GENDER, SUBJECTIVITY AND SEXUAL IDENTITY:
How young people with Disabilities Conceptualise the Body, Sex and Marriage in Urban India

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Abstract

Historically in India as elsewhere in the world, there has been a deep-rooted cultural antipathy to persons with disabilities. Throughout the ages the disabled have been looked down upon with disdain, almost as if they were sub-human. They have been portrayed as medical anomalies, helpless victims and a lifelong burden for family and society. While today there is a general recognition of the need to enhance educational and employment opportunities for persons with disabilities in order to promote economic self-reliance and independent living, their sexual needs, dreams and aspirations are more or less rendered invisible. Sexual and reproductive rights are considered irrelevant for persons with disabilities in India. Using qualitative data, this paper discusses notions of sexual identity among urban Indian youth through case studies of college students in Delhi. Gender emerges as a key analytical category in perceptions of sexuality among young men and women with visual and locomotor disabilities. The paper does not make claims to capturing the complex reality of ‘disabled sexuality’ in India, but highlights some key issues in a hitherto largely under-researched domain.
“… the problem of disabled sexuality is not how to do it, but who to do it with. The barriers to the sexual expression of disabled people are primarily due to the society in which we live, not the bodies with which we are endowed” (Shakespeare 2000: 161).

Gender Subjectivity and Sexual Identity

Approximately 10% of the world’s population suffers from some form of disability or other. A large proportion of the world’s disabled population comprises adolescents and young people. Persons with disabilities are amongst the most socially marginalized groups. They are constantly faced with discrimination and are subjected to neglect, prejudice, revulsion, rejection and pity. They face economic, educational, architectural, legal and health barriers, which prevent them from leading a fulfilling life and achieving their full potential. Indeed, the majority of persons with disabilities pass their lives in total isolation, abject poverty and absolute misery. Needless to say the plight of women with disabilities is even worse, since they face the double burden of being female and being disabled (Lloyd 1992, Londsdale 1990).

Historically in India as elsewhere in the world, there has been a deep-rooted cultural antipathy to persons with disabilities. Throughout the ages the disabled have been looked down upon with disdain, almost as if they were subhuman. They have been portrayed as medical anomalies, helpless victims and a lifelong burden on family and society. Even in religion and mythology, negative characters were attributed some form of deformity, be it Manthara, the hunchback in the Ramayana or Shakuni, the lame of the Mahabharata (Ghai 2002). Indeed, the law of karma decreed that being disabled was the just retribution for past misdeeds. Pity, segregation, discrimination and stigmatisation became normalised in the management of persons with disabilities. Such constructions of the disabled by the non-disabled have the dual effect of not only justifying the complete marginalisation and disempowerment of a whole population group but also leading to the internalisation of such negative stereotypes by disabled persons themselves. This acceptance translates into passivity, dependency, isolation, low self-esteem and a complete loss of initiative.

While on the one hand, persons with disabilities are technically entitled to the same rights under the Indian Constitution as other citizens, and no discrimination is allowed on grounds of disability. Yet, in reality things are very
different. Two events, which triggered public outrage and a nation-wide debate, clearly highlight the extent of the utter dehumanisation of persons with disabilities in society. One was the forced sterilisation of women in a home for the mentally retarded in Pune District of Maharashtra state in Western India in 1994. The primary reason given for the hysterectomies was maintenance of menstrual hygiene. The other was the burning to death of 28 inmates in a private mental asylum in Tamil Nadu state of South India in 2001. The inmates of the Erwadi Dargah were chained to their beds and could not escape the flames that engulfed their thatched huts.

Consequently, instead of giving rights to persons with disabilities and empowering them, a culture of charity and welfare has been systematically promoted in India since the colonial period. The disability discourse has primarily focused on issues related to the medical management, the education and employment of persons with disabilities. This is a crucial step in the disability movement, because it has resulted in the legislation for affirmative action and other policy moves. A landmark judgment, 'Persons with Disabilities (Equal Opportunities and Protection of Rights and Full Participation) Act was passed by the Indian Parliament in 1995. However, since the focus of discussion and activities both by the state and the NGO sector is still confined to enhancing the educational and employment opportunities of differently-abled persons, other critical areas of concern such as their fertility, sexual behaviour and reproductive health have not yet found articulation in the public discourse in this country. Consequently the rights of persons with disabilities to relationships, a family and children have been completely sidelined. It is considered a secondary concern, which can be taken up after basic needs of health, education and employment have been taken care of. Furthermore, negative stereotyping of persons with disabilities as either asexual or sexual perverts finds expression in the media, films and matrimonial columns validating its neglect as a priority in their day-to-day lives. Needless to say the situation of women with disabilities is more fraught as they suffer the double burden of gender and disability-based oppression (Chigier Nosek 2001(a); Nosek 2001(b) and Sexton 1994).

Indeed, not only in India but worldwide persons with disabilities emerge as a sexually disenfranchised segment of the population (Milligan and Neufeldt 2001). There is, in fact, a general social rejection of their sexuality (Block 2000; Cheausuwantavee 2002; Mona and Shuttleworth 2000; Shuttleworth and Mona 2000 and Waxman 1999). Consequently, disabled sexuality is an important area in the discipline of disability studies, more particularly feminist disability studies
Sexuality at core is about acceptance of self and acceptance by others. Indeed, disability and sexuality not only evoke strong emotional reactions but are also mired in cultural myths and misconceptions. Whether in folk tales or contemporary comic strips, the heroine is invariably fair, slim and beautiful, and the hero, tall, smart and handsome. Rarely is a person with an impairment conferred a positive or heroic role. Disabled persons are expected to reject their bodies as asexual. While able-bodied persons may legitimately claim aspirations for the body beautiful and an exhilarating sex life, too many people think that disability automatically excludes those so afflicted from any hope of love and sex. Disabled people are the perennial ugly brothers and sisters. As a corollary to this, their needs for human contact, affection and intimacy are often ignored. The social construction of the disabled identity is more often than not that of an asexual being precariously perched on the margins of society. Indeed, many disabled persons and their parents are convinced that sexual experience does not lie in their destiny. The situation is more complicated in societies like India where sex is a highly tabooed subject. Even under normal circumstances, sexuality is considered socially threatening more in need of control than encouragement and enhancement.

