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Radical (re)naming through a tapestry of autoethographic voices: Finding healing through dis/ability theorizing

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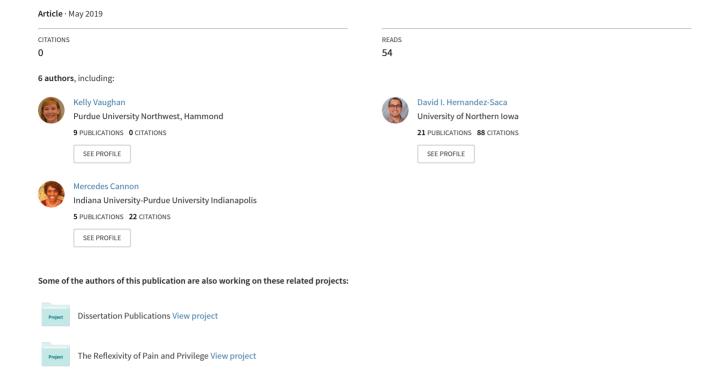
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RADICAL (RE)NAMING THROUGH A TAPESTRY OF AUTOETHNOGRAPHIC VOICES:

FINDING HEALING THROUGH DIS/ABILITY THEORIZING

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"I came to theory because I was hurting" and theory became "a location for healing."

– bell hooks, 1994, p. 5

Introduction

In the Fall of 2016 at the 37th Annual Bergamo Conference on Curriculum Theory and Classroom Practice, the authors of this article participated in an All-Conference Panel Discussion, entitled *Collective Autoethnography and Ableism*. In this article, which emerged from our conference presentation, we engaged in a multi-layered conversation. Initially, the first five authors of this article started a conversation with each other. We crafted individual responses to questions about our relationship to dis/ability[1], our theorizing through various models of dis/ability, and our reflections about how narratives of dis/ability can inform curriculum and education. We read and responded to each other's writings, which enriched our thinking and presentation. Second, we were in conversation with Ann Winfield, a Curriculum Studies scholar and historian, who publicly responded to our work in such a way that she also provided her own experiences and theorizing in relationship to our research question. Our conversations continued as we reflected on our presentation

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[1] By "dis" dash "ability" (i.e., dis/ability) we foreground the psycho-emotional and relational "disability" model as opposed to the medical model. From a Disability Studies in Education (DSE) approach, dis/ability is socially and culturally constructed at the political, social, economic, and emotional levels within local contexts.

and then wove our reflections together to illustrate that there is no single experience of dis/ability; however, there are themes about dis/ability and resistance to disableism that can be gleaned from hearing a multiplicity of voices within a context of intersectionality.

As scholars influenced by Curriculum Studies (CS), Disability Studies (DS), and Disability Studies in Education (DSE), we were engaged, in every step of our writing process, in a multidisciplinary conversation. Within this conversation, we understood that while individuals have psychological and biological differences that often have material consequences, ideas about dis/ability are socially constructed (see Erevelles, 2011; Waitoller & Thorius, 2016). We know that how we understand dis/ability, the stories we tell about dis/ability, and the language we use to express those understandings all contribute to the construction of meaning relative to dis/ability. We present our own experiences grappling with dis/ability and education as a way to challenge invisible assumptions of disableism[2]. As noted, we firmly ground this autoethnographic study in conceptualizing disability oppression as involving social impositions that are not only structural and material but also discursive, emotional, and psychological.

Because our experiences have been profoundly impacted by the hegemonic forces of disableism, our theorizing of dis/ability has become a means for seeking healing through theory rather than the "healing" and "therapies" typically offered to those labeled disabled (see hooks, 1994). As scholars, we bring our varied life experiences, our positionalities in relationship to disability (including disability onset and type of disability), our identification with disability (including some who claim disability as part of our academic identity and/or some labeled by special education in K-12 or higher education), and our intersectionalities to this work. Who we were, are, and are becoming situates each of us in different relationships to healing. In other words, our healing is individual; however, we find value in understanding collective aspects of our experiences.

We frame our work as a collaborative auto-ethnography (Chang, H., Ngunjiri, F. W., & Hernandez, K. C., 2012) in which our positionalities and autobiographies interweave to create a richer and more complex tapestry portraying not only what it means to live with labels but how we might work towards more inclusive theories,

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[2] Although we used the term "ableism" for our conference presentation title, we purposefully choose to use the term "disableism" in our paper to align ourselves with the psycho-emotional disablism model of disability (Thomas, 1999).

practices, and societies. Rather than offering a single conclusion, we seek to use our experiences to "think with disability" (Erevelles, 2014) and to invite our readers to do the same.

