

Visions and Dreams:

NAAJMI Consultation Report on  
National Mental Health Policy

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CitiOtel, Pune, 26<sup>th</sup>& 27<sup>th</sup> July, 2011

Brief background:

The National Alliance on Access to Justice for People Living with a Mental Illness [NAAJMI] is an unregistered coalition of people and organisations active since the year 2005 to consolidate a philosophy on the human rights of persons living with a psychosocial disability in India and advocating for the safe and humane delivery of mental health services<sup>1</sup>.

NAAJMI began in Kolkata in 2005, and by 2008, NAAJMI had become a strong collective voice in the country demanding access to better and humane health care for all persons with disabilities and a range of other services related to disabilities. Ratnaboli Ray gratefully remembered and said that on this occasion the late Mr. D. M. Naidu of Basic Needs India is missed by all, as he was instrumental in keeping the group together. She remembered him as the rational voice who taught the group how to listen to “voices”. The political context of the time when NAAJMI was formed and became active was also interesting for her, as the international disability community was working to see the adoption of the UNCRPD globally. As the UNCRPD supersedes all earlier rights instruments, such as the 1999 MI Principles, and is a new reference point, there has been tremendous scope for NAAJMI to be proactive and address many pertinent issues in the mental health sector today.

Bhargavi Davar recalled that the call for a ‘national’ mental health policy was made first by Late Mr. D.M. Naidu in 1999, and so many persons had been involved and worked together in this journey ever since. Mr. Naidu had called

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<sup>1</sup>Ratnaboli Ray, Founder, NAAJMI, welcomed the participants and gave an introduction to the inception of NAAJMI.

NAAJMI a “train” where many people had got on and got off, but the journey still continues.

NAAJMI’s vision is to assure “A Life of Dignity for Every Person Living with Mental Illness”. In order to accomplish its vision, NAAJMI has a four-point Mission-

- (i) Influence policy and public opinion
- (ii) Capture and apply knowledge in the field of mental health
- (iii) Provide a platform for dialogue among all stakeholders in the mental health sector – especially for the voices that have not been heard so far
- (iv) Cross disability alliancing

NAAJMI milestones:

India ratified the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) in the year 2008, without reservations on any article, including the contested Article 12 on Legal Capacity. The UNCRPD proposes a range of civil political and socio-economic rights for all persons living with disabilities, including people living with psychosocial disabilities. Ratification of the UNCRPD enjoins the Indian government to take several obligatory steps to enforce these rights, including making new laws and policies; and repeal of laws and policies not in line with the UNCRPD. NAAJMI has been very active during the legal harmonisation process vis a vis the UNCRPD in the last 2 years, and some of its actions and achievements have included:

1. Holding a national consultation in New Delhi in 2008, after UNCRPD ratification, to match the human rights vision of NAAJMI with UNCRPD, with support from Human Rights Law Network and Ashoka, New Delhi

2. Floating a white paper for dialogue, in collaboration with Human Rights Law Network and NALSAR, supported by the Disability Rights Fund, on legal harmonization of disability and mental health laws vis a viz the Rights of persons with psychosocial disabilities; dissemination and dialogue thereof in New Delhi on the 'white paper'
3. Developed a "Knowledge Capture" report that advocated comprehensive community mental health services and advocacy against institutional care; disseminated.
4. Developed an 'alternative' or a 're-vision' for mental health legislation, with focus on de-institutionalisation and provision of comprehensive community based services for all persons with disabilities.
5. Active cross disability alliancing with various supportive organizations such as Disability Rights Group, HRLN, Swaadhikar, and others; advocacy for a comprehensive disability law; accent on Legal Capacity and civil political rights, with support of various disability organizations through the legal harmonization process.
6. Active participation in various national efforts at legal harmonization such as reform of National Trust act, Persons with Disabilities Act, Mental Health Act.
7. Active participation in various platforms within the mental health sector, including the National Consultation on the Mental Health Care Act, 2010, in March, 2011, in New Delhi.
8. Contributions to drafting of sections on Legal Capacity and Civil Political Rights in the new "Rights of Persons with Disabilities Bill, 2011"
9. Active lobbying with the Ministry of Health and Family Welfare (MOHFW) on repeal of the Mental Health Act, the limitations of the

proposed Mental Health Care Bill 2010 (MHCA), and the need for a unified disability law

