

#### Pleasure, Politics and Pagalpan

### National Conference on Sexuality, Rights and Psychosocial Disability

13-14 May, 2017 Kolkata, India

#### **ABOUT US**



Established in 2001, Anjali is a not-for-profit voluntary organisation based in West Bengal, India. Anjali operates within an intersectionality framework, bringing 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 Government, the media and civil society.



Established in 1993, ARROW is a regional non-profit women's organization based in Kuala Lumpur, Malaysia. ARROW works closely with many national partners in countries, regional and global networks around the world, and is able to reach stakeholders in 120 countries.

We acknowledge the support from CREA.

**CREA** is a feminist human rights organisation based in New Delhi, India. It is one of the few international women's rights organisations based in the global South, led by Southern feminists, which works at the grassroots, national, regional, and international levels. Together with partners from a diverse range of human rights movements and networks, CREA works to advance the rights of women and girls, and the sexual and reproductive freedoms of all people.

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Pleasure, Politics and Pagalpan Co-convened by Anjali & ARROW Supported by CREA Other partners: OAK Foundation, Hidden Pockets (Media Partner) Published by: ANJALI

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#### **List of Abbreviations**

ARROW	The Asian-Pacific Resource and Research Centre for Women
BDSM	Bondage, Dominance, Sadism and Masochism
DSM	Diagnostic and Statistical Manual for Mental Disorders
ICD-10	The International Classification of Disorders- 10
MHC Act	Mental Health Care Act
NGO	Non-Governmental Organization
OCD	Obsessive Compulsive Disorder
OPD	Out-Patient Department
PILs	Public Interest Litigations

## Introduction "Access to pleasure is the most important accessible issue within psychosocial disability and let's focus on pleasure, which is not just one kind of pleasure, but many different kinds of pleasure." - Ratnaboli Ray

#### Introduction

In the context of India, sex, sexuality and mental health have conventionally been a subject of shame and discrimination. The uncanny silence that exists around the issues pushes an individual in isolation and creates invisibility on issues that are core to that individual. When these already tabooed issues (sex, sexuality, mental health) break their boundaries and intersect with each other, it faces severe opposition and resistance. Just the thought, that a person with psychosocial disability can have sexual desires and they can act on it, is nothing less than blasphemous. On being labeled as 'pagal' (mad), the individual immediately loses agency over their body, life and decisions related to it. Violation of consent becomes an everyday reality for them. In this context, exercising their sexuality, desires, fantasies and pursing pleasures, becomes next to impossible. Owing to these restrictions they become 'desexualized' and are further pushed to the edge. Predominantly, the conversation on mental health is focused on recovery and sexuality often finds no space in the conversation.

Given this context, Anjali Mental Health Rights Organization and ARROW (The Asian-Pacific Resource and Research Centre for Women) co-convened 'Pleasure, Politics and Pagalpan'- a national level conference on sexuality, rights and psychosocial disability with support from CREA. The two day conference was organized on May 13 and 14, 2017 in Kolkata, India.

On the first day, the conference started with a keynote address titled **Sexuality**, **psychosocial disability and psychosocial wellbeing**. It helped in establishing the rationale for the conference and setting the context for discussions on psychosocial disability and sexuality. Speakers focused on the current paradigm, politics and conflicts around sexuality. This was followed by the second session **Practice: The concerns and dilemmas in dealing with sexual expressions of persons living with psychosocial disability.** The panel consisted of caregivers and mental health professionals. The discussions focused on strategies and approaches used by individuals and organizations to bring together the issues of sexuality within the mental health framework. The third session of the day was **Sexuality and its connects**. The session brought out the intersections, pathways and possible connections between sexuality and psychosocial disability. Discussion during this session also focused on consent, diversity in sexual expressions and made its connections to the existing discourse on sexuality and disability.

The second day of the conference started with the session *Pleasure*, *danger*, *eroticism and fantasy*. The session explored various forms of sexual expressions, pleasure, consent, agency, access and autonomy. The second session for the day, *Determinants*, focused on social, cultural, legal, medical factors that act as barriers to sexuality and its expression. The *Concluding session*, provided a summary of the discussions that took place over two days and looked at ways forward.

The conference brought together the three issues of sexuality, rights and psychosocial disability and created a dialogue where intersections of these three issues can be viewed together. It brought together mental health professionals, academicians, women's rights activists, film maker, lawyer, writer and social justice activists together on one platform to locate sexuality and rights within the realm of mental disability. During the conference a range of evidences from personal and professional spaces were shared to substantiate the existing gaps in the current discourse around sexuality and psychosocial disability. The conference also helped in substantiating the relevance of these issues and various challenges were discussed around addressing sexuality and rights within the mental health framework. Focusing on the lacunae, the conference established that there is a need to have a holistic and inclusive conversation on sexuality and sexual expressions within the mental health framework. It was agreed that going forward, the conversation must be taken out of the academic and intellectual spaces to reach out to more number of people.

This report is based on the proceedings of the 'Pleasure, Politics and Pagalapan' conference. It focuses on four themes that emerged out of the conference. The themes are: **Sexuality and Psychosocial Disability: The Disconnects**; **Agency and Consent: Key Elements**; **Pleasures and Desires**; **Challenges and Progress** and **Way Forward**. The report explores each of these themes through the dialogue that happened across six sessions, and lays out a direction to take this conversation forward.

## Sexuality and Psychosocial Disability: The Disconnects

"We don't speak about psychosocial disability, we don't speak about sexuality...sexual behavior is controlled by: law, medicine and society itself. So within law, you may become illegal, within medical sciences you will become ill and within society you will become illicit."

- Chayanika Shah

#### Sexuality & Psychosocial Disability: The disconnects

#### **Sexuality**

Sexuality covers a wide spectrum of issues that encompasses sexual, emotional, desires, fantasies, erotic, social etc. The conference touched upon some of these issues like sexual behavior, sexual and gender identity, sexual orientation and preference, fantasy, romantic relationships, affective state- keeping psychosocial disability at the center. Speakers upheld, reinforced and validated that individuals experience and express sexuality in different ways.

In India, sexuality is spoken primarily in the context of Sexual and Reproductive Health and violence. The focus is generally on sexual abuse, unsafe sexual practice(s), unwanted pregnancy, infections and abortions. While these are important issues to deliberate on, the concept of pleasure, which is also core to sexuality, rarely gets addressed.