Research Methods and Methodology

We are cognizant of the collective power of our collaborative auto-ethnography (Chang, Ngunjiri, & Hernandez, 2012) as a way to speak back to dominant narratives about dis/ability at the boundaries between not only Disability Studies in Education (DSE) and special education, but also Curriculum Studies (CS). In particular, we foreground the following core principles of autoethnography in both the research process and in our individual and collective writing: 1) the personal is sociocultural and political (Burdell & Swadener, 1999), in other words, self-reflection and examination are a species of broader social realities; 2) in turn, these social realities are particular narratives that persist and are often institutionalized. In our cases, we turned to autoethnography as both a theoretical and methodological framework to critically and carefully self-examine our experiences with dis/ability and disableism. In our self-examination, we engaged 3) in radical (re)naming through our individual and collective study to create new narratives about dis/ability at our positionalities and intersections. We understood our 4) autoethnographic writing as "privileging concrete action, emotion, embodiment, self-consciousness and introspection" as the autoethnographic tradition entails (Ellis, 2004, p. xix, as cited in Douglas & Carless, 2013, p. 85). In so doing, we were able to tell our narratives and let them go, literally and metaphorically, deeply knowing that our 5) tellings of them are "partial, situated and incomplete" in the autoethnographic process of further knowing and discovering who we are (Douglas & Carless, 2013, p. 85). Given our positionalities and autobiographies at the intersections of dis/ability, race, ethnicity, and disableism, we entered into a purposeful self-examination to contribute to the literature base and our disciplines. This desire to contribute is an additional tenet of autoethnography: that is, that 6) one's writing is in "purposeful relation to an audience" (Jones, Adams, & Ellis, 2013). This last tenet informs the first five in foregrounding our purposes for engaging in our collective autoethnography about disableism: we seek to enter into autoethnographic interdisciplinary work and disciplinary expansion and to bring ourselves and dis/ability out of the basement through the process of getting to know ourselves.

According to Allen (2015), autoethnography can facilitate the process of becoming more fully human when he states: "a human being has so many skins inside,

covering the depth of the heart. We know many things and through careful self-examination, we are able to know ourselves" (p. 35). Here, we mean that through careful exploration of how our experiences with dis/ability and disableism have led us to theoretical insights we come to know ourselves more fully, we are able to lay bare our humanity collectively as a means to ground theory in the real world, extend theories on which we draw, and disrupt dominant narratives of dis/ability. In so doing, we each allowed the healing process to start and/or continue through our individual and collective theorizing (hooks, 1994). In other words, through our collective autoethnographic study, we engaged in the healing process, by radically naming and re-framing our disability oppression at our intersections, and in turn, contributed to our critical emotional self and societal praxis (Freire, 2005).

Collective Contemplations

Our Relationship with Dis/ability and Disability Studies

In writing this article, it was vital for us to share themes learned from our work collectively, while also highlighting the individual voice and experiences of each author. In this section, we highlight each author's relationship to dis/ability and to the fields of Curriculum Studies and Disability Studies.

Jamie Buffington-Adams, a teacher educator and Curriculum Studies scholar, reflected:

> *I do not often think of myself as someone who has a disability. I understand that I live with an atypical moderate binaural hearing loss, or as I explain to my six-year-old son, "Mama's ears don't work quite the way yours do." The medical model does not assist me in understanding my own experience so much as it has afforded me language and details to help describe my experience to others. When framed by the medical model (Gabel, 2005; Phillips, 2001; Shakespeare, 1996; Thomas, 1999), which insists on charting which frequencies I can hear at which decibel levels and the accuracy of both my language reception and (re)production, the scientific evidence of my hearing loss and the "need" for hearing aids is clear. However, the truth is, when left to my own devices, I rather like the way I experience the world. It is when life necessitates interaction with others that I find myself disabled.*

David I. Hernández-Saca, a Disability Studies in Education scholar and teacher educator, also described his relationship with his dis/ability by exploring the way the labeling in the medical model influenced his experience. He wrote:

> *Our self-expression and self-determination are keys to who we are and who we want to become. The system of special education has been, in retrospect, an integral part of my self-determination and human development, given my childhood experiences with disability. I had a high fever at the age of two while migrating to the United States with my oldest brother, sister and mother from El Salvador in 1984 due to the civil war. As a result of the fever, I experienced both physiological and psycho-emotional convulsions up until the 4th grade. Due to these disabling experiences, I was then placed in special education and eventually also diagnosed with an auditory Learning Disability (LD). As a child, I was aware of having the convulsions within schooling contexts. ... I was viscerally and spiritually aware, in retrospect, of the effects of being in special education and being labeled with LD. The consequences included self-doubt, hypersensitivity about being bullied, which resulted in the stigma that I still experience ... LD and my experiences with special education have become conflated with ideas about who I am. … Deep down I seek healing from these past experiences and fortunately my professional life has provided a forum to not only provide myself with information and tools necessary to succeed in overcoming my LD and the effects of my childhood condition of convulsions but my psycho-emotional life as well. In turn, this has also provided a way that I can serve and be a model for others as I serve those within the system of special education as a teacher educator.*

Mercedes A. Cannon, a Disability Studies scholar, educator and administrator, discussed ways that she has cultivated a sustained identity through faith and academic work. She wrote:

> *I have a keen and experiential knowledge about what being [labeled] dis/abled means, which started in my early elementary education when I was labeled with a speech disorder. In turn, through pull-out programs, I experienced elementary education differently than my peers in general education … In the fall of 2013, I began to develop an academic critical consciousness as I began to read scholarly work from the field of Disability Studies (DS) and Disability Studies in Education (DSE). ... Since, the age of 32, I have found my voice and realized the role that my faith in the Lordship of Jesus Christ played. I*

