



SEXUAL RIGHTS OF WOMEN WITH PSYCHOSOCIAL DISABILITIES:

INSIGHTS FROM INDIA

Ketki Ranade and
Anjali—Mental Health Rights Organization

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Ketki Ranade and Anjali—Mental Health Rights Organization

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SEXUAL RIGHTS OF WOMEN WITH PSYCHOSOCIAL DISABILITIES: INSIGHTS FROM INDIA

Ketki Ranade and Anjali—Mental Health Rights Organization

FROM MENTAL ILLNESS TO PSYCHOSOCIAL DISABILITY: A DIFFICULT PROPOSITION

There are multiple, sometimes uneven, but often related ways of conceptualising and talking about suffering and illness. The most predominant model among these conceptualisations is that of bio-medical psychiatry. Psychiatry with its tools of classificatory and diagnostic systems expresses the narrative of distress through the language of mental illness and medical treatment and management programmes for the same. There are other narratives of psychological, interpersonal, social and psychosocial origins of distress that use tools of psychometric testing, psychotherapy and a range of counselling and rehabilitation services. Whether these approaches locate individual problems within brain dysfunction, dysfunctional personality structure, familial dynamics, or social position, they are all focused on managing and reducing symptoms, distress, or deficit. The broad term “medical model” is used to describe this range of approaches, which views individuals with impairments as deficient and conceptualises disability as something to be fixed, cured, treated, or rehabilitated. The core belief within this model is that with adequate and appropriate support, persons with disabilities can lead “near-normal” lives, i.e., as close as possible to what is regarded as the social norm (Gibson 2011).

The social model of disability, particularly as conceptualised in the United Nations Convention on Rights of Persons with Disabilities (UNCRPD, adopted in 2006) moves away from the medical model and the social welfare approach of viewing persons with disabilities as passive recipients of services. It is primarily centred on the principles of autonomy, dignity,

and equality. The core belief here is that human beings come in an infinite variety of characteristics (Gibson 2011) and impairment is seen as “infinitely various but a universal feature of the human condition” (Bickenbach [in Gibson] 2011, 13). While impairment is understood as a problem in body function or structure, including mental ones, disability is seen as emanating from social stigma, stereotypes, and discrimination that act upon the individual. Thus, disability originates from social restrictions and not from biological features (Jaramillo Ruiz 2017).

What can this shift from a medical model of mental illness to a social model of psychosocial disability give us? First, the medical model locates pathology within the individual and sees it as an individual failure to cope, and as a result, frames the treatment as focused upon the individual who in turn has to take responsibility for the remediation, treatment, and the process of recovery and maintaining wellness. On the other hand, the social model of disability holds the environment accountable to accommodate difference and impairment. Thus, change and onus of this change is not any more on the individual but on the system. This does not however mean that individual impairment or disturbance is overlooked or that environmental accommodation would mean that impairment completely disappears. However, by moving beyond a restrictive focus on symptom management, the language of psychosocial disability opens the possibilities of talking about lived realities and rights of persons with psychosocial disability that is not merely restricted to the right to healthcare. Another gain that the framework of disability provides is that articulations of lives of persons with psychosocial disability is no longer determined by expert knowledge and language. This is very well captured in the slogan of the disability rights movements—“Nothing about Us without Us,” implying unconditional participation of persons with disability in knowledge making, policy making, and programme planning

and implementation. Thus, a shift from mental illness to psychosocial disability is not just a shift in language but a shift in perspective and praxis.

The question then is whether this shift is viable in the context of India. There is no straightforward yes-or-no answer to this one. The policy, programme, and legal environment in the country currently is entrenched in questions of care and treatment. One of the many reasons for this is the sheer magnitude of impairments caused by psychiatric and addictive disorders and issues such as self-harm and suicide affecting young people (National Institute of Mental Health & Neuro Sciences [NIMHANS] 2016, Naik 2015; World Health Organization [WHO] 2003). In India, the medical model with its bio-psycho-social solutions is the most predominant one. The relevant question then is, whether it is possible to address impairments, while upholding values of autonomy, equality, and dignity. The social model of disability in fact suggests that autonomy, self-determination, and need for support can co-exist. This is an interdependence paradigm, wherein “capacity and support can be co-terminus” (Dhanda 2008,48). Thus, receiving support or care for a mental disturbance does not imply that the person’s right to seek gainful employment, make decisions about their life, get married, or raise a child are diminished. In fact, the UNCRPD recognises that a person with disability may need support to exercise capacity; yet obtaining support does not mean that capacity does not exist (Dhanda 2008). This however does not imply that the medical and social model of disability can simply co-exist without any challenges and differences. This is primarily because the underlying assumptions and values of the two models as well as their goals and priorities are rather different. For instance, the medical model would advocate for a “treatment first” kind of approach with an “expert-centric” position whereas the social model would advocate for an “experience-centric” (over expert-driven) approach and may want to address a range of socio-economic, civil, and political rights before (or alongside) support; moreover, the understanding of support itself may differ from the medical idea of treatment.

For many who are invested in human rights and are proponents of right to self-determination and life of dignity for all, a shift from mental illness to psychosocial disability may seem like a welcome change. However, this shift is presently not too visible in India among persons with psychosocial disabilities themselves or among their caregivers, professionals, and policy makers. There could be several reasons for this. Davar (2015)

However, by moving beyond a restrictive focus on symptom management, the language of psychosocial disability opens the possibilities of talking about lived realities and rights of persons with psychosocial disability that is not merely restricted to the right to healthcare. Another gain that the framework of disability provides is that articulations of lives of persons with psychosocial disability is no longer determined by expert knowledge and language.

attributes this difficulty in openly embracing an identity of psychosocial disability to the structural exclusion enabled and sanctioned by laws—a range of civil, family, and common laws alongside mental health legislations that render the person disenfranchised. The disabling role of law for persons with psychosocial disability will be discussed later in detail in this paper. While structural exclusion and violence through law is a grave concern, identity formation, particularly political identity formation as a person with psychosocial disability (or any other articulation such as former patient, survivor, or user) around which rights-based advocacy and collectivisation can take place is a complex process and several factors can prove to be hindrances. Some of the hindrances (apart from law) within the mental health sector include expert-led policy and planning processes, wherein participation of persons with psychosocial disability is tokenistic, if at all present. As a result, the narrative continues to be dominated by expert concerns within the sector, such as access to treatment, quality of treatment, and so on. While the framework and language of psychosocial disability has a lot to offer, it is currently often being used as a substitute for mental illness. Anjali, a Kolkata-based mental health rights organisation and proponent of this paper, knows this only too well.

In this paper, we use both the terms mental illness and psychosocial disabilities, not interchangeably. We use mental illness in referring to existing research, policy, and legal documents that use this terminology as used within the medical model described above. Given the dominance of the medical model within India’s mental health sector, we use the diagnostic language of mental illness and its treatments from a critical lens to raise issues of power, dominance, surveillance, and social control. On the other hand, we use psychosocial

disability to refer to the psychosocial model of disability. We use the definition of persons with disabilities as defined in the UNCRPD: “those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others” (2006, Article 1). Use of the term disability in this paper is not meant to homogenise experience or to be inattentive to variations such as disability that results from congenital conditions as opposed to acquired impairment, temporary loss of function versus relatively stable impairment, visible versus hidden disability, disabilities linked with advancing age and increased life expectancies and so on; instead disability is used here to refer to a framework of analysis to talk about lives of women with psychosocial disability.

WOMEN, GENDER, AND PSYCHOSOCIAL DISABILITY

In addition to the disability lens, this paper also employs a gender lens to understand experiences of women with psychosocial disability. Using a gender lens here means that women’s experiences of impairments and disturbance are viewed as being located within their disadvantaged social position in patriarchal societies and are seen as a consequence of or mediated by circumstances of inequality, violence, limited access to resources, and mobility, as well as limited social capital and support. Several studies on women and mental health have framed women’s distress in the context of their social circumstances. For instance, data from studies in India suggests that female gender, poverty, being a housewife, being a daily wage earner or agricultural labourer, and lack of access to formal education are some of the factors that put women at a greater risk for certain kinds of mental illnesses (Davar 1999, Patel 1999, Vindhya 2001). Some of these studies would be examples of using gender as an analytical lens and not merely as a background/demographic variable.

The use of a gender lens also means employing a social constructionist approach to understand the body, sex, gender, and sexuality. From a biologically determined framework, sex, gender, sexuality and the body are fixed conditions that give rise to binaries: male v. female, masculine v. feminine, heterosexual v. homosexual, and able bodied-minded v. disabled. A social constructionist approach however disrupts this naturalised, universal, “normal” body type that is organised into a rigid binary of sex-gender system determined by biology (Jaramillo Ruiz 2017). This is not to say that biology

is unimportant; this is to examine it alongside the cultural question (International Council on Human Rights Policy [ICHRP Report 2009) of what is a “normal,” socially desirable body-mind? How is it constituted? What are normal/normative gender expressions/ gender roles? How do they emerge? And what is their relationship with normative sexuality?

To use a gender lens is also to move away from the binary understanding of gender as consisting of the two, opposite categories of male and female. This kind of a non-binary way of looking at gender does not fix all women into a single location of femininity, and instead views gender as a spectrum with diverse gender expressions. In this paper, we primarily focus on women with psychosocial disability, a group that Anjali has been engaged with for over a decade and half. However, when we use the identity “woman,” we do not fix it to mean only a “cisgender,¹ heterosexual woman.” We also talk of women with same-sex sexuality, trans women, trans persons, and gender non-conforming persons. While these issues find mention in the paper, due to the limited scope of the paper, these are not discussed at length.

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SEXUALITY AND PSYCHOSOCIAL DISABILITY

Popular notions, as well as considered positions, such as that of disability rights movements in India, seem to evade the question of sexuality (Addlakha 2008) and in doing so maintain a discursive silence around disabled sexuality. Sexuality, sexual expression, desires, fantasy, and consensual sexual acts, as well as access to affirmative information on sexuality, contraception, and sexual and reproductive health services are seen as legitimately linked only to able-bodied persons (this may get further qualified with a range of conditions, such as heterosexual marriage) and everyone else is assumed to be asexual. As a society, our commitment to able-bodied and

marital sexuality is extremely high. This is well-illustrated in an incident noted by Murthy (2013) in her article “Taking on ‘FULL’ Sensual Lives with ‘HALF’ Sexual Bodies,” where a woman was asked to keep aside her mobility aids during the marriage rituals so that they do not look “odd and out of place” in the function.

Times when the sexuality of persons with disabilities are made visible are during instances of perceived threat, such as in the face of sexual abuse and violence against persons with disability or when there is display of “inappropriate” sexuality, for instance stripping, masturbating in public, and so on (Shildrick 2007). Thus, sexuality of persons with disability becomes a point of discussion usually in the context of their protection or safety; here, “persons” refers to women and children as they are traditionally seen as the constituency that is often in need of protection. Vulnerability to sexual abuse of men with disabilities is not visible even in this context. Another instance when the sexuality of people with disabilities gets discussed is when regulation and channelling of what are seen as sexually inappropriate behaviours is necessary (Schaaf 2011). There are several possible reasons for this silence and invisibility around the sexuality of people with disabilities. We discuss two of them here.

