I, Too," Sing Neurodiversity," is inspired by a DuBois poem.

Sometimes, I just pour out my thoughts, like a journal entry. Since the reader knows my inner thoughts, where anyone else mentioned in the writing does not, I end up "breaking the fourth wall." I compare it to Patricia Hill Collins' quote about public intellectualism as literature, music, etc.

> Books, stories, and poetry allowed oppressed people to communicate one with another and to produce a sense of shared identity. Such cultural expressions have historically given voice to the voiceless. Those who were denied political or academic power could express their ideas and experiences through story and poetry. As long as the political majority could read these as 'fictions,' as long as they weren't faced with the facts of oppression, blacks were allowed these cultural outlets in 'race markets.' (Collins, 2000, p. 100-106)

Writing isn't the only work I do as creative collaboration. I have other work that I do as a leader and ally in different spaces that also falls under creative collaboration. There are lots of examples: co-running a national Black disability feminism lab; participating in panels; advising and/or leading groups dedicated to worldwide community-based change, research, health, policy, education, etc.

I agree with Collins' claim that theory lets me to "see all of these associations with fresh eyes, while concrete experiences challenge the worldviews that are offered by theory." (Collins, 2000, p. 35) I try to develop creative collaborative work that creates positive change. I pair facts and feelings in my work, so that the material feels personal while still being based on solid information. Later, I might make changes as needed, but its essence remains unchanged. For me, it needs to feel "right," or I cannot continue. By combining facts and personal thoughts, my work radiates powerfully; warming the heart and mind, while also staying true to who I am.

APPENDIX A: OXYGEN - ADVOCACY & ACTIVISM ACROSS CAUSES, CONTEXTS, & CONTINENTS

Oxygen has a few qualities that tie to the fire analogy in this paper. First, in nature, oxygen can exist in more than one state; this is called allotropy. (Khademzadeh, 2014, p. 1-9) Under normal conditions, oxygen prefers its stable form of two oxygen atoms combined in one molecule called dioxygen. But under extreme conditions, oxygen may show up in other forms that are less stable. (Brasted, 1998)

Next, oxygen is what's referred to as an "oxidizing agent." This means it can absorb electrons. (Electrons are negatively charged particles inside an atom that make up the atom.) This oxidation process makes oxygen change its size and what it is made of. It's a permanent change to make room for these outside electrons to move in. It also produces energy when the extra electrons move in. This trait makes it so a fire only needs a small amount of oxygen to burn (typically, oxygen is only about 16% of a fire). On this planet, oxygen is almost everywhere. And nearly all living organisms need oxygen to live—so much so that not having oxygen can cause death.

For this next section, I'm going to compare oxygen and ozone, which are both formed naturally. In this comparison, oxygen is made up of two oxygen atoms, and ozone is made up of three oxygen atoms combined together. Oxygen has no color and no smell; ozone is pale blue and stinks. Oxygen has lower boiling and melting points than ozone. Oxygen is everywhere in the Earth's crust, atmosphere, and sea. Ozone is rare. (Diffen, n.d., para 3-5) However, most importantly, while we *must* breathe in oxygen to survive, breathing in ozone slowly poisons us. On the ground, ozone is air pollution that damages all living things. (Diffen, n.d., table, para 3-5)

Considering the comparison above, it would be easy to classify ozone as "bad" and oxygen as always "good." But this is not always the case. Sometimes, something that is generally harmful has good uses, and something that is usually helpful can cause problems. Ozone and oxygen display this idea well. Some things about ozone protect life. For example, in the upper atmosphere, ozone filters out dangerous ultraviolet rays. Ozone can also help filter sewage and clarify water. It can be used to disinfect. (Brasted, 1998, section 3, 5) Meanwhile, there are times where oxygen can actually be dangerous. When oxygen is under *a lot* of pressure, like oxygen in tanks with deep sea scuba diving, oxygen can be poisonous. If someone breathes too much oxygen too fast, oxygen can damage the lungs and nerves of that scuba diver, causing seizures, lung scarring, and possibly death. (Donald, 1947, p. 667-672) Also, lots of pure oxygen stored together can catch fire and cause explosions. (Weiss, 2008)

Advocacy + Activism = “Advocism”

According to Collins (2000), some people are born advocates; it becomes their purpose in life. It’s who they are. This is something that is true for me. I am an advocate. I don’t know how *not* to be one; it seems as natural to me as breathing. Like oxygen, advocacy has allowed me to survive. I am also an activist. (I have come up with a few words by combining advocacy and activist: “advocist” and “advocism.”) I deeply believe that humans can make powerful changes with our words and actions. I know this because I have seen it, have experienced it, and I have done it.

Like oxygen, my advocacy and activism show up in several forms. Here is a list of several examples: forums, demonstrations, protests, vigils, public campaigns, panels, research based on community participation, global radio, television and media broadcasts, civic action, art, digital mobilization, etc. Advocacy can be inspiring and push us to take action. It can also respond to situations with an explosion of ideas and emotions. This is true with activism too.

I remain true to my values and let my activism take on the best form for its purpose. Sometimes, activism includes self-care. There’s a cliche about oxygen that people use when the topic of self-care comes up: “Put your own oxygen mask on first before helping others.” People need to take care of themselves in order to serve their community. Activism is like the blood in our veins when it comes to community action.

When I think about my journey as an activist, I can relate to the plot of *Drumline*. *Drumline* is a movie, from 2002, about the marching band at a Historically Black College/University. The main character’s name is Devin Miles. Devin is a first-year college student. He taught himself how to play the drums so well that he earned a full college scholarship to play in the band. At first, Devin doesn’t always make a positive impression on people. He can come off as arrogant. But his creativity, musical skill, and natural talent as a drummer are noticed by others, especially his bandmates. (Elie, 2021, para 1-6)

Devin is an extraordinary drummer. He doesn’t just play music; he becomes one with the music. However, Devin is keeping a secret: he doesn’t know how to read music. He has such a natural ability for music, and so much drive, that he learned everything he has ever played, including his own creations, completely “by ear” and memory. Devin lives in constant fear that someone will find out the truth. He’s afraid they will decide that he isn’t good enough and doesn’t belong. Even though Devin has a lot of talent, this could undo everything for him.

Public Intellectualism

Like Devin, I have also felt like an “imposter.” I have wondered if I have the “right” skills to be considered a real advocate and activist. My life has taken a strange path, one that is uncommon for an advocate and activist. I’m surprised I have lived this long. I could have never guessed that I could ever be who and where I am today. And I think the most important part of my international advocacy and activism has been, and still is, my sincerity and truthfulness.

When I first became an “advocist,” I didn’t know about things like “Theory of Change,” “socio-ecological frameworks,” “social movements perspectives,” “collective action,” or any of that. Like Devin from *Drumline* that I mentioned above, for years I didn’t have the formal tools to guide my work. (Honestly, I didn’t even know there was such a thing.) I imagine that in his early years, little Devin felt an urge to pick up a drum and recreate the rhythms he felt on the inside even though no one had taught him anything about music. He had no idea what he was doing. Younger Morénike got involved in advocacy and activism without theories and formal knowledge. Technically speaking, I didn’t know what I was doing either. But part of me did know something, because I answered something that came from deep inside of me.

As a “baby” advocate, I couldn’t have explained my position using philosophy or theory on …well, anything. I didn’t have enough of an understanding of things to even know how much I didn’t know! The luxury to think about theories and concepts never existed for me. Even though I couldn’t specifically say what I was doing or why, I knew to do it. I just *had* to. I followed the prompts of what naturally came to me. I played by ear, so to speak, and I kept going. The results I got encouraged me to continue, even though I had no way to know if I was doing it “right.” I knew what I believed; I knew what I felt; I knew what I’d seen and heard; I followed what I felt compelled to do as it needed to be done. I was sincere and I was ALL in, following the intuitive guiding light that had stirred my soul.

Black public intellectualism had described my path long before I was born. Collins analyzes Sojourner Truth’s iconic “Ain’t I a Woman?” address in *Black Feminist Thought*:

> By using the contradictions between her life as an African American woman and the qualities ascribed to women, Truth exposes the concept of woman as being culturally constructed. Her life as a second-class citizen…points to the contradictions in the use of the term woman. She invokes her status as a mother of children…sold into slavery, asks, “And ain’t I a woman?”

> Rather than accepting the existing assumptions about what a woman is and then trying to prove that she fit the standards, Truth challenged the standards themselves. Her actions demonstrate the process of deconstruction—namely, exposing a concept as ideological or culturally constructed rather than as natural or a simple reflection of reality. (Collins, 1990, p. 14, 15)

Collins points out Sojourner Truth was a former slave, a Black woman, and a person of low social status. She was also an impressive champion for abolishing slavery and women's rights, including the right to vote. Her impact is still felt today. In her address that evening in 1851 (at a meeting for women's rights), Truth's words show the deep specialized knowledge she'd gained as a "connected knower." Her lived experience, often painful, gave her great insight when investigating and reflecting on her life through the "process of self-conscious struggle." (Collins, 1990, p. 12-17, 19, 258)

Devin Miles was unable to read music; Sojourner Truth was unable to read (or write) anything.

I believe deeply in the value of learning and growing. We can always gain knowledge from different sources, from mentoring, from practicing. However, it is possible to learn and know something without a formal education. For example, a person can know how to drive a car while not having a driver's license. Marriages, partnerships, and unions can be 100% committed even if they don't exist on paper. There are families whose members are bound by love instead of DNA.

And just as Sojourner Truth was a "real" woman, to me, Devin was a "real" musician regardless of his ability to read music. And I know my sincerity, conviction, and labor made me, despite my ignorance, a "real" advocate.

I have a "North Star" that has guided my uncommon approach to activism, and it's guided by three leading Black voices: Sami Schalk, Wole Soyinka, and E. Grollman. (It should be said, however, their voices are very different from one another.) I refer to their work to help explain important aspects of my international advocacy and activism. I include specific goals, campaigns, and tools. It's important to recognize the contributions of future Devins, Sojourners, and Morénikes, even when their paths are very different from "standard" and acceptable path society lays out. Ignoring the value of uncommon paths, like mine, isn't just a risk; it's flat out dangerous.

A lot of my work is focused on trying to bring awareness to issues that might not be well understood by people who haven't had certain experiences. Systemic racism and ableism need to be understood as background for a lot of my work, including the global #JusticeForKayleb campaign.

To explain that, current social systems have rules and ways of doing things that have built-in racism and ableism. This causes an unequal number of disabled BIPoC teenagers who “graduate” from the special education system and end up going to prison. This pattern is often called the “school to prison pipeline.” Though sadly, such a pipeline exists in several states and countries, it is really bad in the state of Virginia. After Kayleb Moon-Robinson, a Black autistic 11-year-old from Virginia, kicked a trash can out of frustration during the first week of school, a school police officer then handcuffed and arrested Kayleb, who was only in the sixth grade. He was charged with “felony assault.” (Center for Public Integrity, 2015)

I learned about Kayleb’s situation online. It made me very upset. He was a stranger living across the country, but I launched a global campaign and a petition for Kayleb’s innocence with the help of Lei Wiley-Mydske who is also an autistic activist. Our petition went viral, getting international attention and more than 150,000 signatures. Days before Kayleb was supposed to go to court for the case, I traveled to Virginia to deliver the petition to the prosecutor’s office with Kayleb and his mother. The media came with us—and ALL charges were dropped! I was honored with the Autistic Self Advocacy Network’s annual “Service to the Self-Advocacy Community" Award because of these efforts. (Change.org, 2015-2016; Autistic Self Advocacy Network, 2015)

Disabled people of color face more risks within the legal system than just the school to prison pipeline. Because of that, my activism stretches to other intersections of race and disability. To give an example of this, I served on the committee that coordinated the Million Moms March against police brutality in Washington, DC. Many people who are racially profiled by authorities are disabled as well as Black or Brown. Led by several “Mothers of the [Black Lives Matter] Movement,” the event got attention from the international media. With thousands of supporters from around the country, and the world, we crowded the nation’s capital on Mother’s Day to let the world know that:

> We march in solidarity with mothers who have lost their children to police and vigilante violence. We demand justice and demand answers. We march against the culture of silence that allows these types of atrocities to occur. We are marching for our lives, our children’s lives, and for a better tomorrow. (Giwa Onaiwu, 2015, para 8)

I was sharply aware of the higher risk among disabled BIPoC suffering from police brutality. I knew about this even before serving on the committee. Part of the reason I knew about it is because of the “legacy of disability justice” within Black liberation work. (Schalk, 2022, p. 6)

But since I had helped with smaller rallies in my city, Black Lives Matter demonstrations, and similar events, my knowledge was strengthened by my own experience "with the privilege of my position as an academic and with the risks of my positions as an activist." (Schalk, 2022, p. 8, 22)

Changes were happening all around me. People in the community were really bothered by so many people being killed. I was hurt and bothered by it in my own life, too:

> There were more unarmed individuals whose lives were cut short with no criminal charges or indictments afterward…more meetings, vigils, protests, die-ins…We held hands…people recited poetry, shared sobering statistics, read lists of victims' names, sang songs…The stack of protest signs in my trunk grew larger and larger – until one day my three-year-old son told me that he was tired of going; that he was tired of "marching because someone died."
>
> My heart was ablaze with emotions I couldn't describe…They say wisdom comes out of the mouths of babes. My son is tired of marching because someone died, and I agree with him. I am tired of marching because someone died too. I'm tired of the injustice, of the callous disregard for life, of fearing for my children as they get older and begin to resemble black men more than black boys. I'm tired of questionable court findings and victim slandering. I'm tired of video and photo footage of grief and anguish. I'm tired. (Giwa Onaiwu, 2015, para 2-6)

Next, I want to talk about the work of Wole Soyinka. Considered "one of Africa's most creative artists." (Lindfors, 1994, p. 25-26) Wole Soyinka is an internationally recognized Nigerian playwright and activist. He won the Nobel Prize in Literature in 1986, the first African to do so.

Soyinka has published a lot of written works, including drama, poetry, novels, short stories, memoirs, and essays. He has gone through harsh treatment due to his activism, including arrests, detention, attempts to take his life, and exile. (Munshi, 2021; Ogunyemi, 2021) Regardless, however, of the hardships he has faced, 88-year-old Soyinka has used his influence for decades to speak out against injustice, human rights abuses, and violence. He even used his Nobel Prize acceptance speech for activism rather than for personal gain (dedicating his award to Nelson Mandela, who at that time was unjustly imprisoned in South Africa because he spoke out against the racism and injustice created by his government; Mandela fought for decades to end an unfair South African policy (law) – apartheid – that separated and discriminated against people of different races). In his work and in interviews, Soyinka often stresses the importance of living in a way that is true to your beliefs and conscience. He shares the role his writing has helped him play in activism through his work:

> You cannot live a normal existence if you haven't taken care of a problem that affects your life and affects the lives of others, values that you hold which in fact define your very existence…
>
> I don't know any other way to live but to wake up every day armed with my convictions, not yielding to the threat of danger and to the power and force of people who might despise me." (Akinyoade, 2020)

Finally, I would like to look at the work of E. Grollman, who is a Black, queer, non-binary social justice advocate, researcher, and educator. Grollman is a lot younger than Soyinka, but the self-described "activist gone academic" Grollmam also uses their influence for "necessarily challenging injustice." They use public digital humanities in their activism. Public digital humanities are written works based on the human experience that are published digitally. Grollman does this, using personal narratives and slang.

Unlike Soyinka, who has more of a broad focus, a lot of Grollman's work deals mostly with sharing the ways that universities and researchers can improve how they run things and how they treat professors, students, staff, and people in their research studies. Grollman wants to make higher education (colleges and universities) fairer and more humane. They believe that social media and online resources are important tools for intellectual activism. Similar to something that Collins believes, Grollman dislikes the idea that one must be an "objective, detached, apolitical scholar–not an activist." (Grollman, 2015, para 15-16; 2016, para 8-12, 14, 16-17)

Multinational Activism and Multimedia Advocacy (activism and advocacy of different types)

Like Soyinka and Grollman, my activism shows up in different ways and I have also been able to use my influence to help with activism. I have worked alone and also in teams. My activism has included online campaigns, multimedia and photo-visual campaigns, law-making campaigns, activism about global research and how it's done, and meaningful community involvement. (Portfolio, Oxygen) Sometimes my work is at the city or state level. Most of the time, however, the focus is national (dealing with things that affect people all throughout one country) or even international (dealing with things that affect people in different countries).

Another part of both Grollman and Soyinka's activism that I relate to is being very upset by injustice and having a strong feeling that I should try to use my words to help somehow, especially through creative writing as well as social media. (Odelberg, 1986; Munshi, 2021; Nobel, n.d.; Onuzo, 2021; Grollman, 2013, p. 7-8)

I served as an expert panelist at the White House Inaugural Forum on Civil Rights of Parents with Disabilities, and I gave a talk about the maze of obstacles families run into with different social systems, such as disability services, schools, medical care, and similar systems. The forum was by invitation only, but they recorded and shared it on the White House official media broadcast, the White House YouTube channel and website.

I returned to the White House a second time when I was invited to the White House Forum on the LGBT and Disability Issue. This was held on National HIV/AIDS Testing Day. Along with my colleague Angel Hernandez, a queer Puerto Rican activist, I officially represented the Global Community Advisory Board of multinational AIDS Clinical Trials Group. The Forum looked at community-led efforts for LGBTQIAP+ people with disabilities. The Forum also hosted a discussion on best ways to include everyone. (White House, archive; ACTG, n.d., About)

Soyinka has participated in advocacy work with the United Nations. So have I. I consulted as an invited expert for the United Nations Programme on Disability (within the United Nations Department of Economic and Social Affairs). I have attended important meetings with the Joint United Nations Programme on HIV/AIDS and the United Nations Global Communications as well. I helped with a written supplement for a report to the United Nations Special Rapporteur on Violence Against Women.

I also had the honor of being an invited presenter at the United Nations Headquarters for World Autism Awareness Day. I spoke about the unique and intersectional challenges of autistic people with multiple marginalizations, including race, gender, sexuality, and serostatus (Serostatus is something specific antigen, like HIV, that can be detected or not with a blood test). I also shared the importance of empowerment and having meaningful involvement and representation in social systems, like education, health, policy, etc.

(This year [2022], I was again invited by the United Nations for their virtual observance of World Autism Awareness Day, but I couldn't make it due to illness.)

Reading and writing come naturally to me, but not all of my activism is writing. The #JusticeForKayleb campaign I described earlier also had a photo-visual component. I asked Kayleb's supporters to submit images of frogs and the Justice League (his special interests) online using his hashtag before his court date. This was a way to show him and his family support. Happily, he received a LOT of images, since the Change.org petition we'd launched went viral (the petition to have the unjust felony charges dropped against Kayleb had 151,000+ signatories from all over the world)!

I was also part of a photo-visual activism campaign about disabled families in partnership with POSITIVE EXPOSURE and Reel Abilities. POSITIVE EXPOSURE was founded by award-winning photographer Rick Guidotti to challenge "traditional ideas of beauty through the beauty and richness of human diversity to promote a more inclusive world." (Guidotti, n.d., About) Reel Abilities is "the largest festival in the US dedicated to promoting awareness and appreciation of the lives, stories and artistic expressions of people with different disabilities." (Reel Abilities, n.d., About)

My portrait and name were displayed during a ten-day disability festival and then later on in art galleries. This campaign was the first time I publicly declared my identity as a disabled person, instead of as a parent of children with disabilities like I'd done before. Like I wrote earlier, Black disability policy does not require a disability-centered identity, because it might not match the experience of many in the Black community. Plus, some Black people might not identify themselves as having a disability for good reasons as Schalk explains: "The whiteness and racism of the disability rights movement and disability studies as a field…often excludes or alienates Black disabled people and…Black activism and cultural work." (Schalk, 2022, p. 6)

There is also a high "cost" of being recognized as a disabled parent of color. You can even lose custody of your kid(s) to the foster system because of being disabled. (Powell, 2021, para 4-14) For these reasons, I understand why for a lot of people it isn't always safe or necessary to connect with the word "disabled." In fact, after my years of activism, I now advise my disabled peers to think carefully about the pros and cons of telling people you have a disability and whether in the long run it's a good idea or not.

Yet even with all this taken into account, for me, calling myself "unapologetically Black and disabled" helped me feel "freer" on the inside. It also helped me (someone who has a disability that is more "hidden") to be united with people whose disabilities are more noticeable than mine.

I fully agree with Schalk refusing to “act as if I am separate from the communities I write about, live within, and learn from every day.” (Schalk, 2022, p. 2) I struggle, and I am marginalized in lots of ways. But I also have privileges others don’t have. When I can, I choose to use my privilege to help my communities. This has pushed me into constant activism, including visual projects using photography and other mixed media.

For example, participated in the “We are HERO” photo-visual campaign. This campaign was a way to get people to support a bill that would create a new city law. The Houston Equal Rights Ordinance, or HERO for short, wanted to stop discrimination for people in Houston.

Basically, the new law was saying that if it got enough votes to be passed, it would be against the law to discriminate or mistreat anyone who had “protected characteristics” including: “sexual orientation, gender identity, sex, race, color, ethnicity, national origin, age, religion, disability, pregnancy, genetic information, family, marital, and military status.” If the bill became law, it would apply to all housing, businesses, services, workplaces, amusement parks, etc. with 25 or more employees within the city limits. (City of Houston, 2014, p. 1-36)

Only Houston residents could vote on HERO, but the issue got national and international interest from both supporters and challengers. The ordinance was supported by many groups and people: various Chamber of Commerce committees, civic organizations, advocacy groups, progressive faith leaders, universities, non-elected community leaders, LGBTQIAP+ activists, celebrities, and more. But there were also lots of people and groups in Houston and across the country who didn’t want HERO to pass. Many conservative and religious leaders in Houston and other places who disagreed with HERO unkindly called it the “UnEqual Rights Ordinance.”

Several critics of HERO focused on gender identity and bathroom use. HERO had a lot of transphobic people who created and continued a “bathroom bill” smear campaign. To fight against this, we gave the bill a human face by publishing “We Are HERO” all over the place, especially in the media. “We are HERO” shared portraits and stories of individuals from each of 15 groups whose civil rights HERO would protect.

Giving the bill a human face seemed to work with voters. It was believed that HERO passed and was made into law partly because of our activism. Unfortunately, our HERO was targeted by conservatives and removed the next year. (Ura, 2015)

Another non-writing campaign I participated in was a podcast called "My Life-Changing Autism Diagnosis" on the BBC. BBC podcast hosted by journalist Kim Chakanetsa. I was featured in that episode with another person, British author Sara Gibbs. We discuss our experiences as women who were diagnosed with autism as adults. This episode aired on BBC World Service, BBC News, and more than 1,400+ affiliated stations in ~39 languages. (BBC, 2022, About) The autistic spectrum includes a very wide range of clues, cues, behaviors, and abilities; however, the world mostly recognizes autism as a very narrow set of behaviors. My goal in this project was to spread awareness that autism doesn't always look like people think. Autistic stereotypes cause people to go undiagnosed (or misdiagnosed) for years because their behaviors don't match that stereotype; this is especially true for racial and gender minorities.

To Make Change, One Must Be the Change

I contributed to a few different activism projects with . One in particular was for the "International Disability Day of Mourning". This annual day of remembering was created by autistic activist Zoe Gross. It is held on March 1st in many cities, states, and some countries. This day mourns the loss of disabled people of all ages who have been killed by family members and/or caregivers. I joined event host Ly Brown, Dr. Temple Grandin, and the Matthew Reardon Center for Autism in Georgia. This event was photographed by Lynne Turner of *National Geographic*. The goal was to remember the lost lives and to challenge the story of such murders being "mercy" killings. We demand justice and protection under the law for the lives of all disabled individuals.

I was part of a ten-minute video titled "What Women with Autism Want You to Know," with Condé Nast and other autistic women. The video took aim at autism myths and how they are often wrong. The video went viral with over 3.6 million views the first year. The group I collaborated with, Condé Nast, is a "premier global media company" that owns many famous brands including Vogue, Vanity Fair, Glamour, Brides, Self, and GQ (Condé Nast, 2022, About).

Later, I helped with a project "focused on innovative autism storytelling to change perceptions and end the stigma of autism." This was printed in *Zoom Autism Magazine* in a special issue about women with disabilities. I was a featured guest along with actress Alyssa Milano, activist Mia Ives-Rubee, AWN executive director Sharon daVanport, ASAN executive director Julia Bascom, and Senator Tammy Duckworth. My contribution, "From Feeling Powerless to Owning My Own Power" was written to inspire people with disabilities and allies to resist ableism and empower one another.

All of the above campaigns, involving art and activism and advocacy, were planned. However, my involvement with the "A Day with HIV" global campaign was completely unplanned! Since 2010, *Positively Aware* magazine has set aside September 9th each year to have "a single 24-hour period in the lives of people affected by HIV," with participants from all over the world. (Positively Aware, n.d.) Throughout the day, photos (of people who are living with HIV and people who are not) show up on the campaign's website and on social media with the hashtag #ADayWithHIV.

The images include family members, self-advocates, researchers, educators, married couples, activists, health care providers, etc. (Positively Aware, n.d.) When I posted an image of my family wearing our matching "NO Shame About HIV" AIDS Walk t-shirts, I was simply participating; something I had done for several years. I never expected for our (unfiltered!) image to be chosen for publication! But it was. I was contacted and asked to consent to our photo being used, which I did. Although HIV impacts my family personally (this makes us a serodifferent household), it is an intersectional issue that should be everyone's concern, just like COVID-19. Plus, HIV is not a crime nor a sin; it's a manageable health condition; a disability. My hope was that by showing our family—real people living our real lives—we could change the story surrounding HIV (and serodifferent households, to use the phrase above), and hopefully inspire others to do the same.

Different types of global advocacy and activism, both traditional and nontraditional, make up the biggest part of my work. They have provided opportunities to add to my academic work on activism, especially by adding real-world involvement and participation to the creative collaborative care work I've done. The main types of global advocacy and activism included in my work are: Black public intellectualism, Black Disability Studies, multimodal practice-based national and global activism, and public digital humanities. These are compared with work and quotes from Sojourner Truth, Sami Schalk, Wole Soyinka, and E. Grollman, who are Black luminaries.

The examples here don't represent the full size, scope, and significance of my global advocacy and activism. I have included a portfolio of my work to add to what's been briefly covered here.

In the examples above, one can practically feel the puffs of air, representing oxygen, working with the fuel and heat to form fire, referring to the three-sided fire pyramid mentioned in the introduction. Also, the work I mentioned above can be compared to the life-sustaining role of oxygen. This is important to note because I truly seek to make these concepts into living and breathing ones in my life as an advocate and an activist. As such, I must lead by example, not just by words.

I recognize that throughout this thesis, I have compared myself to individuals who, because of how much they have accomplished, are more like role models to me than peers or equals. I am nowhere near the level of achievement of people like Audre Lorde, bell hooks, Wole Soyinka, Patricia Hill Collins, and Sojourner Truth. All of them have had a huge impact on the world and made important differences. I do not use them as examples because I think I'm on their level. I know that I'm not, but I choose to write about them purposely because I look up to them and I have high standards.

There is a saying, "We stand on the shoulders of giants" that talks about how much people before us have helped to pave our way and make our successes possible. But I am not satisfied with just "standing" on "the shoulders of giants." That's not enough for me. Instead, I take it even further; I have decided to try my best so that I can *be* like those giants too.

APPENDIX A: BURNOUT (Fire’s Risks & Rewards)

In the early part of this thesis, I introduced the three-sided pyramid of fire. When discussing fire, I mentioned that fire allowed humans to develop new ways to communicate and move around, as well as new forms of work. Our modern way of living exists, partly, because of fire. It is a necessary element in our lives.

Fire has a lot of benefits, but it also creates problems in life. A few of those can be attributed to fire itself, like burning too much and burning out. Things can catch fire and start burning very suddenly, such as in the case of wildfires, lightning strikes, and volcanic explosions. Burning can also be caused on purpose, such as lighting a pilot light, planned fires for farmland, and cases of arson. Enormous damage can happen if a fire burns out of control. Out of control fire is a terrifying thought, but it can be addressed with fire prevention and protection.

Interestingly, however, the greatest risk humans face from fire isn’t the burning flames directly. Most of the harm comes from the pollution from the burning process itself. Harmful gases are released from fire as waste—similar to the waste of humans getting rid of sweat, urine, and feces from our bodies. The unwanted parts of fire are smoke and carbon monoxide, which causes most of the injury and death for humans by fire. Breathing in smoke, or being poisoned by carbon monoxide, causes serious damage to lungs. This prevents breathing in enough oxygen. Not breathing enough can make someone faint and can also cause organs to fail, which is often deadly.

We can usually see burns plainly, almost as soon as they happen. But smoke and/or carbon monoxide might not be noticeable at first, so it gets overlooked. Carbon monoxide is really dangerous because it has no smell, color, or taste, and it can stay around for up to two months. It is really important for someone who may have breathed in smoke or carbon monoxide to be examined by a health professional. The person might seem unharmed, but they could be on the verge of death!

As someone who believes deeply in being totally honest, I want to note that though my work—my fire—has been positive in many ways, there are also negative effects too. Some I would even compare to the danger of breathing in smoke and/or carbon monoxide. As the sayings go, you cannot have rainbows without rain, and every rose has its thorn.

It hasn’t all been love, light, peace, and unity. Sometimes, the weight of it all feels like too much to bear. I can’t count how many times I’ve cried. There has been despair and disappointment.

