

# Report - Bill of Rights

Insights of a Mad Pride campaign [2005-2008]

by



National Alliance on Access to Justice for  
Persons living with Mental Illness - [NAAJMI]

**NAAJMI**

Our Vision

To assure a life of dignity for every person living with a mental illness

Our Mission

To influence policy and public opinion

To capture and apply knowledge

Provide a platform for dialogue of all stakeholders, whose voices have not been heard

Learn from other movements and network with them





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**For NAAJMI**

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# CHAPTER I.

## INTRODUCTION

### A. GROUND REALITIES OF HUMAN RIGHTS IN THE MENTAL HEALTH SECTOR

In India, we have had at least two decades of human rights thinking and praxis in various Development contexts, including women, children, dalit and other marginalized groups. A human rights based approach is considered as a given, within this context. The public health and other life consequences of deprivation and marginalization, and the need for addressing self and identity politics, are well recognized here.

Contrarily, mental health, human rights within the mental health sector, and the psychological impact of social and economic development processes on self and identity, has not been given much importance in public discourse. The mental health sector itself is divided, not having any platform for involved discussion or dialogue on human rights from the many stake holders. Various myths and fallacies about the personal rights of those living with a mental illness prevail- that the search for self and personhood is a western concept, “post-modern”, “western”, abstract, not pertaining to ground level realities, not “practical”, not suited for our “culture” and not “basic” to human existence, like food or shelter. There is also the misconception that essential services should first be provided, before we embark on a discourse of rights. The Erwadi tragedy of 2001 was the proverbial tip of the iceberg, showing that just creating an essential service is inadequate as a strategy, and that human rights must go hand in hand with service development. “Essential services”, in the form of 50 or so private and public mental hospitals, and the National Mental Health Program, with its huge coverage of various districts around the country, along with a good smattering of private clinical services in urban India, has existed for 30 years, if not more. But many tens of thousands of men, women and children enter and exit the predominantly custodial and bio-medical mental health care system in India, coming out of it more disempowered, disabled, deskilled, diminished and stigmatized than before. Most hospitals still retain ‘cage beds’, or popularly known as solitary confinement, a ‘service facility’ which has been challenged by a SAARTHAK, petition before the Supreme Court, joining

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4 with international movements against them. Here, too, a frontally humanrights question cannot be fully answered by posing them

in terms of service delivery [e.g. in terms of, ideal confinement facilities, 'good practice guidelines for solitary confinement', etc.]. The ground reality of the mental health sector is that, while attention has been continually given to (public and private) financing, and replicating unevaluated and very poor mental health care models, the necessary service correctives and alternatives, coming from human rights thinking, is yet to take off. Service development and financing has to factor in human rights questions in tandem and as a part of strengthening the mental health sector. Creating a value based vision for mental health, which is rights based, may lead to the creation of a range of exciting and non-violent services.

Yet another area for questioning is the prevalent view favouring the participation of "all stakeholders" in the mental health system. This view obscures the fact that various barriers, including legal and attitudinal barriers, to the full participation of persons living with a mental illness, exists in our society. Through the campaign process, we have often heard the view from some stakeholders that persons living with a mental illness cannot be "given" universal rights as other people. Another often heard view, particularly from the medical care providers, is that human rights should be "given" depending on the "nature and stage" of the illness. Further, that for "some people" seen as "seriously disturbed" or requiring "high support" consent may not be suitable and force must be considered. These attitudes show a high level of power imbalance in the sector, where some stakeholders have taken the position of granting or "giving" rights to some others who are seen as beneficiaries of the system. Persons living with a mental illness are the primary stakeholders of the care giving system, and their full participation, freedom of expression and self advocacy for change cannot be substituted. NAAJMI is a movement by, for and of PLMI, and is inclusive of all people concerned about structural changes within the Indian policy environment.

## B. HUMAN RIGHTS, DEVELOPMENT AND MENTAL HEALTH





World data bases suggest that social and economic inequality and loss of basic human rights in various development contexts (gender, poverty, economic hardships, unemployment, displacement, immigration, migration, conflict situations, etc.) create psychosocial disability of varying degrees. However, there are few research data or tools in India, designed to measure or describe mental health status, linking it with human rights, development, empowerment, marginalization and deprivation. The linkages are relevant and necessary to make: For example, recent research suggests that poverty, domestic violence and son preference are independent causes of mental disability. Further, running self help groups within a community mental health program can enhance support and recovery.

Psychiatric scales, which are essentially medical symptom inventories based on the Diagnostic and Statistical Manual of the American Psychiatric Association, pick out approximately 2-3% of the population with a diagnosis of a Severe Mental Disorder (schizophrenias, bipolar disorder, other organic disorders); And, a broader spectrum of psychiatric diagnosis is given to 10-25% of the population, depending on the human development context (age, educational status, marital status, whether in conflict or disaster situation, economic status, social status, exposure to violence, etc.) Sex is an important social determinant of being diagnosed with a mental illness. Socially marginalized groups (women, elderly, poor, etc.) are picked out more often on medical epidemiological surveys than other groups, showing higher levels of psychosocial distress. The linkage with social inequality, violence, trauma and deprivation is largely untested, because of the lack of research frameworks and tools. Domestic, cultural and child related abuse and violence are highly pertinent in the context of women and mental health. Typically also, going by the data gathered from primary health care sites in India as well as elsewhere, physical health, reproductive health, neuro-endocrinological health, nutritional health and mental health are co-determined, as a psychiatric diagnosis majorly correlates with a general medical diagnosis. There is a need to make the linkages between public health and mental health through future research. Compared to needs, services in India for mental health are extremely poor, being devoted to the large and unsustainable mental hospitals. Mental hospitals, regulated by the penal Mental Health Act, are anti-development, totally lacking in values such as right to life and liberty, autonomy, equality, dignity, and self determination. Most

hospitals still retain 'cage beds', or popularly known as solitary confinement, a 'service facility' which has been challenged by a SAARTHAK petition before the Supreme Court. There is a 90-95% national deficit in the numbers of clinical psychologists, psychiatric nurses and psychiatric social workers, making the mental health system focused only on hospitals, in an unregulated manner. Community mental health itself through the District Mental Health Programs has become mere drug dispensing activities of the state. The spin-offs of Development create more socio-economic and cultural inequality and vulnerability. In this process, people likely to be labeled or diagnosed mentally ill, particularly those who do not fit in with the expected stereotypes of "normalcy", is expected to increase phenomenally. However, psychological and psychosocial theories and practices, linking development and empowerment with quality of life and overall well being, are totally absent. Development cadres, with a rights based approach and providing a range of psychosocial and alternative services, are also completely missing from the mental health scenario, though some fresh initiatives are being started in some development project sites, which NAAJMI has attempted to capture.

### C. HISTORY OF NAAJMI

The Ashoka [Innovators for the Public], through their Law for All<sup>1</sup> initiative led by Ruchika Bahl, encouraged two Ashoka Fellows, Ratnaboli Ray [Kolkatta] and Bhargavi Davar [Pune], both user-survivors of psychiatry, to collaborate towards a national consultation on human rights for persons living with a mental illness [PLMI]. Both the Ashoka Fellows, having a strong experiential as well as professional background with respect to mental distress and disturbance, found merit in this joint venture. Ratna initiated the idea of a National Alliance to openly dialogue about Human Rights for persons living with a mental illness and to develop a context for policy making as well as public mobilisation. The national campaign, initialed the "Bill of Rights Consultations" began in 2005, as consultations on improving "Access to Justice for persons with a mental illness" in Kolkatta. Mr DM Naidu [Basic Needs, Bangalore] joined in the efforts. We also conducted further consultations in Bangalore, Pune and New Delhi, with Monica Kumar [Manas Foundation] and Deepika Nair [Saathi-All for Partnerships]. This happened during the time that the international disability community was working to see the adoption of the UN CRPD [Convention on the Rights of Persons with Disabilities] globally. A final, national consultation was held in New Delhi, in October, 2008, in partnership with Rajive Rathuri [Disability Unit, ICHRLN] and Abdul Mabood [Snehi], during the Mental Health week, 2008. The objectives were





- a) to consolidate and disseminate our work
- b) to launch NAAJMI
- c) to debate its perspectives and actions against the present CRPD standards.

