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Reconceptualising disability: Beyond the Medical Model, Agency, Voice, and Disability Identity in Malini Chib's One Little Finger

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Abstract

This paper explores the evolving landscape of disability narrative through Malini Chib's biography "One Little Finger" which focuses on reconceptualisation of disability from medical which favors of "fixing" the disabled individual to social model which argues that disability is rather a social construction created by exclusionary societal attitudes and systematic inaccessibility. Intersectionality of gender and disability has also been discussed as women with disabilities face "double oppression" by both their gender and disability that leads to their being perceived as asexual, dependent or broken. The paper shows the contrasts of the pervasive apathy and lack of physical disability in India with a more inclusive environment and right based countries like England and USA., Where the people with disabilities are more empowered to lead independent lives and hold on to positions of power as normal people. Furthermore the paper also examines inclusive education and employment as essential markers to make people with disabilities empowered that leads to their established identity formation in the society. Ultimately, the paper serves as a critique of societal norms which challenges the binary of "impaired" and "non disabled". The paper advocates charity and pity to a right based inclusive society where disability is treated as a character trait rather than a tragedy.

Introduction

This paper focuses on the twenty-first century autobiographical novel "One Little Finger" written by Malini Chib, by typing with only one finger as she has Cerebral Palsy that makes coordination of body and speech very difficult. It has been adapted as a movie Margarita with a Straw, directed by Sonali Bose. Malini Chib is an Indian Disability Right Activist who actively works for ADAPT, a spastic society is established by her mother Dr. Mithu Alur which is now independently being run in sixteen states across India. This society helps in bridging the gap between the society and disabled individuals. One Little Finger is an effort to look into the present scenario of disability in India on the basis of her experiences and life being disabled and how she was treated in India and other countries like the U.S.A. and England. Despite the fact that

women and men with disabilities go through equal levels of devaluation, isolation, exclusion and prejudice. Disabled women are often viewed as motivated, unfortunate and unwanted. Generally they are considered as broken, damaged and infantilized, always in need of care and safeguarding. Disabled women in India have only recently begun to defy the cultural misconception of disability and the belief that being crippled is abnormal and unnatural. It depicts the shift from charity to right based on disability being a social, cultural and political phenomena. Chib also introduces the term 'invisible disability' that means everybody has an invisible disability as no one is totally independent, everyone is dependent on one another. There are fifteen chapters and four sections entitled "Roots", "Growing Up", "A Slice of Freedom" and "Reflections". Malini says, the lived reality of a disabled individual can only be represented by the disabled himself just as Malini Chib's autobiographical novel "One Little Finger" depicts a subjective account of a disabled character which can rarely be seen in other literary works. She says people with disabilities are considered a being who has no identity. People forget that it is the body of the disabled that is weak, not his mind and individuality as they also have feelings, emotions and desires like normal human beings. This kind of attitude forces her to question herself: "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 54). Chib observes, "I believe that nobody is perfect; we are all, in some way or the other, disabled. Our disability is more visible; others have what I like to call, an invisible disability."

Reconceptualising disability: Medical vs. social models

This autobiography of Malini Chib is a critique of the medical and social model of disability. Malini has also done justice with the fact that disability is a social construction rather than a biomedical perception. When a disabled has to face difficulty in having access to educational and professional institutions, his disability cannot be blamed for this; rather it is the malfunctioning of infrastructure that restricts him. The medical model of disability believes in fixing, fitting and curing the disabled. On the other hand, the social model of disability is the exclusionary laws, societal attitudes moreover the environment to which disabled belongs needs to be fixed not the person.

She also says that the worst thing that can happen to the children is their disability related condition which leaves them alone being detached from social interactions. As she could not grow achieving any developmental milestones like a normal child, it made others falsely believe that she is intellectually disabled too as she was not able to speak properly and perform even simple physical activities like walking, eating etc. In London she attended one communication seminar; she realised that people who were severely disabled than her could communicate without any difficulty. Chib shares, "My speech was incoherent and terribly difficult to understand. It continued to depress me...To me, communication is like water, the essence of life". But on the other hand she also shares inequality of opportunity policy for a disabled. When she was pushing her Master's Program in London, it was not that easy to get accommodation inside her institute. Chib says that nobody was ready to take the responsibility of ensuring that a disabled person was safe. Another incident she felt humiliated when she visited university canteen a gentleman offered help to her but a female friend of that gentleman ridiculed her.