10. A published report of our campaign on “Bill of Rights” from 2005-2008
11. Participation in DRG supported trainings by International Disability Alliance in New Delhi, on shadow reporting and collection of information for the shadow report through RTIs, legal studies, etc.; and various other regional forums such as DPI, etc.
12. Mobilisation and active participation of user survivors and user self advocates through the campaign process, particularly in this last meeting in Pune, where a majority of participants were users survivors.

#### Title of the consultation

The title of the consultation reflects the spirit of Mad Pride sentiments, which NAAJMI endorses: visions and dreams are the basis of creativity and personhood!

NAAJMI, in these years, has provided safe spaces for users and survivors to speak out, while maintaining a posture of dialogue and negotiation with various other stakeholders.

NAAJMI has been supported by people with disabilities and has support, within the disability movement notably from the Disability Rights Group, Mental Health Rights Group, Human Rights Law Network, Swadhikaar, Action Aid and various others in the country. These organizations have helped amplify the feeble voices of users and survivors of psychiatry in India, creating and mentoring forums where we can speak out safely against our exclusion and marginalization within the country. These organizations have without fail included us in their own advocacy and lobbying work. Through these alliances

we were also able to recognize and appreciate a common shared disability experience.

### Objectives of the consultation

NAAJMI is a recognized name within the human rights and disability movements today in India and internationally. Our hard advocacy against the Mental Health Care Act led to it being put on the back burner: The MOHFW initiated a “Mental Health Policy Task Force” in April 2011.

On the New Disability Rights Legislation, said to be in harmony with the UNCRPD, NAAJMI has expressed serious reservations about the ‘Limited Guardianship’ provisions, which have crept in, in the last draft.

It is against the background of these national developments on law and policy, that NAAJMI proposed to conduct another National Consultation in Pune, bringing together various actors within the disability movement. The Law For All Initiative of Ashoka and Antara Lahiri supported the consultation.

The objectives of the meeting were:

1. To discuss the recent developments in MOHFW regarding the new MHC Bill versus the National mental health policy
2. To provide NAAJMI's ideas to the government on its expectations from the law (covered through earlier consultations), and from the policy (NAAJMI's new expectations)
3. To make a wish list for a national mental health policy
4. To make a well documented report that will be submitted to the government as NAAJMI's recommendations.

Participants to this face to face meeting included people whose voices needed to be heard within the policy making process. It was hoped that people with disabilities, users and survivors, arts-based therapists, clinical psychologists

and other mental health professionals, counselors, those in primary health care, social scientists working on health and rights issues, public health professionals, disability law advocates, disability activists / researchers, and psychiatrists who have served in the public mental health system diligently over the years would be represented in this consultation. It was also a plan that the final report will be widely circulated for comments from those who 'wished they were there'!

### Our learnings in the last year

The 'Bill of Rights: Insights of a Mad Campaign (2005-2008)' report was published and disseminated at this consultation in Pune. Our Bill of Rights work and Charter had been developed through several regional consultations, and evolved over a 3 year period. In a national consultation of 2008 in Delhi, we compared our Bill of Rights with the ratified UNCRPD. NAAJMI was guided in this effort by Prof. Amita Dhandra of National Law School (NALSAR, Hyderabad) and Mr. Gabor Gambos, Human Rights Defender and Visiting Fellow from Hungary, Ashoka International Fellow Exchange Programme. In fact, NAAJMI work was seen by the experts as giving local or grassroots content to the UNCRPD, particularly in the context of people with psychosocial and intellectual / mental disabilities. The interesting part for the experts was the 'dialogue' method we had adopted throughout, significant, from their point of view, of a 'deliberative democracy'. Deliberative democracy referred to a spiraling method of including more and more actors into the dialogue process, at the center of which were the users and survivors. The coalition also fostered, through the visit of Gabor Gombos, a perspective on 'self advocacy' by users and survivors of psychiatry, and led to a national mobilization of self advocates in different regions.