Prof. Amita Dhanda [NALSAR, Hyderabad] and Mr. Gabor Gombos [Visiting Fellow, Ashoka International Fellow Exchange Program] facilitated the New Delhi meeting. Thus, NAAJMI has seen two phases:

A first phase of partnership building and developing the core components of a “Human rights discourse in mental health” through dialogue and consensus building.

And a second, of organizational development, fund raising, programmatic actions, advocacy and lobbying with the government for policy and legal change.

#### D. NAAJMI ENVIRONMENT – INSTRUMENTS FOR DISABILITY & HUMAN RIGHTS

International instruments which provided a basic framework of reference for disabilities, and also found in many court and public interest litigations in the pre-CRPD era, were

- The Universal Declaration of Rights (UDHR) – 1948
- UN Principles for the Protection of Rights of Persons with Mental Illness – 1991
- UN Standard Rules for Equal Opportunities and Non-discrimination of Persons with Disabilities

At the national level, the regulatory mechanisms available are:

- Mental Health Act, 1987
- Persons with Disabilities, Equal Opportunities & Non-discrimination Act, 1995
- The Human Rights Act, 1993
- Commitments of the National Human Rights Commission [NHRC, 1999, Quality Assurance in Mental health, New Delhi.]
- Many years of Public Interest Litigations, particularly against the mental hospitals, which provide good case law for a more human rights sensitive service domain
- The Erwadi case initiated by and resting with the Supreme Court since the Erwadi tragedy in the year 2001

These international and national instruments covered, in more or less terms, the following aspects



of human rights universally as well as within the disability / mental health sector:

- Civil and Political Rights
- Social, Economic and Cultural Rights
- Care and Treatment Rights

These legal mechanisms were to provide the basic stepping-stone for a human rights regime in mental health. PILs have been filed in many states and Union Territories, including New Delhi, West Bengal, Assam, Bihar, etc. Also, High Courts, such as Mumbai, have invigilated and decreed on maintenance of standards in the institutions in their respective states. Where vigilance by the local court was strong, the States have been able to uphold humane standards in the institutions. Through various local initiatives in the hospitals, small changes have also been brought about, such as increase in voluntary admissions; more OPD treatments; greater role for family in rehabilitation; some occupational activities in hospitals; increase in staffing; better community outreach; etc. Even the penal Mental Health Act had a human rights chapter, and had several provisos for protecting the rights of persons living with a mental illness. For example, the right to appeal against the Reception Order and the right to legal representation are both found in the MHA, but unutilized by aggrieved parties. However, the overall limitations of the present statutory environment cannot be ignored, as NAAJMI duly recognizes:

- The 1991 MI Principles has been criticized by mental health activists in India and around the world for liberally allowing forced treatment and involuntary commitment, thereby depriving persons of a fundamental right to life and liberty.
- The accent of all laws pertaining to persons living with mental distress and disturbance remains on involuntary commitment in admission and discharge. The Mental health Act has only 1 section on voluntary admission and three on involuntary admission. Even the section on voluntary admission poses restrictions when it comes to voluntary discharge.
- A majority of State mental hospitals and state run community mental health





programs run primarily as drug or ECT dispensing centres, with little or no arrangements for therapeutic support and recovery in the form of psychosocial rehabilitation or alternatives.

- “Trans-institutionalisation”, or the legal shunting of people with disabilities between various custodial institutions [e.g. mental hospitals, jails, beggars’ homes, police custody, remandhomes, etc.] is a reality which continues to be highly dismissive of human rights.
- The multifarious civil, criminal and family related laws in the national context, and in local as well as national case law, suggests a very high level of discrimination and disempowerment, on “persons of Unsound Mind”. For example, the Marriage Divorce act is widely used in the family court context to discriminate against particularly women living with a mental illness or women perceived / accused of being “mentally ill” as being unfit for marriage. Legally established concepts of being “unfit”, “lacking insight”, “incapable”, “dangerous to society”, etc. have ensured the universal application of disempowering laws in all walks of life of PLMI.
- Disability instruments, international and national, which ensure positive rights to some extent, have never been mobilized in the mental health sector. Psychiatrists by and large do not recognize the disability dimensions of mental health, and are making no efforts at integrating disability into mental health.

Throughout, we have consistently engaged with matters relating to policy. India does not have a national mental health policy. The National Mental Health Program is very poorly evaluated, even while the Government of India has been making attempts to support DMHP programs in all districts of the country, following Erwadi.

## E. RECENT NAAJMI OPPORTUNITIES FOR BUILDING A HUMAN RIGHTS REGIME INTO THE INDIAN MENTAL HEALTH SECTOR

Recent developments in the mental health sector have impelled NAAJMI to pursue platform and alliance building, active lobbying and structured advocacy interventions.

### 1) National level – Erwadi related actions:

A fire broke out at one of the private shelters in the precincts of the Erwadi Dargah, Ramanathapuram district in Tamil Nadu in 2001. On 6<sup>th</sup> August, the hutments in which the inmates were housed, chained

to their beds, caught fire. 11 women and 14 men died when the fire broke out early in the morning. In all, 43 persons were kept there. 3 persons died later in the hospital. As a response to this major human rights disaster in the Indian mental health system, remarkably, the local government awarded families who had dumped their mentally ill relatives in these private asylums with monetary “compensation”, instead of applying criminal action or other penalties. The Government also issued instructions to the District Collectors to inspect shelters for the mentally ill to see that no shelter functioned without a valid license.

The NHRC set up its own commissions to inquire into various local healing centers. After this incident, the Supreme Court initiated suo moto action against the State Government of Tamil Nadu and all other states of India (vide Writ Petition Civil No.334 of 2001). As a pronouncement on human rights, the SC asked all the state governments to implement the Mental Health Act, 1987, and to close all shelters not covered by the Act. Importantly, the supreme court demanded to know whether mentally ill people were treated badly or kept in chains anywhere in the respective states. Orders were also passed to build more mental hospitals, particularly in states where none existed, contra, the highly incriminating evidence presented about mental hospitals in various reports, PILS, the NHRC, the media and in other public discourse.

As a recognition of financial need in the sector post-Erwadi, the GOI released Rs. 190 Cr. through the tenth Five Year Plan. Paradoxically, while the program allocation largely favours community mental health, states such as Bihar, HP, Kerala, Tamil Nadu, Maharashtra and Assam have been building mental hospitals in the post Erwadi era. Most mental hospitals chose to refurbish the drab hospitals with the monies received, without further development of human rights based services. Through a curious turn of events, the state governments are using this petition to witch hunt traditional healing centers, causing further hurts to communities using traditional mental health resources.

While budgets are being allocated for service provision and replicating existing models, no explicit provision is made for human rights monitoring, reviews, evaluations, or more generally, the inclusion of civil society and disabled persons’ organizations. Though the motivation for change came from human rights thinking, at the implementation level, that value base is lost to the “ground realities” of service provision. It is important for civil





society to mobilize around greater human rights advocacy around these developments, including human rights compliant proposals for service development alternatives. There is also a big need to advocate for national and state level mental health policies. NAAJMI has continued to provide a national platform for some of these mobilizations, and has worked in tandem with various other local and national campaigns and advocacy actions.