Chib shares: “When I believed all was well, his companion arrived, she was awful; she was very rude. She came up to the table and ignoring me said, how is she alone? She can’t be alone as she doesn’t know her mind...they are mental. Who are you with? ‘I am on my own’, I said with great conviction but it was useless”. Thus Malini Chib unveils the insensitive and indifferent attitude of society towards the disabled people. Malini shared the lived reality of disabled individuals through her story that clearly showcases the concept of disability as pity, charity and deterred behaviour of the social institutions. As time progressed, Malini became independent and confident enough to manage everything. Chib says, “I was managing my own chores, my own shopping, my own social interactions-I was free, and not dependent on others around me. I felt empowered and was keen to face new challenges”.

Intersectionality: Gender and disability

Recently, disabled women activists have proved that disabled women are oppressed because of their gender as well as disability. In fact, they have accused the disability movement for being gender-blind because it completely ignores the discrimination against women socially and economically, sexuality, stereotypes, and oppressive norms regarding the issue of childbearing and motherhood. They have also criticized the feminist movement for ignoring the problems of disabled women because of not addressing the disability perspective. (Mehrotra 407).

women have to go through double marginalization when it comes to education, accessibility, state policy and research. This is the reality for women with disabilities in a society where a woman is solely supposed to be a wife and mother.

Anita Ghai states in this context: The bitter reality is that disabled women have been relegated to the margins of society by virtue of

their disability as well as social/cultural factors which segregate them into categories formed on the basis of characteristics such as caste, class, or place of residence. Hence, the identity of disabled women may be complex, consisting of multiple aspects which make their life confusing and challenging. She has also discussed how the notion of gender has become a social construction of disability as mostly disabled male is being treated differently from that of a disabled woman as a male can get married to a normal woman but the same is not possible in the case of a disabled woman. A disabled woman is considered not to be fit in the society. Malini was optimistic about life as she says everyone has his own trauma but one has to face it on his own. She also feels that mutual cooperation is the only way to provide equal status to disabled communities and that is how they will come into the mainstream of the society of normal people. The issue of sexuality is also discussed through the life story of Malini Chib. Disabled women are considered to be asexual. A disabled woman has always been in a position of subjugation through the cultural and political force. Ghai writes: Nonetheless, the crucial distinction between being sexual objects and objects of the stare has not yet been fully comprehended. If male gaze objectifies ordinary women, then the stare objectifies the disabled object to make him look like a grotesque figure. Women with disabilities are oppressed of being a woman in a male-dominated society, as well as dominated by able-bodied people... there was cultural association to disability with dependency, childlikeness and helplessness. A disabled man on the other hand is viewed as a wounded male while a disabled woman is not able to fulfil the cultural expectations. (Chib145).

Malini's misery is evident, “People did not really want my company. They were oblivious to my needs and could not see my physical difficulties with eating” (Chib 67). Malini out-

raged her voice at male chauvinists who would only stand and look at the women with disabilities rather than reaching out to help them. She started avoiding going to social gatherings because she could sense being unwelcomed. In literature, a disabled woman has been depicted as having no gender and her sexual identity and sexuality are never discussed. Chib has written in her article, "feelings, passion and expectations of disabled women like any other non-disabled women. All the feminist texts need to go beyond this binary". Disability can never decide whether a disabled person is useless or worthless but in Indian society disabled individuals are treated as having no identity that separates the disabled people from able bodied people whereas in western context, the status of disability is completely different.

Comparative Global context

The issue of disability has been ignored as an issue of identity within India, whereas other marginalized communities have been taken into consideration. This is the reason why the disabled persons should participate in the democracy of India and talk about the future of identity politics. In India, disabilities are not usually considered to be a single community, and the disabilities are quite different from one another. (Ghai 262-63) The first section, entitled "Roots", begins with the birth of Malini Chib in 1966; when people were not much aware about disability in India. The wrapping of umbilical cord around her neck during her birth blocked oxygen supply to her brain and it resulted in cerebral palsy. She compares accessibility in India and England. In England, accessibility of lavatory was not an issue for disabled children and buses had ramps. Accessibility of the classroom was also a big hurdle for her as the lectures used to be on the third floor where lift could not reach. Employment is greater for the disabled individuals. Malini exposes the different attitudes of Indians and Britons towards people with disabilities. Help-