Further, society has a fixed way of understanding sexuality. It includes able-bodied individuals, a heterosexual (man-woman) relationship, peno-vaginal sexual act which is aimed towards reproduction. So any individual that fits this narrow definition is accepted by the society as a 'normal' individual, while others are labeled as 'deviant' or 'abnormal'.

#### **Psychosocial Disability**

During the conference, speakers focused on chronic mental disorders, psychosocial disability and the effect of physical disability on mental health. These issues were viewed in close conjunction with sexuality.

Society, culture, law and science have conveniently divided individuals in binaries of *pagalpan* (individuals who have mental disorder/disability) and *non-pagalpan* (individuals who are classified as 'normal'). It means that any individual who does not fit in the set criterions laid by the society is labeled as *pagal* (crazy/mad). For example- individuals who want sex that is more than the designated limit set by the society, individuals who are not interested in sex, individuals who do not follow the heteronormative beliefs, individuals who do not identify with the gender assigned to them at birth- are all labeled by the society, law, culture and science as 'mad'. Breaking the two binaries of *pagalpan* and *non-pagalpan*, one of the speakers pointed out that the two categories created by the society are not as distinct as it would like to believe. Instead "pagalpan is a spectrum on which we all stand at different points, in different ways, at different times in our life."

#### **Disconnects**

There is a common thread that connects sexuality and psychosocial disability. Sexuality is not just limited to the body. In fact it extends to include both mind and emotions. Society through

its set binaries looks at sexuality from a very narrow perspective. It only approves of heteronormative behavior and anything that is outside this definition is labeled as deviant. Similar to sexuality, society also has rigid ideas and fixation with able body and sound mind. And anyone who doesn't fit into this normative structure is termed as disabled. But talking specifically about psychosocial disability, which contains words like 'psycho' and 'social' it clearly indicates that psychosocial disability is not just limited to the mind. Infact, mind, body, feelings and society plays a huge role in it. And we consider all these things when we talk about sexuality.

Both the issues are highly stigmatized and there is complete silence around it, to the point of ignoring its sheer existence. Individuals with psychosocial disability are often considered asexual and if their sexual desires do not match the 'normal' sexual behavior, it automatically comes under the realm of psychiatry. And this is where, disconnect between sexuality and psychosocial disability begins to widen. Psychiatry follows a stringent view on sexuality and any type of sexual expression that falls outside the realm of the 'normal' sexual expression is labeled as deviant. This deviancy is classified under the medical world as sexual disorders/abnormal behavior.

In earlier times, homosexuality was seen as a kind of mental illness. This dominant discourse was challenged by sexual rights activists and because of their efforts homosexuality was depathologized. But there still exists several kinds of sexualities and sexual expressions that are pathologized. ICD-10 (The International Classification of Disorders) has classified fetishism, sadomasochism, exhibitionism, voyeurism and pedophilia all in one category of mental disorders. The reference point for all these different kinds of sexual expressions is only one kind of sex, which is the heteronormative, peno-vaginal sex that is aimed at reproduction. Consent and autonomy, finds no place in this classification.

In addition to this, the classification is also gendered in its diagnosis. F-52 under the ICD-10 focuses on erectile dysfunction in men. In order to know that the problem is psychogenic and not organic/physical in nature, the diagnosis tries to ascertain that the man is getting an erection while masturbating, sleep or while having sex with another partner. Contrary to this, there is vaginismus or dysperonia, which is painful intercourse or inability to have intercourse, where the only thing that is mentioned is that it is unusual for women to complain of primary vaginal dryness except as a symptom of post-menopausal estrogen deficiency. However, the classification does not take into consideration that women too can get sexually aroused.

Psychosocial disability comes with a sort of 'invisibility'. This means that individuals suffering from psychosocial disability might pass off as 'normal' individuals. It may be hidden by individuals and their families out of shame and fear often deprive them of most of their rights.

Given the invisibility and silence that exists around sexuality and psychosocial disability, the society through its various structures tries to control behavior of individuals so that they can fit into a narrow binary of 'appropriate, acceptable and normal' behavior. But if an individual breaks away from this binary and the so-called norms, various structures (law, medicine and society) of the society come together to exercise control over their behavior, punish and confine such individuals. Thus within the law, they become illegal, medicines declare them as ill and

society defines their behavior as illicit. These structures also come together to set norms and create a sexual subject which fits into a narrow understanding of what a sexual act can be, what kind of sexual relationship can exist and what kind of sexual transaction society will accept and reward. Quite often, in case of a deviancy from the set norms, these structures use corrective measures such as forced marriage, rape and sexual or other forms of violence and abuse, to bring them back to 'normalcy'. During the entire process, agency, autonomy, consent and decision making ability of such individuals are grossly abused and disregarded by all the institutions (family, legal, psychiatric). This control is often justified to be done in the interest of individuals with disability and 'for their own good'.

Even though sexual desires are considered as inherent to every individual and it is the most fundamental need of human beings, yet society fears the free expression of sexual desires, especially by women. The social institutions thus work together with law, medicine, language, culture and religion to repress and control sexuality.

#### Medicine

Psychiatry has a very uneasy relationship with sexuality. Freud pathologized various expressions of sexuality and stated that a lot of psychiatric issues emerge out of problems related to sex. Infact, Frued also claimed that homosexuality is a problem of development and it happens because an individual is 'stuck' at the anal phase. Although now DSM has done away with homosexuality and gender identity disorder, yet psychiatry's views on sexuality still remains questionable. A lot of sexual expressions are still classified as 'disorders'. Till now, students of

psychiatry are still being taught about sexuality from pathological perspective. This results (social professionals workers, counselors, psychiatrists and nursing staff) at the mental health institutions, failing to respond sensitively to situations when clients express their sexuality. For example, there is no space for privacy for clients who want to engage in pleasure seeking activities. The medical world tries to control such expressions using different ways. Medicines that are often prescribed to clients (suffering from depression and anxiety) have

"In OPD, 80% of the patients have common mental illnesses which are anxiety, depression, OCD. These persons have full legal capacity and psychiatrists have no role there in decision making. However the drug that we prescribe has sexual side effects." – Anirudh Kala

severe side effects on sexual desires of individuals. There is complete silence about it and no effort has been made to reduce side-effects of the medicines that are prescribed. The story of forcing surgery on individuals, within mental health institutions, to control their reproduction and sexual desires are not new.

