Ralph James Savarese’s essay “River of Words, Raft of Our Conjoined Neurologies” (2012) provides an eloquent and moving account of how his autistic son D. J. emerged into literacy. As he learned to read, D. J. experienced extreme, often painful identifications with literary and historical figures. Like Harriet Tubman, he saw himself engaged in a type of “political freedom fighting” (43) on behalf of those, like himself, who can’t speak and instead type to communicate. Much as I loved the essay, I was dismayed to find that D. J. described this group of autistics as oppressed by the mistaken presumption that they are “retarded” (45). I am the parent of a child with Down syndrome, and the ugly word “retarded” never fails to hit me like a slap in the face. I could understand D. J.’s resistance to being branded with that stigma and his own need, as a child who had been abandoned by his birth parents and brutalized in foster care, to affirm himself in this way. But I was also reminded of a regrettable dynamic in which people with disabilities often justify their own value by asserting their difference (and presumed superiority) to some less-capable group. During an illuminating email exchange, Ralph mentioned my reaction to D. J. Here is how Ralph related their conversation to me:

“All I said was that I resent testing that mistakenly identifies kids as retarded,” [D. J.] persisted.

“I know, but what if you had said that you generally resent mistaken assessments of human potential and value?”

“Auties and Downies and all sorts of disabled people together? That would have been better,” DJ conceded. “Please understand that I intended no insult. I wrote that line in middle school.”

I value this exchange for exposing the very real difficulties of imagining Disability with a capital D, a category capacious enough to

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include not only “Auties and Downies” but people with such disparate conditions as paraplegia, vision impairment, deafness, chronic fatigue syndrome, and fatness. The challenges of maintaining such a category are evident in the teenaged D. J.’s objection to being associated with the reviled label “retarded.” Quite sensibly, he tried to escape by proving his own abilities. It is to his credit that, in hindsight, he could see the possibilities of an alliance with others who have been devalued by limited standards for judging worth and potential. It is the work of disability studies scholars and activists to determine how best to define and theorize an umbrella as vast and unwieldy as Disability in appropriately inclusive ways.

Disability studies has now been around long enough to have an institutional history of its own. In 2003, historian Paul Longmore documented two chapters in the emergence of disability studies that correspond to the trajectory of many prior identity-based fields. The first involved a struggle for civil rights that culminated in the landmark 1990 Americans with Disabilities Act. The next comprised the search for collective identity and creation of a disability culture. This second phase corresponded to the emergence of disability studies as an academic field.¹ But even as Longmore was writing, that sense of collective identity had begun to fissure. New work in the field attests to the emergence of a third, and overlapping phase of disability studies, in which tensions and conflicts come to the surface. The signs of this third phase are found with particular clarity in two interrelated areas. On the one hand, there is a growing investment in probing the challenges and opportunities of intersectionality, as disability scholarship explores, in increasingly complex ways, its affinities with, and divergences from, other fields devoted to the study of identity. On the other, there continues to be an ongoing bifurcation of the intellectual from the physical that reflects the difficulties of maintaining disability as a unified category. As has been true of other cognate fields, disability studies promises to be strengthened rather than debilitated by the challenges of this growing diversity. Rather than forecasting the field’s dissolution, these tensions should be seen as a sign of its vitality, since they create opportunities for productive debate and intellectual development.

1. Intersections

Virtually from the beginning, disability studies understood itself in intersectional terms. When Irving Zola, a pioneer in the field and founding member of the Society for Disability Studies, published his memoir in 1982, ² he described it as “an unraveling of
a social problem in the manner of *Black Like Me*.” However, unlike John Howard Griffin, the white journalist who darkened his skin to explore racial segregation, Zola wrote as a person with a physical disability whose difference could not be concealed, “for me ‘passing’ was not an issue” (“About”). Implicit in this contrast is an analogy with race that bespeaks an openness to recognizing the affinities between the experiences of people with disabilities and those of other marginalized groups. A relative latecomer to the academy, disability studies had the virtue of being able to model itself after other identity-based interdisciplinary fields. As the framing of Zola’s memoir suggests, intersections among categories like race, ethnicity, gender, and queer have often informed recent academic and activist conceptions of disability.