ers used to come forward from the grocery stores, the pharmacist and the book store but this was unusual in India. People in England never get derogatory comments or strange looks like she did in India. Even her friend Fiona is excited to visit her in France for the summer. Malini, who felt awed by the depth of her thought, "I could not possibly imagine anyone wanting to take on the challenge of taking me, the wheelchair for a holiday" (Chib 124). But, in India, she finds that people are pessimistic about people with disabilities. Even the Vice Chancellor of Bombay University says, "These exams are a waste of time. They are useless, and these students would be better kept at home" (Chib 49). In India, Malini and her family have to face pain and humiliation. She is considered to be a passive child despite having a 120 IQ level. But in England children like her are described as "an intelligent mind with a disobedient body" (Chib 9). Malini gets admission at Cheyne in a special school for children where she gets a variety of activities along with education.

In India, ignorance about disability is prevalent. There were no schools for the children like her. Malini exposes the deplorable condition of the medical system in India. She says "I went to a leading Children's Hospital for my treatment. They spoke about me in front of me, often not directly addressing me. They poked and examined me as if I did not feel any pain. Well, I was just a patient and not a human being. 'Does she need a collar to hold her head up?' 'I think homeopathy will help her... why don't you try that?' 'Oh. She cannot hold a pencil, she cannot tie her shoe laces, and she cannot undress or dress independently and cannot feed herself.' The paramedical staff treated me as if I did not have ears or could not understand. To them, I was a non-thinking person who needed fixing and fitting into the mold of being normal". (Chib 16) After completing her graduation Malini

visited the U.S.A. she says it is the most favourable country in the world for maintaining the dignity of people with disabilities. The library, restaurant, theatre and even a museum is accessible for the disabled people. Such accessibility provides a sense of freedom to people with disabilities which she never experienced in India.

Malini Chib has also discussed how a disabled woman has to face more difficulties in her life. Malini finds sexual exploration for people with disabilities particularly women, are few in India. She liked only one boy named Zubin but their friendship had a painful ending as he was gay. Chib says, "For me it was a devastating heartbreak. It was not to be. The realisation saddened me". In her article "No sex Please, You're Disabled", she says, "Like most women, sometimes I crave to be in the arms of man. Most men look at me as asexual". As the time progressed, she became strong enough to move ahead in her life. While working at Bombay's Times for a short period where she experienced the problem of accessibility As Chib states, "The canteen was out of reach, so I could never join my colleagues for a cup of coffee or lunch. I felt hugely isolated during lunch time and hated it...The basic problem of working in India was the lack of accessibility". She questions whether when one cannot walk as others do, will that person become isolated from everything in life? She goes on to state that every time she walked past each classroom, the lecture would stop talking, and everyone's attention in the class would focus on her, until she had passed by. Being the cynosure of all eyes is always an agony. (Chib 53). Thus, the task of establishing herself among normal people as disabled woman was very challenging for her but she did try her best to do it. In India, people with disabilities have to face issues related to autonomy all because of inaccessibility. Malini moves to London where she joins Thomas Delarue School and learns to be assertive

about her needs as she was easily accepted there. In London she felt a kind of independence as she could travel in the city for grocery shopping and laundry shop related work outside without her personal attendant. She says, "I was free! Free to go anywhere I wanted. This was very different from the situation in India. It made me forget that I could not walk" (Chib 117). All this became possible for her because of the accessible architectural structure of colleges, libraries, restaurants, hotels and schools.

Family Dynamics and disability

The parents of children with special needs play a crucial role for the better growth of their life. They should not treat special children as abnormal rather be democratic, empathic and receptive since their choices will affect their interpersonal, emotional, physical and intellectual development. Malini's parents and her entire family provided a lot of support and encouragement. She shares how people take her condition in an indifferent manner but her family accepted her the way she is as they did not consider her condition as something abnormal.

Chib says, "My parents did not give up. My parents had to give up their large house. My father resigned from his job at a crucial moment, as he was just beginning to do well. My parents gave up their cushy life and said goodbye to their friends and their life as they had known it. (Chib 7-8).

