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# Leah Lakshmi Piepzna-Samarasinha. (2018). *Care Work: Dreaming Disability Justice*. Arsenal Pulp Press, 2018. ISBN: 978-1-55152-738-3.

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This book review contains references that may not be suitable for some readers. There are mentions of suicide and death.

Informed by her experiences as a queer disabled femme person of colour activist in Canada and the United States, Leah Lakshmi Piepzna-Samarasinha<sup>1</sup> has written an incredible book on the development of the disability justice movement. The movement was formally created in 2005 by Mia Mingus, Patricia Berne, Sebastian Margaret, Leroy Moore, and Eli Clare in response to the erasure of the queer, trans, Black, Indigenous, People of Colour (QTBIPOC) and LGBTQA2+ communities from the white-centred mainstream disability rights movement (Piepzna-Samarasinha, 2018). Using the web of care, disability justice, and anti-oppression frameworks<sup>2</sup>, she chronicles how the QTBIPOC community organizes care and fights for disability justice in a collection of personal essays. Piepzna-Samarasinha is a Canadian and American disability justice activist, writer, and educator (Piepzna-Samarasinha, 2018). She has

<sup>&</sup>lt;sup>1</sup> In Leah's most recent book, *The Future is Disabled: Prophecies, Love Notes, and Mourning Songs*, she indicates preference for she/they pronouns.

<sup>&</sup>lt;sup>2</sup> For more detailed information on these frameworks, the following websites provided helpful information: the <u>Sins</u> <u>Invalid</u> website and <u>Disability Visibility</u> website.

published several social justice books chronicling her experiences as a disabled, queer and trans person of colour and abuse survivor.

Piepzna-Samarasinha's book is compelling as she writes her essays in a personal, relatable, and realistic manner. She speaks to her audience of fellow disabled QTBIPOC comrades and normatively-minded and -bodied people who want to provide community support. Instead of presenting her disability as an "illness that she overcame," she wrote about collective struggle and community building. The book also contains interviews with disability justice activists Stacey Milbern and E. T. Russian, a history of the movement in Toronto from her perspective, and caretaking that places the disabled client as an expert (known as fair trade emotional economics). Other interesting topics the author covered include practical advice on staying well if you are chronically ill (e.g., heating pads, community acupuncture, and fragrancefree products), factors that lead to femme suicide, and inclusive performance spaces through Sins Invalid.

The author begins the book with a resonant chapter called "Care Webs: Experiments in Creating Collective Access." For many people with disabilities, applying for government-funded care through the Supplementary Security Income (SSI), Social Security Disability Insurance (SSDI), Access-A-Ride, and Ontario Disability Support Program (ODSP) is difficult because applicants must present medical proof of a disability or disabilities (Piepzna-Samarasinha, 2018). Those who seek care provided by the aforementioned programs, may be subjected to treatment that lacks dignity and respect. It is a bureaucratic system that does not truly care about the needs of its clients (i.e., profits over lives). She critiques the state and other institutions that perpetuate ableism and the biomedicalization of health. Instead, she embraces radical care/love as forms of healing and the web of care as an option to the charity model of care. The web of care framework

is a form of mutual aid where a group of people work together to provide care to one another. It is also a community-building strategy, where the same group of people will identify its needs and find internal or external resources to help with those needs (Spindel, 2021). We can see this framework being utilized throughout the book.

Piepzna-Samarasinha also focuses on the work of several disability justice activists throughout the book: Eli Clare, the late Stacey Milbern, Elisha Lim, E.T. Russian, and more. She incorporates and acknowledges individuals who have been historically excluded from the mainstream disability rights movement. This is important as there is not supposed to be a "face of disability justice." The author does not want to "erase all of [her] comrades and fellow artists, thinkers, and organizers, particularly those who face certain kinds of ableism that are more overt and killing" (Piepzna-Samarasinha, 2018, p. 25). Better still, she included a further reading section at the back of the book, comprised of websites, books, and blogs by other disability, racial, and healing justice co-conspirators. Her conversations with Stacey Milbern and E. T. Russian also stood out. Milbern talks about the idea of "crip doulaing," where disabled people support one another with transitions in their disability (or diagnosis) – by instructing them on how to code switch, hire attendants, and live with an intellectual disability (Piepzna-Samarasinha, 2018). Disability is viewed as a form of rebirth, a way to resist "how the transition(s) are seen by ableist culture" as death (p. 241). These supports exist because, as Milbern describes, there is little societal acknowledgement of their existence (Piepzna-Samarasinha, 2018).

A quick search of academic journal databases of (disability) AND (sex) produces articles that discuss sexual health disparities and the disadvantages of being disabled and wanting a sexual relationship. In a 2010 conversation with E. T. Russian that she transcribed for the book,

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they discuss the recognition of crip love, lust, and sex. Piepzna-Samarasinha (2018) describes crip sex as "crips lusting for other crips" (119) and expanding people's ideas of sex. It is a form of cross-disability solidarity that is predicated on the appreciation of one's body. This revolutionary notion of crip love also challenges the dominant (and wrong) idea that people with disabilities are inherently asexual. Piepzna-Samarasinha recognizes their contributions for impacting how she lives her life and advocates for disability justice.

The book's biggest weakness is its inconsistent writing style, where there are long and incomplete sentences. This makes it difficult to read and follow. If you have trouble reading conversational-style books, listen to the audiobook version, which is readily available online. While it is unclear whether these mistakes are intentional, they are worth noting. Nonetheless, the book – or a handbook or toolkit – provides a refreshing and personal perspective on the growing disability justice movement in North America through the lens of a disabled person. It contains the theoretical and real-life knowledge required to be an informative yet entertaining read. This book is for disabled, chronically ill, sick, and mad people who have been subjected to heteronormative ideas of "being well" but who want to learn more about community care.

### References

- Piepzna-Samarasinha, L. L. (2018). *Care work: Dreaming disability justice*. Vancouver: Arsenal Pulp Press.
- Spindel, P. (2021). Changing communities (2<sup>nd</sup> ed.): A guide for social and community activists. Toronto: Canadian Scholars.