Critiquing Cultural and Climatic Norms for the Disabled in India:

Reading Malini Chib's *One Little Finger*

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Abstract

A culture is the construct of a number of components commencing from a society's people, beliefs, ideologies and principles to the conduct of the values emerging out of them. Tersely speaking, a culture is the composite whole of the socially transmitted beliefs, behavioural patterns, institutions, arts and all possible products of human thought. If we go by this definition of a culture, can we create a 'composite culture' if we relegate a particular section of a society to its periphery? Climate, in this research paper, is referred to as the surroundings, the ambience for a particular culture to flourish. Now, the question arises, have we created the climate or the ambience for every section of our society to grow, especially in a South Asian country like India? Are we ready to sacrifice the concept of unjustified 'norms' defined by our culture on the altar of plurality? The marginalized section this research focuses on is disabled people, medically termed as 'impaired', socially labelled as 'divyang', and truly made 'disabled' due to social and cultural constraints of Indian culture. The conflation of quoted literary instances and social and cultural labels assigned to people with disabilities, both in the West and East in this paper speak volume about the similar treatment towards them across the world. However, there are myriads of differences in the socio-politico-economico-cultural status of people with disabilities of North and Western countries and that of the South Asian countries owing to their 'developed' and 'developing' status respectively. Advertently or inadvertently, disabled people have been viewed as a homogenous group; they are expected to fit in the 'norms' defined by a 'culture', and they have always been treated as 'second class citizens', the issue being more grave in South Asian countries. There is an *urgent need to retrospect and introspect about the treatment of the theme of disability to create a much needed heterogeneous, diverse but inclusive culture. This paper will try to critique the aforementioned aspects and their nuances through analysing Malini Chib's autobiography, One Little Finger.*

Keywords: *Disability, Normalcy, Culture, Representation, Inclusion.*

Introduction

This paper seeks to interrogate the 'norms' defined by 'culture' and the place of certain marginalized sections of the society with reference to South Asian countries, particularly India. The hierarchy or the social order created by the society relegates certain sections of the society to an extent that they are considered beyond the periphery of the society. In such a scenario, is it possible to imagine and construct a healthy and 'composite' culture? The section referred to in this paper is disabled, and the medium opted to question and review their status is autobiography. The position, representation and inclusion of disabled people in India will be assessed by analysing Malini Chib's autobiography, *One Little Finger*. The reason behind opting for an autobiography as primary text is to avoid the distorted and mediated representation of the subject matter. The argument may sound trite and well-exerted, but the truth is that despite the pressure of agency, the dilution of memory and many other mediating factors, the information and narrative provided remains first hand and more trustworthy unlike being represented by other agencies which can manipulate and present the narrative according to their needs and convenience. G. Thomas Couser rightly points out: 'Historically, the cultural representation of disability has functioned at the expense of disabled people in part because they have not controlled their own images' (Couser 2005, 603). Hence, an autobiography, which is usually the product of unadulterated experiences, has been opted as the primary source material for this research. Disability is an inevitable part of human existence. It is so subtly and intricately integral to human life that this theme remains either overlooked or taken for granted. This statement, in any manner, does not connote that the theme of disability has not been represented. Disability as a theme has overtly and covertly been hyper represented in mainstream culture, whether in South Asian Countries or Western World since thousands of years unlike the themes of racial, ethnic and other oppressed minority groups. 'They have not been disregarded so much as they have been subjected to objectifying notice in the form of mediated staring' (Couser 2005, 602). David T. Mitchell and Sharon L. Snyder have very tactfully and meticulously demonstrated how Western culture, since its inception to the contemporary era, has deployed the theme of disability persistently, and to be exact, obsessively, both in literature and media. In their work, *Narrative Prosthesis: Disability and the Dependencies of Discourse*, Mitchell and Snyder demonstrate how disability has been used as a prop, a prosthesis based on which the entire narrative is developed (Sharon and Snyder 2014). The literary examples are diverse, starting from Sophocles' Oedipus, Shakespeare's Richard III, Melville's Captain Ahab, William Faulkner's character Benjy and beyond, perpetuating the theme of disability. Even in Indian culture, disability has been used as an overtly hyper-represented theme. Beginning from the religious texts such as *Mahabharata* and *Ramayana* to Bollywood's inception and present-day Indian cinema, disability has been treated as a cultural commodity. What I mean to suggest here that there has not been any dearth of the representation of disabled people, or the theme of disability. The obvious crisis, however, has been that disability has been highly 'misrepresented', and in a country like India, it has been relegated to the margin of the society. Disability as a metaphor is often used to conflate plot and character, and, it provides the back story for the narrative if it does not generate the narrative in a direct manner. A crippled, a scarred, a hunchback, a blind or a deaf character may be embittered, resentful or traumatized, such as Captain Ahab in Moby Dick, Richard III in Shakespeare's Richard III, Manthara in Ramayana or Dhritrashtra in Mahabharata; they are, in most cases, stringently punished for their villainy, reinforcing the idea that disabled people are fated to deserved hatred; they are cursed and doomed. On the other hand, there is super-humane portrayal of the disabled in most types of mainstream cultural representation of the disabled. Hence, there is an urgent need to find the true voices of disabled people in order to ensure an appropriate cultural climate for their all-round progress, in enhancing and enriching their skills to make them contributing beings of a culture, and, most important of all, dissolve the concept of ‘ableist culture’. Therefore, this research seeks to undertake an autobiography as the primary text written by a disabled woman which incorporates the aforementioned facets.