NAAJMI people and groups did a lot of studies 2008 onwards through a variety of consultations, participation, preparation of manifestoes, data, experience sharing, networking and active lobbying. These activities brought more and

more constituencies into the discussion, until NAAJMI had covered a wide spectrum of voices within the mental health and disability sectors. At each spiral, the voices of the users and survivors amplified.

We realised through the Bill of Rights consultations (2005-2008) that the broad spectrum of civil political rights (especially Article 21 of the constitution on Right to Life and Liberty) and right to full legal capacity are going to be a big area of controversy for the future. It was a contest where users, survivors, parents, advocates, social scientists, human rights activists, professionals, disability activists and mental health service providers occupied a variety of positions and convergence was very difficult. NAAJMI has slowly gathered insight on these critical topics. Some learnings which came our way were

(1) The UNCRPD in our understanding seemed still very 'physical disability' based and needed proactive interpretation from the point of view of people with psychosocial disabilities. While not denying the importance of socio economic rights, we had to start building the rights discourse by scratching the bottom and reaching down to the fundamentals: right to life, survival, personhood, citizenship, freedom of speech, right to be protected from abuse and violence, ... etc.

(2) Certain rights like the right to freedom of expression, right to life, right to be "you", the right to dream, to have aspirations, the right to live with strange beliefs, curious thoughts and experiences, the right to recover on one's own terms, the right to stay well, the right to have an emotionally conducive environment, the right to be in a violence free environment, could be read into the UNCRPD.

(3) Through 2 consultations in 2010 (Pune and Bangalore), NAAJMI consolidated its vision for a new mental health paradigm that is compliant with the UNCRPD, and inclusive of the above human rights related to selfhood, identity and citizenship. At the turn of the year in 2010, the new disability law



seemed promising, having provided for abolishment of guardianship and making way for supported decision making.

(4) We learnt in the process of our cross disability alliancing that 'unsoundness of mind' is about a whole range of disabilities, and not just about mental illness. We felt close affinity with the experiences of people with mental, and intellectual disabilities; with multiple physical and sensory difficulties; people who are most deprived within the disability movement such as those in institutions, the poor disabled, and those confined to their homes. This sharing of experiences across disabilities gave us the necessary sensibilities to work cross disability.

(5) We have tried to integrate these concerns within the larger social and human rights movements, such as child rights and human rights movements. We have not been able to make many inroads into the mainstream women's movement. And the reason for this could perhaps be that the women's movement has other priorities, and disability is not among those priorities. As we have developed our own consciousness as being 'movement based', we have found that our closest allies are not from the mental health sector, but from the larger Development and empowerment sector.

(6) There are challenges in cross disability work, because we face the same stereotypes within the disability sector as in the outside world. Particularly with those groups higher in the pecking order within the disability sector, establishing our full legal capacity has been a big struggle. The effects of this politics is also evident in the way the 'Rights of Persons with Disabilities Act, 2011' was eventually finalized with sections on Limited Guardianship.

(7) We have anguished over the question of the humongous human rights violations that are happening in the context of institutional care. While the disability sector is not paying much attention to these violations; the mental health sector is actually promoting the creation of more institutions. We have

voiced our concerns about the hundreds of private institutions created in the aftermath of the Erwadi tragedy and the increasing exposes in the media.