Talking about love, touch and sexual desires are completely forbidden within mental health institutions. If authorities get to know of clients engaging in sexual activity or having intimate relationship, they try to control it. Psychiatrists increase their medicines, nursing staff deprives them of things that they like and they are further pushed into isolation. Therefore the issue of

sexuality is very systematically brushed under the carpet and it remains a restricted, forbidden and a prohibited sphere for both men and women within the mental health institutions.

Breaking away from these constraints and controls, Banyan, a mental rehabilitation NGO (based in Tamil Nadu, India) tried acknowledging sexuality and expressions of sexuality within the mental health framework. But their effort was challenged and criticized and ultimately they had to close their initiative.

#### Society

Society exercises a lot of control over the expression of sexuality by individuals with mental disability. Society has a heteronormative view of sexuality and it dictates sexual expressions in various ways —who can a person desire, what can give someone pleasure, who can a person have sex with, how much sex can someone have and who can have sex?

The idea of love/relationship is influenced by age, gender, caste, class, religion and conduct and any deviations from the set norms are to be controlled and punished. These rules and control become even more stringent when we talk about an individual with mental disability. Even within the framework of mental disability and sexuality, gender plays a key role. The chances of

a man with psychosocial disability finding a partner/getting married is much higher as compared to a woman with a similar disability.

Focusing on the context of sexuality and mental disability, family is the first stage where an individual with mental disability loses their agency and ability to "Madness is merely a social construction. It's a cultural construction, it's a mythological construction." — Val Resh

take decisions for themselves. This is replicated in multiple ways by other controlling factors (medicines and legal systems) that exist in the society. In addition to this, if an individual is diagnosed with some mental disorder, the disease becomes a lifelong identity of that person and all their experiences, activities, expressions, viewpoints and ideological stances are interpreted from the very lens of a mental disorder. Stigma and discrimination that is attached to mental disability knows no bound and simultaneously it reduces the chances of- finding a job, partner, stability and the space to define and explore recovery from client's perspective.

#### Legal

In the current context, laws in India are not very supportive of the sexual rights of individuals with disability. However, two new disability related laws have been introduced, namely the Mental Health Care (MHC) Act and the Rights of Persons with Disability Act. The MHC Act guarantees the right of individual with mental disability to live with dignity and provides protection from cruel, inhuman, degrading treatment, right to privacy, right to adequate space, sanitation, access to articles of personal hygiene, right to be protected from all forms of vernal, physical and emotional abuse. The Rights of Persons with Disability Act has similar provisions

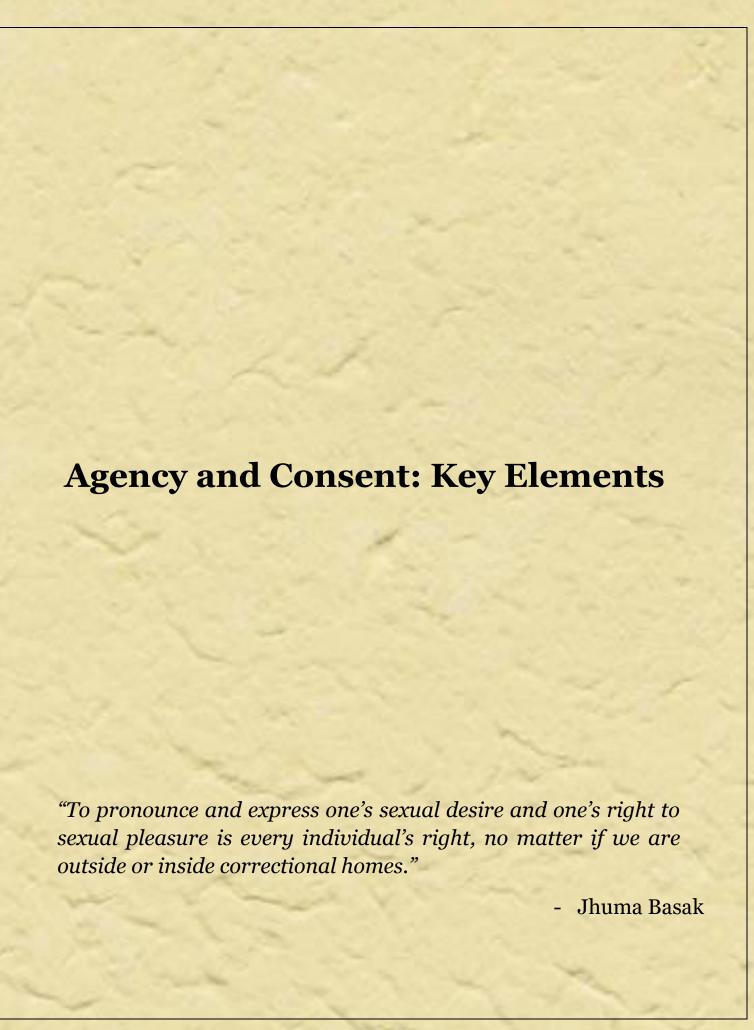
to the MHC Act and guarantees rights to equality, dignity and personal liberty of persons with disabilities. However both the laws are designed in the context of marriage and reproduction. In addition to this, effective implementation of these laws is another issue altogether to focus on.

Even within the laws governing marriage, one of the requirements under the Hindu law is that an individual who is capable of giving valid consent can get married. It means that the person should not be suffering from mental disorder or should not be unfit for marriage and

"Sometimes the law is very black and white, but cases are not black and white."- Jayna Kothari

procreation. This particular section is used extensively by individuals, especially men, to get out of relationship/marriage. It clearly reflects a discrepancy within the legal framework where on one hand the disability laws recognize their legal capacity but on the other hand, it is not recognized within marriage laws.

There also exists disconnect between sexuality, mental health and legal structures at some level. Focusing on BDSM (Bondage, Dominance, Sadism and Masochism), a type of sexual expression, consent plays a crucial role in the act. But the medical world looks at it as a sexual disorder and places it at the same level as pedophilia where consent is absent. The legal structures, on the other hand, finds it easier to cast things in the binary of black and white and fails to capture the fluidity and nuances of what consent means.