First, the sexuality of persons with psychosocial disabilities has the potential to challenge the dominant idea of normal/natural sexuality—heterosexual, reproductive, peno-vaginal, vanilla,² within marriage or in the context of romance and relationship—often male-dominant sexuality (Schaaf 2011). In other words, “real sex” is seen as the one that starts with foreplay, involves penetrative intercourse and culminates in an orgasm (Talking About Reproductive and Sexual Health Issues [TARSHI] 2010). Sex as divorced from marriage or even romance, as being about sexual release, addressing “skin-hunger,”³ non-reproductive, non-monogamous, non-heterosexual, involving sex toys, stimulators, masturbation, assisted sex, and sexual activities that do not involve penetration or stimulation of genitals but are sexually gratifying, threaten the idea of normative sexuality. People with disabilities with activity, emotive, social, and cognitive restrictions defy the notions of able-bodied-minded⁴ sex and talking (instead of silencing) about these as legitimate, “real” sexual expressions poses a challenge, a threat to the “natural-normal-reproductive-heterosexual” order.

Thus, sexuality of persons with disability becomes a point of discussion usually in the context of their protection or safety; here, “persons” refers to women and children as they are traditionally seen as the constituency that is often in need of protection.

Second, sexuality is often seen as being about desire and not about need or as a necessary condition for a life of dignity. Addlakha (2007) suggests there is a general recognition, reflected in policy, law, and within the disability rights movements in India, of the importance of educational and employment opportunities to promote self-reliance and independence among persons with disabilities, however, “their sexual needs, dreams, and aspirations are more or less rendered invisible” (2007, 1).

Shakespeare in his book entitled *Disability Rights and Wrongs* (2006) states that for disabled persons, sexuality, which implies access to relationships, family, and parenthood on an equal basis as others, cannot possibly be a secondary issue. In fact, it is a window to achieve full acceptance and inclusion in society. By discussing sexual rights⁵ alongside social and civil rights, Shakespeare reveals the inherent link between sexual rights and social inclusion. He states, “The more people with disabilities achieve their other civil and social rights, the more they will have the confidence, self-esteem, and desirability that make relationships possible” (2006, 220). In other words, not having access to education, job, and money would mean lack of cultural capital, isolation, lack of a rich network of friends, and dwindling possibilities of socialisation (Shakespeare, Gillespie-Sells, & Davies 1996). Thus, Shakespeare (2006) suggests that for sexual rights of people with disabilities to become a reality, an attitudinal shift is essential; from viewing disability as an object of pity and charity to viewing people with disabilities as rights-bearing subjects/citizens, which increases their desirability as partners and lovers. However, Addlakha states that presently, “[s]exuality is an area of distress, exclusion, and self-doubt for persons with disabilities” (2007, 4). This points to the often-experienced isolation, loneliness, lack of opportunities for social contact and friendships, fear of rejection, and vulnerabilities of people with disabilities in the context of sexual/romantic/marital relationships.

The fact that people with disabilities are viewed as asexual, dependent, in need of care, and therefore often treated as being child-like and innocent, adds to stigma and shame around sexuality of disabled persons.

A report by TARSHI on *Sexuality and Disability in the Indian Context* highlights a range of issues including those of poor body image, low self-worth, feelings of incompleteness and unworthiness for sex, love, companionship, and marriage. The report states that, “[p]eople with disabilities often grow up believing they do not deserve to be in a relationship as they are not attractive or worthy enough” (2010, 50). This is internalisation of social attitudes and stigma towards disability, which can lead to feelings of shame about one’s sexual desires. The report further explains that many people with disabilities may be overcome with doubt when someone, especially a non-disabled person, shows interest in them. There is always the fear of being used in a relationship, fear of being abandoned, and if things do not work out then the person is most likely to believe that the reason for the same is their disability (TARSHI 2010). The fact that people with disabilities are viewed as asexual, dependent, in need of care, and therefore often treated as being child-like and innocent, adds to stigma and shame around sexuality of disabled persons.

In the context of persons living with mental illness, some of the stereotypes include hyper-sexuality, promiscuity, disinhibition, and inappropriate sexual expression. Linked to these is the idea that persons diagnosed with mental illness lack capacity for rational judgment/decision-making. These attitudes lead to practices such as being denied any kind of privacy, including having no private space for sexual stimulation, masturbation, or space to be able to have sex with a partner, and surveillance of behaviours within the home as well as outside. For instance, rules related to use of the phone, internet, social interactions, who, when, how long to meet, how often, where and so on. The surveillance and control of people with disabilities, possibly by well-meaning care providers, is common within families and homes as well as institutions. This surveillance and shaming or damning messages are heightened for women with psychosocial disability and often lead to internalisation of sex-negative and body-negative ideas.

Marriage (heterosexual) continues to be the overarching institution within which sexual expression is allowed and

socially sanctioned for all. In the case of people with disabilities, particularly persons with psychosocial disability, marriage has been seen as a range of things that often have very little to do with rights such as right to intimacy, companionship, and sexuality. Some of the primary motives include marriage as cure of illness, as source of unpaid long-term care, assurance for old age, and so on. Thus, while on the one hand, the marriageability level of people with disabilities is seen as low, marriage, particularly for disabled men with poorer non-disabled women, or women who are not seen as highly desirable in the marriage “market” such as divorced, widowed women, or even women with lesser degree or more hidden nature of disability is seen as a solution by parents and family members for long-term care of the person. Non-disclosure of mental illness prior to marriage is another issue that is partly linked with looking at marriage as an opportunity to shift burden, not just of care but also of the shame associated with an unmarried daughter living with mental illness. Marriage then seems like the only opportunity to grant some sense of respectability to a woman, who has had tumultuous, intense relationships, is known to have had a history of substance abuse, has had difficulty with academics, work, and so on. Marriage and women with psychosocial disability will be further discussed in the context of marriage laws in a later section.

Some of the critical issues around the rights of women with psychosocial disability are intimately connected with their ability to exercise their sexual rights, for instance, the right to privacy, bodily integrity, competence and capacity for sexual (and other kinds of) decision making, consent, autonomy, non-discrimination and so on. Advocating for these human rights for women with psychosocial disability would in fact form the enabling conditions for meaningful fulfilment of sexual rights.

One of the side effects of long-term psychiatric medication is sexual dysfunction in the form of loss or diminished sexual desire and erectile dysfunction. This brings up issues such as reporting of these side effects by persons with psychosocial disability, who may often lack the necessary empowerment or

assertion to bring these up in a clinical encounter (especially if they are not married), medical management of these side effects, defaulting on medication, and so on. However, in addition to clinical management, a primary concern is that of the patient's right to information about possible effects and side effects of medicines that they are taking for short- or long-terms. In the absence of this information, the person is unable to make informed decisions and may not recognise sexual dysfunction as a side effect of medicines. Similar issues arise about other kinds of side effects, such as weight gain, decreased fertility, and so on.

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SEXUALITY AND WOMEN WITH PSYCHOSOCIAL DISABILITIES: EXPLORING THE GROUND COVERED SO FAR

In this section, we explore existing research and literature that discusses sexuality of women with mental illnesses.⁶ We explore two main strands here. The first strand is reproductive health and mental health research that discuss, though indirectly, women's sexuality through a reproductive health lens. The second is research on violence against women with psychosocial disability in the public and private domain that covers studies related to sexual violence and do not really focus on sexual rights. This implies that in the Indian context there has been a dearth of any concerted study and dialogue on women with psychosocial disability and their sexuality, pleasure, or desire.

WOMEN'S REPRODUCTIVE HEALTH AND MENTAL HEALTH

Literature within the disciplines of psychiatry, psychology, and other related fields in mental health have for a long

time engaged with the issue of women and mental health. The nature of this engagement has mostly been limited to considering gender as a significant demographic variable, thus producing data for instance, on gender-wise prevalence of certain disorders. Sexuality has been traditionally alluded to while discussing aetiology of mental illness in women, for instance, the idea of the suffocated/restless, wandering uterus causing hysteria or the tendency to look for disturbances in women's biology, reproductive organs, hormones, and bodies that makes them more prone to mental illness; these have been indicative of a wider belief within mental health sciences, regarding the innate (read: biological) tendency in women for mental illness. This belief in many ways has led to a great deal of research attention being paid to a "hypothesised relationship between reproductive related events such as menstruation, pregnancy, miscarriage, child birth, infertility, abortion, menopause, and higher rates of depression among women" (Astbury 1999).

What is significant to note here is that while sexuality, desires, and pleasure of women with psychosocial disabilities has not received much attention, pathology and illness as associated with reproductive events has been regularly discussed. In these discussions on women's reproductive health, sexuality is the unspoken, ever present background.

While none of the research has on their own been able to explain the gender differences in the prevalence of depression, women's mental health problems are often equated to reproductive health concerns and these are treated as the primary, urgent health concern that women face, irrespective of whether women think so or not. Moreover, in this equation of women's reproductive health to their mental health, men's reproductive health concerns and psychological impact of reproductive events in their lives such as infertility, unplanned pregnancies, and still births, is completely ignored (Astbury 1999), implying that men either have no such thing as reproductive health or that it has no impact on their mental health. Sexuality, sexual drive, and sexual performance on the other hand are significant themes within men's health and mental health discourse. What is significant to note here is that while sexuality, desires, and pleasure of women with psychosocial disabilities has not received much attention,

pathology and illness as associated with reproductive events has been regularly discussed. In these discussions on women's reproductive health, sexuality is the unspoken, ever present background. On the other hand, the relationship between men's sexuality and its mental health implications is much more articulated, but there exists very little research on the relationship between men's reproductive health and mental health (WHO 2002). This underscores an old gender bias in health research, that men have sexuality and women have reproduction.

Studies on women's reproductive health and mental health have focused on a bi-directional relationship between mental health and reproductive events, i.e., reproductive events and organs as causing mental illness and impact of mental illness on reproductive events. Jones et al. (2014), in their extensive review on women with severe mental illnesses, pregnancy, and post-partum illness, suggest lowered fertility rates among women suffering from severe mental illnesses, especially schizophrenia. They cite several studies listing factors to explain these lower fertility rates. These include higher rates of abortion among women with psychiatric disorders compared to women in the general population, the role of prolactin-raising anti-psychotic drugs that make conception difficult, and the challenge in forming and sustaining relationships. Jones et al. (2014) further state that when women with severe mental illnesses do get pregnant, their pregnancies are more likely to be unplanned and unwanted as compared to the general population. They cite studies focusing on pregnancy-related relapse of mental illness, role of drug default (discontinuation of psychiatric medication) once pregnancy is known, hormonal changes, sleep deprivation, and psychosocial factors associated with pregnancy and childbirth that make pregnancy and the post-partum period a difficult one for women already living with a mental illness. Other studies by Fuhr et al. (2014) and Fisher et al. (2009) underscore the need to study suicide as cause of maternal and pregnancy-related deaths, especially in the context of adolescent pregnancy, unwanted pregnancy, and situations of physical/sexual abuse.