## 2) International Level : The United Nations Convention on the Rights of Persons with Disabilities [CRPD]

The UN-CRPD is the first human rights convention in this century. The CRPD is a “hard law”, comparable to the CEDAW and the CRC in terms of international commitments and vigilance. Various human rights conventions subsist, such as Covenant on Economic, Social and Cultural Rights; Covenant on Civil and Political Rights; Covenant on the Elimination of all forms of racial discrimination; Convention for Elimination of Discrimination against Women; Convention against Torture applied to persons with Disabilities.

It is noteworthy that in the preamble, which otherwise includes every other extant human rights covenant, treatise or guidelines, the 1991 MI Principles is not included. For the mental health sector, the CRPD supersedes all earlier rights instruments and is a new reference point, particularly on the topics of legal capacity and force. The role of NAAJMI with respect to various laws regulating the lives of persons living with a mental illness, especially the Mental Health Act, has to be proactive. NAAJMI demands unconditional full legal capacity for all persons living with a mental illness; as well as, a non-custodial approach to service provision. The state machinery and agents of the State cannot interfere in lives and choices of PLMI arbitrarily, as is happening presently.

The CRPD, presently in force in India and globally, is an international legal instrument, requiring legal interpretation that is consonant with the spirit with which the document was created. The disability movement has been with the difficult task of interpreting the text of the Convention. With reference to the SC actions described above, the SC has stayed the proceedings in lieu of the awaited CRPD. Now that the instrument is in force, we hope that the SC proceedings will resume. NAAJMI has taken several actions to provide a platform for strengthening the use of the CRPD for the mental health sector, and equally importantly, integrating with the disability sector.

### 3) XI Five Year Plan:

The recent XI Yr Planning process has showed that of the 190 Cr. allotted, almost half of the money was returned by various governments unutilized. The NMHP and its implementation design, the DMHP [District Mental Health Program], have been much criticized. Visioning for the mental health sector based on a rights based approach for the XI Plan s a must. The Table below reflects a comparison of the X and XI Plans.

Programme Component	10th Five Year Plan (INR in millions)	
DMHPs	775	6800
Modernisation of Mental Hospitals	600	Nil
Strengthening of Medical Colleges	375	3210*
IEC & Training	100	750
Research	50	Nil
School Mental Health Programme	Nil	2230
Monitoring	Nil	150
NGOs	Nil	100
Total	<u>1900</u>	

The XI Plan promises a “multi-pronged strategy to raise awareness about issues of mental health and persons with mental illness with the objective of providing accessible and affordable treatment, removing ignorance, stigma and shame attached to it and to facilitate inclusion and acceptance for the mentally ill in our society will be the basis of the National Mental Health Programme (NMHP)”. The Plan also envisions making linkages with the National Rural Health Mission, providing for the strengthening of the DMHP by promoting greater family and community participation. The Plan promises to fill up the human resource gap in community cadres as well as professional cadres, particularly by incorporating mental health into existing health trainings. The Plan also provides for greater involvement of NGOs and CBOs in its execution. The stated objectives of the XI Plan are as follows:

- To recognize mental illnesses at par with other illnesses and extending the scope of





medical insurance and other benefits to individuals suffering with them

- To have a user friendly drug policy such that the psychotropic drugs are declared as essential drugs.
- To give greater emphasis to psychotherapeutic and a rights based model of dealing with mental health related issues
- To include psychiatry and psychology, and psychiatric social work modules in the training of all health care giving professionals
- To empower the primary care doctor and support staff to be able to offer psychiatric and psychological care to patients at PHCs besides educating family carers on core aspects of the illness.
- To improve public awareness and facilitate family-carer participation by empowering members of the family and community in psychological interventions.
- To provide greater emphasis on public private participation in the delivery of mental health services.
- To upgrade Psychiatry departments of all Medical colleges to enhance better training opportunities
- To improve and integrate mental hospitals with the whole of health delivery infrastructure that offer mental health services thus lifting the stigma attached
- To provide after care and lifelong support to chronic cases.

11th Five Year Plan  
(INR in millions)

11430

(US \$ 42.3 million)

(US\$ 254.0million)

operationalised in human rights

These plans, while being comprehensive, need to be further operationalised in human rights terms and in terms of the extant CRPD. NAAJMI has a big role to play in influencing the XI and XII Plans, and further, to a studied analysis of the X Plan budgets.

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(Footnotes)

<sup>1</sup> Launched in December 2003 the Law For All Initiative at Ashoka aims to : 1. spread the principles, experiences and models of Ashoka fellows who have used law as a tool for ensuring the rights of the marginalized sections in the region 2. facilitate a process of peer learning, sharing of experiences and cross-pollination of ideas between Ashoka Fellows and other human rights leaders. The Access to Justice workshop series were instituted by the LFAI with the objective of creating a space for Fellows to learn and draw from each others experiences of successfully using the legal system in their respective campaigns and building capacity of practitioners by providing for learning opportunities to interact and learn each other.

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## Chapter II.

### The Bill of Rights Consultations

From 2005-2008, it was an active phase of mobilization and consensus building for NAAJMI on having a common language of Human rights within the mental health sector.

#### A. CAMPAIGN PURPOSE, OBJECTIVES, PROCESS AND OUTCOMES:

NAAJMI started of as a mental health advocacy campaign of, by and for PLMI. However, NAAJMI does not believe in ghettoization. It is a broad based campaign and is inclusive of all those with a personal commitment to see sector changes. It is an all inclusive national lobby taking sides with and promoting human rights and equal opportunities for people living with a mental illness. NAAJMI's purpose was to broad base mental health advocacy into the Development and the Human Rights discourse in India. We wanted to make all efforts to clarify misconceptions that persist about the incapacity and lack of insight of PLMI. Such attitudes contribute to the second-classing of mental health issues within the movement for the rights of disabled persons.

**The need for a national campaign:** The Bill of Rights consultations of NAAJMI, done over 2 years, was based on the awareness that people with mental illness are not enjoying their rights to the fullest extent possible. In this time, we recognized that:

- Persons diagnosed with mental illness have decision-making rights and choices in their own treatment and care
- The mental health service delivery system must be based upon values of dignity, respect, liberty, autonomy and self-reliance, rather than on management needs
- Healing opportunities for recovery and living an independent, self determined life must be included within the treatment and care package
- There must be mechanisms for guaranteeing all universal rights as citizens

NAAJMI, as a small initiative started by two user-survivors, began with the following limited purpose



- To build a mental health platform where stakeholders from various backgrounds and working or using the mental health system could exchange ideas, experiences etc.
- To develop a National Coalition for further advocacy and to influence policies on mental health.
- To build a pressure group
- To initiate a dialogue with civil society and people in governance for the purpose of influencing policy

### The goals of the campaign were:

- Determine a common human rights discourse for people with disabilities, including psychosocial disability
- Develop a common minimum understanding in mental health advocacy
- Explore linkages between various Acts [MHA, PWDA] and the NAAJMI Charter of Rights
- Bridge the gap between individuals and organizations working in the sphere of disabilities and mental health, and the government, particularly in the context of the XI Five Year Plan
- Contextualize international instruments, particularly the CRPD and UN MDG, to the Indian situation
- Facilitate dialogue between differently thinking groups within mental health

### Outcomes expected:

- A methodology of doing multi stakeholder consultations, on principles of dialogue
- A Bill or Charter of Rights with local application at every Bill of Rights consultation

## B. PROCESS

4 dialogue process workshops were held, in the four regions of India [Kolkatta, Bangalore, Pune and New Delhi]. The goal of each workshop was to negotiate values and to build consensus on a Bill of Rights for the mental health sector. Each workshop resulted in the drafting of a Bill of Rights. The Calcutta and New Delhi experiences taught us that the dialogue process may result in conflicted views. For building a consensus, more dialogue was necessary and various development and disability sectors need to be included. The process of how we arrive at a consensus, how we view each other as adversaries





and opponents, and how we talk to each other, was as important as the outcome. Can we articulate our dilemmas? For e.g. while we all uphold the fundamental right to liberty, where and how do we see forced treatment. Can we talk clearly and communicate our understanding?

