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EDITORIAL

The shadow of the pandemic left its mark on our various activities, on life in general and certainly on the academia; its retreat too, has cast another type of shadow which people call the 'new normal'; we note sadly that it is the ever-problematic normal, that gets redefined. To come out of such shadows is even more of a challenge for a journal centred around disability and run partly by disabled people. On top of all this, the pressure put by the various administrative machineries has been relentless, leaving us reeling under its weight.

Due to such real causes, the publication of this volume took more time than scheduled. Due to an inordinate delay in administrative requirements and in receiving reviews on time, we have decided to publish this combined issue — the papers and reviews included in this volume make the issues 1.2 (from July/ August 2021) *and* issue number 2.1 (from January/ February 2022). The next issue (2.2), for obvious reasons, is therefore delayed too and is likely to be published by October, 2022. However, starting 2023, we hope the various shadows, administrative or otherwise, will retreat and will allow us to grow at our own pace.

The three main articles in this combined issue travel a wide range of issues and constituencies, ranging from construction of disability experience by women with locomotor disability in Assam, to Gujarati short stories that render their female protagonist disabled, to the connection between dyslexia and English learning in London. The two provocation pieces take up the role of disabled students in protest demonstration and how must a language issue look when we take the language of disability seriously.

Staying close to literature and culture, the reviews present characterisation of disability in literature and films, the latter, in fact from two slightly differing perspectives: a disability film festival from the 'eyes' of a disabled and non-disabled person.

Unlike the first issue, however, we are not able to carry a Commentary section jotted with comments and interpretations from our members on important disability related articles, a dissection in the style of the *CDSI* (Critical Disability Studies in India) reading group—the force behind the birth of this journal.

Tanmoy Bhattacharya & Anita Ghai

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Making Sense of the Occurrence of Impairments among Women with Locomotor Disabilities in Assam

Jyotishmita Sarma

ABSTRACT

This paper elaborates on how women with locomotor disabilities and their family members make sense of the occurrence of their impairments in the specific contexts of their lives. The paper argues that the binary distinction between impairment and disability as espoused by the social model is irrelevant in the context of persons with disabilities in the majority world. The study was conducted among 18 women with different locomotor disabilities who had acquired their impairments early in life in the district of Kamrup Metropolitan in Assam. Using intersectionality as an analytical framework, this paper helps in understanding how the interplay of a multitude of factors such as nature of impairment, social class, social capital, access to healthcare, parents' knowledge about child health and, place of residence work simultaneously to co-construct the experience of impairment, which in turn helps to go beyond the refrains that people usually use to make sense of their impairments.

Keywords: Intersectionality; Disability; Impairment; Majority World; Assam

Introduction

In disability studies, the lived experiences of persons with disabilities are described by using different models (Ghai, 2003). These models represent socio-cultural assumptions about disability and persons with disabilities in various periods of human development, along with the ways they have been subjected to different forms of stigmatization and discrimination (Ghosh, 2012). These models were developed in the minority world, where persons with disabilities took the lead in demanding equal rights (*ibid*). Mike Oliver is credited as one of the pioneers on the discussion of models of disability. He conceptualized these models as the binary distinction between, what he termed as, 'individual' and 'social' models of disability (Oliver, 1990). The two fundamental tenets of the individual models are: firstly, the 'problem' of disability is located within the individual, and secondly, the causes of this problem originate from the functional or psychological limitations which are assumed to arise from disability (Oliver, 1990). Oliver considers medicalization as a significant component of this model (*ibid*). This is because disability is often looked at as a medical deficit, and medical professionals frequently dominate over the lives of persons with disabilities (Ghosh, 2012). The medical model explains physical, sensory or cognitive disabilities in terms of a medical etiology and emphasizes on the causal relationship between the origins and outcomes of various types of disabilities (Ghosh, 2012). Cure and overcoming the disability are the central features of this model, which are to be sought by the individual who is afflicted by it (Ghai, 2003). The medical model has been criticized for giving undue emphasis on clinical diagnosis, which in turn provides a partial and inhibiting view of the individual (Brisenden, 1986). It is argued that the problem with this model is that it not only determines the kind of treatment that is suitable for persons with disabilities, but also the type of life that they are supposed to lead (*ibid*).

In contrast, the social model of disability is a rejection of all the tenets listed above, and instead locates the problem of disability within the society (Oliver, 1990). The important tenets of this model are: firstly, it does not refute the importance of appropriate medical and rehabilitative interventions in relation to disability. Instead, it demonstrates the drawbacks of this approach in the cause of empowerment of persons with disabilities. Secondly, the model makes a conscious effort to shift the attention away from the functional limitations, physiological and cognitive impairments of the individuals, to the ability of the society to systematically oppress and discriminate them (Lang, 2001; Barnes, 2003; Barnes, 2012). This model has played a critical role in the emergence of groups of persons with disabilities and the growth of a positive disabled identity (Shakespeare & Watson, 1996).

In spite of the positive role played by the social model, from the 1990s onwards, an increasing number of disability scholars, informed by the feminist and post-modernist debates, have raised the internal critique about leaving out the body from the experience of disablement (Crow, 1996; Morris, 1998; Shakespeare & Watson, 2002). Some have argued that this model works well on a grand scale to challenge discriminatory social structures and shows the requirement for civil rights legislation to protect the rights of persons with disabilities. However, it lets them down at a personal level (Crow, 1996). The binary distinction is a product of the fear of articulating any negative feelings about the bodies of persons with disabilities, as it may result in passing a wrong message that their lives are not worth living. However, Morris (2001) considers it foolish to deny the distressing experiences of the body as impairment can a be salient element for many persons with disabilities (Shakespeare & Watson, 2002). Few disability scholars have also tried to reconcile the differences between disability and impairment in their versions of the social model of disability (Crow, 1996; Swain & French, 2000), while others have rejected the social model completely and have urged for the adoption of newer theories to comprehensively understand the experience of disability and impairment (Shakespeare & Watson, 2002).

While a lot has been written about the social model, its applicability to the majority world has not been questioned until very recently. Even to this day, minority world disability scholars are divided in their opinion about the relevance of this model in the majority world. Some like Stone (2001) and Sheldon (2005) have opined that the social model is as much relevant in the majority world as it is in the minority world; others like Grech (2009) have considered using the social model in the majority world to be problematic. Grech (2009) acknowledges that the social model has been inspirational for persons with disabilities, but argues that the exportation of this model to the majority world has very many problems: The first major problem of this model, in his opinion, is that *"it is grounded in and highlights the concerns of western, white, urban, educated disabled academics in industrial settings"*(Grech, 2009: 775). According to him, while attempting to understand disablement in a particular society, it is imperative to understand the broader socio-cultural, economic and political environment. All these factors, however, are easily forgotten when life is viewed from the lens of the industrialist, welfarist and individualistic viewpoint of the West. According to him, in a context of high levels of deprivation, the emancipatory paradigm becomes a highly dubious endeavor (*ibid*). His second criticism of the social model is that *"it promotes a 'universal discourse', which, […] runs the pervasive risk of being contextually and culturally inappropriate"* (Grech, 2009: 775). He argues that the sharp distinction between impairment and disability negates the importance of *"the phenomenological aspects of functional limitations and pain and [completely abandons] the theorization of impairment"* (Grech, 2009: 776). These issues, however, have rarely been discussed across cultures. He argues that in the countries of the majority world, impairment remains a fundamental concern because poor livelihoods and ultimately their survival depend on hard physical labor that makes a healthy body an imperative. This becomes even more risky where health and social protection systems are either absent or segmented. He argues that since the subject of impairment is directly related to medical issues,

> [s]oftening the issue of medical needs, even if for the purpose of politicizing disability, can become extremely dangerous in developing countries agonizing over the most basic health care and where functional abilities influence life activities and often survival
>
> (Grech, 2009: 776-777).

Grech's (2009) final criticism of the social model is that it makes a homogenizing assertion that all persons with disabilities are oppressed and excluded. Grech (2009) argued that different studies have shown that persons with disabilities experience both positive as well as negative attitudes along a continuum, even within countries. Moreover, persons with disabilities are not a homogeneous group and due to this their experiences are shaped by a myriad of factors such as the type of impairment, gender, religion, tribe, roles and rights and finally depends upon what is culturally, socially and ideologically valued. He cautions us that representing a person to be belonging to an oppressed group, when they do not consider themselves to be one, may only serve to marginalize and stigmatize that person (*ibid*).

Taking the above critique of the social model into consideration, this paper uses intersectionality as an analytical framework, to understand how women with disabilities and their family members, make sense of the occurrence of their impairments, in the specific context of their lives in the Kamrup Metropolitan District of Assam. The paper elaborates on the broader socio-cultural, economic and political environment surrounding their impairments, in order to understand how the research participants make sense of it. Such an understanding is important in order to critique the widely held understanding prevalent in disability studies, that negates the importance of impairment and usually point out the barriers present in the environment. As an analytical strategy, intersectionality helps us in understanding that human lives are multi-dimensional and their lived realities are shaped by diverse social factors and power dynamics that though are interlinked can change over time and space. Nonetheless, the importance of any category or structure in the study of social problems cannot be predetermined and must be discovered during the process of investigation (Hankivsky, 2014). Intersectionality also alerts us that at the micro level people can experience privilege and oppression simultaneously, and a multi-level analysis that links individual experiences to broader social structures and systems are crucial for revealing how power relations are shaped and experienced (*ibid*). In the last few years, the popularity of intersectionality has increased manifold, and is now considered to be a scholarly buzzword and a leading feminist paradigm with expansive interdisciplinary reach (Davis, 2008). Intersectionality has been adopted to examine the co-construction of race, gender and class in determining individual, collective and structural conditions (Naples, Mauldin & Dillaway, 2019). In spite of the analytical power of this framework to integrate analysis of varied forms of power and inequality, unfortunately disability does not find much space in intersectional scholarship (*ibid*). This drawback has now been rectified by critical disability studies, which views disability both as a lived experience as well as a social and political definition on power relations prevalent in the society, and also examines the intersection of disability with other markers of identity such as gender, class, race and sexuality to understand how these influence wider relations of power and personal experiences (Reaume, 2014; Owens, 2015).

Method

Setting of the Study

This paper is a part of the author's doctoral research on the lived experiences of women ageing with locomotor disabilities who had acquired their impairments earlier in their lives (prior to the age of 20 years). The fieldwork for the study was conducted in the district of Kamrup Metropolitan in Assam, India, between April 2015 and December 2016. The state of Assam is located in the northeastern part of India which, after partition of the country in 1947, is connected with the rest of the country via a narrow stretch of land known as the Siliguri corridor. Assam shares its border with West Bengal, six other northeastern states and the neighboring countries of Bhutan and Bangladesh. Assam comprises of people belonging to different national, ethnic, religious, linguistic and tribal groups who have been living together for centuries (Srikanth, 2000). Since independence from British rule, Assam has been severely plagued by insurgency, economic underdevelopment, continuous ethnic movements, resurgent sub-national movements and unchecked foreign infiltrations, as a result of which it has been one the most underdeveloped and destabilized states in the country (Das, 2005) until very recently.

Kamrup Metropolitan is one of the 33 districts in Assam. It was carved out in 2003 out of the erstwhile Kamrup district. In the predominantly rural state of Assam, this district is an exception as out of the total population of 1.2 million, an overwhelming majority of

1 million individuals reside in the urban areas of the district. Available statistics shows that out of the total population of persons with disabilities in the country, a vast majority reside in the rural areas under extremely poor conditions with little access to the services meant for them (Klasing, 2007). It was felt that the rural-urban differentials for the district would give a unique picture of the experience of disablement of women with disabilities. In addition to this, the presence of several established disability organizations made it easier to recruit the participants for the study.

The Research Participants

The study was conducted among 18 women with different locomotor disabilities in the age group of 18-57 years. These women were contacted with the help of four disability organizations, out of which one was working in the rural areas of the district, while rest were working in the urban areas. The main inclusion criteria for the study include occurrence of locomotor disability below the age of 18 years, and their ability and willingness to talk about their life experiences. Since most of the disability organizations cater to poorer sections of the society, a majority of the study participants also belong to the poorer families, with a hand-to-mouth existence. One of the limitations of the study is that the sample is not representative of the total population of women with locomotor disabilities in Assam, but only of women who are associated with disability organizations and are, therefore, more privileged in terms of access to different services than others. In spite of this limitation, the study throws valuable insights on the lived experiences of the women that have been shaped by the intersection of a multitude of factors. In this paper, the focus will only be on how the women and their family members have made sense of the occurrence of their impairments.

Research Design

This research uses qualitative methods because of its ability to access several aspects of women's experiences that have been neglected by traditional social science research. Qualitative methods enable the participants to express themselves, to discuss their experiences and have their knowledge(s) legitimized, and to do so in their own terms (Ironstone-Catterall et al, 1998). The research uses life history approach as the primary tool for data collection. This approach provides a framework which allows the stories of the research participants to emerge as well as to explore these stories within the social, political, historical, cultural, familial and psychological contexts within which they are embedded (Matiss, 2005). The research participants were asked to elaborate on their experience of living a life with visible physical disabilities with a specific focus on what they thought were important events of their lives. The interviews lasted between one and a half to two hours, and the interviews were conducted either at the disability organizations or in their homes, according to their convenience. Sometimes the interviews were conducted over multiple settings, depending upon their work schedule and availability. In a few instances, the family members of the women, especially their mothers, were also interviewed for a deeper understanding of the participants' narratives. All the interviews were conducted in Assamese language. The interviews were recorded with the permission of the research participants and were later translated and transcribed into English by the author.

Data Analysis

Data collection and analysis happened simultaneously, as is characteristic in qualitative research (Hesse-Biber, 2007). Every day after coming back from the field, thoughts about the interactions with research participants were noted down. The author transcribed their interviews as soon as possible so as to not forget about the nuances of their interactions with the participants. The transcribed interviews provided rich material which was then analyzed manually using the intersectionality framework according to the themes that emerged from their narratives.

Ethical Consideration

The study has been approved by the Institutional Ethics Review Board of the university where the author was enrolled for her Ph.D. Before starting the interview, the research participants were explained about the nature of the study, the nature of participation in the study, as well as the kind of questions that they would be asked. They were told that participation in the research was voluntary and they have the right to withdraw from the study at any point. The participants were also requested to sign the informed consent form, and they were assured that confidentiality regarding their identities would be maintained.

Findings

The study participants had different types of locomotor impairments, some of which were congenital, while others were acquired due to infective causes in childhood, while still others were acquired due to traumatic causes in adolescence. Due to this reason, the women and their family members also explained the causes of their impairments in different ways. Four different themes were identified during the course of the interviews. Due to the paucity of space, this paper has clubbed the findings under three themes. Regardless of the nature of their impairments, all the research participants talked elaborately about their experience of seeking treatment for their health conditions and the impediments they faced along the way. Such experiences helped them in making sense of their impairments.

Making Sense of Congenital Anomalies

Congenital anomalies are defined as structural or functional anomalies that occur during intrauterine life and can be identified prenatally, at birth, or sometimes may only be detected later in infancy (WHO, 2016). It can contribute to long-term disability, which can significantly impact the individual, his/ her families, healthcare systems and the society in general. About 50 per cent of all congenital anomalies cannot be linked to any specific cause and very often it is difficult to identify the exact cause of the impairment (*ibid*). In this study, the causes of congenital impairments of the research participants were sporadic in nature. Due to this reason, it was found that the women and their family members think about different reasons that may have caused the impairment, as explanations from the health personnel are usually lacking. The following narrative illustrates this point.

Minakkhi, 42, was born with a congenital impairment which is clinically referred to as syndactyly[1]. Minakkhi said that she had never asked her parents about her impairment. She has, however, heard them talking to others that her hands turned out to be like this because when her mother was pregnant with her, her father had a fight with the other villagers, and to block these people from coming into their home, he had cut a log of a tree to create a barrier between their household and the other households in the village. Minakkhi elaborated that in their community (Assamese), there is a belief that one should

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[1] Syndactyly is the fusion of adjacent digits, and is the most common of all congenital hand deformities with an incidence of 1 in 2000 live births (Jordan et al, 2012). It can be both hereditary as well as sporadic in nature. Syndactyly has a large functional and aesthetic significance for those who are born with this condition. Operative management is the only definitive care for persons with this impairment (Ibid).

not cut a tree or kill an animal when there is a pregnant woman in the household. She believes that her hands turned out to be like this because of her father's actions.

A few months later her mother was interviewed at their home, which is about 45 km from Guwahati. She said that many people in the village feel that Minakkhi's hands are like this because her father had a pet tortoise which he had left in their family pond with the help of a plastic net. Her mother said that she was *unsure* if her daughter's condition is because of this reason, or she has been like this since her birth. She, however, believed that it is because of her *beyakormo*(bad deeds) and *bhagyor dux* (faults in her destiny) that this has happened to her daughter. She explained said that in her youth she might have made fun of persons with disabilities in the streets, and her daughter's disability could be a punishment for that sin.