Several studies have focused on reproductive events such as childbirth causing mental illness, for instance post-partum depression and post-partum psychosis. Two prospective studies on pregnant women, in the states of Goa (Patel, Rodrigues, & De Souza 2002) and rural South India (Chandran et al. 2002), detected depressive disorder in 23% and 16% respectively, with depression persisting six months

after child birth in 11–14% of women. Risk factors included poor marital relationship, intimate partner violence, unhappiness about the gender of the child, poverty, and having a living female child. Patel et al. (2006) state that younger age at first pregnancy and multiple pregnancies, as well as gynaecological complaints of vaginal discharge, lower abdominal pain, and irregular menstruation, put women at risk for common mental disorders.

Another dimension that has been documented by mental health advocates and human rights defenders in the context of reproductive rights of women with psychosocial disabilities is that of a long-standing history of forced sterilisations, hysterectomies, abortions among women with intellectual disabilities and psychosocial disabilities. Such practices have been considered as institutional measures to manage menstrual hygiene, avoid pregnancies that are always read as unwanted for women with psychosocial disability, deal with pregnancies, especially those that are a result of sexual assault, and protection from loss of familial honour that may result from pregnancy of unmarried women. In cases of childbirth, particularly while the woman is in an institution, this would further extend to the woman being forced to put up the child for adoption.

Thus, while there has been an overemphasis on women's reproductive functions in understanding their mental health, with time, research linking women's reproductive health and mental health has moved away from a mere biological lens to adopting a more interactive perspective that studies women's bodies and psyches in context of relational, socio-economic, and cultural realities. Though research has gone beyond the study of hormones and reproductive organs and opened up our understanding of the role of poverty, female gender, violence, and other deprivations in the lives of women, they have not looked at sexuality, desire, intimacies, and their role in mediating experiences of distress and well-being.

Another dimension that has been documented by mental health advocates and human rights defenders in the context of reproductive rights of women with psychosocial disabilities is that of a long-standing history of forced sterilisations, hysterectomies, abortions among women with intellectual disabilities and psychosocial disabilities.

VIOLENCE AGAINST WOMEN WITH PSYCHOSOCIAL DISABILITIES

Some research has been conducted in India on violence faced by women with psychosocial disability within the private and public domains and on factors that make them vulnerable to this violence. Chandra et al. (2003) conducted a study with 146 women admitted to a mental hospital in a city in South India. This study reveals that 30% of the women interviewed reported some form of sexual coercion. Women reported that they experienced abuse most commonly from their husband or intimate partner, followed by a person in a position of authority in their community (e.g., house owner, village chief, teacher, religious leader, employer), or a relative other than their husband (e.g., uncle, brother-in-law). Some women reported abuse from more than one perpetrator. These events were not isolated incidents, and occurred more than four times for most women reporting these experiences. The most commonly reported experience was sexual intercourse involving threatened or actual physical force, and in several instances also included involuntary intercourse resulting from continual argument or pressure and sex play (non-penetrative but unwanted sexual activities). In another study, the Interventions for Support, Healing, and Awareness, a Delhi-based NGO, noted a higher incidence of child sexual abuse and violence in the lives of women who had received a psychiatric diagnosis in their adult lives (Purewal 1999). A study by Maitra (2003) on the status of women in mental hospitals in Maharashtra notes in several case studies a history of sexual abuse and rape in childhood or adult life of women that pre-dated a diagnosis of mental illness and institutionalisation of these women.

An overemphasised bio-medical gaze to explain mental illness means that contextual factors within the social or psychic life of a person fade into the background and are not seen as relevant or significant in the assessment or treatment process.

In the study of Chandra et al. (2003) mentioned above, in contrast to the 30% of women who reported sexual coercion during interviews, only 3.5% of the medical records contained this information. This points to the silence around issues of sexual abuse within mental healthcare services. Several reasons for this silence and underreporting have been noted.

These include lack of adequate training in assessment, exploration, and working with issues of sexual trauma. An overemphasised bio-medical gaze to explain mental illness means that contextual factors within the social or psychic life of a person fade into the background and are not seen as relevant or significant in the assessment or treatment process. Powerlessness and disenfranchisement of women living with psychosocial disability within their families and within the highly medicalised mental health services is another major reason for the sustained silence.

There is also an all-pervading bias common in mental healthcare systems against patients with mental illness as lacking sound/rational judgment, and thus report of abuse by such patients maybe seen as part of their symptoms or as malingering or as attempts to seek attention.

Women with psychosocial disability are not a homogenous group and there exists a great deal of diversity among them, not just in terms of the medical impairment they have, but also in terms of resources and support they have access to, their socio-economic class and caste background, geographical location, family situation, and so on. Some of them are living within institutions for several years, sometimes for the most part of their adult lives. Institutionalisation can make women with psychosocial disability more vulnerable to abuse and they may feel much less able to stop this abuse. Even when not living inside closed institutions, women with psychosocial disability who are dependent on their caregivers, hired help, and family are more vulnerable. Then there are those with severe disability and difficulties with communicating experiences of abuse (TARSHI 2010). The homeless is one of the most marginalised groups among women with psychosocial disability. They are often likely to get caught in the cycle of trans-institutionalisation, i.e., being picked up by police and shunted between mental hospitals, beggars' homes, homes for destitute women, and among others.⁷

There is also an all-pervading bias common in mental healthcare systems against patients with mental illness as lacking sound/rational judgment, and thus report of abuse by such patients maybe seen as part of their symptoms or as malingering or as attempts to seek attention. Such bias

not only make reporting and putting an end to the abuse difficult but also provide impunity to abusers and further increases vulnerability of women with psychosocial disability. A Human Rights Watch Report (2014) focusing on abuses against women and girls with psychosocial disability and intellectual disabilities in institutions in India has reported several incidents of physical, verbal, and sexual abuse, with sexual abuse being most hidden due to several of the reasons cited above. The more recent incident of the plight of patients at the Behrampore Mental Hospital⁸ that was brought to light by Anjali in August 2016 is one of the many examples of institutional abuse. At this hospital, patients were found stark naked with lice in their hair, unhygienic wards, toilets, and food, and other inhuman conditions. Apart from apathy, corruption, and lack of accountability among the officials of the hospital, the primary attitude at work here is that people living with mental illness are lesser humans, and therefore the question of according them human dignity and bodily integrity does not arise.

Women and young girls with psychosocial disability are often likely to get excluded from sex education programmes, may find it hard to access contraception, and may lack affirmative information, role models, or peer support to talk about and explore their sexuality as the society expects them to be asexual, undesirable, and incapable or unworthy of forming intimate relationships (TARSHI 2010). In the absence of affirmative information and experiences around sexuality, confusion about what one wants or desires and how to say “No,” maybe experienced by several women, which adds to their vulnerability to sexual violence.

Several incidents of violence against women with psychosocial disability in public spaces have been recorded in recent times. While the violence in most of these can be explained by stigma around mental illness, there is also a gendered element to the nature of violence. For instance, tonsuring a woman, parading her naked, and labelling her a witch are certainly examples of gendered violence in a patriarchal society. Recent media reporting of the mob lynching of Otera Bibi,⁹ a 42-year old woman in Murshidabad district of West Bengal (June 2017), and Maan Devi,¹⁰ a 62-year old woman from Agra in Uttar Pradesh (August 2017), are stark examples of these. In both cases, these women had wandered away from their homes in nearby villages and were labelled by locals as a child kidnapper and a witch respectively. Villagers, mostly young men in both these incidents, decided to execute justice by tying up, beating,

tearing off clothes and in one case tonsuring the woman. In both these instances, the women’s homes were not too far from where they were killed and had they been simply reported to the local police or administration (since they were believed by the locals to be engaging in some unlawful activity), the reality that they were living with a disability would have come to light and their lives perhaps saved.

Another form of abuse against women with psychosocial disability that occurs in the context of mental health services is that of sexual boundary violation in the doctor/service provider-patient relationship. Aravind, Krishnaram, & Thasneem (2012) use the term “slippery slope” to refer to sexual boundary violations between the doctor and patient. Simon (1989) states that it often starts with small gestures such as transition from last name to first name, then some amount of body contact such as a pat on the shoulder, progressing to hugging, conducting sessions outside at lunch, and so on. Kurpad, Machado, & Galgali (2010) conducted a study among psychiatrists and psychologists in the state of Karnataka, India about their awareness of sexual and non-sexual boundary violations in the doctor-patient relationship in India. A third (33%) of the respondents stated that they had heard of at least one allegation of sexual boundary violation that was investigated but a larger number (51%) had heard of at least one allegation of sexual boundary violation that was not investigated.

Forms of sexual boundary violation include inappropriate or unnecessary physical examination, inappropriate touching, sexual talk or jokes with patient, sexual touching, and sexual intercourse with patient. One of the respondents in this study is reported to have stated, “that a long handshake/hugging in a consoling manner [of patients] with panic disorder is not a boundary violation.” This respondent believed that these actions were helpful to the patient. The same respondent also felt that “pentothal abreaction” would work only if [the] patient and [the] doctor are alone,” and that, in sexually abused patients, “physical examination helps” (Kurpad et al. 2010, 77). Issues related to sexual boundary violations in relationships between doctor/therapist/counsellor and patient/client within the mental health sector is complicated by the fact that this is an enduring, often long-term, trusting, and nurturing relationship, wherein the power differential is starkly in favour of the professional. As a result, in addition to the trauma and confusion suffered by the clients, clients may also feel disempowered to report the boundary violation. They may fear

Thus, violence within domestic and public spaces has a significant impact in the lives of women with psychosocial disorder, both as a cause and a consequence of psychosocial disorder and hence strategies to deal with violence against women need to form a significant part of any work toward advancing their sexuality rights.

loss of contact with their therapist, and that no one will believe them as they are seen as not having a sound mind, while the professional is seen as an expert and has more credibility.

International and Indian studies on domestic violence and mental health point to a bi-directional relationship between the two. Oram, Kalifeh, & Howard (2017) report systematic reviews that have demonstrated an association between depression and subsequent domestic violence and also that domestic violence increases the likelihood of depression in women with no previous history of symptoms. Oram et al. (2017) report a meta-analysis that suggests a three-fold increase in the likelihood of depressive disorders, a four-fold increase in the likelihood of anxiety disorders, and a seven-fold increase in the likelihood of post-traumatic stress disorder for women who have experienced domestic violence and abuse. Work with trauma survivors has shown a great deal of similarities between symptoms experienced by combat survivors, soldiers, and victims of domestic and sexual violence (Herman 1992). In the Indian context, common mental disorders such as depression and anxiety are seen to be closely associated with female gender and poverty. Some of the factors associated with the gender disadvantage faced by women are excessive partner alcohol use, sexual, and physical violence by the husband, having low autonomy in decision making, and having low levels of support from one's family (Patel et al. 2006, Shidhaye et al. 2010). Spousal violence has also been found to be specifically associated as an independent risk factor for attempted suicide in women (Chowdhary 2008).

