

The Curriculum of Disability Studies: Multiple Perspectives on Dis/Ability Introduction: An Invitation to Complicated Conversations

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We aim to crip the curriculum¹ (Erevelles, 2011), by bringing attention to the kinds of work constructs do to advance anti-oppressive curriculum, curriculum leadership, and curriculum theory. Through critique that tears at the limits of the paradigms that threaten to [~~“blind”~~] bind us, we hope to spur work(s) and study/studies that refuse(s) a scripted curriculum (Agosto, 2014) and welcome dis/orderly and dis/orienting reflection (Agosto, White, & Valcarlos, 2019).

They say your expectations and the reality of your situation are mismatched (Seidel, 2019).

THE *JOURNAL OF CURRICULUM THEORIZING* has a rich history of publishing interdisciplinary articles that expand notions of curriculum theorizing while seeking to impact classroom practice. In this special edition, we invited scholars from the fields of Curriculum Studies and Disability Studies to present work about the curriculum of dis/ability. The scholars featured in this special edition have taken up the call in a variety of ways, including auto-ethnographical reflection, analysis of existing curricula, arts-based theorizing, and reflections on classroom interactions. Through these works, we offer not a prescriptive approach to infusing Disability Studies into Curriculum Studies (or vice-versa), but rather an invitation to our readers to theorize through intersectional and interdisciplinary lenses.

We understand this special edition as a continuation and deepening of a conversation that began at an all-conference panel that we organized at the 37th Annual Bergamo Conference on Curriculum Theory and Classroom Practice. Jamie and Kelly organized and participated in this panel discussion between five scholars, some of whom identified primarily as Curriculum Studies

scholars and others who identified as Disability Studies in Education scholars. Our hopes for that panel presentation were similar to our hopes for this special edition of JCT: to invite our Curriculum Studies colleagues to engage in a complicated conversation about how Disability Studies (DS), Critical Disability Studies, and Disability Studies in Education (DSE), can influence Curriculum Studies (CS) scholarship and classroom practice.

Contextualizing Our Conversations

While this brief introduction cannot summarize the depth of contributions or scope of work happening in Curriculum Studies (CS), Disability Studies (DS), or Disability Studies in Education (DSE), we do offer a few notes on each of these fields as to contextualize the contributions of scholars in this special edition.

Curriculum Studies

We draw attention to the description of JCT given on the Journal’s website: “Historically aligned with the ‘reconceptualist’ movement in curriculum theorizing, and oriented toward informing and affecting classroom practice, JCT presents compelling pieces within forms that challenge disciplinary, genre, and textual boundaries.” While early curriculum workers were primarily concerned with *developing and implementing* curricular initiatives in schools, since the 1970s, the reconceptualized field of Curriculum Studies has shifted to focus on “an interdisciplinary academic effort to understand curriculum: historically, politically, racially, autobiographically-biographically, aesthetically, theologically, institutionally, and internationally, as well as in terms of gender, phenomenology, postmodernism, and poststructuralism” (Pinar, 2010, p. 267). The work of Curriculum Studies scholars within the reconceptualized (or even post-reconceptualized) field, according to Eric Malewski (2010), includes “politically inspired scholarship with the capacity to meet the promise of a democracy yet to come, one that engenders imagination, deliberation, and creativity” (p. 3). Yet, while the field of Curriculum Studies is often aligned with a commitment to social justice, we would argue that, until very recently, many CS scholars have not theorized dis/ability as part of the social justice conversation. While some scholars are working in both CS and DS, there is much work to do to theorize how a Disability Studies perspective can address the quintessential curriculum studies questions: What knowledge is of most worth? Who decides? Who benefits?

