

BOOK REVIEW

Demystifying Disability: What to know, What to say, and How to be an Ally

by Emily Ladau (2021),

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Demystifying is perhaps the most befitting word that could be used to describe this book as it clears the air around disability for the (temporarily) able-bodied population. The author, a disability rights activist, makes an impassioned and well-founded case for the need to understand disability and the experience of it, our conception of disability, our interactions with disabled people and our responsibility as 'allies and accomplices'. Throughout the pages, there exists a common theme of emphasis on inclusivity. It demands that the reader engage with their existing ideas around disability, disabled people, and their interconnection with the oft ignored/invisibilized largest minority of the world. The emphasis on the circularity between our thoughts and our language is well established throughout the book.

The description of the book by the author as 'a safe space to explore the questions you might have but aren't sure how to ask', is substantiated by the fact that at many points the book reads like a conversation where the author is speaking to you, addressing confusing issues, sensing your discomfort, and assuring you of her non-judgement. Due to its non-jargon heavy and comprehensible language, it is accessible to a significant chunk of the population. Utilization of common tools of narration like anecdotes, 'do's and don'ts', referring to precedents, experiential storytelling, prompting the reader to draw emotional parallels, makes it a profoundly user-friendly practical guide.

The introduction provides a brief background into the author's life and their disability. Several disclaimers about the content and about the fact that the author's expertise does not make the advice generalizable to each and every disabled person in all contexts, are made. Intellectual humility and curiosity with respect to disabled populations is encouraged in the reader through this introduction. Refreshingly, though the book largely caters to individuals who do not have the experience of disability, some snippets of contact with the possibly disabled reader are also evident.

Chapter 1 'So, What is a Disability, Anyway?' is essentially preparatory in that it tries to set the fundamentals straight with respect to labels, significance of language, do's and don'ts for the uninitiated. It is akin to putting on the safety vest before the big dive. It is perhaps a testament to the complexity of the topic that after almost each declaration, a necessary forewarning needs to be added. Ladau has managed to make these smooth transitions in a way that seems effortless and which could help other disabled people broach these topics with the able bodied populace as well. With respect to setting the limits of acceptable language, the author is, neither too reprimanding nor too ambiguous or lenient, which is a significant feat.

Chapter 2 'Understanding Disability as Part of a Whole Person' introduces us to the diversity in disabled experiences and the frameworks via which disability has been understood by people and institutions. The running theme in this chapter is that disability is an umbrella term that includes a myriad of experiences, exemplified by the fact that every person at some point in their life will fall under this category. The underlying attempt by the author is to deconstruct both the idea of 'normal' and the arbitrary categorizations around it that exist in our collective psyche. The ultimate question to arise in the mind of the reader is about the grounds on which their status/identity as an able-bodied person are based and the impermanence of it all. The exercise is heterogeneizing (pointing out that we are different) yet homogenizing (pointing out that we aren't that different) in this sense.

The conversational style that is advantageous in the previous chapters, is in stark contrast with Chapter 3: 'An (Incomplete) Overview of Disability History'

which heavily references details of historic events of importance for the disabled community in the USA. The significance of learning the history of an oppressed minority cannot be understated, however, compared to the rest of the book, the category of history reads as more impersonal simply due to the deviation from the style of the remaining text. Cross cultural relevance of these historic events also can be questioned as disability in India is compounded oppression in that it is often inextricably linked with other marginalized identities especially socio-economic status and gender (Ghai, 2002). Therefore, in keeping with these needs, historic precedents in India with respect to disability have largely been legal interventions focused on medical and vocational rehabilitation. But certain occurrences like disenfranchisement, positive and negative dehumanization, segregation, and eugenics based solutions seem rather culturally similar.