Legal harmonization process in India and NAAJMI's role<sup>2</sup>

National Trust for the welfare of people with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities was the first government agency in the country to initiate the legal amendments process, in 2008, immediately after the UNCRPD was ratified by India. NAAJMI members were active through this process, attending the regional consultations. Rights to a legislation that will guarantee full legal capacity, and the abolishment of plenary guardianship were some of the major issues taken up. There is the harsh reality in the country that certain persons (seen as of 'unsound mind') are not considered as 'legal persons' in the Indian courts. Because the laws dismiss the personhood of these persons, to the extent of refusing suffrage rights, society at large also invisibilises them. This category of people is not a strictly defined category and has in customary practice, included vulnerable women, elderly, people with multiple disabilities, mental and intellectual disabilities, and people with psychosocial disabilities. 'Unsoundness of mind' was a colonial construct, and had social, not medical implications until late colonial times. While nearly all laws came up for progressive reform in the post Independence period, laws relating to Unsoundness of Mind did not come up for similar reform, reflecting societal prejudices of the times. Article 326 of the Constitution, made in the post Independence period, explicitly denies suffrage rights to persons of 'unsound mind'.

In the present scenario, where people with disabilities have firmly contested plenary guardianship and limited guardianship, there is a lot of anxiety among professional groups, the care givers' groups and various service provider organizations around the country. Guardianship system is a system we are

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<sup>2</sup>Presented by Bhargavi Davar at the Pune Consultation, on 'Visions and Dreams'.

habituated to. Guardianship system is also beneficial to third parties because of its economical benefits. (e.g. in the context of marriage or take over of property). Various bureaucratic systems, procedures and 'precedents' have been deployed since the late colonial times to uphold guardianship practices. There are jobs involved for various gate keepers: Finding alternatives seems an economic as well as an ideological challenge.

The Ministry of Social Justice and Empowerment is preparing a new Disability Act. The Ministry of Health has put up a MHCA, 2010. Then the Rehabilitation Council of India has also put up its own legislation in the last few months.

NAAJMI has always advocated for a single comprehensive law for all persons with disabilities. Supporting the Disability Rights Group, we have demanded a separate Ministry for Disabilities, with a full Minister heading it, and a separate Ministerial budget.

#### Is the MHA a Disabilities Act?

NAAJMI has advocated for a single comprehensive law for various reasons, the most important being that: having a special law like the mental health act, has only marginalized people with psychosocial disabilities. It has created a set of medico-legal penal practices in the name of 'special' needs. NAAJMI has further advocated for inclusion of all disabilities within the structure of the National Trust, and for the integration of the NTAct within the new disability legislation.

There are over a hundred civil, criminal and care and treatment laws which exclude people with 'unsound mind' and which allow them to die a 'civil death'. Many of these laws have a colonial history, hitherto not deconstructed. While there are several programmes for people with disabilities, they do not cover people with psychosocial disabilities. For example, the MHADA scheme in Maharashtra includes only blind people and is presently being seen as a turf issue by the beneficiaries of that scheme. When services have been traditionally held by a particular beneficiary group, it requires magnanimity to share it with

other people with disabilities. This is what the UNCRPD enjoins all people with disabilities to do, to be fully inclusive. Despite several rounds of negotiations with the Parivaar group by various NAAJMI members, care giver leadership staunchly refuses the inclusion of people with disabilities into the National Trust as beneficiaries. So there is tremendous scope for advocacy to include a whole range of people with different types of disabilities in various government legislations and schemes (National Trust, Right to food, education, housing, etc.).

The Mental Health Act is not a disability Act. It has a history of about 200 years, and is more like the CrPC or the Beggary Prevention Act. It provides procedures and institutions for deprivation of liberty. A law with a primary objective of deprivation of liberty

NAAJMI has advocated for the repeal of the Mental Health Act, and if at all a new law or policy for people with psychosocial disabilities is envisaged, it would be on a completely different positive rights paradigm. Such a positive rights paradigm was put up in 2 separate consultations, one in Bangalore, and the other in Pune, in December, 2010. While staunchly advocating for a comprehensive law, ingredients for a new mental health act were being envisioned by NAAJMI, as a mind exercise:

[1] to stimulate the imagination of the mental health sector to think beyond institutions

[2] to apply the UNCRPD to the lives of people accused of, attributed or living with a mental illness , including placing them and their experiences at the center of the human rights and policy discourse

[3] to bring robust dialogue processes between the mental health and the disability sectors

[4] to raise awareness on the plight of persons accused of, attributed or living with a mental illness [PLMI] in most marginalized situations and

[5] to advocate for the repeal the present Mental Health Act.