From Minakkhi and her mother's narratives, it can be seen that both of them have internalized the *traditional animistic beliefs* about the cause of disability, that it is a cause of punishment for bad deeds (karma) (Stone-MacDonald &Butera, 2014). Stone-MacDonald &Butera (2014) in their review of literature on cultural beliefs and attitudes about disability in East Africa, have noted that among the Nandi of Kenya, it is considered a taboo to kill animals without good reason, during a wife's pregnancy (Ogechi&Ruto, 2002, as cited in Stone-MacDonald &Butera, 2014). The review also found that laughing at persons with disabilities can cause an individual to have a child with disabilities, cause an accident that would harm that individual or cause the future generations of the family to be cursed (Stone-MacDonald &Butera, 2014). Minakkhi and her mother seem to hold similar beliefs about her impairment. Minakkhi's mother also seems to have internalized the widely prevalent notion in India and other parts of Asia, that the disability in the child is due to the faults of the mother (Ghai, 2003; Koydemir&Tosun, 2009; Crabtree, 2007).

While Minakkhi and her family held traditional beliefs about the cause of her impairment, it was found that such beliefs did not hinder her parents from seeking treatment for her condition. Her mother said that when Minakkhi was about three-four years old, she and her husband, at the advice of some relatives, took her for a consultation to a tertiary hospital in Guwahati. In the hospital, the doctor told them that they would be able to cure her impairment by surgically separating her fingers. However, considering her young age, the doctor asked them to come back a few years later. When she was eight years old, Minakkhi's *Aita* (paternal grandmother) accompanied her to the hospital for the surgery. Her parents were not able to accompany because of their busy work schedules at home and in the agricultural field. Minakkhi's mother said that at the hospital, the doctor was able to separate only two of her fingers in both her hands and he asked her to return back a few weeks later to complete the procedure. Unfortunately, at that time her *Aita* fell sick and passed away, because of which Minakkhi was not able to return back to the hospital and her surgery remained incomplete. According to both Minakkhi and her mother, her fingers joined back as a result of abruptly stopping her treatment.

From the interview it was clear that her mother considered herself responsible for their inability to continue Minakkhi's treatment. Her mother's guilt was further accentuated by a recent interaction with a *Gonok* (a sub-group of Brahmins who are in the hereditary occupation of astrology), whom she had consulted to know if and when Minakkhi would get married. The *Gonok* told Minakkhi's mother that when she was pregnant, a bad spirit had entered her body because of which her daughter was born with this impairment. Hearing this, Minakkhi's *Bou* (elder brother's wife), who was nearby, started laughing and said, *"They are from the older days. They believe in such things"*. Minakkhi's mother, however, did not care what her daughter-in-law thought about her beliefs. Her *Bou* further said that at that time the healthcare facilities were not very adequate and it is due to this reason that Minakkhi's hands remained like this. She argued that a child with the same condition from the current generation would have been cured because of the advancement of medical facilities and the availability of healthcare facilities nearby. Minakkhi's mother interrupted her and said that Minakkhi could have been cured even at that time, but it was because of their mistake that they were not able to continue her treatment. She feels that if they had taken Minakkhi to the hospital at the age of 12-13 years, probably her fingers would have been separated. But unfortunately, this thought did not occur in their minds at that time because they had to look after so many things. It is important to note here that the road connectivity and transportation facilities from their village to Guwahati was very poor at that time, which could also be one of the factors that hindered her parents to take her back to the hospital later.

The above narrative suggests that traditional beliefs about impairment often coexist with the faith in the healing powers of biomedicine. In order to understand why this is so, one must also keep in mind the situation of Assam in the 1980s and 1990s which was marred by ethnic and political strife, insurgency and underdevelopment, making it increasingly difficult for people residing in rural areas to seek treatment from healthcare facilities located far away in the city. Although Minakkhi's mother did not mention the political context of the state directly, this aspect cannot be overlooked while analyzing Minakkhi's barriers to seek treatment for her condition. In effect Minakkhi's mother's guilt at not being able to cure her daughter shows in part her sorrow at not being able to change her daughter's *kopaal* (fate) despite a cure being available for her condition. On the other hand, it can be seen that being more educated than her unlettered mother-in-law, and not bearing witness to the lifelong struggles that Minakkhi has had to endure, her *Bou* considered Minakkhi's impairment to be a result of inadequate healthcare facilities and not a result of an intersection of a number of factors including the nature of her impairment, her rural residence, her parents' poor financial condition and the political context of the time when she was growing up. Her comment also shows that there has been a definitive shift regarding impairment among the younger generation, wherein they do not ponder much about the cause of the impairment. Rather, they emphasize more on the 'cure' of the impairment.

Importance of medical explanation about disability

The study found that medical explanation from healthcare providers about the cause of impairment helped the women and their family members tremendously in making sense of their impairments. It was seen that such participants did not ponder much over the cause of their impairment. They were also better adjusted in their lives and had accepted their impairments as something that was written in their *kopaal* and would have happened no matter what they had done to prevent it. In contrast, the women who had not received an adequate explanation from their healthcare providers remained confused about their medical conditions and sometimes also blamed others for their impairments. The study also found that access to appropriate healthcare and thereby access to appropriate medical explanation about impairments is determined by a number of intersecting factors such as social class, parents' awareness about child health and social capital. These points are illustrated in this section with the help of narratives of two women with the same medical condition (poliomyelitis) acquired several years apart, but who belong to different strata of the society.

Mayuri, 57, grew up in Shillong, the former capital of Assam, where her father was posted at that time. When Mayuri was one and half years old, she and her mother paid a visit to her mother's natal family in Guwahati. At that time, they had gone to visit one of her mother's cousins. Mayuri's mother believes that her daughter had contacted polio from her cousin's son who was defecating on his pot, while Mayuri was standing close to him and talking to him. She said that at that time she was not aware that polio spreads in this way and she was also not aware that the other child was infected with polio . Within a few days, her mother observed that Mayuri had very high fever, and was unable to turn on her right side. She also observed that her right upper and lower limbs would cling to her body. Mayuri's mother consulted her *Pehadeu* (father's sister's husband), who was a doctor and had received training in polio management from Bombay (now Mumbai). With one look at her, the doctor was able to identify that this was a case of polio. Thereafter, he took her blood samples and was able to confirm that this was indeed a case of polio.

Mayuri's mother said that at that time they had never heard of a disease called polio and so she asked for details from her *Pehadeu*. The doctor then explained to her in great detail about the etiology of the disease. She, for instance, was able to explain to me that polio spreads through the feces of the infected child, and due to this reason she kept herself and her daughter locked up in a room in the top floor of her mother's home in Guwahati for three months. She also said that even though she was aware that the incubation period was three weeks, she did not allow her daughter to interact with any of her brother's children for three months, out of the fear that they would also get the infection. She said that this would have made her very upset.

Mayuri's mother also remembers that the doctor massaged Mayuri's body with some special oils at night to bring back the strength of her body. The doctor started living at the mother's home and took it upon himself to massage his patient. Mayuri's mother feels that it is because of the dedicated care from her *Pehadeu* that Mayuri recovered from her illness within one and half months. She said that her happiness knew no bounds when she saw Mayuri move her hands after her illness. She also said that some people had advised her husband to take Mayuri to Bombay for treatment, but her *Pehadeu* stopped them from going anywhere and told them that he would provide the best quality care to her in Guwahati. She also feels lucky that both of them were in Guwahati at the time of onset of her illness, amidst her family members. She does not know if she would have found someone to care for her daughter in Shillong.

The above narrative shows that the perception about polio was absolutely limited at the time when Mayuriwas infected. In spite of this, her family received adequate medical explanation that enabled them to cure her condition without any severe impairment. It is apparent from the narrative that this has been possible because she is from an affluent family, which could have even afforded her treatment from outside the state, if they had wished. But they did not have to take this route because Mayuri received quality treatment at her maternal grandparents' home. Apart from this her family's affluence was also visible from the fact that her mother was not burdened with any household responsibilities during those three months when she and Mayuri remained locked inside her maternal grandparents' home. As would be visible from the following narratives, this is a luxury that was not available to the mothers of most of the other research participants. It was due to these intersecting factors that Mayuri and her mother never pondered about why this disease afflicted her. Her mother simply replied, *"It happened naturally. This was in our kopaal"*. Like in the previous section, this comment again shows that the traditional and biomedical explanations about impairment are not mutually exclusive of one another, but often coexist together as a means to help people make sense of their impairments.

In contrast to Mayuri, the other research participants who had polio or other fever induced impairments belonged to socio-economically poor households. It was found that families of these women suffered from immense difficulties while seeking healthcare for them and when they did find a healthcare provider, they did not provide the patients' families with adequate medical explanation for the condition. In such cases it is seen that the women and their families use the names of different diseases with different etiological causes interchangeably. In certain instances, they even considered their doctors to be responsible for their conditions. The following narrative gives a glimpse of this.

Nayana (30+) was about two and a half years old, when one day she had developed very high fever. At that time, her parents had only recently shifted to Guwahati from their village in the Dhubri district, and had started working as live-in domestic workers for an affluent family. During the one week when she had very high fever, Nayana's parents gave her several over-the-counter medicines to cure her. These medicines, however, had little effect on her condition. Thereafter she developed an abscess in her umbilicus, and it was only at this point that her parents rushed her to a doctor. Nayana said that this doctor was 'not able to identify her condition', and gave her medicines for 'malaria' instead. After taking these medicines, her condition deteriorated further. Later her parents took her to another doctor, but he didn't want to take any risks by treating her, as her condition was very critical. After much pleading, this doctor gave her one 'good medicine' which, according to Nayana, stabilized her condition.

This, however, was not the end of her parents' agonies. After a few weeks, her parents started to notice that unlike earlier, Nayana did not move at all, and would lie down on the bed all the time. When one month passed like this, her parents got very worried and took her to an orthopedic for consultation. This doctor told her parents that she was infected by 'typhoid' and it could not be cured. He also told her parents to stop seeking treatment for her condition, as she could not be cured even if she was taken out of the state for her treatment. He, however, taught her parents a few exercises and asked them to continue those at home.

After her recovery from the illness, Nayana could never walk again. Through the help of his employers, her father was able to get a wheelchair for her to ease her mobility. Apart from mobility, her impairment impacted her life in other ways also. Nayana's parents tried very hard to get her admitted to government schools, but none of the schools that they had approached, was willing to give her admission citing accessibility issues. Eventually, she was admitted to a special school for children with intellectual disabilities, despite the fact that her impairment was only physical in nature. It was only at this school that Nayana heard the word 'polio' for the first time, but still used it interchangeably with 'typhoid'.

Nayana said that her father was a strong believer in God, and after she fell sick he was not able to make sense of her condition. According to her, he was very depressed for a very long time about this. However, her parents did not blame God for their sufferings. Instead, they consoled themselves by thinking that it was God's will, and would have happened no matter what was done. According to Nayana, such an understanding helped her parents in making sense of her impairment, and arguably relieved them from their guilt as well for not taking her to a doctor in the very beginning of her illness episode when she started showing symptoms. Nayana, however, blamed her father's employers for her impairment. She said that as 'non-literates from the village' who had recently migrated to the city, her simple-minded parents were not aware about what to do when a child falls sick. As domestic workers, her parents had to meet all the requirements of their employers, and this eventually left them with very little time to care for their own needs.

According to her, it is because of this exploitation that she had to suffer from the debilitating effects of 'typhoid'. She also considered the first doctor who gave her wrong medicines to be responsible for her impairment. With regards to this also, Nayana felt that her father's employers should have guided her parents better regarding what to do when a child falls sick.

The two narratives above show how the life trajectories of both the women have been different due to the intersection of factors such as social class, level of awareness of their parents regarding child health and social capital. In spite of the fact that both of them had the same condition (polio), although about three decades apart, Mayuri received much better care and much better explanation for her medical condition because of her stronger social capital. This enabled her and her family members to reconcile with her medical condition. In contrast, as a daughter of poor migrant daughter, who were dependent on the goodwill of their employers, Nayana faced a lot of vulnerabilities. It is very likely that her treatment was also interrupted by the frequent skirmishes in the state during the period of her illness. Since an interview could not be scheduled with her mother, this is only a speculation about her treatment.

Disability and Poverty

It is now widely acknowledged that disability and poverty exist simultaneously in the majority world (Meekosha, 2008). This is because of two reasons: first, the root causes of impairment in the majority world are malnutrition, lack of services and landmines, and these are likely to hit the poorest the hardest; and second, people with impairments are more likely to be poor worldwide due to the disabling barriers that prevent them from getting an education, employment, access to appropriate healthcare and other services (Stone, 1999). It has been argued by Ingstad (1990) that among poorer households, having a member with disabilities affects all other family members as the resources available to the household have to be redistributed keeping into consideration the needs and concerns of the disabled person (cited in Grut, Olenja&Ignstad, 2011). This was also found to be true in the case of the study participants. The following narratives illustrates how poverty limited the access to healthcare and rehabilitation facilities for one of the research participants (Sobiha), while for another participant (Dolly), poverty forced her to work at a hazardous workplace at a very early age, that eventually exposed her to her impairment and limited her life opportunities in the future. But over and above these two individuals, the other members of their families were also adversely affected for having a person with disabilities in the family. Both the women blamed their *kopaal* for their conditions.

Sobiha's mother, a poor Bengali Muslim woman, had married a relatively affluent Christian man, who was more than double her age. He had another wife before her, and had converted to Islam to marry Sobiha's mother. Sobiha's younger sister said that when her mother was seven months pregnant with Sobiha, she fell down from the stairs on a rainy day. After her fall, she suffered from pre-labour rapture of membranes (PROM), but was not able to go to a hospital immediately as she was all alone at home. She was taken to a hospital only after three days when her husband returned home. As a result of this fall, Sobiha, 18, was born with cerebral palsy that has affected her intellectual abilities, speech and her gait. Her doctor diagnosed her problem immediately after her birth, and due to the absence of state-run physical rehabilitation centres at that time, referred her to a disability organization for physical rehabilitation. This organization, at that time, was located very close to their home in Guwahati, which enabled Sobiha's mother to access physical rehabilitation for her daughter. However, a few months later, she was pregnant again due to which she had to discontinue her treatment. This setback to her treatment was quickly followed by the death of Sobiha's father when she was only two years old and her sister was only nine months old. After his death, there was no financial support for the three of them, as her father's pension along with his property went to his first wife. She also did not receive any financial help from her siblings because they were also very poor. As a result, the responsibility of running the family fell on the shoulders of Sobiha's mother. She soon started a small shop in a footpath. Following this, her mother had little time to spare for Sobiha's physical management. By this time, the disability organization had also moved to its permanent location in another part of the city. Sobiha's mother said that money was so scarce during this period that she spent whatever little money she had on buying milk for her children, instead of buying medicines for Sobiha or for taking her for physical rehabilitation to the disability organization. Sobiha's mother further said that no one ever told her that daughter's condition would deteriorate if her medicines were not continued. Listening to her mother narrate the story of her impairment, Sobiha reflected, "*Ma fell down, that is why I am like this. What to do now? This is my kopaal.*"

The above narrative clearly shows difficult familial circumstances (like marriage with an already married and much older man, and his death only a few years after marriage), and dire financial condition increased the vulnerability and helplessness of Sobiha's mother. This in turn hindered Sobiha's access to physical rehabilitation, despite the fact that her condition was diagnosed at birth. It can be seen that both Sobiha and her mother had resigned themselves to their *kopaal*, which according to them was responsible for all the hardships that they had to endure in their lives, including Sobiha's impairment.

Unlike Sobiha, Dolly, 34, acquired her impairment as a consequence of poverty. Her right forearm was amputated when she was about 13 or 14 years old. One year before this incident her father, who was the only working member in the family, had passed away. Dolly has three siblings, out of which her older sister and younger brother were studying at that time, while her youngest sister was only one year old. Dolly was not much interested in studies, so she voluntarily dropped out of school after class 5 to help her mother earn a livelihood. After the death of her father, Dolly's mother had received a sewing machine from the garment shop where her father had worked. With the machine she and Dolly used to sew *mekhela*[2] for their neighbors, but this fetched them only a small amount of money, and was not sufficient to run a family with five people. In order to supplement the family income, Dolly started working as a helper for a printing press. She had only worked there for a few months when a wood cutting machine, which was not working properly, fell on her right forearm, severely injuring it. After the accident, she was taken to a government hospital where the doctors said that they cannot treat her and referred her to another government hospital. At the second hospital, the doctor told her mother that they will not be able to save her forearm as it might get rotten from inside. Since she was left with no other option, her mother had to agree to amputate her daughter's right forearm. The expenses for treatment were met by the printing press.

After this incident, Dolly's life has changed tremendously. Even though the amount she earned was meager, her life transformed from being an active earning member of the family to someone who was not able to find any well-paying jobs because of her impairment. Additionally, before her accident, she was also able to help her mother in her sewing work. Perhaps what she regrets most is that her *Bhaiti* (younger brother) had to drop out of school in order to take the responsibility of the family. About five years before the interview, Dolly found a job in an organization that worked for the physical rehabilitation of persons with disabilities. Even though her job paid her a meager stipend,

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[2] The bottom portion of the traditional Assamese dress.

and she was in the lookout for better opportunities elsewhere, she was happy to have found this organization as she met many other persons with disabilities here who helped her in forgetting about her miseries. She also said that she sometimes suffers from intense pain in her amputated limb but she has been told that there is no cure for that, except painkillers. This lingering pain makes her very frustrated and sometimes she hits herself hard in her frustration. Doctors had also suggested that she might consider wearing a prosthetic limb, but the one that her second employer bought for her was of low quality and it further intensified her pain. As a result, she stopped wearing it after one or two attempts. When I asked her if she blames anyone for her accident, Dolly replied that this was written in her *kopaal*. She further said that her mother had asked her not to work, but she was adamant to continue working at the printing press due to the financial condition of her family. She also said that she strongly believes in God despite the fact that she has had to face many hardships in her life.