While Chapter 4, 'Ableism and Accessibility' tackles the systemic issues that arise for persons with disabilities at a macro level. Chapter 5, 'Disability Etiquette 101' attempts to explain ableism at the dyadic level and train the reader at making their interactions with other disabled people less ableist. Connecting these two aspects is important as the negative stereotypes and ill-formed concepts that mar everyday interactions with disabled people are borne out of systemic biases. It is possibly the most distinctive feature of the book, as many studies point out the significant negative effects that overt and covert discrimination especially in social relationships, can have on the well-being of persons with disability (Tough et. al, 2017). Disabled people may face ableism in different forms, ranging from benevolent (positive dehumanization) to ambivalent (condescending, paternalistic) to overtly hostile (negative dehumanization) (Nario-Redmond et. al, 2019). The impact of microaggressions - subtle verbal, behavioural, or environmental slights and insults that communicate a hostile or derogatory message based on an individual's social status - is also well documented (Lett et. al, 2020, Olkin et. al, 2019). Together these chapters drive home the point of how systemic ableism influences accessibility and in turn, this lack of accessibility limits the opportunities for inter-abled dialogue and continues the cycle of overt/covert systemic and individual discrimination.

Chapter 6, 'Disability in the Media' can be beneficial when it comes to understanding the representation of disabled people and how that has had

an impact on our understanding of disability. The insider perspective that this section offers is valuable information for anyone who consumes media in today's time. The negative and even positive portrayals of disability in media are often the first introduction of the disabled community to the able bodied community. The impact of positive portrayal of disabled people is connected to disabled joy, which the author alluded to in the introduction itself mentioning how having a mother with the same disorder as hers was like having a person built into her life who just *gets her*. A powerful reminder of the impact that even the slightest positive support or representation can have on people's lives.

The conclusion in the end is an instructional guide on how the able-bodied community can fight alongside the disabled community and how the curb-side effect works. When rights of disabled people are assured, it directly translates to the rights of all people. Essentially that a better and more accessible world for disabled people is a better world for all people. So the responsibility needs to be shouldered by everyone while prioritizing those with disabilities and their experiences.

However, the cultural applicability of the book in the Indian context is lesser, especially with respect to the chapter on history. As mentioned earlier, disability in India is usually accompanied with multiple marginalizations including poverty, regionalism, caste, gender, linguistic and religion based discrimination. Structural discrimination against disabled people in India may very well start with infanticide. The immediacy of concerns has a different hierarchy in India for the disabled. Architectural inaccessibility may be considered a higher priority in metropolitan cities which are unlike certain rural parts of India where even accessibility to a road network is sometimes lacking. Prolonged poverty and deprivation, deficient healthcare systems (especially when it comes to conditions at childbirth), and malnutrition are some of the major contributors to preventable acquired disabilities in India. To tackle dehumanization, we need exposure to the disadvantaged population and inaccessibility hinders possible inter-abled community interactions, affecting advocacy to a great degree, which is what is required to bring about tangible change. Though the book does allude to accessibility and advocacy of rights as being closely connected (in

Chapter 4 and in its conclusion) its applicability in the Indian context remains to be examined.

As the content of the book is largely aimed at destigmatizing disability, the conceptualization of stigma therefore is crucial. The emphasis on the societal dimensions of disability necessitates the integration of cultural ideas like religion, morality, and community. This is evident in the way that different disabilities are treated in India. Example, physical disabilities are more likely to be seen as tragic whereas mental disabilities are more likely to be seen from a moral or religious angle. These fundamental ideas about the origin of disability and misinformation about the same are still the most prominent obstacles in India. The book is not aimed at an Indian population, and thus it is insufficient to understand the full breadth of the social experience for disabled people in India.

A catch-22 situation arises because though the conversational style of the book is advantageous, it can be a possible impediment too as the text can be read as non-academic and therefore non-serious. Ironically the text is also largely informational/instructional and sometimes falls short of getting into a vulnerable position which could help build empathy in the reader. But in defense of the author, it is indeed difficult to present a vulnerable narrative in case of disability without activating the 'tragedy' archetype in the mind of the able-bodied reader.

To conclude, the book can be considered an essential and a handy reading for the general population regardless of their academic ability as it provides key insights into the world of disability without shying away from complexities and technicalities. It is a useful starting point for anyone who seeks to develop for themselves a favourable lens to seek to be more connected to the disabled people in their lives, and, for disabled people who want to better advocate for themselves. Though, lacking an Indian context, the book in its commitment to demystifying disability through increasing meaningful social interaction among diverse populations provides a relevant read.

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