

# An Introduction to Race, Gender, and Disability: Intersectionality, Disability Studies, and Families of Color

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*A Special Guest-edited Issue*

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The idea for this special issue of *Women, Gender, and Families of Color* on race, gender, and disability came from a deep commitment to foregrounding intersectional analysis and doing so from cross- and multidisciplinary perspectives. We, the guest editors, represent both this commitment and the potential of going across disciplinary boundaries. We come with understandings in the fields of disability studies, critical race theory, feminist of color critique, Latino/a/Chicana studies, critical prison studies, racial and ethnic health disparities, and policy implications for families of or with disabled individuals. We say this at the beginning of this introduction not only as a form of identification (or disidentification) but to disavow from the outset the idea that “disability,” “race,” “gender,” or “family” are monolithic constructs that can be interrogated on their own.

It would be useful from the outset to define what we mean by the term “disability.” As stated elsewhere (Ben-Moshe et al. 2013), under the critical framework of disability studies,

Disability is fluid and contextual rather than biological. This does not mean that biology does not play out in our minds and bodies, but that the definition of disability is imposed upon certain kinds of minds and bodies. . . . But more than that, disability, if understood as constructed through historical and cultural processes, should be seen not as a binary but as a continuum. One is always dis/abled in relation to the context in which one is put. A person has a learning disability if put in a scholarly setting; using a wheelchair becomes a disability and a disadvantage when the environment is inaccessible; someone who wears glasses may be disabled without them when attempting to read written language or see far away, but this can change depending on the context that they are seeing and being seen within. (210–11)

Certain conditions get defined as medical “problems” (that is, disabilities) as a result of specific understanding of what is “normal” by those with the power to exert these definitions on others.

We, therefore, leave the definition open as to what “counts” as disability and let the authors in this special issue define it for themselves. For example, in this issue, both Susan Burch and Eliot Hamer and colleagues convey the shifting definitions and outcomes of being labeled “feebleminded” and incompetent and highlight the historical conflation of disability and race. In the article on disabled Cape Verdeans’ in the United States, Dawna Thomas analyzes how this group defines disability differently from mainstream U.S. definitions. Jenifer Barclay writes about how disability among slaves in the antebellum South was determined by the economic value of the bonded individuals as defined by slaveholders.

It might be easier to define “disability studies” than to define “disability” as a critical study that takes the constructed nature of disability as its point of entry. This should not be confused with “the study of disability” more generally. According to Linton, “Disability studies takes for its subject matter not simply the variations that exist in human behavior, appearance, functioning, sensory acuity, and cognitive processing but, more crucially, the meaning we make of those variations” (1998, 2). These meanings are socially constructed by people’s thoughts, words, and physical manifestations (such as the built environment) and become ways of defining human experiences that take on cultural and historical meaning, often of a negative tint. Disability studies and disability culture also, therefore, aim at breaking down the perception of disability as personal tragedy, pathology, or deficiency. Some in disability culture and activism view disability as a source of pride, some as a form of biodiversity.

But even this desire to depathologize dis/ability from notions of deficiency, which is at the core of a critical disability studies stance, gets complicated when an intersectional analysis taking into account race, gender, sexuality, class, and other constructs is being introduced. It is important to highlight this tension between the desire to untangle disability from medicalization and diagnostic categories (and reclaiming it as an identity and culture) and the ability (and sometimes desire) even to become a subject under the medical gaze. For many people of color or those who have no access to quality medical care, not being diagnosed is due less to viewing disability as a source of pride or as a fluid state and more to disparities. We see these disparities in service provision and access to doctors and medical services (such as therapy, medication, early detection, and so on) because of inequalities based on class, color, language, and geographical barriers.

It is clear from the literature that people of color (POC) are at greater risk for losing ability capacities, often in conjunction with lower socioeconomic or immigrant status (Sears et al. 2012). There are also numerous barriers for disabled POC in obtaining quality rehabilitative and specialty services (Balcazar et al. 2012; Magaña et al. 2012) and health care services (Magaña et al. 2012).