#### **Agency and Consent: Key Elements**

Even though the conference mostly centered on drawing connections between sexuality, psychosocial disability and rights, pertinent issues around agency, consent and the politics of control were also discussed. It is not new how society uses its various structures (gender, class, caste and religion) to govern and control life of individuals. This control is not only focused on limiting interactions of individuals from different groups but also extends to their private life and controls their concept of pleasure, channelizes their desires in terms of who they can enter in a relationship with and ultimately how they express their sexuality. Thus, systematically, individuals who are 'able bodied' and have a 'sane mind' lose their agency and control over their life decisions at multiples levels. Gender also plays a crucial role in this and as a result men have more agency over their life-decisions as compared to women and individuals of other gender orientation. Validating the idea, one of the speakers, pointed how socialization plays a crucial role in making children dependent, helpless and vulnerable, which is unconsciously/consciously targeted towards making them disempowered. While growing up, children are made to believe that somebody else knows about their body and desires much more than they do. While growing

up they (children) imbibe these values and slowly loose agency over their life.

Drawing attention to physical disability, one of the speakers reinforced how disability makes an individual much more vulnerable as compared to others and its impact on mental health. Talking about agency, she pointed towards issues around 'privacy', which is one of the biggest challenges faced by individuals with mobility impairment. Disability

"I was married for 10 years before
I came to the institution, so why is
it that now I am being told what
to do and what not to do? I feel
like a child. And is this fair?" - A
woman confined within a mental
health institution.

brings in dependency on other family members and has a huge impact on individual's self-esteem, power to decide for themselves and also impacts their sexual expressions.

Society, on the other hand, has a completely different way of looking at individuals with psychosocial disability or having other forms of mental disability. With support from its various structures (culture, language, medicine. law) and institutions, society goes out of its way to invalidate sheer existence of individuals with mental disability. Following this, their expressions, desires, needs, aspirations and identity become invisible and inconsequential in the eyes of the society. They are neither considered 'capable enough' to give consent nor are they given any agency to take decisions or make choices for themselves. After being labeled as 'pagal' (mad), individuals lose their agency and control over their life, their body and their right to decide for themselves.

Sabotaging agency of individuals with psychosocial disability, starts from the family level and extends to every other aspect of their life and structures they approach (medical facilities, legal structures etc.). After being labeled as 'mad', their consent on issues related to their life holds no significance and it is rarely asked for. Desires, sexuality and sexual expressions of such individuals become the prerogative of the family members and they go to any extent to control

and repress it. If for instance, an individual having psychosocial disability or any other form of mental illness wants to establish a consensual sexual relationship or get married, they are taken out of therapy, locked, deprived of basic amenities and end up facing a lot of violence.

This repression is much more distinct within a mental health institute. Infact the medical field 'normalizes' the absence of desires, pathologies any form of touch and goes to a great extent to restrict, prohibit and forbid manifestation of desires and suppress an individual's freedom. These prohibitions are not just limited to sexual desires or intimacy. Infact it extends to their access to basic and simple pleasures like dressing in nice clothes, eating things that one likes, desire to be accepted without any stigma and to just be.

On reaching a mental health facility, such individuals further loose whatever little agency they were left with over their life. Their consent on issues related to their medicines and treatment, relationships and other aspects of their life, holds no significance when they enter a mental institution. Approach of the institution and its staff is often condescending in nature and the 'incompetency', of individuals with mental disability, 'to give consent' is often assumed. And based on the assumption, decisions are often taken for them without their knowledge or any consultation.

Attitude of the staff is often loaded with patriarchal notions and the institution has no qualms in enforcing control. Most of the hospitals follow a 'no sex policy' and provides no space to talk about desires and pleasure and address issues related to sexuality of individuals with mental disability. Medicines, that are often prescribed to them have severe side effects and reduce their sexual desires. But these issues rarely find a space to be talked about as the main focus is on 'treating' the client and sex should be the least of the worries. Such medicines and surgeries (hysterectomy) are often forced on individuals with mental disability to control their agency over their body, life and sexual and reproductive choices. In addition, all these controls are justified under the pretext of 'working towards recovery and betterment of the client'.

But who holds the power? Talking about it, one of the speakers shared their experience of integrating sexuality in their work around mental rehabilitation. Based on the demand of some of their female residents, Banyan (a mental rehabilitation NGO in Tamil Nadu, India) opened a cafeteria within their premises to provide a safe space to their (female) residents where they could invite people from the outside, sit, talk, flirt and socialize. This effort caused a huge uproar in the society and Banyan was accused of sexually exploiting their female residents under the garb of running a rehabilitation center. Because of the backlash, they were forced to close the gates for the residents. It clearly indicates that society through its various structures work together to decide who should have the power to decide for themselves, how much can they decide for their life and it lay down in most uncertain terms who should be left with no agency over their life. Society works cautiously to draw these boundaries for individuals and anyone who tries to move over is punished and confined. This is often justified under the pretext of 'protecting' the rights of individuals with disability.

The protectionist approach is extremely problematic at multiple levels. Even though, theoretically, the recovery model, under medical science, focuses on the agency of individuals (with mental disability); reality has an altogether different story to narrate. A similar approach

is followed at the societal level as it clearly distinguishes and discriminates between agency, competency (to give consent) and decision making ability of individuals with mental disability in comparison to 'normal' individuals. In a daily life situation, every individual exercises their choices and based on risk assessment, take decisions for their life (relationships, love, career etc.). Outcome of some of these decisions are positive and sometimes it results in negative outcomes. But having negative consequences does not deter a 'normal' individual to take future decisions for their life. In this case, the society and its different structures, do not rush in, to take away rights of take future decisions for their life. Contrary to this, a decision with a negative outcome, in case of an individual with mental disability, means giving away their right to control and decide for their body, life and rights.

The interference of medical science does not end here. It violates an individual's right to explore their sexuality by classifying them as 'sexual others'. It means that individuals whose sexual choices and preferences do not conform to the heteronormative, peno-vaginal sexual act, are classified as 'abnormal' and offered treatment. Agency and control of individuals (with or without mental disability) gets challenged at every juncture because of their choices, actions and even their fantasies. For example, if a person gets aroused by non-living objects (fetish) or if a person gets pleasure by sexual activities that involve bondage/pain/humiliation (e.g., in BDSM), that makes a person dangerous and the person's condition should be diagnosed, as it interferes with the societal notion of sexual activity. There is no space to talk about consent, pleasure, desire and violence in classifications of mental disorder. So, two or more consenting adults who engage in BDSM are labeled as abnormal. But at the same time, a sexual relationship between a man and a woman (without consent/violent) within the institution of marriage is happily accepted as a norm and it becomes a standard yardstick to judge other sexual activities.