An open ended, case study and problem solving approach was used in most of the workshops to facilitate communication and to come up with new solutions. Illustrations, group work, case studies were developed and used to facilitate more open ended dialogue and discussion. NAAJMI is built on the premise that various stake holders need to talk to each other and dialogue about their differences. The process part – articulating controversies and conflict resolutions - became an outcome in itself. Facilitators of the consultations tried to provide an emotionally holding environment for dialogue. There was faith in human solidarity, creativity and wanting to break our own thought barriers to imagine new solutions.

We took cognizance of the often cited fact that no one intentionally commits a human rights violation, but sometimes solutions may not be found or available. NAAJMI addressed this gap with an intention to dialogue, explore and understand, and not just address the issues in black/white. NAAJMI thus collected ‘insights’ for a humane mental health sector through study, and reflective dialogue processes. The mental health system all over the world, but also in India, requires new ideas. NAAJMI in future aims to work with these issues longitudinally and in an inclusive manner, fuelled by the UNCRPD, so that collectively we can improve the imagination of the mental health sector over a period of time to make the system caring and humane.

### C. OUR ETHOS

In its initial imagination, NAAJMI went beyond demanding “basic needs” for persons living with a mental illness, recognizing the conflict between fighting for basic needs and fighting for universal human rights. When we consider only food, shelter and clothing as rights, we ignore self related rights, such as right to positive emotions, right to emotional safety, right to wellness, right to be listened to and the right to selfhood. Programs looking only at basic needs may result in a protection regime and maintaining the status quo. We have focussed quite a lot on civil political rights, inclusive of the right to being oneself.

NAAJMI is on the side of people’s dreams: We have seen that, against all odds, disabled people have the potential to move forward, are creative, and can experience themselves in positive, well being

states. NAAJMI provides a space of social justice where, making the mental health system congruent with people's inner most aspirations, can be discussed with positive solution based strategies at the programs level.

We believed that listening and dialogue is the spirit and the life force for mental health and for the Alliance. We believed fully in human interdependence and humanizing processes as a foundation for mental health. We envisioned NAAJMI to be a cross-disability alliance, working with a rights based approach, including individuals, organizations, and other coalitions. Faith in the transcendence and freedoms of the human spirit is an important value for NAAJMI.

Respecting and accepting each other for who they are, enjoying difference and having people focus rather than management focus, are other important values. We had unconditional belief in human potential, functional abilities and fulfilling one's personal calling and one's aspirations. We believed that it is possible to recover from mental health problems through diverse life affirming opportunities. We also acknowledged that to choose recovery was in itself a matter of choice. Agreeing to disagree was our belief, too.

#### D. NAAJMI STRATEGIES - WHAT WORKED

The signature of "NAAJMI" was adopted in January, 2008, and an "Alliance" defined more strategically, by the people who initially started the campaign. Naaz means "Pride" in Urdu, and seemed to resonate with the Mad Pride activism of users and survivors of psychiatry around the world. The "Beehive" with its promise of bonding and inter-dependence (Honey), as well as boundary and negotiation (Sting) seemed appropriate.

A reflection of NAAJMI through the 3 years of work on building consensus on Human Rights within the mental health showed:





1 There was no doubt that the campaign was led by people with disabilities. But the strategy of broad basing the quest for human rights in mental health, within other civil

liberties and political movements, actions and programs was a sound one. This does not result in a ghetto of any kind, and is inclusive of everyone's opinions, faith, mutual trust as well as evidences. Homogenous groups are not motivated to think new thoughts as they build their group process on agreements already prevailing. The richest conversations in the consultations were held when diversity of views was the highest.

2 In broad based human rights coalitions, the child and women's rights movements, and the cross-disability movement, fundamental rights such as life, liberty and self determination are accepted universally. Having self advocates in the general field of disability also greatly contributed to a culture of human rights in the mental health field at the consultations.

3 We found NAAJMI to be a human process of mutual support building and a dialogue forum. It has been most effective in those workshops where the group intent to break through thought barriers, self reflect and dialogue was high. A process oriented workshop design allowing for flexibility, diversity of opinions, summarizing and reiteration of consensus and other gains, group validation, holding through conflict, "speaking from the heart", intent to tread new paths, providing emotionally holding environments was consciously adopted in at least two of the workshops. This showed us, as facilitators, that consensus is not a given but needs hard work using multiple faculties, and not just cognition.

4 At least two days were required for a successful Bill of Rights process oriented, consensus building workshop.

5 The consultations were an educative, insight building platform and did not have an aim, to begin with, of influencing governance. This came later in its development, as external factors started coming in, such as the CRPD, the Five Year Plan, etc. X I

6 At every consultation, we aimed to arrive at a clear document that would enlist the fundamental human rights of persons living with a mental illness. Only in Delhi did we fail to achieve this outcome. Data of each Bill of Rights event according to agreements, disagreements and a charter of rights in the other three consultations.

7 Doing local process workshops in different regions was a sound strategy. While various human rights documents have existed, these need to be understood and internalized in a local way, through local perspectives and practices. Each workshop brought its own local strengths and flavours, local case studies and illustrations, to the workshops.

8 Urgent personal solutions to people's problems could not be found through the NAAJMI process work. However, the emphasis was on building collectively, the imagination and the problem solving ability of the sector, so that new solutions can be found for problems and controversies plaguing the sector for many decades (e.g. the question of consent).

9 To get into discussions on whether the participants or the campaign was 'pro' or 'anti' psychiatry seemed irrelevant. These were not timely concepts, allowing the escape of focus and content, and not to be used. It was important to find authentic questions, articulate them, dialogue about them and answer them. This approach side stepped fruitless questions such as 'are we in favour of medication or against it', etc.

10 An important personal outcome for us was the build up of solidarity, confidence and the determination to hold together and continue with NAAJMI signed processes and dialogue forums around the country in small and big ways. NAAJMI was a cherished product for each of us, as it brought us together, talk to each other, made us think through difficult subjects, and gave us new visions and imagination for our own work. Each of us went back to our organizations enriched and back to the drawing boards of our own programs. Consensus building among the core members was felt to be needed and useful.





## E. A REGIME OF HUMAN RIGHTS IN THE MENTAL HEALTH SECTOR: RECOLLECTIONS FROM THE BORS

At every consultation a **Charter of Rights** was drafted as the first steps towards a consolidated advocacy and campaign initiative throughout the country for ensuring the rights of persons with mental illness. Every consultation was organized to enlist by a consensus building process, a collection of human rights in the following domains through participatory methods: a) Community and Family b) Parameters of Care and Treatment (c) Institutions (d) Grievance and Legal Redress. In the following Table, we present a comprehensive list of rights discussed in the consultations.

