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Abstract

The sexuality of the disabled person has largely been ignored. If it is at all acknowledged, then it has been largely through a 'medical lens. The understanding of sexuality not only as a personal dimension of the of the individual self but also as a political act with reference to the collective is brought out in this paper. It specifically explores how the sexual and reproductive health needs and concerns of persons with disabilities have been ignored if not denied. The focus here is specifically on women with disabilities and how the added dimension of gender makes disabled women's sexuality even more ambivalent. The discussion of this paper is framed within the larger context of other interrelated domains of life like employment, education, marriage and family because it is contended that disability, sexuality and reproduction cannot be understood in isolation. The paper highlights in particular the limited space available to disabled women in the arena of sexual and reproductive choice. For instance, the phenomena of forced contraception, abortion and involuntary sterilisations on disabled women's bodies are a testimony not only to the larger social discourses of eugenics but also gross violations of sexuality and reproductive health rights of individual women. The paper argues for enlarging the private and public spaces for discussions of sexual and reproductive rights of disabled persons in societies where sexuality is still largely a taboo subject.

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Introduction

After decades of facing invisibility it is only in the recent past that issues surrounding disabled people have started gaining prominence. With its ratification of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)³ in 2007, India made a commitment to work towards changing many of its laws, policies, regulations, notifications programmes and schemes related to people with disabilities. However, not much work appeared to have been done for upliftment of persons with disabilities particularly women with disabilities, when India submitted its first country review report eight years after ratification (Singh, 2016). The last few years have seen some activity around disability legislation and policy. Launching of the Sugamaya Bharat Abhiyan (Accessible India Program), training imparted under the 'Skill India' programme has brought some visibility to people with disabilities. The enactment of the Rights of Persons with Disabilities (RPWD) Act, 2016 has further fore-fronted the needs of the disabled in the country in public policy. The last census (2011) based on seven categories of disability reported that there were 26.5 million people with disabilities in India. The RPWD Act has increased the number of categories of disability to 21⁴ which means that in 2021 census we are likely to witness an explosion in the number of disabled people in the country. The increase in numbers is likely to strengthen the position of disabled as full-fledged citizens of the country whose presence requires systemic changes in every sphere of life.

In the current scenario with several programmes related to disability as mentioned above and the enactment of the RPWD Act 2016, it appears that the political space available for discussions related to disability seems to have enlarged. A separate Department of Disability Affairs was carved out in the Union Ministry of Social Justice and Empowerment on May 12, 2012. The Department was renamed as Department of Empowerment of Persons with

3 Disability is referenced in various parts of the sustainable Development Goals (SDGs) 2015-2030 specifically in parts related to education, growth and employment, inequality, accessibility of human settlements, as well as data collection and monitoring of the SDGs.

4 Blindness, Low-vision, Leprosy Cured persons, Hearing Impairment (deaf and hard of hearing), Locomotor Disability, Dwarfism, Disability, Mental Illness, Autism Spectrum Disorder, Cerebral Palsy, Muscular Dystrophy, Chronic Neurological conditions, Specific Learning Disabilities, Multiple Sclerosis, Speech and Language disability, Thalassaemia, Hemophilia, Sickle Cell disease, Multiple Disabilities including deaf blindness, Acid Attack victim, Parkinson's disease.

Disabilities on 08.12.2014. The Department acts as a Nodal Agency for matters pertaining to disability including effecting closer coordination among different stakeholders: related central ministries/ state, union territories, NGOs etc. There is currently a national web portal on education, training, and empowerment of persons with disabilities called Punarbhava (www.punarbhava.org) which is a collaborative project of the Rehabilitation Council of India. Different state governments are organizing camps for distribution of aids and appliances, and recently the Railways has reserved the lower berth of a third AC coach in every train for disabled passengers. These developments show that there is a certain visibility of issues related to accessibility for disabled persons. Even though the driving impulse behind such measures may not be completely rights-based, but there is at least the beginning of acknowledgement of the challenges faced by people with disabilities because of social and structural conditions.

However, one area that still appears to be confusing, conflicting and shrouded in secrecy is the area of disabled sexuality, and in particular the sexual and reproductive health rights of women with disabilities. This paper attempts to explore the intersections between gender, disability and sexuality with particular reference to contemporary India.

Disability, Gender and Sexuality: Overview of Issues

Disability and Sexuality are two terms which have been automatically identified with the 'body'. Considering that both the terms have 'body' as their pivot; it is surprising that the intersections between them have for so long been ignored, or deliberately made invisible. Sexuality has more often than not been viewed in narrow terms. It is figured as the domain of the (hetero) normatively embodied (Shildrick 2004), and mainstream culture refuses to acknowledge the possibility of gender or sexuality for people with disabilities, who are presumed to either have no sexuality at all or it is regarded as perverse (Garland-Thomson, 2002). Disabled people are therefore perceived as either asexual or hypersexual. This perception stems from the inability to regard any area related to the disabled or disability as 'normal'. The understanding of sexuality in terms of sex i.e. heterosexual intercourse and reproduction is very limiting. It actually includes a very wide spectrum of potentialities and experiences like gender roles and identities, social norms and values, attitudes, sexual orientation, eroticism, beliefs, intimacy, desire and pleasure (Garcia & Parker, 2006).

Working on the issue of sexuality invariably necessitates working on sexual and reproductive health and rights as well. Good sexual and reproductive health is a state of complete physical, mental and social well-being in all matters related to the reproductive system. It means that people are able to have a satisfying and safe sex life, the capability to reproduce, and the freedom to decide if, when, and how often to do so (UNFPA, 2016). Although both sexual and reproductive rights are often discussed together, it is also important to understand the manner in which both are violated separately. Ideas related to perversion (sexuality) and eugenics (reproduction) influence the manner in which sexual and reproductive rights of the disabled are viewed. Furthermore, in order to understand the various aspects of disabled sexuality, there is a need to look at issues like sexual desires and pleasure, intimate relationships, marriage, parenting, child care, contraception, abortion and sterilizations in conjunction. For disabled people, the added aspect of disability creates new challenges in all the above-mentioned processes. And there are hardly any studies available on this sensitive topic in the Indian context.

