

Authoring Disability, Documenting Struggle: an Analysis of Naseema Huzruk's *The Incredible Story*

P. Boopathi, Ph.D.

Assistant Professor

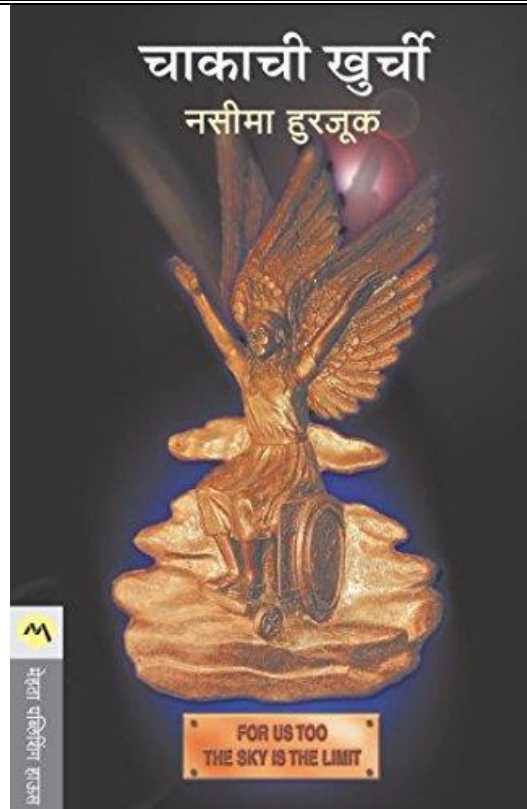
Department of English Studies

School of Social Sciences and Humanities

Central University of Tamil Nadu, Thiruvarur 610005

pboopathi@cutn.ac.in

Mobile: +91-9843693951



Courtesy: www.amazon.com

Abstract

Disability life narratives, written with the equal vigor and vitality of other marginalized life narratives, narrate the countless struggles and discriminations endured by the disabled in their day today lives, while challenging “Ableist Culture” and “Corporeal Normativity.”

Emerged as purely “Ethnocentric Narratives,” the life narratives of the disabled foreground the untold and marginalized stories of the disabled in a more poignant manner by documenting their distinct life experiences. Having drawn inspiration from Civil Rights and Feminist Movements, the disabled people, mostly activists of the Disability Rights Movement, have begun recording their struggles as part of documenting disability history throughout the world in the latter half of twentieth century. In such process, they felt the need for their self-representation, for their representation in literary writings by the non-disabled has downgraded their dignity and reduced them to a mere objects of self-pity and charity. In the Indian context, the life narratives of the disabled recount various kinds of discriminations faced by the disabled people such as religious, gender, social, caste, class and cultural.

The text *The Incredible Story* (2005) selected for this paper is an autobiography of Naseema Huzruk, a disabled woman belongs to the state of Maharashtra. Her autobiography is one of the pioneering texts of the disabled in India. It is considered to be the first women disabled life narrative published in the subcontinent. A founding text of disability life narratives in India, Naseema’s autobiography touches upon various issues such as rehabilitation, accessibility, education, healthcare and employment pertaining to the disabled people in India in the latter half of the last century. Her text is a telling account of the countless issues faced by the disabled before the enactment of first disability legislation (PWD Act) 1995. The text also documents how Naseema, being a Muslim woman, encountered hurdles and challenges posed by the upper caste Hindus in her ceaseless struggle for the empowerment of disabled. This paper, by reading Naseema’s life narrative as a document of disability history in the Indian state of Maharashtra, will attempt to unearth her stupendous struggles to promote the countless disabled at the time when there was no legal protection for the disabled.

Keywords: Naseema Huzruk, Disability Life Narratives, Disability History, Self-Representation, Disability Rights Movement and Ethnocentric Narratives.