While both men and women with disabilities are disqualified from performance of conventional adult roles, there is reinforcement between traditional notions of disability and womanhood as both are characterised by innocence, vulnerability, powerlessness and sexual passivity (Fine and Asch 1988). So while dependency needs in males are extremely stigmatising, the same tendencies may to some extent be endearing in a female. This disjunction between traditional notions of what it means to be a man-aggressive, strong, self-reliant and providing financial security and social status to the family - and being a man with a disability...
in need of assistance - has led some researchers to opine that the fate of men with disabilities is worse than that of women with disabilities (Shakespeare 1999 and Tepper 1999a and 1999b).

While disability does have negative repercussions on the sexual and gender identities of both men and women, ground realities show that patriarchy does to some extent attenuate the situation of men with disabilities at least in societies like India. The absence of systematic data notwithstanding, from anecdotal evidence and random observations of social life we cannot deny that men with disabilities have greater access to health, education and employment opportunities than their female counterparts. They also find it easier to find sexual partners, both with and without disabilities. Indeed, being male shields them from some of the more dehumanising consequences of being disabled that women with disabilities cannot escape. A woman with a disability is considered incapable of fulfilling the normative feminine roles of homemaker, wife and mother. Then, she also does not fit the stereotype of the normal woman in terms of physical appearance. Since women embody family honour in the Indian context, disabled girls are more often than not kept hidden at home by families and denied basic rights to mobility, education and employment. Parents become more protective and restrictive, especially after the adolescent girl reaches puberty. Travelling to school is a double burden, transport difficulties coupled with the danger of sexual abuse and violation. Furthermore, there is the reasoning that there is no point investing in a disabled girl's education, as she will never anyhow be able to earn. She will eventually be a life-long burden on the natal family because marriage is also not a realistic option. So, it is economically unsound to invest in her education or vocational training. Under these circumstances, they may be married off to older already married or men in poor health. Annulment of marriage on account of disability is a major factor in the lives of women with disabilities. There are more divorced/separated wives than husbands with disabilities. Very often this happens because the natal family chooses to conceal the disability, especially if it is an invisible one like mental illness, at the time of marriage. At other times the disabled married woman may be expelled from the marital home for other reasons, ranging from her inability to satisfactorily perform household chores to bearing a disabled child. In short, women with disabilities do not have the same options of marriage and motherhood as non-disabled women. Being nurturing and caring are core components of normative constructions of femininity, but women with disabilities are themselves in need of care. This inversion reduces them to the status of being lesser than women.
It is evident that there is a great need for detailed surveys on the profile of disability in India to develop a deeper and more nuanced macro understanding of the phenomenon at both macro and micro-levels. Commonsense understanding is very valuable and often approximates the truth but it needs to be subjected to analytical and empirical scrutiny. Since disability studies is not yet a priority research area neither in the academy nor in public policy, the underlying assumptions remain unpacked. And yet any research on disability (including this work) has to engage with these a priori notions, at least as a point of departure.

The case studies discussed in this paper highlight the dilemmas faced by young persons with disabilities, as they struggle to construct their sexual identities within dominant heteronormative discourses of conjugality in the Indian context. Adolescents and young people were chosen, as this is the period of crystallisation of adult sexual identity. Adolescents and young people with disabilities must cope with all physical changes, emotional anxieties and social conflicts of able-bodied adolescents, in addition to those produced by their disabilities. Young people with disabilities may not have access to peers and develop low self-esteem. Clothing and fashion, music, and the media, community activities, social events and school experiences contribute to the development of personal identity at this age. This is a time of learning by watching, doing and rehearsing. Parental values and beliefs are challenged and replaced by peers and the media. These years are full of sexual overtones, messages and activities for those who can access them. However, the adolescent with disabilities may be more of a spectator on the sidelines than a participant in this flurry of socio-sexual activity. Although special schools do offer opportunities of peer interaction, there may be a general isolation from mainstream society for extended periods of time. Spontaneity, risk taking and rehearsal of roles for the adult world may not be available to those studying in such schools. They may experience greater dependency and internalise a perception of helplessness and withdrawal. On the other hand, adolescents with disabilities may feel alienated in integrated settings where the experience of being different and excluded may be heightened, if conscious efforts are not made to involve them in different activities. Absence of role models with disabilities and negative social perceptions of persons with disabilities are the major stumbling blocks for youth with disabilities as they struggle to cope with both the pain and excitement of growing up in general, and the personal challenges posed by disability in particular.

A desire to capture the interface between gender youth and disability and considerations of access determined the choice of the field site. The special school
system and reservation in educational institutions has resulted in a considerable number of persons with disabilities reaching higher education. Many persons with disabilities also see the teaching profession as a viable professional option. Consequently, the Central Institute of Education (CIE) of Delhi University was chosen as an important field site, along with a few Delhi University colleges. While it is true that this represents a minuscule privileged section of the disabled population and is in no way representative of any particular group or category of persons with disabilities, my objective here is to capture a moment in an ongoing journey of life. The informants are at a transitional state of the life cycle whose families have supported them in reaching this level of attainment. They are living in the relatively sheltered environs of the university. The everyday travails notwithstanding, the brush with hard reality of the outside world is still a thing of the future. Psychologically it is a period of optimism, hope and anticipation of the future. It is within this highly circumscribed space that I seek to explore that which animates their being as sexual (and gendered) persons.

Given the sensitive nature of the topic of research, the life history approach was followed (Bertaux and Kohli 1984; Denzin and Lincoln 2003). The focus on how individual agency, institutional constraints and serendipity intersect in the life course of an individual is a useful way of unravelling the ways in which disability and sexuality intertwine in the development of personal identity. The case study method was used to operationalise this approach in the context of this paper, since it gives paramount importance the subjectivity of informants, which is critical to understanding different dimensions of identity. Multiple in depth semi-structured interviews were conducted with informants, which were tape-recorded with permission and then translated from Hindi into English. Subsequently, the transcribed material was subject to content analysis in terms of certain broad categories, such as medical history of impairment, health seeking behaviour, family and educational history, sexual perceptions and experiences, career and marriage plans for the future etc. to constitute the case studies. The narratives reveal that although gender is a major defining element of the disability experience in general and of the self as a sexual being in particular, it does not operate in isolation but intersects closely with other equally important variables such as social class (and caste in the case of India), family composition and dynamics and geographical location. Secondly, the segregation-inclusion discourses influence informants’ opinions of marriage and family life as also their actual social behaviour. Thirdly, although the charity discourse on disability is slowly giving way to the human rights perspective in the public sphere, the transition to
a social model approach is far from complete. Indeed, as the case studies show individuals with disabilities may selectively appropriate both perspectives as strategic devices to further their goals. Lastly, my aim is not to throw up broad generalisations on sexuality and disability in India, but to initiate a discussion on how sexual perceptions, behaviour and attitudes are experientially configured at the micro-level.

