Ranu Uniyal
Fatima Rizvi *Editors*

# Understanding Disability

## Interdisciplinary Critical Approaches

Springer

# Understanding Disability

Ranu Uniyal · Fatima Rizvi
Editors

# Understanding Disability

## Interdisciplinary Critical Approaches

Springer

*Editors*
Ranu Uniyal
Department of English and Modern European Languages
University of Lucknow
Lucknow, Uttar Pradesh, India

Fatima Rizvi
Department of English and Modern European Languages
University of Lucknow
Lucknow, Uttar Pradesh, India

ISBN 978-981-99-4924-3 ISBN 978-981-99-4925-0 (eBook)
https://doi.org/10.1007/978-981-99-4925-0



This Springer imprint is published by the registered company Springer Nature Singapore Pte Ltd.
The registered company address is: 152 Beach Road, #21-01/04 Gateway East, Singapore 189721, Singapore

Paper in this product is recyclable.

# Contents

# Chapter 21
# Shaping the Disability Discourse: From Theoretical Groundwork to Lived Experiences


**Amrita Sharma**

**Abstract** 'Disability studies,' as an emerging field of discourse, has shaped itself as a discipline across the later decades of the twentieth century through a range of contributions by theorists, disability rights activists, and writers. The long-associated stigma with a 'disability' in any form is gradually gaining wider attention with a growing demand for equal rights for persons with disabilities in the society. This paper aims at analysing the literary factors that have and continue to play a crucial role in shaping this disability discourse. While a few theoretical concepts and studies remain foundational in laying the groundwork for future scholarship within the disability studies, a number of literary narratives emerging out of a direct lived experience of disability also remain significant. The paper thus attempts to highlight this theoretical groundwork and lived experience that play a role in shaping the disability discourse.

**Keywords** Disability · Lived experiences · Literary discourse · Narratives · Theory

As the reaction to prolonged marginalization and oppression has often led to the creation of a 'new' discourse that refutes the identity politics, 'disability' remains one of the crucial constructs that has emerged as a significant subject of study. With a long history of discrimination and oppression relating to persons with disabilities, an effort to deconstruct the disability stigma has led to the creation of anew discipline. Formally established by the Modern Language Association as a 'division of study' in 2005, 'disability studies' remains particularly sensitive to the concept of 'disability as a social construct' and its perception among the masses. Having evolved as a distinct discipline within the literary and academic circles, the subject remains a crucial combination of contributions made by both the persons with disabilities having a 'first-person experience' as well as theorists or writers presenting a 'third-person' account of it.

A. Sharma (✉)
Department of English, Sri Venkateswara College, University of Delhi, Delhi, India



R. Uniyal and F. Rizvi (eds.), *Understanding Disability*,
https://doi.org/10.1007/978-981-99-4925-0_21

While the discourse relating to the rights of persons with disabilities has recently emerged in the late twentieth century, it significantly draws upon the works of theorists like Erving Goffman and Michel Foucault as well as disability rights activists and their real-life encounters. The literary and cultural narratives emerging as a part of this discourse also remain a composite of the theoretical concepts as well as the activism surrounding social injustice. With persons with disabilities actively coming forth with narratives drawing upon their own personal experiences, an interrelated dynamics operates between the larger intellectual framework that included disability as a part of the overall social discourse and the lived experience narratives. The paper presents an analysis of a few key theoretical ideas that have emerged central to the discipline, followed by examples of select literary narratives that draw upon the first-hand experiences of the authors. Though distinct in their approach, both the former and the latter collectively contribute to the discipline.

Many sociological studies on the discrimination with people suffering any form of 'difference' from the mainstream also included an analysis of the condition of persons with disabilities. A key text in this regard remains the sociological treatise titled *Stigma: Notes on the Management of Spoiled Identity* written by Erving Goffman. Goffman, often regarded by many as the most influential sociologist of the twentieth century, remains one of the earliest social psychologists dealing with the condition of 'disability' as a 'stigma' whose works remain significantly influential for providing a theoretical framework. In *Stigma*, Goffman points:

> The stigmatized individual is asked to act so as to imply neither that his burden is heavy nor that bearing it has made him different from us; at the same time he must keep himself at that remove from us which assures our painlessly being able to confirm this belief about him. Put differently, he is advised to reciprocate naturally with an acceptance of himself and us, an acceptance of him that we have not quite extended to him in the first place. A PHANTOM ACCEPTANCE is thus allowed to provide the base for a PHANTOM NORMALCY. (Goffman)

While theorizing on 'stigma' as a larger concept, Goffman's work remains notable for articulating a clearly distant theoretical record of a sociological study that also finds relevance in understanding disability as a social stigma. As a disabled individual is often forced to associate with a community of other disabled persons, Goffman's theory helps in understanding the notion of ambivalence that a stigmatized individual may experience when going through such forced associations. The form and extent of disability and its interplay with everyday experiences of an individual thus become secondary to the psychological trauma experienced as a result of such social stigmatization.