### CIVIL & POLITICAL RIGHTS

Right to Equality

Right to Freedom and Liberty

availability of various modes of healing and approaches

Right to Life

Right to Equal Opportunity

### SOCIO-ECONOMIC RIGHTS

Right to be seen as equal before the law and recognition of full legal capacity  
Right to opportunities for preserving and enhancing personal autonomy

Right to live, work and receive healing and treatment within the community  
Right to community care  
Right to accessibility/  
treatment, health and rehab including non-drug

Right to Basic Needs  
Right to Development  
Right to Higher education, creativity and opportunities for self enhancement

Right to Inclusion,  
Right to family, work, relationships, sexual orientation, contraception, RH choices, Right to **social**

security, including insurance, an adequate of living, with special provisions for people with mental illnesses with multiple disadvantages

standard living

Right of access to Justice

Right to recreation and leisure activities

Right to legal counsel and aid on site

Right to legal recourse against being used as research subjects without informed consent

Right to self determination

Right to make choices

Right to contract

Right to financial, assets and employment opportunities

Right to dignity information Right to spirituality

Right to Insight Right to Mental health Right to

Right to bodily integrity treatment

Right to violence free environment Right to refuse

harmful practices

Right to voluntary treatment

Right to protection from cruelty and torture /

Right to political participation

Right to be listened to

Right to privacy and confidentiality

Right to mobilize, form and be a part of associations

## F. DILEMMAS PRESENTED

As the consultations from one region to other, tandem with greater awareness of the CRPD and human rights, several ideas and convictions shifted. The Kolkatta BOR set the ball rolling, succeeding in at least bringing together diverse people on the subject of Human Rights for PLMI. With every consultation there was more ease with the disability language and interest to work cross disability.





User survivor identity development through the NAAJMI consultations and participation also saw a steady increase. The Pune consultation saw powerful contributions by user survivor voices, while the most insightful care giver perspectives were presented in the Delhi consultation. Concepts used in Kolkatta consultation such as 'least restrictive environment', given a medical hue and colour by the mental health system, were replaced by explicit arguments and sharing of experiences against the use of force.

Choice and consent became more operationalised in specific terms. From universal, prescriptive discourses on rights, the consultations moved to more specific rights and challenging contexts (guardianship, legal capacity, force, involuntary commitments, alternatives).

From medical and professional groups who attended the first consultation, the consultations moved to include more community groups including development rights, child rights, sexual minorities, health rights, disability rights, women's rights, etc. bringing the campaign squarely within a Development context. In this process, we also were witness to a spectrum of human rights perspectives and positions.

i) **Mental illness / disability:** There were differences about seeing mental illness as a disability, even though the CRPD as well as the PWDA includes it within the scope of disability. Much discussion went into 'naming' the campaign, as 'psychosocial disability' did not seem to touch personal identities or movement politics. There was all around dissatisfaction with the disability terminology. Preference was given to 'persons living with a mental illness'.

ii) **Right to care/ right to well-being / right to wellness:** A hierarchy of rights was perceived here. These are rights that are defined differently by the different approaches in the mental health sector. The right to care was a Right in general that had to be upheld. We need to see whether the right to care will also include the 'right to getting well', 'right to wellbeing', or whether it will remain at the level of the right to medication and being functional. The Bangalore group argued staunchly for the 'right to being and staying well'.

iii) **Right to dignity in the context of care:** Various treatment related rights were discussed in the consultations, including rights relating to diagnoses, choice of treatment, individualized plans of treatment, right to refuse treatment, and the right to violence free treatments. In the dialogue around these rights, there was a clear divide between the bio-medical and psycho-social practitioners / development / human rights workers on the nature of the "problem" and its treatment. The differences covered all dimensions of mental health care: How is mental health looked at; diagnostic practices; treatments; prescribing practices; solitary confinement and ECT; and various other medical matters such as hysterectomies and medical



termination of pregnancy. While in principle the Right to mental health was widely accepted, the fight was in the details, for e.g., whether ECT without consent / direct ECT was a form of ‘torture.’

iv) **The right to liberty versus the right to health care** was also a dilemma through all the consultations. The use of force within mental health system was a deadlocked issue. How to deal with mental health emergencies was also much discussed. How do we describe “torture” and “cruelty”, how do we define “harmful practices”, etc. were also contested issues. How to understand and deal with “violence” within the mental health system were hotly debated. Some resolutions were reached at the Pune consultation, due to the clear expectations presented by user survivors present here. The right to consent and to refuse treatment, which is part of all bio-medical ethics, was a touchy topic, not only among medical professionals but also among Development professionals. There was also a need to address the question whether remaining in an institution (and being shifted around between different custodial institutions) could ever be a choice. Users survivors and other human rights / disability activists were clear that right to consent was a universal right.

v) **The right to full legal capacity of persons living with a mental illness versus guardianship**, including all civil political and socio economic rights on an equal basis as others, was widely debated. Decision making was considered possible with respect to some socio economic rights, such as right to employment, right to continuing education, etc. But when it came to managing property, and taking more important life decisions, consensus was difficult to achieve. Whether the sector can move towards an ethos of full legal capacity and supported decision making seemed to be a major concern.

vi) **Family care giver / user**: The role of the family care giver in the process of ensuring rights was also a favourite subject for heated dialogue. It was difficult to arrive at solution based thinking on whether self determination was always possible. Other dilemmas included the problems of people living with a mental illness within the custodial institutions including the criminal justice system; how to respect diversity (e.g. people with different sexual orientation); how to enforce rights when resources are not allocated; etc.

G. WAY FORWARD

Norms and policies





Human Rights belong in the realm of law, whereas norms belong in the realm of policy. India does not have a mental health policy. Some small initiatives have been started by various states of the country. The mental health law has not served the purpose of ensuring rights. Laws have set up human rights violations. The omissions of the mental health law are pernicious to people living with a mental illness. The Mental Health Act being roundly criticized at each NAAJMI consultation, there is a great need for talking about a national policy. The language of Rights must percolate into programmatic visioning and planning, particularly the XI Five Year Plan. The NAAJMI charter of rights for persons with psychosocial disabilities can give some reference point in this regard.

### Convention on the Rights of Persons with Disabilities [CRPD]

When we started the NAAJMI campaign, there was no CRPD. Today we have the UN CRPD, signed and ratified by India, and is now in force. It is against the CRPD that we should take stock of any future activity on Human Rights in the mental health sector. CRPD is a legal instrument, developed with a certain historical spirit developed over several years of negotiations and hard international legal thinking. In NAAJMI, we must take the time to study and reflect on the CRPD against this context. The over-determining environment of the CRPD was physical disability. How to make the CRPD fully relevant in the mental health sector is a challenge. For example, we have to consider whether the right to Life includes the right to wellness. Some articles such as Article 12 have frontal relevance. Every stakeholder will have their own 'interpretation' of the CRPD. To arrive a consensual agreement on interpretation is going to be a humungous task of the future. NAAJMI committed itself to this process for the future.





## Chapter III.

### Charter of Rights to enhance Access of Justice for PLMI

#### I.

#### THE KOLKATTA CHARTER, AUGUST, 2005

Rights of persons living with a mental illness were explored in three domains:

1. Parametres of care
2. Rights within family & community
3. Grievance redressal mechanisms

#### A. PARAMETRES OF CARE

##### A1. Right to Quality Care:

1. Right to least restrictive and least intrusive treatment, including prohibition of arbitrary/ unnecessary isolation.
2. Individualized plan for care, periodically reviewed and recorded
3. Preserving and enhancing individual autonomy
4. Access to multidisciplinary teams and non-medical care
5. Right to live, work and receive treatment within the community, without discrimination

A2. Right to protection from cruelty and torture, with torture being defined as physical torture and unauthorized experimentation

A3. Right to basic needs within services like food, space, clothes, personal hygiene

A4. Right to confidentiality

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A5. Right to voluntary treatment, with involuntary commitment restricted to standard protocols for assessing dangerousness to self and others, lack of competence not based simply on diagnostic category, and with right to appeal for review with legal aid available on site.