Such intersectional analysis in the field of education, for example, repeatedly demonstrates the overrepresentation of students of color in special education. Here they are disproportionately labeled in “soft” disability categories<sup>1</sup> such as emotionally disturbed, ADHD, and, historically, “mental retardation” (Harry and Klingner 2006; Smith and Erevelles 2004), warranting two formal investigations by the National Academy of Sciences (1982, 2002). As Adams and Meiners (2014) suggest,

Classification as special education masks segregation, and pathologizing “students of color as disabled allows their continued segregation under a seemingly natural and justifiable label” (Reid and Knight 2006, 19). Students labeled with these disabilities receive differential access to high-quality education, are not tracked toward college, experience higher rates of suspension and expulsion, and are disproportionately represented in juvenile justice prisons.

In other words, after desegregation in schools based on race/color (that is, after *Brown v. Board of Education*), segregation in education is being seen as race and gender neutral, but instead justified as related to students being disabled and needing to be placed in special education (Ferri and Connor 2006).

This overwhelming connection between race, gender, disability, class, and other factors in creating and reproducing inequalities in the field of education has led to a call to connect these issues in a more methodical and critical way. Annamma, Connor, and Ferri (2013) coin the term “DisCrit” to denote the need for connecting critical race theory with disability studies to highlight the interdependent, intersecting, and mutually constitutive aspects of race and disability in education and beyond.

Another source of tension arises when bringing in an intersectional analysis of disability, race, and gender to family studies or to focus on families, as this journal aims to do from a critical stance. The chasm between parents and families of people with disabilities (PWD), as opposed to PWD themselves, is visible in relation to disability movement, activism, and scholarship. One of the major differences lies in the fact that parents often do not have the same opinions as their children, especially when the children are adults. In

the disability rights movement, the slogan “nothing about us without us” comes to represent this very paradox, to state that people with disabilities should control their own lives and decisions regarding their lives. It is also understandable that many parents have concerns about their children, and they disagree with their choices, including such choices as not taking psychiatric drugs or refusing treatment. The problem comes to bear when these are not perceived as choices but as representing the inability of the person to govern his or her own life. For instance, the National Alliance on Mental Illness (NAMI) represents the views of some people with psychiatric labels but mostly the views of their family members. On the one hand, they are united in fighting for services and against the stigma of what they define as mental illness. Still, there are many others with psychiatric labels who disagree with NAMI on issues such as medication, hospitalization, and other policies. As with other organizations, the voices of the parents often override the voices of those with the disability labels (Ben-Moshe 2011).

This tension within families (mostly parents and siblings) and those who identify as disabled also becomes obvious from analyzing the historical emergence of the disability rights movement; a movement that also gave rise to the field of disability studies in terms of understanding disability as a form of identity and culture, and not a pathology or lack. Historically, parents particularly of those with intellectual and developmental disabilities, were not an integral part of the disability rights movement. As Carey (2010) shows “the inclusion of parents seemed to undermine the presentation of people with disabilities as autonomous decision makers” (137). It is also important to point out the disability rights movement has borrowed much of its tactics in the 1970s and onward from the civil rights movement and women’s rights movements (Fleischer and Zames 2001; Scotch 1984), which also points to the need for a more intersectional analysis in this regard. But, again, as Carey demonstrates in relation to parents of those with intellectual disabilities, “parents typically did not want to bring negative attention to themselves or their children by presenting themselves as troublemakers, radicals, or communists or by ‘parading’ their disabled children through the streets” (138).

The difference between the voices of people with disabilities (who have families of their own, of course) and those of their parents or siblings is also found in research and scholarship. For instance, in *Family Relations*’ recent special issue on disability (Farrell and Krahn 2014), there was no article written from the position of someone who identifies as disabled and only one article represented the voices of people with disabilities. Race was mentioned as a demographic variable, but the differing perspectives of families

of color were not brought to bear. The intersectional tension between race and disability in family dynamics is demonstrated by the assumption that disabled people (or anyone, for that matter) should be independent from their families, a view that can be seen as stemming from an individualistic culture. A disabled person from a more collective cultural approach may rely more on her family and view interdependence as a good thing if she comes from a more collectivist culture (Magaña and Smith 2006). Thomas makes this point in her article about Cape Verdeans included in this issue. In this special issue, we have attempted, therefore, to bridge this gap in the scholarship. Specifically, we provide various perspectives to foreground an intersectional understanding of disability that takes into account the complexities of race, gender, and family dynamics as complicated and interrelated categories.

