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From Existence to Resistance: Critical Disability Studies

*A Note From The Author*

What does it mean to create a world where different minds and bodies can exist in harmony and community? To find and build connection? To rethink what capitalism has defined as valuable? This is Critical Disability Studies. In the pages of this book, I put myself in dialogue with disabled writers, activists, and scholars to explore disability as a social construct, a political identity, and a personal reality. My work is influenced by both by what I’ve learned in the classroom to my experience as an educator, caretaker, and Unitarian Universalist. Recognizing that our capitalist society values some voices more than others, some labor more than others, and some times of scholarship more than others, I resist by engaging creatively with these ideas. I abandon the comfort of a structured academic paper for the risk and freedom of an art project. I hope this book will embody the principles of Universal Design for Learning that call for multiple means of representation, engagement, and expression.

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I begin this book with voice and self advocacy. The original mission of this book was to raise the voices of disabled folks, so I incorporate direct quotes from videos, articles, and books. With an iPad, I hope to demonstrate that this communication can happen in many different forms. As a field observer in a classroom for students with CP, I was amazed by the flexibility of assistance technology that gave the students access to communication: students used their hands, heads, and eye movement to control their text to voice technology. But the richness of communication goes beyond technology: braille, sign language, and touch sign are all used as alternatives to voice. This book serves as an alternative way of communication in itself, weaving narrative with art. The piece that I pulled McBryde Johnson’s quote from, Unspeakable Conversations, lends itself to the title of this book. In this piece, she tells how she had to argue that she was worth existing on this Earth. This demand for simply existing runs throughout this book, as disabled folks do advocacy simply so they can exist in public spaces, in inclusion classrooms, and in movements.

On the next page, I portray the social model of disability. I challenge my readers to rethink what disability means and see the problem as society (and possibly their own stereotypes and prejudices) rather than the person. In “What’s Wrong With Society,” I portray how disabled folks have to demand to simply be allowed to exist in general education classrooms, schools, public transportation, and employment.

To portray community, I recreate Matisse’s “Dance I.” This painting has always symbolized connection and celebration of community to me. In the original, the naked dancers seem free to be themselves, and I hope to depict the pride that Rosemarie Garland-Thomson describes when she comes into her own in my recreation. I chose dancing specifically to challenge the notion that only able-bodied folks or people with a specific body type can do dance. Together, the dancers create a community of people in wheelchairs, people stimming, and people sharing resources. While this is meant to be a joyous celebration of togetherness, it is not an attempt to silence the difficulties that disabled folks face--this is portrayed on other pages. However, it is an attempt to find moments of freedom, love, and community in an accessible world.

Rethinking independence is personal to me. As a caregiver, I constantly strive to think about my praxis and how I can use my work to empower. I depict one of our usual Sunday routines--making lunch--because it is an area where he exercises choice and control over his life. I hope to continue to consider how I can use our time together to improve the quality of his life.

In access intimacy, I depict two hands reaching out for each other across a collage of newspaper. The newspaper represents everything that’s going on in the world that we can't necessarily change, but the hands say, “I’ll be here, no matter what.” Mia Mingus’s quote inspires me to reconsider my relationships with disabled folks to become more conscious of their access needs. I particularly liked that access intimacy is not dependent on someone having a political understanding of disability, meaning that access intimacy is accessible. One doesn’t need to take disability studies in an ivory-tower, higher education institution to be able to connect.

I incorporate changing language because critical disability studies has challenged me to think about the impact of my words. One of my first encounters with disability rights was watching a movement I was a part of, “Standing on the Side of Love”, change to “Side with Love.” While this language was important, it symbolized something greater: striving towards making movements, and life in general, more accessible. It means listening to what disabled folks are saying and taking their words seriously.

In the last page of this book, I explore the idea of resistance. Eli Clare states, “to transform self-hatred into pride is a fundamental act of resistance.” In a country that idealizes individualism and links worth to labor, to proudly claim an identity that others see worthy of pity is resistance. I compliment this quote with a collage of related form of resistance: pride and protest. All of these signs, with the exception of the flag, come from photos of disability movements. I choose to have the White House in the background, as a reminder of the role government has played in granting or denying access. I create a flag, a combination of the disability rights flag and the LGBTQ+ flag with black and brown stripes, as an attempt to strive for the inclusive, intersectional movement that Eli Clare calls for in *Exile and Pride*.

Citations

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