Case studies 1 and II show how two visually challenged young women attempt to dhere to normative constructions of femininity. Notwithstanding the multiple disadvantages characterizing the lives of women with disabilities in general, both Mira and Payal manage to salvage a positive body image and choose to follow the heteronormative script. Case studies III and IV present similar versions of disabled sexuality within the cultural construction of masculinity. Although having different disabilities and studying in the same class, Amit and Lalit show almost equal levels of low self-worth and alienation, which are in sharp contrast to the optimism exuded by their female counterparts. Indeed, it appears that disability complicates gender issues in significant ways.

**Case Study I: “If I go home, my ‘self-dependence’ will be finished.”**

Mira is a 21 year old visually challenged young woman pursuing a bachelor of education (B.Ed) degree in the Central Institute of Education (CIE) in Delhi University. Her hometown is Allahabad in the neighbouring state of Uttar Pradesh, where her parents and siblings continue to reside. She is the youngest of seven siblings, three brothers and three sisters. Her father is a retired bank employee and her mother is a housewife. Two brothers and a sister are married. While her father and siblings have obtained university education, her mother is illiterate. At the time of meeting Mira, two brothers were unemployed and her elder sister was completing her doctorate in psychology. Mira did her schooling from the National Institute for the Visually Handicapped (NIVH) in Dehradun in Uttarakhand state. Subsequently, she did two years of her undergraduate degree from the Indraprastha College in Delhi but had to complete the degree through correspondence due to financial reasons. Thereafter, she enrolled for the B.Ed degree and got a place in the CIE hostel.

Mira lost her vision at the age of three years after suffering from diphtheria and related complications that occurred after administration of an injection (details not known to her). Describing the illness episode she said:
First I had 'diphtheria'. It was diagnosed very late when I was in its last stage. Then the injection, which the doctor gave me for It led to 'meningitis', a brain problem. I went into 'coma' for six months. When I came out of the 'coma', I had lost my 'eyesight'. My mother told me that during the 'coma' I was just about breathing; everything else had stopped. My brain had stopped working. After my 'eyesight' went, my parents took me to many doctors. They were even willing to donate one of their own eyes saying they would be able to manage with just one eye. But the doctor told them that 'nerves' had been damaged, and that there was no medical treatment.

Apart from medical facilities in her hometown, Mira said her parents had taken her for medical consultation to leading ophthalmology centres in cities like Aligarh and Sitapur in Uttar Pradesh, Indore and Amritsar in Madhya Pradesh and Punjab respectively. Besides the visual loss, Mira feels the childhood infections have had other permanent adverse consequences on her health like general stunting of growth and 'water and calcium deposits in her brain' for which she was taking homeopathic medicines. In addition there was some hormone imbalance in her body. She had to undergo gynaecological intervention to initiate menstruation at the age of 18 years.

Her formal schooling began at the age of seven years at NIVH in Dehradun. While initially she had difficulty adjusting in the hostel, gradually she got used to the place. Although much was wanting in levels of cleanliness and the general demeanour of the school authorities, Mira rated her experience there in positive terms. She said:

What I liked the most was all of us living together like a family. I had joined the school at a very young age. I stayed there for 10 years and all of us lived together like siblings.

Even though the passage from a special residential school to an integrated college hostel in a different city was a major move in terms of geographic mobility and change of daily routine, yet Mira had a relatively smooth transition form her description of the two years she spent in the Indraprastha College Hostel in Delhi. Describing the hostel atmosphere she said:

I really 'enjoyed' being in the 'hostel'. First, I was somewhat scared how the other 'normal' people will behave with me. Then, there is also 'ragging' of the 'freshers' in colleges. But when I actually went there, I found that people were 'good-natured', and they helped me out a lot. I 'adjusted' to the place very quickly, and participated in college functions and festivals even winning prizes in 'poetry and essay competitions'.

also got the Miss Fresher Award in the hostel and Miss Fresher Runner Up Award in the college.

However, looking at the situation from the perspective of the non-disabled other, Mira commented:

‘Normal’ people do not have any experience of being with visually challenged people. They would get disturbed when we listen to our tapes in order to complete our assignments using the Braille slate. Even though I used headphones to decrease the disturbance, my roommates often got disturbed.

Several factors induced her to leave Indraprastha College in the third year of her graduation. These included the discovery of her ‘brain problem’ through CAT and MRI scans, father’s retirement and associated financial constraints on the household with two unemployed brothers and one unmarried sister. But she managed to complete her BA through correspondence staying in the university hostel with friends. Then, since admission into a professional course like B.Ed promised the option of a job, she was allowed by her father to pursue it. So, from the outset it can be seen that Mira charted her life course in accordance with the aspirations of a non-disabled person. Despite occasional opposition from the family, her parent’s supportive role cannot be overlooked. Reiterating the supportive role of her mother, Mira said with pride:

My mother wanted me to study. All her ‘big dreams’ are attached to me. She wants me to study and do something.

In Mira’s opinion the special school in Dehradun gave her a kind of independence and confidence that she may not have otherwise developed. She wants to remain in Delhi, since opportunities for ‘handicapped people’ in terms of studies and jobs are much more than in Allahabad. She also commented wryly:

I also feel that if I stay at home, my ‘self’ dependence would be finished.

After completing her B.Ed, she plans to enrol in a post graduation course in Hindi Language and Literature, which would entitle her to hostel accommodation, and simultaneously try to get a permanent teaching job in a government school. Furthermore, she feels it was her duty to earn and give some money at home. From one perspective Mira has not done badly for herself at all: she is the only family member who in a high status position as she is living in Delhi University, doing a professional course, getting a stipend for the disabled and has the option
of getting a job through reservation. Her elder sister, who was completing her doctorate in psychology at the time, even asked her to look for a job for her in Delhi.

Mira’s sexual development was obstructed both by absence of menstruation and development of secondary sexual characteristics during the major phase of adolescence. Although her mother had given her a vague idea about menstruation when she was around 12 years old, she did not perceive anything amiss when all her classmates began getting their periods. But when girls in the hostel younger to her also reached menarche, many people got to know and advised her to seek medical help.