It may be of interest to note that, recently, the World Network of Users and Survivors of Psychiatry has put out a statement seeking worldwide endorsements, demanding the repeal, world over, of all Mental Health Acts <sup>3</sup>. NAAJMI has advocated in its earlier consultations last year, that the Ministry of Health and Family Welfare should have the law repealed and create a policy environment that would:

- create and enhance pathways towards overall community well being and good mental health for all peoples including people with disabilities;
- promote community care and support for people living under environmental stress and conditions of vulnerability;
- enhance choices for total health and well being of communities at large;
- protect those accused of, attributed or living with mental illness against the high levels of stigma, discrimination, violence and exclusion that exists today in our society.
- Implement de-institutionalisation and phase out penal mental institutions in a stepwise and deliberate manner.
- facilitate the movement of society's attitudes to think and practice inclusion, in the case of all PLMI, including and especially those seen as 'severely' or 'chronically disturbed'.

Our futures <sup>4</sup>:

1] We expect to put out our draft workshop report and gather more recommendations from various other experts who could not attend the

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<sup>3</sup> The WNUSP endorsement was read out at the Pune Visions & Dreams Consultation, and endorsements sought from the floor.

<sup>4</sup> Presented by Bhargavi Davar, co-founder, NAAJMI, at the Visions & Dreams consultation in Pune.

workshop; refine the document; and present it to the health ministry by October end.

2] It is significant that the MOHFW is putting out a national mental health policy, which we were advocating for way back in 1999 as individual organizations. The Knowledge Capture work supported by Ashoka is already a stepping stone in the direction of policy. We need to, in the time from now until a year ahead, collect a 'mosaic' of all the community mental health programs the NGOs have developed, compile the information together and submit it to the government as innovative community work. Hopefully, this will replenish and rejuvenate the government programs on mental health care.

3] Contesting the constitutionality of MHA in the supreme court or High court, and the new legislations as they are emerging, is also important. NAAJMI members are gearing up for this, by raising human rights funds.

4] NAAJMI members are participating in the shadow reporting process supported by the IDA and DRG; and various other advocacy and cross disability forums.

General Policy Recommendations to the Ministry of Health and Family Welfare:

TOR for Policy group<sup>5</sup>

A circular titled "Constitution of a Policy Group to frame a Mental Health Policy for India" had been sent out by the Minister of Health and family Welfare, Mr. GhulamNabi Azad in April 2011. NAAJMI had responded to the Minister quoting Dr. Govindaswamy, one of earliest visionaries of psychiatry who had clearly outlined the scope of mental health in India as early as 1948. He had said "The field of mental health in India has THREE objectives. One of these has to do with mentally ill persons. For them the objective is the restoration of health. A second has to do with these people who arementally healthy but who may

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<sup>5</sup> Abdul Mabood's presentation at Pune Visions & Dreams consultation

become ill if they are not protected from conditions that are conducive to mental illness which however are not the same for every individual. The third objective has to do with the promotion of mental health with normal persons, quite apart from any question of disease or infirmity. This is positive mental health.’

Then the Terms of Reference (TOR) of the Mental Health Policy Group was read and shared with all. After receiving this information there was a lot of discussion on the formation of the policy group and most participants felt that it really was not a balanced group. The participants' critique on the formation of the policy group and its composition should be made known to the concerned ministry.