There has been rage; there has been pain. In a very raw 2021 online essay, entitled “Shattered Beyond Repair,” I pour out my emotions:

> I have been burned over and over again. Sometimes directly – things being done to harm me. Sometimes indirectly, in the millions of little micro aggressions and bigoted words and actions. Either way, it’s too frequent and it’s too much.
>
> I am so very tired of having malcontent ascribed to my genuine and heartfelt actions. So tired of being punished for wanting better.
>
> I don’t know how much more I can reasonably be expected to take. I’m destroyed…every part of me. (Giwa Onaiwu, 2021a, para 7-10; Giwa Onaiwu, 2021, para 6-7)

Quite frankly, this work has taken a lot out of me, both weighing on my own well-being and that of my loved ones. My work requires an unending amount of time, effort, emotional and intellectual labor as well as money, (a lot of my work is pro bono and unfunded) of which I have little to spare. It has taken away a lot of my innocence and good-natured beliefs of the world.

Time and time again, I have discovered that many things weren’t what I’d thought they were. People and organizations that I looked up to have left me disappointed, shaking or losing my trust in them.

> I keep trying. Keep speaking out; keep trying to believe; keep trying to make change. Only to be consistently and callously immolated by people who don’t like what I have to say. If the truth hurts, they’re going to make sure *you* hurt for the crime of uttering said truth as opposed to fawning over the non-existent garment being flaunted by the emperor.
>
> The price for refusing to imbibe the enticing blue pill of falsehood is a very, very steep one. Maybe one day I will learn. (Giwa Onaiwu, 2021, para 4-5)

I have lost relationships with people as well as organizations that I cared about. Often, we weren’t on the same page. Sometimes the difference of opinion has been too great to find *any* common ground. I have made what felt like impossible decisions when the needs of the different communities I am part of and/or work towards end up conflicting with one another.

It has cost me precious memories with my family. It has also caused my mental health to worsen.

> Stupid, stupid, stupid Morénike. When will you learn? No one *truly* wants all these things we all talk about…you know, justice, equity, inclusion, acceptance. Those are just pretty buzzwords. The only fool who actually believes in these concepts is you. You're not supposed to *really* want it to happen. I was so hopeful and so energetic that together we were all going actually to change this world, make it a more accepting and inclusive place. I honestly believed that. I don't now. (Giwa Onaiwu, 2021, para 18)

Activist and Autistic Burnout

I don't quit. But it has caused me to slow down, and, at times, consider just giving up completely. (Several times, in fact.) I am scarred, inside and out. I have a habit of pushing myself past my limits, leading to burnout, low energy, overwhelming exhaustion, a constant feeling of not-being-well, reduced brain function, and challenges with just managing my everyday life. This state is often referred to as "running out of spoons" in disability communities. It's a very real thing, and common for people like me. I'm learning to use my spoons more carefully. However, I've had much harder time dealing with the hell-like fires of systemic racism and ableism (as talked about earlier in the thesis), activist fatigue, and autistic burnout (I will refer to this tiring trio as "burnout" going forward in this thesis).

> Truthfully, this hasn't felt like a community to me in a long time now, but I just couldn't put down the "hopium" pipe.
>
> There is no "us."
>
> There never was; I just believed the Wizard behind the curtain was real. (Giwa Onaiwu, 2021a, para 6-8; middle and end sections)

Like smoke and carbon monoxide, fire releases the unwanted outcome of burnout. It tends to "come with the territory" and is hard to deal with. There are lots of reasons why people like me (and me!) are prone to burnout. Paul Gorski, a scholar who studies equity, has done valuable research about people who act as activists in social justice and human rights, as well as educators and other activists (including anti-racism, climate change/environment, peacekeeping, multicultural education, etc.). Gorski noticed that activist burnout research looks a lot like job burnout research. (Gorski, 2019) According to Gorski and colleagues (Gorski, 2019; Chen & Gorski, 2015), activist burnout is defined as the combination of "debilitating deterioration of physical health," "debilitating deterioration of psychological or emotional health," and "debilitating deterioration of hope." It has four main causes.

One primary cause of activist burnout is the intense pressure activists put on themselves to create social change. Activists usually have a strong commitment to their cause; activists tend to be deeply emotionally invested. Realizing how big the problems really are also adds to internal pressure. Activists face a very sober reality when they see what they are up against. and it can be discouraging.
(Gorski, 2019; Chen & Gorski, 2015)

A second cause is outside stress. Activists face so many outside stresses! First, as a way of life, activism doesn't pay very much, if at all. Also, the planning part involved in being an activist is enormous. Then there is the part where society resists change, and any blowback often ends up on whistleblowers and activists. Taking that one step further is the risk of getting a target put on your back (Gorski, 2019). These threats can range from bullying and smear campaigns to arrests to actual death threats.

External stress often happens along with the third cause. The third cause is psychosocial stressors. Psychosocial means the combination of personal thought and social factors. In this case, a lot of human rights and social justice activists come from the communities they are working for, especially those who are BIPoC. As a result (tying into the paragraph above), they are more likely to have health problems, troubles supporting themselves, and having to deal with the discrimination they are fighting against, day-in and day-out. (Gorski, 2019)

Given these stressors, it is not surprising that Gorski and colleagues noticed over 70% of BIPoC activists studied had signs of depression, including fatigue, sleeping too much or too little, reduced interest in activities, and less interaction with their partners and children. (Chen & Gorski, 2015)

The vulnerability of these stressors can also cause issues with credibility. An activist's reputation may be impacted by struggling with daily life, reducing the opportunities they have. This leads to more fatigue…interfering with the success of their activism work. (Gorski, 2019)

These three factors take a huge toll on one's physical health, as noticed by Gorski and colleagues. (Chen & Gorski, 2015) The average lifespan for autistic adults is already shorter than our non-autistic peers. If we are still alive by our late 30's, we've beaten the odds.

You go numb when you constantly have to go to funerals (or pay respects in other ways) to this person or that person whose lives have ended too early - in their 20's, 30's, and 40's - before they have had much of a chance to start to really experience things and "live" their lives.

This doesn’t even factor into the quality of life for those still living. People whose quality of life is disturbed with having repeatedly been hospitalized or are fighting for their lives in some other way. It doesn’t include mental health struggles, dealing with suicidal thoughts, and sometimes (involuntary) psychiatric hospitalization. (Gardiner, 2022)

Even though there is clear, trustworthy research about the challenges faced by marginalized activists, one vocal group insists there isn’t much difficulty for “high functioning” individuals of the “activist class.” (Escher, 2022) This group parrots these lies loudly. Having firsthand experience with social justice communities, with activists from all types of marginalized or disadvantaged backgrounds, for nearly all my adult life, I strongly disagree. Those people have their own difficulties too.

The fourth cause of activist burnout mentioned in Gorski’s research is the most damaging. It is in-movement stress. In-movement stress is a type of psychosocial stress (the third cause mentioned above). However, it weighs so heavily and frequently that it gets its own category. Activists, especially activists of color, are weighed down with specific stressors that happen in the movement they are activists for (which is why this category is named in-movement). It’s common for activist communities to have a martyr-like “culture of selflessness” which leads to burnout and other negative mental health issues. (Gorski, 2019) The idea behind the culture is the expectation is that a person who is really committed to a cause must do whatever it takes, regardless of the personal problems it might cause. (Chen & Gorski, 2015)

According to Gorski and colleagues (2015), other reasons for in-movement stress include conflict between activists that can include “infighting, backbiting, and struggles for power.” Gorski’s findings match the thoughts of BIPoC queer autistic organizer Ly Brown that trauma is continued by the autistic community. First, Brown noted that small, somewhat isolated groups such as the autistic community often develop “cult-like” behavior. Next, in addition to being small, Brown explains that the (autistic) movement is also quite young; the newness of the movement and its members getting to know each other likely add to the group tensions as well. (Brown, 2022, February 5th Twitter thread)

The final two factors Brown mentioned are “It’s a giant trauma fest!” and “artificial scarcity.” As many autistic adults have had a life full of trauma, they may not have the life skills to be with other people outside of the trauma framework they are familiar with. This makes relationships difficult, even when we are fighting for the same movement as someone else. It’s the truth of the saying “hurt people tend to hurt people.”

Artificial scarcity is a term that means people think there isn't enough of something, when in truth, there is plenty of whatever that something is. In this case, scarcity can deal with leadership or approval. The false sense of scarcity, and the fear of missing out, can cause harmful behavior in a group. Brown describes this as "Tall Poppy/Hitler or Jesus Syndrome" in which leaders and activists are put on a pedestal at first, only to later be bad-mouthed for not being perfect or because of other people's jealousy:

> Activists and organizers have gone back and forth for decades and decades about whether our movements should recognize charismatic leaders or not, whether we should highlight individual people's work or instead focus on orgs/collectives' work and not recognize individuals. And there's really good arguments to be made that we need both, because not recognizing individuals can fuel erasure and exploitation of multiply marginalized people, especially poor, disabled, queer, trans, women, [people] of color, etc., and…also focusing too much on "celebrities" disempowers mass movements and creates a top-down structure that's easy for the state/corporations to sabotage by taking down/out one leader. (Brown, 2022, February 5th Twitter thread)

A fifth cause has been suggested by Mary Doherty, who is an autistic doctor, advocate, and parent. Her Twitter handle is @AutisticDoctor. Doherty's suggestion meshes with what Brown said: the fact that within the autistic community there is an "inability to resolve interpersonal conflict. Minor disagreements lead to irrevocable splits. People go from colleagues/friends to enemies in an instant." (Doherty, M., 2022 in (Brown, 2022, February 5th Twitter thread) Doherty's comment really points out something important. Social justice and human rights activists do not receive formal education or learn how to cope with these in-movement stressors, according to Gorski and Chen (2015). This lack of support is the norm, which takes a huge toll on activists. Activist turnover can be as high as 60% (Can you imagine if a job had a 60% turnover rate? That's huge)!

Finally, one must look at autistic burnout in particular. The Academic Autism Spectrum Partnership in Research and Education (AASPIRE) defines it as follows:

> Autistic burnout is a syndrome conceptualized as resulting from chronic life stress and a mismatch of expectations and abilities without adequate support. It is characterized by pervasive, long-term (typically 3+ months) exhaustion, loss of function, and reduced tolerance to stimulus. (Raymaker et al, 2020, p. 132)

The exhaustion in autistic burnout is more than just "being really tired." It is a total lack of energy from doing way too much in daily life. This may sound like the person would just be tired, but the side effects are much more than needing a nap. Autistic burnout can literally burn out someone's ability to communicate, think, or deal with emotion so the person can't function in normal, everyday life, even if they had no problems doing so beforehand. It can also cause the person to be much more sensitive to their environment, leading to meltdowns, shutdowns, and stimulus avoidance. Autistics often hide their autism to blend in, referred to as "masking." Masking plays a huge role in autistic burnout. Several studies have discovered connections between masking and depression and anxiety; other studies show a link between masking and suicide risk. (Raymaker et al, 2020, p. 132-143)

Danquah, Lopez, Wade, and Castillo (2021, p. 526-529) recommended some ways to avoid burnout. These are aimed towards BIPoC women and femme activists in the US especially. First, activists should learn the signs of burnout, so they know if it's happening. They should also have a self-care plan they can use if they experience burnout. Deep breathing, gentle stretching, and feeling one's whole body can all help. Even better, these methods help people relax, so their blood pressure goes down. This is very important for women of color who tend to get more than their fair share of stress and burnout. Being mindful, relaxing, and recharging are very helpful skills, as well as being able to vent and get professional mental health care when needed. (Danquah et al, 2021, p. 527-528)

Autistic activist Brown also shares how they have coped with the challenges of the autistic community:

> I have been sick + tired of these dynamics for most of the last decade, and I have chosen to focus on building community with people who are also willing to talk through trauma who care less about "activism clout" and more about what we are doing to care for each other. Many of those people have happened to be autistic. But I haven't really been part of the "autistic community" in years since being functionally pushed out by various factions/people engaged in a smear campaign/character assassination campaign against me, and I'm okay with that. My mental and physical health are better for it. (Brown, 2022, February 5th Twitter thread)

Burnout happens because something is burning too much, so think of these methods and strategies like a fire extinguisher. How well they work can vary from person to person. However, building a supportive community that knows the importance of being sensitive to people's limits, being mindful, and relaxing, are critical, as noted in Audre Lorde's wise advice:

> I had to examine, in my dreams as well as in my immune-function tests, the devastating effects of overextension. Overextending myself is not stretching myself. I had to accept how difficult it is to monitor the difference. Crucial. Caring for myself is not self-indulgence, it is self-preservation, and that is an act of political warfare. (Lorde, 1988, p. 130)

Sometimes burnout cannot be stopped. This is similar to when firefighters let a fire burn because *not* extinguishing a fire is useful. A common example of this is when part of a forest is burned to prevent the spread of wildfires. The logic behind this is if there is nothing to burn, the fire will be stopped. The burned-out space creates a barrier of sorts. In some cases, the powers that be may allow burnout to manage the masses. In this sense, burnt out activists stop the fire of their cause, and this is allowed to keep things like they are.

Ideally, the fight of a movement would be big enough and have enough people involved that even if those closest to the flames get burned out, the movement can help heal them while others work to keep the oxygen flowing so the movement doesn't stop. Fixing the pitfalls of society should fall on the shoulders of everyone in that society. We should *all* be taking on that task, together.

Our allies and society can take active steps together to try to change the status quo and limit burnout. There are many ways to do this. Below, I briefly describe some possible solutions that were mentioned in my *Autism in Adulthood* editorial. I also include quotes about fire:

> Commit to doing the work to know what is happening. Make concerted efforts to show these important concepts to others so they can be more informed. And, through practical and consistent action, show that you do, indeed, care. It will require some innovation and some patience on your part, but it can be done. Seek opportunities to make progress, even if seemingly small or unconventional. (Giwa Onaiwu, 2020, p. 272)

Quotes About Fire

> "You cannot, you cannot use someone else's fire. You can only use your own. And in order to do that, you must first be willing to believe that you have it." - Audre Lorde

> "Light up the fire of love inside and blaze the thoughts away." - Rumi

> "...the poet is actually a thief of Fire!" - Arthur Rimbaud

> “Don’t set yourself on fire trying to keep others warm.” - Penny Reid
>
> “The mind is not a vessel to be taught. It is a fire to be kindled.” - Plutarch
>
> “How you walk through the fire says a lot about you.” - Mohadesa Najumi
>
> “I burn, and I hope.” - Jesmyn Ward
>
> “It is not light that we need, but fire; it is not the gentle shower, but thunder.” – Frederick Douglass
>
> “...The light of love is always within us, no matter how cold the flame. It is always present, waiting for the spark to ignite, waiting for the heart to awaken…” - bell hooks

Combating Burnout with Camaraderie, Support, and Self-Growth

Originally, I ended this with the quotes above. But weeks later, I came back because it didn’t feel complete or balanced. Discussing the risk of fire and how to stop it from killing you misses something important: the rewards of fire. Therefore, I continue this section to discuss some of fire’s rewards as well.

The first things that came to me were the faces of why I fight: Cherita & Noah, Daniel, Amina, Anthony, Legacy, Lukas; DeJonte, Lola, Kam, Preston, Ezra, Londyn. My babies, as well as my nieces, nephews, niblings. Appreciation and love are such a huge part of the fire that burns. How do I express how my love for them motivates me to keep going and to keep trying day-in and day-out?

How do I express how much my husband and biggest supporter, Lucky, has supported me and played a role in all my achievements because of his unwavering love and support?

And how exactly do I discuss my loved ones properly in relation to fire? My family, my friends, my communities…numerous unseen, unheard people who have supported me over the years in so many ways that I am unable to remember (much less name) all of them?

My mom’s daily prayers and words of encouragement were “food to my soul.” My dad’s sacrifices throughout the years allowed me to go out into the world and discover myself. Kay and Erica loaned me money even though I had a poor track record of paying them back, and they always showed my family so much love. Link and Andrea kept me grounded.

Cherry and Bruce were always “down for whatever.” My mother-in-law’s patience and unconditional love were a lifeline. Monique always kept us in her thoughts. My father-in-law offered practical advice, love, and thoughtfulness.

Outside of my family, the support of individuals and organizations have also kept me warm. AWN sent my family funds for meals and transportation and created many opportunities for me. Leslie checked on me a lot; helped solve various dilemmas, gave countless rides; prayed for us constantly.

Mrs. Judy scrambled out of bed on many early mornings to help me with school drop-off on days where I was running behind, simply out of kindness. April always lent an ear and a shoulder. FDM offered me growth, stability, and friendship. Gabby, Terra, Bryan, Claudia, Nicole, Marta, Wayne, and Deanna had my back at work. The IEC sent me flowers (and wine too!)

Kind Theory sent me chocolates. Anna, Shaun, Caren, Ly, Jane, and my church family fought tirelessly for my children. Bev, Daman, Jules, Heather, and others sent me money that I know they didn’t have to spare. The HIV Clinical Trials Networks, especially my beloved ACTG, IMPAACT, and HPTN families and HANC, mentored, supported, and held me. So many have been there for me.

Yes, there are significant risks associated with fire, including burnout, smoke inhalation, and getting burned. It is important to acknowledge, prevent, prepare for, and handle these very real risks. But we cannot focus on the risks of fire while overlooking its many rewards. The sense of community one can gain in this work is invaluable, even in the pain. Even more importantly, there are valuable lessons you learn. Burnout is a reality, but it doesn’t have to be the end of your story. You have to fight to keep that flame lit!

When oxygen, heat, and fuel combine, fire is born. Fire is the resulting event; it is a process; it is the “grand finale.” Fire is the consequence; fire is a reaction. Similarly, advocacy, activism, and resistance are often lit up as a reaction to injustice, stigma, and oppression.

A fire first begins with a spark that surges to a flame of brightness and heat. Fiery and passionate, it might blaze with intense heat. It might get even hotter as fuel and oxygen are added. It might exhaust its fuel source and fizzle out quickly. It might not have one of the three necessary elements (oxygen, heat, and fuel) and be extinguished.

On the other hand, the fire, like social movements, may evolve. Rather than burning wildly or dying out, fire can create balance. Such a change happens sometimes in nature, but usually, that has to happen on purpose. If we put forth the necessary time, work, and resources, we can make a controlled, steady fire. Like the cozy fire in a fireplace, the image creates a feeling of safety and security. It provides light and warmth but doesn't destroy everything in its path. It is the fire of life; a fire of change that lasts. Fireplaces are a meeting place for family and community, offering many uses and meeting many needs.

We maintain fire by respecting the power fire has, and balancing fuel, heat and oxygen correctly. This needs effort; fire is ever-evolving, as are we. We will always have needs to meet, things to learn and do. Though there will be change, growth, and loss as we travel life's winding paths, we can—we *must*—still celebrate the journey itself.

APPENDIX A: Additional Resources for Combatting Burnout

Throughout this section, I share several many challenges of burnout. Here is a list of resources that might be helpful if you are experiencing burnout.

This Poem Will Change Your Life | Rudy Francisco – Short Video: Complainers: https://www.youtube.com/watch?v=1E3Wr2AoEho

Mind (Mental Health Integration & Navigation Database): https://mindapps.org/Home

Programs - Mental Health First Aid: https://www.mentalhealthfirstaid.org/programs

Tools for Transformation: https://atctools.org/tools-for-transformation/

International Society for Traumatic Stress Studies - Public Resources: https://istss.org/public-resources

National Center for PTSD: https://www.ptsd.va.gov/index.asp

Text for Humanity: https://www.textforhumanity.com/

Resource Library - Green Mountain Self-Advocates: https://gmsavt.org/resource-library

Resources - Self Advocacy Resource & Technical Assistance Center: https://www.selfadvocacyinfo.org/resources/

US Bureau of Primary Health Care (public health clinics): https://bphc.hrsa.gov/

Local Help | Workforce/Employment Service – Career One Stop: https://www.careeronestop.org/LocalHelp/local-help.aspx

Crisis Text Line: https://www.crisistextline.org/

Disaster & Emergency Resources | Ready.gov: https://www.ready.gov/resources

Mood Tools: https://www.moodtools.org

Index Of Articles & Advice About Mental Health | Better Help: https://www.betterhelp.com/advice/

Portia Jackson-Preston: The Missing Ingredient in Self Care | TED Talk: https://www.ted.com/talks/portia_jackson_preston_the_missing_ingredient_in_self_care

Sangu Delle: There's No Shame in Taking Care of Your Mental Health | TED Talk: https://www.ted.com/talks/sangu_delle_there_s_no_shame_in_taking_care_of_your_mental_health?language=en

Travis Heath: Self Care to Communities of Care | TED Talk:
https://www.ted.com/talks/travis_heath_self_care_to_communities_of_care

(Research) Article about Life Crafting to Find Purpose and Meaning in Life:
https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6923189/

(Research) Article: Existential positive psychology and integrative meaning therapy:
https://www.tandfonline.com/doi/full/10.1080/09540261.2020.1814703

Weave Silk Online Interactive Generative Art: http://weavesilk.com/

Online Sketchpad: https://sketch.io/sketchpad/

The Trevor Project (Support for LGBTQIAP+ Youth): https://www.thetrevorproject.org/

National Domestic Violence Hotline: https://www.thehotline.org/

Nature Relaxation Films: https://www.youtube.com/c/dhuting/videos

Josu Relax Videos: https://www.youtube.com/c/JosuRelax/videos

Bjorn's Chill & Relax Visual Effects Videos:
https://www.youtube.com/c/ChillRelaxwithVisualEffects/videos

Calm Videos, etc. (from Calm App): https://www.youtube.com/c/calm/videos]

APPENDIX A: FUTURE RESEARCH IDEAS (Bonus Content)

The term future contingency (futura contigentia, from one of Aristotle's arguments) refers to possible outcomes that depend on how the future unfolds. (Shain, 2011, p. 124-137) More research like what's in this thesis needs to be done–scientific research that is accessible. That research should be sensitive to cultural differences; have good principles that include everyone; and be designed to involve the community in a way that actually helps them. Also, such research should keep going to find ways to help marginalized groups have better lives. Such research could help fix inequality issues in our social and health systems. (Braveman 2014, para 7-10)

In specific, one area where future studies would be very helpful is looking at methods that have worked successfully, especially when there has been success for more than one group with different goals. Several such methods have been identified by Dr. Dazon Dixon Diallo (a Black activist-scholar living with HIV) and colleagues. Their findings take place at the woman-of-color-led grassroots organization Sister Love. Sister Love spans two continents and focuses on reproductive justice. (Diallo, 2004, p. 124-128) Other such methods have been shared by AIDS United and the U.S. People Living with HIV Caucus. (2019, p. 37-39, 41-57) Research that uses the methods created by these groups includes self-evaluation for groups, and also looking at involvement from others outside of those groups. Research should cover many bases, including whether methods are practical, how well they can be planned, and the leadership needed. Such studies should also look at different groups in all different types of circumstances and cover both the short-term and long-term.

There is also a critical need to change how research is done, so that it includes the voices of those the research is about. Changing how research is done would include how clinical teams and health providers write about their research. The changes would also include changes to internal and outside communication; policies, research methods, programming, and/or design (including objectives, wording, and how information is collected).

All of these changes should be made to make the studies accessible, sensitive to culture, and include those the study is about. It's also important to be respectful when different points-of-view and methods come up outside of the "acceptable" and established points-of-view and methods. McNally (2015, p. 197-198) and others' work offers a useful framework in how to include marginalized groups in a range of diverse communities in studies about them.

Since this work is intersectional, future researchers might find Dillard’s pairing of Critical Narrative Analysis and Critical Participatory Action Research useful (Dillard, 2020, p. 47, 55-57). Basically, this approach develops individual personal narratives and other tools to challenge the dominant points-of-view that cause marginalization in the first place. (Dillard, 2018, p.61-66; 82) This promising and newer method of research offers a way to build on the work of Black feminists and Disability Studies scholars, and to implement recommendations from Bailey and Mosbey (2019). It also intends to get rid of blocks that happen in academia itself, when there is conflict between two disciplines of study. As Dillard clearly states, combining disciplines can be applied to “any research that centers other lived experiences that, similar to women of color, do not fit into and are harmed by a dominant narrative’s invisible and sustained hold on beliefs, values, norms, expectations.” (Dillard, 2018, p. 67)

Future research should also look at the promising practices that have been used by Black public health scholar Dr. Vida Henderson. (Fred Hutch, 2022, para 1) Henderson, whose work looks at underrepresented groups, focuses on inequality in healthcare by looking at several aspects between systems, biases, and other things, like race, gender, and socio-economic status. Including ideas from Black Disability Studies as well as the growing amounts of activism research, especially that of Satterwaite (2014), Gutierrez and Lipman (2016), abolitionist educator Csillag (2020 - 2021), and Gorski (2015-2022), will be helpful for developing solutions that are doable and inclusive.

Additionally, there are already suggestions from the autism community, which include collaborations with researchers and healthcare providers. These include the Academic Autism Spectrum Partnership in Research and Education which has been doing research since 2006 (Nicolaidis, 2019, p. 79-81; AASPIRE, 2020, para 1-6); the Autistic Researchers Committee of the International Society for Autism Research, which was formed in 2020 (INSAR, 2022, para 1-2); the Autistic Researchers Review Board of the Autism Intervention Research Network on Physical Health formed in 2021 (Brown et al, 2022, p. s1-4); and the Autistic Faculty of the State Public Health Autism Center, formed in 2022. (AMCHP, Title V National Performance Measures)

These are several ideas to consider when thinking about future research. Hopefully, future studies will discover information that can be used for services and practice recommendations that are based on evidence. Such research could validate the experience of marginalized people, help their voices be heard, and could help fix unmet needs. Ideally, such research would also make the quality of life for marginalized people better. Other helpful outcomes would be to increase access to trials and to services, add to knowledge of the situations at hand, and create more equality for everyone.

APPENDIX A: CONCLUSION

This doctoral thesis examines my intersectional research, activism, writing, and practice over the past fifteen years. It includes published and creative works (chapters, articles, etc.) and has the format of a qualitative study. (Moustakas, 1994, 21-27) Most of this work attempts to show the perspectives of those who, like myself, have more than one marginalized identity, as those identities determine whether a person has privilege or is oppressed. (Williams, 1994, p. 93-118; Yep, 2015, para 1-4)

Activism, by nature, is unpredictable. This means activists have to adapt. This can be done by increasing our ability to think and act with strategy, when faced with different circumstances, like not having enough money or being in danger. Also, being who you really are, and having positive connections with others is important to be successful with the public as well as having a healthy community. (This ties into the section on engaged pedagogy.) The principles I have shared form the basis of my work and the strategies I have shared give me a welcome balance between what is predictable and circumstances in which I have no control. The “walk my talk” connection between my private and public self is a sign of all my efforts, including activist-scholarship, creative collaborations, and global advocacy and activism efforts. When combined, all these factors help to make me “me.”

My work is a mix of many things. It is sincere. It is fueled by my lived and learned experiences, my various identities, and the communities that I am part of. Words are my craft, born from something deep within. It’s like you just have to go with it...heed its call to make, to create, to speak, to act…or your soul will not be at rest. It causes change, and can even be disruptive—a powerful, almost bone-deep experience. I stopped resisting it; now I completely let it move through me.

According to Aristotle (Sachs, n.d.), rhetoric has three parts. First, there is *logos,* which checks the logic of the argument. Next, there is *pathos,* which focuses on the feelings caused by the argument. Last, there is *ethos,* which ignores the argument completely. Ethos worries more whether the storyteller is trustworthy than about the story because ultimately our lives are our stories...the story of self.

This thesis represents over a decade of my work, I want to be sure that it is a truthful and accurate picture of my life and therefore my story.

I urge you, dear reader(s), as you develop the plot of your own life, please be certain that you are crafting a story of self that is true to who you are. If you succeed, your ethos shall be one that is solid and unshakeable indeed.

This work is a combination of publications, multimedia, speaking engagements, critical narrativism, collaborative advocacy, and expressive art. It come from different academic (school) subjects. Here is a list of these disciplines: cultural studies (namely Black public intellectualism and Black disability studies), public digital humanities, pedagogy, sociology, etc. I also included new and combined disciplines. The list of these is: ethnomediaology, equity literacy, engaged research, and related subgenres (including "autie-ethnography").

Blending the core topics discussed earlier (Public Intellectualism, Engaged Pedagogy, and Disability Justice), the work represents years of earnest efforts. It includes mistakes made; lessons learned; "blood, sweat, and tears" I've shed. All of these have led to firsthand understanding, influenced policy, and inspired others. The material—which promotes activist scholarship, creative collaboration, and international advocacy—along with critically looking at it, contributes something important. It contributes to the understanding of the lived experiences of and perspectives of marginalized people, particularly with Black disability studies. Even more, it demands more (and better) research, so we can look at how laws are made, how standards are created, and society's worldviews overall.

It is my "life's work," and it is also my lifeline in that it contains my essence, my life story. In telling that story—as well as that of communities that I am a part of—it documents the life story of people like me. The reality and the necessity of resilience, challenges, triumphs, and hope throughout our ongoing quest for the acceptance, equity, justice, and empowerment that, as humans, is our birthright.

We who live at the intersections of marginalized identities have learned hard lessons from life. However, our existence is more than our struggle. We rebel and resist, but at the same time, we live, learn, and love. Our painfully learned knowledge has given us the ability to adjust our pain into platforms for growth; our regrets into resourcefulness; our crying into creativity. Thus, collectively, those of us whom society calls "other" help and care for one another. We do this while working towards a tomorrow we realize that many of us will likely never live to see.

Those of us at the margins of the margins...for whom intersectionality is our lived reality...continue to fight to bring fire to the people-—through scholarship, collaboration, activism, research, practice, art, policy, mutual aid, technology, advocacy, and various other means. May the glow from that fire forever light the way to progress, hope, and a just world that honors and celebrates us all.

Appendix B: Augmentative Content (32,097 words)

Bringing Fire to the People: Activist Scholarship, Creative Collaboration, & International Advocacy Through the Lens of Black Disability Studies

M. Giwa Onaiwu | University of East Anglia Doctoral Thesis | 2022

Contents of Appendices

Contents of Appendix B

*107,066.