Drawing upon popular ayurvedic notions of amenorrhea, it is the imputed consequences of such an affliction, which bothered her more than the absence of secondary sexual characteristics per se. As she explained:

*The normal discharge of heat and other impurities that happens regularly through menstruation was not taking place, leading to their accumulation in the brain. The possibility that this might affect my brain and hinder the fulfilment of my dreams of becoming something in life really frightened me. As it is memory declines with age and I did not want my 'memory power' to be affected.*

During her last year at school, Mira and her mother consulted a medical practitioner during her summer vacation in Allahabad. The initial prognosis was bleak with the doctor saying she would not be able to reach menarche due to inborn defects. While Mira maintained she received this news stoically, her mother’s reaction to being told that her daughter may not develop sexually like a normal woman was one of extreme alarm and distress. This response contests the perception of disabled persons as asexual. Her mother desired that her daughter should have the assigned sexual identity, even if marriage was not in the reckoning on account of the visual disability. Having a disabled daughter with an inadequate sexual identity was too frightening and dismaying a possibility to contemplate, since it involved negotiating multiple marginalities.

Despite the negative prognosis in Allahabad, Mira did not lose hope and consulted a gynaecologist in Dehradun whose treatment resulted in the onset of menarche at the age of 17 years. The momentousness of this even in her life can only be captured in her own words:

*One day after taking the medicines, I thought something was wrong. I felt very wet. There were several girls in the hostel because we had our music exam. There was only one partially sighted girl among us, but I did not really know her and so could not ask...*
her directly. I just asked her to look at my suit to see if it was dirty, but she said there was nothing wrong. Then, I thought that if my clothes are stained, the maid will surely tell me. I washed my clothes thinking they were normally dirty; but they were actually badly stained because it was the first time and the flow was very heavy. However, when I discussed the matter with totally blind girls like myself, they said it was not there even after I told them how I was feeling. Then, one of the blind girls gave me a pad and told me to show her the pad before throwing it away. She touched it and said that there was no period. She even smelt it. But it was there for a week and when I went home, my mother said all the clothes were so stained she had to soak them for several hours to get the stains out. She said it was amazing that no one had pointed it out to me. Anyhow I got the 'confirmation' from my mother and both of us were very happy that they had come at last.

Subsequently due to frequent movement between Delhi, Allahabad and Dehradun in the process of joining college, Mira was not able to continue treatment regularly and her periods again stopped for one whole year. She decided not to self-medicate; even though she knew that if she took the prescribed medicines, menstruation would begin. Subsequently after settling down in Delhi, she again made the trip to Dehradun to consult her old gynaecologist who made a referral to her sister-in-law, also a gynaecologist practising in Delhi. Mira is under regular treatment now taking such hormonal medicines as Ovral-G and Ovral L®.

The challenges notwithstanding, Mira has been able to carve out a heteronormative pathway for herself with a boyfriend and plans for marriage and motherhood. At the time of our meetings, she was in a steady relationship with another visually challenged postgraduate student for the past two and a half years; and they planned to marry as soon as he found a job. Initially Mira said she was ambivalent because she feared her gynaecological problems would preclude having a normal sexual life and children. Her boyfriend knows about her medical problems but felt that the ‘understanding’ they share could not be sacrificed at any cost. Mira explained:

He is fully aware of the situation because he accompanies me to the doctor. It is a double problem with me because in addition to the disability, I have these other problems. Then we are also from different castes, which will be a major issue at the time of marriage with our families. But I feel in the case of blind people, there is no caste or religion. There is only the disability. I know my father and brothers will oppose our match because he is from Bihar and of a different caste. But then no one is going to find a match for me at home. They did not even arrange my elder sister’s
Mira’s personality and life projects strongly contest widely prevalent views of women with disabilities. In the face of multiple challenges, she emerges as an independent, autonomous, ambitious and sexually active woman. Although there are some enabling features in her social environment like family support, it is her grit, intelligence and enthusiasm for life firmly embedded in self-respect and confidence that contribute to her sense of well being.

Case Study II: ‘They should be told that we can do everything. ‘Blinds’ can do their own work.’”

Payal is a 19-year-old visually challenged undergraduate student in the second year of her BA pass course in a women’s college of Delhi University. She resides in the hostel. Her family lives in a village in Bulandshehar District of the neighbouring state of Uttar Pradesh. Like Mira she is one of seven siblings, four brothers and three sisters. While her father was engaged in agriculture, two of her brothers are schoolteachers. One brother is in Delhi and the other one is posted in the southern state of Karnataka, where they live with their wives and children respectively. She has one younger sister studying in ninth standard. Like Mira her mother is also illiterate. Payal attended a number of special schools for blind girls in Delhi. From the first to the seventh standards, she was at Janata Adarsh Andhh Vidyalaya in south Delhi and subsequently her schooling was done at the Rajkiya Virjanand Andh Kanya Vidyalaya, a government aided residential school for girls situated in west Delhi. Thereafter, she followed the trend set by many of her senior classmates by enrolling in a Delhi University women’s college for an undergraduate degree.

Like Mira, she acquired her visual disability at the age of three years after a bout of fever. In her words she got ‘eye flue’ which resulted in her eyes being closed for three days. Thereafter, her vision was gone. Being in the village, she was not immediately taken to the doctor nor does she have details of her medical history. However, she does know she was operated upon twice in childhood; once in a town called Bhiwani in the neighbouring state of Haryana and subsequently at the age of nine years at the All India Institute of Medical Sciences in New Delhi. Neither operation resulted in any improvement in her condition.
Being in the first year of college, Payal largely confines herself physically to the college premises and socially to the company of other visually challenged girls. Describing her social interaction with the other girls in the college and hostel, she said:

*I feel most comfortable with ‘blinds’ in the hostel. Everyone stays with his or her own friends. In passing they will say ‘hi’ or hello’. Sometimes they come to our room or we go to theirs. They have their own group and sometime we are included and sometime we are not. There are four blind girls in my class among the day scholars. If I were the only blind person, then maybe the sighted girls would have kept me with them more.*

Nonetheless, she was effusive in her gratitude to the assistance given by her sighted college mates ranging from reading and recording lecture notes to running errands for her outside the college premises.