Malini Chib is a woman with cerebral palsy, a neurological condition which may result in body muscles and speech impairment. It is somewhat similar to stroke in an adult. Contrary to the society’s belief, this condition may leave cognitive functions unimpaired, as in the case of the author. Though she does not try to create a ‘triumph narrative,’ her unyielding attitude towards life despite societal and cultural apathy portrays her as the beacon of hope. She is certainly a living example of fortitude for the disabled, but she also encourages other disheartened people including discriminated minorities to raise their voices against social and cultural injustice meted out to them. Through her autobiography *One Little Finger*, she conveys the message that resilient perseverance along with activism and academics may be one of the best mediums to protest, and that it is imperative to fight the cultural injustice through any means possible. One of the best Indian examples of ‘coming-out narrative,’ her autobiography *One Little Finger* records her journey beginning from her impaired infancy till she finds employment as an event manager. Despite her permanent severely crippling disability, her positive aptitude and attitude is remarkable—her zeal for living life to the fullest, her guts to question the prevalent cultural values, defining future for herself and that of the other disabled after taking lessons from the past and her own experiences, and having a solution-oriented approach instead of problem-oriented. A French existentialist and feminist, Simone de Beauvoir very aptly writes in her magnum opus, *The Second Sex* that a woman is not born a woman, rather she becomes one (de Beauvoir 1949). Chib, through her autobiography, seems to convey that a person may be born ‘impaired’, but a culture or a society makes her/him a ‘disabled’. As far as the issue of disability is concerned, ‘South Asian context has failed to move beyond mere catchy slogans’ (Ghai 2009, 281).

The emergence of nonconformist theories such as Queer Theory, Subaltern Theory and Disability Study have questioned the very foundation of the ideas like culture, society and 'norms.' Every culture is bound to have its norms, and its people are supposed to adhere to them. The concepts of 'normal', 'normalcy' or 'normality' are so intrinsic, that people crossing the boundaries are rejected out rightly. Disabled people, on the contrary, belong to a sect which hardly fits the normal world.

Particularly in a country like India, disability is regarded as a result of sin, bad karma, and retribution of some kind. 'From one generation to the other, there has been a progression in the way people perceive the disabled. The latter have been thought of as outcasts, as people different from the mainstream people; and were subjected to biased assumptions, harmful stereotypes; were looked upon as pitiful individuals who were unfit and unable to contribute to society, or the family; they were ridiculed and for some, they were objects of entertainment'(Kedia). Unfortunately, these thoughts prevail even in the 21st Century. There is an emergent need to redefine, or to put it more clearly, deconstruct disability and redefine 'normalcy', for it is terribly misconstrued or misinterpreted, even by the so-called informed class.

There is an urgent need to study intersectionalities such as class, gender and poverty, which starkly affect disability. The reading of this book becomes all the more significant, for apart from dealing with the theme of disability it also unravels its subtleties, and questions the socio-economic-cultural-educational systems of India.

It is not merely an autobiography, but also a critique of the two prevalent models, namely medical and social model, a treatise on feminism and disability, a critique of education system for disabled students, a glimpse of Disability Movement, and most important of all, the representation of a disabled person as a human being with flesh and blood. It is a symbolic book, resonating multiple voices altogether, the voice of a disabled for inclusion in the mainstream, the anguished cry of a disabled woman for her right to womanhood, and the voices of all disabled children who are deprived of their rights to proper education, who eventually feel incompetent, less confident and baffled in life.