Sexual and reproductive health needs are present throughout the life cycle. Different age groups face different challenges. For example, adolescents go through puberty and ideally require information about the changes in their bodies and emotions and age-appropriate sexual and reproductive health behaviours. Adolescents with disabilities also need the same information, but they may also need additional information concerning sexual abuse and violence due to their greater vulnerability to violations. It is important to ensure that sexual and reproductive health (SRH) services are friendly to youth with disabilities. On reaching the age for having a family, women and couples with disabilities, like everyone else, have the right to decide whether and when to have children and a right to sound, unbiased information on which to base these decisions (WHO/UNFPA, 2009: 11). Sexuality and reproduction constitute a very broad area which impact a person much beyond the reproductive years. For instance, what are the sexual needs of the elderly in general and of the disabled elderly in particular?

In our country, where issues related to sexuality are considered taboo in general; disabled sexuality constitutes a further layer of silence, exclusion and invisibility. Sexuality of disabled people is relegated to the domestic sphere (Das & Addlakha, 2001) which has particular consequences for women with disabilities. This denial increases their vulnerability to divorce, abandonment and domestic violence (Buckingham, 2011:423) as well as exclusion from

the mainstream of social life, neglect of disease (like sexually transmitted infections), mental health problems like depression and denial of a good quality of life (UNFPA, 2009). More importantly, it renders invisible the multiple forms of abuse, particularly sexual abuse which they may suffer without any recourse to redressal because of an imputed asexuality arising out of being disabled. A Report by Disabled People's International (India) and its partners stated that almost 80% of women with disabilities are victims of violence; and they are four times more likely than other women to suffer sexual violence (Masoodi, 2014). Disabled women, like women in general, are considered to be most vulnerable during the reproductive years. Realizing the importance of the intersections between violence and disability, the Centre for Women's Development Studies (CWDS) is currently engaged in a research project on this theme with a particularly focus on legal empowerment. This two-year research-cum-advocacy project is being supported by the South Asia Women's Fund (SAWF). Such projects are important for disabled women as their needs have not been at the centre of either the women's or disability rights movements. Due to their marginalised location, women with disabilities have been ignored by both the movements leading to further infringement of their rights.

Movement Discourses

While, race, ethnicity, class and caste gained importance as hierarchies of inequality within the women's movement, disability and non-normative sexuality have only recently been explicitly acknowledged as axes of women's oppression. With a few exceptions the women's movement has largely invisibilised disability (Addlakha, 2017:13). Davar (2008) has outlined the manner in which the women's movement has engaged with disability and mental illness without reference to the disability paradigm.

The invisibility of disabled women by the women's movement has also been highlighted by Ghai (2009). She argues that Indian feminist thought has failed to recognize that the problematisation of women's issues applies equally to disabled women's issues. She cites the example of a girl with cerebral palsy who was abused by her father. This was given wide media coverage by the national Indian media but women's groups only addressed it perfunctorily (ibid, 2009:420).

In a workshop organized by CWDS on Creating Bridges between Visually Challenged Young Women and the Women's Movement in 2016 a workshop

participant pointed out to the neglect of discussions on disability and sexuality in the mainstream women's movement—a disabled woman's body is not regarded as a sexualized body; the general understanding is that those with a disabled body cannot suffer from sexual harassment. While sexuality has been an important issue within the women's movement, it has been conceptualized more as a homogeneous collective identity—of upper class, upper caste and able-bodied women (Addlakha, 2017:15). According to Geetanjali Mishra⁵ of CREA women with disabilities and their concerns are nowhere in the horizon of sexual and reproductive rights. It is not in the Government's agenda. It is also not part of the agenda of disability rights activists, nor gender, sexual and reproductive rights activists (Goyal, 2017; Ghai, 2003; Thomas and Thomas, 1998).

Neither do issues of disability and sexuality find a visible space in the disability movement in India. The disability rights movement has almost exclusively focused on social change in terms of entitlements like accessible physical environment, inclusive education and reservation in employment. The movement has largely ignored the needs, wants and desires of the 'impaired body' (Ghai, 2009; Mehrotra, 2011). Failure to take into account the 'body' means that issues related to desire, attractiveness, relationships, intimacy, marriage, reproduction, parenting etc. are not given enough attention (Addlakha, 2007). This implies that sexual and reproductive health needs and desires of a large portion of the population remain unmet. In order to understand the extent of the issue in all its complexity, the next section presents a brief demographic picture of disabled persons in the country.

Demographics Of Disability

Sexuality and reproductive health needs cannot just be understood in terms of the disabled individual in isolation. Gender, class, caste, religion, place of residence, education, work status, all intersect to influence the choices that are available to disabled people to live in a certain manner. This makes it important to look at the other contextual variables to see what is happening to people with disabilities in a holistic fashion. Such an intersectional perspective also determines the person's access to sexual and reproductive health services.

The only up-to-date source of macro-level data on disability in India is the Census. The following data is culled out from the latest Census of 2011. We

⁵ Interview in the Disability News and Information Service , Volume 9, issue 5, May 15, 2012

begin with looking at the total number of disabled persons in terms of gender and place of residence.

**Table No. 1:
Number of disabled males and females in urban and rural areas**

Residence	Persons	Males	Females
Total	26,810,557	14,986,202 (55.89%)	11,824,355 (44.10 %)
Rural	18,631,921 (69.49%)	10,408,168 (55.86%)	8,223,753 (44.13%)
Urban	8,178,636 (30.50%)	4,578,034 (55.97%)	3,600,602 (44.02%)

Source: Census of India, 2011.