Like Mira Payal was also told by her father and brothers not to venture outside the precincts of the college alone. She told me that she did not like going out on her own. She said:

*No, I don’t like going out much. I am scared. There are some weird people one can run into. I am more scared of strange people than cars and bicycles. When we were in the school hostel, we felt we should be allowed to go out on our own. But now that we have the ‘freedom’, we are scared to go out on our own.*

When asked what she wanted to do after completing her BA she said laughingly:

*“I will either get married or do an MA”*

She said that her parents do not talk about her marriage, even though her sisters were married at an early age in keeping with the practice of child marriage prevalent in much of rural India. When asked the reason for this, she said:

*They want me to be independent as I am blind. Everyone cuts down on their own expenses so that I can study. Even though my elder brothers are also supporting our parents in the village and running their own households, they are also funding my education and hostel stay.*

But marriage still constitutes Payal’s ultimate aspiration. When asked what she though she would be doing 10 years later, she said she would be married. When asked why she wanted to get married, she said that her brothers would not continue to support her economically for an indefinite period of time. Besides her parents would not be there to look after her for all time to come; and her brothers and
sisters’-in-law may not continue to be nice to her: so it was imperative for her to marry. When asked how she wanted her marriage organised, she said her brothers would arrange her marriage because:

*If something goes wrong, they will at least support me. If I do it on my own, they won’t help because they will say it was my choice; and now I should manage things on my own.*

When asked whether she had any particular preferences with regard to her future spouse, Payal said she would want to marry a ‘partially blind’ person like herself. Drawing upon the notion of similitude, she felt that a partially sighted person would be in a better position to understand and live with her than either a totally sighted or sightless person. Explaining in more detail, she said:

*Most boys with disabilities want a sighted girl. Visually challenged girls, on the other hand, mostly want a similarly disabled person as their partner. They think a non-disabled person will not be able to cope with them and may even leave them; I also think like that. I am ‘partially blind’ I should also get a ‘partially blind’ person.*

Payal considers herself an introverted person. While most girls go to socialise and watch TV in the hostel common room in the evenings, she prefers to listen to the radio in her own room, which she shares with another visually challenged student. Her social network includes a group of both visually challenged and non-challenged persons. When asked to comment on the element of asexuality associated with persons with disabilities, Payal said:

*No there is nothing like that. Disabled people can also engage in sex. Don’t disabled people have children? It is not necessary that disabled persons will also have disabled children. There are many disabled persons who have children and they are good parents giving their children love and good education. I had a blind classmate whose maternal aunt and uncle are also blind. They have two daughters. Her uncle is some official and their elder daughter is going to a very good school. Everyone should know that disabled people can do everything. Some people even think we can’t perform tasks like washing and cleaning our room, but that is not true. Disabled people can also do sex like everyone else ‘Blinds’ can do everything.*

When asked to comment on the limited options for disabled people in experiencing their sexuality, Payal agreed and said:

*‘Normal’ people can make friends with anybody very fast. It is different with blind people. They are mostly attracted by the voice. Then, it’s ok to have friendship if the*
other person is intelligent. But normal people go after the beauty or looks. So, they make more friends.

Both these case studies show there is a significant value placed on economic self-reliance both by visually challenged educated women and their families. During our meetings, Payal was vacillating between doing a B.Ed. an MA in history or learning computers and short hand after completing her B.A. Since disability significantly diminishes the marketability of women as suitable marital partners, compensation is sought through employment as both a way of enhancing the young woman’s marital chances as also offering her a means of economic self-sufficiency should she be left to fend for herself. On the other hand, economic empowerment is the primary concern for men with disabilities as the remaining case studies show.

Case Study III: ‘I am very ‘egoistic’ and I ‘presume’ a lot.’

Amit is a 25-year-old student pursuing a bachelor's degree in education from Delhi University. He is the second youngest in a family of three brothers and one sister. His father passed away when Amit moved to Delhi for his university education. His widowed mother lives with her two married sons and their families in their native village in Pauri District of the state of Uttrakhand. He went to the village school for a couple of years before moving to Dehradun to continue his schooling. After completing his schooling at the National Institute for the Visually Handicapped, he did his under-graduation and post graduation in Hindi from colleges in Delhi University before opting to pursue a B.Ed. He has been a hosteller throughout his school and college education. This makes him the most educated member of his family. While his eldest brother is an employee in the state postal service, the other brother is in the army.

Amit’s vision started noticeably declining at the age of nine years when he was in the fifth standard in the village school. Describing the exacerbation of his vision, he said:

I think it was since 'birth’ but nobody noticed it. Even I did not know about it. I was just a child; so how could I know about it? But others also did not take note of it. Then in the sixth class, my eyes became very weak and others also noticed it. I remember that I always had to sit in front of the blackboard, but nobody really bothered about it in the village.
He was initially treated at a government hospital in Dehradun and informed by the doctor that he had cataract for which he underwent surgeries in both his eyes.

Talking about his life in the school hostel at the National Institute for the Visually Handicapped in Dehradun, Amit pointed out that unlike the girls, boys had greater freedom to move out on their own. Social life in the hostel included going out in small groups or pairs at night and having soup at a nearby stall or smoking and having a drink. They tried to include at least one partially sighted person in the group for the outing. Elaborating the point, he said:

You will notice that every ‘blind’ ‘internally’ wants that even though he can walk independently, he still feels more comfortable if he is in the company of someone with ‘vision’. I also don’t want to go out with a person who has the same problem as me.

Unlike Mira and Payal, Amit feels less comfortable in the university where he is forced to interact more with non-disabled peers. Comparing hostel life in the integrated and non-integrated settings, he said:

The difference is that in a hostel of our ‘community’ or ‘society’, we don’t feel alone, whereas in the other hostel we feel we are away from our own society. One feels somewhat lonely, as there is not much ‘interaction’ with other people. In the other hostel, nobody saw us from that angle (drishti) and we could do whatever we wanted like singing in the hallway, shouting etc. But we cannot do such things with ‘normal’ people here because we feel some ‘hesitation’. There are major differences in communication and understanding. If someone does not talk and just passes you by, then it is obvious that there is no interaction. When ‘normal’ people see and pass us by they (sighted people) wonder ‘have they (the visually challenged) seen us? Have they not seen us?'