The challenges of intersectionality motivate two recent collections: editor Christopher M. Bell’s *Blackness and Disability: Critical Examinations and Cultural Interventions* (2011) and editor Kim Q. Hall’s *Feminist Disability Studies* (2011). Despite the field’s persistent suturing of race and disability, Bell alleges that there is “whiteness at the heart of Disability Studies” (3). It isn’t enough just to recognize a kinship with blackness, writes Bell, since disability studies has rarely included the voices and concerns of people of color. Black studies has been equally limited. Despite a longstanding investment in examining the black body as a site of wounding, endurance, and struggle, critics have failed to consider disability as such or to recognize alliances with the agendas of disability studies. *Blackness and Disability* is intended to redress this absence by identifying points of intersection between fields. While the title might suggest a rather narrow coupling of these two signature terms, the essays explode this polarity by considering intersections with gender, sexuality, and other forms of racial identity. The volume grows out of a conference, and most of the contributions have the slim, underdeveloped feel of oral presentations. This unfinished quality must be due, in part, to Bell’s untimely death before the collection was ready to go to press. However, despite the absence of heft, the contributions yield some valuable insights, such as Michelle Jarman’s reading of Bebe Moore Campbell’s novel *72 Hour Hold* (2005) as a window into African Americans’ conflicted relationship to discourses of mental health; Robert McRuer’s discussion of the irreverent and often shocking revelations of Gary Fisher in *Your Pocket* (1996) as an instance of “crip non-compliance” (98); essays by Stella Bolaki and Therí Alyce Pickens on race, sexuality, and illness in the work of Audre Lorde; and Moya Bailey’s analysis of the ableist language of hip-hop.

*Feminist Disability Studies* also takes on the challenge of intersectionality, this time through the lens of gender and sexuality.
While disability studies scholars have nearly always worked out of a strong awareness of, and commitment to, feminism, feminist scholarship has often neglected disability, even when attentive to other forms of embodied difference. Fittingly, the collection begins with a reprint of Rosemarie Garland-Thomson’s important omnibus review, for which it is named. Garland-Thomson employs a method she calls “recruitment” to retroactively claim such key texts as Susan Bordo’s *Unbearable Weight: Feminism, Western Culture, and the Body* (2003), Audre Lorde’s *The Cancer Journals* (1980), Judith Butler’s *Gender Trouble* (1990), and Donna Haraway’s *Simians, Cyborgs, and Women: The Reinvention of Nature* (1991)—none of which was written with disability in mind—for a new critical endeavor she calls feminist disability studies (43). Looking back at the piece, initially published in 2005, she concludes, “the review essay thus established an archive, even a canon, of feminist disability studies and set an agenda for future scholarship” (43). The ensuing essays attest to Garland-Thomson’s success at inaugurating such a field. Favoring the humanities, they reconsider well-known authors like Charlotte Bronte, Gwendolyn Brooks, Anita Desai, Marge Piercy, and Judith Butler, showing how we gain a new perspective on their work by examining it through the lens of disability. They also use the conjoined vectors of gender and disability to examine topics such as war, sexual democracy, eugenics, fatness, chronic illness, and feminist theater. Together, *Blackness and Disability* and *Feminist Disability Studies* show the value of working at, rather than simply assuming, intersectionality. More than one contributor observes that disability offers a particularly apt lens for examining identity. It is not simply an additive term, but one that challenges and refines the ways that identity is currently understood. As Tobin Siebers puts it elsewhere, “the presence of disability creates a different picture of identity—one less stable than identities associated with gender, race, sexuality, nation, and class—and therefore presenting the opportunity to rethink how human identity works” (*Disability Theory* 5). Disability scholars and activists use the term “temporarily able-bodied” to describe the fact that a person can become disabled at any time, that she may be disabled by some environments and not by others, and may move in and out of the experience of disability. Theorizing disabled identity entails a particular urgency and universality, given that everyone who lives long enough will eventually become disabled.