Those were the total number of words - excluding the references/bibliography, glossary, figures, and appendices - that were in what I'd assumed to be a close-to-finished draft of my doctoral thesis (referred to more commonly in the United States as a "dissertation") the day I submitted it - 471 pages in all excluding the references and appendices - to my doctoral advisors. I was *so* proud of myself. It had been extremely difficult for me to trim the word count down; it had previously been 119,593 and 553 pages. However, because university guidelines limited it to 85,000 - 100,000 words, I'd had to work to remove a LOT of content. I was still "over" the word count, but felt it was close enough for me to turn it in and receive constructive criticism.

My advisors had been extremely supportive to me. They'd suggested resources, answered questions, and regularly provided me with thoughtful feedback on my outlines and ideas throughout. However, until this point, due to internal anxiety and various other factors, I hadn't yet granted them an opportunity to read what I'd written in its entirety. Although the timing was not what anyone had anticipated, I hoped, now that I had submitted it to them, that they would find it well "worth the wait." I sincerely hoped that they would be pleased with what I'd written.

So…imagine my shock when we met shortly afterward, and I discovered that I'd terribly misunderstood the information regarding the word count! (I realize this might seem strange, but it's true.)

I'd known that for my particular doctoral program, students were required to submit a comprehensive portfolio of high quality, original work along with a critical analysis of the material; both would constitute the thesis. But I had been somehow under the (false) impression that the maximum word count for the critical analysis alone was between 85,000 to 100,000 words. I hadn't realized that in actuality, the portfolio was expected to be -85,000 words and the accompanying critical analysis could be no more than 15,000 words - resulting in a *total* word count of 100,000 maximum for *everything.*

Basically, I had written ten times more than what was allowed. I would only be able to use, at best, a little more than a tenth of what I had. 90% of it would have to be eliminated.

I'm surprised I didn't faint upon learning this news.

Please understand that I am not implying in any way that someone misled me. The stipulations were stated in multiple places, including the university catalog, postgraduate student handbooks, and even in the fine print of the doctoral supervisory meetings. No one hid it from me; this was purely my mistake. Apparently, I had somehow misread or misunderstood the guidelines, and hadn't thought to seek clarification because all this time I thought I'd understood fully.

***107,066** - otherwise known as **Preface** (continued from previous page)

I am grateful to have discovered the truth. But, to put it mildly, that revelation changed *everything.* Knowing that there was no way to delete that much of the original thesis and still have it make sense, I knew immediately that I was going to have to completely start over. Not in terms of redoing the research (thank God!), but the entire thesis was going to need to be re-imagined and restructured; then rewritten. The thesis that I'd written was going to have to face sudden death so that a new thesis could be reborn.

That ^ backstory is important for anyone who chooses to read what's in these appendices. It not only explains why this section (the appendices) is unusually large, but it also gives helpful context regarding what was lost as a result of the changes. Initially, I had huge ambitions with regard to my thesis (some of which you will read about in my notes). I'd envisioned a colorful, creative, non-traditional thesis. It was going to be laden with imagery on nearly every page and different fonts and spacing in various places. It was going to have a fully digital companion site (I'd had the "placeholder" url ready months prior).

My thesis was also going to (hopefully) have an audio version. It was going to have a plain language version as well as an easy read version. It was going to be translated into Spanish, Arabic, French, and Pidgin English. I was also considering creating an infographic version and a possible version that would closely resemble a comic or a graphic novel. Oh, I had *big* dreams, y'all. And in retrospect, perhaps I was being overly ambitious to begin with. (Not perhaps; most certainly.) In fact, ~~some~~ much of that probably wasn't going to be feasible. I do believe that at least a portion of the aforementioned *would* have happened, because I would have been relentless in making it come to fruition. These were factors of great significance to me, and many of them were non-negotiables: either I produced them, or there would be no thesis. It was a "package deal" scenario in my mind.

There's a saying, however, that expresses the sentiment that humanity "...proposes; God disposes." I don't know the origin of the phrase, but I think that there's certainly some truth in its insinuation that though we might make plans and come up with ideas, there aren't any guarantees that things will unfold that way. As such, all we can do is try to live our best lives.

As of now (the time period in which I'm drafting this explanatory summary), I am still in the process of reconstructing a new, shorter thesis that will adhere to the stated requirements (apologies to my advisors for the additional work and thank you for not giving up on me despite everything). Given all of this, I am no longer certain whether I will be able to accomplish the numerous ambitious yet important original goals for my thesis with regard to accessibility, etc., but I will do what I can. Notably, I will salvage what I can from the deleted material and place them in the appendices as helpful supplemental context, as I just can't fathom just dumping it all into the abyss like trash. Hopefully someone will find it useful and informative!

*Prologue

Reflecting upon the themes that emerged after analyzing the work as a cohesive whole, the fire tetrahedron was an ideal analogy for a multitude of reasons. Like Prometheus (Cartwright, 2013), I had long empathized with and felt haunted by the plight of humanity - particularly other individuals who were, like myself, excluded and perceived as less than and/or “other” - shivering in the cold darkness. Remnants of corpses sprinkled about the barren landscape surrounding me provided an eerie and unwelcoming foreshadowing of what my future held...what our collective future held: pain and further suffering, followed by premature death. Though this was the only outcome I knew to even be possible, something inside of me - perhaps stubbornness, or denial, or foolishness (most likely a combination of all three) - refused to accept it. Knowing no warmth would be gifted to us by the gods, I sought some sort of solution, opting (unlike Prometheus) to resort to labor as opposed to trickery.

Armed with little but internal determination and a faint sense of hope, in some of the most desolate circumstances of my life, I steadied myself on the ground - the same cold, hard ground upon which I had repeatedly fallen. Though weakened and scared, I rose painfully and willed myself to try to come up with an idea, find something/someone who could help me, or discover some way that I could help myself, however futile my efforts might be, as the alternative (giving up in defeat) would most certainly result in my death.

Locating a few sturdy twigs, I studied them carefully and then, clutching them tightly in my palms, began to rub them together. Right there on the ground, enveloped in the cloak of night, despondent and nearly numb with cold and despair, I rubbed and rubbed...and observed, with immense relief, that these laborious efforts were rewarded with sparks. I rubbed even more vigorously, generating more and more sparks, and eventually, flames.

Despite its difficulty, that experience proved to be an invaluable lesson for me; one that not only changed my life, but likely *saved* my life. Learning to make my own fire (survive adversity; educate myself; make change) has helped produce heat to soothe many aches. Furthermore, I’ve discovered that in addition to the revitalizing warmth, the fire produces beams of light that grant me the ability to see, even in the midst of the night. And if I cultivate the fire just right, the light that it casts helps me to better navigate what had previously been shadowy, dark places of confusion, misinformation, and misunderstanding.

Having developed the knowledge and ability to create that illuminating and hard-earned fire, I feel compelled to share what I have gained with others. But how? There are a number of people who cannot be persuaded to approach the fire. Although the darkness is cold and harsh, they are accustomed to it and have some sense of what to expect. Whereas fire, with its bright glow, smoke, and dancing flames, is too unfamiliar for some; they shy away from its potential and danger, admonishing others to stay away from it also. Generally, there is no intended malice in their actions; they are merely acting out of fear and/or ignorance.

But now that I know the power, light, and warmth of the fire, I cannot fathom ever returning to an existence where I must dwell perpetually in the cold darkness. Nor can I bear for my people to languish in it either. I know that this fire *must* be shared. Thus, as long as there remain those individuals who, for various reasons, cannot and/or will not come to the fire, the onus is upon me, and upon you...we must bring the fire to the people.

To “bring” fire, fire must first be created - through the combination of oxygen, heat, and fuel. Though noticeably distinct from one another, they are interwoven as each of these components is necessary for fire’s manifestation as well as its sustenance.

Yet is not enough for the fire merely to exist - as depicted in the earlier illustration of fire’s development, as fire cannot adequately warm the shivering clan from a far-off distance. Once it has been lit, more is required…some must draw near to it - taking care to employ sound judgment in the process while also being cognizant of time and other constraints – to be able to acquire some of its warmth to take back to the people. This must be done strategically or else two very undesired results can occur: 1) burning up or 2) burning out. While the risk of burning up poses an overtly discernible danger, the risk of the flames burning out and dying exists as well; proactive action is necessary to prevent that from occurring.

It seems fitting, then, that each of the themes that were unearthed during the iterative analyses of the collective submitted work correlates to what is stated above according to their respective characteristics within the fire tetrahedron (National Fire Protection Association, 2019). Additionally, the components of the fire tetrahedron (oxygen, heat, fuel, and fire), which are explored in greater depth in the exegesis, portfolio, and appendices, also present an insightful analogy for the categorization of the published and creative work.

Purpose, Process, Accessibility

(Note: I am drafting this section prior to thesis "completion" and do not know whether I will have the opportunity to return to it afterward; as such, when you come across this supplemental section when it's within my "finished" thesis, please pardon any unforeseen inaccuracies.)

I created the initial drafts of this thesis using Google Docs. I started by copying a doctoral template from a university that already had pre-set margins, a title page, a table of contents, chapter headings, and references. I added in other sections that I wanted, rearranged some things, and initially placed "lorem ipsum" text as placeholders. At some point I am going to have to incorporate a different formatting tool, because Google Docs has some significant limitations with regard to pagination and other things that I won't otherwise be able to rectify. I will probably switch to Word since 1) I've had to convert the Google Doc to Word format anyway each time I've shared it with my advisors because that is their preference, and 2) being an 80's baby, I'm extremely familiar with Word (grew up with it). Doctoral student peers have recommended options such as LaTeX and Overleaf, and though those might indeed be great options, being that I am unfamiliar with those, I don't think right now is an optimal time for me to experiment with something new). However, Google Docs has been a godsend in many ways. Because it is cloud-based and automatically saves most changes every few seconds, I don't live with the existential dread of fearing that I might lose all my work; when I'm mobile I can easily access my in-progress thesis from my phone; I can opt for offline access if necessary. Also, converting to Word from Google Docs is pretty simple.

Using Google Docs is but one of various accessibility "hacks" I have used and/or plan to use as I create this thesis. Though it is uncertain whether or not I'll be able to implement any/all of my other accessibility ideas, I will still discuss some of them. First, I plan/hope to have more than one version of this thesis, including at least one "fully digital" version. When I conceived of this idea, I tried to envision some ideas for possible structure. I knew that, if possible, I wanted something that was 1) more than simply an online PDF with a lot of hyperlinks embedded; 2) user-friendly with a dedicated url; 3) filled with a variety of multimedia content; 4) viewable on a desktop computer as well as mobile devices; and 5) similar in appearance and function to a standard modern website with multiple pages and tabs. As an individual who utilizes concepts from media, literature, science, music, etc. in my work, I don't want my thesis to merely consist of a bunch of words plus a few charts thrown in for "good measure" - not if I wanted to consider it something that was authentically "mine," as *I* need to find the finished product interesting.

I hope to liberally incorporate imagery, quotes, video clips, infographics, etc. as necessary to augment the thesis like I do in my work; I think my thesis should be reflective of all of that. However, I am not entirely certain how that will turn out; in an earlier draft, I tried to intersperse various images (several figures and illustrations I'd identified that could be helpful) throughout the text of the thesis, using the "text wrapping" feature in Google Docs. The result was not aesthetically pleasing at all (#MajorFail), so I took the images out of the body of the thesis and moved them all to the appendices. Thus, at the time I am writing this, my thesis is mostly "traditionally" formatted overall, but contains what is probably considered an unconventionally large number of images in the appendix (not unusual for those whose theses are in visual arts, etc., but probably unusual for many other disciplines).

I'd held out hope that perhaps I might still be able to develop my thesis into a more creative and, in my opinion, a more visually appealing form than the standard thesis format. I wanted to make it into something that felt more "me." I researched different options as I tried to figure out how to proceed and also sought clarification from the university to avoid violating any policies. I needed to know, for example, whether, if all the content, research, editing, etc. is done solely by me, I am permitted to pay to have a professional interior layout and/or cover for my thesis that is formatted by someone else? And if not, in selecting a tool for doing it myself, are there any restrictions I should be aware of?

I have looked into some "do it yourself" (DIY) resources; specifically, the following software applications): Canva; Draft 2 Digital; Reedsy; Designrr; Adobe; SciWheel, and InDesign. I've also recently come across an article about Justin Schell's digital dissertation that was written by the US chapter of the International Association for the Study of Popular Music to commemorate a special issue of *Ethnomusicology Review Journal*. Schell, a filmmaker, created a "traditional" dissertation as well as an accompanying website that contained the dissertation's content in an online form with explanatory text, video clips, and images. (The project, *We Rock Long Distance*, which evolved into a full-length documentary, could potentially be a helpful guide for the digital component of my thesis.)

There are additional unique aspects of my thesis that differ from the status quo, including the fact that I have more than one set of "acknowledgements." I have a lot of people I wish to thank, so rather than having one excessively long set of acknowledgements occupying space in the front matter, I have split them into two sets of acknowledgements (one intended for the front; the other for the back). I'm not aware of any justifiable reason why I can't.

Regarding other differences, I’ve listed my remaining points (which, like most of those that preceded them, are not shared in any particular order) in bulleted form. This is not to imply that they are of lesser importance; rather, it is because several of them are fairly “self-explanatory” and therefore require little context. It is also a sincere attempt at brevity on my part (if such a thing exists in relation to something as long as a doctoral thesis).

Other factors relevant to purpose, process, and accessibility with regard to the thesis include:

- I am *technically* capable of writing the “right” way. I just choose not to. Ultimately, why should I be forced to accept that way as the “right” way if it doesn’t feel “right” for me and it limits comprehension and/or access for others?
- Academic dishonesty frightens me. As a result, I tend to err on the side of caution when it comes to crediting sources for their work. In my opinion, in the midst of such subjectivity, "over attribution" is better than unintentionally plagiarizing!
- Similar to what I shared about attribution…I’d rather provide *more* context than less. This tendency does not always lend itself well to footnotes, so even though I personally prefer footnotes, I often use endnotes (noted by chapter) and/or hyperlinks.
- I’m autistic. I like scripting...and quoting, to me, is a lot like scripting. I realize that “excessive” quoting is a faux pas in academia because it seemingly indicates that you aren’t capable of original thought or whatever, but...oh well. That’s not what it signifies to me; and determining what is “excessive” is highly subjective.
- I typically don’t refer to myself nor to others using what I perceive as stigmatizing or othering terminology. For example, unless I’m quoting something, I won’t refer to myself as having “autism spectrum disorder.” I am *not* “disordered;” I just possess neurology that is different.
- I use inclusive pronouns and descriptors when applicable - in other words, in addition to using people’s chosen pronouns, preferred names, people's chosen self-descriptions, etc. I also try to be neutral when speaking generally and/or if I don’t have specific information. If I am referencing “Taylor Smith” I will default to their name and/or use “they/theirs/themself” pronouns in the absence of details about Taylor’s preferences; in an image description I might describe someone as a “person” rather than an “man” or “woman” etc. since I don’t know someone’s gender by outward appearance. Similar approaches are taken with age, race, etc.

- I’m American, not British. I don’t use British English. So outside of quoting, I use color as opposed to colour; realize as opposed to realise; I use “ in places where others might use ‘ and I also place my punctuation inside, not outside of quotation marks.
- I am not always capable of providing specific content and trigger warnings as they occur, so I try to provide a “general” or “blanketed” one at the onset when I can.
- I redact and/or replace certain things for privacy and related reasons.
- All of my images have alt text containing fairly detailed image descriptions within them as opposed to minimally descriptive alt text that requires going elsewhere for a lengthier description.
    - I “outsourced” several of the image descriptions in the thesis to a disabled colleague who was compensated for their efforts.
- I try, when possible, to spell out and/or otherwise explain when using certain acronyms, colloquialisms, etc. for the first time, but do not always succeed.
- I hope to provide “plain language” options for this thesis, such as lay summaries and/or audio versions for greater cognitive accessibility.
    - If permitted, I might “outsource” much of the plain language rewording to others due to time and internal capacity constraints.
    - To date, I have created my own plain language summaries, but it is time-consuming.
- I acknowledge that most American doctoral dissertations are in American Psychological Association (APA) format; double spaced, etc. However...
    - I wish to provide a full bibliography to credit all sources consulted as opposed to just listing references/citations, so I might not be using traditional APA.
    - To me, double spacing and certain font requirements are restrictive, so I don’t intend to adhere to these “rules” unless I have to (per the university, I don’t).
- If I am not fully depleted upon completion, I might provide an (optional) resource list and possibly (optional) discussion points/questions for any interested readers

*Important Context

I'm of West African descent, and there is a particular meal (a type of stew, or "soup" as she calls it) that my mother made quite frequently when I was growing up (Sokoh, 2021). Although the core ingredients remained constant, she would often vary the type of protein used (fish instead of chicken; goat instead of beef, etc.). She might opt to add spinach or egusi or bitter leaf or okra or a boiled egg. But whatever the ingredients, it needed to be stirred and checked on at various intervals. The way it looked, smelled, and tasted (when you placed a small portion of it on your palm to check it) determined it was "done" - not the cooking time.

When it was done, you just *knew*.

I've probably eaten it over a thousand different times a thousand different ways throughout my lifetime.

In many ways, this thesis is like that. It bears similarity in some ways to a "traditional" thesis, just like the base ingredients of my mom's stew. Because of the heterogeneous nature of my work, the range of applicable content is broad and can vary widely. However, the essence of the stew remains the same (delicious!). I invite you to bring a hearty appetite and your favorite bowl to dine with me.

The thesis contains obligatory front matter, including more than one abstract (namely, plain language and "layperson" versions of the abstract, a dedication and acknowledgements, and a frank author's note about its accessibility (in relation to its structure, content, mode of delivery, etc.). It also contains a content/trigger warning, a prologue, and various introductory and supplemental information: foundational context via an illustrative narrative; research methodology; and an overview of the literature review's search strategy and its content, conceptual frameworks, and discussion of my praxis.

The exegesis focuses on public intellectualism, bell hooks' engaged pedagogy, Black disability studies, and disability justice to offer a review, analysis, and discussion of the literature and my work. It incorporates a range of concepts throughout, including analogies and, most significantly, thematic patterns that emerged during data collection and iterative analyses, portrayed via hermeneutic inquiry, as the fire tetrahedron (National Fire Protection Association, 2019). The portfolio contains select contributions of my transdisciplinary published and creative work (Lawrence, 2010). Next are the extensive appendices, which, though optional, provide important information. Their content includes summaries that are written in "plain language" as well as a variety of crucial auxiliary material excised from earlier drafts. Various institutional content and relevant back matter close the thesis.

Therefore, this, as you have probably already gleaned, “ain’t” your average doctoral thesis. It is a legitimate postgraduate research project, but it is also embedded with my literary DNA. I am not an objective external party making commentary on a random subject. This is my life; this is me. I can’t simply pretend that this is any arbitrary thing I am writing about as if it matters little to me, as it matters very much. I care.

I am comforted by the fact that the consensus among my interlocutors (people who have deeply inspired me) seems to be one that is similar to mine: It’s nearly impossible to be “neutral” about something that matters so much. Furthermore, in the book *Black Feminist Thought,* sociologist Patricia Hill Collins affirms that, “All knowledge is intrinsically value-laden and should thus be tested by the presence of empathy and compassion…Emotion indicates that a speaker believes in the validity of an argument.” (p. 263) Black luminary W.E.B. DuBois expresses a similar sentiment in his work. The influential scholar discusses the difficult nature of reconciling contradictory situations. Empathizing with others who are feeling pressured to “calmly” navigate complex matters, particularly when one is personally impacted by them, DuBois candidly reveals that “So intense was the feeling, so mighty the human passions that swayed and blinded men.” (DuBois, 1903) Even he of the “Talented Tenth” philosophy understood how vital sharing this information with others.

*Disability Disparities from the Womb to the Tomb

Ableism takes a significant toll on our lives...from our healthcare, economic, educational, and legal systems to our sense of self, family unit(s), and our role(s) in the community. This is in addition to how it magnifies any additional marginalization(s) that might exist (i.e., race, gender, sexuality, age, socioeconomic status, country of origin, etc.) As unacceptable as it may seem in theory, inequity in its various forms tends to be the "rule" as opposed to the exception for far too many disabled individuals.

Devaluation Before and After Birth

Ableism contributes significantly to measurable disparities faced by individuals with disabilities across the lifespan, often beginning at a very early age. Sadly, disabled lives are devalued long before we ever take a breath. Many facts attest to this; one of which, the practice of prenatal screening designed to "detect" our existence, is part of the recommended standard of obstetric care.

It is also evident in the increasing frequency of "wrongful birth" lawsuits that occur as well as the fact that if a parent is expecting a child suspected to have one or more of certain diagnoses, medical geneticists, and other medical professionals counsel a "no intervention" approach during labor. In some cases, it has been documented that even the use of routine and generally considered noninvasive tools such as fetal monitors that are regularly used in the child birthing process for nearly all parents, is discouraged when the person who is pregnant is confirmed or highly suspected to be delivering a disabled child. Furthermore, it is apparent in the shrinking numbers of children born with Down Syndrome (DS). It is believed that ~70-80% of pregnancies are terminated once screening results indicate that the child likely has DS.

And though DS has been at the forefront of public and legislative discourse on this topic, these eugenic practices are not limited solely to DS. Existing laws such as the 1967 United Kingdom Abortion Act permit late and even full-term pregnancy termination that is not medically warranted/necessary to occur in any instance where "there is a substantial risk that if the child were born it would suffer from such physical or mental abnormalities as to be seriously handicapped."

Community advocacy efforts to oppose this law include 26-year-old DS activism Heidi Crowter's recently dismissed High Court lawsuit (BBC, 2021) and the viral #DontScreenUsOut international campaign.

Devaluation From Childhood to Adulthood

The devaluation of disabled lives that begins before birth continues throughout childhood and adolescence; this is evident in a number of policies and procedures that have different standards for disabled and nondisabled individuals. One of the most blatant examples exists in Belgium, where euthanasia for adults and emancipated minors with disabilities has been legal since 2002. In 2014, the law was amended to include children with disabilities; there is no minimum age criteria (PBS).

Devaluation Across Systems and Institutions: Public Education

With regard to disability, disparities persist across a plethora of systems and institutions. Despite federal laws, societal devaluation of disabled lives is particularly evident within the public school system, which, in the US, is charged with rendering special education services to all eligible individuals with disabilities who are at least three years of age through their 21st birthday. Prior to the COVID-19 pandemic, public schools in several states were failing to even identify disabled students (Schaeffer, 2020); much less, presumably, meet their needs by upholding their right to a free, appropriate public education with their peers in the least restrictive environment.

As such, there was considerable alarm that a federal coronavirus relief program proposed by Senate Republicans in 2020 contained explicit wording that would grant the US Secretary of Education authority to exempt public schools from their current obligations under the Individualized with Disabilities Education Act, Section 504 of the Rehabilitation Act of 1973, and Title II of the Americans with Disabilities Act under the guise of “limited flexibility...during the emergency.” (Greene, 2020) Proponents of equity in education note that such action could set a dangerous precedent that could be detrimental for both current and future students (Greene, 2020). This is especially concerning when one factors in that pre-COVID-19, for nearly a third of children with neurodevelopmental disabilities, attending school was their only organized activity outside of the home.

These fears are not without merit as there were significant disparities in public education prior to the early 2020 onset of the global COVID-19 pandemic. For example, families with one or more disabled students in the home report an astonishing lack of school engagement - less than half of what exists in nondisabled families. Also, according to the US Department of Education (2014), students with disabilities are only half as likely to graduate from high school as their nondisabled peers (10% of non-disabled individuals have less than a high school diploma compared to 20% of people with disabilities).

Additionally, per the US Department of Education (2014), nondisabled students are significantly more likely (~83%) to graduate from high school "on time" (within four years) than special education students (~65%). Nondisabled students are also afforded more latitude in instances of behavioral challenges; disabled students are punished with suspension and expulsion two times the rate of their nondisabled peers.

Devaluation Across Systems and Institutions: Health, Law, Congregate Care

Individuals with disabilities typically present with worse health outcomes than their nondisabled peers - even in aspects of health that are unaffected by and/or unrelated to the disabling condition(s). Data suggests that for many, these disparities are at least in part due to ableism (discriminatory practices and beliefs regarding disability), which can negatively impact not only access to care, but also the quality of care that individuals with disabilities are receiving. Ableism can manifest itself in both subtle and overt ways.

In one study of pediatric medical residents, 71% of them expressed that they disapproved of using aggressive treatment and life-saving interventions when the patient in question was a child whom they perceived to have severe disabilities...even when such treatment in nondisabled patients is typically considered part of the established standard of care. These professionals, trusted medical authorities charged with preserving the health and life of the most vulnerable in our population, are essentially declaring that in their opinion(s), death is preferable to living a disabled life.

However, the health care system is only one institution; there are several others that also perpetuate unacceptable disparities between disabled and nondisabled individuals, including the legal/criminal justice system and congregate care settings such as foster homes, residential treatment placements, and similar programs. For example, people with disabilities are 11% more likely to be a victim of a violent crime than nondisabled individuals. ~One third to half of the total of individuals killed by law enforcement are disabled according to a 2016 study.

Youth with disabilities are overrepresented in the juvenile justice system, where they comprise ~33% of its population. Furthermore, within that 33%, a disproportionate amount of the youth met the diagnostic criteria for one or more neurodevelopmental disabilities: an astonishing 85% of them. Disappointingly, nearly 3/4 of those youth had not been receiving disability services or accommodations in the year before entering the juvenile justice system, including those who had formal, well-documented diagnoses on file prior to their stint in juvenile.

Devaluation Across Systems and Institutions: Higher Education

Federal law mandates the incorporation of transition planning into special education services no later than preadolescence. In the procedural guidelines for individualized education plans (IEPs) that schools are mandated to adhere to, it is explicitly stated that transition age students with disabilities should not only be included as part of their IEP team; said students should also be strongly encouraged and given support to take active roles in helping to determine their future trajectory. To comply, many schools invite incoming secondary school aged students with disabilities to attend one or more IEP meetings, particularly meetings that occur at significant periods of transition (i.e., when a student is changing from middle school to high school; when a student is departing high school; etc.)

As such, presumably most students' transition plans should be perceived as an accurate depiction of their intended future aspirations. According to data compiled by the National Center for Education Statistics, over 80% of students at or approaching transition have college explicitly listed on their individualized education plans as a goal (n.d.).

It seems, however, that nearly nine out of ten times that goal never comes to fruition, as collectively, only ~11% of all US students currently enrolled in a college, university, or comparable institution of higher education are reportedly disabled (US Department of Education, n.d.). Overall, compared to nondisabled peers, disabled individuals are only half as likely to complete college.

Moreover, there are ~600 colleges that reportedly had *no* students enrolled at all in a particular year of the early 21st century who are identified as disabled (US Department of Education). If this is correct, then disabled students are not present in ~12% (or more) of all institutions of higher education in the US. A separate but related concern exists regarding many US legislators' growing interest in tying annual allocations for publicly funded post-secondary institutions more closely to specific metrics that advocates fear will further disincentivize enrolling and/or retaining students who might need additional support, including first generation students and students with disabilities.

About half of all students with disabilities do enroll in an institute of higher education at some point. In fact, within the two year/community/technical college system, statistically the enrollment of disabled students surpasses its peers: individuals with disabilities are twice as likely to enroll in a two-year college than a four-year college (the reverse is true for their nondisabled peers). Unfortunately, in both the two-year and four-year college settings, many students with disabilities will encounter the same fate: they will not successfully complete their studies (BLS).

Ableism could be part of the reason there is such a high attrition rate; 25% of college students with disabilities in the US report not receiving adequate accommodations. (National Center for Educational Statistics). This could potentially impact the amount of time that it takes for students to complete their academic requirements as well. Over 33% of disabled college students enrolled in traditional four-year institutes of higher education will obtain their undergraduate degree, but the median time to completion for these students is between six to eight years instead of the standard eight traditional full-term semesters taken over four consecutive academic years.

Disabled college students who pursue other types of postsecondary schooling fare somewhat better; 41% of disabled college students enrolled in two-year institutes of higher education such as community and technical colleges will obtain their certificate or degree. However, the median time to completion is approximately four to six years instead of the two years such programs are supposed to be completed in (USDE). Reasons for the lengthier time to completion range from students enrolling part-time instead of full-time; needing to take breaks from schooling due to health, financial, or other circumstances; lack of clarity surrounding program requirements, etc.

Devaluation Across Systems and Institutions: Workplace and Economic Sector

National employment and economic statistics for people with disabilities in the US are grim in comparison to their nondisabled peers. Collectively, disabled individuals across the lifespan have unemployment rates twice that of their nondisabled peers. Educational attainment, often lauded as a bridge to opportunity, seemingly changes very little for many individuals with disabilities in terms of income generation and/or providing a professional advantage. A longitudinal national sample of disabled and nondisabled young adults found that high school graduates who received special education services for one or more disabilities typically earn ~$4 less per hour than their nondisabled peers who were in general education and had not received special education services. Outcomes are even more concerning for those who attend and complete college: disabled college graduates are employed at only ~one third the rate of non-disabled college grads (26% versus 76%).

Among both high school and college graduates, those "fortunate" enough to be employed will likely earn substantially less money than their nondisabled peers (BLS). People with disabilities are also nearly two times as likely to be only employed part-time in comparison to individuals who are not disabled. This inability to secure full-time work may contribute to higher rates of entrepreneurship among people with disabilities. Compared to their nondisabled peers, disabled individuals are twice as likely to be self-employed (11% vs 6%). Self-employment might represent an alternative for both disabled and non-disabled individuals - to full-time employment that is appealing and accessible.