Interestingly, the play upon the word seeing in Amit’s description highlights the extent to which standard language incorporates the perspectives of non-disabled society. We are struck by a visually challenged persons’ use of the verb ‘seeing’ because it is visualised more or less exclusively as the activity of the sense of sight. But engagement with the external world through touch, sound and other communicative modalities may be analogous to seeing in the absence of vision.

Amit feels that the avoidance behaviour of non-disabled persons was directly linked to the presence of the disability. Endorsing Payal’s opinions in another form, he said:

If a person is ‘normal’, then people can talk to him in any way but that is not the case with us. With us they only talk of ‘important’ things but not of ‘general life,’ things
like what are you doing, where are you going etc. These things can easily be asked among normal persons. For example if they see us going to the mess, they will say ‘You are going to eat?’ They will make you sit but they will not talk of anything else. It is like they want to get away from you as soon as possible: whereas if it is a normal person, they will go ahead and talk of other things. With us they become quiet, and there is a ‘separation’.

Amit described himself as a ‘closed’ or ‘introverted’ person finding it difficult to relate to people both in the intimate and formal spaces. For instance, he said he did not address his relatives by the appropriate kinship terms. He did not even address his mother as mother. In a culture in which individuality incorporates the family, such familial disaffiliation marks a significant departure from established notions of both individual identity and interpersonal communication.

In the face of perceived and actual quotidian attitudinal barriers, Amit had devised more specific avoidance behaviour strategies, as if to shield himself from loss of face in the integrated setting. He explained:

At lunch my situation is such that I try to go to the mess a little earlier than others, and to eat very quickly. Firstly, I don't want to face many people. Secondly, if one goes later, then the chairs are all occupied. Here the procedure is that you have to take your food and then go to the table. Now, the distance between the food counter and the table is not the problem. But if the room is full, you can bump into someone. It is normal for us to bump into people but I don't want that to happen. Sometimes the situation can grow nasty. So, I come early to the mess.

Summing up the discomfort he experiences in the company of non-disabled persons, Amit concluded tersely, ‘People are living with us and accepting us but not ‘internally”’. He gave examples of situations when he felt overtly self-conscious and actively worked to avoid such situations. For instance, like Payal, he preferred to return to his hostel room during free periods instead of hanging around the college. Furthermore, he said that he avoided personal contact with people in positions of power and authority. Then, he tried to keep a distance with his teachers as well. Explaining the rationale behind such behaviour, he said:

Suppose I am going to that teacher's class and I have a personal relationship with him, then he will look at me in a different way and treat me differently at that time. I want to be a ‘normal’ student around him and enter the class in a ‘normal’ way. I am always aware of my limitations due which I hesitate to move forward.
Amit’s behaviour is embedded in a complex grid of salvaging an autonomous self defined by non-disabled society in the face of overwhelming physical, social and psychological barriers that he has himself internalised in the course of socialisation as a middle class Indian male. He feels his social status and self worth are diminished if he has to solicit assistance. The act of being helped is perceived as an onslaught on his sense of self, which he goes to great lengths to shun. Interacting with non-disabled males is the social context in which he feels the most vulnerable. Explaining the dilemma he faces in such situations, Amit said:

So I am moving in a group with ‘normal’ boys. If I tell them that they should walk slower so I can keep up with them, then they will lose the sense of me as a ‘normal’ person. They are all walking engrossed in themselves. Each one thinks that the other will look after me if he goes ahead. But in the end, I am left behind all alone.

Making an interesting gender-based comparison, Amit felt that visually challenged girls like Mira from his school in Dehradun are managing life much better than him.

I see how these girls are doing everything, walking around everywhere. I get scared going out alone. I am not so much fearful of automobile accidents, but suppose I get ‘unbalanced’ and touch an electric wire; suppose I get lost. I am so scared of society.

Despite an expressed diffidence, Amit affirmed his masculinity by talking with relative ease about several heterosexual attractions or encounters. He said he had been involved with a visually challenged girl for several years while both of them were at school. Then, he gave vignettes of intimacies with sighted classmates in college. Two such narratives are sufficient to highlight the intricate mental negotiations between disabled masculinity, desire and personal dignity that Amit experiences in everyday life.

There used to be a girl who would regularly accompany him from hostel to class and back. She used to spend hours talking to him. People linked them together as a pair, and their names were scrawled on the blackboard. But he knew she was doing this ‘out of sympathy for him’. More recently, one of his classmates gave him a gift for Diwali (a major festival of the Hindu calendar), a pair of trousers and matching shirt. Earlier, she had refused the advances of another classmate and told him,” I would rather marry Amit than you”. This boy, who was also a hosteller, told Amit what the girl had said. Subsequently, she gave him a Diwali gift. While giving him the gift she had said to him that that while he
lacked vision, she also had a shortcoming, namely, she was not beautiful. Amit felt she had chosen him because both of them had some ‘weakness’. While she does try to meet him, he does not go out of his way to meet her. He is also uncertain about the genuineness of her intentions. Two interrelated questions arise in his mind: is she interested in him as a man or as a disabled person? Is she being kind and showing pity or does she really like him? Amit candidly admitted that these incidents could also be ‘dreams’. Given the slim chances of reciprocation, Amit felt a blind person cannot tell a sighted person about his feelings.

All these inhibitions notwithstanding, he identified sight as the main criterion for his spouse. He said:

I have ‘low vision’. I don’t want a totally blind person. She should be able to see at least something. One does not want to just live in a forlorn way. If you want to lead life ‘systematically’, sight is important. How can one manage life well, if both the partners are sightless?

In addition to being sighted, he also desired that his spouse should be a well-educated woman. Although his family would look for a match for him, he felt that they would not be able to find a suitable person. He did not want to marry an illiterate girl from the village with whom he could have no ‘understanding’.

It is interesting to compare and contrast Amit’s aspirations with his experiences of life in the integrated and non-integrated settings. On the one hand, he said that he experienced more alienation and loneliness in the college hostels in Delhi University like being passed over by non-disabled persons, yet on the other when it comes to the choice of a spouse, his priority is that she should be sighted. The inference one can make from this is that personal well being experienced in the company of other visually challenged persons is not adequate compensation for the advantages of being aligned with a non-disabled spouse in a society which regretfully equates absence of vision with individual invalidation and social disenfranchisement. His classmate Lalit holds similar views, even though his disability is not visual.

