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Quest for Accessibility and Inclusion in Disabled Women's Autobiographies in India

Disability has been widely misunderstood by Indian society due to constant social marginalization and a lack of sensitization and awareness. It is often stigmatised in the narratives surrounding religion and mythology. People tend to view disability with disgust, suspicion or sympathy. Disabled people are systematically excluded, separated and socially disempowered. The socio-cultural environment in India still lacks adequate amenities for the disabled.

Disability studies is still an emerging discipline in India. There is very little research available on the lives of disabled women in India, except for some studies conducted by voluntary agencies or NGOs. These were concerned mostly with the objective conditions of women with disabilities and the ways in which they were doubly discriminated against in a sexist and ableist society. However, such an objective understanding of gender and disability does not allow us insights into the life worlds of disabled women, their joys, sorrows, motivations, anxieties, social pressures and individual manifestations. There has been very little effort made to study disabled people within their socio-cultural and economic context and to understand the experience of disablement from the perspectives of a disabled person. The thrust remained on normalization through medical or therapeutic interventions to enable disabled people to function as 'normally' as possible in society (Ghosh,2)

Disability life writing is a highly flexible category; it includes first-person and third-person accounts as well as collaboratively written works about a wide range of experiences about disability. According to Couser, Autobiography is a particularly important form of life

writing about disability, written from inside the experience in question, it involves self-representation by definition and thus offers the best-case scenario for reevaluation of that condition (605). Internationally, the array of disability writing is now vast, as are the types of disabilities represented by them. But in India, people with disabilities have only recently assumed the initiative in representing themselves. Through the medium of life writing, disabled people have begun to challenge their marginalisation and inscribe themselves in the cultural mainstream.

In this paper, I propose to examine two autobiographies written by disabled women in India. They are *One Little Finger*(2011) by Malini Chib and *No Looking Back*(2014) by Shivani Gupta. Though these autobiographies write about many aspects of the disability experience from a gendered perspective, in the main, they present a strong case for inclusion in the mainstream as a productive, valuable member of society. In this context, the texts foreground a demand for an enabling environment and equal opportunities rather than concessions and reservations to nurture their abilities to become equal members of society.

Both Gupta and Chib write about surviving challenges of disability in a country that takes little account of the daily difficulties and indignities faced by them. *No Looking Back* is a moving and quite inspiring story of a young, independent girl full of life, who developed tetraplegia after an accident at the age of 22. *One Little Finger* is the autobiography of a woman with very severe cerebral palsy. Cerebral palsy is a neurological condition that affects motor skills and makes walking, talking, and eating difficult activities. The book took almost two years to write, due to her physical state. In the first case, disability resulted from an injury to the spinal cord in a freak car accident, in the second case, a result of umbilical cord getting stuck around the neck during delivery, lack of oxygen to the brain of the baby caused a lifetime of a severely disabling condition. Both women were confined to wheelchairs for life as a consequence.

There is a tendency to celebrate autobiographies of marginalised, disadvantaged persons as individualistic stories of triumph against insurmountable adversities. Valorisation of individual achievements takes precedence over the rigid social structures and cultural barriers that have been instrumental in marginalising groups in the first place. It is important to understand disability as a socio-cultural and political phenomenon to counter the notion of disability as an inherent unchallengeable trait located in an individual. The narratives are indeed much more than stories of triumph and ‘overcoming’ adversities. Both Chib and Gupta put forward a rights-based approach to disability and seek reorganization of society to include disabled people.

The autobiographies consistently reject the ‘charity framework’ and prefer the discourse of human rights and dignity of individuals to frame their arguments.

No Misery Literature

Contrary to general expectation that the autobiographies of disabled women would give detailed accounts of the physical pain they experience on daily basis, a sense of victimhood or helplessness, these writings primarily focus on the pain experienced because of their mobility impairment. They are negotiating with the limitations imposed by disability every day. The central focus of the narratives is on the pain caused to them by society. In the main, these narratives seem to direct our attention to the fact that the problem of disability lies not only in the impairment of a function and its effects on an individual but also, more importantly, in the area of their relationship with ‘normal’ people.