An intersectional analysis of race, disability, and family will not be complete, of course, without paying careful attention to the way gender manifests and intervenes in such constructions. Of particular importance are the gendered aspects of family dynamics. When one discusses parenting or caregiving, it is often done in a neutral way, but much research has shown that these roles are often relegated to women (Traustadottir 1991) and, when done for pay, often women of color (Erevelles 2011). Even in relation to advocacy and activism, it is often women as mothers (see Naples 2014; Panitch 2008) as well as daughters as caregivers, often for their own mothers. In this issue, not only are mothers primary caregivers of their children with disabilities (Barclay, Thomas), but people with disabilities are “feminized” and used as caregivers of other slave’s children as in Barclay’s account of mothers of children with disabilities under slavery; or forced to provide care to their medical caretakers’ families, as described in Burch’s case study of a Native woman who was placed in an asylum. Such analyses start to connect feminist understandings of caregiving, which often see disability as a caregiving task, with analyses of the value of disability and interdependency from a disability studies stance, together with the perspective of critical race theory which further analyzes the paid and unpaid labor of those who “care.” Such analysis, which we hope this special issue brings to the forefront, foregrounds the importance of intersectionality as a critical tool of analysis and action, as opposed to interpretations that favor analogies (“race is like disability”) and hierarchies.

Despite major lacunas in the field/s, we do not wish to imply that this special issue is the first to address this important intersectional work. In fact, we would like to state the opposite. We rest on the shoulders of many pioneers whose work emphasized the nexus of race and disability from a critical

stance. We want to acknowledge especially the work of those who have not lived to see the circulation of their work and ideas, in large part due to the uneven effects of disablement and chronic illness on bodies of queers and women of color. So we begin this special issue with an acknowledgement of the work of Chris Bell,<sup>2</sup> Carlos Clarke Drazen,<sup>3</sup> and Cheryl Spear.<sup>4</sup> We wish to dedicate this issue to them.

In “White Disability Studies: A Modest Proposal” (2006), Bell emphasizes the field as “White Disability Studies” and encourages us to think deeply about the consequences of a lack of deep engagement with race as intersecting with disability, as well as the lack of scholars of color engaging in these issues, also endemic to the field<sup>5</sup> (and perhaps to academia more broadly). It is important to note though that, even in these seminal works, race is discussed from a rather narrow and specific stance, that of color. For instance, Bell focuses on race in relation to blackness (as in the name of the anthology he edited in 2011). Although this is done to fill a gap in the scholarship, it is important to note the specific ways in which race is read in U.S. contexts, in which color is often the default for racial discussion. But since disability studies see disability as a fluid and changing construct, it is important to note that so is race.

Taken as a complex identity formation and historical construct, disability studies has enjoyed a surge of work that demonstrates the myriad ways in which race, gender, and disability intersect both as social constructs and as chosen identities and movements. Susan Burch’s (in this volume), Susan Schweik’s (2011), and Kim Nielsen’s (2012) for example, bring attention to Native American history in relation to the construction of disability, both in its gendered nature and its consequences. Cyndy Wu’s work connects Asian American studies and disability studies, for instance, in the construction of Chang and Eng Bunker as the “original Siamese twins” (2012). There are other notable additions, such as Mel Chen’s work (2012) on toxicity, racial mattering (human and nonhuman) and queer affect; Ellen Samuels’s recent book *Fantasies of Identification: Disability, Gender, Race*; and the scholarship of such authors as Anita Ghai, Nirmala Erevelles, Helen Meekosha, and Petra Kuppens, who masterfully connect postcolonial discussions to disability and gender. In Chicana studies, Bost (2010) disrupts the binary of color in racial analyses of disability through reanalyzing Chicana writers’ literary accounts of chronic illness, pain, and disability, and their contribution to bringing deep descriptions of these carnal issues to the feminist scholarship world. Gloria Anzaldúa, Cherrie Moraga, and Ana Castillo wrote about disability experiences as part of their daily lives but have not been recognized as disability studies scholars (Bost 2010). The irony with

respect to scholars performing intersectional analysis is that they may not choose to identify as disability studies scholars; they see these issues as part of their overall racial, cultural, and sometimes marginalized experiences—an example of how disability identity is experienced in different ways by persons with disabilities who are not white and middle class.