> *began to understand who I was and what it means to intentionally pursue a sustained identity facilitated by the Christian faith. I conceptualize sustained identity as one that [positions each person to be] responsible to continually value and love God and her neighbors as herself. ... Thus, my purpose ... is to help people understand that dis/ability is something that many women of color (e.g., Black, Latina, and Native American) face and at multiple intersections of oppression.*

Sandra Vanderbilt, an educator and Curriculum Studies scholar, spoke against the silences within academia and community. She wrote:

> *I have known silencing imposed on my body by my disease and imposed on me from outside forces. My disease had a silencing impact in physical ways as I struggled with speech after a bout of issues with my central nervous system, but I also felt the emotional repercussions of potential silencing in my future. As I struggled through the potential inadequacies that might be perceived by others in the professional and academic world, I have experienced silencing knowing the way that a life-threatening chronic illness could impact the value colleagues and superiors could place on my work. This silencing happens even in the context of loving situations. My voice in long-term decision making with my extended family has been quieted as family members give responsibility to other members of my generation who are expected to live longer. My experiences with being silenced have invaluably aided the ways I move through the world and interact with others, the fervor I bring to work through which I try to contribute to dismantling the effects of silencing the voices of others. In response to the silencing I have known and others know, I suggest that we need to cultivate a dialogic. This dialogic must see the voices and experiences of those who have suffered through the ascriptions of disability as valuable so that we might engage in a space of invention that could result in new possibilities for a more equitable society.*

Ann Winfield, a curriculum historian who joined our project when she served as a discussant at our conference presentation, shared her own experience with a chronic illness, but also her experience as the mother of a child with an Attention Deficit Disorder label. She reflected:

> *I myself come to the subject via two paths: historical and personal. I understand that my historical work on eugenic ideology and its role in*

creating and maintaining a system of public education which serves to sort, hierarchicalize, and categorize students is deeply implicated in the issues that [Disability Studies] is concerned with. As a historian, I find I am relieved by the distance that focus allows me to maintain from the content of this work. I crave this distance, yet I engage in an internal debate over whether and how I am a participant in this conversation, just as these panelists have interrogated internalized questions of relevance, dominance, qualification, group membership, and definitions of aspiration within the context of societally mediated definitions of identity, merit, health and well-being. I find I cannot fully participate here without contending with and acknowledging publicly the places where I personally intersect, for to avoid this would be to fail to make the primary point I want to make, which I will put forward in the form of a question: Who is in need of healing?

... I have a son, who I have parented alone since 1995, and who was diagnosed with ADD in first grade, the year before I started as a part-time evening student in master of arts in teaching program of study at North Carolina State, (where I eventually was awarded a Ph.D. in 2004.) So it is the case that alongside my intellectual and academic journey to this place, I grew and learned as a mother, as a navigator charting a course through the shoals of the education system. I recognize my privilege as someone who was in part able to achieve a level of understanding and a consequent path of excavation of my own internalized narrative of success and ability: when my son was entering high school, I had just completed my first year as an assistant professor of education. In other words, I was a terrible mother for a long time, wanting from my son an image that didn't fit him, realizing even now that I am not done excavating.

... I intersect in another way with the deeper implications of this piece in that I carry a diagnosis of a chronic disease: Rheumatoid Arthritis. Never having publicly acknowledged this, I realize that it is largely through my experience internally that I am able to understand others' experience of the intersections of dis/Ability. Denial, shame, the internalization of the dominant medical model of vigor and strength have all rendered me silent, wanting to dismiss my group membership. I struggle to walk on a daily basis, and yet feel unwilling to disclose, to succumb—and then I realize I am using the very language that suppresses.

Kelly Vaughan, a Curriculum Studies scholar and teacher educator, also reflected on her experience as a mother of a child with a dis/ability. She noted:

> *My theorizing of dis/ability began with my desire to understand my experience and the experience of my family within a broader context of dis/ability, schooling, and justice. While enrolled in a doctoral program in Curriculum Studies, my 3-year-old child walked into my room and began to speak to me when, in midsentence, he fell to the floor and had his first seizure. We were rushed to a hospital only to be released a few hours later and told to follow up with a neurologist. Following more seizures, we were back at the hospital the next day. We left with a diagnosis, new medicine, and the understanding that after he went two years without a seizure, we would stop giving and life would return to "normal."*
>
> *During those first few months, we regularly reset that two-year countdown date, the date on which two years from that moment we would be done with our experience with epilepsy. It took us close to a year and dozens of re-sets to begin to accept our new "normal" as a family. This experience prompted me to problematize ableist notions of normalcy in schools and society. ... As both a parent and an educator, I turn to [Disability Studies] to understand and act upon ableist systems that can disable my child and other children labeled with disabilities.*

We share our own experiences with dis/ability because we believe that such experiences inform our theorizing. Vanderbilt, referencing the work of Michelle Fine and Greg Dimitriadis (2012), utilized the idea "that we 'work the hyphens' of our multiple identities" (p. 64). She reflected that she enters the work with a *particular embodied experience and it informs the way [she] approach[es her] research, the way [she] interact[s] with others, and [her] interpretations of various data sources*. For many of us, Disability Studies has provided a framework to understand how ideas about dis/ability were socially constructed. For example, Cannon recounted that it was not until she was middle-aged that she developed:

