# Life Narratives of Persons with Disability in India: A Critical Discourse Analysis

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Abstract: Historically in India as elsewhere in the world, there has been a deep-rooted cultural antipathy to persons with disabilities, wherein they have been portrayed as medical anomalies, help-less victims and a lifelong burden for family and society. In recent years, research surrounding the intersection of disability, sexuality and gender and its importance in the lives of those who are in the centre of it has been gaining recognition. Representation of persons with disability in disability scholarships would provide an opportunity to view the world through their lens. Life narratives in this case, have the potential of bringing forth the 'personal', which helps in understanding a community objectively and empathetically, which is essential for synchronous functioning in a diverse society.

The primary material for this paper includes the narratives and first-hand accounts of persons with disability in India in an edited book titled *Skin Stories* (2019) wherein the disabled individual is the subject of enquiry. These narratives shed light on a different discourse of sexuality for the disabled individual. We find an active desiring sexual subject in these narratives, in contrast to the passive and objectified view of disabled lives. The methodology for this study-discourse analysis through a critical theoretical framework – would enable an in-depth understanding of the sociocultural, historical, and political context of these narratives. Through my study, I have tried to explore the intersection of disability, gender and sexuality in the lives of persons with disability in India. and shed light on the diminished social, economic, political, cultural and interpersonal rights of the people from the disabled community, and enable one to think critically not only about disability but also other historical marginalized groups.

Keywords: Disability, gender, sexuality, life writing, discourse analysis

#### Introduction

"To define ourselves, name ourselves, speak for ourselves instead of being defined and spoken for by others." (Lorde 43)

Dis-ability, as the word suggests, has always had an existence contrary to 'ability' (Ghai). One would assume that this makes the understanding of disability unidirectional and linear. However, over the years disability studies theorists, academicians, activists, policy makers, doctors and persons with disability have actively tried to contest this understanding of disability (Goodley). With years of research in the domain of disability studies, scholars have suggested that disability, in fact, can be understood in more than one way. In the simplest form, it could either refer to one's inability to perform a task, or even the act of stopping one from performing a task. These polysemic and paradoxical understandings of disability lay the fertile ground for the inception of, and association with the stereotypes, prejudices, negative attitudes and beliefs surrounding disability as well as the persons with disability.

Negative attitudes towards people with disability exist in any society (Ghai). Such attitudes often affect their quality of life and at times even their basic human rights, particularly in developing countries like India (Ghai) . In a study conducted by Prof. Ajit Dalal to understand the discrimina-

tory attitudes towards people with physical disabilities, it was discovered that people with physical disabilities often tend to suffer more due to the societal attitudes and prejudices, than due to their bodily impairments. To this effect, one could also state that the disability policies, programmes and practices in any country reveals the attitudes of the larger able bodied society (Ghai). Such negative, paternalistic attitudes and prejudices create barriers in lives of these people with disabilities which often prevent them from living a full life. Thus, there is an imperative need to find a solution to this problem of 'disability' experienced by persons with bodily impairment in any society.

The solution to the problem of disability lies partly in how the problem is understood, and where it is located (Ghai). A person with disability in India is defined as, "someone with long term physical, mental, intellectual or sensory impairment which, in interaction with barriers, hinders their full and effective participation in a society equally with others" (Rights of Persons with Disability). This definition sheds light on the general understanding of disability, where any kind of disability is considered to be caused by an 'impairment', which renders the person with disability, a status of being defective or lacking something (Galvin). The problem with this definition much like most of the definitions that have been before it is that, firstly, the onus of the disability is primarily on the individual with 'impairment', rather than social factors around them like negative attitudes, stereotypes, inaccessible infrastructure, inaccessible transportation system, communication system, lack of quality education and employment opportunities etc (Ghai); secondly, disability here, is being viewed as something inferior and less desirable, which negates any possibility of establishing equal participation in any society for persons with disability. Finally, persons with disabilities here are seen as the 'other' in contrast to the larger able bodied society, which dictates the rules of performance for participation, based on a hegemonic, understanding of the binary codes of abled and disabled. This lays the ground for examining the political debates concerning disability, the models of understanding disability and exploring the possibility of understanding disability in relation to other intersections like gender and sexuality, wherein the questions surrounding representation could be addressed by studying the lived experiences of people with disabilities.

Disabled people have been spoken about, and spoken for, but rarely listened to. (Sherry165) Beth E. Ferri in her paper titled 'Disability Life Writing and the Politics of Knowing', talks about contemporary disability life writings, which have the potential of critiquing oppressive ideologies and shaking the foundation of the normative or the 'fixed center' (Ferri). The dominant discourses then, are contested by such life writings with its relevant, politically grounded counternarratives.