Disability History, relatively a new branch of Disability Studies, gained the attention of academia in the last decade. The epistemology of disability, fostered through the discipline of Disability Studies, internalizes Disability History to unearth the status of disabled in the past. Like other marginalized studies such as Dalit, Women, LGBTQI and Minorities, Disability Studies also emerged from rights movements in the early 1980s. As it adopted the models like rights, citizenship, social and minority followed by the Disability Rights Movements in England to study the subject position of the disabled in the early period, it did not take up the history of disabled as its focus. Since charity, medical and individual models of disability dominated the discourses on disability till the 1990s, scholars in Disability Studies were mostly occupied with countering such Ableist approaches. Further, owing to these prevalent approaches towards

disability, the fields such as law, sociology, psychology and feminism formed the theoretical bases of Disability Studies before 2000. The historical approach towards disability, propelled by the plight of disabled people in nineteenth and twentieth century Europe, employed by historians to revisit the history of America and England to analyze the treatment of disabled.

While the scholars in Disability Studies use the historical approach to study the predicament of disabled in the past, there has also been an attempt in the recent times to critically evaluate the Western history against the backdrop of disability epistemology. As the analysis of available Western histories proved to have excluded the disabled, the disability scholars felt the need for the history of their own to explicate socio-political, economic, cultural and educational condition of disabled people in the past throughout the world. In this attempt of writing history, several texts have been authored by scholars who work on the intersection of disability and history on the status of disabled in the Medieval Period, Age of Enlightenment, nineteenth century, Two World Wars, etc. Such texts constitute what later came to be called Disability History in the mid of last decade. For the process of writing this history, religious texts, philosophical books, literary works and historical volumes from various centuries have been analyzed. The literary works, especially, provided enough materials to discuss how the disabled were looked at in the particular period and offered sufficient references for the historians to argue the socio-political and economic status of disabled in the specific time. Besides the huge compendium of non-disabled texts belonging to different centuries, the ethnocentric narratives of disabled in the form of life writings, poetry, short stories and novels serve as the vital source for documenting disability history in the contemporary times. This paper, by elucidating the process of writing disability history, will try to analyze Naseema Huzruk's *The Incredible Story* to reveal how the texts by narrating the struggle of Naseema recounts the disability history of Maharashtra. It will also explicate how the disabled life narratives document the disability history through narrating the life stories of individuals like the life narratives of Dalit, Tribal, Transgender and Refugees.

As other conditions, disability has also been a biological, cognitive and sensory difference of human beings since the beginning of human race. Yet, such differences have been seen as anomaly, deviance, deformity, etc. in the various time periods. Human expressions like literature, art and sculpture produced in various periods, indeed, bear a testimony to such claim. The development of philosophical thoughts, scientific inventions, formation of cities and the rapid expansion of industrialization, surprisingly, marginalized and excluded the disabled from public view in the nineteenth and twentieth century quite apparently. In the twentieth century, the Two World Wars, Israeli-Palestinian Conflict, Sri Lankan Civil War, Vietnam War, etc. created more number of disabled people including both civilians and soldiers. This, in fact, brought the presence of disability to the public appearance. While the above mentioned wars increased the

population of disabled people in the western countries, the strong protest of disabled people to include them in the society, to create accessible environment, to have equal opportunity, to ensure equal rights and so on established their presence more obviously in the latter half of twentieth century. This stanch and persistent protest constituted a wider movement called Disability Rights Movement (DRM) in the 1970s, including all types of disabled people.

As discussed earlier, disability was studied in the fields such as education, sociology, law and psychology till the beginning of this century. The discipline of history, however, did not make a foray into the domain of disability studies until the mid of last decade. On the other hand, history also did not include disability as one of its focus until disability studies emphasized the need for it. As discussed by Carl R. Weinberg in his short essay “Disability History,” disability offers a new way to study history: “Disability is not a new word, but for many of us, it is a new way to look at history” (1). This further suggests that disability in history has not been discussed owing to its obscurity and prevailing of dominant ableist culture. Another aspect of disability history, according to Weinberg, is the impact of DRM in changing the name from disabled people to people with disabilities (1). While the former places disability as an immediate identity to discriminate, the latter, nonetheless, by keeping disability as a secondary one, accentuates equality of all people. Given the wider reach gained by disability history in the western academia, Weinberg envisages that after 20 years it will become inevitable part of curriculum in the secondary and post-secondary levels.