> *… a language to discuss the emptiness that I felt. I had no idea how intersecting oppressions could affect my identity formation. Although I knew there was racism and white supremacy, my knowledge of it was vague and ill-informed. Although I knew there was a thing called sex and violence, especially violence committed against women by men, I had no way to explain*

> *the effects of the ways I viewed myself due to experiencing these oppressions (see Gold & Richards, 2012). And, although I knew there were people with disabilities, I had no idea how to think about or understand my childhood experiences of being pulled out to classes to work with a pathologist. Together at these intersections of all these human experiences I had no idea how to understand the social constructs that were related to each, nor how they impacted my collective identity.*

Hernández-Saca shared that before his work in Disability Studies in Education (DSE), he did not understand *how [his] special education category disability label [intersected] with [his] other multiple identities.* In this way, DSE provided language to help make sense of what Hernández-Saca discussed *as the ways that my labeled dis/ability influenced how [he] viewed [him]self* .Vanderbilt explained the power of DS as a tool *to theorize [her own] experiences with an atypical, devalued body.*

We share our experiences with dis/ability because we hope that sharing our experiences will encourage scholars from the field of Curriculum Studies, a field that has often ignored the perspective of dis/ability, to embrace Disability Studies theorizing about curriculum.

Cross-Disciplinary Analysis and Our Relationship to Disability Studies

Each of us draws from both Curriculum Studies and Disability Studies, which influence our work in teacher education, special education, curriculum history, and various approaches to qualitative inquiry. Vaughan explained that even while studying curriculum history in a social justice-oriented Curriculum Studies program, she rarely read about dis/ability or disability justice. Yet, her experience mothering a child with a dis/ability while studying about the early progressive movement illuminated connections between curriculum history and dis/ability. She wrote:

> *…when completing my dissertation study on the relationship between progressivism and accommodationism in the American South, it was also clear to me that I was also learning about the problematic relationship between "progressive" reforms and special education. When writing about the impact of eugenics ideation, the prevalence of social behaviorism in education practices, and the normalization of white, middle class, typically developing children on students of color, it was also clear that such policies contributed to*

> *inequitable and often dehumanizing policies for many students, including those marked as "other" because of class and/or dis/ability.*

Ann Winfield also explained that her understanding of history, and of the blended nature of eugenic and education policies was one of her entries into thinking about dis/ability. Buffington-Adams and Vanderbilt both noted that a focus on language and literacy impacted their understandings of dis/ability. Buffington-Adams wrote that:

> *…much of the way I frame my own experience with disability stems from my work in language and literacy, an interest which eventually led me to thinking deeply about issues of discourse first through exposure to Gee's (2008) work and later through the lens of post-structuralism. Like Gee's (2008) work in discourses, poststructuralism rejects the notion that language is a transparent medium which we use to merely reflect our reality: "[R]eality is not reflected by language but produced by it" (Eagleton, 1983, p. 108 cited in Pinar, et. al., 2004, p. 458). Contrary to what many might believe, language is not an idle, neutral tool used to merely describe reality but rather it must be understood both as contextualized within specific historical and social realities and simultaneously as a generative force behind those realities. Consequently, because discourse constructs reality, knowledge can no longer be understood as an objective body of facts which represent reality. Rather, knowledge is subsumed under discourse. This new understanding of knowledge is crucial because it shifts the focus from who has knowledge or power to how and under what circumstances specific discourses shape reality and either empower or marginalize individuals in the process (Foucault, 1977/1995; Foucault, 1984; Pinar, et al., 2004). And when we link our use of language to questions of power, the terms we use to talk about disability become deeply troubling.*

Drawing from her previous work, Buffington-Adams (2012) discussed how her understanding of language influenced her understanding of dis/ability:

> *In the case of dis/ability, we are linguistically poorly equipped. Linguistically speaking, the very terms disability and disabled necessitate positively construed opposites (Smith, 2006). These able/disabled and ability/disability polarities expose the ways in which notions of disability are socially constructed and rely upon a singular, positivist normalcy against which*

individuals are measured, allowing for the other-ing and subsequent devaluing of those who negate the norm (Linton, 1998; Gallagher, 2006). In failing to subsist as an approximate match to society's conception of normalcy, one is said to deviate from the norm. If one deviates from the norm then it is no linguistic leap to branding one a deviant, and inclusion among humanity and access to the full experience of being human starts to slip from one's grasp (Becker, 1963). It begins with the forced passivity of being disabled, in which one becomes the direct object rather than the agent of action, and continues through the discussion of one's abnormalities until one is inevitably placed away from the rest of society, on the margins of the human experience. Language is both a powerful and dangerous thing (Buffington, 2012, p. 2).

Cannon's work asks readers to understand and oppose how negative stereotypes, prejudices, and discriminations affect people with disabilities. She wrote that:

…different frameworks (i.e., Collins, 2000; Dillard; 2012; Dudley-Marling & Gurn, 2010; Eiesland, 1994; Morton, 1991), which include other factors that contribute to one's identity formation, have assisted in my realization of knowing what "I am supposed to be doing with my life—connecting to my God consciousness"... The empowerment to believe in God and "live safely in the Spirit's leading", as I support Black women with dis/abilities who are seeking a critical consciousness, serves to critique spiritual, personal, social, and intellectual ways of knowing, which is humbling. As I learn and grow, I will engage in collaborating processes with other women' coming to their critical consciousness, and inspire others to find a way in everyday life that perseveres in the face of oppressive forces. "I will tell about my God consciousness, a supernatural force moving in my life and in the context of my education to help provide a counter-narrative to the ridiculous marginalization and (mis)representation of African American women and women of color in the education literature" (Cannon & Morton, 2015, p. 149, 154).