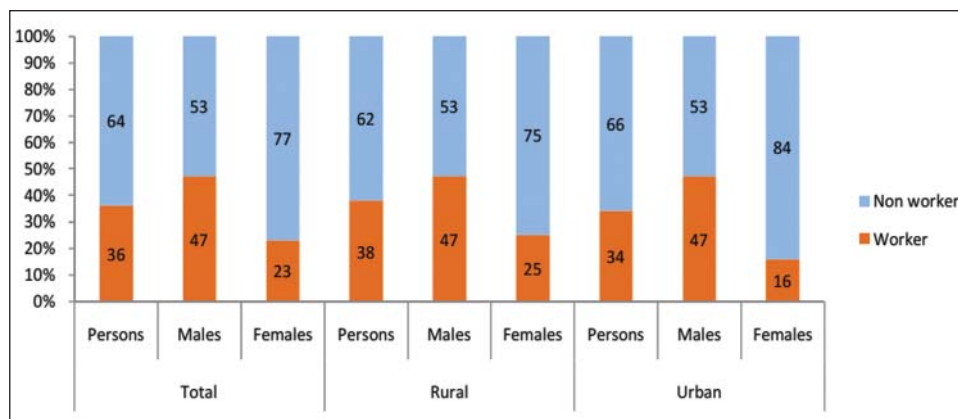
Table No. 1 shows that there are larger number of disabled persons in the rural areas. In rural areas accessibility, availability, and utilization of health and rehabilitation services and their cost-effectiveness are major issues (Kumar et.al, 2012); and therefore there is a need to understand the lives of the rural disabled in more detail. Women with disabilities in rural areas face challenges which maybe unique to them. Ghosh and Bannerjee (2017) explain how using wheelchairs can be severely limiting for girls in villages. One of the girls with cerebral palsy confined to a wheelchair found herself restricted because of the terrain inside and outside her house. The mud house surrounded by large fields restricted her access to the outside world. The authors further point to the lack of medical and rehabilitation facilities available to girls in remote areas. Parents of girls with intellectual disabilities in remote areas of Jharkhand were unable to get adequate support from professionals on how to better address the needs of their severely disabled daughters which affected the quality of life of both the girls and their parents (ibid:65).

The complexity of issues faced by women with disabilities in rural areas is brought out in Mehrotra's (2006) work in rural Haryana as well. Since there is a rigid division of work and women's manual work is indispensable in agriculture, especially after marriage, disabled women are pushed towards working like any normal individual in society. This creates a complicated picture of disabled women in rural areas. One understanding is that women are not isolated but incorporated into the household, depending on their age, type and severity of disability. Age and status within the family determine the way a disabled woman is treated. In childhood, she may enjoy parental care and support, but

is socialised in a limited fashion into the norms of womanhood. After marriage, she is put to work and this is the most strenuous phase of her life. With age, she gains more social and moral authority in household affairs. With the expansion of the family, there are more supporting hands in the form of sons, daughters, daughters-in-law and grandchildren for her social and physical support. The needs of rural disabled women find no place in the policy frameworks, and therefore they remain marginalised (Mehrotra, *ibid.*)

Mehrotra’s work in Haryana brings out the manner in which disabled women are incorporated into the household, but at the same time this also entails confinement to the household domain often leading to domestic violence. Disabled women’s labour is utilized by the family but their health and education needs are not prioritized; and many of them do not/ cannot go for regular medical check-ups. This means that efforts to make them independent are minimal. This is reflected in the educational status of disabled women in the rural areas as compared to urban areas. 63% disabled women are illiterate in rural areas as compared to 39% women in urban areas. The corresponding figures for men are 42% illiterate in rural areas and 28% in urban areas. Overall, Census 2011 reveals that among female disabled children (5-19 years), 43% are attending educational institutions, while among the male disabled children, 57% are attending educational institutions. As compared to boys with disabilities, girls with disabilities have less educational opportunities and these opportunities are the least for those living in rural areas.

Fig 1: Distribution of disabled people by work status in India



Source: Census, 2011

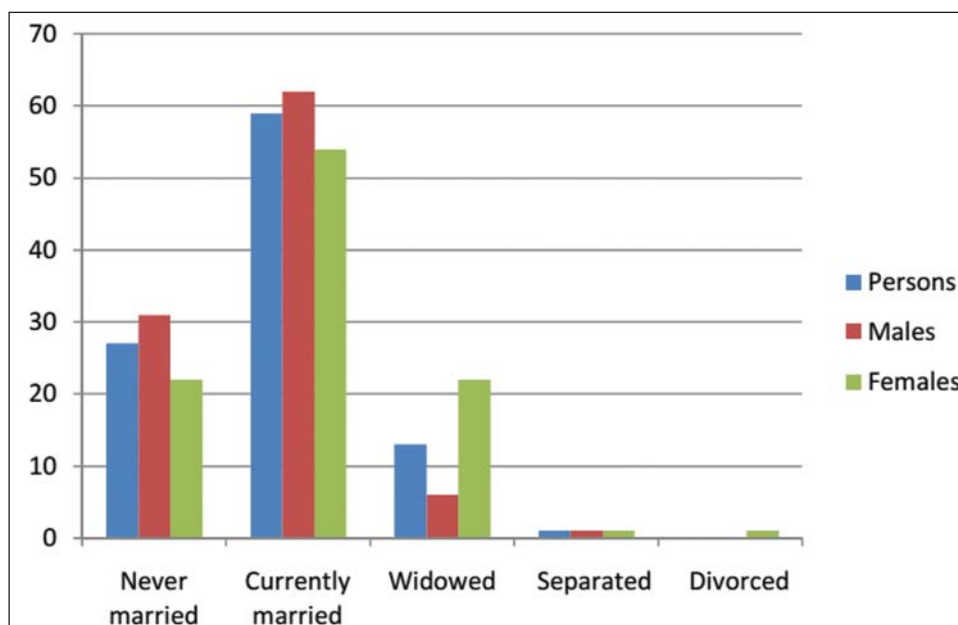
The vulnerability of rural female disabled can be seen in the work status as well (see Figure 1). Although less educated, more rural female disabled (25%) are working as compared to urban female disabled (16%). Less education reduces the opportunities for gainful work. Therefore, rural female disabled are likely to be involved in unskilled and low paid work requiring less formal training. This makes them more vulnerable to exploitation and ill health. While some may argue that rural disabled women are more empowered because of their greater participation in informal work in comparison to their urban counterparts, the conditions of work do not in any way enhance their well-being nor do they receive adequate compensation for their labour neither in cash or kind.

Overall, fewer disabled women (23%) are working as compared to disabled men (47%). Deprivation of education and work opportunities lead to increased isolation and vulnerability of disabled women. This in turn reduces their ability to access their sexual and reproductive health rights.

Another indicator of access to sexual and reproductive health is the marital status of the individual. Since within the Indian context marriage is the legitimate space for living out sexual needs and desires, married people are expected to have access to sexual and reproductive health information and facilities. Figure 2 presents data on marital status of disabled persons from the Census.

Figure 2 shows that out of the total disabled population 59% are currently married and 13% are widowed. Among the male disabled, 62% are currently married and 6% are widowed while for female disabled, the corresponding figures are 54% and 13% respectively. In terms of divorce (only figures for disabled women are available (less than 5%). Women with disabilities, who are never married, widowed, separated or divorced are less likely to have access to sexual and reproductive health knowledge and services as compared to currently married disabled women. Disabled women find it harder to find suitable partners and marry; this leads to a large percentage of disabled women with lack of or inadequate access to sexual and reproductive health knowledge and services. Disability often leads to a denial or repression of sexual and reproductive aspirations by disabled women themselves. Negative body-image is another factor which has an impact on disabled women's ability to find suitable partners. The impact of societal messages regarding disabled bodies on the body and self-image of women with disabilities is explored in the next section.