Hall notes in her introduction to *Feminist Disability Studies* that scholarship in the field not only focuses on the body, but offers new ways of conceiving embodiment that might be instructive to cognate fields. We see this, for example, in Elizabeth Donaldson’s excellent essay on women and madness, where she shows how the
feminist tendency to romanticize madness must be tempered by a consideration of psychiatry, mental illness, and institutionalization: “[W]hen madness is used as a metaphor for feminist rebellion,” she writes, “mental illness itself is erased” (94). Another fine example is a piece by Nirmala Erevelles, which argues for an intersection between feminist disability studies and third world feminism that would address both limitations in the disability studies critique of difference and the erasure of disability within third world feminism. Abby Wilkerson’s illuminating essay “Disability, Sex Radicalism, and Political Agency” notes that both disability studies and queer theory stand to gain from a greater appreciation of the relationship between sexual agency and democracy: “Together, queer and disability perspectives help reveal why sexual agency must be understood as an important and, in some ways, key component of the liberation struggles of all disenfranchised groups rather than a luxury to be addressed after achieving goals that might be perceived as more basic” (197). Each of the essays in this collection offers a valuable contribution in its own right. Read together, they make a strong case for the value, indeed necessity, of including disability perspectives in future feminist scholarship.

Intersectionality is also essential to Susan M. Schweik’s brilliant and comprehensive book, *The Ugly Laws: Disability in Public* (2009). Schweik anatomizes the emergence and afterlife of local ordinances against unsightly persons that appeared in the US between 1867 and 1920. The intersection of disability with poverty and economic justice forms a through line for the entire book; however, a section called “At the Unsightly Intersection” devotes individual chapters to racial, gender, and ethnic or national difference. Arguing against the principle of analogy (a black person is like a person with a disability), which risks evacuating historical and experiential specificity, Schweik favors intersectionality, which she describes in terms of “as with” (as with blackness, so with disability). In Schweik’s study, the intersection has a literal as well as a figurative meaning. “The street-corner metaphor, particularly apt for the situation of the unsightly beggar, sharply underscores the harm that can happen there,” (143) she writes. As Schweik points out, ugliness is gendered: it means something very different for a woman to be unsightly than a man. During this period, middle-class femininity was defined as being private and reserved, meaning that a woman who displayed disease or deformity in public violated convention on multiple fronts. On the flip side were disabled men whose mendicancy overturned assumptions about the wholeness, ability, and the productivity of the male body.

The rise of ugly laws coincided with anxiety about the effects of immigration on urban life, and it is no accident that being ugly
was often equated with being alien; this despite the fact that the historical record suggests that nearly all beggars were American-born. Interestingly, in these cases ugliness often meant more than physical appearance. It also had to do with the cacophony of immigrant voices heard in the streets, which were perceived as ugly sounds that needed to be silenced. So too, *The Ugly Laws* illuminates the intersection of disability with race since unsightly beggar ordinances developed concomitantly with those that enforced racial segregation. Like race, disease and disability occasioned anxieties about the inscrutability of the body. In the same way a black person might pass as white, a person with epilepsy or tuberculosis might go undetected. Black beggars were more likely to be associated with disease, and when arrested, they were subject to more abusive treatment than their white counterparts. As a result, the most frequent accounts of resistance to policing were found in the black press, which constitutes a vital archive of strategies used by beggars to protest their unsightly status.

Of course, intersectionality has never been about the simple addition of one term to another, but rather how differences define and reinforce one another. Intersections are the sites of unpredictable collisions and pile-ups but, as this new scholarship shows, they are also opportunities for mutually transformative recognition. These works represent the more recent contributions to an ongoing effort within disability studies to recognize affinities with other forms of identity and embodied experience. And yet, as we will see, the field has not always been so successful at identifying points of internal intersection. Ultimately, it may prove easier to find common ground between race, class, gender, sexuality, and particular forms of disability than it is among the many diverse constituencies that claim the category of Disability.

2. Divergences

If Christopher Bell claims to detect whiteness at the heart of disability studies, therein also lies a wheelchair. This is to say that the field of disability studies emerged out of, and has been dominated by, the priorities of people with physical disabilities, the iconic figure of which is the wheelchair user. We know it is challenging for D. J. Savarese to imagine an alliance between “Auties and Downies.” The difficulties are amplified when we seek affinities among people with intellectual disabilities and those with chronic illness, mental illness, and/or physical disabilities. Colleges and universities that have made considerable strides toward accommodating students and faculty with physical disabilities have not been equally
successful at including those with mental illness or intellectual disabilities. Similarly uneven progress is reflected in the intellectual life of disability studies, which has tended to prioritize the physical body. This isn’t surprising, given that most of the disabilities claimed by scholars in the field are physical or sensory (blindness or deafness), rather than cognitive. Their experiences have offered a rich resource out of which to build a more systematic theorization of disability. However, those theories often fail to encompass intellectual disability or mental illness.