Some disability models have been proposed by the newly-burgeoning field called Disability Studies. It is important to have a quick glance at some prevalent models—charity model, medical model and social model, for Chib witnesses a number of incidents of segregation and unfair treatment towards the disabled people based on the charity model; she is partly assisted but gravely traumatized due to the medical/individual model, and she decries the lack of social inclusion of the disabled people in the mainstream culture, an inevitable factor to ensure cultural affinity, which can be ensured through the social model. The advent of charity model can be traced back to the time when there was no concept of the disability model. In this model, religious institutions like church, mosques, temples and synagogue were responsible to cater to the need of disabled people apart from their families. This model opined that disabled people deserved charity, and that they were deemed fit to receive alms and other forms of charity. This model prepared ground for individual model, for many religious organisations opened separate hospitals, schools and other institutions for different disabilities such as blind, deaf and the like, segregating and ghettoizing them from the so-called 'normal' world. Charity model contained multiple explanations for disabilities—resultant of some bad karma, outcome of parents' sin, a test assigned by the Almighty and many more. To be precise, disability was associated with sin more or less, and the cure, if at all, could be found in alms and prayers. The charity model was followed by medical model. In the medical model, disability is seen as disease, and the remedy, if possible, can be ensured through medical intervention. Alms and prayers are no longer the cure for such diseases, for disabilities, according to this model, occur due to genetic or other scientific reasons. The institutions such as mosques, churches and temples were replaced by hospitals, clinics and nursing homes; the cure or remedy for disabilities could be prosthetic devices, surgical or technological intervention. The most radical model in the subsequent succession is the social model which refuted both charity model and medical model. Arising in the latter half of the twentieth century, this model proposed 'impairment/disability' approach, contending that impairment becomes disability when impaired people are not provided with the barrier free and conducive environment. The aim of social model is to eradicate social, cultural and political stigma by agitating and reimagining an 'inclusive society.' 'In the social model, as opposed to the charity and medical ones, the problem is discrimination by society and the remedy is removal of barriers and addition of accessibility and accommodation. In addition, the social model was initially formulated as a Marxist model that saw impairment, along with class and race, as qualities selected by a capitalist society for disabling discrimination' (Davis 2017). Malini Chib seems to support and endorse social model whole-heartedly through her autobiography. In South Asia, charity model is still used for and by the organisations for the disabled. The blind, the lepore and the like are the worthy recipients of alms, and they are the objects of pity and charity' in South Asia. 'Charity and philanthropy thus remain the 'predominant response to the predicament of disability' in South Asia (Ghai 2002). In India too, charity model has been prevalent since time immemorial. The sight of disabled beggars, and disabled as beings in need is considered as natural phenomena. But unlike many other South Asian countries, the status of disabled people in India is not so bleak. Owing to the efforts of activists and academicians, charity model was replaced with a human rights-based model in 2006, when the Government of India signed the National Policy on Disability. Besides, Indian Right-Based Movement has its own history, commencing from 1970s to the enactment of PWD Act 1995, and signing the United Nations Convention of Rights of Persons with Disability, a human right treaty in 2006 and ratifying the same in 2007. Chib, through her autobiography, briefly records the Disability Movement, though from a cerebral Palsy woman's perspective. There is also a hint at introducing a new model with the amalgamation of social and medical models, for it is impossible to eschew any aspect of the lives of disabled in a South Asian country like India.

Elizabeth Barns argues that 'to be physically disabled is not to have a defective body, but simply to have a minority body' (Barns 2016). Scott Hamilton believes, 'The only disability in life is a bad attitude. But do such beliefs change the reality? The issues and challenges faced by disabled and their experiences are barely given importance, and the fields which discuss disability, have been terribly misrepresenting it, namely, medicine and psychology. Chib suffers intensely due to highly individualistic, medical Model, where only she is responsible for her condition. She succumbs to the disease called cerebral palsy which was the resultant of a medical term anoxia. 'The birth was hugely traumatic, and the pediatrician in charge kept repeating to himself "it was a mistake I should have carried out a caesarean...".' (Chib 2017, 2).