A6. Right to information on care and treatment

A7. Right to social security, including insurance and adequate standard of living, with special provisions for mentally ill persons with multiple disadvantages (e.g. women / children / poor/ homeless / facing calamities and conflict / physical disability)

A8. Right to free medical and non-medical care at primary health centres and district mental health programme levels, as well as on site and within the community

## B RIGHTS WITHIN FAMILY AND COMMUNITY

B1. Right to information and education for person with mental illness and family on nature and level of illness, as well as treatment and care needs

B2. Right to accessibility to / availability of various modes of treatment, help and rehabilitation

B3. Right to work and gainful employment under conditions of equal opportunity and equal remuneration not less than the nationally determined minimum wage and entitlements under the Indian Constitution

B4. Right to privacy of home, family, correspondence, intimate relationships, sexual relationships, including alternative sexualities, marriage, giving birth and parenting, living with children, and protection of law against all discriminatory practices

B5. Right to owning property, with provisions for necessary assistance, depending on the level of incapacity / disability determined through standard protocols, and protection of law against all discriminatory practices

B6. Right to voluntary contraception, including tubectomy, hysterectomy, medical termination of





pregnancy for women; vasectomy and sterilization for men

B7. Right to vote and hold public office

### C. RIGHT TO GRIEVANCE REDRESSAL MECHANISMS

C1. Right to information about all redress mechanisms, including those relevant to institutions, land & property, marriage, divorce, guardianship, adoption, custody, contracts, work & employment

C2. Right of access to redress mechanisms, including legal aid & representation, with special focus on women and children in institutions; in case of inhuman / harmful treatment; and with special provisions for legal safeguards for temporary incapacity / disability

C3. Right to mobilize, form and be part of associations towards effective grievance redressal

C4. Right to protection and legal redress against custodial and criminal offences, including offences committed in the community

C5. Right to legal redress against indiscriminate transfer between custodial institutions, with special focus on homeless persons with mental illness in institutions

C6. Right to legal recourse against being used as research subjects without informed consent

## II.

### THE BANGALORE CHARTER, JUNE 3RD & 4TH, 2006

Right to Life was a core theme at the Bangalore workshop. Therefore, it is being put up as a separate theme on Rights.

#### A. Right to Life

1. Right to self, self understanding, self care, self help and self growth
2. Right to wellbeing [getting well and staying well]
3. Right to love and intimacy
4. Right to positive identity construction
5. Right to Insight

6. Right to liberty and free movement
7. Right to 3 Rs- Routine, Recognition and Resilience
8. Right to safety and violence-free environment
9. Right to Development [Basic needs, empowerment]
10. Right to choice
11. Right to quality time
12. Right to privacy including right of access to one's own 'spaces'
13. Right to bodily integrity

#### B. Parameters of Care

1. The right to medical as well as non-medical care and treatment
2. The right to treatment information in a language that the user understands
3. The right to a continuum of treatment with user choice- accessible, affordable, good quality treatment, early intervention and continuing care
4. Right to standardized comprehensive and multi- axial assessment and care
5. Right to maximum participation in their own treatment
6. Right to privacy and confidentiality
7. Right to dignity and respect in treatment contexts
8. Right to rehabilitation and recovery services
9. Right to choice of diverse service facilities
10. Right to good quality services closer to the community and available at the doorstep
11. Right to non-hierarchical treatment
12. Right to protection against sexual and economic abuse in the context of care and treatment
13. Right to audited and structured systems of care
14. Right to rational drug treatment





15. Right to individualized care
16. Right to unite and form healing support groups
17. Right to full informed consent in treatment, research and drug trials
18. Right to refuse treatment
19. Right to the political representation of marginalized voices within the mental health sector: People with alternate sexuality, children on the streets, prostitution
20. Right to be protected from human rights violations in treatment context, especially ECT
21. Right to holistic care including general physical and nutritional care
22. Right to local resources in mental health (e.g. Panchayat, community mental health program, NGO programs)
23. Right to minimised involuntary treatment and maximized participation

### C. Community Rights

1. Right to livelihood [employment opportunity, entrepreneurship, insurance, security, trainings]
2. Right to overall health and nutrition
3. Right to free, basic and higher education
4. Right to be equal opportunity
5. Right to manage property
6. Right to inclusion
7. Right to fun, play, recreation and leisure activities
8. Right to participate in social, cultural and community life
9. Right to liberty and non-institutional life
10. Right to Family and community life
11. Right to decide who is one's family / support system
12. Right to recognize care givers and other community support networks
13. Right to necessary assistance



## D. Right of Access to Justice

1. Right to full legal capacity
2. Right to information [policies, laws, schemes, services, programs, treatments]
3. Right to a life free from stigma and discrimination
4. The Right of access to justice through legal recourse (redressal mechanism, settlements)
5. Right to form support groups and associations
6. The Right to assert one's rights – freedom of expression (within courts, treatment settings, community settings)
7. The Rights of the mentally ill – special rights
8. Right to political participation [voting, standing for elections, public office]
9. Right to legal aid
10. Right to grievances redressal
11. Right to participation in review of acts and rules relating to mental health
12. Right to laws which enable rehabilitation
13. Right to inclusion in all statutory decision making bodies
14. Right to be recognized as equal before law
15. Right to simplified procedures in accessing justice

### III.

## THE CHARTER OF RIGHTS, PUNE, MAY, 2007

Other rights as above being reiterated, the special rights that were highlighted at this Consultation were:

1. Right to self





2. Right to mental health
3. Recognition of the insight to human rights as a patient
4. Right to love and affection
5. Right to be listened to
6. Right to proper diagnostic procedures
7. Right to gender equality
8. Right to sexuality
9. Right to alternative sexuality
10. Right to sexuality within the context of institutions
11. Right to be protected from gender linked abuses
12. Right to childhood
13. Right to creativity
14. Right to spirituality
15. Right to a speedy trial
16. Right to legal recourse under the Domestic Violence Act

# Chapter IV.

## Rights in Treatment

The above Charters of Human Rights for PLMI gives the broad spectrum of rights covered in three consultations. There was broad based consensus on full legal capacity, rights within institutions and rights to community life. However, there is still large scope of dialogue among all the stakeholders on the key controversies of Guardianship and use of Force. This section develops the continuous spectrum of human rights within care and treatment as they emerged through the dialogue process. The section is presented in order to appreciate the fact that on a line of human rights thinking in mental health, we may position ourselves at different points. No one is in a position of judging any of these, in any way. However, some positions make more demanding changes within the mental health sector, and may be explicitly articulated as the Ideal towards which we all aspire towards, particularly within a CRPD environment. Any future version of the Mental Health Act will have to move in this direction. In principle, everyone in the consultations had faith in the universal values of dignity, liberty, equality, freedoms, etc. The major variable was the 'practicality' and the attitudinal barriers. Here, the broadband of rights positions within care and treatment is being elucidated.

### a. Right to dignity

Cruelty and abuse should not prevail, according to everyone, though the meaning of these key concepts remained contested. All passive human rights violations within the treatment settings and outside of it must be eliminated, for example, not addressing basic needs. The right to participation in all care and treatment settings is imperative, for most. For some participants, especially those with a strong user centered perspective, the user must be treated as a full person, capable of making decisions on behalf of their care and treatment.

### b. Right to information

Some were of the view that the Right to Information must be exercised with discretion, depending on the stage and nature of 'illness'. Only so much information must be given to the user though the information to be given to family care givers was considered to a higher degree. Whether diagnosis





related information should be given out or not was majorly contested by doctors. Others were certain that medico-legal rights are applicable to everyone accessing health care and must be universally applicable. Still others viewed the Right to information as an unconditional right on all dimensions of care and treatment, as well as other domains.