Thus, violence within domestic and public spaces has a significant impact in the lives of women with psychosocial disorder, both as a cause and a consequence of psychosocial disorder and hence strategies to deal with violence against women need to form a significant part of any work toward advancing their sexuality rights.

STRUCTURAL EXCLUSIONS AND INSTITUTIONAL BIASES: BARRIERS TO WORK ON SEXUALITY AND PSYCHOSOCIAL DISABILITY



In this section, we discuss three primary influences that pose obstacles in work on affirming sexual rights for women with psychosocial disorder. These include institutional biases within the knowledge system and practice of mental health sciences, the role of long-term institutionalisation as a modality of care increasing exclusion and reducing life chances of women with psychosocial disorder, and finally the exclusionary role of law.

REPRESENTATION OF WOMEN WITHIN THE MENTAL HEALTH SCIENCES

Mental health sciences in their claim towards being value-neutral and objective sciences have also asserted a gender-neutral stance in producing knowledge, as well as carrying out practice. However, several feminist thinkers have challenged this claim and while it is not within the scope of this paper to elaborate on feminist scholarship in this area, in this section, we do cite some of the work on feminist critique of psychiatry and psychology from a gender lens.

First, it is suggested that knowledge within the mental health sciences and the very conception of what is normal and abnormal/pathological is gendered in nature. Here, we take the example of a study conducted by Broverman et al. (1970), focusing on understanding the role of sex-role stereotypes and self-concepts and their impact on clinicians' diagnostic and treatment practices. They studied 79 practicing mental health professionals including psychiatrists, psychologists, and social workers. In the study, professionals were given three different sets of instructions. They were asked to describe a healthy, mature, socially competent a) adult or b) male or c) female, using a 122-item sex-role stereotyping questionnaire. The questionnaire included several bipolar questions (participants were asked to rate between two extremes such as "not at all aggressive" and "very aggressive"). Results indicated that participants believed that a healthy adult and a healthy male shared virtually all the same characteristics. A healthy female, on the other hand was thought to possess different qualities.

This has been one of the most influential studies to argue that the very conception of mental health is androcentric and that the male norm with trait descriptions of being active, independent, competitive, and logical is the primary reference point for defining mental health.

Adults and males were said to share a “competence cluster” of traits such as confidence and independence, while women had a “warmth-expressiveness cluster” that described kindness and concern for others. What this implies is that if women demonstrated traits that were considered healthy for a woman, they were simultaneously classified as unhealthy and psychologically immature adults. Thus, women conforming to the prescription of “dependence, passivity, nurturance” by definition were on the side of irrationality and closer to insanity. This has been one of the most influential studies to argue that the very conception of mental health is androcentric and that the male norm with trait descriptions of being active, independent, competitive, and logical is the primary reference point for defining mental health. The irony of this has been brought out very well by Chesler (1972) who states that women are labelled as being ill/pathological, when they conform to the sex-role stereotype, as well as when they deviate from it.

Psychiatric diagnostic and classification system and women’s representation in these is another area of critical study. Epidemiological studies suggest that women tend to be overrepresented in certain psychiatric diagnosis, such as depression, anxiety, panic, somatoform disorders (one or more bodily symptoms including pain, not explained by organic/physical cause), whereas boys and men tend to be diagnosed more often with conditions such as conduct disorders, attention deficit hyperactivity disorder, anti-social personality disorders, and substance abuse disorders (WHO 2000). In other words, women are more commonly seen to suffer from what are called “internalising disorders” (directing one’s problems inward towards oneself) and men are seen as suffering more from “externalising disorders” (directing one’s problems outward). It is obviously important then to ask questions about the role of socialisation in expression of distress, both in men and women; but it is also important to ask what this socially-prescribed gender script of distress does to the medical practice of diagnosis. In other words, it

is relevant to ask how the mental health professional, who is also embedded in a similar socio-culturally determined gendered distress script, processes and produces certain diagnosis for men and women. Thus, it may be useful to know if as many women as men in India are likely to be asked during a psychiatric assessment about substance use behaviour and whether the same quantity, and frequency of substance use in a woman is likely to be more pathologised than that in a male client/patient.

Writing on specific diagnostic categories such as Borderline Personality Disorder (BPD), which was traditionally seen as a female malady, have raised questions about the gendered nature of this diagnosis, as well as the gendered nature of the practice of assessment and diagnosis. BPD is characterised by symptoms such as instability of mood, poor self-image, pattern of intense, unstable relationships, intense fear of abandonment, impulsive and dangerous behaviours, such as unsafe sex, rash driving, self-harm, and recurring suicidal behaviours. Several explanations have been proposed to account for overrepresentation of women in this diagnostic category. These range from biological/hormonal to socio-cultural differences between men and women and finally due to bias in research sample of BPD studies (more women than men included in the study) or bias in diagnostic practice, wherein women were more likely to be diagnosed with BPD and the symptoms (that are not associated with traditional ideas of masculinity) in men remained undiscovered and undiagnosed (Skodol & Bender 2003). A similar picture is seen with other personality disorders such as histrionic and dependent personality disorder, diagnosed predominantly among women and antisocial personality disorder diagnosed primarily among men. More recent research on BPD points out that there are no real gender differences in the prevalence of BPD among men and women, though the expression of symptoms maybe different for both the sexes (Silberschmidt 2014).

Another set of diagnostic categories in psychiatric assessment that are of particular interest in the context of this paper are sexual dysfunction and disorders of sexual preference. Here, we refer to the International Classification of Diseases 10 ICD-10 (WHO 1992)¹² in discussing these two broad diagnostic categories—F52 and F65. F52 in the ICD-10 is titled, “Sexual Dysfunction not caused by organic disorder or disease” and “covers the various ways in which an individual is unable to participate in a sexual relationship as he or she would wish” (ICD-10, 149). This section is further divided into several

In a culture in which women's chastity, virginity, and innocence is celebrated, one wonders, when this diagnosis of lack of sexual enjoyment is used and what is its role in the construction of ideas of "normal sexuality?"

sub-sections such as F52.0 Lack or loss of sexual desire, F52.1 Sexual aversion and lack of sexual enjoyment, and so on. It is important to note that there are several underlying assumptions to this section on sexual dysfunction. These include the belief that all sex is heterosexual, all sex is peno-vaginal penetrative in nature, that there is such a thing as the right amount of sex and right amount of pleasure in sex for everyone. It is based on these kinds of assumptions that criteria for sexual dysfunction are described. Let us take two sub-categories under F52 as an example:

F52.1 Sexual aversion and lack of sexual enjoyment

F52.10 Sexual aversion

The prospect of sexual interaction with a partner is associated with strong negative feelings and produces sufficient fear or anxiety that sexual activity is avoided.

F52.11 Lack of sexual enjoyment

Sexual responses occur normally and orgasm is experienced but there is a lack of appropriate pleasure. This complaint is much more common in women than in men.

The idea of aversion to sex, avoiding sex, and not enjoying sex have been presented as clinically "abnormal behaviours" with no description of the need to assess any background information such as psychosocial context, presence of or previous history of violence/sexual abuse and force, quality of relationship between the sexual partners, relationship histories of the partners, issues related to body image, shame, guilt in a sex-negative culture, access to affirmative sexuality education, role of fatigue and dual burden on women in domestic and familial spaces, sexual orientation of the partner/s, and so on. One of the sub-categories mentioned above also describes the highly subjective attribute "lack of appropriate pleasure." It would be interesting to note whether this refers to pleasure as experienced by the woman, as reported by the man, or

as judged by the clinician based on overall reporting by the couple? In a culture in which women's chastity, virginity, and innocence is celebrated, one wonders, when this diagnosis of lack of sexual enjoyment is used and what is its role in the construction of ideas of "normal sexuality?" It is important here to note that the ICD-10 also has a diagnostic sub-category of F 52.7 Excessive sexual drive.

Another example that we would like to cite is that of F 52.2 Failure of genital response.

F52.2 Failure of genital response

In men, the principal problem is erectile dysfunction, i.e., difficulty in developing or maintaining an erection suitable for satisfactory intercourse. If erection occurs normally in certain situations, e.g. during masturbation or sleep or with a different partner, the causation is likely to be psychogenic. Otherwise, the correct diagnosis of nonorganic erectile dysfunction may depend on special investigations (e.g. measurement of nocturnal penile tumescence) or the response to psychological treatment.

In women, the principal problem is vaginal dryness or failure of lubrication. The cause can be psychogenic or pathological (e.g., infection) or estrogen deficiency (e.g., postmenopausal). It is unusual for women to complain primarily of vaginal dryness except as a symptom of postmenopausal estrogen deficiency.

Includes: female sexual arousal disorder, male erectile disorder, psychogenic impotence.

Interestingly, while establishing psychological origin of erectile dysfunction in men (ruling out an organic cause), the criteria suggest that the clinician should explore if erection is normal during masturbation or during sex with another partner. While discussing failure of genital response in women, the criteria refer to several organic/hormonal causes for vaginal dryness in women; however do not guide the clinician (as was the case with men) to explore sexual experiences of women during masturbation or sex with another partner. Moreover, the criteria suggest that it is unusual for women to complain primarily of vaginal dryness. What does "unusual" here really mean? Does this simply mean that it is biologically/physically

unlikely or are there socio-cultural, gendered realities underlying this statement about women's sexual desires, pleasure, arousal, culturally sanctioned silences around pain during sexual intercourse, and so on?

The second diagnostic category that we wish to discuss here is that of disorders of sexual preference, F65 in the ICD-10 (WHO 1992). A few examples of disorders under this category are listed below.

F65.0 Fetishism

Reliance on some non-living object as a stimulus for sexual arousal and sexual gratification. Many fetishes are extensions of the human body, such as articles of clothing or footwear. Other common examples are characterised by some particular texture such as rubber, plastic, or leather.

Fetishism should be diagnosed only if the fetish is the most important source of sexual stimulation or essential for satisfactory sexual response.

Fetishistic fantasies are common, but they do not amount to a disorder unless they lead to rituals that are so compelling and unacceptable as to interfere with sexual intercourse and cause the individual distress.

Fetishism is limited almost exclusively to males.

F65.2 Exhibitionism

A recurrent or persistent tendency to expose the genitalia to strangers (usually of the opposite sex) or to people in public places.

Exhibitionism is almost entirely limited to heterosexual males who expose to females, adult or adolescent, usually in some public place.