Both Chib and Gupta write from their location as members of middle/ upper-middle-class families in an urban, cosmopolitan milieu. They highlight the importance of familial ties and the constant encouragement and support of their parents as the most crucial factor that sustained

them through the uphill struggle. Malini's parents moved from India to England when she was young, leaving behind a good life because they knew her needs would be better met in England. Gupta was a hotel management graduate planning to go abroad on the eve of the accident. They also give a fascinating account of changing family relationships in the process of growing up, becoming independent and negotiating with their respective impairments.

Collision Between Two World Views

In general, disability is a very negatively valued condition in India. the popular belief is, that it's better to be dead than to be disabled. Disability in everyday thought and language is associated with failure, dependency, with not being able to do things. However, the view that death is better than disability is rather extreme. The disabled people certainly do not think so. Though disability does involve some indignity, physical discomfort, and pain, there are relatively few accounts of pain in autobiographies. rather they dwell on a different kind of suffering derived from the collision between two different world views: the world view of the non-disabled and that of the disabled. What makes them suffer is a clash between what they see and what the rest of the world insists on seeing.

Gupta writes, "I had never thought of disability before my accident. Neither had I known anyone who was disabled. Disability had meant social work sessions at school and a feel-good factor from having assisted a disabled person in crossing the road. Disable for me, until now, had been 'them' (45). However, "With my first-hand experience, there appeared to be a strong contradiction between what I thought disability was, and how I felt like a disabled person. I did require assistance to do things, but I didn't feel completely helpless. Despite my impairment, there was still a lot I thought I could do. I felt like the same person inside; it was just my physical appearance that made me uncomfortable about facing people... It was difficult to fit myself into the picture of a disabled person painted by society. I was determined

to draw a line between my physical condition and my spirit, which seemed stronger than the body” (52-54). Chib writes, “A so-called able-bodied person manages to slip into multiple identities, so can people with disabilities. My disability is one of the components that make up my identity. I am a disabled, heterosexual, and Asian upper-middle-class woman. My disability is only one part of my identity, yet sadly, that is the only part the society decides to see or even acknowledge” (Chib, 2015, 106). Thus, one cannot view an individual exclusively through the prism of disability, that is not how they understand themselves. Being wheelchair-bound is simply one piece of their lives, one that while significant, is certainly not the core of their identity, nor their principal motivation.

Negative Cultural Conceptualisation of Disability

Whether it is a textual representation of disability or the way it is understood in popular culture, the very conceptualisation of disability is negative in India. Often, they are looked upon as objects of pity. Karmic conceptualization of disability sees it as suffering that disabled people have to go through as a result of misdeeds committed in their past life. Due to this, disabled people have to face attitudinal issues in terms of abuse in their everyday life (Chakravarty,72). Anita Ghai writes that labels such as *Bechara* (poor/ unfortunate) accentuate the victim status of the disabled and that the root of such attitude lies in the cultural conception that views disability as a result of an individual’s fate, and thus beyond redemption. Destiny is seen as the culprit and disabled people are seen as the victims. (Ghai, 2001). Such conceptualisation undermines the agency of the individual whose life is not restricted to such formulation.

Gupta writes about how, once in a queue for darshan at Haridwar, she was mistaken to be a beggar by a poor middle-aged woman and handed a twenty-five paisa coin. She was casually dressed in a nice t-shirt and trousers. “This was something that had never happened to me before, and I had not imagined that it would ever happen—she had thought that I was a

beggar!” (63) The only thing that distinguished Shivani from everyone else there was her using a wheelchair. The woman had thought her a beggar simply because she was disabled. “She had assumed that because I was disabled, I was needy. With her one little ‘charitable’ act, the woman had managed to make me question my being... It was a reaffirmation of what I had always been aware and conscious of—that people judged me on my outward appearance alone. No one seemed to have the time or inclination to get to know me as a person with my strengths and weaknesses, just like anybody else. Providing me with charity was probably much easier than trying and understanding what I needed” (ibid)