Figure 2: Marital Status of Disabled Persons (15+ years) in India



Source: Census, 2011

An important source of information on reproductive health knowledge and access to services is provided by the National Family Health Survey NFHS (3 Rounds: 1992-93, 1998-99, and 2005-6)⁶ data. Questions on sexual and reproductive covered married women and youth, which may have included disabled informants. We can look at some of the main findings related to sexual and reproductive issues from NFHS 3 (2005-6) which would be largely be equally applicable to people with and without disabilities. Employed married women with decision-making power in their households in financial matters are more likely to be using a modern contraceptive method in comparison to women who are not employed. Controlling for education, wealth, residence, and children ever born, women who have earnings and women who make decisions alone about large household purchases are more likely to be using modern contraception. While knowledge of modern contraceptive methods like

⁶ Kishor, S and Kamla Gupta (2009). Gender Equality and Women's Empowerment in India. National Family Health Survey (NFHS-3), India, 2005-06. Mumbai: International Institute for Population Sciences; International Institute for Population Sciences; Calverton, Maryland, USA: ICF Macro.

sterilisation, the pill, condom or IUDs among both men and women was found to be quite high, knowledge about the emergency contraceptive was less than 20%. Interestingly, the reported use of traditional contraceptive methods like rhythm was less than 5%. When it comes to STI (Sexually transmitted Infections), including HIV/AIDS, knowledge about risk factors was considerably higher among men.

Although we do not have separate data for disabled women, these findings have relevance for them. Since very few disabled women are working (as seen in Figure 1), they are less likely to have knowledge and access to modern contraceptives. Secondly, since education of mothers is positively related to ensuring their children's immunisation, disabled mothers who are illiterate may not be aware of/or not be able to ensure full vaccination of their children. This can further reinforce the myth that disabled women have disabled children as they may not be able to complete the recommended immunization schedule for their children.

The NFHS data also shows that access to sexuality related information amongst youth is not complete. Most of the data is only available for married youth. Information on sexually active unmarried male youth is available to an extent, but the same remains unavailable for female youth as more than half of the females in the age group of 15-24 were found to be married. Among the unmarried youth 12% of the men and only 1% of the women reported having sexual intercourse. Living in a society where sex without marriage is considered taboo, young women may be reluctant to reveal information about sexual activity which may explain the low figures.

Therefore, official data on sexual activity of both women and youth is largely restricted to married populations.

Embodiment Of Disability

For women with disabilities the imperfect body comes to signify absence of femininity; since they may not look like 'normal women' and their bodies may not function like 'normal bodies'. In some respects, they may not be able to take on the roles of normal women without support, and hence they may be regarded as less than women. Sexuality, conjugality and motherhood are associated with normative, desirable, fertile bodies, whereas the disabled body is regarded as defective, undesirable and, thus, devalued (Vaidya, 2015). These viewpoints exist even though several studies and work by disability rights

activists clearly bring out the fact that young disabled women are interested in and feel themselves capable of following the hegemonic standards of beauty. Limaye (2008) shows out how two adolescent girls with hearing impairment understood the impact of their physical attractiveness on others and tried to enhance their looks by wearing good clothes and sporting different hairstyles. Disabled activist and writer Malini Chib (2015) speaks about how personal and sexual needs of disabled women are hidden and ignored as they do not match the notions of a 'normal' feminine body. She adds that that they are socialized into feeling ashamed about their bodies, and thus they themselves come to deny their sexual needs and feelings.

[However, in reality,] disability does not hamper a person's emotional need to be touched and loved on an emotional and physical plane just like everyone else. Our sexual organs are not damaged or affected, and hence we do long for and are able to enjoy pleasurable sexual experience. (Chib *ibid* cited in Vaidya, 2015:521).

These pleasurable sexual experiences as well as relationships are important for disabled women as they are signifiers for other things. Liddiard (2014) cites an example of a 21-year-old recently-single woman with a congenital impairment, who said: '...being in a relationship is a constant reassurance in my worth as a person and a woman' (*ibid*: 120). Therefore, the intimate relationship could serve as a space to embody (gendered) desirability, contradicting dominant cultural representations of disability and the impaired body as both degendered (Shakespeare 1999, c.f Liddiard, 2014) and monstrous (Shildrick 2002, c.f Liddiard, 2014). Her study also reveals how for disabled people being in an intimate relationship signifies a certain amount of 'normalcy', i.e they are like others capable of establishing affectionate and loving relationships.

Existing patriarchal ideology ensures that there are more privileges for men with disabilities than women with disabilities. The position of disabled men is considered to be better than disabled women as they can be seen as economically productive and have more options for education, work and marriage. Addlakha's (2007) work with youth on body, sex and marriage brings out the sexual and marital hopes and desires of young women with disabilities. The young visually disabled women interviewed, who are independent, look for and form relationships with other visually disabled young men who they believe will be more understanding of their situation. The young men in her study, on the other hand, preferred non- disabled partners. Similar findings

were reported by Limaye (2008) wherein hearing impaired girls preferred to choose a disabled partner as they felt that they would be accommodated more easily by a disabled man and his family. These concerns about accommodation are comparatively less for disabled men because of patriarchal advantage. For instance, patrilocal residence makes disabled women more vulnerable as they are the ones who have to make adjustments to a new environment after marriage.