The most powerful critiques of this imbalance have come from scholars who are also the parents of children with intellectual disabilities. Eva Feder Kittay criticizes the mainstream disability rights movement for leaving behind people with the severest forms of intellectual disability. Of the social model, which locates disability predominantly in environmental barriers rather than the limitations of individual bodies, Kittay writes, “Advocates of disability rights have insisted that the independence and productivity that are essential to being considered equal citizens in a liberal society are no less attainable for the disabled than for the nondisabled. They have argued that their impairments are only disabling in an environment that is hostile to their differences and that has been constructed to exclude them. Yet the impairment of mental retardation is not easily addressed by physical changes in the environment” (558). In an essay about his son August, Chris Gabbard addresses the academy more directly. As a university professor, he chose a career that rewards intelligence above all else. Gabbard describes how having a profoundly disabled child challenged his belief that personhood was tantamount to reason, competence, and self-control. He uses his experiences as a parent to call for a more widespread reconsideration of the standards for measuring human value upheld by the Western intellectual tradition. “Especially in an academic environment that rewards being smart,” he writes, “how do I broach the idea that people with intellectual disabilities are fully equal? We academics advance in our careers by demonstrating how clever we can be, and because so much depends on flaunting intelligence, it is harder for us than for most people to steer clear of prejudice.” The last few years have seen the publication of a few excellent books devoted to precisely these questions, as they explore the political, social, and philosophical challenges raised by intellectual disability. These include Licia Carlson’s *The Faces of Intellectual Disability: Philosophical Reflections* (2010), Allison Carey’s *On the Margins of Citizenship: Intellectual Disability and Civil Rights in Twentieth-Century America* (2009), Kittay and Carlson’s edited collection, *Cognitive Disability and Its Challenge to Moral Philosophy* (2010), and C. F. Goodey’s *A History of Intelligence and*
“Intellectual Disability”: The Shaping of Psychology in Early Modern Europe (2011). Responding to an imbalance in the field, these works deal exclusively with intellectual disability. Questions remain of how to arrive at a version of disability studies that genuinely encompasses disability in all of its diversity and whether a theory that is so inclusive would be at all useful.

It’s not easy, and new work in the field bears the marks of this tension. Take, for example, Emily Russell’s smart and sophisticated Reading Embodied Citizenship: Disability, Narrative, and the Body Politic (2011), a book that focuses almost entirely on the physical. For Russell, “embodied citizenship” has a double significance, referring to the alignment of the body politic with the physical body, as well as the way that disabled bodies are burdened with an excess of ideological significance. The paradox of disability, she claims, is that it serves as a metaphor for the nation (the conjoined twins Chang and Eng as a figure of national unity), while also reducing personhood to the materiality of the body (we cannot imagine Chang and Eng as anything other than their conjoined bodies).

Russell’s basic argument is that confrontations with physical difference throw key aspects of American identity into crisis. Focusing on what she calls “flashpoints in the history of twentieth-century American embodiment” (18), she explores this dynamic through narrative, which, she proposes, informs both public perception and efforts to legislate the rights of persons with disabilities. It is worth wading through Russell’s laboriously dense prose to get at the underlying analysis, which is often nuanced and insightful. Of particular value are fresh and illuminating readings of Ruth Ozeki and David Foster Wallace, authors who have not previously been discussed from the perspective of disability studies.

