



Book Review - Care Work: Dreaming Disability Justice

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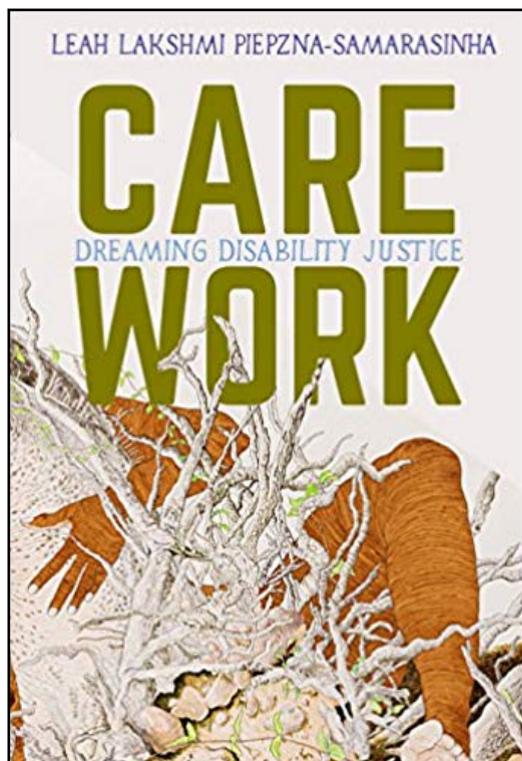
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Leah Lakshmi Piepzna-Samarasinha is a queer disabled performance artist, an activist, and a writer of Burgher/Tamil Sri Lankan and Irish/Roma ascent. She is the author of numerous books, including the memoir *Dirty River: A Queer Femme of Color Dreaming Her Way Home* (Arsenal Pulp Press, 2015), *Bodymap* (Mawenzi House, 2015), and *Consensual Genocide* (TSAR Publications, 2006). She also co-edited *The Revolution Starts At Home: Confronting Intimate Violence in Activist Communities* (AK Press, 2011) with Ching-In Chen and Jai Dulani.

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Inspired by personal experiences of living with chronic illness and of working with other disabled people in the queer and trans community, Piepzna-Samarasinha's *Care Work* is a refreshing collection of essays, interviews, and manifestoes that explores disability at the intersection and looks at the issues sick and disabled queer/trans people of colour (SDQTPOC) face in contemporary North American society.

From a disability justice standpoint, ableism - discrimination against people with disabilities - is intertwined with racism, sexism, queer/transphobia, and social inequality, therefore discussions of disability and disability rights should also engage with these other systems of oppression. In 'Care Webs', she presents a postcolonial critique of disability and points to how institutional racism and the deterioration of socialised medicine lead to an unequal distribution of care resources that disproportionately disadvantages poor disabled people of colour. Sick and disabled people who do not fit the state sanctioned criteria for disability, such as those with chronic, non-visible, or 'unapproved' illnesses like Chronic Fatigue Syndrome (CFS), either have no access to care or must access care at the risk of receiving queer/transphobic and racist abuse from care attendants.

As indicated by the subtitle of the book 'dreaming disability justice', Piepzna-Samarasinha's provocations proffer dream visions of an accessible future and espouses a new kind of 'prefigurative politics' that imagines and works towards that future by creating accessible spaces in the here and now (p.149). In light of the inadequacies of the existing exploitative capitalist model of paid attendant care, she looks to possibilities of creating 'care webs' that allow access to care without shame or ramifications,

such as the Sick and Disabled Queers (SDQ) online community where disabled queer people of colour shared practical care advice and adaptive equipment; and her own Creative Collective Access (CCA) project where she and other disabled queer/trans people of colour coordinated and organised access to help each other get to the Allied Media Conference in Detroit.

Then, in 'A Modest Proposal' she presents a manifesto calling for a 'fair trade emotional economics' that rewards disabled and queer/trans people for their contributions and emotional labour that they are often asked to perform for free by way of educating others about oppression. For Piepzna-Samarasinha, forming care webs is a way of redistributing emotional labour fairly to achieve disability justice, though there are still issues of sustainability and practicality in these approaches in the long-term, especially when many volunteers are disabled and have limited resources themselves.

Behind these dream experimentations is the fact that reality as it currently stands is unlivable for many femme and disabled people. Femme is a term used by people across the gender and sexuality spectrum who identify as feminine but do not always conform to traditional notions of femininity. One of the most moving and important discussions in *Care Work* is the reflection on trauma and trans suicides. In 'Suicidal Ideations 2.0' and 'Things I Know For Sure About Femmes and Suicides', where Piepzna-Samarasinha writes of her own experiences of suicidal ideation as a neurodivergent disabled femme with complex trauma and of the friends she lost to suicide. The two chapters offer a sobering analysis of how society's failures to protect its vulnerable and marginalised members directly and indirectly lead to suicides of disabled

femmes. Mainstream media frequently celebrates assisted suicides of disabled people as acts of bravery and identifies disability as the main cause for suicide, yet seldom discusses the multiplicity of factors outside disability that contribute to disabled femmes' suicides. Many victims of sexual abuse or assault who are also disabled, trans, or black are unable to access support services because of the ableism, transphobia and racism endemic to legal and medical institutions.

Common perceptions of queer/trans disabled femmes as being 'too much' of a burden on others, the cultural taboo on owning vulnerabilities, and the vitriolic transphobic, ableist abuse femme leaders receive both online and in real life all increase their risk of suicide. In critiquing the structural failures that lead to suicides of disabled femmes, Leah Lakshmi Piepzna-Samarasinha's analysis offers a powerful indictment of the multiple forms of institutional oppression against disabled people and prompts readers to seriously rethink the language

we use to discuss disability and suicide. Amid the grief, outrage, and hope, *Care Work* is a defiant defence of disabled survivors' right to be 'unfixed' and imperfect. In a world dominated by profit and gains, the very idea that care can be enjoyable and should be free to everyone is radical. By centring stories of disabled, working class femme of colour, Piepzna-Samarasinha subverts the white-dominated, Euro-Americentric history of disability and demonstrates the creativity and power of the politicised intersectional disability community.

Care Work is a highly-engaging and much-needed addition to emergent conversations on disability justice. For medical students and practitioners, this is an important book on disability studies and intersectionality that will help them better understand how patients of diverse backgrounds experience illness and disability outside the clinic. Scholars and researchers who are interested in queer/trans experience and social justice are sure to find it a valuable resource.

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