The concept of desire/pleasure and fantasies does not really fit the clean binaries that are set by the society. It stems from an individual's unconscious state and need not always be politically correct. Infact, to a great extent an individual's fantasy is conditioned by the society and more so by things that are strictly prohibited and restricted by the society. This applies to both individuals with mental disability and one's with no disability. Even though immense shame and stigma is attached to desires and fantasies, controls that are imposed on desires are different for individuals with mental disability. Love, affection, touch, fantasies, desires, relationships are concepts that must stay outside the boundaries of mental health institutions. Because if they get to know, then psychiatrists will increase the medications, the hospital staff will cut down on basic amenities and the individual is further pushed in isolation.

Despite the fact that consent and agency was mostly spoken in the realm of violence during the conference, one of the positive things that came out was in the form of two laws- MHC Act and the Rights of Persons with Disabilities Act. Both these acts, recognizes the agency of individuals with mental disability and upholds their right to equality, dignity and personal liberty. During the conference, an example was shared that depicted how the legal system works towards protecting agency and rights of individuals with disability. In *Suchita Srivastava Versus Chandigarh*, the Supreme Court upheld and protected the reproductive rights of a woman with mental disability:

The court passed the judgement that the applicant has a right to autonomy and if she decided to have a child, the court cannot take away her rights.

Although spoken strictly in the context of reproductive rights, the judgement also reinstated that:

An individual's right to privacy, dignity and bodily integrity should be respected.

The judgement also implied that no restrictions (in terms of participation in sexual activity or usage of contraceptive methods) must be placed on reproductive choices of an individual. Having said that, the legal structures along with other structures in the society, still have a long way to go before they understand the spectrum of sexuality and nuances of consent, within the context of mental disability and integrate it in their systems.

# **Pleasure and Desire** "Both pleasure and pagalpan are political issues and that is something we don't usually talk about." - Shampa Sengupta

#### **Pleasure and Desire**

During the conference, speakers and panelists drew connections between sexuality and psychosocial disability by looking at the concept of desire and pleasure. Additionally, they looked at how different structures in the society work together to control the agency of individuals with mental disability to express their desires and seek pleasure. Moving away from the popular understanding of desire, which generally means only sexual desire, panelists looked at a broad spectrum of desires. It ranged from the desire to look good or attractive, to wear make-up, to be loved and give love, clothes, food, touch (including sexual touch), reproduce, to care for someone and give affection, to be oneself, to be accepted by the society and have an identity.

These desires not only differ from individual to individual but are defined and influenced by culture, norms and structures laid down by the society. Even though desire is different for each individual, society goes out of its way to limit it by creating a binary of 'appropriate' and 'inappropriate'. Based on gender, class, caste and religion, these desires are then forced to fit in this binary. It means that a relationship between two individuals can only be explored within the institution of marriage and that it must only happen between individuals of opposite gender (man-woman) from the same caste, class and religion. This is defined by the society as 'appropriate' and if an individual desires anything outside these rigid boundaries (other forms of sexual desires like fetish, homosexuality or BDSM), the society labels it as 'inappropriate' and goes to any extent to stigmatize, constrict and punish such desires. Such norms also define who can have desires and what the object of their desire should be. Thus a man can have uncontrolled sexual desires whereas a woman's desires are to be restricted for 'their own good'.

The constraint amplifies multifold when we talk about individuals with psychosocial disability or having other forms of mental disability. Individuals with such a disability are often denied the right to seek pleasure and desire for things/people. In case they try and express their desires through their clothes, by wearing make-up or food, things which are usually considered fundamental for other individuals, they are often mocked at, stigmatized and punished for both 'having' and 'pursuing' such desires. And to top it all, their access to such 'basic' desires is restricted. Their psychiatric diagnosis overshadows their personal identity, envelops their entire life and defines their desire, imagination and thought process.

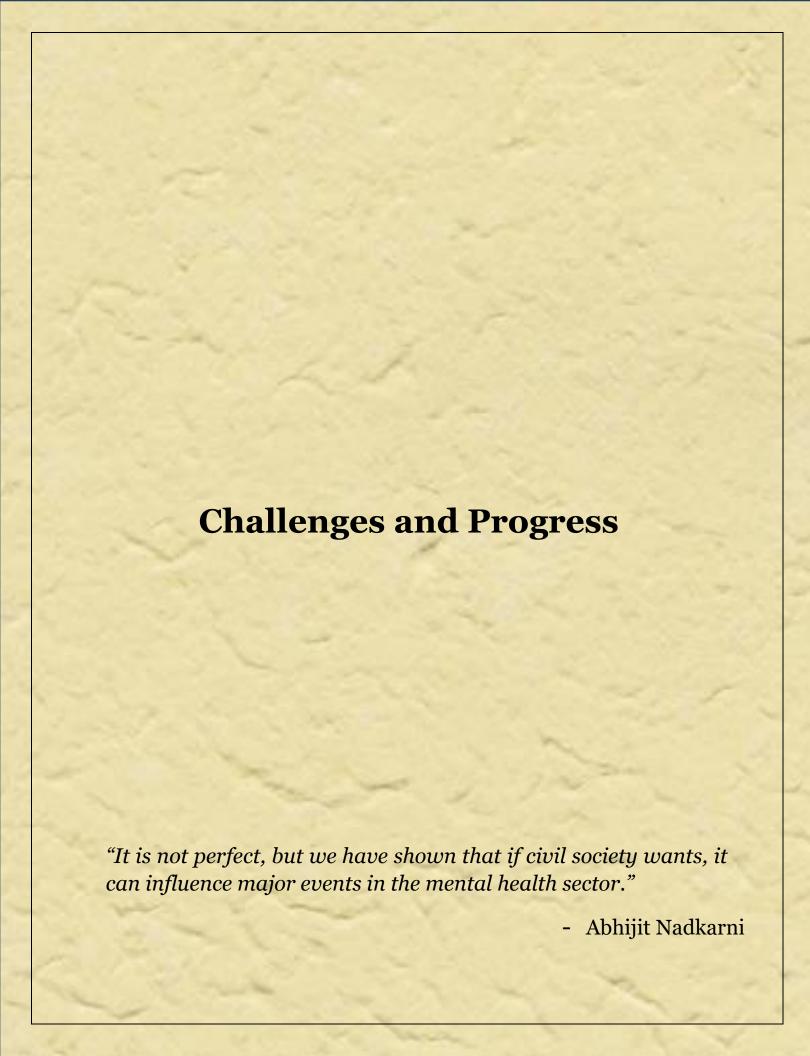
Their desires, when viewed from the lens that society offers, often seem flawed and are deemed inappropriate in the 'normal' world and rigorous efforts are made to control and repress their desires. Under these circumstances, even getting access to scrumptious food is highly stigmatized. Desires around sex/intimacy/love/care/reproduction/parenting are completely out of the question. The control and repression is much more within mental health institutions, where the institutions follow a strict 'no sex policy' and provide no space to talk about desires and pleasures of individuals. The attitude of hospital staff is often patriarchal and they exercise their power to control any pleasure seeking behavior of those in institutions. To top it all, medicines that are prescribed to them often have severe side-effects and reduce their sexual desires. Forced surgeries (hysterectomy) are often carried out on women with mental disability with complete disregard to their agency over their body, life and sexual and reproductive

choices. Such repression is often justified under the garb of 'recovery'. Both society and mental health institutions often consider their desires for intimacy and relationship as inconsequential and their access to such pleasures is often trivialized by comparing it with their access to healthcare services & medicines, which often takes the focus, when talking about mental health.