"No body, no voice; no voice, no body. That's what I know in my bones" (Mairs 96). An interdisciplinary approach of understanding disability through the medium of popular culture, first person narratives, films and other forms of art, gives one the vantage point to delve more meaningfully into the domain or field of enquiry. These works deliver counternarratives which provides the opportunity to "imagine disability otherwise... and move beyond overly deterministic normalizing discourses of cure and care" (Ware 146).

Life writings are able to create 'counter discourse' which challenges the dominant understanding of disability as lacking (Mintz). The subjectivity of the individual and their contextual identity as a result of their complex socio-political position legitimizes their narratives of their life experiences (17). By constructing the society's understanding of raw, individual life experiences, and giving it a coherent meaning through stories, life writings do cultural work (Garland-Thomson 121). This can be seen for instance in the book 'Storyteller', where the author Silko connects her personal narratives with stories of Laguna Pueblo, so that she can situate herself as a voice bridging multiple cultures (Smith and Watson 17). Such narratives offer an important forms of social critique.

## Popular Culture and Construction of Disability

Construction of disability and the life experiences of persons with disability in cinema and television for instance, has also been largely based on the dominant understanding of disability as a curse,

inflicted on the disabled due to their past karma or as an object of pity and charity (Ghai). The other extreme of their representation has been observed in cinemas where either popular able-bodied actors play the roles of PwD, or storylines are built where the person with disability is expected to see beyond their disability and accomplish extra ordinary achievements in life, celebrated for 'rising up, despite their disability'. Such ways of narrativizing disability in order to make it 'pleasant' for a largely ableist society portrays the disabled as the inspirational "super-crips" (Mintz, 17). Life writings offer insightful glance into the lived realities of persons with disability and bring forth a rather unadulterated picture, talking of the facets of their life without the much unwanted use of euphemisms or catering to ableist assumptions.

Butler contends that perhaps what one fails to notice here is that 'we are never outside language.' One could express themselves, only through the language that is available to them (p. xxiv). In the case of disability, normative frameworks determine who is allowed to claim subjectivity and who is not. Thus, in the process of narrating one's story, the individual arrives at a position where they must use the existing, normative language to build upon their story. The writer finds themselves to be inevitably caught within the webs of meaning informed by normative assumptions. This is particularly problematic for the domain of disability since most of the normative assumptions revolve around the concepts of 'seeking cure'. Rosemarie Garland- Thompson writes about how most of these stories are those of despair, catastrophe, loss, excess, suffering, and relentless cure-seeking" (114). Nevertheless, one must engage in this dominant discourse to be able to put forward life writings. In doing so, one brings forward the dominant hegemonic scripts, simply by engaging with them. Perhaps reiterating how one needs to be 'in the system to change the system'.

People from within the community have nevertheless engaged in the task of changing the society simply by reclaiming voices which have been colonized by a largely able-bodied society. Disability life writers like Mairs and others continue to write "bare brace and . . . tongue hanging out" (105), as an effort to continue their goal towards disability politic grounded in lived experiences and necessarily embodied.

#### Disability through a Critical Lens

As an analysis method, critical discourse analysis is most clearly defined for understanding how alternate words can be used to create an impression of the same thing and examining how the words used are also capable of creating new ideas and impressions. Both these roles of discourse analysis have been central to the discipline of Disability studies, which is aimed at exploring how 'disability' is created in the society through the use of language. The development of discourse perspective in disability studies can be traced back to the late 1990s and early 2000s in both the United Kingdom and America (Snyder & Mitchell), where the construction of disability by linguistics, culture and society was scrutinized and the concept of intersectionality explored. Discourse analysis was used to study other domains and disciplines which were thematically more or less similar to disability in questioning the unequal power relations, marginalization and discrimination, be it through media representation and power (Fairclough), gender (Wodak), identity (ibid.) or racism (Wodak & Van Dijk). Moreover the concepts of gender and sexuality, which are key in this research study have been exclusively focused in discourse analysis, along with disability (Grue). For the purpose of studying life writings of persons with disability, narratives from the book, 'Skin Stories' are analyzed through a critical discourse analysis.