From the above narrative it can be seen that it was the death of her father, who was the only earning member in her family, and poverty that exposed Dolly to her impairment. Dolly blames her amputation on her *beya kopaal,* which brought misfortune not only for herself but for her entire family as they lost a productive member because of this reason. She also regrets that because of her, the entire family had to go through very rough times.

Discussion and Conclusion

Taking majority world theorist Grech's (2009) criticism of the social model of disability, this paper attempted to understand how women with locomotor disabilities and their families make sense of the occurrence of their impairments. It was found that the social model distinction between impairment and disability made no sense for the study participants as they were too engrossed in their socio-cultural, economic and political circumstances. It was found that these circumstances hindered the women from accessing healthcare for their conditions that in turn aggravated their health conditions. For instance, in the case of Nayana, her treatment was hindered because of her family's socio-economic status that made them very dependent on their employer's goodwill. As a result of this there was a delay in seeking treatment, which resulted in her permanent disablement. For Sobiha, even though her condition was diagnosed at birth, her mother was not able to continue her treatment due to the difficult familial circumstances like the birth of her younger sister and death of her father soon after. This necessitated that her mother prioritize earning a livelihood for her family instead of seeking physical rehabilitation for her condition. For Minakkhi her rural residence and distance from the healthcare facility located faraway in the city, where her condition could have been corrected, hindered the cure of her condition. Arguably the political events of that period also hindered her access to healthcare. Although Dolly received proper healthcare after her accident, it was not followed up by the provisioning of a good quality prosthetic forearm which could have reduced her pain substantially. Among all the research participants only Mayuri received appropriate healthcare because of her affluent socio-economic background and strong social capital. The findings of the study corroborate what Grech (2009) had stated about the importance of studying impairment in the majority world context, because it is of fundamental concern for the people here. Additionally, it is evident from their narratives that the study participants faced a myriad of different problems which intersected to form unique experiences for each one of them. Thus, it is imperative that more emphasis is put to study the heterogeneous experiences of persons with disabilities rather than homogenizing their experiences and rendering those who are further marginalized due to factors like caste, class, religion, gender, ethnicity or place of residence, voiceless. In this regard, intersectionality is very helpful because as it makes it clear that human lives are multi-dimensional and their lived realities are shaped by a multitude of social factors. As mentioned earlier in the paper, no category or structure can be predetermined in the study of social problems and it can only be discovered during the process of investigation (Hankivsky, 2014). In this study, it can be seen that social class, nature of disability and place of residence have determined the lived experiences of the people. On the other hand, other prominent social categories like gender, ethnicity, caste, religion and linguistic identities have not emerged as important categories that have shaped their lives. Future studies on the lived of experiences of persons with disabilities in Assam must explore these categories more deeply.

In the available literature on disability models from India, it is seen that one of the predominant models is the *religious/ moral model.* According to it, disability is regarded as the divine retribution for past sins committed either by the individual or by his/ her ancestors. In this model, the concept of *karma* governs the basic assumptions about disability and persons with disabilities are considered to be suffering from the wrath of

God (Ghosh, 2012). Another related notion within this model is that God inflicts suffering on good people in order to test their resilience and inner strength. The common factor in both these explanations is that disability is God's will, which must be respected (Dalal, 2002). This model or the *karma* theory within this model is so popular in the literature on disability in India in the minority world that anybody who is not interested in emphasizing on this model is forced to reconsider (Kumar, Hiranandani & Sonpal, 2013). As a result, the focus on the *karma* theory is overarching in the existing literature. Unfortunately, much of the literature on disability in India has emerged from the metropolitan cities like Delhi, Mumbai and Kolkata. As a result, there is not much representation on how people belonging to other cultures make sense of their impairments. In this study, it has been found that the research participants use different refrains to make sense of their impairments which include *kormo* (*karma*), bhagyo (destiny), *kopaal* (fate) and God's will. How each of the participants and their family members has used these refrains, however, varies from context to context. *Kormo* (*karma*), for instance, is used to refer to the outcomes of bad deeds committed either by the individual or his/her family members in their present or previous lives. In this study, only Minakkhi's mother blames her *beyakormo* (bad deeds) and *beyabhagyo* (bad destiny) for her daughter's impairment. As shown above, the reasons for this could be that her daughter's impairment is congenital and that they were not able to seek healthcare for her condition despite the fact that cure was possible. In some cases, the participants used the refrain of *kopaal* (fate) to make sense of their impairments. This was used when the parents of the participants had done everything in their capacity to improve their child's condition, yet they could not be successful because of factors beyond their control (in the case of Mayuri, Sobiha and Dolly). *Kopaal,* therefore, was used as a refrain to reconcile themselves to their fates, instead of fighting against it. It was found that such an explanation liberates them from the feelings of sorrow and guilt and helps them in coping with their altered life circumstances. Apart from these, the study also found that some of the research participants and their parents were staunch believers in God and regardless of the severity of their impairments and the hardships that they had faced as a result of it, they do not doubt the blessings of the Supreme Being on them (Nayana and Dolly). Belief in God also gives them the strength to realize that their impairments were part of God's plan for them and would have happened, no matter what they would have done to prevent it. Thus, these refrains helped the research participants in psychologically coping with their impairments and their life situations, especially when they were aware that cure for their conditions were available but they were not able to access it due to circumstances beyond their control. As a result, the participants used both traditional and biomedical explanations to make sense of the occurrence of their impairments and this is only a reflection of their vulnerabilities and helplessness in a peripheral state with crumbling health and social infrastructure.

In conclusion, this paper attempted to understand the complex ways women with disabilities and their family members make sense of their impairments in the context of an urban district in Assam. It is evident from this paper that understanding the occurrence of impairments is of vital importance in a study on how people make sense of their impairments in the majority world with limited access to healthcare services. Intersectionality as an analytical framework helped tremendously in understanding how the interplay of a multitude of factors such as nature of impairment, social class, social capital, access to healthcare, parents' knowledge about child health and place of residence, work simultaneously to co-construct the experience of impairment. As can be seen from the paper, the use of intersectionality helps in going beyond the refrains that people usually use to make sense of their impairments.

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Disablement of Women: A Comparative Study of *Lohi ni Sagai* by Ishvar Petlikar (1916-83) and *Shruti ane Smruti* by Chandrakant Bakshi (1932-2006)

Zarana Maheshwari & Divya Shah

ABSTRACT

The present paper undertakes a comparative study of two Gujarati short stories 'Lohi ni Sagai' (Engagement of Blood) and 'Shruti ane Smruti' (Shruti and her Memory) by Ishvar Petlikar (1916-83) and Chandrakant Bakshi (1932-2006) respectively, and attempts to study how narrative of the stories devises various narrative techniques and disables their female protagonists Mangu and Smruti in 'Lohini Sagai' and 'Shruti ane Smruti' respectively. The paper further attempts to study how the bodies of both these women characters are rendered 'abject' (Butler, 1993), how they are relegated to a 'heterotopic space of deviation' (Foucault, 1984), and how they are denied citizenship at the end. It further brings to the fore how 'abject bodies' of people with disability pave the way for creation of the normative bodies and make the normative bodies more viable and desirable and eventually make them fit into 'paradigm citizenship'.

Key Words: Disablism, Abject, Heterotopias, Deviance

Introduction

Disability has emerged as an excessively devised trope in characterization in various cultural forms as a social category of deviance, as a symbolic vehicle for meaning making (Mitchell & Snyder, 2001). The perpetual circulation of the images of 'extraordinary bodies', their culturally filtered representations and 'disabling constructions' have led to 'normate reductionism' (Garland-Thomson, 2012, Mitchell and Snyder, 2001, Padilla, 2021). The literary and cultural representations become important cites, where discourses of disability and deviance are formed, sustained and circulated. As Garland-Thomson (2012) asserts that the medical, legal, political, cultural and literary narratives construct the discourses of disability through which the physically disabled are produced. These discursive practices constitute disability subjectivities and bring into being disabled subjects and these subjects understand and act in the world in the way in which they do' (Tremain, 2015).

The present paper attempts to study the discursive formation of two disabled characters in two Gujarati short stories 'Lohi ni Sagai' (Engagement of Blood) and 'Shruti ane Smruti' (Shruti and her Memory) by Ishvar Petlikar(1916-83) and Chandrakant Bakshi (1932-2006) respectively. 'Lohi ni Sagai' is a story of a mentally disabled character Mangu and her mother Amratkaki. Amratkaki showers incessant love on her daughter, provides intensive care and tries to tame her daughter Mangu. However, Amratkaki does not succeed in restoring Mangu's sanity. On account of her failure in coping with the societal pressure, she sends Mangu to a mental hospital. 'Shruti ane Smruti' is a story of Shruti who loses her ability of hearing and speaking because of some ailment. Shila and Suhas, that is, Shruti's parents accept their daughter's disability and train themselves and their daughter in coping with the disability. Shruti however meets with a road accident and dies at the end.

Methodological Discussion

The present paper explores the discursive constitution of disablement by undertaking a textual analysis of the two narratives in both the short stories. By drawing insights from Butler's notions of 'abject bodies' and 'unintelligible and 'ungrievable bodies', it analyses how the protagonists Mangu and Shruti in 'Lohi ni Sagai' and 'Shruti ane Smruti' respectively are rendered deviant and abject, and how their lives become ungrivable lives. It further explores the way in which their disability is exploited as a 'narrative prosthesis' in order to reach resolution. The paper further brings to the fore the discursive practices woven in the narratives which establish the deviant bodies of Mangu and Shruti as a foil to the notion of 'paradigm citizenship' and relegate both of them to the 'heterotopic space of deviation' (Foucault, 1984:4-9).

Theoretical Framework

Butler (1993) in her seminal work *Bodies That Matter: The Discursive Limits of Sex*, argues that constructions are perceived as dispensable, but she posits that constructions are constitutive, without which there is no 'I', no 'we'. These constructions produce the domains of intelligible and unintelligible, unliveable, and unthinkable bodies. She further argues that the domain of 'unintelligible' is not the opposite of the intelligible, as oppositions are part of intelligibility. The unintelligible is the 'excluded and illegible domain that haunts the intelligible domain as the spectre of its own impossibility, the very limit to intelligibility' (Butler, 1993). The materiality of the body is constituted by the regulatory norms that work in a performative fashion to serve the consolidation of the heterosexual imperative (Butler, 1993, 1997). This process of materialization through the discursive means enables the heterosexual imperative to make certain sexed identifications visible and foreclose and/or disavow other identifications (Butler, 1993). This exclusionary matrix by which subjects are formed thus requires the simultaneous production of a domain of abject beings, those who are not yet 'subjects,' but who form the constitutive outside to the domain of the subject (Butler, 1997). The paper by drawing some insights from the concept of 'abject body' attempts to analyse how certain bodies in their representations are rendered 'abject' and help the formation of 'normative subjects'.

It is important to note that these 'abject bodies' are also 'ungrievable bodies'. Butler (2009) in her book *Frames of War: When Life is Grievable*, elaborates on the notions of 'frames' which according to Butler, are interpretative structures that regulate the recognizability of life and loss. Frames in her view generate 'specific ontologies of subject' (Butler, 2009). The subjects are constituted through norms and when these norms are reiterated, they produce and shift the terms through which 'subjects are recognized'. She further argues that some conditions make it possible to apprehend a life or set of lives as precarious (Butler, 1993). Life has to conform to some conception of what life is in order to become recognizable, and thus, the norms of recognizability shape and are shaped by the schema of intelligibility (Butler, 1993). The apprehension is generated from something which is living, but is not recognised as life (Butler, 1993:7). However, the living figure outside the 'norms of life' is essential to the production of normativity (Butler, 1993:7). The short stories under analysis in the present paper produce the living figures who do not conform to the norms of life. They contribute to reiteration of normativity, and these abject and ungrievable lives are relegated to 'heterotopic space of deviation', as they do not meet the conceptions of 'paradigm citizenship' (Wendell, 1996:37).

Wendell (1996) in her book *Rejected Bodies: Feminist Philosophical Discussion,* while elaborating upon the concept of social construction of disability lays down perceived social paradigms that form citizenship. According to her, 'Societies that are physically constructed and socially organized with the unacknowledged assumption that everyone is healthy , non - disabled, young but adult , shaped according to cultural ideals , and ,often , male , create a great deal of disability through sheer neglect what most people need in order to participate fully in them' (38). She further posits that the entire 'physical and social organization of life' is founded on this ableist assumptions which leads to an idea of 'paradigm citizenship' (Wendell, 1996:38). While providing insights into the culturally cultivated binaries of entitlement and help, she argues that those who meet the social paradigms of 'performance and productivity' (Wendell, 1996:38) of physical and social organization are 'entitled' to the services and the facilities such as education, transportation, communication, healthcare and so on, for they conform to the norms of 'paradigm citizenship' (Wendell, 1996:38-39). Those who are in need of different facilities or services, the facilities and services are called 'help' and not 'entitlement', because people availing such services are socially dependent and hence misfit for public life (Wendell, 1996:40). Wendell's insights are useful in analyzing how both the stories under discussion, through the notion of 'paradigm citizenship' reiterate the discourse of normalcy and establish the discourse of deviance. These deviant bodies are relegated to the 'heterotopic space of deviation' (Foucault, 1984:4).

Foucault (1984) in his essay 'The Other Spaces' delves into the concepts of 'utopias' and 'heterotopias'. In his view, there are some real spaces which are formed in the very foundation of society, which work as counter sites, through which the real spaces can be represented, contested (Foucault, 1984:4). He further elaborates upon various principles of heterotopias such as juxtaposition, crisis, and deviation. According to him, heterotopias of deviation refer to those spaces in which individuals whose behaviour is deviant in relation to the required mean or norm are placed. The rest homes and psychiatric hospitals, and prisons exemplify the heterotopias of deviations (4). The insights from Foucault's notion of 'heterotopias of deviation' help comprehend the metrics through which the disabled characters are relegated to a space which is inhabited by deviant bodies.

The formation of a deviant body in the respective stories is not only a part of an orchestrated design of normativity, it also serves as an important device 'narrative prosthesis'

(Mitchell & Snyder, 2001) for the stories to reach a resolution. Mitchell & Snyder argue that literary efforts to illuminate 'dark recesses of disability 'generate a discursive subjugation (Mitchell & Snyder, 2001:6). Narrative prosthesis' implies discursive dependency of literature upon disability (Mitchell & Snyder, 2001:1-35). In their view, to prosthesise is to compensate for a body which is lacking, which is not functional or which is inappropriately functional (Mitchell & Snyder, 2001:7). However, prosthesis always carries an 'ideological aberrant (Mitchel and Snyder, 2001:8). Narrative prosthesis institutes body within the zone of tolerable and if disability is too far to conform to the norms, it aims at erasing the difference (Mitchell and Snyder, 2001:8). The short stories under analysis devise disability as a narrative prosthesis in order to fix the familial complexities and erase the difference in order to reach a convincing resolution.

Analysis

> 'Mangu ne ganda na davakhana ma mukva ni salah loko Amratkaki ne aapta' (People used to advised Amratkaki to admit Mangu to the hospital for the mad)
>
> (Petlikar, 2017:78)

With the above quoted words, the story 'Lohini Sagai*'* by Ishvar Petlikar opens and introduces Amratkaki and Mangu as the major protagonists. The story revolves round the characters of Mangu and her mother Amratkaki. Mangu, a thirteen-year-old girl is mentally challenged from childhood. She urinates and defecates anywhere. Moreover, because she is mentally challenged, she is depicted as unable to speak and it is assumed that she is dumb. As mentioned above, people in the village advise Amratkaki to admit Mangu to the mental hospital but Amratkaki's heart bleeds the moment she thinks of doing so. The narrative further unfolds that a girl named Kusum from the village who used to throw tantrums out of her mental illness developed at a later age, got admitted to mental hospital and her illness was cured. Seeing Kusum recovering from her illness, Amratkaki convinces herself to admit Mangu in the same hospital. However, her motherhood forces her to step back but societal pressure stops her from doing so and Mangu is admitted to the hospital. The visuals of the bleak atmosphere of the hospital resurrect in Amritkaki's mind and she herself slips into madness at the end of the story.

If the story 'Lohini Sagai' begins with the societal voice which collectively endorses the idea of admitting Mangu to the mental hospital, the story 'Shruti ane Smruti' begins with the scene where a twelve- to thirteen-year-old girl named Shruti is in the hospital. Shruti is unconscious and is battling with life. As the narrative unfolds, the readers are informed that Shruti is a daughter of Suhas and Shila. Shruti is not deaf right from her birth but develops deafness out of Typhoid which she once slipped into. Like Amratkaki, Shila loves Shruti a lot and works hard to cater to Shruti's needs. Suhas and Shila gradually get accustomed to Shruti's deafness but soon after, Shruti meets with a road accident. The story ends with the depiction of Shruti's cremation.