In a family where the term 'handicapped' was new, the birth of a spastic child was a shock for the family. Simple activities like balancing herself, walking, talking, rolling, which are taken for granted by other children, were herculean tasks for Chib. Doctor's advised that she would not be anything more than a vegetable, society's constant gaze at her and unsolicited advice which was offered to her, though without addressing her, confirmed that she was a disabled. A disabled body, which failed to fit in the normal world. In turn, the society had to offer her certain favours such as isolation, estrangement, sense of guilt and a strong feeling that she was different, the other, the disabled. In India, as a growing child, she becomes so conscious that she starts questioning her own behaviour despite being mentally sound. A sensitive being, she tries to adhere to the cultural norms, and, as the society fails to acknowledge her effort, she starts losing her self-esteem. 'When I went out, I became conscious of all the stares that I provoked, the hushed whisperings when I appeared, the unsolicited advice that was proffered. My mother writes that when I met strangers, or entered a room full of people, I began to put my head down, terribly conscious of myself and the fact that I was different from others' (Chib 2017, 6).

A general belief that a disabled body has a disabled mind is still difficult to challenge in a country like India. Despite the fact that her IQ level was more than an average child (120), and the child who was full of imaginative power, nobody, except her family and some friends treats her as 'normal.' She decries the fact that people treat disability as the ultimate truth. A disability becomes Disabled people's primary identity; and society does not acknowledge the fact that if one sensory function is impaired, the others are not defunct. The same happened in the author's case and her experience is quite appalling. She would often be shocked to notice why people could not realize that though she could not express in spoken language due to speech impairment, she could well comprehend. In Chib's case, as well put by her, hers was an intelligent mind with a 'disobedient body.' This was declared by the doctors in England. Though she was a person with a 'disobedient body,' she was able to accommodate herself in London, for the social ambience provided there for the disabled was praiseworthy. But here comes the point where intersectionality is at the interplay. The protagonist belongs to an affluent class, educated family, and upper caste of India, thus having the opportunity to switch between India and England. What about the plight of those disabled who are deprived of even the basic needs of life? Do they even have the right to question their plurality?

There is certainly an urgent need to redefine, rethink and deconstruct disability. People in India are not able to come out of the pre-conceived notion of disability; they are not able to shun the belief that they can, in any way, become assets for our society. The very act of naming and renaming them confirms this statement. Terms like 'differently abled', 'Divyang', and (specially abled) all the more confirms the fact that they are never viewed as 'ordinary' beings, that though they can be provided with the needed resources for survival owing to some 'special' policies, they cannot belong to the 'normal' world. According to the scholars of Disability Studies such as Mike Oliver, GN Karna, Anita Ghai and Lennard Davis, Disability was viewed completely differently before the advent of capitalism and industrialism. 'the social process of disabling arrived with industrialization and with the set of practices and discourses that are linked to late eighteenth- and nineteenth-century notions of nationality, race, gender, criminality, sexual orientation, and so on' (Davis 2016, 12). It clearly shows that it is a mere societal construct. Had it not been the case, she would not have felt confident, independent and assertive in England, which is quite opposed to the feelings of dependence, utter helplessness, and lowered sense of self which formed part of her experience in India. 'Although I did not like the structure and the regimentation of life, Delarue taught me to grow up and be responsible for myself.

It taught me to be assertive about my needs, organize my time, and in a sense it prepared me for a regular college like St Xavier's College in Bombay' (Chib 2017, 45).

Disability is relegated to such an unnoticed and marginalized position of the society, that it becomes a stigma to fall into that category. Chib took a long time to accept disability as her identity. The very idea of redefining and deconstructing it for herself was out of the question. But once she accepted it, the world to which she belong became much more bearable, which was a dystopia before. She could assert herself, educate others about the needs and contributions of disabled people in the society, and instilled in herself the desire of transforming this world. 'It took me a long time to come to terms with it. I began questioning myself' (Chib 2017, 54).

What, or who is normal, is an argument which emerges as an unresolved riddle till date. The idea of normalcy is based on the power structure, which is different from time to time and varies contextually. Moreover, the concept of normalcy as much discards the concept of abnormal or abnormalcy as the idea of gifted or extra ordinary.

Lennard Davis' essay, 'Normality, Power and Culture' lays ground for this contentious and debatable issue. He argues that human beings have a desire to fit in the 'normal world', which represents mediocrity. This urgent need to fit in the normal world, or, an average world discards anything which are subnormal, or even above normal. 'As with recent scholarship on race, which has turned its attention to whiteness and inter-sectionality, I would like to focus not so much on the construction of disability as on the construction of normalcy. I do this because the 'problem' is not the person with disabilities; the problem is the way that normalcy is constructed to create the ''problem' of the disabled person' (Davis 2016, 2).