Disability Studies

According to the *Society for Disability Studies* (2016), Disability Studies is a multidisciplinary field that “challeng[es] the view of disability as an individual deficit or defect”; draws from multiple perspectives on disability “with an aim of placing current ideas of disability within their broadest possible context”; and centers the participation and leadership of disabled people (n.p.). DS scholars reject the medical/deficit model of disability, which 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 (Goodley, 2014, p. 8). There are multiple alternative models of disability offered by DS scholars. Beginning in the 1970s and 1980s, the most widely known alternative model was the social model of disability, which defines “disability as a political category and provide[s] a vocabulary for contesting the processes of disablement: social, economic, and cultural barriers that prevent people with impairments from living a life like their non-impaired brothers and sisters” (Goodley, 2014, p. 7). Michael Oliver (1998), citing the 1986 Disabled Peoples International, explains that:

impairment is the functional limitation within the individual caused by physical, mental or sensory impairment; disability is the loss or limitation of opportunities to take part in the normal life of the community on an equal level with others because of physical and social barriers. (p. 1447)

Many (but not all) who embrace the social model differentiate between impairment, or an individual’s physical or physiological difference, and disability, which is a socially constructed condition created when barriers hinder full inclusion/accessibility. For example, if a child who uses a wheelchair cannot enter a classroom on the second floor of a school, the medical model may identify the child’s impairment or need for a wheelchair as a “disability.” However, those who embrace the social model would argue that the child’s “disability” or disablement was caused not by his/her impairment alone, but rather by the lack of accessible entrances.

In the decades since the social model became the dominant alternative to the medical/deficit model, many from within the DS community critiqued the artificial barriers between impairment and disability and/or the inability to theorize embodied and intersectional experiences of people with disabilities (see, for example, Erevelles, 2014; Shakespeare, 2016). Newer models extend the social model. Thomas (1999), for example, asserts the need for a psycho-emotional model with an emphasis on the psychological and emotional lives of people with disabilities. More recently, Alison Kafer’s (2013) political-relational model “builds on social and minority model frameworks but reads them through feminist and queer critiques of identity” (p. 4). While these models have originated in Disability Studies, they have relevance to how Curriculum Studies scholars conceptualize disability. For example, scholars have identified ways in which contemporary practices in schools, like the process of creating Individualized Education Programs, often are reliant on a medical/deficit view of dis/ability (see Valle, 2009). Curriculum Studies scholars can ask: How can conceptualizing dis/ability differently impact curricular and pedagogical practices for children with disabilities in schools?

Linton (2004) offers that the project of Disability Studies is “to weave disabled people back into the fabric of society, thread by thread, theory by theory” and “to bring disability perspectives and voices into the curriculum and simultaneously increase disabled people’s participation in society” (p. 518). In understanding, contesting, and reimagining such participation in society (and schools), many scholars illustrate the intersections of race, gender, class, and dis/ability. For example, Goodley (2013) explains that “[c]ritical disability studies start with disability but never end with it: disability is *the* space from which to think through a host of political, theoretical, and practical issues that are relevant to all” (p. 632). Mia Mingus (2011), as cited by Erevelles (2014), articulates the work of “disabled people who are people of color; women, genderqueer and transgender; poor and working class; youth; immigrants; lesbian, gay, bisexual and queer; and more” to cultivate solidarity (n.p.). Disability rights activists are leading intersectional, collective re-visioning of schools and society.

Disability Studies in Education

Beginning in the late 1990s and early 2000s, critical special educators and scholars studying disability began to question conventional ideas about disability. Scholars and educators began to move away from positivist inquiry and problematized conceptualizations of disability as deficit. Many early DSE scholars, including those working in the field of special education, recognized unjust practices in schools and called for “alternative ways of envisioning, talking about, and writing about the lives and possibilities of persons with disabilities including many traditions of scholarship (social science, humanities, arts, spiritual traditions, etc.)” (Connor, 2014, n.p.). In 2000, the Disability Studies in Education Special Interest Group (DSESIG) at AERA was formed with the mission “to promote the understanding of disability from a social model perspective drawing on social, cultural, historical, discursive, philosophical, literary, aesthetic, artistic, and other traditions to challenge medical, scientific, and psychological models of disability as they relate to education” (DSESIG, 2019, n.p.). DSE scholarship, according to Danforth and Gabel (2006), emerged in part as a reaction against the “objectification of disabled and labeled students and the scientized reification of deficit constructs and identities” and the “evident failure of special education researchers to wholeheartedly support the cause of inclusive education” (p. 3). DSE scholars also asserted the need for critical educational researchers to focus on disability when discussing power and justice in schools. Danforth and Gabel (2006), for example, stated that the:

standard critical trinity of class, race, and gender, even if fortified by constructs such as sexual orientation or immigrant status, fails to provide relevant, persuasive insight into the dynamics of power and identity within public schools by ignoring the most vulnerable students (those with significant cognitive impairments, for example) or by adding-on disability without fully exploring the ways in which disability transforms arguments about power, identity and justice. (p. 3)