However, despite its merits as an option for generating income, entrepreneurship does not necessarily beget financial stability, much less measurable profit. Across the lifespan, disabled individuals are twice as likely to dwell in poverty than nondisabled people (29% vs 15%). Collectively, there has been an 8% or more poverty gap between disabled and nondisabled people across the lifespan over the last 11 consecutive years. If we isolate the data to only include those who fall within the national "working age" (individuals who are between 18-64 years old), although the total number of disabled and nondisabled individuals is fairly equivalent, the employment rates are not. Only 36% of people with disabilities in that range are employed. Conversely, 77% of "working age" nondisabled people are employed - a difference that is at least 40% or higher!

Numerous challenges persist even for those working age individuals who are able to obtain employment: people with disabilities ages 18-64 years are 2.5 times more likely than non-disabled people to dwell in "persistent poverty" (which is defined as being at or below the federal poverty level for 24 consecutive months or longer. Disabled workers' median annual national salary is ~$10,000 lower than their nondisabled peers.

This trend has been observed for longer than an entire Census period (10 years) and is ongoing. When one evaluates working age outcomes by state as opposed to nationally, there is little change. Although there are a few states where disabled workers fare better than others, similar (and, in some cases, worse) employment disparities exist in more than 34 of 50 states and in several US territories as well. Many of these state-level suboptimal employment outcomes have also persisted for several consecutive years.

One possible contributing factor to these economic disparities might be the 1938 Fair Labor Standards Act "sheltered workshop" clause. The clause permits some employers the right to pay certain workers (some people with disabilities, incarcerated individuals, etc.) considerably less money for their labor than what is classified as the US federal minimum wage and/or any existing state minimum wage as well, if applicable. (Iowa Center for Human Rights, n.d.)

There were more than 1,200 companies in the United States and its territories that actively possessed special certificates permitting them to pay subminimum wages to their employees as of the year 2020 alone (Diament, 2021). Appallingly, in one particular year (2016), over 241,000 American "subminimum wage" workers, mostly disabled individuals, were literally paid pennies on the dollar - some as little as $0.04 per hour (GAO, 2021). This is not a statistical anomaly; the data from that year is fairly typical of the years proceeding as well as following it.

Devaluation Throughout the Lifespan

Currently, there are an estimated 16 million Americans (inclusive of children, teens, and adults) with intellectual/developmental disabilities (I/DD). Individuals with I/DD often have complex health and social needs that are inadequately met, resulting in significant inequity and poorer outcomes across the lifespan. Families with one or more disabled members have higher risk for poverty and illness, but only 13% of caregivers of a disabled loved one who resides in the family home receive comprehensive support services (i.e., respite, personal care, subsidies).

Caregivers are urged (and in some cases, feel pressured) to pursue legal guardianship under the guise of "protecting" their disabled loved one(s) even if they reside in a geographic location where less restrictive alternatives (i.e., supported decision making) are possibilities. Guardianship represents disenfranchisement as it hinders one's ability to have autonomy over various important aspects of daily living such as housing, health care, voting, finances, sex, family planning, transportation, activities, and overall agency over one's own life.

Many chronic health conditions affect people with I/DD at a younger age than peers without I/DD and/or at higher rates. Individuals with I/DD are between three to five times more likely to have psychiatric disorders than others, and there is also increased suicide risk. Institute for Exceptional Care (2021) lists several conditions that occur at higher rates among people with I/DD than the rest of the population:

> "...sleep disturbance, hormonal imbalance, blood disorders, digestive disorders, anxiety depression, post-traumatic stress disorder, seizures, hearing impairment, eating disorders, substance abuse."

These factors are complicated by the reality that people with I/DD receive less preventative health care services such as vision and hearing checks; cancer screening; and/or blood pressure or cholesterol monitoring (Institute for Exceptional Care, 2021). Moreover, large segments of both the I/DD and caregiver population are aging exponentially. ~25% of caregivers are age 60 or older; 50% are age 40 or older. One million persons with I/DD will be over 60 years old in 2030.

Overall, the I/DD community faces social isolation and inadequate emotional support, especially the 30% that are Black, brown, and/or low-income (Institute for Exceptional Care, 2021).

*Disparities at the Intersection of Gender and Disability

Suboptimal Outcomes/Social Determinants of Health

Across almost every social determinant of health, gender minorities who are disabled fare worse than their nondisabled peers, particularly those of more privileged gender identities. A substantial form of discrimination faced by gender diverse individuals is erasure and blatant lack of representation in data. Binary/limited options for accurate depiction of gender abound in nearly every sector...research, practice, media, health, education, law, etc., resulting in missing, incorrect, incomplete information, potential microaggression (including but not limited to misgendering), unaddressed needs, and stigma.

Such inaccuracies are pervasive - they exist even within this very thesis as in many of my sources I was unable to obtain comprehensive data about anyone other than “men” and “women” - and those categories were still imprecise because gender and sex are often misunderstood and used as if they are interchangeable. As such, it is difficult to ascertain, for example, whether data about “women" is inclusive of all individuals who identify as women, whether it includes individuals who were assigned female at birth regardless of gender, etc. Moreover, despite its prevalence among individuals within the autistic and neurodivergent communities, gender diversity is alternately ignored and/or pathologized. Individuals who identify as a gender that is not “male” or “female” might find themselves cast into a nebulous “other” non-category - or misgendered. Diagnostic disparities in relation to gender, such as the fact that depressive disorders occur in women at a rate that is 12.5% higher than males and the fact that (cisgender) boys are four times more likely to be diagnosed with ADHD, autism, and other neurodevelopmental disabilities, persist.

Beyond diagnosis, there are many other disparities at the intersection of disability and marginalized gender, including education and finances. According to global estimates, nearly ¾ of all women with disabilities are unemployed. The women with disabilities who are “lucky” enough to be employed typically do not have adequate job security as they often encounter ableism and/or gender discrimination at work. They also tend to earn less than their male counterparts and women without disabilities. Women and girls with disabilities are three times more likely to be (functionally) illiterate than disabled peers who were assigned male at birth (UNESCO) and are also more likely to be institutionalized than their disabled male peers.

Women with disabilities were significantly more likely than women without disabilities to report having experienced rape, sexual violence other than rape, physical violence, stalking, psychological aggression, and control of reproductive or sexual health by an intimate partner (IPV) regardless of age, family income, race, ethnicity, and education. Though it is speculated that the actual numbers are probably much higher, particularly when there is financial and physical dependence on the intimate partner, 85% of women with disabilities in one national study reported that they have never had any medical provider offer or attempt to screen them for potential IPV.

Higher Likelihood of Abuse: Women with Disabilities

Abuse rates of disabled women compared to nondisabled women:

- 4 times more likely to experience rape
- 2.5 times more likely to experience sexual violence
- 2 times more likely to experience physical violence
- 3 times more likely to experience stalking
- 2 times more likely to experience psychological abuse
- 2 times more likely to experience denial of reproductive rights/autonomy

Autism/IDD and Gender Disparities

It is well documented that autism diagnoses among girls are only a fraction of that of boys - less than a fourth by some estimates[5]. Autism screening and identification occurs much less frequently in girls, and often much later as well. Campaigns such as "Light It Up Blue" © for autism awareness (blue is widely perceived as a "boy" color) emphasized the autism prevalence in boys (George, 2016). "Extreme male brain" theories and autism representation in media and entertainment i.e., *Atypical*, *The Good Doctor*, and *Parenthood* (Luterman, n.d.) contributed to the invisibility of autistic girls.

This disproportionality, however, persists beyond the childhood years as autistic women are equally if not even more unseen than young girls (Bargiela et al, 2016). Autistic women and girls might appear more adept at "camouflaging" their differences through carefully cultivated social scripting and/or by mimicking their typically developing peers (Lai, 2019). Research indicates that these differences in the way that autistic girls and women present often contribute to women's autism being discovered later in life, inaccurate diagnoses of other conditions, or missed diagnoses altogether.

This is further exacerbated by the likelihood that statistically autistic women have reduced access to support. They exhibit higher rates of co-occurring psychiatric and intellectual/developmental disabilities (I/DD), including anxiety, depression, ADHD, and intellectual disability. They also tend to have elevated rates of health conditions such as epilepsy, Ehlers-Danlos Syndrome, and polycystic ovarian syndrome than similarly matched non-autistic women do (Hull et al, 2017; Cherskov et al, 2018; Kassee et al, 2020).

Research also indicates that autistic women are at greater risk for suicidal ideation and/or attempts than their autistic male peers. Moreover, compared to autistic males as well as to their non-autistic female counterparts, autistic women experience significant additional health disparities beyond the conditions previously listed, and have more severe symptomatology (Cawthorpe, 2017). Yet not only does recruitment, enrollment, and retention of women and girls lag noticeably behind that of men and boys in autism research, autistic women are also vastly underrepresented compared to non-autistic women in various research disciplines, including reproduction and perinatal research. Sadly, as aforementioned, gender diverse autistic individuals (those outside the more commonly known binary) are even more underrepresented than autistic women and girls are in the literature and largely, tend to be missing entirely.

Disparities at the Intersection of Race and Disability

Historical Context: Invisibility and Inequity

Existing at the intersection of various devalued identities (in this case, disability, [particularly neurodivergence] and race) increases individual and group vulnerability in a myriad of ways, resulting in significant disparities between people of color and non-minority peers and contributing to the erasure and invisibility of those at the margins of the margins. This is not a new phenomenon, but one that has a lengthy and sordid history.

Though a formal term (intersectionality) would not be coined (initially by attorney, policy analyst, and professor Kimberle Crenshaw) until the 1990's, long before then there were numerous scholars, authors, poets and activists of color (from Sojourner Truth, and Harriett Ann Jacobs to others) who had thoroughly documented the harsh reality of occupying multiple social categories that intersect with oppression and privilege; in these instances, race, gender, and both inherent and acquired disability.

Missed/Late Diagnoses; Less Access to Services

It is well documented that autistic children of color are frequently diagnosed later than their white peers (Institute for Exceptional Care, 2021). Research indicates higher frequencies of suboptimal provider interactions with parents of color**.** Data indicates that communities of color might have less health literacy than their white counterparts as well as more limited communication with health providers, especially white providers. Unfortunately, literature also indicates that when a young child of color who is exhibiting characteristics attributed to autism, white doctors are less likely to make a referral or even use gold standard screening tools with. Typically, this results in ~15.5 months of delay overall.

Studies have indicated disparities in providers' perceptions of Black parents of children who are later diagnosed as being on the autism spectrum as "reliable historians" compared to white parents of children with similar profiles. Although Black parents did not conceal that their children exhibited what are generally considered hallmark autism characteristics, the way that they conveyed the information was relatively neutral - a stark contrast to that of white parents who tended to explicitly convey a sense of alarm. As such, Black parents' observations about their children were largely dismissed or ignored.

Sadly, Hispanic/Latine parents reported that providers had dismissed their concerns at even higher rates than Black parents. This was the case for bilingual (English and Spanish speaking) as well as monolingual (only English speaking, or only Spanish speaking) Hispanic/Latine parents, but monolingual Spanish speaking parents experienced this at higher rate than parents who were native or fluent speakers of English.

School districts often denied evaluating children of color for autism more frequently than their white peers, citing largely unsubstantiated assumptions that the children were demonstrating "social maladjustment" and/or "environment, cultural, economic disadvantages" as the rationale. This trend has been seen in multiple communities of color, especially Hispanic/Latine and Asian children. Black parents who persisted, reporting their children's behavioral concerns at a rate equivalent to that of white parents, found themselves isolated and that their children had often been misdiagnosed with something other than autism.

Diagnostic Disparities: By the Numbers

White children on the autism spectrum are ~2/3 more likely to be receiving multiple services than children of color with the diagnosis. Additionally, white children are 19-30% more likely to be diagnosed with autism than Black children and 50-65% more likely to be diagnosed than Hispanic/Latine children (even after controlling for socioeconomic status). Black children, who are often diagnosed with autism one and a half to two years later than white children, often experience up to a three-year time lag between obtaining their diagnosis and accessing services, especially those who are of what is considered to be a lower socioeconomic status.

Disparities in Special Education

Disparities at the intersection of both race and disability are plentiful. Students of color with disabilities are more likely to have non-IDEA school labels (i.e., Oppositional Defiant Disorder and Conduct Disorder) and thus receive fewer and less effective services. Black children with disabilities are more likely to be misdiagnosed as some other condition; specifically, while white students are more likely to be labeled "autistic" than are students of color, Black students in particular are at the highest risk of all races for being labeled with the broad term "specific learning disabilities." In previous academic years, Black students with disabilities have been twice as likely as Latine, four times as likely as Asians and 1.4 times as likely as whites to receive special education services for "emotional disturbance."

Research strongly indicates that being integrated into a setting with non-disabled peers as opposed to being primarily segregated results in better academic and social outcomes for children with disabilities. White students with disabilities are 10% more likely to be in the general education classroom for 80% of the school day while their disabled peers of color spend a substantial portion of the school day segregated from non-disabled peers.

Students of color also experience higher rates of disciplinary action and suspensions. More than one in every four Black boys identified as having disabilities may be suspended during the academic year according to the US Department of Education's Office of Civil Rights. In non-Black boys of color classified with disabilities, namely Indigenous, Pacific Islander, and multiracial boys, suspension rates for disabled children of color eclipse that of their white colleagues.

Disparities in Custodial and Family Rights

People of color make up a disproportionate number of parents who have experienced child custody challenges, including loss of parental rights. Disabled parents of color are at even higher risk. In 35 US states, disability can be used as grounds for termination of parental rights. In 10 US states, disability can be used as a factor in determining custodial rights (in the case of divorcing a non-disabled spouse, for example, or in the case of potential adoption, managing conservatorship, and or seeking guardianship), *even in the absence of any allegations of child abuse and/or neglect.* (Powell)

*Disparities at the Intersection of Race and Trauma/Mental Health

Racial Trauma (Overview)

Mental and emotional injury caused by encounters with racial bias and ethnic discrimination, racism, and hate crimes. Racial trauma is, sadly, part of the "status quo" for PoC. Race-based discrimination detrimentally impacts individuals and communities. Prolonged incidents of racism can lead to symptoms like those experienced with post-traumatic stress disorder, including depression, anger, recurring thoughts of the event, physical reactions (e.g., headaches, chest pains, insomnia), hypervigilance, low self-esteem, and mentally distancing from the traumatic events.

> "Is this America," she asked as tears welled up in her eyes, "the land of the free and the home of the brave, where...our lives are threatened daily, because we want to live as decent human beings, in America?" - Fannie Lou Hamer

Racial Trauma: Direct, Indirect, and Transmitted

Direct racial traumatic stressors occur as a direct result of existing in a society laden with systemic racism whether or not one has been on the receiving end of individual racist physical and/or verbal attacks and/or other microaggressions (NAMI, 2020).

People of color are at risk for different types of indirect racial trauma as well, including vicarious and transmitted trauma. According to the National Association of Mental Illness (NAMI, 2020), "Vicarious traumatic stressors are the indirect traumatic impacts of living with systemic racism and individual racist actions. Vicarious traumatic stressors can have an equally detrimental impact on BIPOC's mental health as direct traumatic stressors.

Transmitted traumatic stressors refer to the traumatic stressors that are transferred from one generation to the next. These stressors can come from historically racist sources or may be personal traumas passed down through families and communities.” (NAMI, 2020)

Examples of Various Types of Racial Trauma

- Viewing videos of brutal police killings of Black people, such as the video associated with the horrific 2020 public murder of George Floyd, can cause traumatic stress reactions in the people who view them - especially in Black people
- Of Latine/@/x youth that immigrate to the U.S., two-thirds report experiencing one traumatic event with the most common traumatic event reported during and post migration being witnessing a violent event or physical assault (NAMI, 2020)
- Many Native American children are vicariously traumatized by the high rates of societal homicide, suicide, and unintentional injury experienced in these communities (NAMI, 2020)
- The descendants of Holocaust survivors display an increased vulnerability to developing psychological disturbances in addition to stressors related to Holocaust loss. This vulnerability is directly related to the negative life experience of the previous generation.
- The chattel enslavement of Africans in the U.S. and other countries continues to serve as a source of traumatic stress for Black people today. In fact, this sustained collective trauma makes Black people highly vulnerable to developing mental health disorders.
- Historical trauma shared by Native Americans including boarding schools, massacres and forced violent removal from their tribal lands represents a severe communal loss and source of traumatic stress. Native Americans today continue to experience symptoms of depression, substance dependence, diabetes, and unemployment due to the psychological impact of the trauma. (NAMI, 2020)

LGBTQIAP+ People of Color and Mental Health

Queer people of color have higher rates of psychiatric disability than both their heterosexual peers of color and their queer white peers. Specifically, they bear a disproportionate burden of conditions, including anxiety disorders, major depressive disorder, eating disorders, substance and/or alcohol misuse. There is also a dearth of openly queer mental health practitioners.

Suicide Rates of Youth of Color

"Stigma is one of the main reasons why people with mental health problems don't seek treatment or take their medication. People of color, particularly African Americans, feel the stigma more keenly. In a race-conscious society, some don't want to be perceived as having yet another deficit." - Bebe Moore Campbell’s aforementioned quote illustrates the painful, debilitating impact of unaddressed mental health needs, which generally increases suicide risk. From 1991 to 2017, suicide attempts in Black teens increased by 73%. In the last decade alone, the suicide rate for Black youth nearly doubled. These rates are increasing faster than any other racial/ethnic group.

However, other people of color display similarly alarming rates of attempted and completed suicide. For example, although death by suicide of Asian Americans is ~half that of their white peers, it is still astonishingly high. In fact, suicide is the leading cause of death for Asian American and Pacific Islander youth aged 12-19 years old and Asian American youth 15-24 years old. Suicidal ideation in Latine/Hispanic individuals who are 18-25 years old have increased over 22% in the last decade. However, the suicide rates of Indigenous/Native youth are the highest across all ethnic and racial groups; at 2.5 times higher than the overall national average, suicide is the second leading cause of death among individuals of Indigenous/Native heritage between the ages of 10-24 years of age.

Overall

The section provided an overview of disparities at the intersection of race, gender, and disability, beginning with the gestation period through childhood, adolescence, and adulthood, and in the context of various social determinants and systems. These aspects of identity coalesce in ways that significantly impact outcomes and quality of life, particularly for the multiply marginalized.

Focalized Review of the Literature

Given the vast range of my work, the topics within this focalized continuation of the literature review are heterogeneous in nature; the unifying factor is that they involve equity-focused social justice matters including the intersection between research and activism. The ongoing disparities faced by the I/DD community (particularly autistic individuals), with regard to family dynamics, various social determinants of health, and key aspects of reproductive justice including pregnancy, access to contraception, childbirth, and postnatal experiences (Seltzer et al., 2007; Krahn & Fox, 2014; CDC, 2020) are topics that also frequently warrant concern.

There is a substantial amount of research available about autism (autism spectrum condition[s], or ASC[2]). Additionally, with regard to the very real phenomenon of burnout (something that, due to the nature of the work itself most, if not all, advocates and activists have faced or will face at some point), there are many published works about burnout, particularly within the realm of occupational burnout, a plethora of which are related to various human services disciplines and helping professions (Maslach & Jackson, 1981).

Research about activism, though not as extensive as the aforementioned topics, is growing; within the last decade several studies pertaining to social justice and human rights (SJHR) activism, including several that specifically address activist burnout separately from occupational burnout have emerged (Chen & Gorski, 2015; Cardenas et al, 2017).

Minimal Research on Autism Self-Advocacy, Activism, and Burnout

To date, there is no known empirical research that examines all of these (autism self-advocacy, activism, and burnout) simultaneously, and literature of any type that addresses all three of the aforementioned topics simultaneously is limited. Overall, autism research tends to concentrate more heavily on youth and their (presumably non-Autistic) family members/caretakers than on autistic people themselves across the lifespan (Milton & Bracher, 2013). Sadly, this trend has persisted for several decades. The limited amount of autism research that *is* inclusive of adults typically addresses important issues (i.e., employment, socialization, and/or health), but generally not activism nor burnout (Perry, 2014).

The Crucial Need for Representation

Most autism studies fail to incorporate activism in a meaningful or practical way (if at all) for any age group. Literature on autism advocacy is more abundant, but the concept itself often synonymous with parent advocacy - so much so that “self-advocate” is used to distinguish advocates with autism diagnoses from those without - even when that phrase is technically inaccurate, as in the case of numerous advocates who primarily engage in advocacy for the community at large as opposed to primarily advocating solely for “self.” Actual autism self-advocacy, though lauded as important, is absent, or if present it is either described in an obscure manner, mentioned in conjunction with a particular program/curriculum/product, or relegated to the realm of individualized educational plan (IEP) planning. If fortunate, the phrase also appears in a few brief formulaic sentences within the closing remarks of an article.

However, despite seemingly minimal presence in formal scholarship, in recent years the presence of autistic youth and adult advocates, particularly in digital spaces and social media, has increased exponentially. We are everywhere - hashtags, viral posts and/or videos, media coverage, and more - trying relentlessly to be acknowledged, understood, accommodated, respected. Like our many peers in the struggle who are also laboring for justice and acceptance, at times the burden of our quest takes its toll on our health, our psyche, our relationships. It's impactful and purposeful, but it still is work. And research suggests that as a result of our commitment to the causes we hold so dear, more likely than not we tend to neglect our daily lives as opposed to cultivating a healthy balance (Cardenas et al, 2017). Much to our detriment, we are notoriously bad at prioritizing self-care and equally bad at setting aside much-needed time and energy to enjoy the presence of our loved ones, to eat, to rest, to relax.[3] It's difficult to pace oneself at times given the depth and the breadth of changes that are needed in so many areas. Though progress has been made, it's hard not to be overwhelmed with a crushing sense of urgency when one ponders the reality that we have so very, very, very far still to go.

The current state of autism research is illustrative of this issue. The majority of autism studies focus on perceived deficits in need of intervention (Milton & Bracher, 2013). This is a strong trend that has persisted for several decades; however, it is slowly changing in part due to the efforts of some academics who are helping to dismantle the status quo and promote neutral as well as strengths-based approaches more aligned with frameworks such as neurodiversity and disability justice (Kapp, 2020). Though promising, when compared to the sheer quantity of studies developed with a deficit-based framework, collectively the more progressive and inclusive studies are practically non-existent. Published research that centers the perspectives of individuals on the autism spectrum (autistic people) themselves, especially those from communities that have been historically underrepresented in autism literature and/or are multiply marginalized within society at large, is even more scarce (Chamak et al, 2008; Gillespie et al, 2017; Nicolaidis, 2019).

Given this glaring lack of representation, unsurprisingly stereotypes and generalizations about autistic people as well as the neurodiverse community abound. Among other disturbing and harmful assumptions, there is one in particular that is frequently found in media, public discourse, and anecdotes that is especially harmful: a predominant societal view individuals with intellectual/developmental disabilities (I/DD) experience emotions in an impaired manner compared to typically developing individuals due to deficits in a variety of areas that diminish the capacity for emotion, (i.e., allegedly "impaired" Theory of Mind, lack of empathy, etc.).

Similarly, a related and equally problematic societal view maintains that autistic and/or neurodiverse individuals overall have a “net” negative impact on their loved ones as well as society in general. We are described not as human beings worthy of dignity and respect but instead in terms of symptoms, deficits, fear-mongering statistics, and how much we “cost.”

Moreover, it is largely perceived that the demands of being related to/living with/caring for such individuals has an ongoing detrimental effect on their caregivers, especially close family members such as parents, spouses, and/or siblings. Though *not* substantiated on a macro level by evidence (as opposed to ableist hyperbole), these ideas are widespread and cause tremendous harm to the millions of people with these conditions and their loved ones (Block & Cavalcante, 2014; Krahn & Fox, 2014; Odell et al, 2016).

Disparities Faced by the I/DD Community

The attention and/or resources fruitlessly squandered on these stereotypes could, and should, be of greater use if channeled toward any number of the many unmet needs and measurable disparities readily found in the literature that is actually experienced by this population (Roberson, 2010; Ayers, 2016; Braddock et al, 2016; Yeargeau, 2016; Baker et al, 2017). Research indicates several known characteristics that predispose many people with I/DD to poorer societal and health outcomes than the general population. Though much of this research is about the collective I/DD community and does not specifically separate out those on the autism spectrum, it still paints a dismal picture and increases the likelihood of enormous obstacles (Ripamonti, 2016; Raymaker, 2017), as does the minimal literature of this type that does address these matters exclusively for autism.

For example, collectively, individuals with I/DD are disproportionately lower income, have less educational attainment, report lower levels of employment, and are less likely to be married/cohabiting than their non-disabled peers as well as their peers with other types of disabilities (i.e., only physical or sensory disabilities). They also face higher risk for chronic conditions including diabetes, arthritis, cardiovascular disease, asthma, and psychiatric conditions. They experience frequent and substantial barriers to obtaining and accessing healthcare and home and community-based services. Because of these and other factors, they have mortality rates that are 3-4 times higher than the general population. Sadly, they are also at a greater risk for premature mortality (Krahn & Fox, 2014).

Reproductive Research & I/DD

Gender presents specific reproductive concerns to consider (Bargiela et al, 2016; Akobirshoev, 2017; Kassee, 2020). Research examining reproductive health measures in the I/DD community found that collectively, women with I/DD had much greater sterilization rates - often against their will - (Li et al, 2018), were less likely to have received cognitively accessible sex education and had less access to contraception than women without I/DD (Wu, Mitra, Harris, 2018).

There is also a growing repository of literature that indicates a correlation between having polycystic ovarian syndrome (PCOS) and being autistic (Kassee, 2020). Additional literature notes the increased likelihood of autistic-specific issues related to menstruation, such as unusual age of first period, sensory issues, amenorrhea, and other difficulties related to menstruation, etc. (Pohl et al, 2014).

There is an emerging body of literature that has examined I/DD pregnancy and childbirth outcomes of women; participants' diagnoses included cerebral palsy, ADHD, Fragile X Syndrome, intellectual disability, autism, Tourette Syndrome, etc. (Akobirshoev et al, 2017). These studies found that having I/DD increases one's risk of having adverse pregnancy outcomes including caesarean deliveries, early labor, preeclampsia, and other birth and pregnancy complications - even after adjusting for age, race, ethnicity, and insurance type (Parish et al, 2015).

Although these studies' findings are reported collectively and do not compare results of any specific I/DD diagnosis to another, they reveal areas of concern that are likely at least in part applicable to autistic women (and individuals who were assigned female at birth [AFABs] who do not identify as women). Moreover, in the one known perinatal study that evaluated population data sets from 2006 - 2014 for obstetric information about autism and pregnancy (comparing information about 2000+ autistic women in Sweden, compared to over 875,000 non-autistic women), autistic women presented with concerning outcomes similar to the results of the I/DD studies, namely increased risk of preeclampsia, elective caesarean delivery, and medically necessary preterm birth (Sundelin, 2018).

Only a limited number of studies outside the Swedish population data research isolated results unique to autism. None reported findings that contradict the aforementioned I/DD research to date; conversely, they seem to confirm the likelihood of additional complications. In a recent case study about experiences of eight autistic parents who had recently given birth, most of the participants described difficulties processing the sensations associated with pregnancy. Participants explicitly mentioned enhanced sensitivities to touch, light, smells, sounds, and interaction during pregnancy.

Several reported negative experiences associated with prenatal checkups as well (Gardner et al, 2016). They also described challenges they encountered during labor. The most common themes mentioned were increased sensitivity to lights, sounds and smells and/or a desire to feel as if they could have some sort of sense of control over the circumstances of the birth (Gardner et al, 2016).

In a subsequent qualitative case series, autistic participants reported sensory concerns during delivery and postpartum (Rogers et al, 2017) as well as a plethora of challenging postpartum experiences in adapting to motherhood and infant care (Gardner et al, 2016).

The difficulties that were reported during the postpartum period included:

- significant sensory dysregulation and fatigue during the recovery period
- unpleasant tactile sensations when attempting to breastfeed
- delayed sense of "natural instincts" and/or emotional attachment to their infants
- difficulties understanding their infants' facial cues
- high needs for information about infant care
- needing help to translate information into real-life context of caring for infants
- difficulties with adult social interaction
    - might need help, but not know how to ask for it
    - concerns about not meet others' expectations about the "right" way motherhood should be experienced according to friends, providers
    - fear of others negatively judging their parenting skills and decisions

The case study also revealed several strengths reported by autistic women regarding postpartum experiences in adapting to motherhood and infant care (Gardner et al, 2016):

- heightened ability (in comparison to non-autistic mothers) to decipher babies' sounds (coos, grunts, cries) and thus respond quickly to their needs
- strong intrinsic desire to be good parents
- recognition that they had a need for specialized guidance in newborn care
- insistence on breastfeeding despite intense physiological discomfort based on facts about the benefits of breastfeeding and wanting to do what was best for their infants
- concerted efforts to prepare for parenthood by obtaining relevant, often written, information despite difficulty applying the guidelines they read about in real life

There are several narrative accounts by autistic women and individuals assigned female at birth (AFAB) that can be found in blog posts and other online and print sources that bear many similarities to the case study and case series (Latimer 2009; Latimer, 2014; George, 2016; Nannery, 2018). An eight-part video project, Pregnancy and Support Services for Women with Developmental/Intellectual Disabilities and Autistic Women, contains similar accounts (Oswald, 2022, About & Videos).

Family Dynamics and I/DD in the Research

Compared to the scarcity of literature available on the previously discussed topics, there was abundant material related to family dynamics and autism. Research more holistic of neurodivergence/I/DD as opposed to autism-focused, however, was significantly fewer in number, though still plentiful. The majority of studies (slightly more than half) primarily concentrated on the parent(s) and/or the family as a unit - excluding the relative(s) with I/DD. There were also several studies that focused on the "behavior" of the individual(s) with I/DD. Nearly ¾ of studies in the latter category were interventions and pilot/feasibility studies; very few examined quality of life factors.