The first narrative here, a writing titled "As a woman with a disability, I'm either seen as 'helpless' or 'heroic'" authored by Preeti Singh, gives words to the emotions and thoughts of an eight-year-old girl with disabilities, who was subjected to the absurdities of normalcy at a very early stage in life. The author, now in her mid-thirties, addresses the power hegemonies which were stated clearly to her, of one that exists between a person with disability and a non- disabled individual. The author articulates her predicament as a student, having to repeatedly prove herself, and her worth through

repetitive examinations, while her peers were not required to do it. She rather shares her amazement at her school showering her with awards for being 'brave' and getting educated, 'despite' having a disability and further awarding her friends, for 'extending a hand of friendship' towards someone with disability, shedding light on the vast distance between expectations and realities for children with disabilities. Her reaction of amazement here, can be seen as a transgression, where she mocks the dominant discourses of disability, tending to a charity model and perhaps creates avenues for subversion. The lens of bravery prevents people from really seeing her, the person who might be dealing with her mental health concerns, experiencing heartbreak or simply having a bad day. By focussing on the concept of bravery, she contests the identity politics of persons with disability, for whom 'disability' becomes hypervisible and all other markers of their identity dissolves in the background. The author shares the agony that she experienced at 9 years of age, where during her grandmother's funeral she was told by distant relatives, how she has been a burden for her family. She narrates her lived realities, as she recollects the instances where her dear ones claimed, 'she should have died, and that it was stupid of her parents to spend so much money on her health and education!'. In this context, it is important to gain a clearer view of their socio-political realities, and histories, within which women with disabilities are located. There is a preference for the male child in the Indian subcontinent. So, a woman with a disability suffers multiple layers of marginalization.

The identity of a woman with disability becomes a marker of a wound, a spoiled identity, the preference for the male child in the light of both, the ritualistic relevance of the son in a Hindu family and the social and economic burden associated with the daughters of the family (Johri, 1999). Johri further elaborates on this social construction of the daughters, where they are seen as a *parai dhan*, or another's property. The daughter here, is raised by her family and eventually given away to her husband in the ceremony of marriage, popularly known as kanyadaan, or the gift of a virgin daughter. It is a rather implicit understanding that this gift is perfect in all senses of the word, and in an ableist world, the impaired body becomes a symbol of imperfection (Ghai, 2015). Having a daughter with a disability creates a rather difficult terrain for the father, who would feel compelled to compensate for his daughter's disability. This could be either in the form of large amounts of money and property as dowry, or could translate to a compromise wherein she is married to a significantly older man with children or married to someone who is also disabled. Thus, being a daughter with a disability is often a matter of double burden. Dominant representations of women with disability have highlighted this double burden and constructed her figure as a victim, but on delving into their stories and life histories, we discover the latent transgressive subjectivities expressed by these women. This opens up new avenues for contestation.

The author continues to narrate her childhood experiences, where she can be seen often supressing these emotions, till it was experienced in the form of a depressive episode. She contends that, like the rest of society, people with disabilities are simply carrying on with their lives. Whether they are being pushed away because they are pitied, or pushed forward because they are used as objects of 'inspiration', both ways, they are denied basic humanity. The fight for basic rights in the everyday for persons with disabilities may not be overt or polemical, rather individual and subtle. Such forms of everyday resistances are channels of critiquing the dominant ableist views surrounding disability. She closes her excerpt requesting the reader and the larger able bodied society as well, to let Persons with disabilities be who they are: complex, capable of many things, both good and bad. Through her narrative, she sheds light on how there is a need to realise that the most extraordinary thing about a person with disability is that they are ordinary. Here, the first-person voice of a woman with disabilities brings forth the emotions, thoughts and experiences of a larger subaltern group of persons with disability. It is rather ironic that the dominant stories of disabled individuals have been written by able bodied professionals or academicians, thus largely negating the power and agency obtained by the community to tell their stories in their words. Such narratives subvert the conventional representation of women with disabilities as passive victims or tragic objects of pity or models of heroism.