#### 1. Inclusive health care policy

NAAJMI has in 2010 discussed the roles of MOHFW and MOSJE in 2 consultations, where we had expressed our reservations about the Mental Health Care Bill. We have advocated that

- The MOHFW should keep its role only to the provision of good health care for all people with disabilities. The role of rehabilitation (livelihood, education, and other rights) is with the MOSJE. The MOHFW should create policies that will not hinder the process of rehabilitation and will be in harmony with the rights enshrined in the new mother law for all people with disabilities.
- In its present efforts, the MOHFW is making a special policy for persons living with psychosocial disabilities, whereas, the UNCRPD mandates inclusive policies. There is the concern that, whatever health policy the MOHFW makes, it should comply with expectations laid out in the new disability legislation and should include health care needs of all people with disabilities.

- Participants felt that in so far as the MOHFW had a responsibility of providing health care for all people, the mental health policy being considered would be applicable to all people, including all people with disabilities.

## 2. Is it going to be a custodial or community mental health policy?

- NAAJMI expressed the concern that, having done a year's cycle of work on the law, the MOHFW has brought together nearly the same group to work on the policy. There is the concern in NAAJMI that the policy is going to hitch hike on the present draft of the MHC Bill, 2010, which has set the terms of the dialogue in the sector today within the context of institutional care. NAAJMI is also concerned that the policy should go beyond the blinkers of the District Mental Health Program (DMHP).
- NAAJMI is concerned that the policy should provide for a robust community mental health paradigm of practice for the country. We are not expecting a 'mental illness' policy, rather a 'mental health' policy.
- We are also expecting the integration of community mental health, into existing development services (e.g. CBR) for all persons with disabilities

## 3. Composition of the group

- NAAJMI is concerned about the composition of the policy group members was 'medical-psychiatric heavy' as it comprised too many psychiatrists: one Member is head of state psychiatric institution; one Member represents NGO and is running a psychiatric setup; one is caregiver to a person who is having Symptoms of Mental Illness; one Member is having Symptoms of Mental Illness; one Member is working in public / community health as a doctor; one member, a medical doctor, is from a private funding agency and one member, a doctor, is from the ministry and is the Convener and Member Secretary of the said Policy Group.



- 54% of our population is aged 24 years and below, constituting 35% in the ages 0-14 years and 19% in the age group 15-24 years as per the census records of 2001. This means we have 600 million children and young people. This is a stage where maximum promotion of positive mental health and prevention of mental disorders is possible. There are no professionals and organisations to represent this most vulnerable group; and prevention should be one of the most important components of the mental health policy. Needless to say, the group must have good representation from people with disabilities. Some concerns expressed by the participants are:
- We recognize that practically, we cannot have representation of all the disabilities in the policy group. But we also cannot have seven psychiatrists in the group. The public stature and academic background of the psychiatrists in the group is also important. Role of doctor is only to give medications. Whereas a mental health policy should have a lot more than that.
- User survivors are competent for this role and must be included in more numbers in policy in different capacities.
- The policy making process does not follow the spirit of the consultation process. There is only one person from the development sector and no representation of groups/individuals working at the grassroots level and also not a single person from the employment /recruitment or the HRD section. It was important to have different socio-economic groups as well as individuals from different geographical areas represented in the policy group.
- Child and adolescent mental health care professionals, clinical psychologists, psychiatric social workers, nurses, child health specialists, family therapists, educationists, school counselors, vocational experts,

rehab expert, management professionals, community mental care, those who will study financing the sector, those working in prevention and promotion of mental health, working on women's issues, advocates (the TOR mentions advocacy), experts on communication and those with proven track record in Legal and Advocacy research must be included in a democratic dialogue.