Desires are often influenced by an individual's lived realities, social conditioning and tend to get affected by what is prohibited by society. Language and culture play an equally negative role in suppressing desires that are defined as 'inappropriate'. Anything that does not fit what is considered appropriate by society is deemed as 'sleazy' and 'cheap'. Sex for pleasure is a taboo and is deemed appropriate only for reproduction. There is an absence of positive language to describe sex for pleasure and desires that is not restricted to the binaries of appropriate and inappropriate and that is not for reproduction.

Society uses its repressive ways to create a popular culture and language that validates its ideas around acceptable desires. Challenging the popular culture, one speaker stated that culture should not be seen as a constant and it carries within it the idea of mobility. It means that culture is dynamic and mobile. It keeps changing and provides many opportunities to bring change. Even though currently the popular culture dictates a certain type of language and norms around pleasure, there also exists an alternative culture which tries to break away from the dominant and politically correct language. This alternative culture provides space to be ambiguous, view a spectrum of pleasure and desires, define and redefine concepts and create a language of pleasure that is both accessible and inclusive in nature.

Validating these suggestions, another speaker gave an example of 'Agents of Ishq', a multimedia project that breaks away from the retrogressive and mainstream ideas around sex, love and desire. It challenges the dominance of the popular culture and creates a language around desire that is not restricted to the academic or intellectual space. Through this project, the team has reached out to common people, challenges regressive binaries and understand desire and pleasure in a language that comes directly from people. Additionally, many speakers, during the conference, emphasized on the need to focus on 'access' to pleasure especially in the context of mental disability where the conversation still revolves around treatment, healthcare and infrastructure. They iterated that inaccessibility & restriction to pleasure should be perceived as violence and going forward efforts should be made to ensure access to pleasure within the mental health institutes. Additionally efforts must also be directed towards changing the attitude of the society and challenging social norms. They also emphasized on the need to create a space that is inclusive and moves away from defining and creating binaries; a space that is acceptable towards ambiguity.



#### **Challenges and Progress**

#### **Challenges**

One of the challenges addressed by speakers at the conference was related to the silence around both sexuality and psychosocial disability. Both the issues carry a lot of shame, stigma and discrimination and are culturally treated as a taboo. There also exists a lot of invisibility around psychosocial disability, in comparison to other forms of disabilities. Individuals with psychosocial disability might pass as 'normal' individuals and often their disability goes undetected. Due to stigma and discrimination attached to it, many individuals with psychosocial disability choose not to disclose it which further makes them invisible.

Connections between sexuality, rights and psychosocial disability, emerged out of this conference. However, more efforts need to be invested to tease out these connections in an explicit manner. Currently, most of the discourse around psychosocial disability and sexuality exist in the form of abuse, violation of rights and violence. Given this, important themes like pleasure, consent, capacity, autonomy and negotiation, that are strongly related to the union of sexuality and psychosocial disability remains unexplored.

Reviewing the current situation, the speakers pointed towards violations of rights of individuals with mental disorders, especially around the issue of sexuality and their sexual rights. Such violations are a common feature at the level of society and its structures (family, mental health institutions, legal structures). The society exercises its control on an individual's sexuality and expressions of sexuality right from childhood. It continues to the adult life of an individual and becomes worse in cases of individuals with mental disorder. At the family level, they are locked, confined and face violence at multiple levels.

The situation doesn't improve any further in the mental health institutions. At every stage, their desires, sexuality and access to pleasure is firmly controlled, restricted and punished. This is also because psychiatry follows an extremely pathologized view on sexuality which has been passed on historically. Because of this, individuals who do not confirm to compulsory heterosexuality and do not follow the accepted norms around sexuality are labeled as deviants and suffering from mental disorders.

Additionally, the staff within mental health institutions (psychiatrists/counselors/nursing staff) has been trained on viewing sexuality as pathology that need to be diagnosed, controlled and treated. This is reflective in their patriarchal and power induced attitude while dealing with sexual expressions of individuals with mental disorders. Therefore viewing the issue of sexuality and psychosocial disability from a human rights perspective is currently lacking.

#### **Progress**

Given all these challenges, some progress has been made in the field of sexuality and psychosocial disability. Even though there exists silence, stigma and discrimination around sexuality especially within the realm psychosocial disability, Banyan (a mental rehabilitation NGO) has worked towards integrating sexuality in their work on mental health. Some of their female residents approached the Banyan staff and expressed their desire to go out and meet people. Initially the staff was not ready for this but slowly they came around it and educated them on safe sexual practices. In addition to this, they opened a cafeteria within the premises of the rehabilitation center and provided a safe space where female residents can invite people from outside and talk, flirt, hold hands and socialize. This led to a huge uproar in the society and Banyan was accused of sexually exploiting their residents. The initiative ultimately had to be closed down but it is a small step towards progress. In the current scenario, acknowledging that sexuality is an integral part of individuals with mental disorder and implementing an initiative around it, in itself is a huge step towards viewing the two issues in conjunction.

Recognizing sexuality as an important issue within the disability framework, affirmative steps have also been taken in parts to include sexuality education in special schools. It is a progress in a positive direction, especially in a country like India where sexuality education program (under the name of Adolescent Education Program) faced severe opposition, from politicians, parents and school authorities, and within two years of its implementation, it was banned in 12 states of the country. As a part of the curriculum, issue related to masturbation is also discussed in these special schools. Demand for including sexuality education in special schools is also steadily increasing.