Her desire to fit in the normal world is so immense, that she puts her self-esteem at stake at many points of time: as a child, longing for peers and playmates, at social gatherings, longing for inclusion, and life, a desire to have a companion. Her sufferings have been depicted picturesquely, and most of us can easily connect with her at once. The autobiography *One Little Finger* lays a lot of emphasis on the condition of education for disabled children and youth in India. Hers is a sharp critique of both special education and inclusive education which remains a farce due to a number of reasons. Special education, according to the author, is nothing but a means to ghettoize innocent disabled children alienating them from the normal cultural association and affiliation. The quality of education in special institutions is so inexplicably appalling that students coming out of special institution are completely bewildered and feel incompetent to face the competitive crude world. Inclusive education, on the other hand, is just a mockery of the idea of inclusion. There is no proper infrastructure for them to be included in the mainstream education system, nor there is enough sensitivity towards their needs. Along with social, political, economic and cultural barriers, the attitudinal barrier remains the most challenging and it rains supreme. The condition of special education in India made it all the more difficult for her to fit in the normal world. Having received primary special education in England, when she returns to India, her life comes to a standstill, and she terms this period as the darkest period of her life. The writer belongs to the first generation of disabled students who were imparted special education in India, and as obvious, they were the guinea pigs. Her journey from her school to the completion of her masters, and finally getting a job as an event manager is full of hardships and courageous steps, both by her and her family.

Her real struggle to be a part of the 'normal' world began when she joined her college in India. But, to her dismay, very few could understand her. Her impaired body and impaired speech threw her out of the 'normal' world. It is then that she starts questioning, 'Did I have my own personality? Was I just another disabled girl who needed things done for her? I knew that I was different and trapped in a dysfunctional body, but did others realize I had a spirit and a mind separate from this body? My body did not work like others, but did they realize that my mind was normal? Did they consider thinking that my desires were just the same as theirs?' (Chib 2017, 54).

She constantly strived for excellence and utilized technology for her well-being. And, most important of all, she began using her one little finger, which helped her cover a distance not even thought of by a so-called normal being. She eschews the idea of being a part of the 'normal' world. Instead, she creates her 'new normal' after deep introspection. 'What is normal? Who is normal? Why am I abnormal? Who decides? I cannot speak, I cannot walk; does that make me abnormal?' Coming to terms with herself, she writes: 'I cherish those friends who love me just the way I am. They do not try and make your kind of the 'normal' which I can never be or may not want to be, because I do not know what your 'normal' is. I know only me. I like me. I have learned to love and accept that Life is Beautiful as it is. It is not always easy but definitely beautiful' (Chib 2017, 197-98).

Chib's attempt to address South Asian perspective in general and Indian perspective of disability in particular is immensely crucial, for it propels us to re-examine the concept of 'composite culture'. Such writings play a vital role in understanding the plight of a specific section of the society and different first-hand stances. An important component of Disability Studies, which is still in its nascent stage in South Asian countries like India, such as life writings remain the major source of understanding an oft-viewed but hardly noticed theme such as disability. However, the condition and status of disabled people in India has considerably improved. The very fact that the protagonist and author of the book finds a job as an event manager in India, which is a challenging job, in itself is the proof. India signed and ratified the UNCRPD in 2006 and 2007 respectively, and there has been a constant effort to properly address and represent disabled throughout the country. However, most of the policies and laws are still on paper. For instance, United Nations Convention Rights of Persons with Disability Bill 2016 increased the reservation for persons with disabilities from three to five per cent and three to four per cent in education and employment respectively. But its implementation is still negligent barring some schools, colleges and universities. The irony is that though the reservation has been increased one per cent in employment and two per cent in education, the categories of disabilities have been increased from three to twenty-one. Besides, there are many other flaws.

Nonetheless, there is a ray of hope, thanks to tireless disability activists and academician like Chib. Her defiant attempt to challenge the existing cultural norms is worth consideration and unique in itself. By rejecting the cultural imposition to fit in a normal world, she rejects the ableist culture which tries to patronize and treats the disabled as 'inferiors', as 'aliens', as 'others'. She nonchalantly brings in the issues to the notice of academia which remain either hushed up or too bitter to be accepted. Whether it is her critique on education for the disabled in India, or the question of disability and sexuality, she appears to be equally articulate about all the issues advertently. Her autobiography can be treated as a multi-purpose treatise--for stirring personal experiences, agitating the activists and enriching the academia. This book is an attempt to bridge The gap between 'ablest' and disabled culture and destroy this binary. The questions raised through this book certainly prepare ground for further enriching disability studies at large.

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