It is important to note that both the stories begin with the references to the hospital. Hospital not only sets a tragic tone for the narrative but operates as a trope to establish protagonists as a foil to the healthy beings. Moreover, both of them fail in meeting the paradigmatic criteria of 'production and performance' required for citizenship (Wendell, 1996:38).

Both Mangu and Shruti do not fit into paradigms of 'normative body', as Mangu suffers from cognitive disorder and Shruti from hearing impairment. Mangu's cognitive disorder is proclaimed through authorial voice. The story is told through third person point of view where narrative does not provide an access to Mangu's psyche. The readers are informed: 'Mangu nanpan thij gandi hati' (Mangu was mad right from her birth). Mangu is made to perform all discursively constructed rituals of 'a mad person'. She urinates and defecates anytime and anywhere. She does not listen to the instructions given by her mother. Moreover, repetitive instructions and training by Amratkaki fail in forming Mangu's daily habits. Moreover, she is depicted as incompetent to produce meaningful sounds and it is assumed that her cognitive skills are not developed and hence, she is unable to process language, and is incapable of encoding and decoding it properly. Thus, Mangu's behaviour causes disruption in the smoothly running course of Amratkaki's family in which rest of her children are happily married (Petlikar, 2017:78).

The story 'Shruti ane Smruti' is told from first person point of view, that is, Suhas's friend. Readers are informed by Suhas's unnamed friend that Shruti loses her hearing sense due to the side effects of medicine given to her during typhoid. Like Mangu, the narrative does not allow Shruti to express her subjectivity. Shruti comes on the scene only ones in the narrative, that is to say that she remains physically present only ones and in a while, disappears from the scene. She fails in meeting the standards of 'a normative body', as she does not use her vocal codes to produce language. Thus, she threatens the normative pace and functioning of the society. The bodies of Mangu and Shruti thus prove to be deviant and hence, pose threat to healthy inhabitants of society.

Both the stories devise various narrative techniques in order to establish Mangu and Shruti as deviant. Their bodies are established as 'abject bodies' (Butler, 1993) and they become the subjects of dejection. In her discussion about matter of the body and which body matters, Butler (1993) defines abject body as 'all kinds of bodies whose lives are not considered to be 'lives' and whose materiality is understood not to 'matter' (Butler, 1993: 281). This concept further becomes clear when Butler cites the metaphor of 'an ungrievable life' (Butler 2009: 38). In Butler's view, the abject refers to 'the unlivable and uninhabitable zones which are densely populated who do not enjoy the status of subjects, but whose living under the sign of unlivable is required to circumscribe the domain of the subject (Butler 1993: 3). It is to be noted that both the stories are set in different social milieu and have different time periods. The time period which the present story is set against is the backdrop of post-independence era. As far as location is concerned, it is set in a rural area. Mangu with her mother Amratkaki lives in the village and Mangu's brothers work in a city. The time period in the other story 'Shruti ane Smruti' is not clear. However, reference to the special school for deaf and dumb, the description of the Bombay city's life and fulfilled and unfulfilled desires and fragmented selves invoked through psycho narrations indicate that the story is set roughly in 1970s-80s. Moreover, the setting is urban, as the events take place in Bombay. Despite their different setting and time periods, both the stories situate their 'disabled characters' in similar ways and they devise similar tropes.

In both the stories, female characters are depicted as 'physically or mentally handicap'. Both Mangu and Shruti are of similar age i.e. around twelve or thirteen. Both of them are at the threshold of adolescence. The depiction of female protagonists entering adolescence performs a vital function for the narrative to establish them as abject. Both Mangu and Shruti are neither desiring subjects nor are they the objects of desire despite their physical beauty delineated through narration in both the stories. Mangu's mother Amratkakki while daydreaming about Mangu's marriage thinks: 'mui nu rup evu chhe ke muratiyo ene jota samo ha padi de' (she is such a beauty that a suiter will say yes to her the moment he catches her first glimpse) (Petlikar, 2017). Similarly, in the other story, Shruti is described as: 'Shruti bahu saras ane najuk baby hati. eni mummy jevi dekhati hati' (Shruti was a beautiful and delicate baby ….. she resembled her mother) (Bakshi, 1987). Thus, both Mangu and Shruti are aesthetically appealing. However, the functional impairments of their bodies scar their physical beauty and render their bodies abject. It not only renders them socially invisible but erases their femininity. Both of them cease to be social, aesthetic and cultural beings. Both of them refute 'normative corporeal standards', as Mangu is incapable of following any instructions. She urinates and defecates anywhere. She does not have sense of keeping herself tidy. She lifts her clothes in front of anyone. She does not match cognitive standards as well. If someone scolds her, she smiles in return. She is not attached to anyone. She does not shade tears while being left and deserted by her family in the hospital. Similarly, Shruti's aesthetic appeal is shadowed by her inability to hear. Her speech is assumed to be impaired, as she fails in encoding and decoding the verbal signs used by people around. Her presence invites curious gaze of 'normative people'. Further, the word Shruti denotes sound. However, the character Shruti has nothing to do with sound and thus, the irony invoked by the name establishes the character as foil. Thus, both Mangu and Shruti are neither desiring subjects, nor are they the objects of desire. Their physical impairment renders them desexualized and makes their bodies abject. The marriage of deviant bodies seems a far cry and therefore, Amratkaki's dream of getting Mangu married invokes a tragic tone in the story.

Both the stories disable their physically challenged characters by inflicting injuries through language and rendering them abject through linguistic means. Mangu in 'Sagai' is compared to munga dhor (dumb animal) numerous times. Her sister and her sister in-law think that training animals is easier than training Mangu. The word dhor is colloquially used to refer to all the animals. Comparison of Mangu with dhor renders Mangu as one of the members of flocked animals and relegates Mangu's subjectivity to periphery. It not only eliminates her subjectivity but questions her identity of a human being. Moreover, Mangu's 'rushthprushth sharir*'* (healthy body) becomes intolerable for people, as people find it unsuitable with her cognitive disorder. The act of Mangu's anamalization is not an isolated instance of dehumanization. Davies (2021) in her essay 'Metanarrative of Down Syndrome:

Proximity to Animality' argues that there is a long history of associating intellectual disability with animality, but it is during the course of the nineteenth century that the systematic metrics of association between idiots, colonial subjects and non-human animals becomes entrenched in regular and medicalized discourse. She refers to Charles Darwin's *The Descent of Man* (1871) and cites: 'imitation is a trait found in monkey, microcephalous idiots and barbarous races' (Davies, 2021:9). Charting the genealogy of the practice of locating human and non-human proximity, Davies further cites from John Langdon's brief article 'Observations on the Ethnic Classifications of Idiots' (1866) which coined the classification of Mongolian type of idiocy and connected intellectual disability with racialized categorization (Davies, 2021:10). In her view, the continuum of animal, idiocy and non-white western people became more prominent in twentieth century (10). Various scientific and medicalized discourses asserted that 'the adult chimpanzees, dogs and pigs far surpass the brain damaged infant in their ability to relate to others, act independently, be aware and other capacities that give value to life' (quoted in Davies, 2021:11). Mangu's sister and sister in-law in the story 'Lohi Ni Sagai' reiterate the metanarrative of the disabled's proximity to animality. In their opinion, Mangu not only possesses animalistic traits, but legs behind in competing with even the animals. Moreover, Mangu is put at the end of the continuum of species ranging from human to non-human animals.

If Mangu is compared to animal in Sagai, Shruti In the story 'Shruti ane Smruti', is compared to *vidushak* (clown). Suhas while talking about Shruti's plight says: 'baheru balak bobdu pan hoy tya havbhav kari ne vat samje chhe ane samjave chhe etle e jara vidushak jevu lage chhe, loko ghani var majak karta hoy chhe..baherao ni a jara tragedy chhe' (a deaf person, despite his condition, understands the talk and explains his talk to others using gestures and therefore, he looks like a clown. People sometimes make fun of such people. This is the tragedy of the deaf) (Bakshi, 1987).

The very comparison of a deaf with a *vidushak* renders the subject to matter of laughter. The extra use of gestures does not fit into normative corporeal standards. This corporeal performance is compared with the performance of a clown who deliberately enacts and performs stylized gestures and actions which a normative body does not do, and his performance evokes laughter. Thus, the comparison of a deaf person with *vidushak* renders a deaf person's body a laughable body and the laughter inflicts injury and pain on the body whose body is being laughed at.

Butler (1997) in her book *Excitable Speech* argues: 'Linguistic injury appears to be the effect not only of the words by which one is addressed but the mode of address itself, a mode- a disposition or conventional bearing that interpolates and constitutes a subject'. In her view, when one is called by an injurious name, one is 'being demeaned and derogated' by that name. She further posits that such words function as 'threats to physical wellbeing' and provide an alternative way to sustain certain bodies (Butler, 1997: 5). Thus, the act of inflicting injuries on Mangu and Shruti's body not only disables them but provides an alternative way of sustaining normativity of the normative subjects.

Both the stories further disable their protagonists by rendering them as objects of pity. 'khodadhor ne panjrapol ma mukia avva jevu j e to kahevay' (It's just like putting the disable cattle to the *panjrapol*) (Petlikar 2017:78). When people advised Amaratkaki to put Mangu in mental asylum, she always denied it by uttering the above words. This implied analogy between Mangu and *khodudhor* (handicap animal) makes two things clear: Mangu is almost a handicap cattle and here, the noun *dhor* is suggestive of dumbness assigned to Mangu. Secondly, the concept of *panjrapol* (an asylum for old and unserviceable animals) is suggestive of 'heterotopia of deviation' (Foucault, 1984:4), which accommodates deviant bodies. It also conforms to the metanarratives of tragedy associated with disability which are shaped and shape the charity model of disability where disable deserves pity. This model keeps the disabled outside of the mainstream. Here it is important to note that despite their contrasting settings of urban and rural, both stories support charity model of disability. The story 'Sagai' conforms to this charity model which is prevalent in the rural society. The same is apparent in 'Shruti ane Smruti' as well, where educated Suhas, father of handicap girl Shruti says, 'Andhra balak ne loko hamdardi ni drashti e juve chhe, madad kare j chhe. Out of the way jai ne madad kare chhe' (people behold blind child with sympathy, do extend help to them. Do it going out of the way (Bakshi, 1987:192). Here, Shruti's father Suhas wants people to sympathize with Shruti. He categorizes disability and thinks that deafness is not as conspicuous as blindness, and hence, the deaf do not arouse sympathy in first instance. Suhas wants to make Shruti's handicap visible only to gain sympathy not only for Shruti but for his own fate. The invocation of pity and sympathy to the body renders body deviant. Mangu's sister in 'Sagai' compares mental asylum with *panjrapol* as both not just shelter the handicaps but also provide relief from the handicaps as she jeers of Mangu: 'Davakhanu panjrapol jevu hashe ane kadach Mangu mari gai to eno ane kutumb no chhutkaro thashe!' (If hospital is like a panjrapol and if Mangu dies, then it would be a liberation not only for Mangu but also for the family) (Petlikar, 2017:79). Mangu in the story 'Sagai' is none other than a burden for everyone including the family members. For Amratkaki's daughter in law, Mangu is 'gando hero' (mad hero) whereas for Kamu, Mangu's sister, her death is emancipating. Even for Amratkaki, it is emancipation as the narrator mentions: 'manguna mot ne Amratkaki pan chhutkaro manta hata, jo e kudrati rite aave to' (Even Amratkaki considered Mangu's death as liberation, if it was a natural one) (Petlikar, 2017: 79). Similarly, in 'Shruti ane Smruti', Shruti's death is established as liberation for the family as someone on the cremation ground says: 'saru thayu, Suhasbhai chhuti gaya' (It is good that Subhashbhai got liberated) (Bakshi, 1987). Thus, death of Shruti is not grievable, as her death helps narrative reach a resolution, as elimination or the erasure of deviant body helps form the normative subjects.

The reception of the story 'Sagai' also conforms to Mangu's disability. Mangu's body does not matter to anyone including the critics. Here, it is significant to note that the story 'Sagai' is received in Gujarati Literature as the celebration of motherhood and love of mother for the child despite child's disability. Mangu is almost invisible in front of love of Amratkaki. The story is celebrated for 'mata na apurva vatsalyabhav na nirupan ni vaat' (an ultimate depiction of mother's love) and 'mamtamayi matani lagni nu aalekhan' (an account of the poring of feelings of loving mother). In fact, the narrative also supports this claim especially in these sentences: 'aavi rite gandidikri ne to Amratkaki ja uccheri sake. Bija ne gher hoy to bhukhi tarsi kyarni mari gai hoy ane jivti hoy to pan aavu hastpust sharir to na j hoy' (Only Amratkaki can raise a mad daughter in such manner. If she had been at others' place, she would have died out of starvation long back and even if she were alive, she would not have been so healthy) (Petlikar, 2017). Disability studies Critics have observed that disabled bodies are seen as subjects to constant care. Ghai (2002) in her essay 'Disabled Women and Excluded Agenda of Indian Feminism' posits: 'Strand of cultural construction conceives of disability an eternal childhood where survival is contingent upon constant care and protection'. Both the stories seem to be celebrating motherhood by accentuating dedication and sacrifices made by Amratkaki and Shila in 'Sagai' and 'Shruti ane Smruti' respectively. Amratkaki is uneducated and tries her hands at all possible remedies suggested by the village people. She sometimes consults *vaid* to cure Mangu and visits astrologers to inquire about her good times. Shruti's parents Suhas and Shila are literate. Suhas knows English well and hence, is shown to have worldly knowledge. Shila is literate but does not know English. Shila's inability to speak English comes in the way of Suhas and Shila's conjugal life. Like Amratkaki, Suhas and Shila are also desperate to find panacea for Shruti's deafness. Suhas consults all renowned doctors because he does not want any opportunity to miss in curing Shruti's deafness. Disability of Shruti in '*Shruti ane Smruti'* works as 'narrative prosthesis' (Mitchell and Snyder,) in order to fulfil the lack in Shila and Suhas' conjugal life. The narrator informs in the beginning of the story that Suhas is not completely happy with Shila, as she is not highly educated and does not know English. However, entry of Shruti in their life forces Shila to learn English. Shila learns English in order to communicate with Shruti in sign language. Thus, the short-lived life of Shruti restores companionship of Suhas and Shila. Her disability works as a prosthesis in fixing the fumbling companionship of Suhas and Shila.

It should be noted that Mangu and Shruti are not single child to their parents. Amratkaki has two sons and a daughter and they lead a happy married life. Suhas and Shila have two sons. The happy and 'normal' state of other children compensates for the lack in Amratkaki, and Suhas and Shila's lives, and the exit of the disabled child does not disrupt their family structure. However, unlike Shila, Amratkaki does not attain relief. The guilt of admitting Mangu in mental hospital constantly questions her motherhood. Her failure as a mother voiced through a co-passenger while going to city to admit Mangu to mental hospital aggravates her guilt, and guilt-stricken Amratkaki goes insane at the end. Her insanity is celebrated by critics as an epitome of empathy with her daughter Mangu. Critics' celebration of motherhood can be understood in light of their own conceptualisation of deviant bodies. In his essay 'Response to Ria Cheyne' Roussel (2017:207) argues: 'Character's conceptualization of disability is connected to reader's own concepts of normality'. In Rosemarie Garland Thomson's view, Repetitive circulation of stereotypical images of the disabled is likely to affect the way we understand each other. The disablement of Mangu and Shruti through prolongment of their childhood, their cultural invisibility, and celebration of the sacrifice made by their mothers seem to be a part of the collective consciousness of the narrator, characters and the readers. Their encoding and decoding of Mangu and Shruti as disabled is based on their own conceptualisation of normality which is discursively created through repetition in various cultural forms. Such reading can be understood as a part of exclusionary metrics in order to form a normative subjectivity.