Overall, the literature seems to indicate a connection between positive emotions and positive coping skills, namely situational framing/problem-solving, cultivating supportive relationships, and access to resources. Findings also indicate a link between poor coping skills and negative behavior. However, these results should be interpreted with caution for several reasons. First, although in many studies parents were able to self-report their emotions, very few of the participants with I/DD in any of the studies were permitted to do so. Almost universally, data collected about those with I/DD were often acquired via informant report and/or direct observation; the studies seldom incorporated input from persons with I/DD themselves, even though several studies included participants who were reportedly "high functioning" adults. Thus, the data cannot be easily corroborated.

Moreover, although most investigators had obtained IRB approval for their research when applicable and presumably all of the studies employed what are generally perceived as acceptable standards for ethical research, in my opinion there appears to be substantial evidence of researcher bias. For example, the majority of research conducted with parents assumes caregiver burden by default as indicated by their hypotheses, selection of evaluation tools, and type of wording that is used.

Additionally, the manner in which some studies classified whether or not an individual with I/DD was engaging in "problem or challenging behavior" seemed suspect; in one study, seemingly benign actions such as waking up during the night, toileting problems, having a "miserable" facial expression (as interpreted by a parent, caregiver, or other external party), stereotypy, and/or being solitary were all considered to be problem behaviors - despite the fact that several of those characteristics fall under the diagnostic criteria of various I/DDs. Another concern is the disproportionate ratio of informants to individual participants with I/DD (and, in some cases, used informants *in lieu of* individuals with I/DD), in several studies, which can potentially skew results.

As the literature indicates, due to changing residential patterns/community inclusion, consumer-directed programs, a shortage of affordable and accessible housing, insufficient resources, etc., relatives of individuals who have higher support needs frequently provide continuous care for extended periods of time—sometimes for decades. Moreover, it is not uncommon for parents of individuals with I/DD to grapple with complicated emotions related to not having had a "perfect child" that conforms to societal expectations. Given these factors, the evidence of caregiver fatigue/burden identified in the literature within the parental population is not unusual.

However, it should be noted that in numerous studies, the majority of caregiver concerns articulated do not center around I/DD itself nor "behaviors" associated with I/DD. Rather, in several studies parents openly express their fears and anxiety about what the future holds for the person with I/DD in anticipation of the eventual illness and/or death of the aging parent(s) and/or sibling(s). Though many caregivers have been creative in seeking to bridge the gap, the reality is that public services and support for persons with I/DD and their caregivers as a whole are largely inadequate. As such, it appears that insufficient resources are the main culprit, not the disability.

Study Design: Literature Regarding I/DD, Families, and Emotional Well-being

- Nearly twice as many studies focused on caregivers than on individuals with I/DD
- Findings from the studies of individuals with I/DD demonstrate accuracy in reporting and cross-informant agreement (even among children and/or those with moderate and severe I/DD)
- A third of the studies focusing on individuals with I/DD relied solely upon observations and informant data, literally incorporating *no* self-report information from those with I/DD!
- While over 50% of caregiver studies contained quality of life measurements, >10% of studies focusing on people with I/DD evaluated those individuals' quality of life
- The majority (82%) of studies focusing on individuals with I/DD were interventions
- ~¾ of the studies (of all types) did not interview any individuals with I/DD
- Nearly a third of the studies on individuals with I/DD were overtly deficit-based

Caregivers: Literature Regarding I/DD, Families, and Emotional Well-being

- A slight majority of caregivers reported primarily negative emotions about their loved one(s) with I/DD. ~An equal number of caregivers reported both positive and negative emotions. 20% of caregivers reported primarily positive emotions about their loved one with I/DD
- Caregivers' negative emotions about their loved one(s) with I/DD correlated strongly with psychological concerns (i.e., depression, poor health, aggression, social isolation, sleep disturbances, future planning concerns, lack of resources, poor coping skills)
- Caregivers cited the following behaviors from their loved one(s) with I/DD as most concerning: self-injurious behavior and aggression

- Most caregiver studies focused on parents and/or siblings. A few focused primarily on staff
- Caregivers reported the following coping skills were effective for them:
    - Developing and utilizing positive framing and problem-solving skills
    - Supportive familial and interpersonal relationships
    - Accessing adequate outside/community support
- Nearly ¾ of caregivers and their loved one(s) with I/DD share a home but >13% of caregivers have comprehensive support services (i.e., respite, personal care, subsidies)
- Caregivers often rated their loved one(s) with I/DD as more impaired than the individuals with I/DD actually perceived themselves
- Similarly, caregivers rated the individual(s) with I/DD as having greater autonomy and greater variety of choices than the individual(s) perceived themselves to have
- Families with at least one disabled member have higher risk for poverty and illness
- The I/DD and caregiver population is aging exponentially: by 2030 over 1 million persons with I/DD will be age 60 or older; currently 25% of caregivers are age 60 or older and 50% are age 40 or older

Persons with I/DD: Literature Regarding I/DD, Families, and Emotional Well-being

- 75% of individuals with I/DD in the studies live at home with their families
- Individuals with I/DD are 3-5 times more likely to have psychiatric disorders
- Health, residence, diagnoses, various circumstances, etc. affect the emotions and coping skills of people with I/DD.
- "Behaviors" are often impacted by the following:
    - lack of autonomy
    - impact of various unresolved disparities
    - stress and/or inability to be understood
    - exclusion from exchanges/activities
- Individuals with I/DD reported that they believe their parents/caregivers underestimate the capabilities that those individuals with I/DD possess
- Individuals with I/DD frequently utilize purposeful body and/or object movement and/or somatic changes, expressions, gazing, gestures, vocal, sensory signaling.
    - Unfortunately, these communicative and/or self-regulatory efforts are sometimes misinterpreted by others and may be perceived incorrectly (as illness or stereotypy)
- People with I/DD face chronic health conditions younger than those without I/DD
- Certain disparities may be less prevalent in non-Western cultures and in PoC
- People with disabilities experience a 40% employment gap and ~$26,000/year wage gap when compared to their nondisabled peers
- Individuals with I/DD desire more autonomy and more variety in their overall lives
- Positive emotions in individuals with I/DD were highly associated with:
    - opportunities for increased independence and decision making
    - experiencing variety in choices of meals, purchases, activities
    - opportunities for community involvement and positive connections
    - experiencing feelings of productivity

Research Methodology

Search Strategy

The search strategy utilized for this literature review was an eclectic one. Since an inductive approach was chosen, searching was conducted *after* data acquisition (compilation of the collective published and creative work) as opposed to prior in hopes of minimizing presuppositions and/or preconceptions (Hussein, et al, 2017). The literature review took place over time in a series of searches, not in a sole designated sitting. For example, in one particular search, an outline with standard literature review components was developed in order to help determine the specific terms to be used in the search databases. Initially, with the terms: autism, autism spectrum disorders, and ASD searched, 436,349 sources (from the years 1849 - 2020) were identified. A refined search of the same terms (but with modified search parameters to eliminate the terms if their only appearance was in the body of an article) resulted in 176,210 sources.

Next, additional search terms were added. Autism, autism spectrum disorders, and ASD were paired with various combinations of the following new keywords: neurodiversity, activism, activist, autism rights, Critical Autism Studies, advocacy, advocate, and activist burnout and extensively searched. Despite using a multitude of databases, in several instances, minimal or no sources were found, even with search parameters that included related words/synonyms as well as equivalent subjects.

The search criteria were then expanded to include non-peer reviewed and "gray" literature, resulting in a greater number of sources found. To further augment the search, Google Scholar, Twitter, and other tools were utilized to identify additional information. Moreover, several sources previously known to the researcher were included such as the peer-reviewed journal Autism in Adulthood and relevant lesser-known works about autistics, HIV advocates, and SJHR activists.

Various databases were searched including but not limited to: ScienceDirect, PsycINFO, PubMed, MEDLINE, PsycARTICLES, ProQuest, ERIC, EBSCOHOST, SAGE, ProjectMuse, Research Gate, JSTOR, HealthSource, Family Studies Abstracts, and CINAHL databases. Other sources of information included peer-reviewed articles, books, conference publications, videos, government statistics, websites, blogs, theses, etc.

In subsequent I/DD focused searches of literature on coping strategies that had been published within the current decade, preliminary background data from known and novel sources acquired via mixed methodology (i.e., related websites, articles, policy briefs, meta-analyses, narratives, current and archived statistics, etc.) were reviewed.

Next, keyword searches were conducted from 10 databases. A substantial number of qualified abstracts were evaluated, and from those, all of the recent, relevant peer-reviewed, empirical articles were selected from those abstracts. There were 89 articles total that met the predetermined criteria. I categorized the studies into distinct groups depending upon the target populations and key informants. For example, in one search I differentiated between whether the studies collected information directly from individuals with I/DD (as opposed to solely from informants) to form the groups.

Additional searches were conducted; some in a fashion similar to the aforementioned; others quite differently. For example, although a number of the sources were published within the past decade, select key older sources covering relevant time frames have been intentionally included to provide important perspective and/or historical background. With each search, there were several studies and/or other information I encountered that were relevant to the thesis but were placed into a "catch-all" miscellaneous grouping because they did not fit easily into other categories.

In some cases, I was able to place some of these studies with material that had emerged in subsequent searches that I conducted using additional keywords. Others remained in the miscellaneous category to be later evaluated both individually and collectively with other miscellaneous studies. A curated subset of the information retrieved in all of the searches aided in the development of the literature review is featured in this chapter and can also be accessed within the bibliography section of this doctoral thesis.

Selecting a Research Methodology

Deciding upon the most suitable research methodology for a doctoral thesis can be a daunting task. I had initially hoped to utilize a particular study design for this thesis, but I also knew that I wanted to select the method that was most appropriate regardless of my personal preferences. To help make a more informed decision, I listed as many different types of methods that I could think of (qualitative, quantitative, mixed method, etc.) and then spent time pondering the research question as well as the published and creative work that were going to be the focus of the study.

From this point, I used a process of elimination to help narrow my choices, then pondered some more, and returned to cull the list further. In time, there were only a few methodologies that remained; I decided at this time to compare and contrast these to determine the best choice.

Review of Qualitative Data Analytical Methods Considered

Qualitative research can be utilized for a variety of purposes. Creswell (2013) notes that certain methodologies are characterized by an approach that collects and heavily incorporates study data into its analysis early as opposed to first conducting a literature review. The five predominant ones are narrative, grounded theory, ethnography, case study, and interpretative phenomenological analysis.

> "The researcher typically begins by creating and organizing files of information... Next, the process consists of a general reading and memoing of information to develop a sense of the data and to begin the process of making sense of them...Then, all approaches have a phase of description (with the exception of grounded theory, in which the inquirer seeks to begin building toward a theory of the action or process)."

After eliminating various methodologies, my remaining three options were: 1) ethnography - specifically autoethnography, which is a qualitative method that combines autobiography and ethnography (Ellis et al, 2010), and critical ethnography, which utilizes participants' experiences as a tool to examine power systems and broader social structures (Harvey, 2013); 2) grounded theory (Hussein et al, 2017); and 3) phenomenology (specifically, interpretative phenomenological analysis and modified phenomenological hermeneutical analysis).

Method Considered: Critical Ethnography

Several elements of the two ethnographic methods that I considered were appealing, but I ultimately opted against them. With regard to critical ethnography, while I see merit in analyzing the impact of structures and systemic power imbalances, utilizing this approach would require viewing and classifying subjective experiences and perceived meanings as mere symbolism within a larger dialogue on oppression, and privilege. This seemed incongruent with my personal values. Though the approach's intention is emancipatory, it felt like a form of disregard, silencing, and potentially even censorship of perspectives that had been dismissed for far too long already (both historically and currently). Critical ethnography would not work for the thesis because I needed a methodology that was not only inclusive of internal meaning and lived expertise, but actually *centered* it.

Method Considered: Autoethnography

The autoethnographic approach certainly meets that criteria. In fact, Ellis et al (2010) noted:

> "Autoethnography...attempts to disrupt the binary of science and art…research can be rigorous, theoretical, and analytical as well as emotional, therapeutic, and inclusive of personal and social phenomena. Autoethnographers...value the need to write and represent research in evocative, aesthetic ways."

While the above is true of me as a researcher, I also aspire to have my work taken seriously. I had a number of concerns that utilizing this method would invite significant criticism; autoethnographers have been admonished for their use of personal experience as it has been characterized by some as "supposedly biased data," which allegedly does not "fulfill scholarly obligations of hypothesizing, analyzing, and theorizing." (Ellis et al, 2010). Autoethnography has also been derided by critics as "academic narcissism" and "Me-search" (Pickle, 2017) that is not perceived as scientifically sound. Though there has been debate about whether the aforementioned criticism is steeped in bias, given that my thesis evaluates my published and creative work, such accusations are likely possibilities.

*Gazing at the screen, there's a part of me that feels extremely hesitant about ^what I've written above, and I wonder, given the likelihood my meaning won't be clearly understood, if perhaps I should delete it. After all, as Edward Said wisely noted in *Reflexions on Exile and Other Essays*:

> "Entrance into the public sphere means, as the French writer Genet said, the moment you write something, you are necessarily in the public sphere; you can't pretend that you're writing for yourself anymore…To enter into the public sphere means, therefore, not to be afraid of controversy or taking positions. There's nothing more maddening, it seems to me, in our own time than people who say, 'Oh no, no, that's controversial; I don't want to do it'; or the habitual trimming refrain, 'No, no, I can't sign that because I mean, you know, I may disturb matters and people may think the wrong thing about me.'"

As the American colloquialism states, "This ain't my first rodeo." As a semi-public figure, I am not unfamiliar with the experience of having my words scrutinized by others and potentially misperceived or misrepresented. So, while I am certainly not inviting derision, I'm "no stranger" to it; that would not in and of itself be a valid reason to opt out of an autoethnographic approach.

Moreover, several of my colleagues, whose work I deeply admire, have used elements of autoethnography (including, but not limited to, “autie-ethnography” and “auti-biographies”). Seminal writings of this type are a cornerstone of Actually Autistic cultural development, and practitioners include Remi Yergeau, Nick Walker, Monique Botha, Lisa Morgan, Mel Baggs, Terra Vance, Ly X.Z. Brown, Lamar Hardwick, and many others. I also find much of the writing in this subgenre to be quite interesting as well as thought provoking and wouldn’t want to inadvertently send the message that I somehow perceive this method to be subpar. It’s not that.

It’s hard to form a coherent explanation for something that I feel inside, but don’t know exactly how to describe. I’ll try to convey it through a (true) story. A few of my children have had the privilege of being able to attend accessible, week-long sleep-away recreational camps in previous summers. For the most part, they thoroughly enjoyed themselves as much as I enjoyed the period of partial respite. We still have many “momentos” from those camps, including old t-shirts, pictures, and decorative camper name tags and lanyards.

There is one picture a camp counselor took of one of my children one summer that actually ended up in the camp viewbook (similar to a camp yearbook, it is primarily filled with group, individual, and impromptu images). My child’s mouth is open in mid-bite as they enjoy a slice of fruit during a snack break. Juice from the fruit drips onto my child’s tiny brown fingers as they lean forward to resume eating the snack, which is a massive slice of watermelon.

Although this picture was taken years ago, merely the thought of it makes me cringe even now, just as I cringed the first time I saw it. I’m sure the counselor who took the picture viewed it as a sweet, fleeting moment worthy of being captured on film. A cute kid enjoying a refreshing snack on a hot summer day at camp. But that’s not what I see. Despite the fact that I know that the image is aesthetically pleasing in an objective sense, I can’t be objective about something so subjective. What I see is a picture that depicts a stereotype: my Black child, mouth wide open, devouring an oversized watermelon as watermelon juice glistens and drips in the sunlight.

No matter how benign it is nor how much I am aware that my child does indeed like the taste of watermelon, I cannot help but be disturbed by the optics and the symbolism in the photo. Similarly, with regard to selecting an autie-ethnographic or similar approach as my methodology, the optics at play for me, as a researcher who is not just autistic, but is also a noticeable person of color, are far too jarring for me at this point in my life and career. I rejected this option.

Method Considered: Grounded Theory; Phenomenology

I next considered grounded theory and phenomenology. I felt particularly drawn to the grounded theory method because in addition to offering a structured approach when there is limited information about a topic, by its very nature, this inductive methodology (which was created for the purpose of helping to "legitimize" qualitative research) is "grounded" in the data (Rieger, 2019). I found the data-driven element appealing.

Phenomenological research is similar in some respects to grounded theory in that it seeks to derive information from the data as opposed to forming preconceptions (i.e., hypotheses). But while grounded theory, which uses a cyclical, naturalistic process of data collection and analysis, is primarily concerned with analyzing the data in pursuit of *discovering a new theory*, (Boynkin et al, 2021), phenomenological studies adopt a radically different perspective.

According to Smith & Zalta (2018), phenomenology, as a discipline, examines:

> "*The phenomenon of meaning as experienced* from the conscious central/first-person point of view by analyzing structures—the types, intentional forms and meanings, dynamics, and relevant enabling conditions—of perception, thought, imagination, emotion, and volition and action..."

Method Considered: Interpretative Phenomenological Analysis

The appeal of using interpretative phenomenological analysis (IPA) for this study is evident in its very etymology. When one considers the root meanings of the word "logos" and the word "phenomena" (which, when combined, form the word "phenomenology") together they can be translated to mean "the science/art/practice of letting things be brought to light/appear/show themselves" (Smith & Zalta, 2018; Harper, 2021). Investigators Smith and Nezza (2021), recently described interpretative phenomenological analysis, in this manner:

> "Interpretative Phenomenological Analysis...investigates how people make sense of their lived experience in the context of their personal and social worlds. It highlights convergence (shared experiential themes) and divergence (individualized, unique manifestations of said themes) and is...well-suited to exploring experiences perceived as highly significant, such as major life and relationship changes, health challenges, and other emotion-laden events." (Smith & Nizza, 2021)

Method Considered: Modified Phenomenological Hermeneutical Analysis

Peri Hermeneias ("On Interpretation") is one of Aristotle's oldest known surviving works. As its name implies, the term *hermeneia*, which can be translated as "to utter, explain, and/or translate," is associated with Hermes, the Olympian emissary god who helped to convey and deliver messages between the divine and mortal worlds (Blockley, 2014). It is also the root of hermeneutics, a discipline concerned with the art of understanding and being understood by others (Zimmerman, 2017). While Aristotle's *Peri Hermeneias* focused primarily on words being translations of inner thoughts expressed via speaking and/or writing, the concept of hermeneutics is more complex as it deals with understanding and being understood holistically, encompassing words as well as nonverbal cues, digital communication, signs, events, actions, traditions, etc. (Whitehead, 2003; Zimmerman, 2017; Nabb, 2018).

Modified Phenomenological Hermeneutical Analysis is a qualitative method that seeks to interpret the meanings relation to experience. One way this can occur is to analyze the text to find and decode such meanings. The focus is on searching for themes and engaging dialectically with the data to gain a clearer understanding of the experience(s). As such, I gave this method quite a bit of consideration.

Method Considered: Living Educational Theory Research

Living theory is a research methodology produced by an individual, often drawing on narrative approaches, action research, and/or auto-ethnography, for their educational influence in their own learning, in the learning of others, and in the learning of the "social formation in which they live and work (Whitehead, 1989)." It helps the practitioner to develop the ability to more adequately "understand, improve and explain their practice and generate valid accounts" in addition to contributing to "a global educational knowledgebase." (Whitehead, 1989)

Method Considered: A Mixed-Methodology Combination Approach
(Modified Phenomenological Hermeneutical Analysis + Living Educational Theory)

I felt particularly drawn to two particular methods: modified phenomenological hermeneutical analysis, which assesses for recurring themes in order to determine meaning, and living educational theory research, which utilizes inquiry, action-reflection cycles, and accountability to determine how to make meaningful improvements and more fully live one's values in practice (van Manen, 1997; Whitehead, 2009; Sloan & Bowe, 2014; Crowther et al, 2017; Morgan, 2019; Morgan, 2021).

Unfortunately, neither methodology alone would be sufficient for the purposes of this thesis. As such, I thoroughly considered combining modified with as the research methodology to address that and started the process of determining a practical way to merge them. Shortly afterward, however, I discovered an intermediary qualitative method previously unknown to me, one that falls in between conventional research techniques and newer transpersonal ones. As it already contained elements of my two preferred methods, this eliminated the need to try to figure out a combination.

Method (*Considered and)* ***Selected: Heuristic Inquiry*** ✓

It seems almost like fate how I accidentally stumbled across a method that I was unfamiliar with, heuristic inquiry, after I'd already decided to "Frankenstein" my own combination method (as described above). It was such a perfect fit that at first, I had a bit of difficulty coming to terms with the fact that it was truly something that existed as opposed to something I'd simply dreamed up for myself! As its name suggests, the method is based on heuristics. The word *heuristic* is derived from the 18th century Latin word "heuristicus," which is a term is derived from an ancient Greek verb *heuriskein* that means "to discover," or "to find out."

As a species, humans regularly employ a variety of heuristic processes throughout our lives as we learn to help us process information and enhance our understanding. They can be thought of as mental "shortcuts" that assist us, particularly when faced with limited time and/or resources. Heuristics, or heuristic thinking, has been used widely throughout the existence of humanity, including 13th century philosophical algorithms; in polymath Descartes' 16th century math and science; economics; psychology; even artificial intelligence (AI).

Heuristic inquiry, developed by Clark Moustakas, one of the "founding fathers" of humanism, is a formal, evidence-based research method. Despite the similarities in the name, heuristic inquiry is a much more expansive concept than merely heuristics itself. Rather than simply a shortcut or workaround, heuristic inquiry represents an internal scientific process of discovery that requires the researcher to have had "...a direct, personal encounter with the phenomenon being investigated." These "autobiographical connections" offer the researcher and the reader "...a way of being informed, a way of knowing" through the creation of "...a story that portrays the qualities, meanings, and essences of universally unique experiences" to deepen one's "...knowledge of the phenomenon" and "discover revealing connections with others." (Moustakas, 1990, p. 10, 11, 13, 14)

Moustakas vividly describes heuristic inquiry in his pivotal 1990 book *Heuristic Research: Design, Methodology and Applications*:

> "...The self of the researcher is present throughout the process…one discovers the nature and meaning of experience and develops methods and procedures for further investigation and analysis…while understanding the phenomenon with increasing depth, the researcher also experiences growing self-awareness and self-knowledge." (p. 9).
>
> "...From the beginning, and throughout an investigation, heuristic research involves self-search, self-dialogue, and self-discovery; the research question and the methodology flow out of inner awareness, meaning, and inspiration..." (p. 11)
>
> "...Heuristic inquiry is a process that begins with a question or problem which the researcher seeks to illuminate or answer…a personal challenge and puzzlement in the search to understand one's self and the world in which one lives. The heuristic process is autobiographic, yet with virtually every question that matters personally there is also a social - and perhaps universal - significance" (p. 15).

Heuristic inquiry was an ideal choice for various reasons. Of significance, my work is an extension of me. Much of who I am, and continue to become, is intertwined with it and heuristic inquiry, as a paradigm adapts aspects of phenomenological inquiry while explicitly acknowledging the involvement of the researcher." (Hiles, 2001) The collective body of published and creative works collected here most certainly addressed a range of significant lived experiences that could be reviewed and assessed for recurring themes in order to determine meaning (van Manen, 1997; Crowther et al, 2017). Additionally, as with the other data analytic approaches I'd considered, I preferred an inductive method that enabled me to formulate research questions that would not require me to come up with a hypothesis as the data itself would reveal the answers (Creswell, 2013).

Engaging in Heuristic Inquiry

I sought to assemble as much of my published and creative work as I could. Being that I am the one who created them, I thought this would be a simple endeavor. To begin, initially I went to my blog and assembled the articles that were there. Next, I gathered electronic drafts of my various book contributions (chapters, front matter, etc.), and then I tried to recall various other places where my work has appeared and look all of those up. I created a master document where I kept all of the links I found as well as relevant notes. This document eventually morphed into a Google spreadsheet that I color-coded to help categorize things efficiently. I also maintained a digital folder that contained PDFs and summaries of some of the work that was becoming harder to easily locate and/or access online, as well as select printed copies of certain items.

The process of acquiring a rough collection of my work was quite tedious and time consuming. I was surprised to discover that it required a great deal more effort than I had anticipated. I hadn't realized how voluminous my work actually was, but things do accumulate over the years, and there were a number of years where my output was pretty high. Frankly, I was a little overwhelmed at the growing folder of content...was I truly going to be able to sift through all of that?

I soon encountered problems being able to acquire high quality or "master" versions of certain pieces of work (I did have personal copies in several instances, but unfortunately, they were generally not in the condition that would make them suitable for inclusion in a formal thesis). In one case, the book was soon to be out of print; in another, the site had been revamped and much of its previous content was no longer accessible. In another instance I discovered that unbeknownst to me years ago, as a young and inexperienced writer, I'd signed away ownership of my work and now had to seek permission to reproduce my own material! There were also cases of co-authorship where though I had contributed significantly to the product, I would need my collaborator(s) to indicate as such in writing. I also had some difficulty determining if certain items truly constituted "published work" or not, as I did not wish to try to manipulate circumstances to my advantage; I had a number of pieces that *technically* met the criteria, but it was unclear to me whether they should be included or not. There were also situations where in reality I had been the sole or primary author but had published said piece(s) as a co-authored document, which complicated obtaining clearance(s) for them.

In time, I had successfully identified and compiled over 100 distinct files of my published and/or creative work. They were a combination of various multimedia, including different forms of writing; excerpts from radio, TV, and podcast appearances; public speaking engagements; online content; community advocacy; and expressive art. Having created them all, obviously I was familiar with them, but I needed to gain a clearer sense of what the work *collectively* was about, not just what specific individual contributions were about.

Not exactly knowing where to begin, I decided to arrange everything in chronological order so that it would be easier to review and analyze the work more closely. However, I discovered that was not a balanced way to assess the pieces, opting instead to utilize a different order. Thus, I instead chose to review the pieces in the order that they appeared on the nine-page references document, which was alphabetized by last name in descending order and secondarily by year in ascending order (please review provided for context). After reviewing a piece, I made notes to assist with coding. Capturing my thoughts was important because heuristic inquiry is a person-centered approach.

According to Sultan (2019, p. 10-18), the six phases of heuristic inquiry are:

- Initial engagement
- Immersion
- Incubation
- Illumination
- Explication
- Creative synthesis

With this methodology, it is almost a certainty that some of the phases will be repeated throughout the duration of the study, especially the incubation phase. In fact, it is possible for incubation, which is characterized by a period of detachment that facilitates reflection and/or brainstorming to follow each of the other phases, thus creating an ongoing cyclical feedback loop. However, for the purpose of this thesis, we will begin our heuristic inquiry study at the initial engagement phase. This is where the researcher develops the idea for the study, usually based upon a particular intense experience (and/or series of experiences) that the researcher perceives as personally, and socially meaningful. This is not a passive endeavor nor an arbitrary selection; the researcher identifies closely with the topic, engages in self-dialogue, and feels compelled almost to the point of being called or driven to pursue a particular interest or concern. The research question that emerges is one that the researcher feels intrinsically drawn to, not a fleeting or random inquiry but one that persists.

In the immersion phase, the researcher becomes one with the topic and must concentrate deeply on the question and concepts related to it, engaging in rigorous discovery as they explore the topic more fully. They might utilize self-dialogue, journaling, and research in this phase as well as in the following illumination phase, which involves tacit knowledge and intuition. The illumination phase is characterized by the researcher utilizing speculative skills to integrate data and perception to uncover meanings. This often results in the identification of the study's themes, leading to a breakthrough in understanding. This breakthrough provides the foundation for the next phase, explication. In the explication phase, "indwelling" occurs: the researcher conducts an even more in-depth analysis of the themes, qualities, and experiential knowledge augmented by observations from an internal frame of reference. This eventually develops into the final phase, creative synthesis. The collective data, with the core themes identified and relevant interpretations derived from the data is collated, examined, broken down, and reassembled into a final product such as a poem, narrative account, painting, music, artwork, or other forms of creative expression. (Moustakas, 1990, p. 27-40)

Key Conceptual Frameworks in this Thesis

This part of the thesis, praxis, addresses procedure and practice, including an overview of significant ideologies and movements. My work reflects several core conceptual frameworks. In the thesis, I describe the significant impact that disability justice and engaged pedagogy have had on my work (Crenshaw, 1989; hooks, 1994). I also list, but do not describe additional philosophies that also align closely with my beliefs and are reflected in my practice, including:

"*Nothing About Us Without Us*" or **"Nothing About Us Without Us is For Us"** (from South Africa; also connected to European laborers) correlates to stakeholder leadership and anti-oppression activism.

Equity Literacy can be summarized as "...a commitment to deepening individual and institutional understandings of how equity and inequity operate in organizations and societies, and the...knowledge, skills, and the will to vigilantly identify inequities, eliminate inequities, and actively cultivating equity." (Gorski, 2020)

Neurodiversity refers to "the diversity of human minds, the infinite variation in neurocognitive functioning within our species." (Walker, 2014) The term, coined in the 1990's by Judy Singer (n.d.), has no inherent social or political connotations.

- **The *Neurodiversity Paradigm***, however, operationalizes neurodiversity in its assertion that 1) is a natural, normal form of human diversity; 2) the hierarchical classifications of "normalcy" in neurocognition that exist are merely imprecise social constructs similar to that of ethnicity and gender; and 3) the dynamics within other forms of human diversity, i.e., power imbalances and/or inequality, are present in neurodiversity. (Walker, 2012)
- **The *Neurodiversity Movement*** openly seeks "civil rights, equality, respect, and full societal inclusion for all who are neurodivergent." (Walker, 2014). The term neurodivergent refers to all individuals who are neurologically different in some way (Asasumasu, 1999).

Disability Studies and Critical Race Theory (DisCrit): Coined by Subini Annamma and colleagues, *DisCrit* combines Disability Studies and Critical Race Theory to form a new theoretical framework that explores the intersection of race and disability and how the concepts of racism and ableism have been weaponized within society, how race and ability are co-constructed/given meaning, and ways racism and ableism interdependently uphold notions of normalcy through institutional processes and discourses (Annamma et al, 2013).