F65.3 Voyeurism

A recurrent or persistent tendency to look at people engaging in sexual or intimate behaviour such as undressing.

F65.4 Paedophilia

A sexual preference for children, usually of pre-pubertal or early pubertal age. Some paedophiles are attracted only to girls, others only to boys, and others again are interested in both sexes.

Paedophilia is rarely identified in women.

F65.5 Sadomasochism

A preference for sexual activity that involves bondage or the infliction of pain or humiliation. If the individual prefers to be the recipient of such stimulation this is called masochism; if the provider, sadism. Often an individual obtains sexual excitement from both sadistic and masochistic activities.

Mild degrees of sadomasochistic stimulation are commonly used to enhance otherwise normal sexual activity. This category should be used only if sadomasochistic activity is the most important source of stimulation or necessary for sexual gratification.

The various disorders listed under F65 are a good illustrative example of the role played by psychiatric diagnostic classification system in social control. These diagnostic categories have been produced in a context of hegemonic ideas of "respectable sexuality" that is virtuous, pure, within the paradigm of hetero-reproductive, monogamous marriage. Some deviation from the vanilla sexual acts within this paradigm is acceptable as indicated in the criteria by statements such as, "Fetishistic fantasies are common" or "Mild degrees of sadomasochistic stimulation are commonly used to enhance otherwise normal sexual activity." However, the diagnostic criteria state in no unambiguous terms that "normal" sexual activity is the desired goal of human sexuality and some deviation is fine as long as it occurs within the paradigm of the "normal" hetero-reproductive, monogamous, marital sexuality. This is implied in the diagnostic criteria for fetishism that state, "do not amount to a disorder unless they lead to rituals that are so compelling and unacceptable as to interfere with sexual intercourse." Thus, disorders of sexual preference are clearly conceptualised within the grid of social morality and societal prescription of normative sexuality.

The idea of consent for sexual acts among adults is completely missing in the articulation of disorders of sexual preference. Thus, acts involving sexual violence such as paedophilia, exhibitionism, voyeurism are discussed alongside sexual preferences such as use of objects, bondage, domination/submission, which by themselves do not constitute abuse and in fact are a source of excitement, arousal, and pleasure when carried out in a context of consent, trust, communication, and affirmation of sexuality. The diagnostic criteria thus fail to see

the distinction between consensual, kinky, pleasurable sex, and non-consensual, coercive, boundary violating, abusive sex.

Finally, nearly all the sub-categories of F65 state that these disorders are predominantly or only found among heterosexual males. This serves to further the stereotype of the unbridled, savage, male sexuality that needs to be reined in through institutions such as marriage and family.

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BEYOND THE GENDER BINARY: REPRESENTATION OF THE SEXUAL AND GENDERED “OTHER” WITHIN MENTAL HEALTH SCIENCES¹³

Discussion in this paper thus far has referred to those who fit within the gender binary—two opposite ends of the gender spectrum, mutually exclusive, neatly defined categories of man and woman. However, we know that gender expression is fluid and so is gender identity. Not everyone grows up to fit into the gender assigned at birth and many may not conform to the gender binary of male or female. There are also those of us who do not fit the box of normative heterosexuality (derives from the idea of gender binary and sexual attraction between the two genders) and may have same-sex desires, or may desire people of all genders, or maybe asexual. Mental health sciences have had a long history of pathologisation and medicalisation of non-normative genders and sexual expressions.

Historically, homosexuality has been viewed as a sexual perversion within the medical sciences since the mid-1800s. This view is reflected in homosexuality being classified as a form of mental illness in the first *Diagnostic and Statistical Manual* (DSM) of the American Psychiatric Association (APA). In this first edition of the DSM, homosexuality was classified under “sociopathic personality disturbance.” This later changed to a classification under the category “sexual deviance” in DSM II. Some of the treatment methods that have been historically used to treat homosexuals have included lobotomy, hypothalamotomies, implantation of testicular tissue of heterosexual men into homosexual men, induced seizures, electric shock, and behavioural methods such as masturbatory reconditioning, aversion therapy, and so on (Haldeman 1994, Silverstein 1991; 1996). Homosexuality was later declassified in 1973 as a form of mental illness. While homosexuality as a diagnosis ceased to exist, a new variant in the form of Sexual Orientation Disturbance and Ego Dystonic Homosexuality entered the DSM. It was only in the revised 3rd edition of the DSM in 1987 that homosexuality was entirely deleted from the list of mental disorders (APA 1987). Other classification systems of mental illnesses such as the ICD followed this move and removed homosexuality from its classification in 1992.

Mental health sciences have had a long history of pathologisation and medicalisation of non-normative genders and sexual expressions.

It is important to note how recent these shifts have been in mental health sciences vis-à-vis homosexuality. These shifts have occurred in the Euro-American contexts. However, change in international position vis-à-vis homosexuality does not mean that these are reflected in mental health practice in India. A few studies in India indicate that several mental health professionals continue to use different methods to cure homosexuality such as masturbatory reconditioning, aversion treatments including mild shock and hormonal treatments (Ranade 2015, Narrain 2005, Kalra 2012). These methods have been internationally criticised both on grounds of scientific efficacy as well as ethics (Serovich et al. 2008). Mental health practice in India continues to have an ambivalent relationship with the homosexual in the clinic. Thus, there are mental health professionals, who provide treatment to enable homosexuals to lead a “happy married (read heterosexual) life” (Ranade 2015) and there are mental health professionals, who petition the

highest court in the country in favour of decriminalisation of homosexuality and argue in favour of gay rights.¹⁴

People who express a sense of discomfort with their anatomical sex and related roles have been reported in the medical literature since the middle of the 19th century (Koh 2012). However, homosexuality, fetishism, gender identity disorder, and associated conditions were mixed together and regarded as types of sexual perversion that were considered ethically objectionable until the 1950s. Koh (2012) reports that, the first performance of sex-reassignment surgery in 1952 attracted considerable attention, and the sexologist Harry Benjamin reported a case of “a woman kept in the body of a man,” which was called transsexualism. John William Money (in Koh 2012) studied the sexual consciousness about disorders of sex development and advocated the concept of gender in 1957. Thereafter the disparity between anatomical sex and gender identity was referred to as the psychopathological condition of gender identity disorder, and this was used for its diagnostic name when it was introduced into DSM III in 1980. While DSM I and DSM II mention transvestism, neither of them address the issue of gender identity per se and gender identity disorder finds mention only in DSM III (Vitale 2005). In DSM V that was published in 2013, an affirmative shift in the understanding of gender identity can be seen. First, in the formulation of the diagnostic category, gender identity disorder is replaced by gender dysphoria, which signals an attempt to reduce stigma associated with the term “disorder” (APA 2013). Second, the formulation on gender dysphoria uses the idea of “gender as assigned by others” instead of anatomical sex, thus foregrounding the role of social construction of normative gender and using that as a reference point to understand gender diversity (Koh 2012).

Few studies in India, mostly focused on transwomen and hijras discuss mental health concerns of transgender persons. These suggest that owing to unique stressors such as gender dysphoria, family pressures for gender conformity, loss of family and household early in life, forced migration to cities, stigma and discrimination, violence in private and public life, transgender persons suffer from a range of mental health problems including depression, anxiety, substance abuse, self-harm, and suicide (Jayadeva 2017, United Nations Development Program [UNDP] 2010). Another study with 50 queer persons, assigned female gender at birth, included 28 persons identifying as transmasculine or gender non-conforming (Shah et al. 2015). Participants of this study talked

about mental health concerns related to trauma and violence in familial homes and their struggle with issues such as low self-esteem, loneliness, and suicide. As many as 20 of the 50 participants had attempted suicide at least once (a few had attempted suicide more than once). Access to affirmative care and treatment for trans persons in India is abysmal. While there are no systematic studies on experiences of trans persons in mental healthcare settings, anecdotal evidence and newspaper reports suggest that there exist wide gaps in the curricula of health and mental health professionals in India on issues of gender, leading to practice based on ignorance and bias. This includes treatments aimed at correcting gender expressions to match the gender assigned at birth,¹⁵ resistance to gender affirmative therapies, gatekeeping and refusal to provide certificates indicating the need and fitness for medical gender affirmation procedures.¹⁶ Discrimination in healthcare settings in the form of mis-gendering the person, forcing trans women to stand in male queues and admitting them to male wards, denial of treatment, refusing to touch the person for clinical examination and verbal harassment have been reported.¹⁷ In this context of trans-negativity and ignorance, it is a matter of grave concern that the Transgender Persons’ Bill 2016 (for the protection of rights) mandates that in order to get legal recognition, a transgender person would have to undergo screening by a committee comprising of (among others) a medical officer, a psychologist, or a psychiatrist.

As discussed in this section, andro-centric and heterosexist biases within the mental health sciences and their practices of diagnosis and assessments foundationally affect ways in which cis, heterosexual as well as lesbian, bisexual women and trans and gender non-conforming persons are constructed and treated within the mental healthcare systems.

While there are no systematic studies on experiences of trans persons in mental healthcare settings, anecdotal evidence and newspaper reports suggest that there exist wide gaps in the curricula of health and mental health professionals in India on issues of gender, leading to practice based on ignorance and bias.

INSTITUTIONALISATION AS CARE: VOICES FROM THE GROUND

This section of the paper is based on experiential narratives of women living within a mental hospital. A few narratives from outside the institution are also included.

Anjali is one of the leading nongovernmental organisations that brings human rights, gender, and sexuality lenses to mental health treatment, care, and policy development through a combination of rights-based programs, policy initiatives, and cross-sector partnerships with the Department of Health & Family Welfare, Government of West Bengal, India, the media, and civil society. Anjali aims to secure large-scale systemic changes in the mental health field by making mental health institutions and systems inclusive. Anjali has been working within the mental health institutional system for 16 years and currently runs its institution-based capacity building programme “Voices” in four hospitals in West Bengal and the community mental health programme “Janamanas” (Mind of Collectives) in two locations in West Bengal. Team members of Anjali conducted three focus group discussions (FGDs), two within an institutional setting and one within a community setting. A total of 16 women participated in these three FGDs, 11 in the institution and five in the community setting. Six of the participants were Hindi-speaking and came from places such as Bihar, Kolkata, Punjab, Orissa, and Nepal, the rest were all Bengali-speaking and came from different parts of West Bengal. The age range of the participants was 25 to 45 years; five of them did not receive any formal schooling and the rest have studied upto class 6th or finished schooling. They have worked as homemakers, tea canteen employee, domestic helpers, factory labourer, nurse/trained caregiver and so on. All names of the participants have been changed to protect their identities.