Another example that has challenged the mainstream idea about sexuality and the language used for it is that of *Agents of Ishq* (a multi-media project about sex, love and desire). Often the language used for sex and expressions of sexuality is loaded with shame, disgust and is represented as morally wrong. The web-portal challenges these regressive ideas about love, sex and desire and has created a non-normative space where people can explore and express pleasure in their own language. It has also created videos that explores issues like gender, body and artistically captures the nuances of consent.

Moving to the world of psychiatry, a little progress has been observed in their approach to sexuality. Even though psychiatry holds a pathologized perspective towards sexuality, the discourse has been challenged by sexual rights activists at different levels (socially/legally/culturally). Because of their efforts, homosexuality has been taken out of the classification of mental disorders.

Speaking in the context of laws, recently two new disability laws, the Mental Health Care Act and the Right of Persons with Disabilities Act have been introduced. Both the legislations guarantee individuals with mental disability, to live with dignity; provide protection from cruel, inhuman and degrading treatment; ensure right to privacy, adequate space, sanitation, access to articles of personal hygiene and provides protection from verbal, physical and emotional abuse. It also encompasses the right of every person with mental disability to express their sexuality and uphold their reproductive rights.

## **Way Forward** "When people say they want to get married, and they have psychosocial disability, we are told to tell them, 'no you should not get married.' Nobody has asked us to think outside the box." - Pramada Menon

#### **Way Forward**

The conference made a substantial progress in the direction of building intersections between sexuality, rights and psychosocial disabilities. Considering that currently there exists an awkward silence around sexuality and psychosocial disability and more so, on the issue of sexuality within the realm of psychosocial disability, more efforts need to be put in the direction of continuing the conversation that was initiated through this conference. Inorder to strengthen the narrative (on sexuality, rights and psychosocial disability), going forward efforts must be directed towards bringing out a discourse around the issues that follows an intersectional approach. Additionally, the conversation must be brought out of the academic spaces and language must be simplified to reach out to more number of people. This will help in creating a movement around the issue and will help in ending discrimination and silence around it. Some of the issues that were identified as a way forward during the conference are as follows:

- ❖ The idea of 'real sex' or 'normal sex' needs to be challenged culturally, at the level of the society, legally and within the medical fraternity. Sexuality should be viewed as a spectrum and while talking about sexuality, issues around consent, autonomy, power and agency should be kept in mind within the mental disability framework.
- ❖ Language on sexuality that currently exists focuses on violence, discrimination, abuse and adheres to the popular discourse around compulsory heterosexuality. This need to be challenged at the national, regional and sub-regional levels and the focus should be on creating language(s) around pleasure, sexual expressions and touch that is more open and accessible to include the marginalized sections.
- Sexuality should be viewed from a cultural lens. Rather than importing a western idea and then adapting it culturally, the work around sexuality should be carried forward keeping the cultural and social context that individuals live in, at its core.
- ❖ Discourse on the issue should be de-jargonized and brought out of the intellectual and academic spaces. Going forward, an effort should be made to reach out to more number of people. This can be done in the form of an institute (a training space) where individuals can be trained on the issue and they can be trained to look at the issue through the lens of class, gender, caste, ethnicity etc.
- ❖ A continuous effort must be made in the direction of working with the mental health professionals to find collaborative solutions while working on the intersecting issues of psychosocial disability, sexuality and rights.
- Currently sexuality, rights and psychosocial disability exists as three separate narratives. More efforts should be made in the coming future to ensure that these narratives intersect and are seen in conjunction so that a single discourse comes out of the process.

- ❖ Conversations should not be limited to 'access to health/mental health services'. Rather it should be extended to include 'access to pleasure, intimacy, touch, sexuality and sexual expression'. Going forwards, Public Interest Litigations (PILs) can be filed to ensure that such conversations enter the legal systems.
- ❖ The issue of sexuality doesn't emerge when a child hits puberty. Infact, sexuality starts to develop in infancy. That's the time when children start forming ideas around their body, self-image, self-efficacy, emotions, agency and decision making. Therefore, conversations around sexuality shouldn't be limited to the adolescent and adult group of individuals. In addition to this, dialogues on sexuality should be extended to the clinical space and parents/families should also be a part of it.

#### **Schedule**

#### DAY 1: 13<sup>th</sup> May, 2017

10:00-10:15	Introduction Ratnaboli Ray
10:15-11:00	Sex ka Funda: Funde ka Anda Keynote Address: Sexuality, Psychosocial Disability and Psychosocial Wellbeing
	Speakers: Shyam Bhat & Chayanika Shah
11:100-11:30	Tea
11:30-13:30	Ajeeb Dastan Hai Yeh, Kahan Shuru Kahan Khatam
	Practice: The Concerns and Dilemmas in Dealing with Sexual Expressions of
	Persons living with Psychosocial Disability
	Speakers: Ajit Bhide, Ratnaboli Ray, Lakshmi Ravikanth, Shampa Sengupta Moderator: Jai Ranjan Ram
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13:30-14:30	Lunch
14:30-16:30	Intercourse-Outercourse-Discourse
	Sexuality and its Connects
	Speakers: Anirudh Kala, Ketki Ranade, Jhuma Basak, Jo Chopra
	Moderator: Aniruddha Deb
16:30-17:30	Tea
10.00 1/.00	200

#### DAY 2: 14<sup>th</sup> May, 2017

09:30-11:30	Makhmali Andhera
	Pleasure, Danger, Eroticism and Fantasy
	Speakers: Jaya Sharma, Paromita Vohra, Shals Mahajan, Reshma Valliappan
	Moderator: Debasish Chatterjee
11:30-12:00	Tea
12:00-14:00	Ek Anar Sau Bimar
	Determinants
	Speakers: Jayna Kothari, Paromita Chakravarti, Alok Sarin, Soumitra Pathare
	Moderator: Ruchira Goswami
14:00-15:00	Lunch
15:00-17:00	Do Din Ki Chandni
	Concluding Session
	Speakers: Pramada Menon, Abhijit Nadkarni
17:00-17:15	Concluding Remarks: Sivananthi Thanenthiran
	Vote of Thanks: Sudeshna Basu
17:15	Tea