Disability history, being an alternate historiography, besides documenting the lives of disabled, attempts to study the process of othering of disabled. This is done through foregrounding the treatment of disabled people in various periods in history. Notably, the oppressed subjects whom history terms as marginalized and other do not include the disabled, for disability did not qualify to be an oppressed one due to the process of normalizing it. While a lot of reasons are cited for such concerted exclusion of disabled both from mainstream and margin, the primary, yet often disputed, reason is seeing disability as an individual issue, but not the social one. Owing to such reduced understanding/treatment of otherwise social issue, disability, as discussed earlier, was mainly studied by special educators, social work professionals, psychologists and rehabilitation scholars for a longtime. It is the social model of looking at disability propounded by Mike Oliver, according to disability historian Catherine J. Kudlick, that provided a scope for disability to be studied in history (3). This social approach towards disability problematizes the omission of disability in writing history, despite the presence of disability in the history of any period/century.

The text *The Incredible Story* (2005) is an autobiography of Naseema Huzruk, a disabled woman belongs to the state of Maharashtra. Her autobiography is one of the pioneering texts of

the disabled in India. It is considered to be the first women disabled life narrative published in the subcontinent. The text was originally written in Marathi by Naseema and later translated into English by Aasha Deodhar in 2005. It was edited by a renowned critic Rukmini Sekhar and published by Delhi based Viveka foundation publishing house. A founding text of disability life narratives in India, Naseema's autobiography touches upon various issues such as rehabilitation, accessibility, education, healthcare and employment pertaining to the disabled people in India in the latter half of the last century. Her text is a telling account of the countless issues faced by the unmarried disabled woman before the enactment of first disability legislation (PWD Act) 1995. The text also documents how Naseema, being a Muslim woman, encountered hurdles and challenges posed by the upper caste Hindus in her ceaseless struggle for the empowerment of disabled in the state of Maharashtra. The organization "Helpers of the Handicapped" established by Naseema as part of her rehabilitation struggle in Maharashtra remains to be one of the pioneering organizations established by disabled people for the empowerment of the disabled in India.

In his foreword to Naseema's autobiography, the late disability activist and the founder of Cross-Disability Movement in India, Javed Abidi finds a close connection between disability and poverty, and tries to locate Naseema's activism in empowering the economically weaker disabled in Maharashtra. He explicates how Naseema fought for the accessible and barrier-free environment at the time when there was no awareness among Indians about disability. Abidi in his foreword also demonstrates how the premier organizations like National Human Rights Commission, Planning Commission of India and the Census Commission did not pay any attention to the disabled till 2000. He concludes the foreword by making a historical statement: "Not many people in India know that yellow is the color of disability. And so, I will suggest that after having experienced the green revolution, leading to self sufficiency in food, the white revolution leading to self sufficiency in milk and milk products, it is time now for our country to undergo yellow revolution! We need to create a disabled-friendly India (4). The editor of this book, Rukmini Sekhar writes in her editorial note that Naseema made the hundreds of the disabled live in empowering manor with the key mantra "You lack nothing, you are only different" (5). This, according to Rukmini, enables them to be independent and live with self-respect, the two important traits of human life which the disabled in India are often deprived of.

Having been born in a middle class Muslim family in the state of Maharashtra, the disability activist and the founder of the renowned organization (Helpers of the Handicapped) for physically impaired, Naseema Huzruk acquired her disability of paraplegia when she was in college. She underwent a numerous struggles and agonies owing to the unexpected befall of disability and the lack of awareness to accommodate such condition both in the family and in the

society. As she says in her autobiography about the changes that abruptly took place after she acquired paraplegia:

No one told me but by now I knew that I had become a paraplegic. Do you know what it feels like to be a paraplegic? As a small girl, I had read a story [j^ about a king who had been cursed by someone. Half > his body turned to stone, rendering him immobile, pinning him down in a particular place for years. Then someone came and removed the curse and he became a whole man again. Half my body, from the waist to the tips of my toes had turned to stone. The only difference was that the king in the story was standing whereas I had to lie down all the while. Half my body was going to be listless for the rest of my life. I had no control over my urine or bowels, neither was I aware of when I passed them. (rukmini-sekhar-nasima-hurajuka 14)