Engaged Research*:* As the defining characteristic of engaged research is its commitment to making a positive difference in the world via research that "engages ethically and reciprocally with others," its practitioners orient themselves toward their study participants as well as said participants' communities via seven principles: Relationality, Temporality, Spatiality, Intersectionality, Ontology, Epistemology, and Methodology. (James, n.d.)

Public Pedagogy is a holistic educational theory of learning that extends beyond the boundaries of a formal academic setting - thus theoretically belonging to the public. This includes disaster, emancipatory, cultural and/or civic education online and in public venues. It has five domains: citizenship within and beyond school; pedagogical theory on popular culture and everyday life; informal institutions and public spaces as educative arenas; dominant cultural discourse as public intellectualism; social activism. (Ravenscroft, n.d.)

Transformative Learning Theory describes a ten-phase process people undergo as they learn how to make transformative internal growth, particularly with regard to increasing empathy, motivation, self-regulation, and collaboration. It emphasizes "effecting change in a frame of reference" and builds and/or enhances one's capacity to observe, critically reflect, and consciously make better decisions. Its three components: psychological, convictional, and behavioral, are expanded upon in descriptions of critical reflection, rational disclosure, and centrality of experience (Mezirow, 1997).

Supporting Conceptual Frameworks in this Thesis

While I believe the aforementioned philosophies most closely characterize my work, there are several other important frameworks embodied in my work as well. These include:

Intersectionality as a term was coined in the early 1990's by Dr. Kimberle Crenshaw, an African American attorney, feminist scholar, and researcher. Yep (2015) describes how the term refers to how various overlapping social identities intersect with one another; more specifically, the concept describes how "race, class, gender, sexuality, the body, and nation (among other markers of social and cultural difference) come together simultaneously to produce identities and experiences, ranging from privilege to oppression, in a particular society. Intersectionality posits that people's identities are greater than the sum of individual attributes such as race, class, gender, etc. because identities have historical legacies, power differentials, and political consequences."

As an individual who lives at the intersection of race, gender, and ability identities that are marginalized by society at large while simultaneously having privilege in a number of ways (such as American citizenship, geographic proximity to various resources, postgraduate educational attainment), intersectionality isn't theoretical for me. It's my reality. As such, it is central to my work.

Critical Autism Studies is another important concept. It prioritizes autistic subjectivity, acknowledges the politics of cognitive differences, and scrutinizes "inequities in power relationships in research and practice, promotes diverse accounts of autism that incorporate autistic perspectives, and facilitates more autism-inclusive research and practices (Davidson and Orsini, 2015)."

Reproductive Justice, "the human right to maintain personal bodily autonomy, have children, not have children, and parent the children we have in safe and sustainable communities," (SisterSong, 1997) also greatly informs my work. The phrase, coined in June 1994 at a leadership meeting for women of color in Chicago, fuses "reproductive rights" and "social justice" and global human rights principles (United Nations, 1948).

Community-Based Participatory Research (CBPR) is "an approach to scientific inquiry in which scientific professionals and members of a specific community work together as equal partners to develop, implement, and disseminate research. As a form of action research, CBPR projects aim to make changes in the world that are desired by the community. In a CBPR project, the lived experience of community members and the academic learning of scientific professionals are valued as equally powerful sources of knowledge. Community-academic partners are expected to learn from each other and respect each other's' expertise." (Isreal, 2000)

With ***CBPR***, "researchers and community stakeholders engage as equal partners in all steps of the research process with the goals of educating, improving practice or bringing about social change" (Tremblay et al, 2018).

The United Nations' Convention on the Rights of Persons with Disabilities (UNCRPD) is widely considered to be the most comprehensive modern document across the globe that asserts the human rights of people with disabilities. These principles include the right of inclusion, accessibility, education, employment, and equity for all individuals with disabilities and calls for societal and policy change to achieve these human rights. Specifically, UNCRPD Articles 2, 3, 5, 8, 9, 12, 19, 24, and 27 address education, economic, civil, and employment aspects of society with regard to individuals with disabilities. (United Nations, 2016)

The Denver Principles are a symbol of self-empowerment and self-determination for individuals in the HIV community all over the world. Drafted at a 1983 gathering by a group of activists living with HIV and allies, the Denver Principles is a beacon that has inspired thousands. The document highlights the importance of stakeholder leadership, asserts the value of lived expertise, provides a "blueprint" for treatment and research activism, and denounces HIV stigma. (Denver Principles, 1983).

Ethnomediaology combines practitioner research, narrative/story development, and digital technology, in order to gather, generate, and assess knowledge in a tangible and creative manner with integrity, authenticity and openness (Story Lab, 2021).

Universal Design is "an approach to design that increases the potential for developing a better quality of life for a wide range of individuals...a design process that enables and empowers a diverse population by improving human performance, health and wellness, and social participation" to "create products, systems, and environments to be as usable as possible by as many people as possible regardless of age, ability or situation." (Steinfeld & Masel, 2012; University at Buffalo IDeA Center, 2020)

New Media Art is defined by Lorenzo Pereira (2015) as "any content available on-demand through the internet, accessible on any digital device, usually containing interactive user feedback and creative participation...the genre encompasses artworks created with new media technologies, including digital art, computer graphics, computer animation, virtual art, internet art, interactive art, video games, computer robotics, 3D printing, and art as biotechnology…a defining characteristic of new media is a dialogue or interaction."

Social Movement Activist Research (SMAR)*:* "crosses the boundary between research and the field to find solutions without separating research and activities" via a stance of "critical involvement" instead of being "objectively distanced." As such, SMAR looks for "the cause of issues such as inequality, oppression and violence and aims to deduce results to improve them by working with those who are directly affected." (Lee, 2019).

Critical Technocultural Discourse Analysis (CTDA)*:* Created by Dr. Andre Brock, it is "a multimodal analytic technique for the investigation of the Internet and digital phenomena, artifacts, and culture. CTDA requires the incorporation of critical theory—critical race, feminism, queer theory, and so on—to incorporate the epistemological standpoint of underserved ICT users so as to avoid deficit-based models of underrepresented populations' technology use." (Brock, 2018)

*PHILOSOPHICAL EXAMPLES

International Advocacy and Activism as a Form of "Oxygen"

Oxygen is categorized as an "oxidizing agent," which is an entity that absorbs electrons (external subatomic negatively charged particles). Oxidation requires permanent reduction of oxygen's initial size and composition—shedding some of itself—to make room for it to expand and absorb these electrons. This quality allows a fire to sustain itself with just a minimal amount of oxygen; typically, oxygen is only about 16% of a fire's overall components. (Khademzadeh, 2014, p. 1-9) Outside of oxidation, another interesting characteristic of oxygen is manifested in its allotropy (how it can exist in more than one state.). Under ideal circumstances (i.e., standard pressure and temperature) it prefers to exist as its stable ground state, dioxygen, but under more extreme conditions, it may instead manifest as one of its more volatile forms. (Brasted, 1998, para 6)

Oxygen and ozone, which both occur naturally as opposed to being synthesized by man, are a perfect foil. Oxygen has no color nor odor; ozone is pale blue and has a distinct odor that is extremely strong and unpleasant. Oxygen is plentiful in the Earth's crust, atmosphere, and sea and has lower density as well as lower boiling and melting points than ozone, which exists in much smaller quantities in the Earth's upper portion. However, most significantly, while we *must* breathe in oxygen to survive, breathing in ozone reduces our chance for survival. Ozone in its ground state (smog) is a harmful air pollutant that is toxic to living things. (Diffen, n.d., table, para 3-5)

Despite this dynamic, ozone is not necessarily always "bad" nor is oxygen always "good." Various factors can transform something beneficial into something problematic and vice versa. Some aspects of ozone that are advantageous for living organisms; in Earth's upper atmosphere, ozone is a protective filter for harmful ultraviolet rays. Ozone can also be a helpful commercial product; its uses range from sewage treatment and water purification to disinfectant. (Brasted, 1998, section 3, 5)

Meanwhile, at times, oxygen can actually be dangerous. At atypical pressures (such as that which can occur in deep sea scuba diving), there is increased risk of oxygen toxicity. This can damage the respiratory and/or central nervous systems of living organisms, resulting in seizures, lung scarring, and possibly death. (Donald, 1947, p. 667-672) Also, when stored in an extremely concentrated form, oxygen can become highly combustible, contributing to increased risk of rapid fire and/or explosion.

“Advocism”

According to Collins (2000), critically oriented individuals are intrinsically motivated to want to change the world through their praxis; it’s who they are. This is certainly true of me. I am an advocate. I don’t know how *not* to be one; it seems as natural to me as breathing, and throughout my life advocacy has been as necessary for my survival as oxygen. I am also an activist. (Hence, my made-up terms combining both concepts, “advocist” and “advocism.”) I deeply believe that we, as humans, possess the ability to effect powerful change by our words and/or deeds. I know this because I have witnessed it and I have experienced it; I know this because I have done it.

Like oxygen, my advocacy and activism manifests in various forms. In my work, it ranges from forums, demonstrations, protests, and vigils to public campaigns, panels, community participatory research, global radio, television and media broadcasts, civic action, art, digital mobilization, etc. Advocacy can be contemplative and proactive. It can also be responsive: an explosion of strategies, ideas, and emotions. This is true of activism as well; though much of the activism I have engaged in has been reactive, it assumes various forms while remaining true to my ethics.

When I think about my journey as an activist, I can relate to the story arc of *Drumline*, a 2002 movie about the marching band at a Historically Black College/University. Protagonist Devin Miles, a first-year student, is a talented self-taught musician with a full band scholarship. Devin’s arrogant demeanor doesn’t always make a positive impression. But his creativity, musical acumen, and intrinsic skill as a drummer all have an almost hypnotic effect on others, especially his bandmates. (Elie, 2021, para 1-6)

Devin is an extraordinary drummer. He doesn’t just play music; he truly becomes one with the music. However, Devin is harboring a secret: he has never learned how to formally read (sheet) music. He has such a natural propensity for music and such internal motivation that he has learned everything he has ever played, including his own creations, solely “by ear” (memory) or spontaneity.

Knowing that he will not be perceived as a “true” musician because of his inability to read music, Devin lives in angst that someone will discover the truth and decide that he isn’t good enough and doesn’t belong. Despite Devin’s obvious talent, the fact that he lacks what is perceived as a fundamental component of being a musician threatens to invalidate the very thing he lives for and has devoted years of his life to.

Public Intellectualism Revisited

I have battled a sense of "imposter syndrome" very similar to Devin's…wondering, regardless of my achievements, if I possess the "right" credentials to be considered a legitimate advocate and activist. So many things about my life are quite surreal; considering the less-than-favorable circumstances I have been dealt, I could have never predicted that I would still be alive, much less that I could ever be who and where I am today. Yet here I am. Therefore, before anything else and above everything else, the most critical aspect of my international advocacy and activism has been, and still is, my sincerity.

When I initially became an "advocist," I wasn't aware of things such as "Theory of Change," "socio-ecological frameworks," "social movements perspectives," "collective action," or any of that. Like Devin, for years I had few opportunities to acquire formal tools to guide my work. (Frankly, I didn't even know there was such a thing to be had.) I imagine that years ago, little Devin—captivated by the music he could feel within him—felt an urge to pick up an instrument and churn out the melodious rhythms that dwelled deep inside, even though technically he had no idea what he was doing. Similarly, younger Morénike burst into the world of advocacy and activism with minimal conceptual knowledge.

As a "baby" advocate, I couldn't have explained my philosophical stance on…well, anything. I didn't have enough of an understanding of things to even be cognizant of how much I didn't know! The luxury of ruminating on theoretical concepts simply hadn't existed for me. Yet despite my inability to formally articulate what I was doing and why, intuitively I knew to do it. I just *had* to. I said, and did, what felt intrinsic, and kept going. I had no way to gauge whether I was doing it "right," but the results seemed to indicate that I should continue. I knew what I believed; I knew what I felt; I knew what I'd seen and heard; I knew what I felt compelled to do because it needed to be done. I was sincere and I was ALL in, following the invisible beacon that had stirred up something inexplicable within my soul.

Black public intellectualism had reconciled this notion long before I made my entry into this world. Collins analyzes Sojourner Truth's iconic "Ain't I a Woman?" address in *Black Feminist Thought*:

> By using the contradictions between her life as an African American woman and the qualities ascribed to women, Truth exposes the concept of woman as being culturally constructed. Her life as a second-class citizen…points to the contradictions inherent in blanket use of the term woman. She invokes her status as a mother of children…sold off into slavery, and asks, "And ain't I a woman?"

> Rather than accepting the existing assumptions about what a woman is and then trying to prove that she fit the standards, Truth challenged the standards themselves. Her actions demonstrate the process of deconstruction—namely, exposing a concept as ideological or culturally constructed rather than as natural or a simple reflection of reality. (Collins, 1990, p. 14, 15)

Truth, as Collins points out, was a former slave; a Black woman; an individual of low social status. She was also a formidable champion for the abolition, women's rights, and suffrage movements whose impact persists to this day. In her address that evening in 1851 (delivered, ironically, at women's rights convention), Truth's words reveal the depth of insight and specialized knowledge she'd acquired as a "connected knower" whose lived expertise enabled her to engage in profound critical analysis through the "process of self-conscious struggle." (Collins, 1990, p. 12-17, 19, 258)

Devin Miles was unable to read music; Sojourner Truth was unable to read (or write) anything. If we choose to impede the future Devins, Sojourners, and Morénikes of the world merely because their trajectory and/or methods are different from "standard" expectations, we do so at our own peril.

I believe deeply in the value of learning and growing. We can always gain from obtaining knowledge from various sources, from mentoring, from honing one's craft. However, I am saying that there is such a thing as having the capacity to drive a vehicle despite not possessing a license. There are marriages, partnerships, and unions that are 100% authentic even if they don't exist as such on paper. There are families whose members are bound by love in lieu of DNA. And just as Sojourner Truth was a "real" woman, to me, Devin was a "real" musician regardless of his ability or inability to read music. And I know my sincerity, conviction, and labor made me, despite my ignorance, a "real" advocate.

Sami Schalk, Wole Soyinka, and E. Grollman are three leading Black voices whose work, though very different from one another, can be perceived as a beacon or a "North Star" for unconventional activism. One element of Schalk, Grollman, and Soyinka's work that resonates with me relates to the experience of being grieved and unsettled by injustice and feeling compelled to use my words to help somehow, especially through creative writing methods as well as social media. (Odelberg, 1986; Munshi, 2021; Nobel, n.d.; Onuzo, 2021; Grollman, 2013, p. 7-8) Additionally, like Schalk, Soyinka, and Grollman, I employ a variety of approaches in my activism and have been able to use my platform in prominent ways for the collective benefit of the community in numerous individual and collaborative activism endeavors, including online activism, multimedia and photo-visual campaigns, legislative advocacy, global research and practice, meaningful community involvement., etc (Portfolio, Oxygen)

*PROCEDURAL EXAMPLES

When I think about procedure, what comes to mind is the word “how” as in “How do I do what I do?” And like most things in life, there is no simple answer to this question as my procedure varies. I can be very prescriptive at times, but I can also be very spontaneous. It depends upon the setting, the context, the topic, and/or how much the issue at hand figuratively “weighs” on me. This is the case whether I am writing a chapter or an article, giving a training, developing curriculum, conducting research, or giving a lecture or a speech.

Until I began this thesis, I don’t know if I would have been capable of seeing these connections, but now they seem astonishingly clear. Below are a few examples.

Procedure: Revamped Keynote Address (Bellevue College)

The opening remarks that I shared just before delivering my very first national keynote address, at an autism conference in Washington State in fall 2016, provides helpful insight into a crucial aspect of my praxis - authenticity. That day I found myself candidly disclosing to the conference attendees that I had decided *not* to give the official closing speech I’d prepared and was instead going to give one that was unconventional but felt like it was more “from the heart” and also incorporated my “special interest.” I had no idea whether it was going to be a complete failure or whether it would work; I was fully prepared to refund the honorarium if necessary. But things actually worked out, and by being genuine, I believe I made a greater impression and conveyed a much more meaningful message than if I had just “followed the rules.” That day was not the last time I experienced this; I found myself feeling moved to make significant changes to my prepared material as recently as 1.5 years ago, at a virtual speaking engagement. However, to help illustrate this facet of my procedure I think the way I explained it makes a great deal of sense and provides a helpful glance into the aftermath of the process.

Since then, I don’t feel that I necessarily have to disclose anything to others should I feel led to make some changes. Instead, I just restructure my materials accordingly. However, because 1) I’d had no time to truly “vet” the new speech since I’d only changed it the night before, and 2) the 2016 conference attendees were primarily autistic people and allies whom I thought would hopefully be understanding of my plight, I felt it best to be transparent in this particular instance.

Autistics Present:

A Symposium on Autistic Culture, Identity and Transition

(High School, College & Career)

Saturday
October 22, 2016
10 am - 4 pm
Bellevue College, WA

Opening Keynote:
Ari Ne'eman

Closing Keynote:
Morénike Giwa Onaiwu

Breakout Workshops:

Autism at Work: Microsoft Autism Inclusive Hiring Panel Discussion
Microsoft Employees – Moderator: Dean Betz, Panel: Joey Chemis, Katherine Hart, Max Goldstein

Collaborative Advocacy in the Autism Community :
An Inclusive Framework For Social Change
Parenting Autistic Children With Love & Acceptance
Kassiane Sibley, Jennifer Muzquiz, Lei Wiley-Mydske

Following Your Heart: How to Navigate the Rough Stuff & Build a Better Quality of Life Tailor-Made Just for You
Amy Alward

Forged in Fire: Trauma as a Foundation of Autistic Identity and Culture
Shain Neumeier

History of US Eugenics Movement
Ivanova Smith

Autism at College: Autistic Bellevue College Students Panel Discussion
Bellevue College students,
facilitator Sara Sanders Gardner

Creating Supportive & Inclusive Spaces for Autistic Women
Autism Women's Network
Morénike Giwa Onaiwu, Jennifer Muzquiz,
Lei Wiley-Mydske

Leveraging Interests, Hobbies, and Strengths into Careers
Eve Eschenbacher

Smash the Pathology Paradigm! Disability Justice in Liberation Work
Lydia Brown

The Right to Be Autistic: Re-framing Autism as Neurodiversity
Harrison Scott and Emma Van der Klift

Register Now!

bellevuecollege.edu/autismspectrumnavigators/conference-registration/

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Please see policy 4150 at: www.bellevuecollege.edu/policies/.

Below is a transcript of the opening remarks I gave prior to my first keynote in 2016.

> "So, I want to start off by saying that I really appreciate having the opportunity to be here and you all are actually my first keynote speech! I have done lots of conferences, presentations, panels, but I've never done an official keynote.
>
> When I learned about this, I was very excited about presenting to a group of people who are autistic, as well as supporters, and I wanted to do a good job.
>
> So, like any self-respecting autistic person, I took to the internet, and I researched.
>
> And there is, in case you decide to go look...there are tons of stuff out there about "keynote speech." Like, too much to look at - frankly it's overwhelming!
>
> So, I read, and read, and read, took all these notes, and I incorporated all of their ideas.
>
> And I wrote this speech, and it was the perfect speech.
>
> The speech making gods would have *loved* this speech.
>
> And last night...I ripped that speech up. I wasn't feeling the speech.
>
> Like I just, you know, it felt hollow...it felt inauthentic.
>
> It had all of the ingredients of a good speech, but it wasn't genuine.
>
> And I can't speak about something that I don't believe in.
>
> My new speech is on the same topic, but now it's my real words. No tricks, no gimmicks, no whatever.
>
> So, it won't...it would never be a TED talk, but it's my talk." (Giwa Onaiwu, 2016)

Procedure: We Haven't Finished Yet Song Creation Scene from The Five Heartbeats

The Five Heartbeats is one example. The 1991 film, directed by Robert Townsend, is about the lives of a fictional group of friends from an impoverished community who aspire to become musicians. The storyline was partially inspired by the stories of iconic Black musical groups such as the Temptations and The Dells. Early in the film we see one of the main characters, Donald Matthews (who is affectionately referred to as "Duck" as in "Donald Duck" the Disney character), in his home. Duck, the songwriter for the group, is struggling to come up with the lyrics for a song.

We watch as Duck, repeatedly sighing with frustration, frantically scrawls words to a potential song on scraps of paper, reads them aloud to himself, shakes his head, and then crumples the rejected lyrics into balls of paper that he tosses aimlessly around the room.

Duck's younger sister, who is attempting to tidy up the bedroom per their parents' instructions, grows exasperated by the growing wads of paper and scolds Duck, who admits that he is having trouble getting the words to flow properly. After combining several of the discarded scraps of paper in a different order, Duck's sister spontaneously comes up with a partial song; upon hearing her sing it, Duck is inspired to search throughout the room, digging underneath clothing and even inside the trash, to retrieve more scraps of paper containing other "failed" lyrics he has disregarded while she sings, handing them to his sister to weave into the song as he locates them.

In that manner, together the two of them create an appealing song - derived purely from what Duck had previously assumed to be useless "junk." This little scene - from a movie that is not widely known - whimsically illustrates the way Duck, who was preoccupied and having trouble coming up with the song, gets suddenly stricken with creativity upon hearing his sister sing out his words.

I can relate so, so, much to this. I have been "Duck" many times in my life. Sometimes it's those very things that we initially perceived as useless or problematic that end up having the most meaning. I have certainly experienced this within my praxis!

On the following page, there is a transcript of the opening of the scene. It takes place in a small, crowded bedroom. As it begins, Duck is brainstorming, pencil in hand, surrounded by crumpled balls of paper. His younger sister, in pajamas, has her back turned as she cleans diligently.

Duck: ♪ Some people hold on and work it out together...I believe in you…

(Crumples [another] paper and tosses it to the floor.) You believe...I believe... ♪

Sister (annoyed): Duck, I'm *trying* to clean up this room.

Duck: Well, I'm *trying* to write a song.

Sister: All right...but if this room isn't clean by the time Mama and Daddy get home, somebody's going to be in big trouble.

Duck: If this song isn't written by Saturday, *I'm* going to be in trouble.

Sister (picking up discarded papers and silently reading the song lyrics on them): You know, I don't see what's so hard.

Duck (clearly not paying any attention): Shh.

Sister: All you gotta do...is combine this part...with *this* part…

Duck (still not listening): Sure. Shhhhh.

Sister (begins humming as she prepares to burst out in song): Mmmm…

Below is a video that depicts the siblings singing from one the discarded papers containing the previously rejected lyrics - all cleaning has clearly stopped.

Video: Five Heartbeats (We Haven't Finished Yet bedroom song composition scene, 3:45)

https://www.youtube.com/watch?v=IRwo33a_Ui0

Procedure: The Living Symphony at the Ending of Mr. Holland's Opus

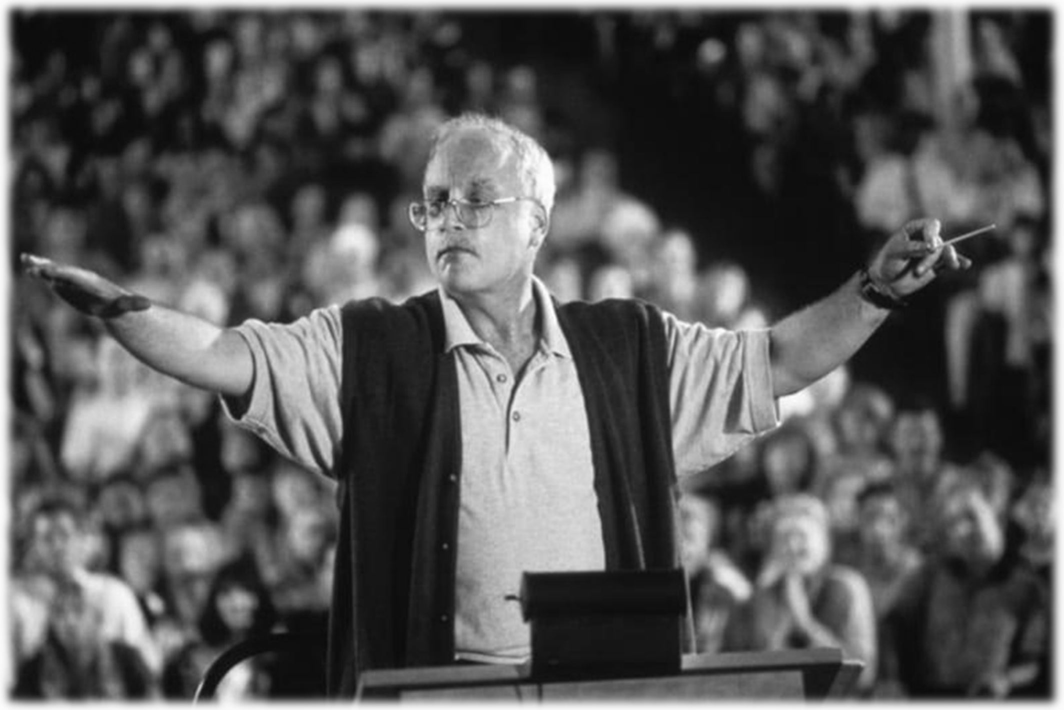
Mr. Holland's Opus, a 1995 film starring Richard Dreyfuss, is yet another example. The fictional lead character, Glenn Holland, is a talented young composer who is newly married and broke. He takes what he intends to be a short-term career detour to teach music at a public high school as a temporary means of income until he can begin his musical career. Despite initially possessing minimal enthusiasm for his job, Holland possesses a natural skill for teaching and gradually begins to make powerful connections with his students. Over the course of three decades, Holland grows in character as a father, husband, and teacher and positively impacts numerous lives. The climax of the film is a magnificent retirement concert that, unbeknownst to Holland, had been planned for him as a surprise and prominently featured many of Holland's former students - so many that they filled the entire auditorium. In a touching ending scene in which the governor (a former student of Holland!) gives a moving public tribute to the retiring teacher, Holland, who had harbored a sense of sadness and regret for having seemingly "wasted" his talent, comes to discover how meaningful his life truly had been. Below is a transcript of the scene.

> "Mr. Holland had a profound influence on my life and on a lot of lives I know. But I have a feeling that he considers a great part of his own life misspent.
>
> Rumor had it he was always working on this symphony of his. And this was going to make him famous, rich, probably both.
>
> But Mr. Holland isn't rich, and he isn't famous, at least not outside of our little town.
>
> So, it might be easy for him to think himself a failure.
>
> But he would be wrong, because I think that he's achieved a success far beyond riches and fame.
>
> Look around you. There is not a life in this room that you have not touched, and each of us is a better person because of you.
>
> We are your symphony, Mr. Holland.
>
> We are the melodies and the notes of your opus. We are the music of your life.
>
> Mr. Holland, we would now like to give something back to you, to you and to your wife, who, along with you, has waited 30 years for what we are about to hear.
>
> If you will, would you please come up here and take this baton and lead us in the first performance ever of *The American Symphony* by Glenn Holland."

As she concludes, the stage curtain is suddenly drawn back to reveal a massive orchestra, composed of Holland's former and current students, at the ready. Unbeknownst to him, his wife had secretly provided the sheet music to the others to allow them to prepare for this very moving surprise. Visibly emotional, Holland embraces his wife and adult son as the audience bursts into thunderous applause. Wiping tears of joy from his face, Holland climbs the stage, takes the baton, and prepares to lead the orchestra in the song he'd believed no one would ever play...the song that, after 30 years, he had finally been able to compose. Below is a video of Holland conducting the audience inside the auditorium.

Video: Mr. Holland's Opus (4:21)

https://www.youtube.com/watch?v=Bz85A_zNiJU



*IMPACT

One significant result of my work has been how it has measurably increased visibility of the experiences and perspectives of underrepresented communities in a number of ways. Despite multiple marginalizations - any one of which theoretically deems me as an individual whose societal ranking should be figuratively low, I am regarded as a known and frequently cited source of information regarding neurodiversity, intersectionality, Disability Justice, community engagement, parenting, and advocacy. Universities, nonprofits, and professionals, etc. frequently request my services in writing as well as technical assistance, consulting, and public speaking as indicated in the summary below.