Contending with and Contesting Disableism

We recognize that our narratives, while personal, also take place within larger ableist systems and within a particular historical moment. In contemplating how we understand dis/ability, it is essential to understand that historically dis/ability was understood through a deficit lens. We argue that the failure of education scholars to

both address the history of disability oppression in our schools and to include theories of disability in understanding school contexts have created a setting in which children (and adults) with disabilities are left with deficit notions of their disabilities.

As Ann Winfield's work has demonstrated, U.S. society's answer to dis/ability and difference has been an ideology that was represented in the 20ᵗʰ century by the eugenics movement, a campaign to address dis/ability by eliminating it. Winfield explains that practices of pathologization, followed by separation and institutionalization, also overlapped with this movement and extended late into the 20th century. Following the passage of mandatory sterilization programs in the majority of states, movement leaders then turned to education as the second policy push (immigration restriction and anti-miscegenation were others) of the eugenics movement. Within this system, schools created, as Popenoe and Johnson (authors of the widely used 1918 college textbook *Applied Eugenics*) described, the "very desirable [condition that] no child escape inspection" (p. 371; also cited in Winfield, 2007, p. 103). Winfield reminds us that while eugenic ideology is no longer accepted by mainstream academics, educators, or medical practitioners the:

> *…construct of biological determinism at the core of eugenic ideology remains within the neo-liberal policy agenda, which casts standards and accountability within an ablest and racist epistemology.*

Vaughan has also commented on standardization and accountability movements:

> *…with reforms that increase standardization of the curriculum, decrease teacher autonomy, and increase "accountability" (although only in the direction from the top down), schools are transformed from public goods to private services on a marketplace. Within a neoliberal system of choice and "accountability," Baker (2002) argues that "[t]he identification of and hunt for disability has been tied, for instance, to a discourse that privileges international comparison of test scores as signs of quality citizenship and economic prosperity" (p.679). Within this marketplace, data-driven interventions are needed—children are tested, labeled, sorted, and prescribed interventions. This is not to say that support services are not needed. It is to say that systems of sorting and labeling can create systems that pathologize and, as Baker (2002) describes it, "re-inven[t] eugenics discourse in a new language that maintains an 'ableist normativity'" (p. 665).*

Buffington-Adams also discussed the ways that schools do not fully embrace inclusion and in practice exclude many children. She explained:

> *we are living in an era characterized by a brand of patronizing accommodation and condescending or half-hearted inclusion. The passing and implementation of the Individuals with Disabilities Education Act (IDEA) in 1975 and the inclusion of individuals with disabilities in public schools were supposed to be landmark victories for those who are disabled. However, the spirit in which inclusion has been enacted has fallen far short of inclusionary ideals with children being housed in the same buildings and classrooms but teachers still divvying students up along abled/disabled lines and arguing whose kids are whose, leaving one to wonder: is the move for inclusion merely an attempt to make normal or to ameliorate those who have been identified, labeled, and disabled?*

Many of the authors of our study talked about the power of alternative theories of disabilities in understanding their own experiences. Hernández-Saca explained that theory helped him to negate *the myths and half-truths that negative ideologies about being labeled with LD, being associated with a disability, and special education come to influence my mental and physical body and spirit.* Cannon explained:

> *…the work of DS studies scholars such as Dudley-Marling and Alex Gurn's work Myth of the Normal Curve helped me to understand some of my struggles. Their work critiques the normal curve and its enduring and damaging myths in American education, disputing the ideology of taking for granted human behaviors and distributing them along the lines of the bell-shaped normal curve to argue normal as superior and dis/ability as inferior (Dudley-Marling, & Gurn, 2010). Subsequently, the social construction of normal and abnormal labels have negatively affected many individuals with dis/ability labels, myself included (Gold & Richards, 2012), and a couple of outcomes are the 'feelings of inferiority' and 'needing fixing.'*

Thinking Through Models of Dis/ability

As we explored ways of understanding our own experiences with and our theorizing about dis/ability, we individually reflected on how traditional dis/ability models including the medical, social, and social relational models (Thomas, 1999;

Goodley, 2011) supported and constrained our understanding of dis/ability as it relates to one's other multidimensional identities.

Historically, within the Disability Studies (DS) literature, the medical and social models of disability have been compared and contrasted (Shakespeare, 2013). According to Goodley (2011), the dominant medical model of dis/ability focuses on the impairment or difference of individuals; characterizes people with dis/abilities as "objects rather than as authors of their own lives"; and focuses upon treatments/ interventions that attempt to "fix" the person (p. 8). This model can be found in many of our schooling practices that seek to "diagnose" and "treat" students with dis/abilities in order to help them become more like their peers without dis/abilities (see Valle, 2009). Within "special education," this model can be seen in attempts to normalize or fix the child (see Hunt, Zajicek, Norris, & Hamilton, 2000). Beginning in the 1980s, the social model of education became a powerful alternative to the medical or deficit model. The social model, popularized by scholars such as Mike Oliver (1998), disentangled an individual's impairment from socially constructed policies or structures that created barriers for full inclusion or participation.