DSE scholars have identified the lack of inclusion of dis/ability in texts about social justice and multicultural education (Connor, 2012); ableist assumptions about dis/ability in the work of critical scholars (Erevelles, 2009; Gabel, 2002); and the lack of theorizing about and resistance to the connected systems of white supremacy and ableism (see Bell, 2017). Some of these critiques are attributed to the “hegemony of special education” (Connor & Gabel, 2013, p. 103); whereas, Connor (2014) explained that, because all conversations about disability were “funneled into the default box of special education,” special education became “an unquestionable reality” even though it was largely “predicated on a deficit-based model” (n.p.)

Recognizing that the “legacy of historical beliefs about race and ability, which were clearly based on White supremacy, have become intertwined in complex ways that carry into the present day,” DisCrit scholars draw upon Disability Studies, Disability Studies in Education, and Critical Race theory to theorize and resist oppressive systems (Annamma, Connor, & Ferri, 2016, p. 10). Within schools, there are calls to address students’ experiences with “interlocking oppressions,” and there is recognition that real change in schools has to be intersectional and include challenges to ableism, as well as white supremacy (Annamma & Morrison, 2018, p. 71).

Within this context, DSE and DisCrit scholars advocate for a shift in curricular, pedagogical, and ideological practices in our classrooms, including an emphasis on inclusive education. Such shifts extend well beyond discussions of inclusion as placement, which, Ware

(2002) points out, can function as “little more than the relocation of disabled students into general education classrooms” (p. 154). As opposed to focus on placement for individual students, there is an effort to promote inclusive education, as defined by Waitoller and Artiles (2013), as:

a continuous struggle toward (a) the redistribution of quality opportunities to learn and participate in educational programs, (b) the recognition and value of differences as reflected in content, pedagogy, and assessment tools, and (c) the opportunities for marginalized groups to represent themselves in decision-making processes. (p. 35)

Within this conceptualization, inclusive education is an effort to confront historically exclusionary practices in education and dismantle oppressive systems (see Kozleski, 2017) and has many implications for Curriculum Studies.

Cross-Disciplinary Work

Each of the fields mentioned above is multidisciplinary. As such, there have already been many connections between Disability Studies and Curriculum Studies. In fact, the field of Disability Studies in Education can be understood as offering an alternative curriculum of disability to a field largely dominated by special education approaches. The work of DisCrit scholars and Critical Disability scholars can also be understood as seeking to disrupt dominant notions of schooling by offering an alternative curriculum of disability. Some scholars are explicitly drawing upon the work of both CS and DS scholars to propose new curricular and pedagogical approaches. For example, Waitoller and Thorius (2016) have discussed how culturally sustaining pedagogy can work with Universal Design for Learning, which calls for multiple expressions of curriculum, pedagogy, and engagement efforts, to benefit all students. In this special edition, we highlight the work of scholars building upon this tradition.

Possibilities and Future Directions

Because both CS and DS (and DSE) have commitments to social justice and political, personal, and pedagogical transformations, we see great possibilities in centering dis/ability in discussions about curriculum theorizing. In both CS and DS, scholars are focused less on prescriptive solutions/treatments and more on understanding, theorizing, and re-imagining personal, political, and social contexts of education. Both CS and DS scholarship have significant traditions of turning inward (toward personal reflection and theorizing), while also looking outward (at political and institutional structure) with an effort to create more just practices.

Curriculum studies scholars often harken back to Pinar’s (2003) description of the theoretical give and take which characterizes the field as “complicated conversation.” One would arguably be foolish to suppose that any field exists without unique points of dissent or tension; scholarship in Disability Studies is no exception. The pieces in this issue work to highlight some of those tensions for the reader as their authors position their pieces’ perspectives within particular frames or as springing from specific individuals’ work, even as they provide possible points of convergence between curriculum and Disability Studies. As a reader, you may notice that authors use many different words to describe disability and ableism. For example, in this introduction, we

use dis/ability to both reject the binary of ability and dis/ability and to highlight that dis/ability is socially and culturally constructed (see Hernández-Saca, Kahn, & Cannon, 2018). Some authors use person-first language, while others use identity-first language. Still others, especially those with more K-12 experience, may use the term “students with special needs.” Each of these terms has a history and offers problems and possibilities. As editors, we did not standardize language intentionally as to present multiple perspectives.