Russell’s emphasis on the physical body necessarily shapes the stakes of her argument. She locates the first generation of disability studies scholars “in a tradition of claims upon the state or the academy,” writing rather dismissively of Simi Linton and Michael Bérubé that “the investment in ‘human dignity’ and a liberal project seeking to resuscitate the promises of the democratic state seem at odds with the theoretical underpinnings of disability, which challenge not just the capaciousness of the category ‘human,’ but its construction and deployment as a social and political tool” (12). Russell characterizes these scholars as belonging to a moment in disability studies that prioritized the need to make civil rights and academic programs institutionally legible over “the radical theoretical challenges of disability” (12–13). She identifies the “liberal project” of disability studies with an individualist logic that has favored isolated accommodations over changes in the organization of space and society (200).
Liberalism emphasizes the rights of the individual, true enough. Still, this representation of first-generation disability activism or scholarship isn’t entirely accurate. I need only walk out my front door to find curb cuts, street lights that chirp as they turn from red to green, and subways equipped with elevators (not always working, alas) and auditory as well as visual cues (also not always working). I can dictate text to my iPhone and watch closed-captioned TV in a noisy gym or airport. Children with disabilities are entitled by law to attend public school alongside their typical peers whenever possible. These are not individual accommodations, but innovations with broad consequences that benefit able-bodied as well as disabled persons. They have transformed the collective space of the city in ways that would not have been possible without the Americans with Disabilities Act, which is very much a product of that first-generation consciousness.

A more important question is how strongly Russell’s critique would stick if intellectual disability were included under the rubric of “embodied citizenship.” Critics such as Bérubé, Kittay, and Martha Nussbaum argue that the challenges of recognizing the personhood of the intellectually disabled put pressure on the very premises of liberalism. Far from accepting the social contract that undergirds liberal democracy, they show how the person with intellectual disabilities requires a reconsideration of its very premises. Russell is right to say that American studies has not paid enough attention to disability and that “an analysis of disability can shake up conventionally held notions of US citizenship” (201). I am suggesting that analysis will be all the more radical if intellectual disability is taken into account.

This isn’t to downplay the challenges of integrating the cognitive and the physical into a single analysis. The difficulties are evident in Schweik’s Ugly Laws. While she focuses predominantly on the physical, she observes that the manifestations of intellectual disability were frequently read as unsightly. Indeed, ugly law ordinances sometimes included prohibitions against the public appearance of “idiots and imbeciles” (10) and unsightly beggars were at times associated with feeblemindedness. Nonetheless, the subject of ugliness necessarily skews toward the physical, as does the historical archive that Schweik so masterfully brings to light. Take, for example, Schweik’s brilliant analysis of “mendicant texts” (256), life stories written by the disabled as a means to support themselves and ward off the charge that they were begging in public. Like slave narrators, mendicant authors used literature as a means to demand rights and assert their humanity. Like slave narratives, mendicant texts followed recognizable generic patterns; however, Schweik
shows how some authors warped convention to protest the circumstances that forced people with disabilities to beg on the streets.

Doubtless, a nontrivial number of those targeted by the ugly laws had intellectual disabilities. But by virtue of their impairment, they are nearly impossible to study. Schweik acknowledges the absence of authors with intellectual disabilities from her section on mendicant texts, explaining that there were none in her archive. It’s not that they didn’t exist, she writes, but rather that they must have lived under “conditions so adverse to their claims that the existence of such a text seems highly unlikely” (258). Obviously, Schweik is not to blame for this absence, which attests to the exceeding difficulty of including people with intellectual disabilities in this kind of revisionist history. Doubtless, those classified as idiots and feebleminded did have their own modes of protest, but they also would have had far less possibility of voicing it publicly, let alone documenting it for posterity, than their physically disabled counterparts. Thus, Schweik’s work suggests that one reason for privileging the physical is the presence of archival evidence that simply did not exist for those with intellectual disabilities.

Tobin Siebers’s brilliant and wide-ranging *Disability Aesthetics* (2010) also stretches, more successfully, to include intellectual disability. Siebers’s definition of aesthetics as “the sensations that some bodies feel in the presence of other bodies” (1) suggests an immediate application to disability. Given the sensations of loathing and disgust aroused by the disabled body, Siebers notes the paradoxical fact that those same bodies are seen as beautiful when they become the subjects of art. We live in a culture obsessed with health, strength, and bodily integrity. Nonetheless, Siebers argues, in the realm of aesthetic representation, those traits become kitschy, as exemplified in the art of Nazi Germany. By contrast, the dominant tendency of modern art has been increasingly to favor bodies that are asymmetrical, disfigured, and abnormal. What Siebers calls “disability aesthetics” is a mode of perception that “prizes physical and mental difference as a significant value in itself” (19). Siebers introduces a broad and inventive array of topics under this rubric such as art vandalism, trauma art, disability in literary and cultural studies, and what his second chapter calls “the aesthetics of human disqualification.” A chapter on the culture wars discloses “a political unconscious [that] represses the role of disability in cultural and aesthetic representation” (57). Siebers illustrates his point by turning to the controversial 1999 Sensation exhibit at the Brooklyn Museum of art. He proposes that those who accused the art of being “sick” were challenged by its radically different vision of health, beauty, and, by extension, the body politic. He finds parallel examples of this resistance in “hysterical architecture,” a term he uses to describe
structures that “encompass plans and design implementations contrived to provide access but burdened by a symptomatic inhibition against disability” (75). Taking his own campus as an example, he describes numerous instances in which a built environment designed for accessibility is blocked or covered over, such as handicapped parking spaces obstructed by planters, piles of grass clippings, snow, and delivery trucks.