Case Study IV: ‘The problem is that everywhere there are stairs’

Lalit is a 21-year-old college student who suffers from polio. His right leg was paralysed at the age of two and a half years. He lives with his parents and younger brother in Tilak Nagar, a lower middle class suburb of Delhi. His father is a freelance priest and his mother is a housewife. His twin brother is also in college;
and his elder sister is married and also lives in Delhi. Both Lalit and his brother completed their schooling in a government school near their residence. Subsequently, they went to the same college to complete their BA. Currently, Lalit like Mira is doing his B.Ed, while his brother is pursuing his MA from the Hindi Department of Delhi University, which is situated close to the Central Institute of Education.

He developed polio after receiving an injection from a local doctor for fever. His parents had just come from the village to work in Delhi and did not know about medical facilities. So, the onset of polio was a 'reaction' to the injection. He underwent all kinds of treatment from both indigenous and biomedical practitioners including surgery. He was taken to health facilities in different cities like Jaipur in the state of Rajasthan. For his operation, the family went to Chennai in Tamil Nadu when he was 15 years old, which did not result in any improvement in his condition. Whenever his parents heard of a new treatment, they would take him there. He said:

Now, I have stopped all medicines. My parents still urge me to go when they hear of some good doctor, but I am so fed up of the treatments. There is so much heat in my body due to the medicines. Some doctors say that my obesity is also due to excessive medicine consumption. Now, it does not matter since I have made my 'adjustment' in life. I don't feel that I have any disability. In fact, I have become so used to it that if one day I am miraculously cured, it is quite likely that I will have adjustment problems in being 'normal'.

Lalit studied till the third standard through home tuitions. Then, he and his brother were both admitted in the same class at school, even though he (i.e. Lalit) was eligible for the fourth standard. But he was put in a lower class so that his brother was always present to help him. This was a purposive parental plan for constant care. Speaking of his childhood, he said:

Everyone at home is very 'caring' towards me. I also got a lot of 'caring' in school till the eight standard when most of the teachers were women. Later, there were more male teachers and their behaviour at times was quite rude. But by then I did not need so much care either because I could mostly take care of myself. Besides my brother, my classmates were very protective of me. They would not let anyone mock or taunt me.

Lalit agreed that there was almost a symbiotic relationship between him and his twin brother. Before his taking up the B.Ed programme, they had always been in the same class at school and college and had even studied the same subjects. His
brother was not only his principal caregiver but also his major confidant. Only now was he moving out of the fraternal cocoon and negotiating with the world as an independent person. Lalit, however, admitted that he missed his brother’s presence as he felt quite alone and a bit lost in the premises of the Central Institute of Education. Although his teachers and classmates were very helpful, he did not like socialising with them preferring to return home immediately after classes. While classes were held on the ground floor for his convenience, yet the existence of several staircases was a major barrier to his free movement within the institute. Thus, several factors contributed to his not spending time in the Institute.

Lalit like Amit is reluctant to receive assistance. For instance, he would prefer to hang his bag on his crutches while climbing stairs than asking someone to hold onto it for him. Even if someone offers help, his immediate reaction is to refuse. Such ambivalence appears to be born out of an aversion to being the object of sympathy. He explained:

*People should not openly be sympathetic or mock the person. They can ask him if he needs help and if he refuses, then they should not insist. If I have to go somewhere, I have to walk there on my own only. No one can do it for me. They can’t pick me up and take me there. Eventually one is alone.*

Coupled with his disability is a range of digestive problems like abdominal distension and need to use the toilet after meals. Since the educational institutions he has attended did not have disabled friendly toilets\(^1\), he prefers not to consume any food when out of the house confining himself to taking only water. Diminished physical mobility and associated problems have resulted in his adopting a more socially sequestered life style.

Lalit felt his attractiveness for the opposite sex was considerably undermined by the fact that he could not walk properly, in addition to being fat. Putting his experiences in perspective, he said:

*My experience with girls is totally nil. Of course, I have gone through attraction because it is a biological thing. It has to happen at some age or other, but I know how to take care of myself.*

Lalit was candid about masturbation.

*I had this experience when I was in ninth or tenth standard. In Indian society this is considered wrong. It is another thing that it is number one activity among boys. So, when I did it for the first time, I felt good at one level because the body’s desires have to*
be fulfilled; but after that I felt sad that I had done it. Later, I realised that guilt will be there but it is 'compulsory' for me to do it.

Nonetheless Lalit said he did not want to get married. He had come across a few cases of some very unhappily married persons with disabilities. His parents want him to marry in the future so that his family life is 'settled'. But according to him:

In a marriage there should be some equality. My family says that my spouse should not be disabled. Otherwise how will she help me, if she is disabled? But if she is not disabled, then there won't be any equality. Then, you can say that the social life might go on well but the personal life will suffer.

So, it is a no-win situation if analysed from this perspective.

Conclusion

While there is a general recognition of the need to enhance educational and employment opportunities for persons with disabilities in order to promote economic self-reliance, their sexual needs, dreams and aspirations remain more or less unrecognised. Absence of a sense self-assurance and confidence in the functioning and attractiveness of the body is one of the major stumbling blocks in the lives of persons with disabilities. Disabled bodies do not fit the cultural ideal of the healthy, strong, independent and beautiful body. In addition to sensory loss, there may be lack of muscular co-ordination, drooling at the mouth, incontinence and other abnormalities. Persons with disabilities may be dependant on others for activities of daily living and their bodies may be deformed and aesthetically unappealing in more ways than one. The disabled body is not valued as a source of pleasure or value (it cannot work, reproduce or be attractive). All these are indicators of a poor body image, which not only refers to appearance but also encompasses the whole range of perceptions about bodily sensations, capacities and functions.

Body image not only influences overall self-assessment of a person but is definitive in determining a person’s sexual self-esteem. Sexual self-esteem is an individual’s sense of self as a sexual being and may be rated as appealing and unappealing, competent and incompetent. It describes a person’s sexual identity and perception of sexual acceptability. When persons have a positive body image, they are likely to have high levels of sexual self-esteem as well. But factors like abuse and disability are injurious to sexual self-esteem. When sexual self-esteem
is damaged, it can lead to mental ill health; since it results in a damaged view of oneself, diminished satisfaction with life and capacity to experience pleasure, willingness to interact with others and develop intimate relationships. As social attitudes towards physical differences are largely negative, body image and associated sexual self-esteem are a problem area for persons with disabilities. Disability may lead to the loss of sense of self as a sexually attractive and sexually functional person.