Select Appointed Roles

- *Interagency Autism Coordinating Committee (IACC)*, which is the Federal advisory committee that coordinates Federal efforts and advises the Secretary of Health and Human Services on issues related to autism in the United States
- *Rice University*'s *Center for the Study of Women, Gender, and Sexuality* (a highly ranked research institution in the US where I was appointed for two consecutive years as a Visiting Scholar in the School of Humanities) "fosters interdisciplinary scholarship related to women, gender, and sexuality" (Rice, n.d.) via teaching and research partnerships with various community organizations
- *Institute for Exceptional Care*, a national entity seeking to revolutionize healthcare for people with intellectual and developmental disabilities in the US
- *Autism Intervention Research Network for Physical Health (AIR-P)*, an interdisciplinary, multicenter research network headquartered at UCLA for scientific collaboration and infrastructure to increase the life expectancy and quality of life for autistic individuals, particularly for underserved and vulnerable populations that is funded by the federal Autism CARES Act
    - *Autistic Researchers Review Board*, a global steering body of autistic researchers with both science and lived-experience expertise who evaluate prospective research proposals for their relevance to autistic people and overall merit within the AIR-P
    - *Gender, Sexuality, and Reproductive Health Research Node* is a branch of the AIR-P that focuses on improving sexual and reproductive care and outcomes for autistic people, especially LGBTQIA+ and gender minorities

- *NIAID's HIV/AIDS Strategic Working Group*, a collaborative global body whose members are appointed by renowned scientist Dr. Anthony Fauci to provide recommendations on scientific priorities for high resource, high impact studies and important cross-cutting issues related to HIV clinical and behavioral research
- The *BIPoC Autistic Inclusion Task Force* sought to increase racial equity in autism within the nation's most prominent autistic-led organizations
- *Gender Infinity Accessibility Committee* worked to enhance neurodiversity and accessibility offerings for an annual conference focused on gender affirmative care, the largest of its kind in the southern region of the United States
- *Texas State Accessibility Project* launched a text-to-voice initiative on 10 college campuses for all staff, faculty, and students to help promote multimodal learning

Select Elected Roles

- *Women's HIV Research Collaborative (WHRC) Co-Chair*: leadership in the development, implementation, and dissemination of HIV research in women
- *Community Partners (CP) Co-Chair*: cross-network leadership, oversight, and representation of global HIV community; facilitating programs and work products

Select Writing/Publications

- Completion and publication of an edited collection with Beacon Press, a renowned independent publisher that is over a century old. (Beacon Press has published bestsellers including *White Fragility, How to Be Less Stupid About Race, Notes of a Native Son,* controversial pieces such as *The Pentagon Papers*, and acclaimed books from Marian Wright Edelman, Cornell West, Judith Heumann, poet Mary Oliver, Viktor Frankl, Octavia Butler, etc.)
    - The book, *Sincerely, Your Autistic Child: What People on the Autism Spectrum Wish Their Parents Knew About Growing Up, Acceptance, and Identity*, has received a starred review from the Library Journal.
- Contributed chapters to several books
    - Published by established US and UK presses
- Lead editor and co-author, additional books and edited collections
- Co-author of various manuscripts
    - Accepted as well as currently under review

- Obtained publishing contract with Jessica Kingsley Publishing
    - *Neurodiversity en Noir*, an edited collection of Black neurodiverse authors that will feature contributors from various parts of the global Black diaspora, including North America, the UK, Kenya, South Africa, Germany, Japan, Jamaica, Haiti, and South America
- In negotiations with Beacon Press for a second, sole-authored book
    - Tentative title: *They Have No Empathy and 20 Other Myths You've Probably Heard About Autism*

Notable "Firsts"

- Co-editor and contributing author of the *first* ever anthology of mostly autistic people of color, which features over 60 contributors from seven different countries
- Spoke as an invited panelist at the United Nations' (UN) Headquarters for the *first* commemoration of World Autism Day to focus on gender
- Appointed as the *first* community liaison for a joint HIV prevention/therapeutics initiative (AHISC) launched by the AIDS Clinical Trials Group (ACTG), which is the oldest and largest global HIV clinical trials research network in the world
- *First* person of color to be appointed to the Board of Trustees of the oldest and largest autistic-led advocacy group, the Autistic Self Advocacy Network (ASAN)
- *First* person of color to be appointed to the Board of Directors of the oldest autism and gender nonprofit, Autistic Women & Nonbinary Network (AWN)
- *First* woman of color elected to chair the ACTG Global Community Advisory Board (GCAB), one of two standing resource committees of the ACTG
- Selected as keynote for the *first* autistic led national conference in the US
- *First* selectee of the Interagency Autism Coordinating Center (the US federal advisory committee on autism) who is an autistic woman of color
- Spoke as an invited panelist at the *first* White House Forum on the Civil Rights of Parents with Disabilities
- Served as the *first* Grant Selection Chair for the Fund for Community Reparations for Autistic People of Color's Interdependence, Survival, and Empowerment ($200,000+ allocated microgrants to people in need within its first two years)

- Helped launch the *first* National Annual Day of Action to End Violence Against Women and Girls Living with HIV; co-led Houston's *first* local commemoration
- Planned; co-led local events for the *first* National HIV Transgender Testing Day
- Formally represented ACTG community leadership (the Global Community Advisory Board) for National HIV Testing Day at the *first* White House Forum on LGBT and Disability
- Contributor to the *first* ACTG community authored manual providing guidance on best practices for recruiting and retaining women in HIV therapeutic research

Notable Stakeholder Leadership Accomplishments

- Official community rapporteur for the 2018 International AIDS Conference
- Successfully petitioned for annual ACTG Network community address
- Took leadership roles in planning, marketing, and coordinating the groundbreaking Mother's Day Million Moms March on Washington in the US against police and vigilante violence
- Successfully campaigned for more inclusive HIV terminology, resulting in 1) the formal revision of the mission statements of three global HIV clinical trials networks (removing stigmatizing wording) and 2) two community members being appointed to an executive global body for communication on HIV clinical trials
- Featured in national disability photography exhibit (Positive Exposure)
- Featured in global anti-HIV stigma media campaign/magazine (A Day with HIV)
- Successfully campaigned award-winning musical artists Drake and J. Cole to remove and apologize for ableist song lyrics
- Led viral #JusticeForKayleb/anti youth of color school-to-prison pipeline campaign for unjust felony charges to be dropped against Black autistic preteen (with Lei Wiley-Mydske)
- Hosted several consecutive national Children's AIDS Day and family friendly World AIDS Day events (predecessor of National Youth HIV/AIDS Day)

Select Media Coverage

- Library Journal (Starred book review)
- NY Times (1st page); Today Show/NBC, Conde Nast/Iris (video with 3 million+ views)
- BBC, UN TV, Center for Public Integrity, Voice of America, NPR
- The Atlantic, Frontline, Salon Magazine
- Spectrum News, Disability and Society Journal; Psychology Today
- The Hill, Al Jazeera News
- Buzzfeed, Daily Kos, HuffPost
- POZ Magazine; PBS SoCal
- Prism Magazine, Diversity Woman Magazine & Inclusion Magazine

Select Keynote, Speaking, and Consulting Appearances

- Duke University
- New York University
- Stanford University
- Rice University
- University of Texas at Austin
- University of South Florida
- Dublin City University
- Drexel University
- Houston Baptist University
- Brooklyn Public Library System
- 23 and Me
- AIDS United
- New York Life
- Autism Society of America
- University of Michigan - Ann Arbor
- National Institute of Child Development
- National Institute of Mental Health
- Center for Disease Control and Prevention

Select Research and Policy Impact of Note

- Led national efforts to preserve government funding for community-based services for low-income children, youth, women, and families living with HIV (Save Ryan White Part D and No HIV+ Women & Children Left Behind)
- Sole US community representative on one of the largest international maternal child HIV clinical trials (Promoting Maternal/Infant Survival Everywhere)
- Successfully campaigned for continuation of international Kaposi sarcoma study
- Advisor on National Science Foundation ethics in autism research project
- Advocated for equitable access to restrooms and public spaces for individuals of all genders
- Community liaison for initial part of a cross-network project to develop revised content for a global "cure-iculum" (comprehensive layperson HIV cure research curriculum)
- Successfully campaigned to double the amount of community representatives on the ACTG Site Management and Clinical Care Committee
- Successfully opposed (with other community leaders) HIV criminalization laws
- Obama administration nominee to federal disability committee
- Successfully collaborated with ACTG leadership on a formal network transition plan to support community participants at de-funded HIV research sites
- Formally represented ACTG community at cross-network consultancy leading to development of a new HIV research workgroup focused on cis and trans women
- Served on research and policy group for inaugural "End HIV" municipal plan
- Served as external IRB member for large public health municipality in the state
- Collaborator on international disability, mental health, and parenting research projects

Select Educational and Societal Impact of Note

- Frequently utilized expert for conferences, broad/podcasts, print and other media, webinars, symposia, research, peer review, guest lectures/keynotes, grant review, and consulting
- Sensitivity reader/reviewer for fiction monograph and academic textbooks
- Writing has had significant global impact, including:
    - Formally reviewed, recommended, and/or cited in peer-reviewed journals, media publications, book lists, and social media
    - Copies have been donated to nonprofits, Historically Black Colleges and Universities, tribal colleges, and Asian and Hispanic Serving Institutions

Select Testimonials

“Educating the community is paramount for me. Morénike’s perspective as a parent of children with disabilities as well as a self-advocate is most insightful, and her passion is evident. She is dedicated to empowering others and promoting acceptance for people with disabilities.”
- Judy Blake, MA: University of Texas LoneStar LEND Family Faculty

“I've worked with Morénike for over five years. She is supportive, task-oriented, passionate, and solution-focused. Morénike is a critical thinker and works well with teams as well as individually to innovate and solve problems. She is immensely well-respected not only by me, but within the fields of HIV and social justice overall. It is a privilege to work with Morénike.”
- Brian Minalga, MSW: Fred Hutch Project Manager

“I had the privilege of working with Morénike at the National Institutes of Health. She is an excellent public speaker and consultant in the field of public health and community organization. Her grasp of complex issues and ability to involve diverse segments of constituencies made a challenging task less daunting and user friendly for all levels of community and professionals involved.”
- Nathaniel Johnson, MSW: Urban Minority Alcohol and Drug Outreach Director

“Morénike cares deeply about the vulnerable, including people with disabilities (especially people with autism) and wants to bring about change. She was highly regarded by the other classmates in her graduate program as a peer leader and a problem solver. She presents with originality and conviction and is known for her creative ideas and initiative. I recommend her without hesitation.”
- Ellen L. Black, EdD: ACSI Christian Philosophy of Education Professor

“I have had the pleasure of working with Morénike on a number of different projects around inclusive education. Whether she is delivering a keynote address, sharing her expertise in a panel discussion, or critiquing program development, Morénike always comes to the work with authenticity, thoughtfulness, and compassion. She is a wonderful collaborator and thought partner who challenges us to push the boundaries of inclusion and to examine our assumptions and biases.”
- Lauren Hough, MBA: NYU Program for Inclusion Neurodiversity Education Director

“I worked with Morénike for a number of years on several committees. She is a skilled facilitator and systems thinker as well as a great leader and community advocate.”

-Nike Blue, Houston Area Women’s Center Vice President of Quality Assurance

“As her former supervisor for over four years, I have great familiarity with Morenike’s work ethics and performance as well as her professional strengths and qualities. She is a reliable and effective team player. However, as a natural self-starter, she shines when working independently and is consistently able to follow through to ensure that the job gets done. Morénike possesses the unique ability to communicate complex information in a way that is understandable for the layperson. Morénike is a loyal, dedicated and hardworking individual who conducts herself in a caring manner.”
- Deanna Davis, PhD: Connect All Dots CEO; Northcentral University Professor

“I had the pleasure of working closely with Morénike as co-chair of the Women's HIV Research Collaboration for more than two years. I learned so much from Morénike. She is passionate, hard-working and an amazing advocate for women of color. Thoughtful and articulate, she speaks from experience and with compassion. We collaborated on several successful meeting abstracts together, and the input she provided was always on point and eye opening. I am extremely grateful for the time we worked together as it made me a better HIV professional and ally.”
- Clare Collins, MS: Magee Women’s Research Institute Communications Director

“All The Weight of our Dreams: On Living Racialized Autism, is the first anthology of its kind to address the intersected realities of race and autism. It relays very personal and often hard truths with poise, creativity, honesty, and love. It is a valuable text for anyone living a racialized autism experience or supporting those who are...this ground-breaking book is a must-have addition to any library intended for readers interested in educating themselves, or others, about the intersected realities of racialized autistic experiences.”
- Canadian Journal of Disability Studies

“Before readers come to this book’s first essay, a sidebar quotation jumps out: ‘I have a place in this world. The fact that I am here is proof of that. Trust that we will find that place, together.’ This may be precisely what readers need to hear in this collection of essays written in the form of letters to parents. VERDICT: This book is absolutely required reading for parents, educators, and caregivers who interact with anyone on the autism spectrum.”
-The Library Journal

“The person that I admire most is my mother (Morénike) because of all that she has survived and accomplished throughout her life.”

-My middle son, senior year state championship press conference

*POSSIBLE NEXT STEPS

The term future contingency (futura contigentia, derived from Aristotle's infamous sea battle argument about modality and truth value) refers to potential outcomes that are contingent upon how future circumstances unfold. (Shain, 2011, p. 124-137) The need for future research to expand on the topics outlined in this thesis is significant. Empirical research that is accessible; culturally sensitive; embodies inclusive, ethical, principles; and is designed to meaningfully and equitably involve the community with intentional, ongoing efforts to incorporate underrepresented groups can help fill critical gaps. Such research could potentially help dismantle, at least in part, some of the pervasive social and health inequities experienced by many multiply marginalized individuals. Thus, future studies would be undertaking an active role in helping to foster health equity. (Braveman 2014, para 7-10)

Specifically, one area of significance that could be studied relates to further examination of and/or building on innovative methods that have shown efficacy, especially related to working effectively with seemingly distinct stakeholders. Several have been identified by Dr. Dazon Dixon Diallo (a Black activist-scholar living with HIV) and colleagues at the woman-of-color-led bicontinental grassroots reproductive justice organization Sister Love. (Diallo, 2004, p. 124-128) Others have been shared by AIDS United and the U.S. People Living with HIV Caucus. (2019, p. 37-39, 41-57) Research that incorporates the instruments created by these groups that have been designed for organizational self-evaluation as well as for externally assessing others' current level of meaningful stakeholder involvement across various programmatic, logistic, and leadership areas with diverse types of constituents in a variety of settings is especially needed—both short-term and longitudinal studies.

There is also a critical need for radical changes in research that will help to amplify and foster acceptance of underrepresented voices in research and practice. Composition of research and clinical teams and their site staff as well as that of other providers (medical, educational, etc.); internal and external communication; policies, research, programming, and/or design (including objectives, wording, and data collection); etc. should be developed intentionally to ensure meaningful inclusion, prioritize accessibility and cultural humility, and accurately and respectfully capture nontraditional perspectives and methodologies.

McNally (2015, p. 197-198) and others' work on enhancing community leadership, engagement, and/or participatory strategies for supporting and/or partnering with marginalized groups in a broad range of diverse communities offers a useful framework.

Due to the intersectional nature of this work, future researchers might wish to consider Dillard's pairing of Critical Narrative Analysis and Critical Participatory Action Research (Dillard, 2020, p. 47, 55-57), which results in the development of individual personal narratives, counter-narratives, and other emancipatory tools for challenging privileged and/or deficit-based larger and/or master narratives that tend to marginalize and decenter certain groups. (Dillard, 2018, p.61-66; 82) This promising emergent methodology offers a mechanism to potentially implement recommendations from Bailey and Mosbey (2019) to build on the work of Black feminist and Disability Studies scholars with the intention of eliminating the "unnecessarily disparate" between the two disciplines, as Dillard explicitly notes that the combined approach can be applied to "any research that centers other lived experiences that, similar to women of color, do not fit into and are harmed by a dominant narrative's invisible and sustained hold on beliefs, values, norms, expectations." (Dillard, 2018, p. 67)

Future research should consider evaluating, extending, and/or replicating promising practices that have been utilized by Black public health scholar Dr. Vida Henderson. (Fred Hutch, 2022, para 1) Henderson, whose her work focuses on underrepresented groups, specifically explores health inequities via multi-level associations between systems, structural bias, and various social determinants of health including race, gender, and socio-economic status. Incorporating insights from Black Disability Studies as well as the growing body of social justice/human rights activism research, especially that of Satterwaite (2014), Gutierrez and Lipman (2016), abolitionist educator Csillag (2020 - 2021), and Gorski (2015-2022), will be helpful for developing solutions that are viable yet inclusive.

Additionally, there are guidelines and recommendations from both established and new autism community, practitioner, and researcher collaborations. These include the Academic Autism Spectrum Partnership in Research and Education which has been conducting community engaged research since 2006 (Nicolaidis, 2019, p. 79-81; AASPIRE, 2020, para 1-6); the Autistic Researchers Committee of the International Society for Autism Research, which was formed in 2020 (INSAR, 2022, para 1-2); the Autistic Researchers Review Board of the Autism Intervention Research Network on Physical Health formed in 2021 (Brown et al, 2022, p. s1-4); and the Autistic Faculty of the State Public Health Autism Center, formed in 2022. (AMCHP, Title V National Performance Measures)

Given the large number of people from marginalized communities who engage in advocacy (so much so that one common euphemism for us, no matter the nature of the work one tends to engage in, is the term "self-advocate" [Abbott & Holley, 2021, sections 1-6]), it is crucial that future research into these practices seeks to intentionally cultivate connections within as well as amplify the perspectives of those who are most impacted as per the philosophy of Disability Justice (Sins Invalid, 2015, list/primer).

Future research should potentially consider ensuring that elements of Black Disability Politics be explicitly incorporated. It would also be beneficial to examine Critical Technocultural Discourse Analysis, ethnomediaology, and rhetorical analysis of autie-ethnographic BIPoC literature.

Building on the scholarship of existing researchers, it would be vital for individuals seeking to extend, replicate, and/or make further progress in many of the topics explored throughout this thesis. In particular, it would be beneficial for research teams to strongly consider exploring what may be uncovered about the HIV, neurodiversity, and Disability Justice communities related to the following:

- elements associated with activist burnout (external factors, in-movement factors, personal, etc., including a culture of martyrdom, lack of self-care, minimal resources, existing violations, and the impact of psychological injury)
- factors contributing to activist sustainability (i.e., resilience, coping flexibility, self-care strategies, helpful mental health tools, and other resources)
- comparisons of perspectives of activists from select communities (specific activism genres/subgroups, certain geographic locations, marginalized identities (i.e., race, gender, etc.)
- examining various instruments that have been utilized to assess burnout in these or similar groups; specific assessments that were noted among the literature included the following:
    - the Activist Flourishing and Fatigue Inventory (AFFI), a 14-item validated tool developed by Gorski and colleagues (2019a, 3a-3e, 2019,) for use with activists
    - the Quick Burnout Assessment, a multipurpose tool for activism and vocational screening (Maslach & Leiter, 2016, p. 103–111; Maslach & Jackson, 1981, p. 99-113)
    - the Copenhagen Burnout Flourishing Scale, which measures physical and psychological exhaustion and is primarily used to assess occupational burnout (Maslach & Leiter, 2016, p. 103–111)
    - various instruments being co-created by collaborative teams of clinicians and community partners, including the Aut-PROM tools from AASPIRE
- musings about allyship from Cevik (n.d.), Cole (2008), and Linehan (2014)'s writings outlining the important role of parents in autism advocacy and activism
- historical and current examination of autistic advocacy, such as the work of Kras (2010), Odell et al (2016), Donaldson et al (2017), and Gillespie et al (2017)

- Kapp’s comprehensive review of the neurodiversity movement (2020), and Person’s (2021), Rozema’s (2022), and Eidle’s (2021, 2022) digital repositories of the movement
- Perry’s (2014) research on leadership, ethics, and autism
- Hughes’ (2015 - 2017) work on online neurodiversity advocacy and making disability and social justice spaces accessible for neurodiverse individuals
- research on stakeholder engagement in HIV clinical trials and programs such as that of Day et al (2018), Karris, Dube, and Moore (2019), Grimsund et al (2020) - plus a cautionary tale of what not to do from Dlamini-Simelane (2017)
- Botha’s (2021) excellent, heart wrenching reflection on autism knowledge production, “Academic, Activist, or Advocate? Angry, Entangled, and Emerging”
- Morgan (2022) and colleagues’ work on amplifying the perspectives of Black autistic individuals as well as that of their families
- Srinivasan’s strength-based examination of intense interests as a tool for enhancing quality of life and connection (2022)
- Gasner’s work on the importance of systems and services integration for marginalized individuals with disabilities, particularly elderly persons with I/DD

Several overarching concepts of the movement for global education reform, most notably the United Nations’ Sustainable Development Goal 4, Quality Education, which aspires to “ensure education for all” through equitable and inclusive education that promotes creative expression, critical thinking, engagement, analytical skills, cooperation, and applied learning with qualified teachers in a positive, secure environment, are aligned with Engaged Pedagogy and could potentially be explored in future research (UNESCO, 2021, goal 4). Action research, particularly when co-designed with students and community collaborators, is warranted in this area.

Future studies of this caliber, as well as earlier suggestions, would be undertaking an active role in helping to foster health equity, as illustrated powerfully in a frequently cited public health report:

> Pursuing health equity means striving for the highest…standard of health for all, giving special attention to the needs of those at greatest risk of poor health, based on social conditions. Health equity and health disparities are intertwined...Health equity means social justice in health. (Braveman 2014, para 7-10)

(Link to) **Illustrative Examples: Assorted Images, Figures, and Other Items of Interest**

Illustration: Artistic rendition of the fire tetrahedron made for the thesis by my 11-year-old

Picture: My family embracing one another (taken as part: the "I am HERO" campaign)

Illustration: A fiery phoenix bird composed of flame with outstretched wings*

Picture: Me laughing, Matthew Reardon (taken by Lynn Johnston)

Illustration: Various characters from Dragon Ball Z/Super*

Picture: My fam, Christmas

Illustration: Garnet from Steven Universe fan art from the creator "Asiey"

Picture: Me standing on a porch reading the "All the Weight of Our Dreams" book

Illustration: A fiery phoenix bird in the dark in mid-flight*

Picture: My parents

Illustration: Dragon Ball Super's Super Saiyan god ceremony*

Picture: Several members of my family representing generations of strong women and girls

Illustration: Fan art Garnet from Steven Universe (from Stronger Than You)*

Picture: Beautiful family members Cherita and Noah

Picture: An open, outstretched palm with flames coming out of the fingertips*

Picture: Family members - Hubby and Queen Helen

Picture: University of East Anglia stuffed bunny with flippy ears wearing a university t shirt*

Picture: My mom and I

Illustration: Fan art "word cloud" of Garnet from Steven Universe (" Stronger Than You" lyrics)*

Pictures: Me and my daughters in two pics ten years apart

Picture: Me and my daughters

Picture: "This girl is on fire!" A fiery feminine silhouette shape*

Picture: Me at a conference in sunglasses and stimming with a "Koosh ball" and other tangible items (taken by Lynn Johnston)

Illustration: Fan art of Garnet from Steven Universe*

Picture: Queen Helen & my babies/her grandbabies

Illustration: Fan Art Stronger Than You Word Garnet from Steven Universe*

Picture: Maria Hamilton, Janet Baker, and me at the Million Moms March

Illustration: Fan art rendition of Garnet from Steven Universe*

Picture: My oldest son at a justice rally holding a protest sign that declares, "I am NOT a thug."

*Source unknown


oxygen
oxygen
oxygen
heat
fuel
chemical reaction

Appendix C: Copyright/fair usage, authorship, and submission statements; works cited; sources consulted (859 words)

Bringing Fire to the People: Activist Scholarship, Creative Collaboration, & International Advocacy Through the Lens of Black Disability Studies

M. Giwa Onaiwu | University of East Anglia Doctoral Thesis | 2022

Contents of Appendices

Contents of Appendix C

SUBMISSION STATEMENT

I declare that the practical and published work submitted is my own original work.

I also declare that the critical commentary of my practice and research is my own account of my outputs and contains as its main content work which has not been previously submitted for a degree at this or any other institution of higher education.

Morénike Sheri Giwa Onaiwu

FINAL THOUGHTS

I want this thesis to be, I hope, an accurate “snapshot” of my work as a whole, not just something done begrudgingly to fulfill the necessary requirements for placing the honorific of “Dr.” in front of my name. (Now, don’t get me wrong; I definitely want that nice gender-neutral honorific [that I have worked d@mn hard for]!) I want people to know, and hopefully grow to love, the “activist” part of me that dwells adjacent to the “mom” part of me. (In fact, I want my grandkids and great-grandkids to be able to read it and think, “Grandma [or Great-Grandma] Morénike was something else!”)

I want those whose lives I touched, even in some small way, during my time on this earth to know that they matter. That sometimes they were one of the few motivations for me not to give up on life.

But more than anything, I want people, in general, to see me, feel me, hear me through this thesis long after I’m gone. I hope it will be a legacy of sorts, like a living piece of me that others can learn from to avoid my mistakes as well as build and improve upon my successes. Though it’s my story and thus may not necessarily resonate with everyone as each person has their own unique story, I’m hoping that some people (maybe even you), will, upon reading/viewing/listening to this, seek to find and cherish a piece of themselves through it too.

It is all interconnected because we are one community, one family, and we rise together. Most likely you have no idea what a significant source of knowledge and strength you have been for me, but like one of my favorite African proverbs wisely observes, “*When spider webs unite, they can tie up a lion.”* When we work together, we can achieve so much!

Lastly, I am eternally grateful for those who are no longer with us and now dwell among the ancestors. Many of them we lost far too soon, but their work, words, beliefs, actions, successes, failures, etc. still nurture, advise, and inspire me. This includes individuals I’ve known and loved: Sharon Maxwell, Monica Roberts, Mary Bowman, “Grandma” C.A.R.E., Carrie Ann Lucas, Sandy Kinnamon, Jae Casper Ross, Lola Daodu, Louie Zimmerman, Ray Allmond, David Hughes, Melissa Murry, Timothy Ray Brown, David Watson, Gene Ethridge, Rosemary Peppers Hernandez. Others have touched my life though we’ve never met: bell hooks, Bishop Desmond Tutu, Rachel Held Evans, Senator John Lewis, Dr. James Gita Hakim, Toni Morrison, Stacy Park Milburn, Ruth Christ Sullivan. Without their efforts, what I do would not be possible. I have built on the monuments of those who came before me just as others will expand and improve upon my labor in the future.

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University of East Anglia

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The thesis seeks to advance the understanding of race, gender, disability, activist-scholarship, and related topics it addresses. Any/all photos, media, video, articles, posts, figures, quotes, etc. are owned by their respective copyright owner(s). Where possible and/or where ownership is known, appropriate accreditation is given. If you are the owner of any copyrighted material(s) and believe the use of any such material(s) does not constitute fair use, please make contact so that I may address the matter promptly.

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If you require any additional information, do not hesitate to contact me at **MGO@MorenikeGO.com**.

Morénike Giwa Onaiwu Morénike Giwa Onaiwu 24 July 2022

This statement has been prepared for submission to the University of East Anglia Doctoral College by:
Mx. Morénike Giwa Onaiwu PhD candidate/postgraduate researcher

Autistic Women & Nonbinary Network (AWN)
Neurodiversity is for Everyone

Author/Editor Contribution Statement: All the Weight of Our Dreams

This statement is intended to provide clarification on authorship contributions for the edited collection, *All the Weight of Our Dreams: On Living Racialized Autism* (*All the Weight of Our Dreams*), a collaborative project of Lydia X. Z. Brown and Autistic Women and Nonbinary Network (AWN) whose first edition was published in 2017 under the imprint DragonBee Press.

Esq. Lydia X. Z. Brown is a disability justice organizer, activist, creator, and attorney in the US who conceptualized and led *All the Weight of Our Dreams*. AWN is a 501c3 nonprofit organization in the US that provided financial and logistical support for the development and publication of *All the Weight of Our Dreams*, an anthology featuring 61 writers and artists from seven countries. Intended to be the first anthology of art and writing entirely by autistic people of color, *All the Weight of Our Dreams* was edited by Lydia X. Z. Brown (LB), E. Ashkenazy (EA), and Morénike Giwa Onaiwu (MGO) with the goal of representing the lives, politics, and artistic expressions of our community. Publication of the initial 2017 edition was discontinued in 2021; the anthology will be re-released in the future as a second edition with new content and a new editorial team.

Please note that the lead editorial team for *All the Weight of Our Dreams* (LB, EA, MGO, and Sd on behalf of AWN) take public responsibility for its content and confirm our respective contributions as listed:

LB's contributions as *All the Weight of Our Dreams'* **Senior Editor** include conceptualization, fundraising, acquisition, methodology, contributor solicitation, contributor coordination, data collection, solicitation and management of editorial and project team, resource development, validation, analysis and interpretation, draft manuscript preparation, review and editing, visualization, software, extensive revision, project administration, marketing, lead editorial duties, project team liaison, copyright, and numerous related tasks.

EA's contributions as *All the Weight of Our Dreams'* **Project Manager & Editor** include: methodology, contributor coordination, grant monitoring/reporting, review, visualization, project management, communication, marketing, and related tasks.

MGO's contributions as *All the Weight of Our Dreams'* **Assistant Project Manager & Editor** include: methodology, contributor coordination, data collection, resource development, analysis, review, project coordination, marketing, and related tasks.

AWN's contributions as *All the Weight of Our Dreams'* **organizational partner** include: fiscal sponsorship, contractual obligations, contributor coordination, validation, copyright, marketing, relevant support and assistance with publishing and related tasks.

Additional support was provided by: Finn Gardiner (cover designs); Remi Yergeau (formatting for publication); Amanda Gaul (legal and financial help); Lori Berkowitz (web development); Shain M. Neumeier (editing assistance); and Claire Barber-Stetson (editing assistance).

CONTRIBUTORS

The following is a list of *All the Weight of Our Dreams'* **contributors** (who assisted in data curation): Amanda Filteau, Angel A. McCorkle, Anmei He, Bijhan Valibeigi, Cindy Facteau (Fragmented Perfection), Christopher Tucker, Confessions of a Black Rhapsodic Aspie (COBRA), Daniel Au Valencia, D. Campbell Williams, Dee Phair (sometimesdee), Deion Hawkins, E. Ashkenazy, Ebru Çelik, Eliora Smith, Elly Wong, Emily Pate (@msemilymarie), Emma Rosenthal, Emmalia Harrington, Miss Fabien, Finn Gardiner, G.A., HarkenSlasher, Jane Strauss, Jennifer Msumba, Jessa Sturgeon, Jim Meunier (Gzhibaeassigae), Joseph "Joey" Juarez, Kaijaii Gomez Wick, Kassiane A. Asasumasu, Keara Farnan, Kelly Bron Johnson (@KBronJohn and/or @OneQuarterMama), kī anthony,Kris Y., Krissy Baxter, Legacy Onaiwu, Leylah, Lydia X. Z. Brown, Louise Thundercloud-Hills, Lucas Vizeu, Maanu Alexander, M.D., Melis Leflef (Melissa Murphy), Mercedes Cibby Acosta, Mikael Lee, Morénike Giwa Onaiwu, Nathaniel Hagemaster (Agony Myers), N.I. Nicholson, Nicole S. Xurd (Shalese Nicole Heard), Ondrea Marisa Robinson, Pharaoh Inkabuss (Timotheus "T.J." Gordon), Pretty Eyes Ellis, Rhonda G., Rikki Katherine Lee Moses, S Henderson, Shane Bentley (shaneisadragon), Shondolyn Gibson, Stephan B., Taiyo Brown, Vivie Bella, Yasmin Khoshnood, Ylanne So, and Yvonne Christian (Uncommon Bostonian).