Goffman also includes an example of a lived experience of disability in his text to highlight the "stigma" associated with it. He provides the example of a 'newly blind girl' who is taken to the Chicago Lighthouse as soon as she leaves the hospital. He describes her nauseating experience as she is suddenly exposed to a world of "destructive segregation" where only the blind people ate, met, sang, and worked together. As the social service agency takes pride in reassuring the girl of a safe world, Goffman explains the horrifying trauma experienced by the girl of being

forced into a community of blind people. Thus, the lived experience of a 'stigma' exponentially grows with segregation and forced associations.

However, while Goffman used descriptions of lived experiences of disability to elaborate on the stigmatization and social devaluation of marginal identities, his work provided a larger intellectual groundwork that was not specifically devoted to the study of disability and its lived experience. Though still significant today within the disability discourse, Goffman's work also faced criticism by disability theorists in particular. Susan Wendell, herself having a lived experience of disability, remains a notable theorist on the subject, and her critique of Goffman found in her work titled *The Rejected Body* also brings forth a contrast between the first- and third-person perspectives on the subject:

> Goffman repeatedly fails to appreciate the possibility that having at least some disabilities may be, like membership in some other groups that are stigmatized, as good as or better than 'normality.' He discusses valuing one's difference only as a coping strategy of the stigmatized, without calling into question the objectivity or permanence of the values that regard them as less than 'normal.' On the contrary, he rates valuing one's difference and identifying closely with those who share it rather low, even as a coping strategy: The first set of sympathetic others is of course those who share his stigma. Knowing from their own experience what it is like to have this particular stigma, some of them can provide the individual with instruction in the tricks of the trade and with a circle of lament to which he can withdraw for moral support and for the comfort of feeling at home, at ease, accepted as a person who really is like any other normal person. (Wendell)

Thus, disability studies activists have gradually moved from a generalized marginal identity towards the study of a disability specific experience that takes into account the social and cultural parameters that emerge out of a disabled identity.

One of the key theoretical concepts that has provided a firm grounding to the perspectives about disability is the distinction between the medical and the social model of disability. While the former treated disability purely as a medical condition within an individual, the social model has radically challenged this former notion. The social model presents disability as an outcome of social factors rather than an individual's condition. Simi Linton, in her work titled *Claiming Disability*, emphasizes the need for "refusing the medicalization of disability" (2) and providing a composite identity to all people having varied lived experiences of disability and the "social and political circumstances that have forged us as a group" (Linton 4).

As the social model provides a starting point for advocating a change in the social and cultural factors, the intellectual framework surrounding disability has further been enriched by scholars who have attempted to deconstruct the disability stigma through diverse approaches. Lennard J. Davis, one of the leading theorists in this field, in his article "Constructing Normalcy: The Bell Curve, the Novel, and the Invention of the Disabled Body in the Nineteenth Century" provides a ground for exploring the idea of the 'normal' in the society and its relating impact on the perception of 'disability' at large. He presents a clear idea of the prevalence of this state of 'normalcy' in the opening lines as he writes:

> We live in a world of norms. Each of us endeavors to be normal or else deliberately tries to avoid that state. We consider what the average person does, thinks, earns, or consumes. We

> rank our intelligence, our cholesterol level, our weight, height, sex drive, bodily dimensions along some conceptual line from subnormal to above-average. We consume a minimum daily balance of vitamins and nutrients based on what an average human should consume. Our children are ranked in school and tested to determine where they fi t into a normal curve of learning, of intelligence. Doctors measure and weigh them to see if they are above or below average on the height and weight curves. There is probably no area of contemporary life in which some idea of a norm, mean, or average has not been calculated. (1)

This idea, Davis states, remains crucial to the understanding of the idea of 'disability' in order to scrutinize the problem at its root. The argument remains significant and provides a wide ground for reflection. It is important to read Davis's work and his arguments on the idea of disability being inherently related to the idea of a 'norm' or a standard that is regarded as normal by the society. Also, pointing to the introduction of a wide range of lexicon relating to this at varying points of history, Davis makes it evident as to how the society has been moulded by a tendency to compare everything to a standard value.

Similarly, Tom Shakespeare in his work "The Social Model of Disability" also does not restrict his analysis to just the "social" approach but rather advocates for an understanding of disability as one that needs varying levels of study "ranging from the medical to the socio-political" (Shakespeare 204). Extending upon the idea of the interaction of a disabled body with the cultural factors, David Mitchell and Sharon Snyder, in their work *Cultural Locations of Disability*, proposed a "cultural model" to understand disability. On the other hand, Tobin Siebers, in his 2008 book titled Disability Theory, presents the idea of "complex embodiment" that defines disability in relation to both the body and the environment and looks at disability as an epistemology that does not attempt to conform to any other law except that body needs to be valued as what it was and willingly accepts any form that it takes or becomes. According to Siebers, disability discourse must provide a ground that brings up both the negative and positive aspects of disability and work as a medium that speaks for and about persons with disabilities.