Many of the authors of this study reflect upon the value of the social model in their own process of theorizing and healing. Buffington-Adams reflected that the social model was helpful in her early theorizing about dis/ability. She wrote:

> *Like many individuals with disabilities, I stumbled upon the world of Disability Studies (DS) and initially found solace in the social model of disability which provided me the language to discuss how being disabled was not limited to the physical impairment I experienced and reassured me that others shared my experiences and perspectives.*

Hernández-Saca also reflected on the social model. He wrote:

> *...I have obtained some relief in the social model of disability given that it takes the medical gaze and lens away from me and places it onto society. For example, critical questions from the social model of disability would have us ask: how has society constructed historical and contemporary cultural and social arrangements and meanings to being "LD" as opposed to purely focusing on what is wrong with me. Gaining theoretical distance from my historical-material and psycho-emotional experiences of ableism, hence violence, has provided me with distance from the negative messages that the*

medical-psychological model of disability would have me believe about myself: "I am broken," "You will go to prison if you don't do your homework and succeed in school," "All LD students, including yourself are lost causes," "Since you experience negative emotionality, you are LD," "Being labeled in the past with LD, means this is a condition you can't get away from and it has complete power over you," "You are a failure due to being associated with LD," and the list goes on and on. As I write these down, I know they are not true and do not define who I was as a student within K-16 and beyond, nor who I am now as an assistant professor of special education. The social model of disability, therefore, helped me move forward towards my healing when I first encountered it. But why do I still feel this weight and deep sadness about being labeled with LD and being in special education?

Yet, many of the authors of this study, like many within the broader field of Disability Studies, also see the need to complicate the representation of disability. Buffington-Adams, for example, explains that the social model acted a *springboard I needed to engage the construct of disability critically, but it does not reflect my current understanding of either the construct or the phenomenon.* For Buffington-Adams, the social model *ignored the physical realities I experienced as both someone with a hearing impairment and a special education teacher (Thomas, 1999; Shakespeare, 1996).* As such, Buffington-Adams's understanding of dis/ability is most aligned with Thomas' (1999) social relational model. Thomas (1999) advocated for a:

> social relational understanding of disability so that it encompasses not only social processes and practices which prevent people with disabilities from 'doing' things (for example, getting paid employment, succeeding in education, accessing suitable housing), but also those disablist social processes and practices which damage our quality of 'being', that is, what I refer to as our *psycho-social* wellbeing (p. 3).

In describing her own experiences, Buffington-Adams wrote:

> *In short, Thomas (1999) asks us to delineate between our actual physical limitations, what she terms impairment effects, and those barriers which are erected by social expectations or interactions instead. For example, my inability to hear thunder is an impairment effect; low frequencies must reach high decibel levels before I register them. On the other hand, individuals who refuse to repeat themselves or services which require me to contact them via*

telephone present social barriers. My experience, however, has taught me that the lines between impairment effects and social barriers are rarely neat and tidy. Take for instance rooms with poor acoustics, speakers with facial hair, which impedes my lip-reading ability, and noisy restaurants. At what point does the failure to communicate stop residing in my hearing loss and begin originating in the conditions in which I find myself? To what degree can we and should we ask our environments to adapt to or accommodate us? And are the things we ask accommodations or mere matters of courtesy we owe one another as fellow human beings? While the social relational model leads me to endless questions about the blurry boundaries between impairment effects and social barriers, it also best exemplifies the tension I experience between my own capacities and the environments I navigate daily.

Cannon, too, values the social model; however, she asserted that it is the minority model that is emancipatory in that it conceptualized dis/ability as a part of a person's identity, instead of a deficit that imposes shame (see Eisland, 1994). Cannon, quoting from Eisland (1994), stated that the minority model gives "people with disabilities and those able-bodied individuals and institutions committed to social equality—those others who care—a framework in which to envision change and feasible ideas for bringing it about" (p. 66). Cannon further asserted*: my theoretical reconceptualization gave voice to my experiences as a student and person with a dis/ability.* Cannon explained that her story encompasses *a transformational journey upon which I had to discover and to embrace that I am not defined; I am not defined and nor are other people by deficit labels of disability.*

Many of the authors in this paper find value in the existing models, but also call for something more integrated, more responsive, more dialectical to address the impact of disableism on individuals in our schools and society. As we collectively grappled with our place in the DS literature, we realized that Carol Thomas' (1999) use of disableism in her work on bridging the two models of disability—the medical and social—was where we aligned ourselves given our autoethnographic experiences of disability at our unique positionalities and experiences, the role of emotionality in disability oppression. As noted in an earlier footnote, we have consciously used the term "disableism" in our paper as to align ourselves with the psycho-emotional disablism model of disability (Thomas, 1999).

Hopes and Desires

Buffington-Adams stated that *as a Disability Studies (DS) scholar, as someone who has been disabled, and as someone who hopes to leave a kinder world for my child, identifying the problem is not nearly enough.* In this work, we assert the importance of centering the experiences and solutions of those impacted by disableism to transform schools and society.