Naseema, like majority of the disabled in India, had to face a great deal of huddles to continue her education, as she needed to be taken to the doctor frequently. It affected her family's economic condition to a large extent of creating unrest among her parents. She recounts how she struggled hard to get her first wheelchair at the time when India hardly had any idea of independent mobility for a physically impaired person through the use of wheelchair: "A wheelchair at last! What freedom from this constant lying down on a bed! I would move around and feel like a normal human being once more and not like a sack of potatoes!" (rukmini-sekhar-nasima-hurajuka 17). The untimely death of her father left her family in deep misery, forcing Naseema and her brother to earn for the livelihood of the family. It is the harsh reality of disabled in India that the majority of the disabled live in acute poverty and they are sadly based in rural areas. This, in fact, struck Naseema deeply to do some kind of service to those disabled who share the same experience of socially ostracized and economically deprived. As a result, she opened her organization to serve the disabled after a massive struggle in her own district Kolhapur. Through this organization, she has empowered hundreds of poor disabled from rural Maharashtra to get education and to avail other facilities like healthcare, employment and disabled sports. She was initially motivated by a veteran disabled activist Babu Kaka in the state of Maharashtra to be self-reliant and to work for the disabled community:

I don't remember exactly what he said, but I do remember being overwhelmed at seeing a man on a wheelchair smile so happily and talk about things like big industry and air travel. I had a strange feeling that I had indeed found my buland man in Baba's khudi ko kar buland poem! He told me how I should complete my education and participate in sports competitions for the disabled. He also told me that I should not only get self-reliant but help other disabled people in Kolhapur. It was a day I could never forget

because for the first time I felt I had control over my own disability. (rukmini-sekhar-nasima-hurajuka 20)

The concluding lines of Nasima's autobiography are worth quoting here to demonstrate her vision of egalitarian and inclusive society for disabled in India:

Despite all the setbacks I still dream. In my dreams I see the able and the disabled attending the same educational institutions and helping each other. I see better R&D facilities for research and production of prostheses and appliances. I see more compassionate homes for the destitute disabled. I see disabled people forming a commune of fortitude where he or she can find a life partner and lead a fulfilled life. (rukmini-sekhar-nasima-hurajuka 123)

As Rukmini says in her editorial note: "To be disabled in India is bad enough, but to be poor and disabled and a woman is a pure hell (8), Naseema's text is a testimony of these harsh discriminations meted out to her on such grounds. As mentioned earlier, besides such three-fold discriminations, she also had to endure different treatments based on her minority status in the society. This intersectional characteristic of a disabled subject is more often than not left out by the activists and Disability Studies scholars in the Indian context. However, Naseema's text calls for such type of approach among readers than the singular notion of disabled subject being a socially and culturally oppressed ones.

Works Cited

- Kudlick, Catherine J. "Disability History: Why We Need Another 'Other.'" *The American Historical Review*, vol. 108, no. 3, June 2003, pp. 763–93. *Silverchair*, <https://doi.org/10.1086/ahr/108.3.763>.
- Nielsen, Kim E. "Using Biography to Teach Disability History." *OAH Magazine of History*, vol. 23, no. 3, July 2009, pp. 41–44. *Silverchair*, <https://doi.org/10.1093/maghis/23.3.41>.
- rukmini-sekhar-nasima-hurajuka, rukmini-sekhar-nasima-hurajuka. *Naseema: The Incredible Story*. Viveka Foundation, 2005.
- Verstraete, P. *Towards a Disabled Past: Some Preliminary Thoughts about the History of Disability, Governmentality and Experience*. 2007. *Semantic Scholar*, <https://doi.org/10.1111/j.1469-5812.2007.00239.x>.
- Weinberg, Carl R. "Disability History." *OAH Magazine of History*, vol. 23, no. 3, July 2009, p. 3. *Silverchair*, <https://doi.org/10.1093/maghis/23.3.3>.

Language in India www.languageinindia.com ISSN 1930-2940 22:4 April 2022

P. Boopathi, Ph.D.

Authoring Disability, Documenting Struggle: An Analysis of
Naseema Huzruk's *The Incredible Story*