This connection between understanding disability and race as well as constructs of family and gender as fluid and contextual is threaded throughout this special issue. In this first issue, we introduce three historical pieces that take us from the antebellum period through the early twentieth century and through to the 1970s, and one paper that discusses a modern-day immigrant group and its experiences with disability. In her article “Mothering the ‘Useless,’” Barclay explores the issue of how the presence of disabilities impacted enslaved children and their mothers. Drawing on slavery studies scholarship, she investigates how disability intersected with motherhood, childhood, and childcare on southern plantations. She describes ways that mothers resisted separation from their disabled children, advocated for their children, and explored the roles and experiences of the disabled children themselves.

Burch expands the boundaries of the American Indian, gender, and disability studies in her essay “‘Dislocated Histories’: The Canton Asylum for Insane Indians.” Here, Burch presents a case study of a native woman who was involuntarily locked into an asylum for Indians, deemed “insane” and “incompetent” against the opinions of herself and her family. This experience coincides with the history of institutionalization of the mentally ill and people with intellectual disability or those labeled as feebleminded. This work highlights the conflation of mental incompetence with race that was prevalent at the turn of the twentieth century.

Some of the practices that resulted from this extreme marginalization of people with mental illness and developmental disabilities, as well as the treatment of racial others as incompetent, included the eugenics movement and the use of sterilization. Surprisingly, a state-run forced sterilization program in North Carolina did not end until 1978, as pointed out by Hamer, Quinlan, and Grano in their article “‘Tired and Hungry’ in North Carolina: A Critical Approach to Contesting Eugenic Discourse.” These authors use a case study to critique state-authorized labeling of sterilization subjects as deviant and disabled and highlight how recent this history is.

Our last paper in this issue, Thomas’s “A Cape Verdean Perspective on Disability: An Invisible Minority in New England” brings us to modern-day experiences of an immigrant community in the United States. Thomas critiques the disability rights movement for not paying attention to how

disability is understood in culturally diverse communities in general, and specifically to Cape Verdeans with disabilities and their families. She provides history and background to the Cape Verdean immigrant experience in New England and provides information to disability scholars and service providers about how Cape Verdeans view family and disability.

We believe that this volume brings together gendered and racialized experiences of disabled individuals and their families to an important venue and audience by highlighting, specifically, the experiences of disabled women of color. It is not meant as a definitive volume but more as a way of opening the door to future intersectional scholarship in this vein. It is our hope that this issue will begin a much needed conversation in multiple fields that have much to learn and unlearn from each other.

## Endnotes

We wish to thank Jennifer Hamer, editor, and Kathryn Vaggalis, managing editor, of *Women, Gender, and Families of Color* for their meticulous editorial work and vision, without which this special issue would have never seen the light of day. We want to also extend a hearty thank you for all the reviewers of manuscripts for this issue, as well as the authors who sent in their articles, whether or not they are published into this issue, for doing important intersectional work.

1. As opposed to autism, for example, in which white children have been historically overrepresented, giving them more access to resources (as implied by Eyal et al. 2010).

2. Chris Bell was an AIDS and disability scholar and activist, former Society for Disability Studies president, and cofounder of the SDS People of Color Caucus. His work explored issues of race, disability, AIDS, illness, class, and sexuality, as well as the relationship between activism and academia. At the time of his death in 2009, he was an ARRT Fellow at the Center for Human Policy, Law and Disability Studies at Syracuse University. We reference some of his work below.

3. Carlos Drazen held a BA in theater and an MA in political communication from Southern Illinois University, as well as an MA in disability and human development from the University of Illinois at Chicago where she was finishing her dissertation in disability studies on the relation between race and disability at the time of her death in 2011. Drazen was a well-known and well-spoken advocate of disability both in Chicago and throughout the nation, and her scholarship connected blackness with disability in multifaceted ways. She was the author of "Both Sides of the Two-Sided Coin: Rehabilitation of Disabled African American Soldiers," in Bell 2011.

4. Cheryl Spear earned a Master's degree in cultural foundations of education and a certificate of advanced study in disability studies at Syracuse University. She was a doctoral student there at the time of her death in 2011. She was a founding member of the Beyond Compliance Coordinating Committee, a student disability advocacy organization at Syracuse University, and of Students for Visual Access Today, which provides support and accessible

course materials for those with low vision. She was the coauthor of *Beyond Compliance: An Information Package on the Inclusion of People with Disabilities in Postsecondary Education* Syracuse, NY: Center on Human Policy, Syracuse University, 2003.

5. Also see Schalk (2013) regarding this gap and its effects on young scholars of color coming into disability studies.

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