Cannon challenged others through her own transformational journey of developing a sustained identity connected to her faith to the need of Disability Studies (DS) and Disability Studies in Education (DSE) *to think more deeply and thoughtfully about disrupting the hidden curriculum that impacts how our students think about themselves in school and society.* Hernández-Saca, too, talked about the importance of listening to the experiences of those impacted by dis/ability and disableism. Drawing from Adorno (1966), Hernández-Saca asserted that *allowing suffering to speak is important for individual and collective liberation movements.* He asked:

> *how can a partnership between Curriculum Studies and Disability Studies in Education (DSE) afford new paradigmatic ways along epistemology, ontology, axiology and etiology lines?*

Vanderbilt argued that the *embodied ways of knowing people with disabilities should be viewed as a strength and an asset that can help transform schools and societies.* Vanderbilt evokes the work of Wang (2004) who outlines a "pedagogy of suffering," and suggested that *we must work to transform the painful experiences of wrongs and the painful experience of living under the oppression of a society that rejects one's very body into something transformative and better.* For Vanderbilt and many of the authors in this paper, part of that transformative process includes a rejection of binaries. Vanderbilt called for:

> *a revolt against the abled/dis/abled duality. It is not a mere elevation and rejection of disabled status; it is the opening up of a new way of knowing—a new way of being in the world for both those with "valued" bodies and those whose bodies are rejected by society. Through the mutual transformation of the construct of able-bodied and dis-abled, well and sick, harmony may "emerge from the interplay of difference" (Wang, 2010, p. 379). The voices of individuals with disabilities are, I argue, essential to imagining new possibilities outside of ableist discourses.*

Vanderbilt also drew upon curriculum theory and the work of Wang to identify:

> *curriculum as a third space allowing for movement between one's positions to open up a new way of knowing, of being in the world. This third space "revolts" against binaries in a way that one enters into a completely new way of knowing that is not related to something as it already exists or is known and neither in binary opposition to what we know. Wang (2010) writes, "What is not makes possible what is." (p. 375). We must suspend our own understandings in a way that we might imagine something outside of what we already know.* It *is my suggestion, though I recognize the singularity of my suggestions based on only my experiences in a landscape of plural potentiality, that we work toward a project of radical naming. I suggest that the beginnings of imagining new futures might be to allow for the sorts of radical naming called for by Freire (1970, 1974). The dialogic I call for should be one that places primacy on radical naming by individuals with disabilities regarding their own experiences, their identities, and the new possibilities that might only be known through a particular embodied experience.*

Buffington-Adams, too, wrote about rejecting binaries. She questioned: *How do we shift the social construction of disability from a deficit-orientation when we lack the language to describe the spectrum of human experience in anything but false binaries.*   Like Vanderbilt's call for radical renaming, Buffington-Adams asked:

> *how we can better align the language we use to talk about disability with the social relational model. Language designed in such a way would acknowledge that disablement is both a social as well as an embodied phenomenon and in doing so would highlight how people can be complicit in disablement through their responses to those who live with disabilities. What if language allowed us to more easily make the distinction and send the message: Yes, I live with a disability, but it is your complacency in an ableist framework which disables me.*

Vaughan reflected that in a time when narratives of disability are often simplified to medical narrative or data-driven Individual Education Programs (IEPs), personal narratives are needed to empower the storyteller and transform the reader and practitioner (see Frank, 2013; Ferguson & Ferguson, 1995). She wrote:

> *It becomes increasingly important for parents of children with dis/abilities to work with their children to share their stories/ narratives. ... These counter-narratives can disrupt hegemonic notions of dis/ability and call into questions policies and systems of oppression that disable students. Counternarratives can ... expose the limits to pedagogical solutions done without a commitment to rethinking and re-theorizing ideas of disability, schooling, and social justice.*

Winfield asked us to think about how our narratives can help us disrupt grand narratives. She shared:

> *My son is 25, finding his way, in his own way, in a way I do not, cannot, and try not to want to, control. I have given myself credit for trying to contribute in some small ways to his graduation from high school with a modicum of esteem for his own intellectuality—even though I forced him to slog through a school system that worked against this at every turn. As I review my work on the eugenics movement, eugenic ideology, and even my own inclination toward the theoretical underpinnings of history and memory, I am aware of a resistance internally to grappling with the real consequences of that ideology as it is embodied and enacted around me. Grand narratives—we all know them—in addition to the meritocratic, individualistic national ones we learned, and then learned to suspect, do not stop there: we have them for ourselves, we have them for our families and children, we have them for our professions, we infuse them into our hopes for the future. What of the inherent internalization of hierarchy imposed upon our lives and thoughts as a result of these narratives? Where might spaces exist outside the relentless crush of hegemony?*

Yet, Winfield reminds us that:

> *Disruption of grand narratives, as they occur internally, will be a calamitous affair. Without the markers and rests, peaks and valleys that we have become accustomed to using to measure who and where we are, we feel an unease, a disease, and we find a place to rest our intellectual and activist spirits, a place that doesn't disrupt too, too much. Am I disabled enough? Is normalization of disability even a thing? Is it a worthy pursuit? The right pursuit? How are the Black Lives Matter movement and Critical Disability Studies connected? Is healing a thing? So, just as history can be explored from virtually any local*

> *and personal point so too does thinking about hegemony, ability, and culpability—we are all participants.*

Emerging Themes

While each author's perspectives and conclusions are based on their own experiences and theorizing, a few central themes emerged from our collective work.