Both the stories find their resolution by relegating their abject bodies to the space which is reserved for abject bodies. As discussed above, both the stories open with the reference to the hospital. Moreover, the story 'Shruti ane Smruti' ends with Shruti's cremation. Thus, hospital and the cremation ground emerge as a 'heterotopia of deviation' (Foucault, 1984:4) in both the stories. Foucault defines 'heterotopias' as 'something like counter-sites, a kind of effectively enacted utopia in which the real sites, all the other real sites that can be found within culture, are simultaneously represented, contested and inverted' (Foucault, 1984:4). He further posits that 'heterotopias of deviation' refer to those spaces in which 'individuals whose behaviour is deviant in relation to the required mean or norm are placed (Foucault, 1984:4). In his view, like public space, heterotopic space is not freely accessible. The entry is compulsory for some individuals or the individuals have to surrender to rites and purification in order to access that site (Foucault, 1984:5). Moreover, one must have permit or one is required to do some gestures befitting that space (Foucault, 1984:5). For both Mangu and Shruti, the entry into the heterotopic space of hospital is made mandatory. Both of them perform actions and gestures which make them suitable subjects of the 'heterotopic space of deviation', that is, the hospital. Their entries into hospital and cremation ground determine their exit from the society. Mangu's bodily performance proves to be unsuitable to 'healthy society', and thus, her entry into mental hospital is justified and made natural in the story. Shruti also fails in meeting the corporeal standards and her presence causes disruption in achieving the objective of creation of healthy society. Unlike Amratkaki, Shila does not lose courage and trains Shruti at home. However, the narrative uses the trope of road accident to reach its resolution. The road accident makes Shruti's entry possible into hospital and subsequently in the cremation ground possible. Amratkaki in *Sagar* wants to have an access to that heterotopic space of hospital. However, she is denied the access. When she comes to the hospital taking Mangu with her, she is not allowed to visit the room in which Mangu is supposed to be kept as the nurse informs her 'andar koi ne jova java deva no kaydo nathi' (No one is allowed to see inside) (Petlikar, 2017:85). Further, when the nurse takes Mangu inside, the narrator says, 'pelu barnu adadhu khulu thai Mangu ne gali gayu' (That half open door engulfed Mangu) (Petlikar, 2017:85).The door metaphorically divides the two worlds here as no permission to see the *andar* (inside) world of disable automatically creates the binary between inside and outside where not only inside world is prohibited for the society but at the same time for disabled also the entry into society is restricted. Moreover, the story provides the glimpse of the inside world in this way: 'tran char strio ne fagfagta vale, astvyast kapdao ma emne andar farti joi' (she saw inside three four women going walkabout with disheveled hair and shabby cloths) (Petlikar, 2017:85). This description of the disabled bodies creates a grotesque image of a disabled body which is abject and ungrievable for the society. Amratkaki finally surrenders to the rites of heterotopic space i.e. the hospital in order to get the access, as the narrator says 'Amratkaki Mangu ni nyat ma vatlai gaya' (Amratkaki got converted into Mangu's community) (Petlikar, 2017:86).

Conclusion

Thus, both the stories 'Lohini Sagai' and 'Shruti ane Smruti' disable their female protagonists by devising exclusionary metrics. Both Mangu and Shruti are discursively rendered 'abject' and their discursively constructed abject bodies help sustain the normativity of the normative subjects and keep the paradigm of citizenship intact. The abject bodies of Mangu and Shruti send them to heterotopic space, and turn down Mangu and Shruti's claims to the citizenship. Moreover, using disability of Shruti as a narrative prosthesis, the story 'Shruti ane Smruti' resolves the differences between the couple, and restores their companionship. Mangu's disability works as a 'narrative prosthesis', as it allows the narrator as well as the readers to interpret 'the unknowable'. However, unlike Shruti, it does not put Amratkaki's familial life in place, as Amratkaki is also relegated to a heterotopic space of deviation. As the story struggles with rendering Mangu's disability tolerable for the normative society, it erases Mangu's difference by rendering her invisible.

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Intersectional relationships between coping with virtual learning spaces, dyslexia and English as a second language during the COVID-19 pandemic: A case study on six female London based higher education learners of West African heritage

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ABSTRACT

This paper addresses the gap in intersectionality discourse by exploring how the move towards online learning during the COVID-19 lockdown in the UK served as an agent of discord resulting in disparities in technology accessibility and support provision. Six West African working-class mothers with a diagnosis of dyslexia in higher education, living in London were recruited for the study using the convenience sampling method. Due to the COVID-19 crisis and restrictions with face-to-face contact, all semi-structured interviews were conducted remotely. The four themes identified, highlighted findings around online learning spaces, dyslexia support, ableist constructions, motherhood and home schooling.

Key words: intersectionality, COVID-19, dyslexia, online learning, marginalisation

> Questions of intersectional identities, identity politics, disability activism and disciplined scholarship are all complicated by the hybridity of the borderlands – a place of contradiction and ambiguity, plagued with a cognitive impairment ….
> (Consensa, 2010).

Intersectionality theory has been broadly explored across different disciplines especially in the area of disability where narratives investigating lived experiences which draw on the relationships between various identity markers, interactions with societal perceptions, social constructs and discriminatory practices have opened up interesting discourse. Using the COVID-19 pandemic as a pivotal point for discussion, this paper aims to explore the impact intersections of disability, motherhood, cultural background and accessibility of technology had on the learning experiences of adults in higher education during the COVID-19 pandemic in the UK. In so doing it takes on a narrow focus and uses an intersectional approach to address how intersectional markers are played out in the marginalised experiences of these learners. While the paper draws out the uniqueness of individual participant experiences it focuses more on how these experiences are interwoven in the fabric of intersection and therefore pays attention to the homogenous narrative of the intersectional experiences of the participants rather than singling out and debating individual participant social, economic or cultural backgrounds. This paper therefore specifically intends to address a gap in intersectionality discourse by exploring how the move towards online learning during the COVID-19 lockdown in the UK for some served as an agent of discord which resulted in widening disparities in technology accessibility and support provision. It is hoped that the paper opens up a portal for innovative discussion amongst professionals around best practices for creating an online learning culture that is inclusive of all learners irrespective of background, disability or learning difference.

Methods

Using participant narratives detailing experiences of learning and support provision during the pandemic, the authors intend to use this paper as a medium to spur broad conversations around the intersectionality as it relates to how issues around accessibility of technology during the COVID-19 pandemic presented as an instrument of unintentional segregation and marginalisation for a very small and specific minority. The specific identity markers that this paper concerns itself with are West African working-class mothers in higher education living in London who are second language speakers and have a diagnosis of dyslexia. The convenience sampling method was used to recruit the six participants aged who engaged in the study. The age of the participants ranged between 30 and 55. All participants were mothers of young children aged between 5 and 15 years. The participants were all on full-time programmes in institutions of higher learning and worked part-time in the healthcare industry. Due to COVID-19 and restrictions with face to face contact, all semi-structured interviews were conducted remotely via telephone. Participants were made aware of the nature of inquiry of the study. For the purpose of confidentiality, personal identity markers have not been used. Technicalities around confidentiality, anonymity and consent were addressed prior to interviews taking place. Data was analysed using thematic analysis.

As only a very small sample size of six higher education students were used for the study, this paper does not seek to make any broad claims or generalisations rather the intention here is to add to discourse on a topical issue – COVID-19, and the impact it has had on many aspects of student life and day to day living and the resultant impositions that have manifested due to the changes and adjustments needed in order to fit in with the 'new normal'.

Findings and discussion

Four core themes were identified from qualitative data gathered through semi-structured interviews from six participants. In summary, the themes which are addressed in the following subsections below highlight issues with online learning from a neurodiverse perspective, applicability of dyslexia to online teaching methods, support for dyslexic learners, female students and learning spaces, home schooling and the home as a chaotic space and ableist constructions of online learning.

An intersectional neurodiverse perspective on the use of online learning platforms for learning as a restrictive learning space

Successfully preparing all learners with the skills and capacities for 21st century citizenship— global awareness, creativity, collaborative problem-solving, self-directed learning—is no small order, and many educational leaders are finding that the traditional forms of education that have evolved through the end of the last century are simply inadequate for achieving these goals. At the same time, while our outer world was transforming, considerable advances have been made in the learning sciences, forcing educators to reconsider how they approach learning, instruction, and the environments created to foster these. Finally, dramatic advances in educational technology have inspired powerful new ways for learners to engage with all kinds of content and activities in their own self-direct learning experiences. The juxtaposition of these three events creates a very interesting challenge and opportunity—a space to reconsider, re-imagine, and re-invent learning environments able to prepare and excel each individual for effective life-long learning.

Preparing students for productivity in the 21st century is a robust task that requires educators to apply new methods of teaching that go beyond traditional teaching methods that prevailed in the 20th century which in today's world is deemed insufficient to cope with the current global trends. Educators are therefore faced with the task of keeping up with recent transformations in the education sector and in doing so they find themselves transforming how teaching and learning is delivered in order for learners to be able to fit in and compete in the transforming world. These new methods of learning have created exciting ways learning is approached. However, these new methods of learning bring with them new challenges both pleasant and unpleasant, and as such create room for debate on how best technology can be used as a tool in the classroom without being seen as yet another agent of marginalisation for students with disabilities. A meta-analysis of 69 studies suggested that students with disabilities performed significantly poorer than non-disabled students participating in the same online/distance education delivery (Larwin and Erickson, 2016).

An emerging theme from the study was technology as a restrictive platform for learners with dyslexia. Participants expressed the difficulties they experienced with the efficacy of technology. Some of the issues highlighted centred around the lack of face-to-face support from lecturers which the participants felt worked better in terms of achievement and participation given participants' limited written and spoken language proficiency. Similarly in a study conducted by Shuetze and Slowey (2002) on student parents with dyslexia it was reported that a fifth of student parents cited a lack of confidence (often due to a lack of earlier educational experiences) and many felt they needed more tutoring support as a result. Shuetze and Slowey's finding is consistent with this present study where participants reported their preferred option for learning and support was face-to-face which unfortunately higher institutions were not able to provide during the COVID-19 lockdown. Participants reported preferring face to face interaction with their colleagues and face to face feedback from lecturers as they were able to ask follow-up questions when further explanation was needed. They believed technology did not afford the support they needed to thrive in their studies:

> "It's not for me and it wasn't as effective as sitting together. It's not my learning style; I need to be in a school environment…Zoom wasn't as effective as sitting together and looking at research together. Online learning wasn't good for me, it didn't work for me…lack of physical face to face placed me at a disadvantage."

It is difficult to view challenges presented in learning as occurring as singular struggles because the nature of learning is complex and not one dimensional and therefore will produce multi-dimensional trajectories. Thinking broadly about how technology and its use in pedagogy can expand or restrict opportunities to thrive in a learning environment is therefore of the essence. A participant reported:

> "Face to face is better because it feels more personal. It's better to be in the same room with someone human than talking through a computer screen. It also feels more individual. It just does not seem as comfortable and because of that I forget to ask questions unless I have written them down beforehand."

Online learning as a form of pedagogical delivering is not a new approach and has over time gradually gathered momentum across various tertiary institutions with some cases of successful implementation among institutions that are better equipped for this pedagogical approach. Innovations in technology have brought about modifications in the way pedagogy delivered in higher institutions especially with regards to online learning, which is presently an important area of development that is continuing to be a popular choice of pedagogical delivery especially in recent times. Being recognised as an effective pedagogical method and tool, online learning is broadly integrated into various types of teaching and learning strategies in higher education. The question however remains; how well can online learning alone be used as a sufficient pedagogical tool? A study by Woodfine et al. (2008) suggests that the most successful institutions use online learning in conjunction with face to face in order to support the needs of those learners with learning disabilities which was a teaching opinion not available during the national lockdown. This study however revealed disparities in online learning experiences during the COVID-19 pandemic in the UK. The lack of preparation time lecturers and learners alike had to adjust to online learning platforms has been highlighted as detrimental to the progress and learning experiences of the participants of the study and raises questions around online learning culture and marginalised practices. The importance of preparation time for both lecturers and learners, especially for those with literacy issues was emphasised in a study on dyslexic learners in Higher Education by Price (2006).

According to research conducted by Fallon et al. (2020) 55% of learners with additional needs failed to complete their work during lockdown. They posit this may have been due to a variety of factors including the learning design or the support structures that were not in place. Online sessions for most respondents of the study tended to follow the traditional learning design of power point led sessions accompanied by short individual tasks, abundant use of audio-visual material and formative assessment by question and answer, to reproduce the conventional format of lessons the learners would have been accustomed to experience. It has been argued, however, by Habib et al. (2014) and Larwin (2016) that this was not a particularly effective way of using technology as it tends to reproduce the problems that teacher centred pedagogy creates in the classroom for learners with writing difficulties and that for online learning to be effective it requires a much more imaginative approach. Normally some of the respondents would take notes in class and record the sessions to supplement their notes and if they needed further clarification they would speak to their lecturers afterwards. Respondents suggested that to some extent they could 'control' the pace of their learning by asking questions or by asking their lecturer to slow down or to recap. According to Quinn et al. (2020) this is central to effective engagement for learners with dyslexia. Some of the respondents felt 'excluded' in many of the sessions, and suggested that the 'limited 'opportunities for interaction in the sessions created barriers to their learning and made it difficult for them to become fully engaged in the classes.

> "My teacher did her best but I' m not good with learning from [online] lectures. I can't keep up with taking notes and there was not much chance to ask questions on Teams unless you can type really quickly or accurately. I learn by doing really and like collaborating with other people and learning by discussion."

Some researchers have highlighted the problems that the text-based nature of online learning can pose for learners with literacy issues (Carmichael et al., 2018). A learner who experiences difficulty with speed of processing may require more time than other participants. Hesitancy in reading may make it necessary to read a message many times before it can be understood, so delaying response times, and causing the learner to fall behind schedule, putting their contributions out of sequence with the lesson. This is supported by research from Habib et al. (2014) who argue the main problem that learners with dyslexia are confronted with when using chat-based tools is not being able to keep up with the speed of communication especially in the areas of writing and reading. This was also evidenced by some of the respondents who struggled with processing speed in relation to writing and reading in sessions that took place online during the COVID-19 lockdown:

> "When we get asked to read something in class I get a bit panicky because it takes me so long to read it and the teacher starts to ask questions before I've finished."

According to Woodfine et al. (2014) messages with multiple spelling mistakes may make contributions hard to comprehend, thus making communication with tutors and other learners difficult. Consequently, contributions by a learner with dyslexia may lose credibility, and therefore be ignored or even rejected. This can develop into a fear of contribution online:

> "Sometimes we get asked to post questions on-line during the class but I don't do it because I'm afraid that I will spell it wrongly which is embarrassing."

Lack of support for respondents' dyslexia

According to Larwin (2016) any collaborative approaches that depend on text-based synchronous activities present problems to students who find it hard to express themselves in writing and that have difficulties with reading, and who have problems with short-term memory. All these disadvantages are experienced by students with dyslexia, creating a clear risk of their being marginalised, demotivated and disappointed. All respondents mentioned problems with organising their learning which were exacerbated by a variety of tensions both related to their learning disabilities and to intersectional pressures. Whilst at their institutions they were used to receiving hard copies of handouts, lecturer notes and power points printed on different coloured paper. These were normally provided before the sessions and they would annotate these during their lectures. During the lockdown they were sent these electronically but some struggled to deal with the differences in format. This is supported by the data from the study by Habib et al. (2014) which suggests that many of the online platforms used for the courses taken by their informants tended to display an overload of irrelevant information, rendering it difficult for dyslexic users to access the information concerning them.

A respondent voiced:

> "Sometimes I got confused about what to download from my inbox because there was so much in there. Other times I forget to download them and so when I got online to the lecture I couldn't follow it."

Students were also accustomed to receiving clear formative feedback on their written assignment drafts in order to make the changes. Shuetze and Slowey (2002) reported that a fifth of student parents cited a lack of confidence (often due to a lack of earlier educational experiences) and many felt they needed more feedback and support as a result. According to Woodfine et al. (2008) learners with dyslexia might suffer from embarrassment, a sense of shame, and even guilt when interacting with other learners in a synchronous environment. Their participation in this type of learning activity seems to contribute to an already established pattern of low self-esteem and low confidence in their ability to learn, which may ultimately cause withdrawal. Their preferred option was face to face feedback which our respondents' higher institutions were not able to provide during the lockdown.

> "I don't think that I got enough feedback from my lecturer about my assignment because there was [sic] big gaps between me emailing drafts and getting them back. And then if I didn't understand a comment I would have to email her and wait for a reply. It took ages. It was much quicker when I was in the office with her and she could answer questions on the spot…It also feels less personal online and it makes me feel more like a student."

Motherhood, home-schooling and chaotic learning spaces: a view through intersectional lenses

According to a study by Hong Meng Tai et al. (2017) female students reported that Peer Assisted Learning (PAL) provided a "safe" learning environment in their institutions allowing them to take more time, let down their guard and ask questions. Many of the respondents attested to the importance of peer support in their learning whilst at college and how the lockdown impacted negatively upon this:

> "I also miss the classroom banter and the little bits of chat in between learning which breaks things up a bit. And I miss the help we give each other during the lessons like looking at each other's notes and explaining what you have missed to each other. …You don't feel that you can ask questions in a Teams session because it slows everything down."

The social construct of motherhood creates ideologies around expectations of motherhood and how a mother should function even in perilous and tasking circumstances. The various levels of parenting engagement identified were as follows mother, teacher and learner. Deconstructions of parenting practices and ideas of 'efficient mothering' using an intersectional approach revealed three sub themes - the home as a chaotic space, feelings of inadequacy and chaotic working.

> "Home schooling was also hard work because I have three children all of different ages. I had to create special timetables for Mummy's school for each one of

> them. I was lucky though that my eldest did some of the teaching and also helped me with proof reading my assignments."

Interviews revealed similarities in how expectations of motherhood impacted the participants' ability to actively engage in their learning. Many studies have highlighted the barriers and challenges faced by women with child caring responsibilities (Leppel, 2002). Their situation has tended to be problematised, identifying the conflict between the role of carer and the role of student, with the two identities at odds with each other (McGivney, 1999).

> "During the lockdown you often had to juggle from being a student to a teacher to a parent in the same day."