The next story "Heart Emojis and High Fives: Finding community in a virtual group of fellow women amputees" is the writings of young Antara Telang who gives an autobiographical account of her journey from being temporarily able bodied to disabled (Telang). The author places her story in the chronological order of events from the day she lost her leg and acquired her disability. She recalls the 'dark and stormy' evening when it all happened, where the 'trees shook violently in the wind', but she chose to listen to music on her headphones, disconnected perhaps, from the reality of a temporarily able-bodied existence. She narrates the accident, in which a tree completely 'crushed' her leg, and perhaps her life too. The second half of the narrative consists of her accounts of understanding her own bodily experiences, starting from being in a locked-up situation, healing mentally and physically from the trauma of the accident, in her bed for weeks on an end to learning to use wheelchairs and crutches. She recounts her efforts of fiercely fighting against the category of 'disabled' that she was put under, mostly by others, till she was completely exhausted. Writing about her 'hatred' for being put under this category, she brings forward her anger of being representative of a community, that had 'nothing to do with her life, till then' (Telang). She conveys her frustration as her 'disability' became her primary identity, and nothing else mattered. Such has been the reported experience of many more persons with disabilities, where their primary identity became their disability itself, conflicting with the person-first language used for addressing them. This phenomenon can be seen operating dominantly in any kind of marginalized communities based on race, gender, caste and class, where their oppressed identity takes the first position, followed by all their other identities. Left with limited options, she takes the path of 'passing by' as 'normal', by actively putting in effort to hide her disability, by wearing long pants, closed shoes and a prosthetic leg (Telang). The author describes her difficulty in accepting this new body and reality, which comes forward in her choice of words like 'I limped back to my old life' (ibid). As she learns to walk again, she recalls the questions and the stares which made her bury herself in her books and work, which turned out to be her new rescue. Books and travel gave her a sense of power and confidence, a feeling that she could be as capable as any other able-bodied person. In the third part of the narrative, she writes about her experience of being part of a disabled women's support group, which went by the name 'Wonder Women'. The group was able to do all that for her which modern medicines failed to do, by creating a support system of people who had similar experiences and more importantly understood what she was going through. It is perhaps interesting to note her emotions regarding being a member of this group evolve at different points in time, from a feeling of anger and frustration for being put in this group, to a sense of indifference and eventually to a state of joyful participation in the conversations that took place.

It is rather thought-provoking to see how the body is conceptualized or represented and how the text takes up questions of 'embodiment' in this writing. The author's perception or understanding of her own body transpires from being merely a part of herself which she rarely had to think about till her accident, nevertheless completed her, to the experience of the loss of her leg, which puts her in a state of turmoil and pain, literally and metaphorically. Her states of grief are narrated across her writing, starting firstly from her phase of denial, where she ends up being in her room for days together to her second phase of anger at herself and others. Though various models of disability that have been posed over time have suggested multiple ways of approaching the subject matter of disability, first person narratives have been addressed only by the empowerment model, which still struggles to find its place in the Indian understanding.

One can see how through the text, the 'disabled body' becomes an alternate source of knowledge for the author. It is rather pertinent to understand the concept of embodied knowledge here, which is the simplest way of acknowledging the body as the knowing subject. This kind of knowledge is similar to the cognitive science understanding of procedural knowledge, addressing knowledge which can be better performed, than verbally explained (Stilling et. Al), On the contrary, the Cartesian idea of mind-body dualism is still dominant in mainstream cognitive sciences. The methodological scepticism of the Cartesian model of understanding the mind and body relationship views the knowing subject to be the mind, while the body is just a mere known object; negating the possibility of 'embodied knowledge' (Descartes). It can be argued that embodied knowledge rejects the claim of the Cartesian dualism and contends that the mind, which lacks a clear representation, is experienced throughout

the body and the variety of experiences that one witnesses within the lifeworld, a state Husserl defined as *Lebenswelt*. Through the analysis of the narrative here, one could see the complex interplay of the

author's mental state and physical state. The change in one significantly affecting the other.

## Intersection of Disability and Gender

While addressing the question of intersectionality, the intersection of disability and gender plays one of the most critical roles for any individual with disability. Starting from the right to live, to the access to healthcare, education, employment opportunities, right to have a romantic relationship, be married or even have a child depends to a great extent on one's gender (Ghai). It is understood that the prevalent traditional gender roles and its expectations make life for women with disability in India more difficult than for their counterpart (Mehrotra). Evidence shows that among older women, their disabilities are often discounted if their spouses are alive. The cultural differences within the country shows that the older women in north India are often enough much more disadvantaged when compared with the same population in the south of the country (Sengupta and Agree). This kind of ignorance or avoidance of the 'disabled woman' can also be seen in the disability movements as well as the women's movements. For the author, her introduction to this intersection became visible after her amputation, when she was added to a women's support group named, 'Wonder Women'. This group of women with disabilities shared almost every aspect of their experience including travel pictures, anecdotes of funny or angering incidents, stories of pain and comfort to even pregnancy concerns like, 'Carrying a pregnancy to term despite other people being mistrustful of their ability to do so'. These woman created a space for celebrating their success stories and those of their failures, it gave them a space to be who they are. The author raises critical questions concerning the experiences of women with disabilities, which in its unique sense, is one of restraining women and questioning their capabilities. Be it one's child bearing ability or caregiving skills, domains which are considered to be the quintessential features of any woman are continuously questioned and criticized in the case of women with disabilities. This could be understood in terms of the blatant dehumanization and seizing these women off their femininity, the qualities which makes a woman identify with her gender. The Wonder Women would spend hours together simply to listen to each other, help each other out even though most of these women of the group had never met each other. The author talks about the possibilities that she was able to see as a part of this group and how it helped her embrace her disabled identity (Telang).