The Need for Multiplicity of Voices and Experiences at the Intersections of Dis/ability

We posit that there is a critical need, given contemporary times within the U.S. body politic, along with the socio-cultural, political, and economic contexts, for people with dis/abilities to anchor how dis/ability and ability is intersectional. Historically, Disability Studies (DS) and Disability Studies in Education (DSE) scholarship have done this through centering the need for a multiplicity of voices and experiences to illuminate the nature of dis/ability. Nevertheless, DS and DSE have been critiqued for not taking into account the complexity that people with dis/abilities experience as it relates to their intersectionality (Goldberg, 2015). Viewing the experiences of those with dis/abilities and their internal and external experiences with disableism and other forms of oppression and domination is critical.

The Need for Centering the Psycho-Emotional and Relational Model of Dis/ability

Our collective auto-ethnographic voices and experiences speak directly to the different dis/ability models that have been within the domain of Disability Studies (DS) and Disability Studies in Education (DSE) theoretical and philosophical debates. By grappling with our lived experiences as they operate within these intersections of dis/ability, we can come to theory to heal (hooks, 1994). The disablism we experience is due in part to a lack of attention to the intersectional, social, and emotional dimensions of dis/ability. We assert the need to re-center a more holistic understanding of dis/ability as psycho-emotional disablism and the relational model of dis/ability that is deeply intersectional (Hernández-Saca, Kahn, and Cannon, 2018 ; Reeve, 2012).

The Need for Cross-Discipline Conversations for Discipline Expansion:
Disability Studies in Education Meets Curriculum Studies

Beyond, centering the above Disability Studies in Education (DSE) and Disability Studies (DS) scholarship tenets and voices of people with disabilities—*Nothing about us without us*—this collective autoethnographic study and project serve as an example of interdisciplinary collaboration. Within our research question, we all wrestled with our connections—some long existent and some new—with the field of Curriculum Studies. We each explicated how the insights that we gathered, given our lived experiences with dis/ability at the intersections, could inform policies and practices with particular attention to praxis—the coupling of reflection and action—for special education. The power of our individual counter-narratives to the medical-psychological model of dis/ability speaks to critical questions in Curriculum Studies, including whose knowledge is most worth? Who decides? Who benefits?

We recognize that CS and DS have shared "commitments to social justice and political, personal, and pedagogical transformations" and, as such, there are exciting possibilities in theorizing in the liminal spaces between/within CS and DS (Buffington-Adams and Vaughan, 2019). Yet, we also understand that the field of CS has excluded theorizing about disability and, until recently, disability was excluded from discussions of social justice and equity that included discussions of race, class, gender, and language (see Connor, 2012; Danforth and Gabel, 2006; Gabel, 2002). Some scholars have pointed to a "hegemony of special education" in which all issues concerning disability were filtered through the more technical field of special education, a field that has been primarily disconnected from curriculum theorizing (see Connor and Gabel, 2013; Connor, 2014). Part of our conversation, and in fact part of our collective need for 'healing' through theory, was a response to the silencing of our intersectional experiences within our educational fields.

We assert the need for CS scholars to include resistance to ableism as a critical struggle in social justice and education justice. Further, we believe that scholars must engage with and in narratives of dis/ability to understand how curricular choices and school practices interact with structural ableism. By centering dis/ability as intersectional and psycho-emotional in effect, dis/ability suffering for a pedagogy of suffering for praxis, our work is a rallying call for counter-narratives against master narratives of dis/ability and ability in schools and society.

Conclusions

Through our work together, each author ends by sharing different questions and/or proposing different ways forward. These include calls: to rethink language that reifies false binaries and a deficit orientation to dis/ability (Buffington-Adams); to center faith, resulting in self-transformation that challenges deficits labels of disability in our schools (Cannon); to frame dis/ability within intersectional identities and building individual and collective liberation (Hernández-Saca); to embrace calls from parents of children with dis/abilities to reject narratives that pathologize our students (Vaughan); and to engaging in a project of radical naming and the creation of a new reality (Vanderbilt.). Ann Winfield has commented that the narratives in this article illustrate that Disability Studies (DS), Disability Studies in Education (DSE) and Curriculum Studies (CS) offer a unique theoretical platform that challenges and resists the hegemony of disciplines, the hegemony of knowledge exclusion (experiential, emotional, and social), and leads us in a direction that is liberatory, empowering and healing.

We recognize that our work, presented here and done in classrooms, universities, and community spaces, must still resist what Winfield described as:

> *racialized scientism, a core concept which conceptualizes ability/disability through a succession of models from medical/psychological, through social, and ultimately even emancipatory models. Models which are embedded in the experiences of the authors in this article … ideas which are simultaneously critiqued, and applied to the self …*

Hernández-Saca reminds us that centering intersectionality as a working concept within theory is essential to moving beyond Whiteness and other forms of discrimination and oppression. If we are to heal, to transform consciousness, society and institutions, what better time than now to start to build the emotional and affective intersectional revolution to and through the collaboration between Curriculum Studies, Disability Studies, and Disability Studies in Education?

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