Entering into a relationship is intrinsically linked to an individual's self-esteem. A high level of self-esteem often goes hand in hand with a strong sense of autonomy. In the United States, Bernert's (2011) and Bernert and Ogletree's (2013) study of 14 women with intellectual disability aged 18–89 showed that most of the women have a strong sense of autonomy⁷, and for many of them this includes expectations of sexual autonomy⁷. However, their expectations were often thwarted by their male sexual partners, and by service providers and their families, all of whom placed restrictions on what the women could do, where they could go, and who they could have relationships with. Bernert and Ogletree (2013) describe how most of the women with intellectual disability in their study had negative perceptions of sexual activity, with only two of the 14 saying that they got any pleasure out of it. A study in Bangladesh with disabled women among the 368 respondents, 231 (62.8%) reported that their first sexual experience was with a man (none of them reported having sexual relations with a woman), 131 reported that they had never had sex, and 6 women refused to answer the question related to sexual experiences. When they were asked to share their first sexual experiences, 41.3% reported that they had wanted to have sex with their partners, while 13% reported being forced by their partners to have sex. 5.7% were tricked into sex, while 2.7% had sex without wanting to (CREA, 2009).⁸

Overall, the intimate relationships of disabled women are such that there are marked asymmetries between needs and desires, and levels of knowledge of sexuality and reproduction. The lack of knowledge about sexuality results in confusion, guilt and silence affecting their self-esteem and capacity for sexual self-actualisation (Nisha, 2013). The common belief that women are

7 In the study, autonomy was defined as data relating to a sense or an act of independence. The authors cite the example of a disabled women who said, "It's my life, not [theirs]," when talking about her family's disapproval of her sexual activity (Bernert, 2011: 133).

8 Sexual autonomy included the right to initiate sex with a partner or planning for sexual activity, initiating and ending intimate relationships and refraining from intercourse while choosing abstinence (Bernert and Ogletree, 2013: 246)

not supposed to have sexual desires combines with the myth that people with disabilities are not sexual and creates a severe barrier to both information and self-expression.

The next section explores the difficulties faced by disabled women even when they are able to follow the 'normative' trajectory of marriage and motherhood.

Marriage And Motherhood

Disabled women who are married and become mothers are often not provided adequate support to fulfil the social responsibilities related to the assigned roles. Ghosh (2010) argues that disabled women are not trained to carry out the traditional gendered roles in Bengal which prevents them from performing the roles of a wife and mother as they have no training for them. This lack of skills is not always because of a disability but because of overprotectiveness by parents during the early years. Domestic, procreative and maternal roles are denied to them as they are perceived as someone always in need of care. But in a country where social security comes about through marriage; this institution is then also highly aspired for by disabled women. Because of their disabled status marriages for them may often be solemnized with men, who in alternative circumstances would not be counted as ideal grooms for the women had they been non-disabled (Satapathy, 2016). If a disabled girl (or her family) is unable to garner adequate resources for her wedding, then compromises on who she can get married to must be made, for example An ailing man, much older man, widower, a disabled man. For disabled women the lack of choice is further compounded by the fact that they are unable to conform conventionally to the norms of being able-bodied, beautiful and efficient homemakers. Nagchoudhuri et.al (2014) conducted a study with women having different types and severity of disabilities. They found that disabled women spoke about having limited choices for marriage partners – the most common option of a partner being a disabled man usually more severely disabled than the woman herself.

Limaye (2008) brings out the dilemma when deaf girls face the challenge of choice of a spouse. If they wish to marry another disabled person, the families oppose the choice as they feel that two disabled people would not be able to manage household and family responsibilities. Children can be taken away from disabled persons, as they are not deemed fit and responsible enough to

be parents. Disabled women face discrimination in the adoption process as well, in the provision of foster care and in getting custody of their children after divorce (Nisha, 2013).

Constant infantilization and regulation by non-disabled others prevent the development of a healthy self-esteem leading to devaluation of sexual selves of women with disabilities. Gartell et al (2017) in their work with women with visual impairment in Cambodia bring out how disabled women believe that marriage will happen for them depending on men loving them. They feel this is an unlikely possibility because men do not see them as attractive or desirable women who are capable of productive and reproductive work of mothering. Women with disabilities do not consider themselves beautiful on account of these negative gender and disability specific norms.

"I'm a person with disability ... no one sees [is attracted to] me ... they think that I can't do much work ... so nobody wants me and my appearance looks bad ... they only want to marry pretty girls who are not disabled." (35 year old interviewee, single woman with mobility impairment, c.f Gartell et al, 2017:35)

Women with disabilities internalise the societal messages about being unfit mothers because they have been made to feel it is they who are in need of perpetual assistance and incapable of taking on the role of a carer. Being an unfit parent is not restricted to disabled women. Men with disabilities face some challenges as well. They face the challenge of hegemonic masculinity which rests on the negation of vulnerability, weakness, and ultimately even of the body itself. Masculinity as an ideological and psychological process is connected to prejudice against disabled people in general (Shakespeare, 1999). Disabled masculinity is a different experience of masculine identity to that of non-disabled men. Disabled men do not automatically enjoy the power and privileges of non-disabled men, and cannot be assumed to have access to the same physical resources. Moreover, masculinity may be experienced negatively in a way which is rare for heterosexual non-disabled men (Addlakha, 2007). These biases towards disabled women and men get exacerbated when they attempt to become parents. This section has presented some of the difficulties' that disabled persons face with regard to parenting. The next section explores another issue related to disabled parenting- decisions about what kind of children can be brought into the world and who is eligible to be a parent in the first place.

Disability and Parenting

In terms of sexual and reproductive rights, disability based selections seem to be of two major kinds - selection of children as well as selection of parents. We will first look at the selection of children and then explore the area of selecting parents which is then related to beliefs about disabled sexuality.

Selecting Children

Disabled people have largely possessed a medical identity, perceived from a predominantly health and welfare perspective (Ghai, 2009:415). According to her, the Indian government policy stance reflects a bias towards the medical model (focussing on genetics and birth defects). Societal ethos also seems to reflect this bias as disability related selection (i.e birth of imperfect children) does not create the same kind of outrage or response as sex selection of a foetus. While there is an ongoing discussion of the ethical contradictions that prenatal testing for finding out the sex of the foetus poses for feminism, prenatal testing to identify and abort children at risk of disabilities does not get squarely addressed in feminist discourse (Menon, 1996, c.f Ghai, 2009: 418).

Currently, many parents are using assisted reproductive technologies (ARTs) for giving birth and planning families. Wherever possible, the technologies are being used for disability selection as well. According to Ouellette (2015) disability scholars have come up with four related arguments critiquing the prevention of birth of babies with disabling traits. First, the purposeful use of technology to prevent the birth of a disabled child expresses discriminatory negative attitudes about disabling traits and those who carry them (Parens and Asch, 1999) Second, disability-based selection signals intolerance of human variation, which causes harm to parental relationships with children. (ibid) Third, selection against disability through pre-implantation screening and selective abortion is based on, and perpetuates, misinformation about the lived experiences of children with disabilities and their families (Sulman, et.al, 2007; Saxton, 1997, c.f Ouellette, 2015). Finally, disability selection reduces individuals with disabilities to a single trait, diminishing and eliminating their value as full human beings (Parens and Asch, 1999).