Some of the major factors flagged up in the study were issues with home schooling their children and the restricted shared spaces for learning. There were marked differences in the way participants were able to engage in their studies post COVID-19. Participants described online learning as difficult and chaotic. Some participants voiced they felt as though their positions as 'mother' were being compromised and as such struggled to perform effectively on various levels of expected engagement in the home environment.

> "The challenges I experienced was the time to teach the children, moving from one child to the other that was the challenge I had and also I had to do my work [studies] and I had to go to work as well."
>
> "My main challenge was children being off school. At the beginning of the COVID-19 thing you had to home-school them…it was difficult having them home and having to work and there wasn't much childcare, everybody was taking precaution so it was difficult being a key worker…"

Sweet and Moen (2007) showed that women unanimously expressed a positive impact of studying on personal satisfaction but also expressed ambivalence, viewing it as an inevitable dilemma in balancing their various roles. Research by Smith (2019) suggested that student mothers also experience high levels of guilt. Participants reported that the conflicting responsibilities between study, work, and motherhood create guilty feelings as well as stress and exhaustion. Research by Ricco et al. (2009) suggests, however, that not all mothers as students experience higher institutions and family microsystems as simply involving competing sets of demands on available resources such as time and technology. Although it can pose as a conflict as in the case of some of our respondents, it can also be the case that sharing of the student role between mother and child can promote a more integrative and positive relationship between the systems.

Some of the respondents were active users of the study facilities of their respective higher institutions and would spend time between classes working on their assignments in workshop situations with their peers. Study in their home environments was much more problematic for them as they had to combine being a student with being a parent at the same time.

> "Because I live in a flat the children felt isolated because they couldn't go downstairs because of the COVID-19; they were stuck in the flat for three months. Keeping the children active at home and as a student I was not able to read when the children were home that was my main challenge. I was not able to read as I should or do research because my children were at home and it did not feel like being in school [university]."
>
> "I share a room with my youngest child and we both share a desktop PC there. I can only work in the bedroom so it can get a bit noisy when she wants to watch TV there or talk to her mates on the phone. It's hard to concentrate on my work then. There's also been times when we have classes at the same time and have to fight over who gets the PC."
>
> "It's also a bit more difficult to concentrate at home because even when I try to do Zoom in the kitchen some of my children are always coming in and out."

Some studies about student mothers emphasise the importance of leaving the family microsystem physically in order to 'fit into' or adopt their alterative roles in the college microsystem as a student (Lyonette et al. 2015; Smith, 2019). This was not an option for the respondents during the lockdown and hence some struggled to be a student at home. Some admitted that working at home was also difficult because of the inability to go out of the house and into their institutions of higher learning. They felt the pressure to complete domestic household duties and to fall into the role of housewife.

> "I try to write lists of things I need to do each day but I rarely manage to complete them because other things get in the way such as doing housework, cooking etc and I haven't got to be anywhere specific. I think that I can always put things off until tomorrow but then I start thinking about the deadlines and I get stressed out."

> "The coursework, the word limit, being at home with the kids and no time to go to the library, study like night time when they've gone to bed then I'm able to do my work but even at that when I wake up in the morning I'm tired because I wouldn't have had enough sleep."

Disablement and ableist constructions of proficiency in the use of online learning platforms

Social inequality, social justice and struggle are deep seated subjects which manifest in how social exclusion and privilege is explored in multifaceted dimensions of oppressive practices (Romero, 2017). Dyslexia being a hidden disability poses challenges for higher institutions (Riddell and Weedon, 2006) as some lectures are not skilled in applying universal approaches to teaching that will help in how pedagogy is received irrespective of one's difference or whether or not these differences have been disclosed. This is supported by many studies about dyslexic learners in higher education (Price, 2006; Price and Gale, 2006; Madriaga, 2007) which relate stories from respondents about not having had the help they require within the educational system, which suggests that some mainstream educators may not have in-depth knowledge about the educational needs of dyslexic students. Some of these adjustments put in place for dyslexic students include extra time or support for assessments and exams (Pino and Mortari, 2014), one to one study skills support and assistive technology. In voicing their lack of reasonable adjustments made in online learning a participant reported:

> "I'm meant to have a scribe and reader during exams or someone to read through my work for me. If they've given me any coursework they will send coursework details to me before that [beforehand]."

Because measures relating to reasonable adjustments are sometimes put in place as an afterthought there is often a lack of robust consideration given to intersectional and integral planning and visioning in institutions of higher learning operations (Miles, Nishida and Forber-Pratt, 2017). As a result, disempowerment resulting from limitations in accessibility to online learning led to limited participation among respondents in comparison to how they would engage normally with face-to-face learning on campus. Participants highlighted how important it was for them to be able to approach their lecturers for face-to-face support which was their preferred method of learning.

> "The lecturer will make it a priority for me to speak to them …she breaks down the coursework for me and tells me what to do."

Research by Peters (1993), Smith and Ferguson (2002) amongst others suggests that online teaching can be most alienating for female learners who have English as an additional language because it can involve levels of social and communal dislocation. Johnson and Change (2014) emphasise how it is important for female learners who have English as an additional language to engage in academic and social development in order to cultivate a cultural and linguistic community in class.

This was evident in some of the responses from the interviewees:

> "I've missed out by not learning with people face to face and talking to them in my own language and I don't think that this has been helpful for me trying to do these resubmissions."

Anxiety and self-esteem are recurrent themes in the literature on dyslexic students' experience in higher education (Price, 2006; Price and Gale, 2006; Madriaga, 2007). A number of sources, including Carroll and Iles (2006) and Riddick (2010), report higher levels of anxiety among dyslexic students than among their non-dyslexic peers, both in terms of academic work and in social settings. The frequent occurrence of low self-esteem among dyslexic students is also an issue, especially because low self-esteem is often connected with low academic achievement (Banks and Woolfson, 2008). The lack of face-to-face interaction impacted on some of them emotionally making them feel isolated fatalistic and frustrated at times:

> "I could never really connect with my assignments during lockdown which was giving me day after day a writer's block because I felt so lonely."
>
> "I used to wake up in the morning sometimes and think what's the point of carrying on with this course as I could die from the virus tomorrow and all my qualifications would be nothing."
>
> "When you are not going in, all you've got is the four walls to communicate with. Online classrooms are not the same thing I think It's made learning a lot more of lonely experience, I guess?"

Learners have the right to enjoy equal levels of participation whatever the chosen medium of teaching and instruction, however this is not often the experience of marginalised groups. Although it is desirable for barriers to be identified and removed so as to enable wide participation and varied opportunities for learning, oppressive practices do not allow for such. The construct of ableism intersects with oppressive systems that serve to disempower students; institutions therefore need to be held accountable for ableist assumptions and restrictive practices that infringe on students' ability to access platforms for learning. Complex intersectional perspectives on how social, economic and cultural demographics shape how pedagogy is received (Tefera, Powers and Fischman, 2018) evidence the need to disengage with middle class ideals of who a student is and take on a more diverse view on complex system of inequality. This approach lends itself well to addressing issues around the intricacies of integrating learning diversity and associated difficulties resulting from the sudden move to online pedagogy which has now (very suddenly) become the 'new normal' approach to teaching and learning post the COVID-19 lockdown in the UK. Hankivsky (2014) considers three approaches to analysing how difference pertains to individuals and learning. The first approach is the unitary approach where only one categorisation of difference is considered when analysing a 'problem'. The second approach is described as the multiple approach which looks at how multiple factors of difference can be added together in the bid to understand and explain a problem. This approach does not utilise an analytical approach to viewing how relationships between factors can help explain problems unlike the third approach, the intersectional approach, which takes into consideration how the relationship between factors of difference and the processes that feature within all intersect to form multiple identities and experiences where privilege and oppression exist on a socio-structural level.

4. Conclusion

We have found that much research about online learning has tended to play down intersectional barriers or assumed that one equality area alone will provide an explanation for an experience of inequality. We have also tried to focus on the distinct lived experiences of our respondents and the interaction between different elements of identity which is a central aim of intersectionality, as different combinations can lead to different lived experiences of individuals. As this paper has demonstrated, intersectionality, as a theory or lens, challenges the instrumental view of online learning in higher education. As a knowledge project, intersectionality advocates a distinctly non-traditional epistemology for generating complex bodies of knowledge, and an expressly political project – promoting social justice and the transformation of the institutional order for historically and multiple marginalised students and teachers.

While intersectionality challenges the dominant instrumental view of higher education, our paper concludes that there is considerable work to be done to actively address the workings of intersecting systems of inequity in online learning impacting on the participation and outcomes of students. There are many unexplored aspects of the workings of intersectional (dis)advantage regarding technology in the higher education context. For example, we suggest that issues of access to technology deserve much more attention than has hitherto been given. It could also be argued that the central question that is not sufficiently addressed in current online policies and pedagogies is how to better engage and prepare students and citizens for the challenges of a "posthumanist" future. An intersectionist stake can be seen as broader social stake that should include education as a site where crucial dispositions of identity and models of oppression are contested shaped and fed. The significant question is how, specifically, technology, education, and race class and gender might better intersect as we evolve into the 'new normal'?

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PROVOCATIONS

“What is she doing here?” Containing identities, foreclosing abilities

Shireen Irani

“Why are women and elders kept in the protests?” asked the Chief Justice of India[1], in January 2021, referring to their participation in the historic protests challenging the new farm laws proposed by the central government of India in 2020. These remarks fetid with patriarchy, were an assault on everything that democracy stands for, given that nearly two-thirds of rural, Indian, working women are actively engaged in agriculture. A similar ableist[2] question was raised in 2014 in a university, where the presence of a student with a disability in an all-student protest on campus, purely as a gesture of solidarity, sparked discomfort among students and authority alike. Ableism of this kind stems from “beliefs, processes and practices which favour species-typical normative body structure-based abilities. It labels ‘sub-normative’ species-typical biological structures as ‘deficient’, as not able to perform as expected” (Wolbring, 2011), justifying thereby, the convoluted ideological ghettos that prohibit hybrid bodies and minds from realising their full potential across all social spheres.

What is common to both these instances of exclusion is not merely the denial of entry into a mainstream sphere, but also an insistence that the labelled ‘marginalised’ stay put in the categories assigned to them. I use here, the image schema of ‘containment’, borrowed from Cognitive Linguistics, to illuminate from personal experience, the consequences of attempting to dissolve boundaries and stepping out of my enclosure to join hands with the categorised ‘abled’.

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[1] https://thewire.in/women/cji-bobde-women-farmers-protest-remarks-rights

[2] The term 'ableism' implies social prejudice or discrimination based on ability. It is the idea that "normal" or typical abilities are superior, and anything less than, or different from such abilities may be subjected to ridicule, criticism, or dismissal.

The privilege of higher education

University spaces play a vital role in the shaping and conceptualising of student identities – often illuminating new ones and negotiating with the several intersecting and overlapping facets of the process. It is in these spaces that critical higher-order cognitive and socio-economic positions become more or less stable, and the bigger questions of one's potential role and contribution to society and social change need addressing. The same platforms also allow young thinkers to question and debate existing social inequities, uninhibited and unconstrained by them. The wealth of knowledge and insight I have received from these institutions is beyond measure, but more importantly, higher education to a great extent, has opened up a world of possibilities, particularly for communities that have largely been deemed physically or intellectually incapable of contributing to the socio-economic growth of a nation.

It is therefore extremely disturbing to witness in recent times, the very ethos of such academic institutions under threat and subversion. The thriving diversity that ought to form the very essence of Indian academia is now being stifled, with universities being coerced into becoming majoritarian homogenous bodies, driven by narrow and fictitious aspirations, and we have indeed seen a surge of reactions from academicians across the country, resisting these forces. What is required for a positively tangible outcome, however, is to sustain these movements on a much larger scale; we need a broader vision of what constitutes a truly liberal and democratic academic culture that in real terms — embraces the fluidity of identities, allowing for full participation in all the social structures, irrespective of class, gender, caste or ability. This stifling of identity fluidity and the containment of students into singular, definitive categories is the central theme of this piece, unfolding by way of some of my own experiences.

To what extent does my identity as a disabled student, in practice, allow or limit my participation and agency in the larger, collaborative endeavours for social change?

How does one reconcile with this evident conflict between the process of self-discovery as products of complex identities on one hand, and being coerced into reducing that complexity to a singular attribute on the other? What would count as a reasonable response to the encumbering contradiction: of becoming the object of restrain within the spaces that are meant to nurture the promise of full participation and agency for change and progress?

The role of protests: freedom from 'unreason'

I imagine that a similar kind of conflict may have driven Rohith Vemula to give up all hope for living in a less stifling environment, as reflected in his writing about his own dreams and aspirations of becoming a scientist, being reduced to his specific caste. His tragic demise is what it took for academia to take notice of and initiate a nationwide resistance against the forces that undermine and misuse the democratic culture of university campuses. It is difficult to conceive of a more non-violent form of resistance, than expressing dissent in the form of symbolic protests and demonstrations, with a demand for social, as against individual change.

Protests are powerful avenues for mobilisation of resources, where students from diverse backgrounds and ascribed identities come together for addressing broader social issues (Polletta & Jasper, 2001). We see student activism at two levels: the target-based protests — aimed at protecting the rights of smaller communities of students (women, dalits, students with disabilities, etc.), with the primary objective of spreading awareness about the physical, and socio-economic factors that have pushed them to the periphery of the narrative of campus culture. The broad-based protests strive towards the broader aspirations of the student body as a whole, with the collective endeavour to safeguard the progressive academic environment they deserve.

I had the opportunity of being part of one such broad-based protest on campus in 2014, against extremely hostile and unreasonable restrictions[3] introduced by the university administration. The protest escalated to the point of us going on a hunger strike – a drastic but necessary measure, as all possible channels of dialogue between the students and the autocratic administration were blocked. I must add here that my participation in the protest was solely in solidarity of the larger purpose of nullifying the new unreasonable demands placed on students. I had no grievances of my own, nor any disability issue that required

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[3] The restrictions included: prohibition of women students from staying out of campus beyond 11 PM, prohibition of students who were 'Junior Research Fellows' from receiving accommodation inside the University campus, and a sudden, unexplained, unreasonable, fee-hike for the hostel residents, without any consideration for students belonging to economically marginalised sections.

resolution. For a change, here was a student (with a disability) participating in an all-student protest that did not involve any particular disability issue, but a larger, more broad-based issue of student dignity, of woman dignity. This to me, is a classic case of merging of identities to the point where they become a single, unified whole, speaking a single language: that of broader equality. This became the subject of much amusement for the university administration and some of my fellow students because they were simply unable to relate to my presence in a protest that did not directly involve a disability issue. I was summoned privately on several occasions, and enticed with various comforts, so that I may leave the protest. The nature of the comforts offered was solely to do with my physical disability. To my knowledge and experience, there could not have been a more illuminating portrayal of the bigoted, myopic attitudes prevalent even in the most 'liberal' academic environments.

Such forms of extraction however, are not the only ways in which the marginalized are 'kept in their place'. The all-pervasive ableist language used in protests too, may often inadvertently deprive large sections within the disabled community, from 'standing up', 'joining hands', and 'marching in step' with the 'able' protesters towards collective endeavours. While they are indeed not a conscious attempt at excluding or undermining any part of the community, the connotations that these slogans have come to bear, may have lasting and damaging impacts. 'Turning a blind eye to demands', or their 'falling on deaf ears' for instance, have begun to often carry connotations of wilful ignorance. Indeed, eliminating vocabulary that might offend individuals/groups may be impossible and unnecessary; A certain level of trust and understanding between interlocutors may go a long way in the prevention of such misrepresentations. We may do well by being mindful of the power and potential of language, and treading carefully, lest we witness all the zest sapped out of every-day expressions, and our creative freedom relinquished altogether.

Identities as metaphors for exclusion

Although this particular experience of mine may be viewed as a stray subjective case, it is important to understand its implications in the larger context of exclusion. The number of metaphors that have been used to describe such phenomena is particularly revealing of their pervasiveness in all social spheres.

First among them, pertains to the idea of a healthy body politic (Bhattacharjee, 2017), who interprets the disabled body in light of the government regulations on how the disabled must conduct themselves during the national anthem, as "lacking in proper mental and physical prowess to be properly nationalist" and therefore requiring discipline and indoctrination in order to close the gap between themselves, and the ideal, healthy, patriotic body politic of the nation. The disabled body therefore becomes a liability in the march towards all forms of progress at all socio-economic levels. Participation in the larger aspirations of larger collectives when one is lacking in the basic physical/ mental abilities, thus prevents the categorised abled, from transcending such myths and embracing fluid, intersectional cohesion.

Such ableist practices of prohibition of rightful entry into public spheres form the basis for the central metaphor: that of containment. This metaphor comes to mind from reading Lakoff & Johnson (1980) as a student of Linguistics, who describe our conceptualisation of the world and our bodily experiences, using a finite set of metaphors or image schemata. These schemata are pervasive not just in language, but in fact govern most of our thoughts and actions, enabling us to coherently articulate abstract ideas simply by understanding and experiencing them using more concrete phenomena.

The classic metaphor 'life is a journey' for instance, enables us to instantly make sense of life, simply by mapping the features of the concrete experience of journey, on to the abstract experience of life: the twists and turns, the bumpy rides, the dead ends and the road less travelled, all contribute to the rollercoaster adventure that we all know as life.