While a range of scholarship regarding the Disability Theory has emerged within and outside academia, disability activism has also contributed significantly in this regard. A notable example of the latter may be found in a human services-based approach called the Social Role Valorization Theory or often noted as the SRV theory. The theory relates to a "dynamic set of ideas" that have laid the foundation of the Keystone Human Services that primarily work in the area of disability. Operating on an intellectual framework of "valued social roles" in the society, the theory remains a significant example from contemporary disability activism. Explaining SRV, Joe Osburn, in "An Overview of Social Role Valorization Theory" writes:

> Social Role Valorization (SRV) is the name given to a concept for transacting human relationships and human service, formulated in 1983 by Wolf Wolfensberger, PhD, as the successor to his earlier formulation of the principle of normalization (Lemay, 1995; Wolfensberger, 1972). His most recent (1995) definition of SRV is: "The application of what science can tell us about the enablement, establishment, enhancement, maintenance, and/or defense of valued social roles for people". (Wolfensberger, 1995a) (7)

Though moving from a broader to a specifically disability-oriented approach in its initial years, the disability studies in the contemporary times again continues to draw in from larger social theories like SRV that include disability as one of their key elements.

While the research on the theoretical groundwork analyses the social dynamics that lead to the marginalization of the disabled community, a range of narratives of lived experiences of disability also contribute to the disability discourse at large. A significant number of authors having a first-hand experience of disability have contributed through various non-fictional and literary narratives and diverse cultural platforms like digital media and life blogs. The following section highlights a few of such narratives and their significance.

A key example of a contemporary expression of lived experiences of disability is the collection titled *Disability Visibility: First-Person Stories from the 21st Century*, edited by Alice Wong published recently in 2020. Appearing amidst the COVID pandemic crisis, the work contains thirty-seven essays by authors having a lived experience of disability, compiled by another disabled writer and activist. With a powerful dedication that calls out to all persons with disabilities, Wong's collection remains notable on many grounds. Brenna Swift, in the review of this collection, notes:

> Wong's highly anticipated collection celebrates the lives of disabled people while making a powerful political statement about the need for disability justice, representation, and an end to violence in all forms. By foregrounding the stories of disabled people of color, it rejects the whiteness of rights-based disability discourses and builds the intersectional strength of the disability justice movement. In the book's introduction, Wong shares that her goal in making disability visible is not to inspire those without disabilities or offer up the lives of multiple marginalized disabled writers for analysis. Rather, the collection is a statement of community, love, and solidarity for disabled people. (2)

With contributions by diverse authors with a wide range of physical and mental disabilities, this contemporary collection of lived experiences significantly contributes towards the strengthening of a disability discourse that continues to thrive against a lack of greater recognition and acceptance.

A dynamic collection of narratives relating to disability and healthcare systems also find expression in the three editions of *The Social Medicine Reader*. With contributions from lived experiences that survey the socio-medical challenges, the compilation contains essays providing insights into the real-life conditions and the human psyche. "On Being a Cripple" by Nancy Mairs, also appearing as a part of the third edition of this collection, presents a moving and powerful example of a lived experience of disability. Mairs, suffering from multiple sclerosis, writes of her own perception of a disabled identity. Her introductory paragraph distinctly encapsulates the potency of a personal narrative:

> The other day I was thinking of writing an essay on being a cripple. I was thinking hard in one of the stalls of the women's room in my office building, as I was shoving my shirt into my jeans and tugging up my zipper. Preoccupied, I flushed, picked up my book bag, took my cane down from the hook, and unlatched the door. So many movements unbalanced me, and as I pulled the door open I fell over backward, landing fully clothed on the toilet seat with

> my legs splayed in front of me: the old beetle-on-its-back routine. Saturday afternoon, the building deserted, I was free to laugh aloud as I wriggled back to my feet, my voice bouncing off the yellowish tiles from all directions. Had anyone been there with me, I'd have been still and faint and hot with chagrin. I decided that it was high time to write the essay. (1)

The acceptance of a disabled identity and its challenges by such lived experience narratives serves to empower the notion of a so-called normal existence and attempts to positively shape the disability discourse. A similarly powerful example of a lived experience narrative of autism may be found in Temple Grandin's *Thinking in Pictures* where she humorously points:

> In an ideal world the scientist should find a method to prevent the most severe forms of autism but allow the milder forms to survive. After all, the really social people did not invent the first stone spear. It was probably invented by an Aspie who chipped away at rocks while the other people socialized around the campfire. Without autism traits we might still be living in caves. (7)

Thus, presenting a positively driven account of coping with severe medical impairments, many examples of personal accounts of living with disabilities have provided dynamic perspectives to the disability discourse. Attempting to deconstruct the stigma associated with disability through their own real-life examples, such narratives make significant contributions to the discipline of disability studies.