Ouellette (2015) in her paper brings out the manner in which legal and medical forces in the United States worked together to prevent both the birth of and reproduction by people with disabilities. She argues that both have

been linked based on the belief that disabling traits are heritable; eugenics laws allowed physicians to involuntarily sterilize those individuals deemed “defective” in order to prevent the birth of babies deemed “defective (ibid: 216).

Within the Indian context Ghai and Johri (2008) have explored the concept of prenatal selection. They argue that since disability is embedded within the medical model, the availability of reproductive technologies, such as prenatal diagnosis is considered a blessing that may pre-empt and consequently prevent congenital disability. Most medical professionals advise parents to abort the disabled foetus without discussions related to information on the nature of disability, its severity and the possibility of raising a disabled child.

Selecting Parents

Continuing the stigmatisation of the disabled in reproductive areas is the disqualification of disabled persons particularly women with disabilities as parents. Disabled people are not considered to be competent parents. As mentioned above the automatic presumption of genetic transmission of disability leads to societal pressure (family, medical personnel) on the disabled to avoid any reproductive activity. Thomas (2009) highlights the manner in which disabled women face social barriers in the form of attitudinal, ideological and the material (poor support during pregnancy from health and social care workers) hindrances in their reproductive journeys. She argues that disabled women have to prove that they capable of being ‘good -enough’ mothers as society often considers that they may not have the skills to bring up children (ibid: 269).

This disabilist ideology is reflected in the manner in which disabled women’s pregnancies are often addressed. Various judgements show how decisions related to continuation or termination of pregnancy by disabled women are not individual decisions but are more in the nature of system driven decisions. This is because there is an underlying assumption that disabled women, especially those with psychosocial and intellectual disabilities, do not have the capacity to make correct judgements about their parenting abilities .For example, Suchita Srivastava & ANR. Vs Chandigarh Administration (C.A.NO.5845 OF 2009 @ Petition(s) for Special Leave to Appeal (Civil) No(s).17985/2009) dealt with motherhood of a young girl with intellectual disabilities. The girl was staying in a Government-run shelter home where she was raped there. She showed

reluctance to terminate her pregnancy even though the authorities of the home wanted her to go in for an abortion. Eventually, she was allowed to continue with the pregnancy when the case reached the Supreme Court. Apart from the unwillingness of the girl to abort the child, one of the main reasons for allowing the pregnancy to continue was that by the time the final judgement came the statutory limit for terminating a pregnancy, i.e. 20 weeks, was fast approaching, and conducting an abortion at that late stage of pregnancy could have harmed the mother (section 3, Medical Termination of Pregnancy Act, 1971).

This ideological bias towards curtailing parenting by disabled persons is affecting the manner in which assistive reproductive technologies can be utilized by disabled couples, who are discouraged from engaging in reproduction in the first place. This discrimination is now being called the new eugenics (Ouellette, 2015). This is reflected in how ARTs are denied to the disabled. Judith Daar (2008) observed, "While the eugenicists of a century ago coerced the 'feeble minded' into surrendering their reproductive capacity through forced surgeries, today's practices act to deprive the disempowered of their capacity to reproduce by withholding the means necessary to produce a child (ibid, c.f Ouellette, 2015: 218).

The project of preventing the birth of children with disabilities then gets linked to ensuring that the disabled do not procreate. This is reflected in bias against disabled women engaging in sexual activity, having intimate relationships and marrying. As women with disabilities are considered less eligible marriage partners, they are more likely to live in a series of unstable relationships, and thus have fewer legal, social and economic options should these relationships become abusive. They are less likely to receive general information on sexual and reproductive health and to have access to family planning services. But should they become pregnant, they are also less likely than their non-disabled peers to have access to prenatal, labour and delivery and post-natal services. Physical, attitudinal and information barriers exist to ensure this (WHO/UNFPA, 2009: 10). For disabled persons, there is a general lack of information per se on sexual and reproductive health, and wherever available, the form in which the information is available is such that it remains inaccessible to persons with various types of disabilities like hearing and vision impairments.

Several studies have been conducted internationally to show the information deficit regarding sexual and reproductive health needs of disabled women in local contexts. For instance, in a study in Ghana deaf women revealed the

difficulties they had in understanding sexual and reproductive health issues and in accessing sexual and reproductive health services in public health centres. The insensitive behaviour of the staff and lack of support meant that deaf people often choose not to access the available services (Mprah et.al, 2017).The stereotypes related to disabled sexuality and parenting then get articulated in the form of discriminatory professional attitudes towards disabled mothers. The attitudes of health and social services professionals can actually deter disabled parents from asking for practical assistance because there is a fear that their children will be taken away from them(Morris, 1998).

Less accessibility to sexual and reproductive health services also makes disabled women more vulnerable to abuse. Different accounts presented in the next section reveal the manner in which disabled women's bodies are abused as a result of existing stereotypes.

Sexual and Reproductive Violence and Abuse

Negative perceptions about their bodies such as absence of aesthetic, productive and reproductive value are internalised by disabled women which further reduces their sexual agency and makes them vulnerable to abuse and violence. Access to sexuality may not always be a positive experience. Findings suggested that sex is generally a negative experience for the women with intellectual disability, primarily due to few dating options, a very limited sexual repertoire that focuses on penetrative sex, and a high level of sexual abuse (McCarthy, 2014; Fitzgerald & Withers, 2011). According to Fitzgerald and Withers (ibid.) disabled women are unable to talk about or recognize their own desires as they are regulated, infantilised and controlled by parents, carers and others. They are sometimes unable to recognise that they are 'proper' women at all. This also leads them to accede to the desires of men without question (ibid).