These features of journey can also productively be mapped onto the abstract experience of love.

'Time is money' is another well-known metaphor, allowing us the indulgence of doing with time, all that we do with money, such as saving or spending it, or even investing it wisely.

Among these and several others, a fitting portrayal of my experience of exclusion and extraction from the student movement can be explained using what Lakoff and Johnson call the 'containment Schema'. This schema involves "a physical or metaphorical

- Boundary

- Enclosed area or volume
- Excluded area or volume”

The containment schema may have additional optional properties, such as:

- Objects inside or outside the boundary
- Protectedness of an enclosed object
- The restriction of forces inside the enclosure
- The relatively fixed position of an enclosed object

The containment schema is one of the most elegant and productive metaphors, yielding a number of conceptual schemata where the body and its parts serve as containers for abstract ideas, thoughts, and emotions (‘hold that thought’, ‘get it into your head’, ‘know it in your heart’, and several more).

We may thus understand the recurrent reduction of people to singular identities, as their being contained in boxes, labelled with that identity as defining, thereby demarcating and isolating them from other structures. The accompanying characteristics of the schema, of restriction of movement, and physical prohibition from any contact outside the containing entity, are all images that correspond with my experience. The unease about my presence in the larger campus structures was viewed as a conflicting image from my lawful place within the enclosure of my disability identity.

Daring to step out of this prescribed container for fresh air brings forth another discerning dynamic: that of a ‘square peg in a round whole’: a “misfit” (Garland-Thomson, 2011).

This seminal concept further enriches the containment schema with its theoretical productivity, capturing the ideas of ‘fitting’ and ‘misfitting’, particularly in the context of disability, as “material”, rather than mere linguistic constructions. Fitting and misfitting in light of disability, represent “the discrepancy between body and world”, when the shape and function of the bodies of people with disabilities comes in direct conflict with the shape and ingress of the built world.

This dynamic captures the scenario where two entities “come together in either harmony or disjunction. When the shape and substance of these two things correspond in their union, they fit". A misfit, on the other hand, "describes an incongruent relationship between two things", quite like a misplaced piece in the wrong jigsaw puzzle. The primary negative effect of misfitting, Garland-Thomson reflects, is "exclusion from the public sphere — a literal casting out — and the resulting segregation into domestic spaces or sheltered institutions" (being put back in one's place/ container). The jarring visibility of the 'misfit' in that position, and the resultant lack of "anonymity" characterizing such misfittings (be they material or sociolinguistic) speaks directly to the subjective experience that rendered me singularly conspicuous and ill-fitted within a broad-based protest on campus.

It is important to note here, the palpable contradiction: between the demands placed on misfits to continue striving to become more normative, able, productive agents of socio-economic growth and their simultaneous prohibition from entering into discourses and spaces that open opportunities for them to visibly demonstrate their capabilities. This is what I interpret as the practice of 'the foreclosing of abilities'; that is, shutting down possible avenues for witnessing them, before giving them a chance to take flight.

The same reductionist image is again eloquently captured by the Nigerian author and story-teller Chimamanda Ngozi Adichie (Adichie, 2013) who illuminates the dangers of placing people into single stories, when we are all in fact, a complex of multifaceted narratives. "Show a people as one thing," she says, "as only one thing, over and over again, and that is what they become." Such are the dangers of segregating people based on the one attribute that renders them different, pushing them to the margins, because power, according to Adichie, is "the ability not just to tell the story of another person, but to make it the definitive story of that person". That is the kind of power that must be denied at all costs, in our endeavours to become part of the social centre.

The same image of enclosures is also fittingly articulated by Shafak (2010), a Turkish writer who talks about the power of circles, as a means to dispossess and destroy the essence of humanness. She aptly captures the process of 'ghettoisation' as our tendencies to form clusters based on sameness, and then create stereotypes about other clusters, which to my mind, is one of the most serious impediments to our larger aspirations today. Such stereotypes then go on to create even more problematic notions such as typical or authentic member of a category e. g. a typical woman, authentically blind with an ear for music, etc., which in

Adichie's words again, may not necessarily be untrue, but they are incomplete. Our singular identities are not all that we are. When we enter into larger discourses, we bring with us the complex of narratives that make us whole, as rational and able participants in the larger rubric of student hood. The university administration however, thought otherwise. The finality of my containment within the disability enclosure was realised exactly two years later, in the form of a denial of a term extension: a provision[4] entitled to women and people with disabilities during the Ph.D. programme, largely as a means of reprimanding my 'changing containers' and participating in the protest.

The way forward

Given this prevalent scenario where there is very little scope for social mobility for those in the periphery of the larger structures even within institutions of higher education, one is compelled to wonder whether these two processes of identity construction and agency for social change, are more interwoven than we would like to acknowledge. Attempts to reduce such a correlation must be made, if we truly wish to have a healthy and growth-oriented academic culture. If we truly wish to move forward in our endeavours, we need to include every single fraction of the student community into a unified collective, working towards the preservation of our democratic academic spaces; because none of us, is just a single story. Each of us is layers and layers of complex interwoven stories, endowed with the powerful ability to scale up and scale down those narratives, as and when necessary.

It is also imperative that we question all the more in recent times, why these liberal spaces that champion the birth of new ideas and collaborations have become so much of a threat, when they are built to be the exact opposite. Most importantly, let us each put one foot in the doors that by right should be wide open to us, and enter those spaces in style, even if it makes certain individuals/ groups, uncomfortable. The ableist notion that people with disabilities (among other marginalised identities), are anomalies in an otherwise 'sanitized world', and that they'd best be confined within their prescribed containers, must be

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[4] http://cbseugcnetforum.in/media/ugc-regulations-2016-minimum-standards-procedure-award-m-phil-ph-ddegrees-www-ugc-ac-in/

challenged at all costs, and in every social sphere, beginning with the family, all the way up to the representations at the national, and also the global levels.

Here's to ripping apart all such containers, and 'compromising the sanitised world'!

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Unfolding (of) theories, not programmes (programs?)

Tanmoy Bhattacharya

ABSTRACT

I question, provocatively, whether disability studies (DS) as a discipline deserves to be called studies. When a field zeroes in on any claim about 'realities', I think, it actually treads on shaky grounds. The general fear of theories necessarily leads to a form of anti-intellectualism that is most often cloaked in an activist's guise. The question really is how does one release DS from this bondage of pragmatism and practicalities. In this piece, I want to talk about a bit of this and a bit of that, aimlessly. In fact, that is the aim, I think.

My work at Equal Opportunity Cell of the University of Delhi was in many ways an attempt to infuse a component of knowledge, into what is predominantly, a service-oriented enterprise, the UGC mandate itself, making it very clear. So it was not surprising to create a collective where we can establish a kind of dominance of knowledge over service[1].

By 2012, I was already in next stage of my thinking of moving somewhat away from mainstream (Disability Studies) DS to Critical Disability Studies (CDS), this move again was formally reflected in renaming and thereby redefining our collective as CDSI in March, 2018. There were other incidents that worked as a catalyst for this move, which I won't talk about here.

Unfolding (of) theories, not programmes (programs?)

There are two linguistic elements in the two sets of parentheses here, *of* and *program* – there is also a bit of Mathematics involved here, the expansions of the two pairs of parentheses are different, whereas opening up the parentheses around *of* reveals a kind of unexpected linguistic phenomenon that changes the message substantially, doing the same

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[1] Those who want to know more about the period and my role in it, may refer to my paper "Service and Knowledge: The Emergence of Disability Studies Extension" in: Mehrotra, N. (eds) (2020). *Disability Studies in India.*

around the American spelling 'program' with a questions mark, does not uncover any significant linguistic phenomenon but only extends/ shifts the meaning. With the opening up of the parentheses also emerges a third degree of linguistic point of interest in the forward ellipses of both *unfolding* and *of* in the second phrase – these are cases of two separate ellipses, clear from the constituencies. This maybe shown by the full expansion of the conjoined combined big phrase, where underline denotes ellipses:

Unfolding of theories, (and) not <u>unfolding of</u> programmes

This third layer of interest is also about the second phrase (*not programmes*) reflecting/ mimicking the first (*unfolding theories*) in its grammatical category, so if the first is verbal/ nominal, the second one is too.

But let me roll-up a bit and talk about the penultimate point, i.e. of meaning expansion or shift (which I said is not a significant linguistic point, you can take me up on that and I will happily talk for hours).

The word *programme* can be used as a noun or a verb, here of course it is being used as a noun, whether as in the form as in the title or in its expanded versions as above. This is so, in both cases (what these both cases are will become clear when I discuss the next/ previous point) the word *programme* is an "object" inside its own phrase (why quotes around the word object here should also become clear when I discuss the next/ previous point).

In its nominal meaning, one set of uses is in its meaning as "a set of activities/ measures with a particular long-term aim", which is the usage I meant here. The other dominant usage is the calendar of events usage, which is not relevant here. Yet another usage which has to do with performances or a list thereof, is going to be defunct sooner or later when we won't have TVs and radios any more or even live performances. So we retain the first meaning usage and note with interest the expressions 'a set', 'activities/ measures', 'long-term', and 'aim'. If this is clear so far, here's a task for you all: examine the literature on DS from the 1970's onwards, and figure out whether each of these 4 expressions appear in them, that is, WHY is social model of disability a model. I am using programme in the sense of model here although these have different meaning imports, especially model here is used in the sense of a particular version (normally of a product). The social model of disability therefore always allowed for other versions to appear or even to supersede it (and they did, e.g. CDS or Disability Justice (DJ) — both focus of my DS reading group). It is not a model in the sense of a replica/ representation or an archetype/ prototype. But is this 'version' any way a set of measures/ activities with a long-term aim?

Anyway, to come back to the nominal meaning usages, there is yet another dominant one, which is usually always spelt with the American spelling *program* – as in coding for computers, in the sense of an algorithm. Interestingly, in the meaning we retained for usage, if we impose a sequencing of the measures/ activities, it in fact produces the algorithmic meaning of program. However, we do not know of any such sequencing requirement of the set of measures that defines DS.

Now, let us roll-up further to the antepenultimate point that I've been holding off all this while – and this is certainly a linguistic point of significance. If you remember, or examine the recoding someday, I said at the start of this interaction "I was … unfolding theories …" if you note carefully, here, *unfolding theories* is used as verbal expression. If we do so, that is, use it as a verbal expression, we must also necessarily follow it up with a verbal form of the next expression in title, namely, *not programmes* (meaning, *not unfolding programmes*, whatever that may mean). Note that I maintain this condition in my opening statement as well, although there I modified the following expression as *not looking … at the programme.*

The point of significance of the first (and linguistically significant) pair of parentheses is revealed now when we discover all of a sudden that the unparentheticalised expression (let's call it a phrase now?) has turned into a nominal phrase! We know it's nominal because we can put an article in front of this: *the unfolding of the theories*, but not so in **I was the unfolding theories.* Convinced? Not yet? Well, observe the following:

(1) a. The organisation is unfolding theories (= training athletes)

*b. The organisation is unfolding of theories (= training of athletes)

(2) a. The organisation's unfolding of theories (= training of athletes)

b. ??The organisation's unfolding theories (= training athletes)

That is, one frame cannot be placed in a slot meant for another.

But, you ask, what has changed? That is, going from verbal to nominal, what have we lost/ gained? I will answer this question terms of linguistics too. And that will be the final point (nail) as far as the title is concerned!

Note that in the nominal use (with *of*), we still have the *-ing*. How come? Isn't this a nominal expression? Why do we have a verbal ending then? Well, that's the property of gerunds, as some of you might vaguely/ nostalgically remember the term from your childhood. I won't bore you further with any technicalities, but rather give you an imagery to live with. This *-ing* is like someone has given you wings but you can't fly. Are these wings useless then? Well, if we were to believe the evolutionary fable (it is a fable, believe me), that's exactly the story of wings, they were there but those creatures were not flying (cf. Bhattacharya (2018) "Being Human, Again, Part 2", *neScholar* vol. 4.1, for more on this). Unfold*ing* here is like a verb trapped in the body of a noun, it's a lot of trapped energy. And that does something to the import of these special phrases, they are like mini-sentences, aren't they? For example, *Benu's scoring (of) a hat-trick* is like a sentence collapsed into a smaller unit, a phrase (it's equivalent to *Benu scored a hat-trick*). This so-called trapped verbal energy adds to a certain dimension to the phrase, namely, a stative meaning, whereas the verbal phrase (in *I was unfolding theories*) denotes action. The gerund here has type-shifted the meaning import from action to a state. The agency is somehow weakened. This is what we gain from a proper linguistic analysis, a totally new perspective.

This wraps up the fun, linguistic part of the talk and I hope that you had enough of me as a linguist, this is in fact the first time that I have done a bit of linguistics at a disability meeting, the other way round, that is, doing a bit of disability in my linguistics has happened at least once while while talking about sign linguistics. I also hope that I was able to demonstrate the kind of linguistic analysis that informs our disability analysis and yet respects certain core aspects of linguistics (and not simply pick on obscure etymologies of disability terms and peddle it as linguistics). This also raises, I am afraid, a serious issue, which is of certain disciplinary tendencies to use disability as a prosthetic to advance their own disciplinary goals. Again, I afraid that this is tendency is noticed most often in case of English literature discipline, in effect, disability there is seen as a spectacle – yet another exotic topic to latch on to. That is another reason (apart from the oil and water issue that I am going to talk about next) why I am reluctant to do my linguistics in my disability research. The kind of linguistics we do is very different and cannot be wrongly or right 'advanced' by 'using' disability. It is a bit like Chomsky's politics and his linguistics, they don't mix.

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REVIEWS

Sandhya Kumari, (ed.). (2019). *Jeevan Sangram ke Yoddha: Divyang Patron ki Prasiddh Kahaniyan*. Delhi: National Book Trust.

Disability Discourse in Hindi Literature: A Review of *Jeevan Sangram ke Yoddha: Divyang Patron ki Prasiddh Kahaniyan*, edited and collected by Sandhya Kumari

Disability has been an integral part of human history. This is evident from the existence of disabled people in history as well as in mythology. One Indian epic *Ramayana* had a character like Manthara who was a hunchback while *Mahabharata*, another epic, had Dhritarashtra and Shakuni, one blind and the other who limps, respectively, who are depicted as negative characters. The collected stories in *Jeevan Sangram ke Yoddha: Divyang Patron ki Prasiddh Kahaniyan* (henceforth *Jeevan Sangram*) represent the era of 'new stories' in Hindi literature. These stories indirectly engage with disability. Sandhya Kumari observes that the new stories are marked for their approach to realism. The stories are rich with themes related to Marxism, existentialism, science, industrialisation and individual consciousness. The main attributes of these stories are imagery and symbolism. Kumari (2019:19) points out that the struggle of disabled people and their family members became the plot of the post-independence writers, more so in contemporary writers. *Jeevan Sangram* edited and collected by Sandhya Kumari is perhaps the first of its kind of collection of stories on disabled characters in Hindi.

This review presents a critical understanding of collected stories from the perspective of critical disability studies. The collected stories help us understand the representation of disability and disabled people in Hindi society. Disability discourse is yet to make its presence in Hindi literature. This collection should create the space of disability discourse in Hindi.

Disability discourse enjoys its space in English literature. There are centres and schools of literary and cultural disability studies in the Western universities that became models from this perspective. However, disability discourse is yet to create its space in Indian languages and universities. It is limited to doctoral research in Hindi literature. Revita

Balbheem Kawale's work on the disabled characters in post-independence Hindi literature (2015) from Dr. Babasaheb Ambedkar Marathwada University is one such work. Other works on Hindi language include the sociolinguistic analysis of representation of disability in proverbs and folklore in the Linguistics department (Kumar, 2018). Sandhaya Kumari's collection adds to the trend. Sandhya Kumari rightly admits in the preface that disability has not been considered as a subject matter of studies the way Dalit and gender have been recognised as subjects of studies and discourse in Hindi literature (Kumari, 2019). Kumari deftly collected the remarkable short stories of disabled characters written by contemporary Hindi writers.

This review deals with the different aspects of disability that are represented in these short stories. The stories deal with the social and cultural perceptions of disability, the intersection of disability and gender, disability and care, and social integration of disability, etc. This review also comments on the choice of terminology in the title and preface. I have tried to provide the translation of the Hindi title of the stories. The collection has thirty short stories that present the disability in its individual, familial and social relations.

These short stories reveal that disability has been part and parcel of Hindi literature and all the prominent writers such as Sacchidanand Hiranand Vatsyayan 'Ageya', Shivprasad Singh, Panu Kholiya, Narendra Nagdev, Simmi Harishta, Upasana, Tajendra Khanna, Manisha Kulshestha, Swati Tiwari, Kusumlata Malik etc. have written stories with disabled character.