Articles in Our Special Issue

From David Connor’s examination of special education’s recent attacks on subjectivity, we learn of the long-standing divide between the technical scientism of special education and the critical subjectivity of Disability Studies. In so doing, we also glimpse the tensions that exist for those who, like Connor, identify as both special educator and Disability Studies scholar. Ultimately, Connor reminds us that there are multiple ways of knowing.

Emily Nussbaum and Maya Steinborn explore how educational landscapes have worked to actively eliminate particular bodies and minds from curriculum discussions. In response, they call for the visibilizing of disability, the rewriting and restoring of dis/abled individuals within education.

What we say matters, but so does how we say it. Agosto, White, and Valcarlos address questions of silences and linguistic misappropriation in educational justice work by analyzing scholarly rhetoric. They remind us that a portion of our work continues to be finding language and frames of reference, which is both generative and generous as well as humanizing.

Schwitzmann examines how her students at a minority serving institution who are preparing to become teachers react to and make sense of dis/ability as a marker of difference in a standalone diversity course. Through the use of excerpts from students’ written responses to course materials, Schwitzmann highlights themes in her students’ writing that bring her hope, even as she problematizes their reliance on ableist ways of knowing and communicating. In doing so, Schwitzmann relies on a rich theoretical tapestry woven from strands of Disability Studies (DS), Disability Studies in Education (DSE), critical race theory (CRT), the intersections of DS/E and CRT, which has come to be known as DisCrit, and Curriculum Studies.

Disability Studies sprang from the arts with a focus on the autobiographical and lived experience of disability and disablement. Through her art, Alexandra Allen works to make visible those disabilities that are largely invisible. In acknowledging art as a vehicle for positive disabled identity development, she calls for the shift from art as therapeutic to the centering of art as a way of knowing, a curricular window into disability culture.

Kai Rands and James Sheldon utilize the work of Deleuze and Guattari along with Warner’s discussion of publics and counterpublics in engaging online continuing education courses aimed at classroom teachers and focused on themes and issues related to disability. Their work opens a broader discussion about how questions of disability are engaged (or not) with teachers both systemically and explicitly through experiences designed to further their education. Ultimately, Rands and Sheldon remind us that, to effect change in how teachers conceptualize disability, we must offer them experiences that engage them in thinking about disability in new ways.

While Disability Studies has stood in opposition to disability as the other, Melanie Janzen's exploration of "mis"behavior constructed as disability argues for the maintenance of mystery in relation to the other through ethical relationships that humanize rather than label.

Joseph Valente invites the reader into his classroom as students engage in puppet making and the production of a puppet show as vehicles for learning about affect and what it means to practice relationality. In doing so, he also touches on questions of what inclusion is or means and from whence it ought to come.

Utilizing Pinar's (2015) discussion of the curriculum of allegory, Mark Helmsing problematizes the overarching lack of a history of disability, as well as the instances in which disability is highlighted in history. In doing so, he illustrates how historical narratives have illustrated disability as epic, horror, tragedy, and romance.

We end this special issue with Jackie Seidel who brings us back to the autobiographical and creative roots of the field through her exploration of what it means to be a theorist and scholar living in the disruptive spaces that persist in practices of diagnosis and intervention in both the medical and educational fields. In her charge to seek out and embrace moments of vulnerability as vehicles for change, she reminds us of Schubert's (2009) assertion that for "the sake of goodness" is a "highly defensible prerequisite for social justice" (p. 3).

In our own way, this special issue is our answer to both Seidel's and Schubert's calls. As scholars who came to Disability Studies not through formal education but through personal experiences, we often operate in vulnerable spaces, ones in which we hope our own self-constructed understandings will suffice. We offer this compilation of voices and perspectives as the springboard for complicated conversations in which we have longed to engage.

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Notes

1. Authors Agosto, White, and Valcarlos (2019) note: "For historical information on the use of crip and crip theory see McRuer (2006)."

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