Apart from the context, the type and severity of the disability also exert an impact on disabled women's lives. Women with intellectual and psychosocial disabilities face more marginalization because of greater communication difficulties and stigma. They may be exposed to severe violence and abuse in the guise of protection. Adequate and accessible information about appropriate sexual behaviour and sexual and reproductive health to ensure prevention of abuse is not provided. Instead, their bodies are manipulated to remove signs of abuse. This is evident in several cases where hysterectomy is used

as a method to prevent pregnancy in case there is sexual abuse. In 1994, forced hysterectomies were conducted on several women with intellectual disabilities between the ages of 18 to 35 at the Sassoon General Hospital in Pune. The hospital authority explained that those women were incapable of maintaining menstrual hygiene. Moreover ensuring menstrual hygiene of inmates was perceived as a burden on their resources and time by the hospital staff (Badjena, 2014). Forced sterilisation was seen as a way to manage menstruation and the consequences of sexual abuse, i.e., unwanted pregnancy. Forced sterilization within institutions and by family is common though it is a human rights violation (Phadke, 1994). Despite GR.No. 24 of the United Nations Convention to Eliminate all forms of Discrimination against Women (CEDAW, 20th Session) 1999 there was hitherto no explicit legal provision that prohibits non-consensual sterilization. Such a prohibition has only been brought into the new disability law in 2016.

In recent years instead of teaching women to manage menstrual hygiene and protecting them from rape, sterilization methods using certain drugs are being tried out on a large scale (Women with Disabilities Network, 2013). This is especially true for women with disabilities living in institutions where living conditions are very poor. In 2014 a report by Human Rights Watch found that in 12 of the 24 institutions visited, residents or staff exploited women and girls with psychosocial or intellectual disabilities, forcing them to cook, clean toilets, or bathe other women with more severe disabilities. In the course of its visits to institutions, Human Rights Watch found 12 cases of verbal, 38 of physical, and four of sexual violence against inmates. Thirty-five of the 68 women and girls interviewed had either experienced sexual violence or had multiple partners. However, unless they were previously involved in sex work, staff in 15 institutions told Human Rights Watch (ibid) that women and girls with psychosocial or intellectual disabilities living in institutions do not have information about or access to testing and treatment for HIV/AIDS and other sexually transmitted diseases. Not only are the women vulnerable to abuse; they also do not have avenues to seek help. Inmates told Human Rights Watch that they seldom report abuse against caretakers and fellow residents for fear of adverse repercussions. In the 24 institutions and hospitals visited, there were no mechanisms to report abuse. Most of these women came from lower socio-economic background and often had little social support. The findings of the above study can be applied to women having physical, sensory, communication and other kinds of disabilities in other residential institutions

like special schools, shelter homes and women's hostels.

It is only through studies done by various organizations (national and international) that we are able to obtain some figures about violence against women with disabilities. Within the government structures very little information is available. Disaggregated figures related to violence against disabled women are not available from National Crime Records Bureau or the National Commission for Women (Nayar and Mehrotra, 2017). This may not be surprising as Valliappan) points out,

"It is not possible for someone like me to receive education, employment, marriage, hold an office or sign any documents according to the Contract Law. The Hindu Marriage Act considers someone like me of unsound mind irrespective whether I am someone who can function in daily life" (2015:7).

Goyal (2017) argues that interference (for example forced abortions, sterilizations and hysterectomies) with the bodies of disabled women does not cause the same kind of outrage which would have come about if this had happened with non-disabled women. These examples bring out the manner in which sexual and reproductive health rights of disabled women remain invisible and unrecognized.

Engagement with the Public Health System

The refusal to recognize the sexual and reproductive rights of disabled persons also gets reflected in the public health systems. Because of having or living in a body which has different needs and requirements, disabled people often have long term contact with the health systems. Accessibility to the public health system is something which is essential for both women and men with disabilities. The contact maybe more during childhood and old age as the specific health and development needs during these periods may require an intense engagement. During the reproductive life span the contact is less and therefore the information that disabled people receive related to sexuality and bodily changes could come from unreliable sources (peers, media) or people may receive no such information at all.

Even when information is received from within the public health system, information on sexuality may be largely shaped by the medical discourse. Professionals from medical, psychological and sexological backgrounds dominate the discourse. The voices and experiences of disabled people are absent in almost every case. A medical tragedy model predominates, whereby

disabled people are defined by deficit, and sexuality is either not a problem because it is not an issue, or is an issue because it is seen as a problem (Murphy, 1987). Diamond (1984) has suggested that sexual issues are perceived as less important than rehabilitation priorities which is why society is unwilling to engage with disabled people's sexuality. Families also try to ignore the issue of sex: 'while they recognize that these are valid concerns, they generally wish the sexual concerns to be ignored (ibid: 210). 'Studies confirm that doctors are far less likely to ask women with mobility and other physical impairments routine questions about reproductive health than they are other women. Even explicit requests for routine reproductive health services like pap smears and mammograms are sometimes denied (Ouellette, 2015:217).

In viewing sexuality and disability from only the 'medical lens' there is a danger of forgetting that sexuality and sexual status of a group are also reflective of their social, economic and political status as they determine the range of choices available to them. The relationship between sexual and reproductive choices and political status has been acknowledged by international bodies like the UN (1993). According to Standard Rules on the Equalization of Opportunities for Persons with Disabilities

'States are supposed to promote their right to personal integrity and ensure that laws do not discriminate against persons with disabilities with respect to sexual relationships, marriage and parenthood. Persons with disabilities must not be denied the opportunity to experience their sexuality, have sexual relationships and experience parenthood (Article 23, Rule 9, p.28).

However, in spite of this formal recognition of sexuality as a part of human rights, there is an enormous gap between what is advocated by international declarations and the reality faced by disabled persons in their daily life (Deepak, 2002). In the everyday lives of disabled people there is a tendency to emphasize interventions which are aimed at limiting their sexual impulses rather than helping them to acquire living skills for expression of their sexuality (Veglia & Zoccorato, 1999, c.f Deepak, 2002). Parents; concerns for safety often lead to a child-like and regulated existence beyond the years of childhood. In his study on sexuality and disability in Italy, Deepak (ibid.) found that a majority of his informants reported overprotectiveness by parents and fewer opportunities for sexual experiences. Unsurprisingly, female disabled participants reported more restrictions as compared to male disabled (ibid: 69).

This discussion of disability and sexuality reveals that a combination of micro factors related to attitudes of family members, peers, professionals along

with macro factors related to disability policy, health systems may be working in tandem to restrict the avenues available to the disabled for expressing their sexuality. The next section deals with some of the ways in which the myths, stereotypes and negative attitudes towards disabled sexuality can be addressed.