### c. Right to Voluntarism

Mental health professionals were by and large careful to accept the routine formulation of “least restrictive environment with necessary safeguards”. “Maximising voluntarism and minimizing force” was yet another mindful formulation, emphasizing the fact that professionals should ethically strive towards this in all care and treatment contexts. Several proposed that keeping an eye on making individualized plans for recovery and having rational drug therapy frameworks would reduce the use of Force in the sector. There was detailed focus on the technology of force, including ECT, sedation and particularly the solitary cells, which, it was universally felt, must go. Efforts must be made to create programs that facilitate non violent environments- This was another express sentiment. “Force is not mental health” was a position favoured strongly by some, particularly the user survivors who participated.

### d. Right to Care

Some considered access to medications and “humane” residential facilities as a basic human right. For others, a multi disciplinary team inclusive of psycho socially grounded mental health professionals was adequate human rights guarantee within the service context. Yet others extended this to ask for “non-medical alternatives”. Many care givers especially searched for such alternatives for healing, but there was little information on these. Some saw the point in the right of access to traditional healing resources and other support networks at the community level. The right to be listened to and the right to give and receive love and affection took the realm of rights to care to a psycho-spiritual level.

### e. Right to being cured and staying well

Right to a correct diagnosis using internationally standardized protocols for assessments was the first step in the human rights discourse to being cured, according to some. This came with a range of expectations including early intervention, rational treatments, multi axial assessments, and ethical protocols for good practice in doing assessments. Another human right described in this context was ‘protection from unnecessary determination of Mental Illness’, as a balance on the right to privacy.

That such human right becomes more complex in the context of crime, however, was noted. To set the outcome of care and treatment at mere functionality was seen as extremely limiting by some. When one's experience of full self and personhood becomes actually restricted by treatment, the right to refuse treatment for the user becomes vital. Users and survivors do also strongly recognize the need of a right to overall well being and healing pathways to recovery.

#### f. Right to Self

How the Right to self, a core mental health aspect, is embodied in legal instruments such as the Mental Health Act, PWDA, or even the CRPD is an open question left to be answered in the future. Within the medico-legal regime of mental health, there seems to be little scope of articulating the Right to Self. While the sector seems to be largely constrained by attributions of 'mental illness' and 'disability', rights to mental health and well being were clearly explicated in the Bangalore and Pune workshops. Other self related rights articulated were the rights to a sexual and spiritual self. The right to bodily integrity [one's own bodily spaces or embodiment to be protected] was also explicated clearly.

#### g. Right to freedom from cruel, degrading treatments and torture

Everyone universally recognized the right to be free from physical and mental torture [broadly coming under the modern legal description of "violence"]. Unauthorised experimentation particularly without consent was similarly widely accepted as cruel and degrading. Passive violations especially pertaining basic physical and mental needs was widely recognized as coming under cruelty. One trend of thinking placed ECT, solitary and other such treatments usually linked with the use of force as being cruel, degrading and torturous, a position harshly condemned by medical professionals.





## A. GUARDIANSHIP FOR PLMI: A DEBATE

### For Guardianship

We are looking at chronic severe mental disorders. Guardianship is required here.

Whenever we make a decision it is in consultation with someone. Our decisions especially the major ones are taken collectively in our society. So if a Guardian is appointed to take important decisions, it will be beneficial, as the burden of taking major decisions is then shared.

Not just mentally ill people, but all of us need guidance and support at different points. For a mentally ill person to have a guardian would actually help in safe guarding him and protecting his rights and enable him to make rational decisions.

Certification should be used to judge whether a mentally ill person is capable of taking

### Against Guardianship

Everybody is capable of taking decisions from birth. It should not be denied on the grounds of capability or chronicity. Even if chronic, people can and do still take decisions.

There is a problem with the family structure itself, which is both hierarchical, and patriarchal as it confers decision-making only to the most powerful men in the family. Property, sexuality and marriage are the areas where a guardian comes in de facto because our society feels the need to control these. We never talk of dignity or respect when we speak of guardianship.

What is guardian – a legal word usually used in the case of a minor or for a child. Here we are speaking of an adult. The concept of Guardianship is based on capability. It is protective, restrictive and power position. A person with a mental illness may need support, but not protection and control.

In certification functional capability is looked at and it is temporary only for 5years. There are

decisions and guardianship arranged accordingly.

Physically ill people also need guardians so why is this being denied to mentally ill people.

Person may make a wrong decision which they may regret later.

Taking care and decision making are very close and it is quite possible that the two may cross over or overlap.

limitations to the certification. Certification is a practice. We cannot decide capacity or incapacity on the basis of certificate.

Guardianship means taking decisions on the other person's behalf. A person with diabetes can carry on with his or her work. He or she needs help in getting care, not in taking decisions.

Anyone can make a wrong decision. Decisions may have certain consequences. Making a mistake in it self is not a bad thing. It is a learning process, but others pass a judgement on it. It would deny a person personal growth if the opportunity to make decisions is taken away from them. It is only when they make decisions will they understand what works best for them.

The "common" ethical code should not be used to determine the quality or correctness of decisions. Then only mainstream values will be touted and the diverse positions of marginal groups and their rights and arguments will be left out.

Very often we do ask our close people about their views, but they do not take the decision for us. They are usually there to take care of us in a crisis even when they are not our legal guardians. On the other hand even if I don't ask 20 people in my community it is still my right to make a decision so why should a person with a mental illness have to open up his/ her life for others to make decision about.

Capacity is not directly or indirectly related to mental illness. In normal situations the phrase "not in a position to" occurs mostly with people who are vulnerable – by virtue of their gender, class, caste, access to and ownership of resources etc. In a household or a family situation, Guardianship is a medico legal term. Guardianship can be spoken of in two contexts – guardian of property/other material things, and guardian of person. The usual reason for guardianship is incapacity.





who is in a position to make a decision about buying land or selling it? People who do not have a mental health problem are also often “not in a position to” make a choice or a decision, according to our society. Therefore does an objective condition really exist where we can decide incapacity and who needs guardianship and who does not? Incapacity is created and accrued over a period of time. Till today, in India, it is the easiest way to get divorce. In the medical field, there are dilemmas that make it difficult to take a decision. For e.g. a person with heart problem may not be able to decide whether he wants to do an angioplasty or an angiography. Not having enough information can be a cause for being unable to decide. In such cases, the doctor will lay the pros and cons but the patient has to decide what is to be done. The eventual responsibility and right of making the decision lies with the patient except maybe if he or she is in coma. Incapacity is a universal phenomenon. It is impossible to link capacity with decision making because there is no standard of a right decision. Once given, decision-making is never legally returned to the person who has a guardian - once incapable always incapable. Decisions with regard to property will be taken by the guardian – losing all control over

resources. Decisions with regard to treatment (ECT, admission to mental institution etc.) – losing control over body, space, mobility. The list is endless. Even if there is one instance where common law cannot be used and we need a special law, then there is reason to keep guardianship, but we are unable to bring up one such instance. The society is built on inter dependence. As human beings we are closely organized and need people around – for various interactions and one of these could be decision making. We are also capable of developing relationships and choosing the kind of interactions we want from these. If we allow for this natural state to exist then what is the need for legal guardianship? Here too there is not need for a special law. Guardianship is a legal function not a caring one. the two functions need to be separated.

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## B. STEPS TO TAKE AS ALTERNATIVES TO FORCIBLY RESTRAINING PEOPLE



“Bad behaviour is bad behaviour and it need not be linked with mental illness. If anyone [user and other] is throwing a tantrum or behaving badly, it must be pointed out to them. Violence is an expression of a human being and unmanageability is not peculiar to users.” Western Region Consultation, Pune.