Although Disability Aesthetics devotes far more attention to physical disability, its theoretical claims clearly apply to those with intellectual disabilities and mental illness. Significantly, the two artists discussed at length in his introduction are Paul McCarthy and Judith Scott. Scott—a fiber artist who had Down syndrome and was profoundly deaf—has received some critical attention, but never in the context of a nondisabled artist like McCarthy. Here, Siebers situates Scott within the history of Western aesthetics, arguing not only for the legitimacy of her art, but also for the limitations of aesthetic theories that fail to account for the “disabled mind” (97). He claims that Scott has been underestimated because she was unable to explain the meaning of her art, a requirement that is not made of nondisabled artists. When Scott incorporated found objects into her work, she was accused of stealing, a charge that has never been leveled against nondisabled modernists using the same technique. “Mental disability represents an absolute rupture with the work of art” (15), writes Siebers. “The spectacle of the mentally disabled person, rising with emotion before the shining work of art, disrupts the long-standing belief that pronouncements of taste depend on a form of human intelligence as autonomous and imaginative as the art object itself” (15). Given the significance of Scott’s accomplishment, there is clearly something wrong here. “What kind of changes in the conception of art would be necessary to include her in this history?” (19), Siebers asks. With such questions, Disability Aesthetics makes a concerted effort to theorize disability in the most inclusive terms possible. Still, it is telling that Scott—whom Siebers acknowledges as an exceptional and isolated case—is the only artist with an intellectual disability to receive serious critical attention in the book. There is more work to be done on the many remarkably talented visual artists with intellectual disabilities who remain unrecognized by the mainstream art world, and more work still to find common ground among the many different constituencies that claim the category disabled.

We live at a moment of profound confusion about disability. In many ways, it has never been a better time to be a person with a disability. Improved medical care, environments structured on universal design principles, legal rights to accommodation, inclusive education, and changing social attitudes have markedly impacted
the quality of life for people with disabilities and their supporters. Disability is now more visible and less stigmatized than it has been for many generations. And yet, physicians and advocates of assisted suicide persistently equate disability with unbearable misery and suffering, people with disabilities continue to be disproportionately poor and disenfranchised, and genetic research races ahead in its attempts to devise forms of prenatal testing designed to prevent fetuses with genetic disabilities from being born at all. How can the same culture advocate improved opportunities, care, and acceptance while simultaneously manifesting a fervent, if often unacknowledged, wish that people with disabilities simply not exist? These contradictions make the project of disability studies all the more timely and urgent. They should remind us that the questions raised by the field are not just theoretical, but have to do with the realities of birth, death, and the quality of life in between.

Given the pressing nature of the issues addressed by disability studies, the ongoing interrogation of disability as a conceptual and political category—whom it includes and excludes, where it intersects with other discourses of identity, and when it pushes new and unexpected revelations—is essential. Scholarship that continues to seek out new points of intersection and dialogue expands and hones our understanding of disability as it overlaps with, and diverges from, other identities. So, too, the field is enriched by the search for common ground within the category of disability itself, the places where “Auties and Downies,” wheelchair users, and people with chronic illness identify shared forms of oppression, struggle, and progress. As these diverse constituencies lay claim to “Disability” as a political and institutional identity, we must also acknowledge their differences and continue to seek out versions of Disability that can accommodate without assimilation. The ongoing effort to devise accounts of Disability capacious enough to encompass such extreme diversity promises to strengthen and expand the field so that it might be possible to genuinely and productively think of auties and downies and all sorts of disabilities together.

Notes


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