Countering the Intersectional Disadvantages

Disabled women with a negative body image, lower self-esteem and consequent limited sexual and social agency have fewer opportunities for social integration. The ability to have healthy relationships has several protective factors. In a study with disabled women in Cambodia, Gartrell et.al (2017) found that women with disabilities who had never married, did not have children and other social support experienced the greatest vulnerability and were most at risk of violence, poverty and social discrimination (ibid: 37). When the needs and desires of disabled women become invisible, then they are less likely than other young people to be informed about conditions like HIV/AIDS and to access necessary prevention and treatment interventions. Misconceptions that persons with disabilities are not sexually active frequently lead to their exclusion from HIV education, prevention and support services (Nampewo, 2017). Such research highlights the great need for sexual and reproductive health information. Information about sexuality also includes making people aware of their sexual rights and providing them with a space to articulate their needs and desires.

Burke et al (2017) found that currently information about sexuality is received from peers and friends; in some cases disabled women got information from their sisters. Other places from where information is accessed include local public health centre or hospital. They also found that disabled women fear being seen accessing SRH services. Other barriers include provider attitudes, parents' attitudes, and physical inaccessibility and communication barriers (for those with hearing impairments). To a lesser extent marriage status, religion and lack of information about where to access SRH services were also mentioned (ibid: 49).

Worldwide, different programmes are being introduced in order to make SRH services available to disabled women. There is widespread recognition of the need to increase access to SRH information and services for young women with disabilities. These services have to be provided in an enabling

environment which ensures privacy and anonymity. Inclusion of community health workers and peer educators would be important in delivery of the services. As mentioned in the study by Burke et al (2017) attitudes of service providers makes a big difference in the manner in which disabled women can access SRH services. This makes it important to provide adequate training for service providers. Services providers must be sensitised about the sexual and reproductive health needs and rights of people with disabilities. People working directly with disabled women require training to impart sexuality education and SRH services. This includes training to communicate effectively with women with different kinds of disabilities, knowledge about referrals and so on.

Within the Indian context Goyal (2017) describes how some organisations like Point of View (Mumbai) are conducting workshops with persons with disabilities. This includes women with visual hearing and or speech and locomotor disability. Most of the women belong to lower middle class/working class backgrounds. They come from both urban and rural areas. In the needs assessment surveys prior to the workshops, it's found that that there is little knowledge about sexuality even among disabled people who attended disability organisations rehabilitation, day-care and skill-building courses. This information is seldom considered important and definitely not prioritised, even in trainings that focused on self-development. During the needs assessment phase, it was found that information on menstruation, puberty and violence and abuse was considered important, whereas information on pregnancy and childcare, pleasure and desire was considered least important.

For women with disabilities, the constraints of gender norms in their cultural contexts created difficulties in accessing information related to sexuality. Goyal (2017) outlines how workshops were organized in Maharashtra (Mumbai, Nagpur, and Pune), Gujrat (Ahmedabad), Uttar Pradesh and Karnataka the following topics were covered: -

- Information on the body, including reproductive organs and pregnancy, as well as on sex, contraception and sexually transmitted infections (STIs);
- Myth busting on sexuality and disability;
- Relationships, choice and consent;
- Understanding gender and gender roles;
- Abuse and violence (ibid: 139)

Similar research needs to be conducted in other parts of the country to enable us to understand the true extent of the issue and the needs and vulnerabilities of disabled women. Based on the assessment of needs it is important to conduct workshops on the issue of sexuality with the disabled young men as well as with service providers who the young people come in contact with. It is the service providers who are often the first contact for people with disabilities when they attempt to access health care for various reasons

Even through international instruments like Standard Rules on the Equalization of Opportunities for Persons with Disabilities (1994), Convention for Elimination of Discrimination Against Women (1979)⁹ confer equal rights on sexuality for disabled people, not enough is being done by the government and civil society to ensure access to these rights. There is a need to create an enabling environment wherein disabled people have access to information and space to articulate their concerns related to sexuality and reproduction. In order to do so it is important to collect disaggregated data related to sexuality and reproduction. Based on this data, awareness programmes for all the stakeholders need to be designed and implemented which would enable disabled women in particular to access SRH services.

Conclusion

The manner in which disabled sexuality is viewed can almost be considered an oxymoron. Sexuality is largely a forbidden subject in the public domain. It has been narrowly defined and framed largely in the discourse of sexual intercourse. When the dimension of disability is added to sexuality it becomes even more difficult to talk about the area. Add to it the additional layer of being a woman and the taboo becomes even stronger. A woman, disabled and sexual?

Sexuality has always been confined to personal spaces. The fact that it has a public and political dimension is only just getting acknowledged and this paper has attempted to consolidate that perspective. Such a viewpoint has been built on the framework that sexuality is a broad term impacted by the social position of the individual. Sexuality of the disabled woman is an intersectional topic for the disability rights movement and women's movement and has hitherto been

⁹ CEDAW General Recommendations No. 19 (11th session, 1992) and General Recommendation No. 21 (13th session, 1994)

largely ignored by both. This has led to the denial of sexual and reproductive health rights of disabled women leading to an increased vulnerability to sexual abuse and violence as explored in the paper. The beliefs related to disability including its possible eradication influence the discourses around disability and sexuality. The Ideas emanating from such discourses imply that a disabled person cannot be seen as a whole person. Somehow, disabled lives are always considered unworthy and unfulfilling. Public and political opinion/ policies then attempt to ensure that such lives remain unfulfilled by imposing restrictions on those labelled as disabled. Furthermore, the idea that, it is possible to eradicate disability by preventing disabled persons from engaging in procreation is woven into such configurations. The reality is that only a very small number of disabilities have genetic moorings. (Less than 2%). Majority of disabilities are acquired due to infections, accidents, environmental factors, chronic diseases and of course ageing. But disabled persons particularly disabled women are presumed to be the carriers of disability, and society creates a plethora of barriers to prevent them from marrying and becoming mothers. For women with disabilities fighting for the right to exist, poor awareness of their bodies, few opportunities to have relationships (any kind of intimate relationships) and marriage, having children and vulnerability to violence create an overwhelming narrative of a highly impoverished and poor quality of life. Through exploring different demographics this paper has highlighted how the social position of the disabled women (in terms of caste, class, region, religion) have an influence on their quality of life and relationships. But narrative of a difficult life can be modified by bringing about changes in the public sphere and ensuring that public and political spaces are flexible through reasonable accommodations. On the other hand, where there is resistance, there is agency, and more empirical studies are required to highlight the sexual experiences, challenges and even opportunities that disabled people, especially disabled women, may create for sexual and reproductive fulfilment in the midst of overwhelming odds.

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