- Do not assume that the person has no insight whatsoever for all times
- Talk to the person
- Find out the cause of agitation – there is always a context
- Separate the person from relatives if needed
- Build rapport with the patient
- Anger and violence is physiological. Give time and space for the body to revert back to normalcy.
- In time of acting out, clear the space of people and organize safety for others
- Don't get into the “I have to control this person” mode by lunging at the user. This is counterproductive: “One of the users in the group shared her experience of forcibly being restrained by being tied. Bandages were used to first tie her feet, then her hands and then her abdomen. But she wanted to be free and she would often tear the bandages. If a person is tied, they get more agitated, angry, and frustrated”.
- Information must be given to a person before restraining a person against the will using cloth, etc. so that the person can re-assess their choices
- Giving space for person's own ways of expressing anger [A user recounted using Brahmahri meditation technique while angry, which made the anger drop. But she was still sedated against her will].
- Sedation with non-psychotic or other psychiatric medication
- Being non-threatening
- Only persons with whom the user has a rapport and can trust must intervene
- Providing space for self expression using art
- No provocation



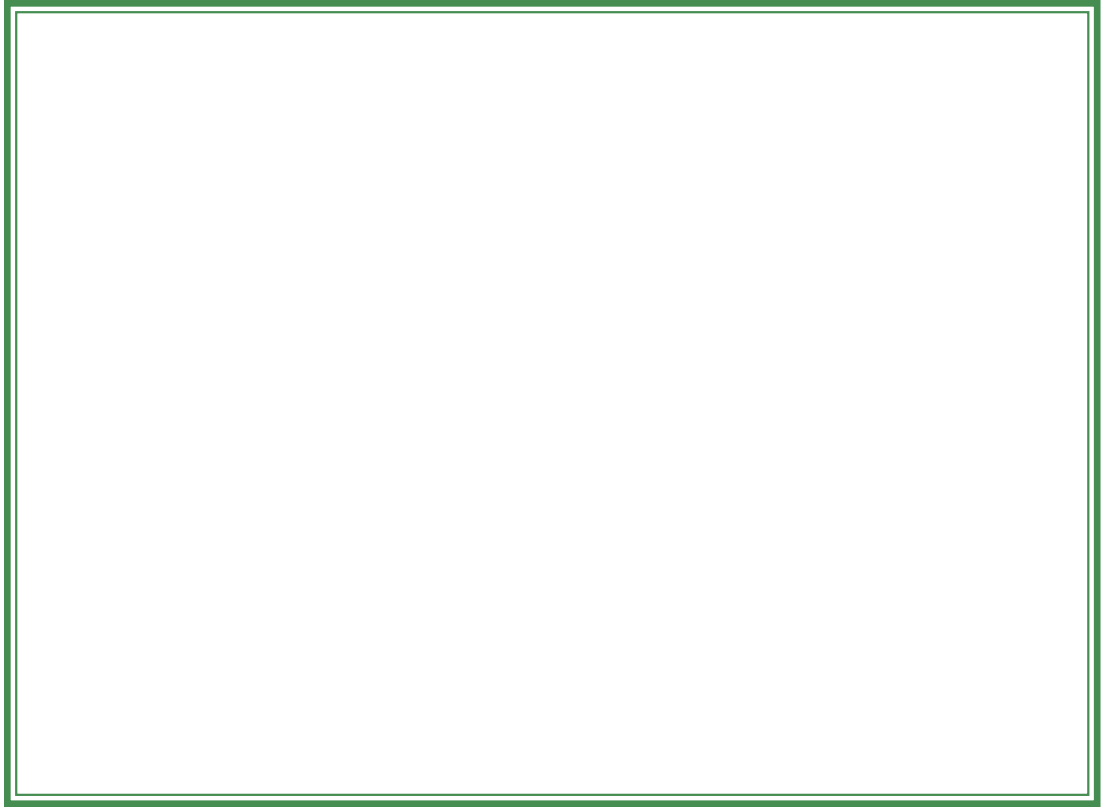


- Respect individual ways of dealing with anger
- Create space for expressing anger
- Ventilation space for anger to express
- Guide the person out of the room
- Learn to deal with violence [address personal anxiety in the face of anger]
- Giving options to calm down
- Human touch where user is okay with that
- Empathy
- NO counter violence [body language, verbal language, physical retaliation] [A user reported about the doctor pulling her hair and jeering at her when she was angry].
- The threat of institutionalization, shock treatment, or solitary confinement is counter violence.
- Make non-violence a value not just for the user but for the community [family, public spaces, etc.]
- Justice should be provided in site where physical restraint, etc. is being used
- Information & training

### C. A CASE STUDY FROM ONE OF THE PARTICIPANTS [WESTERN REGION CONSULTATION, PUNE]

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Violence is anti-mental health. NGOs and civil society has to immediately intervene without waiting for family consent in such cases. Police should be contacted and required measures taken



to restore liberty. This situation is unlawful. Section 25 of the Mental Health Act which specifies the responsibilities of families should be applied. Attitudinal changes within families should be brought about by questioning myths such as: Families are always supportive; Mentally ill people are always violent; PLMI are prone to wandering because of their symptoms and so must be restrained; Institutionalisation is the best option for such people; etc. The cost of not intervening in such cases is higher than that of doing so. The accountabilities of NGOs in “intervening” in “family matters” must be challenged, as happened in the case of domestic violence or violence against children and dalits.





## D. CRIMINALITY AND MENTAL ILLNESS

The issue of criminality was discussed in the western region consultation. There are no choices for mentally ill people if they commit a criminal offence. They hardly get a hearing or any other standard legal procedural intervention available to others. They also get shifted to criminal ward of the mental hospital where they do not see the light of day. In the mental health user movement, there has been a lot of discussion about the linkages between criminal acts and mental illness- Users in the West feel that it is better for them to go to a regular prison than mental institutions. This is primarily because of the extreme violative conditions of the criminal psychiatric institutions.

Criminal behaviour is not a peculiarity of mentally ill people. It is in society at large. Violence due to mental illness is lesser than violence at large, found in families and society. Violence of any sort should be considered within the justice framework. Lawyers in the West may use 'insanity defence' to escape the mainstream system. But in our country, this situation does not prevail; Rather the opposite situation prevails, where people living with a mental illness have no access at all before the justice system. No access to economic resources puts the patient into a more vulnerable condition further decreasing her chances of accessing the criminal justice system or avoiding institutionalisation.

Incidence of infanticide in the post partum period is a likely risk. Women in depression attempt suicide along with any living children. In a local Jail, it was discovered that several women have been sentenced for culpable homicide for killing their child, due to their attempted suicide. The treatment resources available to these women are minimal. It is essential to develop a list of support centres, which people can access in such situations. The law about suicide also needs to be questioned. If a person has the right to life and safety against violence then should she not also have the right to decide when she wants to die. Access to Justice means that everyone irrespective of their condition should get a free and fair trial before a court of law. It should be mandatory that PLMI have access to both care and treatment as well as justice. Absence of one must not delay the other.

1. It was interesting how the analysis looked at the problem through the 4 phases of her life.
2. People who are mentally ill, when they look back at their illness when better they are often able to give very insightful accounts of the surroundings or the reasons why they went into a certain condition. These insights are very important and the information that is given about the

environment should be looked at carefully to reduce it of the triggers it provides to discomfort people.

3. It was felt that the term “insight” was an uncomfortable one. It is mostly used as a diagnostic tool. Doctors often restrict consent of patients blaming them for not having “insight” and therefore use proxy consent.

It was clarified that in this case it was being used positively to learn from the experiences of users about their environment and not for judgement of their capability





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