The intersection of disability and sexuality in the text has been well addressed by the author, leaving no gaps for incorrect assumptions or second guesses to seep in. In fact, she recalls the first few things that she heard from her relatives after her amputation was not about her health or wellbeing, rather it was concerning the most important facet of marriage. They were whispering, 'Poor thing. Who will marry her now? How long will her family take care of her, after all?'

It was not much later when a young boy she likes suggests her how she would be 'better off moving to places like the UK or France', so that she would be around people who could be more open minded about her 'condition'. The author recalls how the thought of her being undatable in that sense was a much more scarier thought, than her being handicapped. Her fear of getting rejecting and never finding a suitable match led her to completely close herself from all potential romantic endeavors. It was only under the influence of alcohol and some good friends that she finally decided to explore her options, through a dating app. Her experience of dating in a virtual world gave her the opportunity to explore her sexuality, without the fear of her disability being her primary identity. Having met people for dates, she was able to enjoy the company of those who went out with her and her experiences were much similar to those that non disabled woman have. Them accepting her the way she was, gave her the opportunity to accept herself.

Much contrary to the popular perception of disabled individuals as 'asexual' beings, the author's own experiences point towards a series of rather optimistic scenarios where she realized that most people she dated were not bothered by her disability, making her feel much acknowledged and appreciated with statements like, 'It's just one foot right? All the rest is there na?'. She recounts how most of the men she went out with are still good friends with her, after which she entered into a relationship with someone, she met offline.

Ghai, while talking about the relevance of 'language' in the context of disability, quotes Stiker when she says that there is 'no speech outside the systems of languages'. She further states that disability ceases to exist outside the periphery of social and cultural constructions. This would further implicate that attitude towards persons with disability originate from the vast social and cultural references and constructions. Disability as a concept is rooted in the religious texts, folklore, cinema, mythologies, poems, proverbs and riddles (Ghai). In a study conducted by Mapley to examine the representation of disability in the children's book 'Read with Biff, Chipp and Kipper', critical discourse analysis was employed. The study revealed that in the text, 'normalcy' was given high regard and idolised, which resulted in the representation influencing the self identity and social attitudes toward disability. The study particularly highlights the construct of 'aesthetic nervousness' which could be resulting from a normative culture which reprimands anything that deviates from what is considered to be normal. Such hegemonic practices produce a repetitive process that plays a significant role in the production of future texts, social justice and creation of an inclusive society (Mapley). Such cultural expectation is mostly reflected in the beliefs, values held, rituals and customs, thus being partial expressions of a world in which 'dualities of domination' subordination, superiority/inferiority and normality/abnormality are relentlessly reinforced and legitimized' (Charlton). These learned systems of meaning and behaviour are usually passed from one generation to the next (Carter and Qureshi). Nevertheless, it is important to note here that cultures evolve with their interaction with history, politics and power and thus no culture remains the same over time (Venkatesh). Though disability, much like caste, gender, class, ethnicity is deeply embedded in one's culture, its meaning across the world has been given a 'transcendent status' (Harry). Questions surrounding who is disabled, the kind of treatment they need, their rights and responsibilities have been an intrinsic part of the global discourse on disability (Priestly) (Hutchison).

The author's use of humor in her writings has been another interesting aspect which captures the reader's attention. This can be seen as her defence mechanism to cope with the anxiety provoking events or to fill in the void that she experiences between her lived realities and what others assumed of her. Thirdly, it could also be read as an attempt to bring in her personhood into her writings. The underlying expectation of every disabled story to be a story of hopelessness, sorrow, grief has been contested by the author through her work. This can be seen clearly in her mention of a dramatic music as she unfolds the story of her amputation, her use of sarcasm when she says, 'I was absolutely so very fine' while narrating her efforts of hiding her disability under her long pants to the rest of the world.

While talking about his views on capitalism, Karl Marx contends that any kind of charity is the 'perfume of the sewers of capitalism'. This view stands true for people with disability also, wherein they are often subjected to the bitter/sweet realities of charity in their everyday life (Goodley). Simi Linton, while describing the disability scholarship, states that, 'the overwhelming majority of scholarship on disability either utilises or implies the third person plural: 'they' do this, 'they' are like that, 'they' need such and such (Linton). This contributes to the objectification of disabled people and their experience of being denied of individuality and selfhood, imposing a collective, generalised identity. Various models of disability that have been posed over time has suggested multiple ways of approaching the subject matter of disability.

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