Agyeya's *Khiteen Babu* (1957), Shivprasad Singh's *Karmnasha ki Haar (The defeat of Karmnasha)*, Sacchidanand Dhumketu's *Ek Thi Shakun Di (There was a Shakun Di)* (1979) are collected on the basis of the fierce characterisation of their central characters. However, the physical disabilities of these central characters are compensated with their extraordinary personality. For example, Agyeya's *Khiteen Babu* works as a clerk who is a wheelchair user and meets with multiple accidents. He is, however, depicted as a jocular person. Bhairon Pande who uses crutches is the central character of *Karmanasha ki Haar* is an audacious person who fights against the whole village to save the life of a new-born. There are women characters with disabilities. For example, Dhumketu's Shakun Di has a hump but is a fierce woman who fights for her niece against the exploitative landlord of the village while Sushma Munindra's Nutan who has physical deformity in *Aap Apne Aap me Anupam aur Adbhut Hain* is quite modern and understanding. She was not married because of her physical deformity but lives life on her own terms. These stories enrich our understanding of individual aspects of disability.

There are stories that depict familial aspects of disability. Panu Kholiya's *Anna*, Narendra Nagdev's *Samapan* and Simi Harshita's *Animantrit* (Uninvited) present the impact of having disabled children in the family. While Upashana's *Mukti* (Liberation) depicts the helplessness of a pregnant mother of an abnormal foetus, Tejendra Sharma's *Mujhe Maar Daal Beta* (Please kill me, son!, 2007) sensitively depicts the helplessness of a son whose father is bedridden and seeks euthanasia. The needs of the family and the liability of disability in Indian middle-class families can be seen in Manisha Kulashestha's *Kathputaliyan* (Puppets), Swati Tiwari's *Vidai* (Goodbye), Kusumlata Malik's *Upahar* (Gift*).* Aspects of accidental disabilities and familial relationship is portrayed in Mridula Garg's *Jijeevisha* (Strong wish for life), Maitraiyee Pushpa's *Sahchar* (Cohabitant) and Ramesh Khatri's *Mai Talaq Le Rahi Hun* (I am taking divorce).

Disability is also related to charity in society. Chandrakiran Saunreksa's *Khuda Ki Den* (The gift of God), Jawahar Singh's *Kangali* (Paupery) and Mehrunnisa Parvez's *Siddhiyon ka Theka* (Tender of the ladder) are important short stories that highlights the charity model of disability. Ghai (2012) rightly observes that disability is considered as the retribution of misdeeds of the previous birth. Because of this reason, common people do charity to secure their next birth. This model of disability suggests that charity is the duty of able-bodied people. Nazzo is at the centre of Chandrakiran Saunreksa's *Khuda Ki Den* (The gift of the God) which normalises begging on the basis of disability. Similarly, Jawaharlal Singh presents the story of Ghasitu (literally, dragged) who has polio and how he is treated as an object. Mehrunnisa Parvez's *Siddhiyon ka Theka* offers an insight into the Muslim community's perception of disability and charity.

Deformed bodies are always gazed upon and that reveals societal perception. Dharamvir Bharati's *Gulki Banno*, Jagdish Chadra's *Aadha Ticket* (Half Ticket), Ramdarash Mishra's *Seema* and Mamta Kalia's *Munni* offer different challenges that people with bodily differences face in terms of marriage that prevent social integration. While Bharati's Gulki Banno was abandoned by her husband, Chandra's Banno was made fun of because of her short stature. The intersection of gender and disability becomes quite vivid here. Proverbs in Hindi language also attests this – for example, *ek to kani ladki ki maai, dusra puchhane walon in jaan khai* (Kumar, 2018). Accidental disability results in dysfunctional wedlock.

Jaya Jaadvani's *Jo Bacha, Vah Shabd Nahi Tha* (Whatever left, that was not speech) depicts the narrator who is deaf and blind with one eye. He is engaged to Priya who is also deaf. However, their engagement is broken because Priya got to know about the artificial eye of the narrator. This story indicates the internal hierarchy that exists within the disabled community.

Anand (2013) stresses upon the need to understand the history of disability in India from Indian perspectives for a more nuanced disability discourse. Markandey's *Hansa Jaai Akela (Hansa goes alone)* and Madhav Nagada's *Zaharkanta* offers us the Indian perception of mental illness. While Markandey's Hansa lost his mental health because of individual and political crises, Nagada's Rama lost his in search of a job who got stuck in a riot in the city. Rama fails to read the communal grammar of the city. Both the stories offer an insight that the reason of mental illness is *dukha* (suffering) that is based on social and political chaos.

Sandhya Kumari also provides a rich discussion on the different aspects of disability in the preface. She points out that the attempt has been made to understand the social, economical and political situation of disabled people in the society (Kumari, 2019:11). The preface also works as guidelines in which the editor has tried to throw some light on. However, the title of the book *Jeevan Sangram Ke Yoddha: Divyang Patron ki Prasiddha Kahaniyan* suggests more emphasis on emotion than on the subject matter. It is acceptable that the life of a disabled person is full of challenges but the able-bodied person wishes to overcome those challenges on behalf of the disabled person. The title of the volume is based on this social rhetoric. Societal pressure prevents us from understanding those aspects of disability that are beyond the obvious of social rhetoric.

Terminology matters a lot in disability studies. Sandhya has used *divyangata* in place of *viklangata* but has not offered any note of clarification on that. As India is witnessing a matured disability movement now, and many disability activists and scholars showed their reservation to the use of the term divyangta or divyang (Chander, 2016, Singh, 2020), it becomes pertinent to clarify on the choice of the terminology. This book will be of great benefit for those who want to engage in disability research in Hindi literature. The writers' introduction is given in the book that is useful for non-Hindi scholars, however the lack of year of publication and reference source makes it difficult to situate the work in the historiography of disability in India.

Santosh Kumar

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REVIEWS

We make Films project, in association with Kirti Film Club, New Delhi & Mumbai

Reviews of Documentaries:
'We Make Film' & 'I Didn't See You There'

A screening of two documentaries, namely 'We Make Film' (dir. Shweta Ghosh, 2011) and 'I Didn't See You There' (dir. Reid Davenport, 2022) was held on 23rd July 2022 as a part of the We Make Film project, in association with Kriti Film Club. The screenings were held in New Delhi and Mumbai as well as over Zoom.

The first documentary 'We Make Film' started with looking at how disabled characters in Indian films are portrayed. A popular film, *Sholay*, was discussed to talk about how one of the characters, Thakur, is made to feel like he is being given the ultimate punishment when the dacoit, Gabbar, threatens to cut his hands. The documentary then goes on to ask as to why there are no disabled actors in the industry and in the very next breath questions if there are any disabled filmmakers? If the filmmakers are all able bodied, then chances are that the actors and characters on screen will be too. The documentary then moves on to explore the lives of three filmmakers who have disabilities. The documentary has the director Shwetha Ghosh conversing with the filmmakers in an informal interview and she is assisted by filmmakers Priyanka Pal and Sumit Singh.

The first filmmaker we meet is Debopriya who is hard of hearing and uses a hearing aid. She relates her story about her growing-up years and the struggles she underwent which included the challenge of facing apprehensions of her otherwise supportive parents when deciding to send her to college. She also speaks about how she was really scared to take up the internship at an animation firm the environment of which she later began to like once she started her work there. She feels that using alternative means of education, such as using animated movies, might be a better pedagogical tool for many children with disabilities, but not just limited to them. She emphasises the importance of including everyone not just for the purpose of ticking the diversity box but also to include people even if it requires restructuring the way in which things have 'always' been done.

The next filmmaker in conversation with Ghosh is Anuja who is blind and has been learning the tropes of filmmaking by using accessible apps. Anuja highlights the fact that even the most accessible apps are not sufficient when it comes to the field of direction. She feels that the audio descriptions that are provided in the apps are only for the general audience. For example, the app does not mention anything about camera angles, hairstyles, shot angles, and so on. She also underscores the need to change the way direction is seen and taught for more students to be included.

The last filmmaker is Mijo who is hearing impaired. He recounts how his school-life experience was a bad one as long as he used to go to a hearing school till class 8. Once he enrolled in a deaf school, he could understand what was being 'said' as Sign Language was finally being used and he, thus, gained confidence. In his professional experience, he says he has noticed that a lot of stories on deaf subjects do not see the light of the day due to many films getting rejected. A producer might notice such a film if by any chance, the film goes viral. Also, the team needed to make a film is quite often not available to a director who has a disability. All this could be due to societal and attitudinal barriers. The process of filmmaking should be an accessible process.

The documentary ends with the underlying message that if and when material technology and filmmaking process are accessible, everyone can make films.

The next documentary 'I Didn't See You There**'** is filmed by Reid Davenport and is from the perspective of what he sees and experiences during the day. Reid has cerebral palsy and he uses a motorised wheelchair to move around in the city of Oakland where he lives. Throughout the documentary, he has the camera either mounted on the wheelchair or positions it at his own eye level. While mounted on the wheelchair, the camera usually captures either the road or the sky or a side view but never Reid's face. We get to see his life lived out from his point of view, both literally and figuratively. The film captures the mundane everyday activities – the settling of flies in kitchen, the answering of the voicemails, the pouring of juice to enjoy in the evening, the drinking of coffee in the morning on the balcony and such.

It is on one of these balcony sessions that Reid points to an orange-coloured circus tent that is coming up at the corner of the street. This circus tent, over the course of the documentary, becomes almost like a second protagonist. He invokes the notion of 'freaks' that have long been associated with circus and also how those with bodily abnormality were seen as. As the documentary progresses, Reid, in his daily commute, captures the tent from closer angles, almost as if it is growing on him and is taking an overwhelming space in both his mind as well as the screen. Throughout the film, he often invokes this concept whenever he sees and comes across the tent.

We also go with him to his house to visit his mother and experience the issues he faces with the wheelchair in the flight while de-boarding. At his mother's, we are also shown a side where his mother fusses over his decision to live independently in another state altogether. Parts of this worry stems from the motherly love and part from the fact that he is a person with disability, on a wheelchair who needs to manage everything on his own. On another trip to his mother's place, she also shows concern about his radical and upfront political opinions, which might get him into trouble. Comparing the two places, Reid says that the town he grew up in is like a purgatory while Oakland is an ethical purgatory. However, he insists on living in the city as it gives him access to commute independently in the form of sidewalls, open well-paved parks, buses and subways.

Towards the end of the documentary, we see two separate incidents that have probably become a part of the routine in his life. In one, while he is driving his wheelchair, it loses balance and he falls. The reaction of the people around him put him somewhat in a precarious situation, where he does need the help, but also does not want to come across as being overly dependent. In another situation, the main ramp that leads to his apartment is blocked off by thick coils of electrical cords being used by workers nearby. He tries to navigate his way around but is not successful. When he tells the workers off for putting a cord there, they apologise and remove it but yet say that the work was only for an hour and would have been removed after that anyway. He does not engage with them much after the path is clear, but he is clearly frustrated once he is home and asks off camera why his path to home should be blocked for an hour when nobody else's is. Why is this not seen as a basic matter of concern? The documentary finally draws to a close with a montage of clips taken from the wheelchair, some aimed to the ground, some straight ahead and some focussed on the sky. We can see the gravel, road, concrete and grass running by at different speeds. We also see people always around but yet never at the same level, never interacting. It winds up with a line in his voice saying, how, even though he is always around, he is told, 'I didn't see you there'. He is always in the line of sight, or the line of stare, but yet, never important enough to be acknowledged, or have his opinions considered in a public setting.

Both the films try to capture the way in which disabled filmmakers create films and pieces of creativity while also talking about the process of doing this. But this is where the similarities end. Based in two different countries and shot from two entirely different points of view, the films in a way portray the insider–outsider perspective – how does the world see the disabled body versus how the disabled body sees the world? Also, while the first film focuses on the challenges to filmmaking while having a disability, the second one is a journey into filmmaking because of the disability. The challenges that they face is governed by the social context of their social location. Their age, gender and class status, in addition to their place of living decide how much accessibility (whether physical in terms of rights or attitudinal) they have.

The film screenings were followed by a panel discussion with both the directors, along with Anita Ghai (Professor, AUD), Prateek Vats (independent filmmaker), Sumit Singh (participatory video specialist/filmmaker) and Priyanka Pal (film accessibility specialist /filmmaker). The panel discussion was via Zoom where Sumit was present physically at the Delhi location, Prateek and Priyanka at the Mumbai location and the rest of the panellist from their respective spaces. The main point that emerged was that, till date, the process of filmmaking is a very ableist process. While there have been attempts to incorporate the disabled perspective here and there, it is mostly from the margins, from the perspective of a 'freak', and a disabled perspective in and by itself is not desired. Filmmaking is not just the actual making of the film but it is the concept which one has in mind. Apart from it being a privileged process, it is not a disabled friendly process at all. The intersection of disability and gender, of the rural and the urban backgrounds also play a large part in the process of filmmaking, which might make it exclusionary not only for those with disability. Or conversely, it makes it even more exclusionary when other marginal identities also exist. However, it is also important to keep in mind as to who is making the film and for whom it is being made. The marketability of the films is always a central concern. Here, it was pointed out that since content, that is, accessibility to the disabled, is naturally accessible to the able-bodied, it should in fact be more marketable as it will include a larger audience. Adding different layers to the process will add to the experience of the viewers. It is therefore the industry which is missing out if it does not take disabled people on board.

Ritika Gulyan

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REVIEWS

We make Films project, in association with Kirti Film Club, New Delhi & Mumbai

Kriti Film Club with Ritika:
A Review of Two Documentaries

Those halls on Lodhi Road are amongst the many places where going alone as a blind person is not possible. However, as will becomes evident, the event to be reviewed below was fulfilling in many ways.

This event churned my thought over the question of why I want to film? What would I see and what would I show through the lens of that camera? Is that camera really mine? Would it do what I want it to do? I watched the two films as dialectic. Watching them together created a dialogue which has many aspects. But I shall just talk about 'is that camera mine?' for now.

Filming is an audiovisual medium to say a story. But what if a filmmaker is a Deaf or blind person? The first film that the club screened, 'We Make Film' is a documentary documenting the dream of filmmakers who due to their disabilities cannot have access either to the soundscape or to the visuals, but still would want to film, not just to capture their imaginations and experiences, but to capture much more as professionals.

It tries to capture the extent and the limitations of the technology available today. More importantly, it focuses on how 'inclusion' in the world of filmmaking is possible. As a blind person myself, it is slightly exciting to see that there are some professionals who wonder about film making and have tried working towards it in their own little ventures.

But while I was watching the film, especially the part where this blind filmmaker or YouTuber is adjusting and handling the camera on her phone with the help of the voice assistance where it could only give the directions of the object or the person as it fits in the screen, it made me think about 'filming' as an art or an activity. I started wondering what capturing the visuals of a scene, or an object would mean to me? What if I click or capture something with a voice-over telling me the directions, but not knowing the visual nuances of the object that is being clicked or barely knowing it through my past visual memory or by how it was being described to me; what visual value would it have to my own self? And what artistic value would that picture have in general? Am I even evoking my imagination there? Well, my curiosity to know more about those who know the medium, and to interact with them, made me ask this question.

But only if 'inclusion' becomes less noisy and more inclusive!

Isn't this an ontological question of a picture or a video? Let's say I make a video of an agitated barking dog focusing on the sound of the barking. I move my camera to the right when I hear the sound coming from and change the focus when the direction of the sound changes. But because the sound of the barking cannot set the visual focus, it captures the trees and the bushes more than it captures the agitated dog. It may sound funny or even sarcastic, but the focal issue cannot be overlooked. Similarly, let me photograph the same agitated barking dog, with the same focus, on the loudness of the barking. I click it when the intensity of the sound is the highest. Now what you see, or I feel on the perforated paper, is a tree which was not on my mind while I was clicking the photo. I feel ditched and the referral problem cannot be overlooked.

Howsoever pessimistic it may sound, it is actually the most optimistic way of thinking about what would filming then mean to a blind person. What could they bring on board with their own epistemic tools? Recognising the limits and walking along the lengths that a disability extends is perhaps a more realistic and an apt way of bringing in the needed 'inclusion'. Filming is an action with an ulterior motive of 'to be seen' along with the obvious motive of 'to show'.

Moving ahead to the next movie in the line, 'I Didn't See You There' is an autobiographical work of making oneself being perceived through who, how and what he is through his own skills with the camera. Filming from the height of his wheelchair creating a new way of cinematography speaks a lot. The analogy that he draws between the title of the movie and the height of his camera is really intriguing. 'I Didn't See You There' is a two-way sort of expressing 'I choose not to see you there this time' and 'I did not see you there where I stand'. It's a pun intending anger and attitude.

The filmmaker takes the audience along with him through the routine journey of the places he goes and the roads he travels – the family settings, the grocery-shops, the driveway, the corridors and so on, but all along moving his wheelchair at its level and pace. The plots are mundane yet engaging. It clearly shows that the wheelchair is in fact his camera! Before I end, I cannot do without mentioning the analogy of the tent. It grows bigger and bigger after certain intervals to perhaps show his zeal and urge to be recognised as an artist, to film professionally with others and for others.

It is interesting and important to see the contrast between the two films shown by the Kriti Film Club. The event made more sense as the two films go hand in hand with each other as the first film stimulates a thought which the second film in its own way, satisfies. The question of what an embodied aesthetics does and can bring in ran all through while Ritika was making me go through the visuals of the film.

The first film in a way questions, 'you didn't see me there' and the second in a way exclaims, 'I didn't see you there!'

Sharmishthaa Atreja

❐