Thirteen out of the 16 women were married at some point in their lives. Ten of these 13 are separated from their spouses on grounds of violence or abuse, and all of them are currently residents of the hospital. The other three women that continue to be in a marriage are living in the community and two of them are caregivers to mentally ill family members and themselves seek counselling services (although not diagnosed with a mental illness) at Anjali’s Janamanas programme to cope with their own distress. One of them suffers from mental illness herself. This scenario of the marital status of the participants (though a small number) does raise questions

about links between gender, domestic violence, mental illness, and institutionalisation. A study by Gove (1972) provides some interesting insights in this context. Gove states that it is not just (any kind of) women who feature prominently in psychological disorders, but it is married women, who experience more emotional distress than married men, while within each of the single statuses (unmarried, divorced, widowed), men are found to have higher rates of mental illness compared to women. Based on these findings, one may suggest that marriage adds to risk of mental illness in the lives of women (with the unemployed housewife being at most risk [Brown & Harris 1978]), whereas it serves as a protective factor in the lives of men.

Some of the areas explored during the FGD included initial sexual experiences when they were younger, sexual relationships and marriage in adulthood, sexuality after receiving a diagnosis, and sexuality within the institution. Several of the participants shared their experiences of sexual initiation and the accompanying feelings of confusion and shame mixed with pleasure. Some talked about sexual abuse that they experienced as children and about not having been able to report it or share with a trusted adult, who increased their trauma and sense of being violated, as well as feelings of shame, fear, and insecurity. While early life experiences would have a sharp influence on later life, here, we will primarily focus on sexuality related experiences after acquiring disability and particularly after institutionalisation.

Several of the participants reported that they had difficult relationships with their spouses and family members, but there were also those who talked fondly about the time when they were married. For most of them, when their disturbances were heightened, and they received a diagnosis of mental illness, a range of other issues cropped up. These included repeated forced institutionalisation, being separated from one’s children, being seen as inefficient, all their behaviours/thoughts interpreted as a symptom by family members, violence due to the same, and abandonment in the hospital. For those who were still single, living with a diagnosis of mental illness meant that they were much more powerless, and had very little say in the choice of partner.

Ujwala, 34, suffered from severe distress since her young days. Her husband married her, with the knowledge that she was under treatment. She shared, “He simply came home one day late at night and put *sindur* (vermilion, a symbol of marriage

among most Hindu women) on me. My family accepted... my mother took out a new *saree* and a *shankha* and a *pawla* (red and white bangles that are worn by married women in Bengal) and got us married. My mother perhaps felt it was a good opportunity, as I just came back from a mental institution and was getting better. I left him however... He was a really bad guy. He would beat me up; he would come home, have dinner, have some fun with me and fall asleep. He wouldn't even ask me if I would have dinner."

Kavita, 40, narrated, "When I started falling ill, my husband would beat me up and the in-laws would constantly harass me saying that I can't do any chores properly. My husband used to tell my mother, 'Your daughter has gone mad!' I have been put in institutions multiple times. I would go back to my in-laws every time. They would take me in, but the beating did not stop."

Some of the participants reported other complications related to pregnancy and childbirth. One of them stated that after she had been diagnosed, she got pregnant and her husband said that this could not be his child and so she aborted out of shame and humiliation. Manjusree, 40, added, "My husband would not let me take medications. He put a baby inside me and told me not to take any medication for the well-being of the child. I kept telling him, 'you have no idea how badly it can affect my health!' He wouldn't listen. I became violent. I told him I would rather abort the child, than lose my sanity. But nothing worked out. I had the baby."

The above quote points to the complex realities of women with psychosocial disability, who often have to struggle without much support with decisions related to pregnancy, readiness for the same, familial pressures, psychiatric medication, and its side effects.

When asked about whether they saw any changes in their intimate relationships with their partner after their illness and treatment started, the most common responses were,

"He left me."

"He didn't come to see me."

"Took my child away."

Manjusree said, "After my illness, all I feel is that there is no one to feel for me."

Ujwala added, "I don't feel like loving anyone anymore. I hate myself. Everybody now knows that I am insane. I am here in a mental hospital." When asked about the boy who is about to marry her, Ujwala said, "He does not know I have mental problems. I ensured it is kept a secret from him, because I know he won't marry a mad person."

Living inside an institution and coping with past experiences of violence, loss, and trauma did not mean that women had stopped living, loving, dreaming, or that they had lost touch with their self or desires.

Kavita, currently living in the hospital said, "My desires have not gone away. I want to hold someone. Be loved. I wish I could be with my husband."

Paromita said, "Of course there is a sexual self. When I was admitted, I used to suffer. There were times when the urge would come, but there was nothing that I could do. I used to remember the times I have spent with my husband in bed. Now, I hardly get time to feel sexual. I work. I take medications and I fall asleep. The medicines make you sleepy."

Konkona, who had visited her home in between her stay in the hospital for a few days said, "When I went back home for the first time after being admitted, I did it with my cousin brother. Desire doesn't go away."

A different kind of an experience was voiced by one of the participants in the community FGD, which poses some questions related to communication, sexual negotiation, incompatibility, and challenges of dealing with the same.

Rina shares, "I have never been in such an environment which allows you to talk so freely. Now that I am here, I feel I can talk a bit. My husband loves me a lot. We do it, but not every day. Neither of us wants to do it every day. When I was better health wise, we had more sexual energy. But I won't at all say it is gone now. There are times when he wants to do it now. But my health doesn't permit. I feel bad for him. I know he wants to do it but I am in a way depriving him. I know he understands. But it bothers me. He has nightfall."

The dialogue took an interesting turn when sexuality within the hospital was discussed. In the first group, a few of the participants fleetingly mentioned that sexual activities do occur within the wards of the hospital, while most the participants denied it. The second group agreed quite strongly to the fact that sexual interactions are common inside the wards.

Swareen shared, “There is one boy who comes here to deliver food. He likes a girl who stays inside. He speaks to her a lot. Everyone knows about it. We tell her jokingly to get married to him. She gets very angry and says, ‘*mat bolo aise, badnaamhojaungi*’ [‘don’t talk like that, my reputation will suffer’].”

Talking about same sex activities and pleasuring oneself, she said, “People do it jokingly at times.”

Sushma added, “There was a girl. She isn’t here anymore. She used touch herself down there all the time!”

Others added, “Yeah that happens here. A lot of them put their hands down there. I have seen it sometimes.”

“Yeah they have sex on their own. They rub with each other also. There are many here. They do it in the wards, in the washroom...”

A few others talked about fantasising about their husbands, film heroes, characters from love storybooks, or about their idea of a man, who would be in love with them.

“I imagine how it would feel to be doing it with my husband.”

“I imagine if a man comes into my life how I would talk to him about love and make love to him!”

It was clear during these conversations that any kind of sexual behaviour, expression, or even talk was severely discouraged by hospital authorities and a moralising, controlling gaze of the staff was ever present within the institution.

Manjusree explains, “They (nursing staff) look down upon these acts. If you are even close to being sexual they don’t miss out on a chance to rebuke. I was lying one day wearing a *salwarkameez* and the *kameez* came over my waist, exposing my belly. The nurse came and said, ‘You lie here naked? For what joy? You are a recovered patient. Why would you be

naked?’ I said, ‘I am not naked!’ She scolded a lot. Another wardmate of mine was also lying with me. We were falling asleep. The nurse said, ‘Do you do these things with her?’ and scolded us a lot.”

As can be seen in the above quote, the nurse is taking a stance of morally correcting behaviours of “patients,” whom she sees are under her “charge” and therefore her responsibility. She is attempting to do this correction by using the tool of shaming. She also invokes the “recovered” status of the woman/patient implying by this that the woman now has some chance at respectability and dignity as a “recovered patient” and that by engaging in these objectionable behaviours, she is throwing away that chance at being moulded/shaped into a recovered (read: respectable) patient. The moral panic of the nurse is not just at the slip/fall of this woman from the recovered status but also at the unnatural sexual urge that is implied here by the presence of another woman lying next to her. The outburst and “scolding” from the nurse is a response to all of this; her need to control, correct, and reform, a feature common to all total institutions⁸ as described by Goffman (1961) in his seminal book *Asylums: Essays on the Condition of the Social Situation of Mental Patients and Other Inmates*.

Swareen, 40, shared that despite this correction or surveillance of women’s sexuality, while ever present, there is no direct or overt talk about sex and sexuality. It is implied by commenting upon dress, clothes, make up, and so on. She says, “I was once getting dressed and a sister (nursing staff) said, ‘Where are you going looking so nice huh? With lipstick and earrings and *sindur*? To show off to whom?’ I told her, ‘Who is there to show off to? I just did it to make myself feel good’. They keep on saying such stuff if you look a little better or dress up. They never directly speak about sexual things much.”

Is life in an institution a liveable one? With histories of violence, suffering, and loss, is it possible to go on? Are conversations about pleasure and desire even possible in a context like this? Swareen elaborates, “We joke a lot in here. I wake up in the morning and keep myself busy, chatting, joking, playing games. Some are adult jokes. Some people take that otherwise perhaps (laughing). If I sit in one place and do nothing, then I will go mad, again.”

LAW AS STRUCTURAL BARRIER TO INCLUSION OF PERSONS WITH PSYCHOSOCIAL DISABILITY

This paper began with a discussion of a shift from mental illness to psychosocial disability and the opening of empowering possibilities with this shift. Laws in India, however, have been unaffected by these changes in mindsets or practice. There has been a history of over 150 years of legislation that has marked the lunatic, the mentally ill person, as a person with an “unsound mind”¹⁹ and therefore lacking capacity to take decisions pertaining to their lives—decisions related to their marriage/relationships, children, property, businesses, health care, inheritance, voting, and so on. In equating what is seen or assessed by the medical establishment as medical incapacity to legal incapacity and taking away any decision-making capacity from the person, makes them into non-persons/non-citizens, who cannot transact or engage with the state except through an appointed legal guardian.

Dhanda (2000, 19) states that there exist several legal provisions pertaining to family life, economic affairs, political status, and personal liberty that curb and render invalid the decisions made by persons deemed to be of unsound mind. Legislations pertaining to family life include provisions of incapacity to adopt a child, incapacity to marry, dissolution of marriage on grounds of unsoundness of mind. Legislations related to economic affairs include provisions related to incapacity to litigate, enter a contract, manage property, hold public office, practice of profession (for instance, The Chartered Accountant’s Act 1949 has a provision stating that persons with unsound mind shall be barred from registering as per the Act) and unsound mind as grounds for dissolution of partnership. Political status includes ineligibility to exercise franchise, stand for elections, or retain elected office. Legislations pertaining to compromise of personal liberty include provisions within mental health legislation that allow for involuntary/forced admissions in a mental hospital for a short and long duration. The Mental Health Act 1987 had several provisions for involuntary (without consent) admissions, and while the new Mental Health Care Act 2017 has protections and provisions for upholding the wishes of persons diagnosed with mental illness, it does have a provision for supported admission, wherein admission to a mental hospital can take place without consent of the person.

In order to underscore the severely disempowering role of law in the lives of women seen as having a mental illness, we will focus on laws related to marriage as an illustrative example.