Many examples of disability narratives also find expression across varying genres of literature. While characters with various forms of disabilities have been a part of literary narratives since the classical ages, giving a central place to characters with disabilities and bringing forth the fictionalized first-person narratives of lived experiences of disability remains a rather recent phenomenon. Some of the examples that stand out for their unique treatment of disability as their central context have gained widespread recognition. The 2003 novel titled *The Curious Incident of the Dog in the Night-time* by Mark Haddon won the Whitbread Prize and the Commonwealth Writer's Prize and remains one such text that includes a first-person narrative of a 15-year--old boy with behavioural difficulties. Presenting a narrative that perceives the world in a different way, the novel's treatment of disability remains exemplary for its emphasis on a unique lived experience.

Apart from non-fictional and fictional narratives, a few other examples of literary texts that portray the lived experiences of disability may also be found in theatre and poetry. An important example from the former is the collection titled *Beyond Victims and Villains: Contemporary Plays by Disabled Playwrights* edited by Victoria Ann Lewis. Lewis, who is the founding figure behind the Mark Taper Forum's Other Voices Project, has been actively involved in disability rights activism and founded the "Other Voices Project" to create a professional space for playwrights with disabilities. Also, poetic works like Ginsberg's "Kaddish" and Gwendolyn Brooks' "sick man looks at flowers" also delve upon the subject of disability in different forms.

As the interrelations between disability and its social understanding by both the ablest and the disabled community remain complex and unclear at times, theorizing disability in its complete manifestation remains difficult. While even within the disabled community, persons with varied disabilities may experience significantly

different challenges, and the theoretical framework may at times appear less flexible in adapting to individualistic concerns. However, at the same time, the diversity of the lived experiences of disability both contributes to its practical understanding as well as problematizes a completely uniform definition.

Thus, as 'disability' remains a human phenomenon that pervades across all cultures and creeds, it remains significant to shape a discourse that gives a voice and space to persons with all forms of disabilities. While the theoretical groundwork to disability studies may have contributions by diverse scholars, an integration of the lived experiences to the intellectual models and literary narratives holds potential for a greater outreach. While no marginal discourse can truly serve the purpose of empowering the disempowered without a constant strife towards the mainstreaming of the subject, disability studies, with contributions from both within and outside disabled community, have witnessed a substantial growth in its scholarship in the past few decades. With a socially rooted theoretical groundwork and culturally interwoven lived experiences, the literary discourse surrounding disability thus continues to evolve. While opening new perspectives and possibilities within literary scholarship and creating awareness of basic human rights, the disability discourse holds tremendous potential for future research and advancement.

## Bibliography

Albrecht, G. L. (Ed.). (2005). *Encyclopedia of disability* (Vol. 5). Sage.
Barnes, C., & Mercer, G. (2010). *Exploring disability.* Polity Press.
Burch, S., & Longmore, P. K. (Eds.). (2009). *Encyclopedia of American disability history* (Vol. 3).
Burch, S., & Rembis, M. (2014). *Disability histories.* University of Illinois Press.
Campbell, F. K. (2009). *Contours of ableism: The production of disability and abledness*. Palgrave Macmillan.
Davis, L. J. (Ed.). (1997). *The disability studies reader*. Routledge.
Goffman, E. (1986). *Stigma: Notes on the management of spoiled identity.* Simon & Schuster Inc.
Grandin, T. (2009). *Thinking in pictures.* Bloomsbury Publishing.
Johnstone, D. (2001). *An introduction to disability studies.* David Fulton Publishers.
Linton, S. (1998). *Claiming disability: Knowledge and identity.* New York University Press.
Mairs, N. (2019). On being a cripple. In *The social medicine reader* (Vol. II, 3rd ed.). Duke University Press.
Mitchell, D., & Snyder, S. (2006). *Cultural locations of disability*. University of Chicago Press.
Osburn, J. (1998). An overview of social role valorization theory. *The International Social Role Valorization Journal/La revue internationale de la Valorisation des roles, sociaux, 3*(1), 7–12.
Shakespeare, T. (2006). The social model of disability. In L. J. Davis (Ed.), *The disability studies reader* (pp. 197–204). Routledge.
Siebers, T. (2008). *Disability theory*. The University of Michigan Press.
Wendell, S. (1996). Disability as difference. In *The rejected body*. Routledge.
Wong, A. (Ed.). (2020). *Disability visibility: First-person stories from the 21st century*. E-book, Vintage Books.