Additionally, some of the aforementioned individuals provided some assistance to the authors/editors with resource development, visualization, and marketing.

COLLECTIVE APPROVAL OF FIRST EDITION

All relevant parties (the editorial and project team members as well as executive leadership from AWN) reviewed and approved the final version of the first edition of *All the Weight of Our Dreams* that was published in June 2017.

Autistic Women & Nonbinary Network (AWN)
Neurodiversity is for Everyone

COMMITMENT TO DISABILITY JUSTICE

As AWN's work is informed and guided by Disability Justice principles, all work is done honoring the wholeness of disabled people and our human limitations. As stated by Sins Invalid, one such disability justice principle is "Sustainability: We pace ourselves, individually and collectively, to be sustained long term. Our embodied experiences guide us toward ongoing justice and liberation." sinsinvalid.org/blog/10-principles-of-disability-justice

AWN commits to do everything in its power to operate according to these principles while acknowledging that there may be times when the demands of the non-profit industry and related factors may cause challenges with honoring disability justice principles and sustainability. Navigating any possible challenges entails flexibility and open, honest communication that recognizes our own limitations and a shared dedication to the long-term sustainability of the cross-disability and neurodiversity movement.

By signing below, I am confirming the accuracy of these contributions to the first edition of the publication *All the Weight of Our Dreams* that are described in this statement.

Lydia X. Z. Brown (LB), Senior Editor

Dec 3, 2021

LB Signature — Date

E. Ashkenazy (EA), Project Manager & Editor

Elesia Ashkenazy

Dec 4, 2021

EA Signature — Date

Morénike Giwa Onaiwu (MGO), Assistant Project Manager & Editor

Morénike Giwa Onaiwu
Morénike Giwa Onaiwu (Dec 3, 2021 10:07 CST)

Dec 3, 2021

MGO Signature — Date

Sharon daVanport (Sd), AWN Executive Director

Sharon daVanport
Sharon daVanport (Dec 3, 2021 18:57 CST)

Dec 3, 2021

Sd Signature — Date

This statement has been prepared and submitted to the Doctoral College of University of East Anglia on behalf of PhD candidate/postgraduate researcher, Mx. Morénike Giwa Onaiwu.

University of East Anglia

Authorship Contribution Statement

This statement is intended to provide clarification on authorship contributions for a publication, tentatively entitled "At the Intersection of Parenting, Race, and Disability throughout the Diaspora: Black Motherhood and the Journey Beyond Diagnosis"

Please note all signatories take public responsibility for the content and confirm the authorship contribution(s) as listed:

Morénike Giwa Onaiwu's contribution(s) to the publication are as follows:

Co-authorship of monograph highlighting disability parenting in diverse Black communities, in partnership with Camille Proctor, Lola Dada-Olley, and Tonye Falughi-Ekezie

By signing below, I confirm the accuracy of the contribution(s) to the publication as described in this statement.

Morénike Giwa Onaiwu	Morénike Giwa Onaiwu	Co-Author	24 July 2022
Full Name	Signature	Title	Date
Camille Proctor	Camille Proctor SIGNED VIA ILOVEPDF	Co-Author	2022/07/25
Full Name	Signature	Title	Date
Lola Dada-Olley	Lola Dada-Olley SIGNED VIA ILOVEPDF	Co-Author	2022/07/27
Full Name	Signature	Title	Date
Tonye Faloughi-Ekezie	Ayegbatonye Faloughi SIGNED VIA ILOVEPDF	Co-Author	2022/07/26
Full Name	Signature	Title	Date

This statement has been prepared and submitted to the Doctoral College of University of East Anglia on behalf of PhD candidate/postgraduate researcher, Mx. Morénike Giwa Onaiwu.

University of East Anglia

Authorship Contribution Statement

This statement is intended to provide clarification on authorship contributions for a publication,

Dazzling Colours of Calm

published by Heady Mix in 2021 and edited by Heady Mix.

Please note all signatories take public responsibility for the content and confirm the authorship contribution(s) as listed:

Morénike Giwa Onaiwu's contribution(s) to the publication are as follows:

Author of a chapter in the book entitled "The Lady on the Plane"

By signing below, I confirm the accuracy of the contribution(s) to the publication as described in this statement.

Morénike Giwa Onaiwu	Morénike Giwa Onaiwu	Contributing Author	23 July 2022
Full Name	Signature	Title	Date
Full Name	Signature	Title	Date
Full Name	Signature	Title	Date

This statement has been prepared and submitted to the Doctoral College of University of East Anglia on behalf of PhD candidate/postgraduate researcher, Mx. Morénike Giwa Onaiwu.

Gmail

Morénike Giwa Onaiwu <mgiwa.onaiwu@gmail.com>

Dazzling Colours of Calm :)

Morénike Giwa Onaiwu <MGO@morenikego.com> Mon, Feb 1, 2021 at 11:10 AM
To: "scarlett@headymix.co.uk" <scarlett@headymix.co.uk>
Cc: Tyler Boyd <t.boyd@morenikego.com>, "justina@headymix.co.uk" <justina@headymix.co.uk>

Greetings Scarlett,

Thank you so much for your email. The collection sounds fantastic and I would be happy to grant permission to have The lady on the plane included in it. All of the individual Respectfully Connected authors retain copyright of our respective articles published on the site, so I can definitely consent to allow it to be reprinted.

Please feel free to reply to this email to notify me if this emailed consent is acceptable for the purposes of your organization. However, if that's too informal and instead there is some type of documentation (i.e. an authorization or release form) that your organization requires for this purpose that I will need to complete, please forward it to my assistant Ty and they will get it to me. (I try to avoid having anyone send things that need follow up to me directly as I struggle with executive functioning and might not remember to complete it; Ty, however, will make sure I get to it).

I hope that the piece will resonate with your readers; I can still picture the woman from that exchange so vividly in my mind...how unnecessarily tortured she had been for years due to societal misinformation when all she was trying to do was love and care for her family.

Thanks again for reaching out!

Autistic Women & Nonbinary Network (AWN)
Neurodiversity is for Everyone

Author Contribution Statement: Sincerely, Your Autistic Child

This statement is intended to provide clarification on authorship contributions for an Autistic Women and Nonbinary Network (AWN) edited collection, *Sincerely, Your Autistic Child: What People on the Autism Spectrum Wish Their Parents Knew About Growing Up, Acceptance, and Identity (Sincerely, Your Autistic Child)*, which is a republication of an AWN anthology entitled *What Every Autistic Girl Wishes Her Parents Knew* that was previously awarded the Autism Society of America's Dr. Temple Grandin Outstanding Literary Work of the Year Award.

AWN is a 501c3 nonprofit organization in the US. In 2021, *Sincerely, Your Autistic Child*, an AWN publication edited by Emily Paige Ballou (EPB), Sharon daVanport (Sd), and Morénike Giwa Onaiwu (MGO), was published by Beacon Press (a US independent nonprofit book publishing company). *Sincerely, Your Autistic Child*, which features a diverse range of perspectives as a collection of essays written in the form of letters to parents, received a starred review from the Library Journal proclaiming the book as "absolutely required reading for parents, educators, and caregivers who interact with anyone on the autism spectrum."

Please note that all *Sincerely, Your Autistic Child* authors/editors (AWN, EPB, Sd, MGO) take public responsibility for its content and confirm our respective contributions as listed:

EPB's contributions as *Sincerely, Your Autistic Child* **editor** include conceptualization, methodology, contributor coordination, data collection, resource development, validation, analysis and interpretation, draft manuscript preparation, review and editing, visualization, software, project administration, marketing.

Sd's contributions as *Sincerely, Your Autistic Child* **editor** include: conceptualization, methodology, funding acquisition, contributor solicitation, contributor coordination, resource development, draft manuscript preparation, review and editing, visualization, project administration, publisher liaison, communication, marketing.

MGO's contributions as *Sincerely, Your Autistic Child* **editor** include: conceptualization, methodology, contributor solicitation, contributor coordination, accessibility, data collection, resource development, validation, analysis, draft manuscript preparation, cultural competency audit, review and editing, visualization, design, project administration, marketing.

AWN's contributions as *Sincerely, Your Autistic Child* **author** include: conceptualization, funding acquisition, contractual obligations, contributor solicitation, contributor coordination, validation, copyright, project administration, supervision, marketing.

All authors/editors confirm that the following *Sincerely, Your Autistic Child* **contributors** assisted in data curation: Jess Wilson, Emily Paige Ballou, Sharon daVanport, Morénike Giwa Onaiwu, Brigid Rankowski, B. Martin Allen, Jane Strauss, Kassiane Asasumasu, Katie Levin, Lei Wiley-Mydske, Dusya Lyubovskaya, Anonymous, Heidi Wangelin, Karen Lean, Jennifer St. Jude, Ondrea Marisa Robinson, Haley Moss, Victoria M. Rodríguez-Roldán, Amythest Schaber, Kayla Smith, Amelia "Mel" Evelyn Voicy Baggs, Amy Sequenzia, HW, Lynne Soraya, Maxfield Sparrow, Anonymous, Mallory Cruz, Kayla Rodriguez, Jean Winegardner, Alexandra Forshaw, Lydia X. Z. Brown, Beth Ryan. Additionally, several of the aforementioned individuals provided some assistance to the authors/editors with resource development, visualization, and marketing.

All authors/editors, contributors, and designated executive leadership of the Autistic Women and Nonbinary Network reviewed and discussed the results and approved the final version of *Sincerely, Your Autistic Child* that was submitted to the publisher, Beacon Press (with the exception of Amelia "Mel" Evelyn Voicy Baggs, who passed away before publication and whose contribution was submitted as is per hir signed agreement with AWN).

COMMITMENT TO DISABILITY JUSTICE

AWN's work is informed and guided by Disability Justice principles. As such, all work is done honoring the wholeness of disabled people and our human limitations. As stated by Sins Invalid, one such disability justice principle is "Sustainability: We pace ourselves, individually and collectively, to be sustained long term. Our embodied experiences guide us toward ongoing justice and liberation." sinsinvalid.org/blog/10-principles-of-disability-justice

AWN commits to do everything in its power to operate according to these principles while acknowledging that there may be times when the demands of the non-profit industry and related factors may cause challenges with honoring disability justice principles and sustainability. Navigating any possible challenges entails flexibility and open, honest communication that recognizes our own limitations and a shared dedication to the long-term sustainability of the cross-disability and neurodiversity movement.

Autistic Women & Nonbinary Network (AWN)
Neurodiversity is for Everyone

This author contribution statement has been prepared and submitted to the University of East Anglia *in December 2021* on behalf of PhD candidate/postgraduate researcher, Mx. Morénike Giwa Onaiwu.

By signing below, I/we confirm the accuracy of these contributions to the AWN publication entitled *Sincerely, Your Autistic Child* described in this statement.

Sharon daVanport, *Sincerely, Your Autistic Child* Editor and AWN Executive Director
Emily Paige Ballou, *Sincerely, Your Autistic Child* Senior Editor
Morénike Giwa Onaiwu, *Sincerely, Your Autistic Child* Editor

Signature: Emily Paige Ballou
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Sharon daVanport (Dec 4, 2021 12:28 CST)
Email: sharon@awnnetwork.org

Signature: Morénike Giwa Onaiwu
Morénike Giwa Onaiwu (Dec 4, 2021 11:05 CST)
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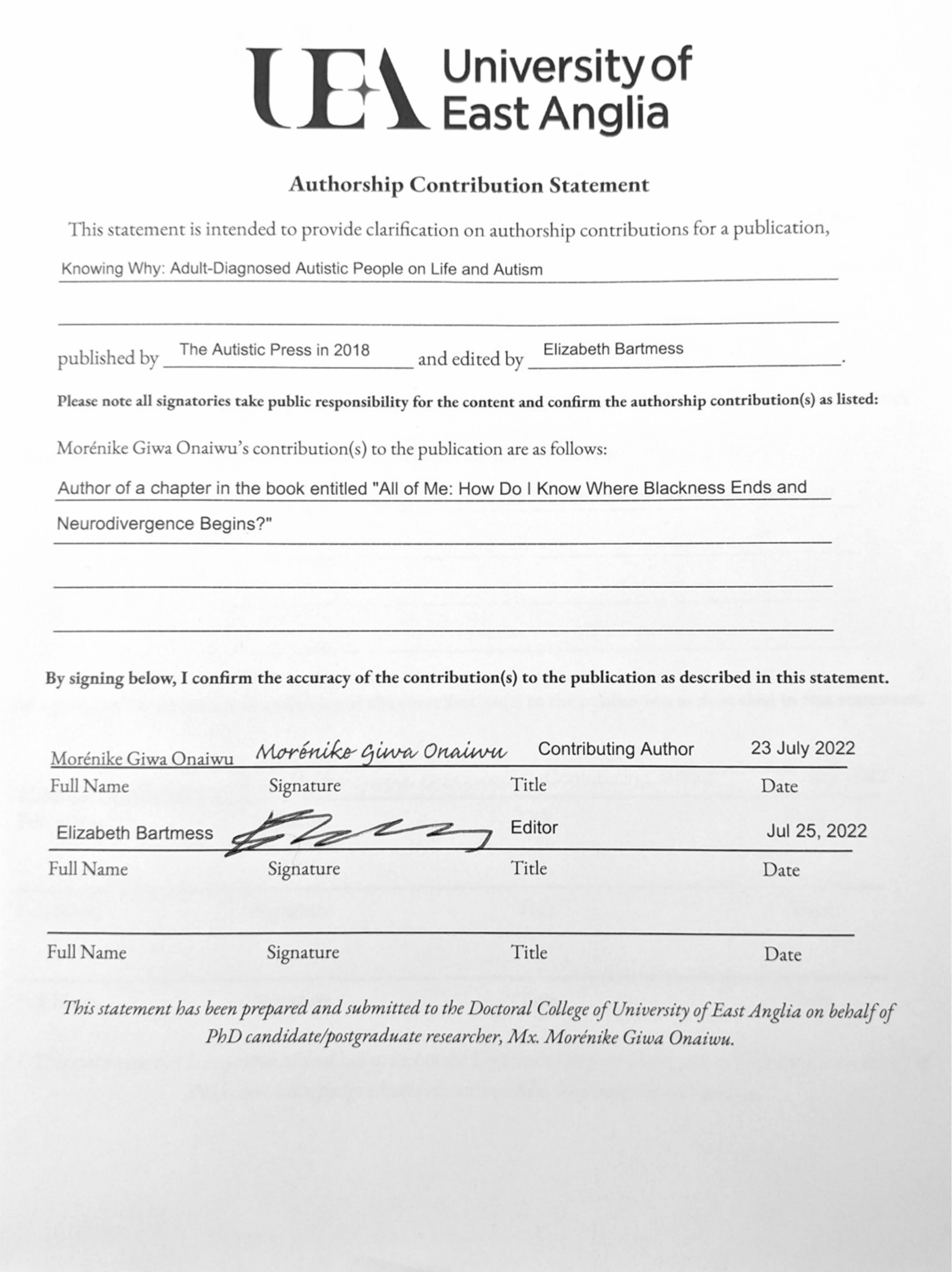

University of East Anglia

Authorship Contribution Statement

This statement is intended to provide clarification on authorship contributions for a publication,

Knowing Why: Adult-Diagnosed Autistic People on Life and Autism

published by The Autistic Press in 2018 and edited by Elizabeth Bartmess.

Please note all signatories take public responsibility for the content and confirm the authorship contribution(s) as listed:

Morénike Giwa Onaiwu's contribution(s) to the publication are as follows:

Author of a chapter in the book entitled "All of Me: How Do I Know Where Blackness Ends and Neurodivergence Begins?"

By signing below, I confirm the accuracy of the contribution(s) to the publication as described in this statement.

Morénike Giwa Onaiwu	Morénike Giwa Onaiwu	Contributing Author	23 July 2022
Full Name	Signature	Title	Date
Elizabeth Bartmess		Editor	Jul 25, 2022
Full Name	Signature	Title	Date
Full Name	Signature	Title	Date

This statement has been prepared and submitted to the Doctoral College of University of East Anglia on behalf of PhD candidate/postgraduate researcher, Mx. Morénike Giwa Onaiwu.

A user of the U.S. Copyright Office's Copyright Public Records System (CPRS) shared these record(s) with you:

Registration record TX0009077102
Sincerely, Your Autistic Child.

Copyright Data

Registration Number / Date:

TX0009077102 / 2021-04-28

Type of Work:
Text

Title

Title:

Sincerely, Your Autistic Child.

Application Title:
Sincerely, Your Autistic Child.

Date

Date of Creation:

2021

Date of Publication:
2021-03-30

Concerned Parties

Copyright Claimant:

Autistic Women & Nonbinary Network. Address: 5100 Van Dorn Street, Suite 6633, Lincoln, NE, 68506.

Authorship on Application:
Autistic Women & Nonbinary Network, Domicile: United States. employer for hire; Authorship: Compilation.

Claim Description

Basis of Claim:

text, Compilation.

Rights and Permissions:
Beacon Press, 24 Farnsworth Street, Boston, MA, 02210-1409

Pre-existing Material:
text, artwork.

Standard Identifiers

ISBN:
9780807025680

Description

Description:
Book, 208 p.

Notes

Nation of First Publication:
United States

Names

Names:
Autistic Women & Nonbinary Network

A user of the U.S. Copyright Office's Copyright Public Records System (CPRS) shared these record(s) with you:

Registration record TXU002225126

Sincerely, Your Autistic Child: What People on the Autism Spectrum Wish Their Parents Knew About Growing Up, Acceptance, and Identity.

Copyright Data

Registration Number / Date:
TXU002225126 / 2020-10-20

Type of Work:
Text

Title

Title:
Sincerely, Your Autistic Child: What People on the Autism Spectrum Wish Their Parents Knew About Growing Up, Acceptance, and Identity.

Application Title:
Sincerely, Your Autistic Child: What People on the Autism Spectrum Wish Their Parents Knew About Growing Up, Acceptance, and Identity.

Date

Date of Creation:
2020

Concerned Parties

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Sharon daVamport. Address: 6100 Van Dorn St. #6633, Lincoln, NE, 68506, United States.
Autistic Women & Nonbinary Network, Transfer: By written agreement. Address: 6100 Van Dorn St. #6633, Lincoln, NE, 68506, United States.

Authorship on Application:
Emily Paige Ballou, 1982- ; Citizenship: United States. Authorship: text, Co-edited anthology.
Morenike Sheri Giwa; Domicile: United States; Citizenship: United States. Authorship: text, Co-edited anthology.

Sharon daVanport; Domicile: United States; Citizenship: United States. Authorship: text, Co-edited anthology.

Claim Description

Rights and Permissions:
Morenike Giwa Onaiwu, mgo@morenikego.com

Description

Description:
Electronic file (eService)

Notes

Copyright Note:
Basis for Registration: Collective work.

Names

Names:
Ballou, Emily Paige, 1982-
Giwa, Morenike Sheri
daVanport, Sharon
daVamport, Sharon
Autistic Women & Nonbinary Network

Author Contribution Statement: AIDS Clinical Trials Group (ACTG) Newsletter

This statement is intended to provide clarification on authorship contributions for select articles that have been previously published in the AIDS Clinical Trials Group (ACTG) Newsletter.

About the ACTG

Established in 1987, the ACTG is the world's largest and longest running HIV clinical trials network. Its mission is to cure HIV and reduce the burden of disease due to HIV and its complications, including tuberculosis and viral hepatitis. ACTG clinical trial units in 12 countries serve as major resources for HIV/AIDS research and training/education in their communities. ACTG studies have had a profound impact on the well-being of people living with HIV worldwide, helping to establish current paradigms for treating HIV and contributing to dramatic decreases in HIV-related mortality worldwide.

Coordinated by ACTG Communications personnel within the Leadership and Operations Center, the monthly *ACTG Newsletter* provides an international group of subscribers with important network announcements, articles about studies, programs, and issues of interest, and upcoming meetings, webinars, and events. In 2016, 2017, 2019, and 2021, Moréniké Giwa Onaiwu (MGO) and Co-Chair were guest contributors on several articles in the *ACTG Newsletter*. Current and select archived issues of the *ACTG Newsletter* can be viewed on the ACTG website:

https://actgnetwork.org/actg-newsletters/

Please note that all authors take public responsibility for its content and confirm our respective contributions as listed:

MGO: **Primary/lead author** of select aforementioned co-authored articles in the *ACTG Newsletter*.

Lionel Hillard: **Co-author** of an aforementioned co-authored article in the *ACTG Newsletter*.

MGO: **Sole author** of select aforementioned articles in the *ACTG Newsletter*.

All authors, editors, contributors, and designated executive leadership of the AIDS Clinical Trials Group reviewed and discussed the results and approved the final versions of the *ACTG Newsletter* articles that were submitted and published.

ACTG
AIDS CLINICAL TRIALS GROUP

By signing below, I am confirming the accuracy of these contributions to the ACTG publication *ACTG Newsletter* that are described in this statement.

Morénike Giwa Onaiwu — Dec 3, 2021
Morénike Giwa Onaiwu (MGO)'s Signature — Date

Lionel M . HILLARD — Dec 3, 2021
Lionel Hillard's Signature — Date

Aisha Patel
Aisha Patel (Dec 3, 2021 13:45 EST) — Dec 3, 2021
ACTG Authorized Signature — Date

This statement has been prepared and submitted to the Doctoral College of University of East Anglia on behalf of PhD candidate/postgraduate researcher, Mx. Morénike Giwa Onaiwu.

Signature: Morénike Giwa Onaiwu
Morénike Giwa Onaiwu (Dec 3, 2021 12:56 CST)
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Signature:
Lionel Hillard (Dec 3, 2021 15:10 CST)
Email: hillardlionel@gmail.com

Page 2 of 2

University of East Anglia

Authorship Contribution Statement

This statement is intended to provide clarification on authorship contributions for a publication,

The Real Experts: Readings for Parents of Autistic Children

published by Autonomous Press and edited by Michelle Swan (formerly Michelle Sutton).

Please note all signatories take public responsibility for the content and confirm the authorship contribution(s) as listed:

Morénike Giwa Onaiwu's contribution(s) to the publication are as follows:

Author of a chapter in the book entitled "Why I Don't Like All of Those 'Get Off Social Media and Into the Real World' Posts"

By signing below, I confirm the accuracy of the contribution(s) to the publication as described in this statement.

Morénike Giwa Onaiwu	Morénike Giwa Onaiwu	Contributing Author	23 July 2022
Full Name	Signature	Title	Date
Michelle Swan		Editor	26 July 2022
Full Name	Signature	Title	Date
Full Name	Signature	Title	Date

This statement has been prepared and submitted to the Doctoral College of University of East Anglia on behalf of PhD candidate/postgraduate researcher, Mx. Morénike Giwa Onaiwu.

University of East Anglia

Authorship Contribution Statement

This statement is intended to provide clarification on authorship contributions for a publication,

From Hurt to Hope: Stories of Mental Health, Mental Illness, and Being Autistic

published by Jessica Kingsley Publishing in 2021 and edited by Mair Elliott.

Please note all signatories take public responsibility for the content and confirm the authorship contribution(s) as listed:

Morénike Giwa Onaiwu's contribution(s) to the publication are as follows:

Author of a chapter in the book entitled "I Don't Really Wanna Fight No More"

By signing below, I confirm the accuracy of the contribution(s) to the publication as described in this statement.

Morénike Giwa Onaiwu	Morénike Giwa Onaiwu	Contributing Author	23 July 2022
Full Name	Signature	Title	Date
Mair Elliott	Mair Elliott		2022/07/27
Full Name	Signature	Title	Date
Full Name	Signature	Title	Date

This statement has been prepared and submitted to the Doctoral College of University of East Anglia on behalf of PhD candidate/postgraduate researcher, Mx. Morénike Giwa Onaiwu.

University of East Anglia

Authorship Contribution Statement

This statement is intended to provide clarification on authorship contributions for a publication,

For the Love of Autism: Stories of Love, Awareness, and Acceptance on the Spectrum,

an edited collection published in 2022.

published by Fig Factor Media and edited by Tamika Lecheé Morales.

Please note all signatories take public responsibility for the content and confirm the authorship contribution(s) as listed:

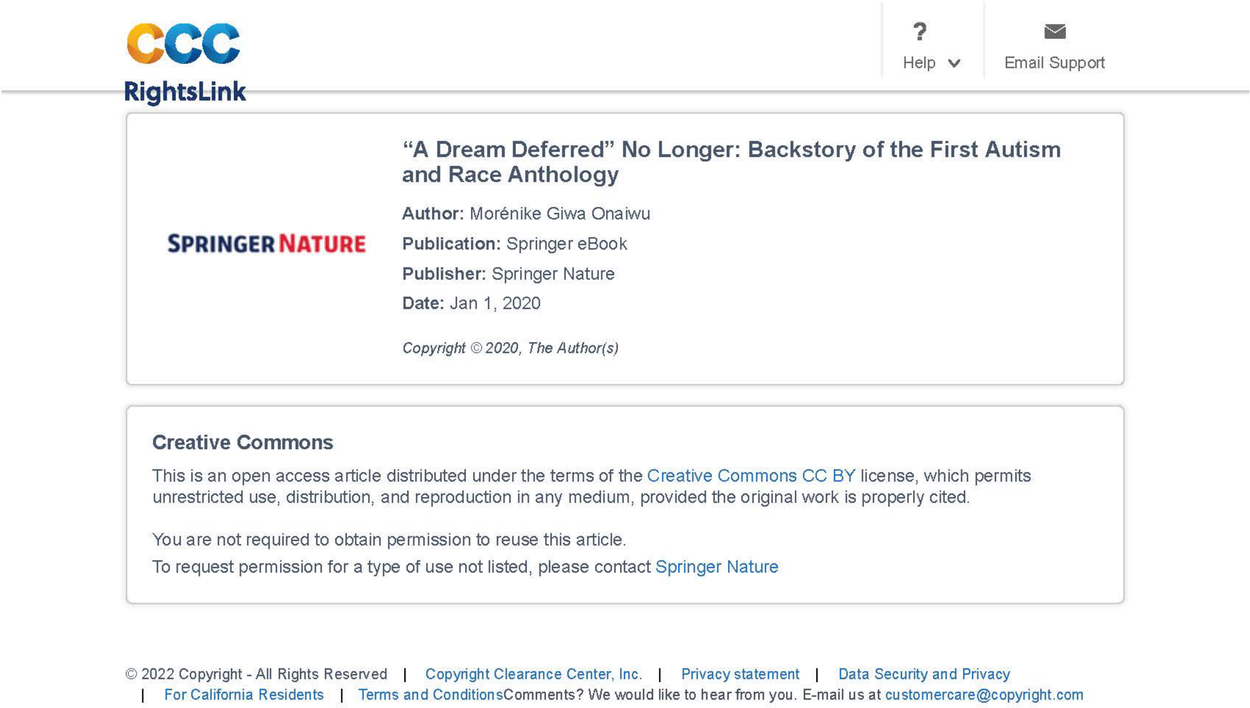
Morénike Giwa Onaiwu's contribution(s) to the publication are as follows:

Authorship of a chapter entitled "Am I Mom Enough? Contending with the Voices in My Head."

By signing below, I confirm the accuracy of the contribution(s) to the publication as described in this statement.

Morénike Giwa Onaiwu	Morénike Giwa Onaiwu	Author	15 June 2022
Full Name	**Signature**	**Title**	**Date**
Gabriela Hernandez		FFM Publisher Rep.	July 25, 2022
Full Name	**Signature**	**Title**	**Date**
Full Name	**Signature**	**Title**	**Date**

This statement has been prepared and submitted to the Doctoral College of University of East Anglia on behalf of PhD candidate/postgraduate researcher, Mx. Morénike Giwa Onaiwu.



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

Author: Morénike Giwa Onaiwu
Publication: Springer eBook
Publisher: Springer Nature
Date: Jan 1, 2020

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SOURCES CONSULTED

Per institutional requirements, I have provided a listing of Works that are cited throughout the thesis. However, in deference to my own limitations, in the appendices I did not incorporate citations as thoroughly as would ordinarily be my preference. In addition to that, word count limits prevented me from sharing a comprehensive list of the works that helped me to develop this thesis. There are many sources that I might not have explicitly cited which I still reviewed in order to help inform this work, and I believe it is imperative for me to give attribution to those whose thoughts, ideas, etc. benefitted me. I would feel dishonest otherwise.

As such, I encourage you to visit the URL provided on this page. At that link, I have an up-to-date, comprehensive list of resources, including “gray” and/or other nontraditional sources. You’ll find peer reviewed articles. You’ll find personal blogs. You’ll find books, websites, and all kinds of stuff. If I learned something from you and it’s addressed in this thesis, you are recognized here, even if you were not formally cited.

Please accept my sincere appreciation and gratitude for helping me grow…THANK YOU!

Feel free to review the sources/references consulted associated with the link below:

Link to Comprehensive Works Consulted List for Bringing Fire to the People doctoral thesis:

https://docs.google.com/document/d/1AI1Sn2PjYROeUDs0eSKA5JhbYX1UnF4UEILDNJEvhrM/edit?usp=sharing

The following page (page 258) concludes Mx. Morénike Sheri Giwa Onaiwu’s 2022 University of East Anglia doctoral thesis, *Bringing Fire To the People: Activist Scholarship, Creative Collaboration, & International Advocacy Through the Lens of Black Disability Studies*.


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