Since many persons with disabilities do not have peer feedback and extremely poor self-visualisation of their bodies the question that they often ask is not “How do I relate sexually?” but “Do I have a right to related sexually at all?” Comparisons with the normal body emphasising physical fitness, sports attainment and the body beautiful projected in the media may lead to feelings of frustration and annoyance at having a disabled body. Even persons with sensory disabilities, such as blindness and deafness, may experience such devaluation, even though they may have no other physical abnormalities. Such negative attitudes and perceptions are internalised leading many persons with disabilities to avoid looking at themselves in the mirror. They may also avoid social interaction and intimacy, and further recede into isolation and loneliness.

It needs to be remembered that low self-esteem in regard to sexual identity is the issue and not sexual function or capacity. Since persons with disabilities are socialised from earliest childhood to view themselves as undesirable, they may not take the risk of communicating sexual interest out of fear of being ridiculed, ignored or outright rejected. Psychological barriers in the form of low self-esteem and body image combine with lack of physical and social opportunities for developing relationship skills. Seclusion in institutions or being policed at home by their own families further exacerbates their plight. Needless to say the situation of young women with disabilities is more fraught than their male counterparts and the challenges to developing positive body image even more daunting.

Furthermore, persons with disabilities may have ambivalent feelings when it comes to relating with other persons with disabilities. It has been found there is a direct correlation between acceptance of one’s disability and the willingness to relate in an intimate way with another person with a disability. Many young men with disabilities in India desire and are able to forge sexual and marital relationships with non-disabled women. On the other hand, young women with disabilities are more inclined to accept a sexual/marital partner with a disability. These preferences are in keeping with the dynamics of the matrimonial market in the country, wherein like is matched with like; but with men having more advantages than women, especially if they are economically self-reliant.
Despite being socialised into enacting a form of desexualised subjectivity (Price and Shildrick 2001), the narratives presented in this paper mark the fissures and points of resistance that enable persons with disabilities to affirm their sexuality. And the resilience of young women inhabiting patriarchal spaces is considerable. For instance, the four case studies reveal that although objectively the plight of women with disabilities may be worse, yet subjectively the mental status of men with disabilities may adversely affect their sense of well being to a far greater degree. Mira and Payal show considerable optimism, while both Amit and Lalit appear to be haunted by a deep sense of personal devaluation and foreboding.

The four informants express experiencing varying levels of alienation in integrated settings, which finds expression in the sphere of intimate relationships. And here there is again a gender difference. While both Mira and Payal prefer a disabled partner, Amit and Lalit favour a non-disabled partner. Both preferences show the importance of the us-them (disabled-non-disabled, normal-not normal) distinction in the experiences of persons with disabilities, be they in the area of education, employment or sexuality.

Given the social stereotypes and misconceptions that pervade the area of disabled sexuality and the unhappiness and trauma persons with disabilities experience on this count, one area which has received considerable attention in the rehabilitation literature is the training of professionals to manage the sexuality of persons with disabilities. Special modules and training programs have been developed to address the sexual and reproductive health needs of persons with disabilities both in domestic and institutional settings. The stigma and discrimination notwithstanding, the last survey on disability undertaken by the National Sample Survey Organisation (2002) reveals that a little over 50% of persons with disabilities are married. There is clearly a need to develop similar culturally sensitive and gender specific programs in India. Addlakha’s (2005b) work is an attempt in this direction.

The need of the hour is not only to highlight the multiple oppressions experienced by persons with disabilities and advocate for their diminution, if not total elimination, but equally importantly to draw attention to the interface between subaltern identity, normativity and normalisation. Disabled sexuality is an important doorway into this critical discourse.
(Endnotes)

1 The Ramayana and Mahabharata are the popular Hindu scriptures. Shakuni of the Mahabharata is the main instigator of the conflict between the Kauravas and Pandavas, two rival groups of brothers battling for the throne of their father, the blind king Bhishmastra. In the Ramayana, it is the maid Manthara who instigates her mistress Queen Kakeyi to insist on her son inheriting the throne contesting the claims of his elder brother born of another queen. What is interesting is that the disabled are portrayed as simultaneously loyal to their respective relatives or masters and the source of major strife and conflict within the group. Such ambivalence underwrites popular representations of disability.

2 Although the Constitution recognises socially disadvantaged groups like scheduled castes, scheduled tribes, religious and linguistic minorities and even women and children, there is a total invisibility of the category of disability in constitutional provisions guaranteeing rights to individuals and groups. Disability is absent, both from Article 15, which prohibits discrimination on grounds of caste, class, sex, religion and place of birth, and Article 16, which guarantees equality of opportunity in employment. So, while the idea of special rights accruing to groups derives from the constitutional framework which acknowledges group rights, there is no specific enumeration of the category of disability.

3 Interviewees have been given pseudonyms to protect their identities. No other identifying details have, however, been altered to preserve the authenticity of their life stories.

4 Words and phrases in single inverted commas indicate their direct usage by informants, i.e. they have not been translated from Hindi into English or vice versa.

5 National Institute for the Visually Handicapped (NIVH) is a premier government institution for education, training and pedagogy of the blind in the country.

6 The college has gained a reputation for sensitivity to the disabled and in providing services like readers and writers for visually challenged students.

7 Note the use of vision-related verbs like ‘see’ and ‘show’ by the visually challenged in situations where they are actually using other sensory modalities like touch and smell. This highlights the extent to which ordinary language is imbued with the perceptions and experiences of the non-disabled, which are in turn internalised by the disabled.

8 Hormone preparations for treatment of postponement of menses, endometriosis; dysfunctional uterine bleeding, including emergency treatment of acute episodes,
dysmenorrhoea, and other menstrual irregularities.

9 The undergraduate degree in most Indian universities involves a specialisation in a particular subject referred to as an honours degree, or studying a combination of subjects referred to as a pass degree. The use of terms like honours and pass highlight the underlying hierarchy in the undergraduate programme.

10 I am using disabled-unfriendly terms like blind here because they constitute integral parts of the proper names of these institutions. For example, Bharat Blind School located in Shahadara, Delhi.

11 Onset of provocative poliomyelitis may occur due to intramuscular injection, surgery or other trauma, when the child is incubating polioviruses.

12 The family has installed a sitting commode at home for his convenience. (The Indian style commode used in most traditional households is a squatting latrine).
References