Section 5 (ii) of The Hindu Marriage Act, 1955 (HMA) states that under certain circumstances, mental illness is accepted as a ground for the annulment of marriage, while Section 13 (1) (iii) states that mental illness is a ground for divorce.

A study conducted by Pathareet al. (2015) at the Pune Family Court indicated that 85% of cases seeking divorce on the grounds of mental illness in spouses were filed by men and 14% were granted divorce or nullity even when both parties were not present. Medical evidence of mental illness was presented only in 36% of the cases and divorce was granted even in the absence of medical evidence. In cases where medical evidence was presented, these included prescriptions for psychotropic medicines and invoices of purchase of psychotropic medicines (material not too difficult to procure in collusion with a pharmacist or a psychiatrist). Independent medical examination was not asked for in any of these cases.

Another finding in this study is that several of the cases that were initially filed on the grounds of mental illness were later converted to mutual consent divorce. This suggests that alleging mental illness in spouse could be used as a strategy to blackmail and evoke stigma associated with mental illness to get the spouse to agree to the terms of the divorce that maybe beneficial to the man/person initiating the divorce. A couple of years ago, Tehelka magazine (2004) had conducted a sting operation in which a psychiatrist at the Agra Mental Hospital was found to be providing certificates of mental illness to men who wanted to use these to seek divorce from their wives for a fee of Rs. 5,000 to 10,000 (approximately USD 75 to 150). The psychiatrist admitted that he had never examined these women whom he was labelling as mentally ill. The study by Pathare et al. (2015) as well as the Tehelka case suggests that under the current laws relating to marriage nullity and divorce, persons, particularly women with mental illness are extremely vulnerable. Similar situations may extend to the custody of children. Addlakha (2007) states that women with disabilities are anyway more vulnerable within their marriages as they are likely to be ill-treated, abused, and even thrown out of their homes for multiple reasons, ranging from inability to perform household duties satisfactorily, to bearing a child with a disability. In this context,

annulment of marriage on grounds of disability becomes a major issue. Addlakha (2007) remarks that there are more numbers of divorced or separated women with disabilities than men.

Thus, in the absence of legal capacity granted to women seen as suffering from mental illness or having an unsound mind, the question of consent, which is really the fundamental value in any conversation on sexual rights becomes completely irrelevant. In addition, social attitudes that are at best, indifferent to sexuality

of persons with disability and at worst, censoring and controlling through forced hysterectomies and abortions, make the situation for advocating for sexual rights of persons with disabilities even more challenging.

The following case study illustrates the extent of difficulty that a woman diagnosed with mental illness faces just to be able to keep herself from being forcefully committed to an institution and be able to keep her daughter's custody.

THE CASE OF PAROMITA GUHA

Paromita Guha, 37, is one of Anjali's recovered participants. Paromita is a trained nurse who had shifted to Mumbai to work as a caregiver. She subsequently got married to a man from the family, who had employed her and later had a child.

There was violence and neglect in her marriage and she was repeatedly called a "mad woman" by her husband and her in-laws, who admitted her in a mental hospital against her will and her only daughter was taken away by the Child Welfare Committee (CWC).

Paromita managed to bring her daughter to Kolkata and stayed with her mother for a while. Her relationship with her mother was strained since childhood. She then left to work in Delhi. When her contract terminated, she had to return. Her mother wanted the money she had earned. Paromita refused and found a house on rent of Rs. 600 per month with the help of a friend. Her mother came to her residence, created trouble took her daughter, and got her evicted. She managed to get her daughter back, and the two of them stayed on the road. At night, they stayed on a tree because she felt that sleeping on the pavements would be unsafe. Police arrested her, and brought her to the All Bengal Women's Union, a residential hostel for women. She fell ill during her stay there. She was institutionalised in Kolkata Pavlov Hospital in May 2016. She engaged with Anjali's sessions and also started working in Cha Ghar, a café/canteen, one of Anjali's livelihood initiatives.

In the meantime, her husband came to Kolkata and lodged a General Diary at Barrackpore Police Station stating that the child should be taken away from her custody on grounds of mental illness. Subsequently, a notice was served to her that a custody petition has been filed before the Ld. Additional

Chief Judicial Magistrate at Barrackpore Court and her daughter was taken away by the CWC when she was institutionalised.

At this juncture, Anjali got in touch with Paromita's mother for her reintegration and after much persuasion her mother took her back home. Anjali as part of the Strategic Impact Litigation, engaged a lawyer to represent her case in court, wherein it was successfully argued that any adverse order based on a past history of mental illness²⁰ with regard to the custody of their daughter and handing her over to the husband would be prejudicial to her rights, claims, and entitlements. The husband moved the High Court in appeal. All the while the child had been residing in a home under the aegis of the CWC. The writ petition was favourably disposed of to Paromita's advantage wherein she was granted visitation rights to her daughter (once every week). The case at the lower court went on and it was on 19 May 2017 that the Magistrate ruled in favour of Paromita and her seven-year old daughter was handed over to her.

Paromita is at the moment independently and gainfully employed at Cha Ghar. She is a dedicated employee and works really hard to provide for her family. She lives with her mother and daughter. She is presently focused on her child's education.

In a single life time, she has been forcefully institutionalised multiple times, both by her own mother and by her husband and in-laws. Her child was taken away twice from her. She won the battle every time. Paromita's journey is a living example of her strength and resilience in face of a system that normalises the violation of human rights of persons who have been diagnosed with mental illness.

The UNCRPD to which India has been a signatory is a document that provides some future direction. Particularly, Article 12 of the convention, which guarantees full legal capacity to all persons with disabilities and recognises the personhood, identity and agency of persons with disabilities, is a very important advocacy document. Legal advocacy work in the context of this article to bring about changes in over 150 provisions (Davar 2015) in domestic laws that currently exclude persons diagnosed with mental illness on the grounds of unsound mind would prove to be an important strategy.

Article 23 of the convention that requires State Parties to “take effective and appropriate measures to eliminate discrimination against persons with disabilities in all matters relating to marriage, family, parenthood and relationships, on an equal basis with others” comes closest to a discussion on sexuality rights.

Sexual Rights within the UN Convention on the Rights of Persons with Disabilities

The UNCRPD has been considered to be a comprehensive, participatory, and affirmative document for policy and advocacy work in the area of disability. However, Schaaf (2011) argues that when it comes to sexual rights, the tension between affirming sexuality versus “protection” of women with disabilities from sexual abuse, exploitation, forced hysterectomies, and abortions is visible in the background and draft documents, as well as the final text of the convention. She argues that there are a range of articles within the convention such as right to health (Article 25), freedom of expression, respect for privacy (Articles 21 and 22), respect for home and family (Article 23) and women with disabilities (Article 6) that though currently do not directly talk about sexual rights, provide for ample scope for discussion on sexuality, pleasure, intimacy, access to sexual and reproductive health services and so on. Possible reasons for omitting direct reference to sexual rights within the convention include sexuality seen as being about “desire” as opposed to other, more pressing “needs” in the lives of people with disabilities, a protectionist stance towards sexuality of people with disabilities, particularly women with disabilities, difficulty to reach consensus on issues right to abortion, which is further complicated with the

question of eugenics and abortion of disabled fetuses (Schaaf 2011).

Article 23 of the convention that requires State Parties to “take effective and appropriate measures to eliminate discrimination against persons with disabilities in all matters relating to *marriage, family, parenthood and relationships*, on an equal basis with others” (emphasis ours) comes closest to a discussion on sexuality rights. The article further specifies right to marry, found a family on the basis of free and full consent of spouses, decide freely on the number and spacing of children, have access to age-appropriate sex education, reproductive and family planning education, retain fertility on equal basis with others, adopt children, and so on.

While the article does emphasise a range of sexuality related rights, it does so within the paradigm of reproductive-heterosexuality and marriage. Jaramillo Ruiz (2017) states that with respect to sexual rights, the convention seems to have paid scant attention to sexual self-determination and has gone back to a medical model, “replicating naturalised, biological, and binary conceptions of gender” (94) and sexuality. Assertion of affirmative sexual rights and the idea of “sexual citizenship” seems to be completely missing. Sexual citizenship (Schaaf 2011) here refers to right to self-definition and live as a minority, demanding enabling conditions for sexual diversity and sexual participation for previously stigmatised individuals and groups. The idea here is not to merely make accessible/visible sex within marriage and parenthood to groups who were previously denied this, but to question the very idea of what is seen as “normal” sexuality. Questioning and changing the very paradigm of sexuality would truly make sexual participation for all, a meaningful reality.

Legislations Related to Mental Health and Disability in India

India ratified the UNCRPD in September 2007 and one of the commitments to the convention sought to harmonise domestic laws in the country to match the spirit of the convention. As a result, changes were made to mental health and disability laws, and in the last two years two progressive legislations in the area of disability and mental healthcare—the Rights of Persons with Disabilities (RPD) Act 2016²¹ (extends to 21 types of disabilities including mental illness, intellectual disabilities and autism spectrum disorders) and Mental Health Care Act (MHCA) 2017²² have been passed.

Legal advocacy and change would have to be one of the central fights in realisation of rights of women with psychosocial disability.

While both these legislations apply to and thus have implications for persons with psychosocial disabilities, the MHCA as the name suggests is focused on issues relating to mental healthcare/service provision for those in need of these services. Thus, while the Act has a whole chapter (Chapter V) that deals with rights of persons with mental illnesses, most of these are related to the broader right to (quality, affordable, accessible, dignified) mental healthcare services. There is mention of non-discrimination on the grounds of sex, gender and sexual orientation in mental healthcare services as well as protection of persons with mental illness from violence and abuse. However, there is no mention in this Act about sexual rights or sexual health services and its link with health and well-being.

The RPD, meanwhile, goes beyond the right to health services and engages with a range of rights, including the right to education, employment, housing, and non-discrimination in all walks of life. In the RPD, too, sex and sexuality enter through the backdoor of the rights to reproductive and family planning information, reproductive health services, right to not be forced to undergo any procedure leading to infertility, and protection from sexual exploitation of women and children. Thus, this Act too is silent on rights related to affirmative sexuality. Both these acts discuss legal capacity, but the MHCA does so only in the context and for the purpose of mental healthcare related decisions. The RPD provides for equal legal capacity to persons with disabilities in matters related to finances and property. Impact of these legislations on a range of other laws, that have a clause on unsound mind, remains to be seen.

Finally, it is essential to acknowledge a central role played by law in deciding on issues of capacity and consent. As Davar (2015) argues, legal incapacity can mean loss of citizenship and civil death of a person. Legal advocacy and change would have to be one of the central fights in realisation of rights of women with psychosocial disability.

WAYS FORWARD

In this paper, we have highlighted issues related to sexuality of women with psychosocial disabilities. We have attempted to summarise existing studies done in this area and challenges in advocating for sexual rights of women with psychosocial disability in India. Some possible directions that have emerged for taking work forward in this area with various stakeholders are listed below.