#### **Panel Members**

#### Speakers

Dr. Abhijit Nadkarni	Dr. Abhijit Nadkarni is an addiction psychiatrist conducting research aimed at developing interventions for alcohol use disorders in low resource settings. He is based at Sangath, Goa where he leads the Addictions Research Group.
Dr. Ajit Bhide	Dr. Ajit Bhide is the Vice President of the Indian Psychiatric Society. He is a psychiatrist, psychotherapist, and an independent researcher based in Bangalore, interested in preventing and adolescent psychiatry. Dr. Bhide is also a theatre personality, and he acted in the film <i>Stumble</i> .
Dr. Alok Sarin	Dr. Alok Sarin is a consultant psychiatrist at Sitaram Bhartia Institute of Science and Research, New Delhi. He is also a renowned author. Dr. Sarin has been a member of the Task Force, set up by the Ministry of Health and Family Welfare, to write a mental health policy for India.
Dr. Anirudh Kala	Dr. Anirudh Kala is a psychiatrist based in Ludhiana, Punjab. He was a member of the policy group which prepared the national mental health policy for the Government of India. He is also a writer, and calls himself a "weekend scribbler".
Dr. Chayanika Shah	Dr. Chayanika Shah is an independent researcher, scholar and activist from Mumbai. She has been involved in the autonomous women's rights movements since the late 1970's. She is the founder member of Bombay based, queer feminist collective LABIA (Lesbian And Bisexuals In Action).
Jaya Sharma	Jaya Sharma is a feminist, queer, kinky activist and writer based in New Delhi. She has worked on issues of gender and education for over twenty years. She has co-founded and been involved with queer forums in Delhi. She is also one of the founder members of the Kinky Collective, a group that aims to raise awareness about Bondage Domination Sado Masochism.
Jayna Kothari	Jayna Kothari is a cofounder of CLPR. She is a partner at Ashira Law, and practices a Counsel in the Karnataka High Court and the Supreme Court of India. She has been awarded the Wrangler D.C. Pavate Fellowship in Cambridge University. Her book, "The Future of Disability Law in India" is one of the first books on disability law in the country.

Dr. Juma Basak	Dr. Jhuma Basak holds an experience of more than 15 years in academics, pursuing in culture & psychology. A trained psychoanalyst, Dr. Basak is a practitioner based in Calcutta. She is an award winning dancer-choreographer.
Jo Chopra	Jo Chopra is a writer and the Founder, Executive Director at Latika Roy Foundation. She has been working in the field of disability services, rights and awareness for over 20 years. She is the mother of Anand, Cathleen, and Moy Moy, who was the original impetus for Karuna Vihar School.
Ketki Ranade	Ketki Ranade is faculty at the Center for Health and Mental Health, TISS, Mumbai. Ketki has been member of the Expert Committee on Transgender Issues formed by the Ministry of Social Justice and Empowerment. Ketki is member of LABIA, a queer feminist LBT collective based in Bombay.
Dr. Lakshmi Ravikanth	Dr. Lakshmi Ravikanth, (PhD) is a certified counsellor and psychotherapist practising for over two decades in Chennai. She has been associated with The Banyan in several capacities since inception. She is also a consultant researcher and faculty at The Banyan Academy of Leadership in Mental Health (BALM).
Paromita Chakravarti	Paromita Chakravarti is a Professor of English at Jadavpur University. She teaches Renaissance drama, women's writing and sexuality and film studies. She has also been both Joint Director and Director of the School of Women's Studies, Jadavpur University where the focus had been on education and sexuality.
Paromita Vohra	ParomitaVohra is a writer and an Indian filmmaker, known for her documentaries on urban life, pop culture and gender. She has written the screenplay of the award-winning film <i>Khamosh</i> Pani. She has developed Agents of Ishq, a multi-media project about sex, love and desire.
Pramada Menon	Pramada Menon is a queer feminist who works on issues of gender, sexuality, human rights and organizational management. She is the co-founder of CREA, a feminist human rights organisation based in Delhi. Pramada is also well known as a performance artist for her show Fat, Feminist and Free.
Ratnaboli Ray	Ratnaboli Ray is a trained psychologist, an Ashoka fellow and a mental health activist. She is a Member of Task Force on Standard Treatment Guideline (GoI). She also the Founder & Managing Trustee of Anjali, a mental health rights organization, based in West Bengal.

Reshma Valliappan	Reshma Valliappan aka Val Resh runs a creative initiative called The Red Door which challenges ideas of normalcy and madness. She is an Ashoka Fellow, Ink Fellow and CAMH Fellow. She works closely on a program called Changemaker Warriors which addresses mental health indirectly through concepts from martial arts and shamanism to turn bullies into healers.
Shals Mahajan	Shals Mahajan identifies as 'gender queer' and is a queer feminist activist and writer. Ze has been a part of LABIA – Queer Feminist LBT Collective for the last two decades. Ze has also published a children's book, Timmi in Tangles, and co-authored No Outlaws in the Gender Galaxy.
Shampa Sengupta	Shampa Sengupta is a Kolkata based activist working on disability and gender rights. She has initiated a non-funded advocacy group called Sruti Disability Rights Centre and has been elected to serve as an Executive Committee member of National Platform for the Rights of the Disabled (NPRD).
Dr. Shyam Bhat	Dr. Shyam Bhat is an integrative medicine specialist, psychiatrist and writer. He is the founder of Seraniti.com where he heads a team who provide integrated mind-body and emotional wellness therapies. Dr Bhat is a trustee at the Live Love Laugh Foundation.
Dr. Soumitra Pathare	Dr. Soumitra Pathare is currently a Consultant Psychiatrist at Ruby Hall Clinic, Pune, and Coordinator, Center for Mental Health Law and Policy at the Indian Law Society. As lead author, he assisted GOI to frame the Mental Health Care Bill, 2013.

#### Moderators

Dr. Jai Ranjan Ram	Dr Jai Ranjan Ram is a Psychiatrist by choice and a feminist by necessity. He is the Co-founder of Mental health Foundation which works around the issue of child sexual abuse.
Dr. Debasish Chatterjee	Dr. Debashis Chatterjee is a Consultant Psychiatrist by profession. He is the Founder member and consultant to Mon Foundation, Anjali, Iswar Sankalpa & other NGOs working in the field of mental health and Human Rights in Kolkata.
Dr. Aniruddha Deb	Dr Aniruddha Deb is a psychiatrist practising in Kolkata for more than 20 years and is an author, photographer and an avid birder.
Ruchira Goswami	An academic activist, Ruchira Goswami teaches Sociology, Human Rights, Film and Law at National University of Juridical Sciences – a Calcutta based Law school. She is the Head of Centre for Child Rights, NUJS set up in partnership with UNICEF. She has been the member of the autonomous women's movement since 2000. She sings with a protest/mass music group in the city and loves to travel at the slightest opportunity.