Though outwardly, Gupta took that incident in good humour, it made her recognize fully the need and importance for her to be self-reliant, “the taste of charity was so bitter that it was not something I wanted to experience ever again. Economic dependence on anybody meant that I needed to have that person support my decisions. I wanted to someday become completely independent—and the only way to do so was to take responsibility for myself and stop relying on anybody for anything” (65)

The Difference in Attitude towards Disability in India and the West

The difference in attitude towards disability in India and the West is a recurring theme in both books. In India, one is not used to seeing disabled people out on the roads. Most of them remain cooped up in their homes. Each time Gupta went out in Delhi, she had to face bystanders being curious about what happened to her and feeling sorry for her. It was during her training in Salisbury, that she saw several people using wheelchairs and going about their lives most routinely. The most important learning for her from the Salisbury trip was the realization that disability was not the end of the road, it was just an obstacle to be overcome through rehabilitation. In Bangkok, she saw how non-handicapping environments addressed the needs of all kinds of disabilities. It was there that she truly understood the importance of

accessibility for the inclusion of disabled persons in society. Thereafter, implementing these insights and working in the field of accessibility for disabled people became her passion.

Chib writes, “In India, if you are disabled, you are simply not welcome”, and “Societal perceptions in India are as fractured and potholed as its infrastructure. Till today, I regularly catch people staring at me as if I were a monkey in a zoo. The polite amongst the masses whisper pointing at me. The rude ones talk disparagingly and pityingly about me right when I am there as if I don’t exist or I exist only for their amusement and ill-informed judgement” (Chib, 2015, 97). Moving around outdoors is not an easy task in India. The pavements are not rounded and hence not accessible to wheelchairs, the roads are full of potholes. Most shops, libraries, cinema halls, museums, book shops, and restaurants are inaccessible and she feels paralysed at home. Due to multiple trips for treatment and education, England has almost become a second home for her. There, in her motorised wheelchair, she could easily access book shops, do window shopping, buy groceries, and medicines, and do the laundry. She felt useful as she could contribute to the household chores in England. People were helpful, nobody asked rude questions. Nobody stared. She feels free and can be independent there.

Her visit to Berkley after graduation was an eye-opener too! “I have never seen so many disabled adults in my life. Each leads an independent life. In Bombay when I was growing up, I rarely saw a disabled adult. So, I invariably grew up thinking that I would be normal once I was an adult” (86). She was pleasantly surprised to find the place teeming with electric wheelchairs. “Wheelchairs had the right of way, the traffic came to halt just to let them cross the road... all the pavements were ramped and the curves were rounded making it a very disable friendly place... every place was accessible... it gives a disabled person a sense of freedom, making one forget that he or she cannot walk. It was unbelievable for me, coming from a country where most buildings are totally inaccessible to wheelchairs (83).

Themes of Social Inclusion, Accessibility, Right to Work with Dignity

Often, disabled people are denied participation in everyday activities such as going to movies, and banks, entering or leaving restaurants, access to shopping, accessing public transport, socialising with friends, and travelling. It makes them feel isolated, left out and unwanted. Invisibility is imposed on people with disabilities, through ideas about their incapability and reduced capacities, hostile physical and social arrangements and insensitive and exclusionary institutional setups. A lot of people construe the disabled as a burden and do not want to waste their time and energy on them. Obviously, one doesn't feel good when someone makes you feel left out but this happens almost daily in the lives of disabled people.

In India, children with disabilities often end up in special schools. Proponents of the social model have critiqued these practices because they tend to further stigmatize persons with disability and re-enforce their alienation from the mainstream. Chib writes that her time at a special school in India was 'the darkest period of my life.' She feels that being trapped in a special school was detrimental to her education. From her own experiences, she strongly supports the idea of inclusive education. She strongly feels that disabled children should study with their normal peers from a young age. It would help them to be part of the mainstream and therefore, would find it easier to be included in all spheres of life.