WORK WITH INSTITUTIONS

- Most mental health institutions in the country are currently gender-segregated, and while this segregation to some extent may be seen as necessary even by its residents for the safety and comfort afforded by these, the need for gender-neutral spaces where people can freely intermingle is essential.
- Currently, in several mental hospitals in India, women residents do not even have a locker or any private space to store their personal belongings. This creates a heightened sense of abjectness and alienation. Furthermore, the very idea of surveillance and control within institutions that is presented as necessary supervision needs to be critically evaluated. Support services for residents should not be punitive and invasive of privacy.
- The Mental Health Care Rules 2017 based on the Mental Health Care Act 2017 have laid down minimum standards for mental health establishments, and while they do not directly discuss sexual rights, they dwell considerably on issues such as privacy, dignity, space for personal belongings, non-insistence on wearing of uniforms within the institution, non-compulsion on tonsuring, or cropping of hair and so on. Advocacy to implement these minimum standards is essential.
- Access to contraception, safe sex, and sexual and reproductive health services to residents within institutions is a need.
- Sensitisation, training, and support of all levels of staff within the institution on issues of gender and sexuality would be the key to create an enabling environment, in which some of the affirmative changes discussed above can be implemented.

- Alongside sensitisation and training, the development of clearly laid out and accessible redress mechanisms to address issues of violation of rights within institutions in necessary.
- Some of the issues raised in this section pertaining to surveillance, protectionism, and denial of privacy may apply to women living in familial homes as well. Training and support on issues of gender and sexuality would be as much necessary with family members and caregiver support groups.

WORK WITH LAW AND POLICY

- Ensure legal reform to remove discriminatory barriers to relationships, marriage, and parenting.
- Consent and capacity or competence to give consent is at the heart of sexual decision making and rights. Advocating for legal reform to remove any clause that denies full legal capacity to persons with psychosocial disability as holders of rights and as actors under law is a vital one.
- Make the process of reporting of sexual violence and abuse within familial and institutional spaces more accessible to women with psychosocial disability.
- Provide access to educational material on affirmative sex and sexuality, sexual health, reproductive health services, especially to younger women as well as guidance and support for parenting.
- Include provision of support services that promote socialisation, reduce isolation, and enhance social, friendship, and dating skills.
- Initiate media and other public campaigns to address issues of stigma and shame related to mental illness and psychosocial disability; replacing silence and invisibility with affirmative and sex-positive narratives, images, and symbols.
- Lobby with both, central and state level ministries of health and family welfare (has jurisdiction over mental health services in India) as well as social justice and empowerment (includes disability rights under its jurisdiction) to implement some of the policy recommendations.

PRODUCING KNOWLEDGE AND RESEARCH

- Invest in research that provides insights on sexual experiences, relationships, negotiations of women with PSDs in varied locations of institutions, familial homes, work places, online spaces, and a range of social spaces. These studies may focus on women in different social locations of class, caste, region, gender expressions,

sexual orientations, and may extend to gender non-conforming persons.

- First person narratives that foreground the voice of women with PSDs are invaluable at this juncture.
- Development of curricula, training initiatives, and affirmative literature on sexuality, sexual rights and negotiating difference is much needed.

WORK WITH MENTAL HEALTH PROFESSIONALS

- Currently, training of mental health professionals neither includes adequate input on perspectives related to sexuality/sexual diversity and its relationship to personhood, well-being, and health, nor does it include skills related to affirmative counselling on sexuality related issues. Influencing graduate and post-graduate curricula of medical doctors, psychiatrists, psychologists, social workers, and other courses in counselling is necessary.
- Rehabilitation professionals, particularly those working with people who have long-standing mental health problems, need to be trained to routinely include sexuality related issues in their assessments and rehabilitation plans.
- Developing ethical guidelines on service provider-client relationship addressing issues of sexual and non-sexual boundary violations would help enhance quality of care.

WORK WITH WOMEN WITH PSYCHOSOCIAL DISABILITIES AND CROSS-MOVEMENTS ALLIANCES

- Collectivise and form support and social networks of women with psychosocial disability to reduce isolation and enhance possibilities of socialisation.
- Make space within disability rights movements and mental health support groups to talk more about affirmative sexuality and sexual rights and help with building confidence, esteem, and solidarities. Likewise, movements and campaigns on sexual and reproductive health and rights need to take on board concerns of women with psychosocial disability.
- Work towards coalition and solidarity building between people with diverse kinds of disabilities.
- Make efforts to include LGBTQ persons living with disabilities in campaigns related to disability and sexual rights.
- Given the close relationship between violence, trauma, and psychosocial disability, initiatives on domestic violence and violence against women need to address and integrate issues of psychosocial disability in their work.

ENDNOTES



1. A cisgender woman is someone whose gender identity matches the gender she was assigned at birth.
2. The term “vanilla” refers to what is regarded as conventional sex, which in most cultures would mean heterosexual sexual intercourse, with man-on-top or missionary position.
3. “Skin-hunger” is the term used by Ratnaboli Ray at the Conference on Pleasure, Politics and Pagalpan (May, 2017) to denote sexual deprivation among women living inside mental hospitals for long periods of time.
4. When we use the term body-mind, we do not mean to reinforce this dualism. However, given the invisibility of the mind and psychic processes in many conversations in the area of health, as well as disability, we are attempting to underline experiences of the mind and hence the use of this term.
5. “Sexual rights” is a broad term used to articulate discrimination and marginalisation associated with certain sexual expressions, behaviours, conduct, identities, and relationships (ICHRP Report 2009).
6. Most of the studies quoted here have been focused on women with mental illness and most do not employ a disability lens to analyse the issues that they raise.
7. See <http://indianexpress.com/article/cities/mumbai/treated-but-abandoned-women-with-history-of-mental-illness-languish-in-institutions-4859706/>.
8. See <http://www.thehindu.com/todays-paper/tp-national/Furor-over-naked-patients-in-Bengal-mental-hospital/article14575827.ece>.
9. See <http://www.hindustantimes.com/kolkata/bengal-mob-lynches-mentally-ill-woman-after-branding-her-a-child-trafficker/story-xMcNPNb6oatfnrrUM7D3HP.html>.
10. See <http://indianexpress.com/article/india/villagers-lynch-mentally-challenged-woman-suspecting-she-was-witch-4780023/>.
11. This refers to injecting the patient with sodium pentothol, a short-acting barbiturate (referred to as truth serum) to help patients recall suppressed emotions and events.
12. It is important to note that the ICD-10 is currently undergoing revision and a new version in the form of ICD-11 is likely to be released in 2018, although it is unlikely to treat sexual dysfunctions categories any differently.
13. Sections of this paper have been previously published in the following two publications of the same author –
 - a) Ranade, K. (2017). Mental Health Concerns of Persons with Non-Normative Sexualities and Gender Expressions/LGBT, Module No. 28, Paper on Mental Health/Social Work, Prepared for UGC E-PG Pathshala. Available at <http://epgp.inflibnet.ac.in/ahl.php?csrno=32>.
 - b) Ranade, K., Chakravarty, S. (2016). ‘Coming Out’ of the Comfort Zone: Challenging Heteronormativity Through Affirmative Counselling Practice with Lesbian and Gay Clients. In Bhola, P. & Raghuram, A., (eds.) *Ethical Issues in Counselling and Psychotherapy Practice: Walking the Line*, Springer Singapore, pp. 141-154.
14. The mental health professionals petition to the Supreme Court is available at http://orinam.net/377/wp-content/uploads/2014/04/CurativePetition_MentalHealth.pdf.
15. For more discussion on treatments for correcting gender expression, read Pyne, J. (2014). The Governance of Gender Non-Conforming Children: A Dangerous Enclosure. *Annual Review of Critical Psychology*, 11, 76-96.
16. Ramanathan, S. When Doctors Turn Gate Keepers: Indian Transgender Community’s Battle for Mental Health, *The News Minute*, July 30th, 2017. Available at <http://www.thenewsminute.com/article/when-doctors-turn-gatekeepers-indian-transgender-community-s-battle-mental-health-66001>, last accessed on 21/10/17.
17. See Chakrapani, V. (2010). Hijras/Transgender women in India: HIV, human rights and social exclusion. TG Issue Brief, UNDP. Available at http://www.undp.org/content/dam/india/docs/hijras_transgender_in_india_hiv_human_rights_and_social_exclusion.pdf, last accessed on 21/10/17 and Dr. Sylvia Karpagam, Trans Persons’ Rights Bill: Ignorant voyeurs are becoming policymakers, and this must change, *The News Minute*, September 12, 2017. <http://www.thenewsminute.com/article/trans-persons-rights-bill-ignorant-voyeurs-are-becoming-policymakers-and-must-change-68277>. Last accessed on 21/10/17.
18. A total institution is a place of work and residence where a great number of similarly situated people, cut off from the wider community for a considerable time, together lead an enclosed, formally administered round of life (Goffman, 1961).
19. Efforts are being made to delink the two concepts of mental illness, a medical issue determined by mental health professionals and unsound mind, a legal issue, determined by legal experts. However currently, in practice the two are seen and used interchangeably often to the detriment of the person diagnosed with mental illness. Read comment by Dr. S Pathare on Supreme Court’s order of medical examination of Justice Karnan for further clarity on the need to make a distinction between mental illness and unsound mind. <https://thewire.in/130987/supreme-court-justice-karnan/>.
20. The New Mental Health Care Law 2017 rules for which have been recently framed in September 2017 states that previous history of mental illness cannot be used to determine (legal) capacity in the person. This provision has been used very well in this situation.
21. See <http://www.disabilityaffairs.gov.in/upload/uploadfiles/files/RPWD%20ACT%202016.pdf>.
22. See <http://www.prsindia.org/uploads/media/Mental%20Health/Mental%20Healthcare%20Act,%202017.pdf>.

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Sexual Rights of Women and Psychosocial Disabilities: Insights from India

This thematic paper is an output of an initiative of the Asian-Pacific Resource and Research Centre for Women (ARROW) and Anjali Mental Health Rights Organization, which focuses on the intersections of sexuality, sexual and reproductive health and rights, mental health, and psychosocial disability.

ARROW is a regional and non-profit women's NGO based in Kuala Lumpur, Malaysia, and has consultative status with the Economic and Social Council of the United Nations. Since it was established in 1993, it has been working to advance women's health, affirmative sexuality and rights, and to empower women through information and knowledge, evidence generation, advocacy, capacity building, partnership building and organisational development.

Founded in 2001, Anjali is one of the leading non-governmental organizations, based in Kolkata, West Bengal (India), that brings human rights, gender, sexuality lens to mental health treatment, care, and policy development through a combination of right-based programs, policy initiatives and cross-sector partnerships with the Dept. of Health & Family Welfare, Government of West Bengal, the media and civil society. Anjali aims to secure large-scale systemic changes in the mental health field, by making mental health institutions and systems inclusive.

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