It is said that parents of disabled children often break up, but in my parent's case I think that as both were so engrossed and involved in work, the conflict of interest was a huge factor that contributed to the breakdown of their relationship, and culminated in a divorce. (Chib 27). Another obstacle for Malini was that her communication tools were not much advanced to help her. As she shares: I could not write with a pencil and could not take down notes. I mostly used a typewriter, as in those days

computers were rare. My mother came up with a new method. She gave my classmates a pad with a sheet of carbon paper. This way lectures could be covered and I would be given a copy. For answering questions in class, I used a Cannon Communicator. (Chib 52).

Empowerment through Education and employment

Malini also stresses an important point that disabled children need to get inclusive education where they can be taught with normal children so that they would be accepted by peers and also contribute to social development. Anita Ghai opines on inclusive education as: In the context of educational discourse, inclusion has been one such term. Inclusive schooling implies that each child has the inherent right to be educated along with his or her peers within a regular classroom in neighborhood schools. The principle of inclusion suggests an inherent respect for differences and thereby celebrates diversity and not the labeling of limitations of human beings. She completed her master's in gender studies along with improving her communication. She started using the computer with the help of her one little finger. She looked through how disabled people came to the forefront of their life to prove their worth and have their rights through reading a lot about literature on disability studies. It helped her to feel more empowered. With the help of her one little finger, she could become more adept in writing essays. Chib shares, "I was, for the first time, able to accept my own identity as a disabled woman, and was proud of being one".

She faced a lot of difficulties in finding jobs as she applied for Disability officer in an institute and cataloguer in the library of the institute but could not get selected for any of them. Chib shares, "The actual fact is that employers could see only my disability not my capability". Later, she joined the Institute of Education where she started giving lectures on a

Power Point as she was self-conscious of her speech. But she observed the scarcity of severely disabled people like her in such jobs. Chib shares, "But the lecture confirmed that the world was beginning to accept us- they did not look at us as if we had come from Mars!"

Malini says, to define the identity of disabled individuals and integrate disadvantaged persons into society they need to be empowered through education and employment. At present, Malini Chib herself is involved in empowerment courses in Delhi, Jharkhand and Gujarat.

She says: "I have learned to love and accept that life is beautiful as it is. It is not always easy, but definitely beautiful. I think that despite the attitudes of rejection, lack of access and the loss of freedom... Hoping to rise up to the struggle and challenge of doing so against a sea of apathy and rejection. Living, hoping and believing that there is a better tomorrow. Finally free to be me". (Chib 198).

Conclusion

One Little Finger consists of many ways of thinking about disabilities which are widespread throughout the world such as changing medical models of disabilities to rights-based models which are called social models of disability. According to this concept, "if a disabled person cannot access offices, restaurants, libraries, etc., it is not because she or he cannot walk but because of the poor design of the environment or negative attitude of the society." Simply put, it is not an inability to walk that stops people from entering a building on their own but rather stairs design which is difficult for a wheelchair user. Disability is socially constructed (Chib 108).

Feminism promotes the idea that people should try to understand how disabled women are being oppressed in daily life. Malini accepted her status as disabled woman. She chose to be self-reliant and learning and receiving acceptance from the so-called conven-

tional standards, she developed the confidence that she can participate in society. She could establish friendships with her peers at the Institute of Education (IOE) as Malini was accepted by them first as a woman and then as a woman with disability. As Ghai states: "Disabled people live lives blemished by discrimination and exclusion.

Disability activists in India have evolved a human rights agenda, which flows from the social model, which argues the environment must be adapted, so that disabled people's needs are prioritised. It is important that the right to be included in schools, job establishments, the right to access to public buildings, public transports, recreation and health facilities and sexual gratification which should not be projected as the concessions given by the able-bodied society". (Ghai 234-35)

The story of Malini Chib supports the idea does not support the view that people with disability suffer in pain and depend on the help provided by others but it aims to change the perspective or thinking of the so-called members of society about disability. The book enforces the reader to think over the inner world of the disabled where they can be seen as putting efforts to fit the structure of the society in which they live. The story of Malini's struggle challenges the existing cultural norms that need to be applauded. The autobiography of Malini is discourse of her accomplishments which she achieved through her strong will-power. The book is an effort to destroy the binary of able and disabled. The queries that book arises in the mind of the reader definitely prepare a solid ground for further enriching disability studies.

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