Both Chib and Gupta write about many incidents in college or the workplace when their friends or colleagues seemed oblivious to their special needs, made plans for socialising, and movie dates in front of them ignoring them completely as if they were simply invisible. Chib writes about her experience of loneliness when her other friends went to a movie. "They must have assumed that I have no feelings and, thus, how could I feel left out?" (55) Gupta writes about a picnic she had gone with her colleagues at the Spinal Injury Centre to Ranikhet and Nainital. She enjoyed this chance to be out with friends. Much later she got to know that none

of them really wanted to take her along because she was disabled and would be accompanied by her carer. She writes, “I was of course, heartbroken when I learnt of the hypocrisy of the people, I thought were my friends. It seemed my disability overweighed me, even in the eyes of my colleagues who worked with me to help other disabled people” (100). Later, she developed a habit of inviting people over to her place rather than going out with them. That way they wouldn’t need to make any ‘special arrangements’ for her.

Gupta writes about going to watch a movie with friends in a multiplex where the management made her sit alone in a corner in the aisle while her friends sat somewhere else. The whole purpose of watching a movie was defeated. She sat alone through the movie, fretting and fuming over this treatment. “By the time the movie was over, I was shaking with anger for being singled out and treated in this discriminatory manner. On my way out I made a point to bring this poor service to the notice of the management. Screaming at their manager at the time felt very good, it helped me vent my anger” (93).

Chib writes about her experience on the prom night in college. Prom nights are generally much-anticipated events of fun and frolic in the life of college students. She had gone with her friends and they were having a good time in a corner. She joined her friends in dancing with her crutches. After a little while, one of the organizers came and said rather patronizingly, “why don’t you sit down, you are bound to fall, you can’t dance with crutches” (65). Neither she nor her friends had any problem with her dancing with crutches, but the organisers somehow couldn’t accept the visual of a girl with crutches swaying to the bits of music! Upset and humiliated, she sat down promptly and her friends dispersed to dance with other friends on the dance floor. Fun was over for her. She sadly notes that human beings were obviously averse to and not used to crutch dancing.

It is important to note that both writers are not resentful or angry – at least not in the way other minorities are typically represented as being in the various attacks on identity politics. Gupta or Chib do not want to limit their friend’s freedom to enjoy the movie or eating out experience, they do not resent the ease with which other people move through the aisles and choose their seats. They feel angry and hurt because other people surrounding them do not recognize them as human beings. This may seem like an extreme statement. But it exposes the fact that denying participation in everyday activities such as going to movies, banks, entering or leaving restaurants, access to shopping, public transport is an attack on their human status more effective and serious than the insignificance of the activity suggests. For it is in everyday life that we win or lose our right to be recognized as human beings.

The point is that both Gupta and Chib understand exactly why their disability limits their participation in the social world. It limits their participation not specifically because they are physically unable to participate, and not because the built environment is inaccessible, although it is. Their disability limits their participation because other people do not welcome their presence sufficiently to make it possible for them to live among them. The non-disabled people resist their efforts for inclusion in the mainstream, either in a condescending patronizing manner or by being outright hostile.

Both the writers dwell on how lack of accessibility repeatedly hampered their efforts at inclusion and made them feel humiliated and unworthy at the workplace. Gupta writes that when she was facing interviews for jobs, it was not so much her disability but the anxieties of the interviewers, where she had applied for jobs that proved to be a major obstacle. They questioned her physical ability and perceived it to be a major obstacle in discharging her duty to the fullest. This kind of behaviour made her feel bad about herself. She had got a job as a program manager in a big corporate house in Delhi. They were keen to work towards improving accessibility for people with disabilities in India. Gupta was quite thrilled because she could

make a great contribution in this area. However, accessing the office place proved to be the first hazard. Entry to the office was accessible to her from what was designated as a VIP gate, and it took six months to be allowed to use that gate. Soon she started to have problems with the HR department because they were unable to appreciate her special needs. It took a lot of ill-treatment to finally resign after ten months.

The resignation was a difficult decision for Gupta because there was an educational loan to be repaid and she had no other source of income. She writes “the discrimination is often very subtle, and many a time it makes us feel that we are being unreasonable by asking for our rights. As in my case, companies are unable or unwilling to make any accommodations for retaining a disabled employee even though they may not get another person as qualified, experienced or with passion for the job. It was easier for them to let the disabled employee go. My abilities were not appreciated, rather my disability was made an issue” (173).

Chib too has shared similar experiences. According to her, the basic problem of working in India was the lack of accessibility. When she worked with the Times group, she was not able to go out on her own. The canteen was out of reach, so she could never join her colleagues for a cup of coffee or lunch. Toilets were inaccessible. The pavements were not rounded to be disability friendly. There are too many people on the streets and the streets have many potholes. So finally, she too had to leave the job. (104)

Chib has worked quite efficiently as an event manager in the Oxford Book store and organised many successful events but here too she couldn't spend the entire day in the office because they didn't have accessible toilets. Something as basic as accessible toilets for disabled people is a pan-India problem. The problem becomes much more acute in the case of disabled women. She asks indignantly, “How are we disabled women to get employed and contribute and be a part of mainstream life if we cannot even find one toilet to go to for miles when we

need to do the most basic of human acts which other people take for granted” (Chib,2015,98). Lack of access means discrimination due to which they had been humiliated, made to feel sorry for themselves and torn to pieces countless times.

Both Gupta and Chib convincingly argue that much of the disadvantage associated with disability stems from social arrangements, environmental barriers and social oppression. They could learn to handle and overcome the problems their disability brought with it but feel frustrated by society’s attitudes towards them. Their personal experiences and academic training made them realise the importance of integrating disabled people into society and making society and the environment accessible to them. The impairment of a disabled person was not the reason for their exclusion from society, actually, it was the society that posed handicaps in environments which restrained disabled people from participating in them to the fullest degree.

Disability studies is an interdisciplinary area that aims at politicising the disabled identity to confront the marginalization that disabled people are subjected to. . People with disabilities face a range of challenges from dealing with personal experiences of impairment to negative attitudes of family and kinfolk to discriminatory social structures and institutional systems like schools, hospitals, and workplaces. the disabled are relegated to the margins in every avenue of opportunity, be it education, employment, transportation, or any other significant life area. In both autobiographies I studied in this paper, the writers write from their middle-class, urban, cosmopolitan location. This location ensures that they are better-informed, educated, and have the cultural capital to articulate their concerns and talk in the language of rights. However, more than 70% of the disabled population in India lives in rural areas and they are simply not aware of their rights.

While disability advocates in the developed world have progressed from issues of service delivery and rehabilitation to an engagement with the multiple nuances/ meanings of disabled existence, the developing world continues to agonize over securing the very basic elements that disabled people need to survive. Thus, the meaning of disability in India is embedded in this basic struggle for survival. The reality of disability in India is marked by a complex amalgam of class, gender, and caste issues. It is sometimes argued that since the basic struggle in India is for cultural understanding and survival, prevention and rehabilitation models continue to be relevant in such circumstances. However, the charity and philanthropy approach and altruistic paradigm adopted by various governmental agencies and NGOs have proved to be quite a response to the predicament of disability.

Therefore, the concerns regarding inclusion and accessibility as raised in these autobiographies are quite pertinent in the Indian context as well. The writers situate their personal stories in the wider social and cultural context and present a strong case for inclusion in the mainstream as a productive, valuable member of society. Both writers, being pioneering activists in this field, in addition to their first-hand experience of disability, critique the charity/ philanthropy approach to the issues faced by them. They believe that concessions and reservations are far easier to offer than creating an enabling environment and equal opportunities that will help them in nurturing their abilities to become equal members of society. They present a compelling argument for inclusion in the mainstream by creating enabling environments for the disabled community.

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