#### WISH LIST for a mental health policy: Generic recommendations<sup>6</sup>

- Mental health should be getting a good share of the budget according to the intensity / magnitude of mental health status in the country. It should also be utilized properly.
- The policy should address all mental health aspects of living in a development context and not merely health services or illness related services. Mental health services should be provided from a bottom-up approach, wherein basic needs of the individuals and community must be addressed first before specific mental health needs are met. Those living in areas or communities with poor development indices must be provided with necessary socio, economic programs to address their

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<sup>6</sup>Several themes were considered as vital for the policy initiative, including: prevention, promotion, life cycle approach, individualized care, gender issues, sexuality and sexual orientation, integration into public health, care in the community, inclusion and mainstreaming, awareness and IEC, Human Resource Development, relevant trainings, research and development, financing, monitoring and evaluation, advocacy. After this general discussion the participants divided themselves into groups which were

1. Prevention;
2. Promotion
3. Community Care & Public Health
4. Advocacy
5. I E C

And Gender, Poverty, Sexuality, Trainings & HRD and Age were the cross-cutting themes for the above mentioned subjects.

disadvantage and uplift their status. Ministry of Health must be proactive and take up this intersectoral issue. Strengthening social development and securities will have positive mental health impact.

- If we are going to make a wish list then prevention, promotion and advocacy of mental health must be clearly spelt out. These areas are of highest priority in building community on a development platform.
- Gender, culture, class, sexuality, religion and age are structural factors that create a disadvantage in our society. These must be factored in as cross cutting themes in the policy at every step.
- Create Support groups and programs for caregivers and PIRs (Person in Recovery). A PIR is able to help others (like a sufipir!) and his or her talents as an experiential expert in this area should be encouraged.
- Whenever we mention 'rehabilitation', institutional set-ups come to our minds but community care should be focused upon. There was much difficulty in describing different community set ups, how to categorize day-care, rehabilitation, and acute centres. Where does institutional care end, and community care begin? Can it happen at all, given the custodial outlook of our laws and societal attitudes? Many transit centers and rehab centers still had the custodial outlook of mental hospitals, including lock up. Even group homes can be oppressive if the freedoms of the people living there are not respected. The group discussed this issue.
- In community, at present, the government is only looking at replicating the DMHP, which has many limitations. The government should be cognizant of those limitations and look at the basic design. We have to describe different community models and their best practices, which the District Mental Health Programme (DMHP) could

tag. The government can support such an exercise in collaboration with NGOs.

- There was much concern about the Five Year Plans and unutilized monies. Unutilised money from the 11th National Plan should go into IEC immediately. IEC has remained at the level of disease identification, and does not carry disability values. It has not addressed the subject of mainstreaming. The nuances, content, what kind of awareness we are aiming at for communities, rural audiences must be looked into cautiously. It was also very important to measure the IEC impact, which is usually not done. IEC should be targeted at grassroots level workers and so should be prepared in appropriate languages.
- We also have to bear in mind that the public health system is so compromised that at the community level we see a lot of malnutrition. Mental health status is directly correlated with general health status, particularly nutritional status. And how to include mental health in overall public health, and make medical services truly integrated, is going to be a challenge.
- In order to address specific mental health issues, training multiple cadres of people is imperative. They may range from the grassroots workers to specific mental health professionals.
- Clinical and psychiatric training curriculum should include aspects related to social and development context. Medical training should include social sciences, ethics, and humanities disciplines; exposure to community life and its realities; and relevant modules on gender, culture, methodology, in order to enhance professionals' interphase with clients.

### Prevention: Recommendations



Finally the group identified the following recommendations with reference to the theme Prevention.

- The new national mental health policy should contain a robust section on the secondary prevention of mental illness in the population at large.
- To prepare mental health prevention approaches, the policy must emphasize a life cycle approach: Awareness about each stage of human development with reference to mental health, what can we expect at which age, with what consequences for mental health, etc.
- Population characteristics should be collected, so that programs can identify socially disadvantaged people who may be at 'high risk' particular to each community.
- Public education and sensitization on various topics relating to mental stress, disability, recovery and building mental resilience, particularly about the specific mental health needs of people at risk.
- Invest in tool and methodology development: How to identify 'high risk' groups in our cultural context; how do people express 'stress' and 'tension'; how to assess sub threshold features of mental morbidity; and what are the most effective interventions. The quality of life tool of the WHO is there; but its cultural, gendered and local validity is not known. Policy efforts need to focus on development of a theoretical and methodological paradigm on 'prevention' in the Indian context.
- The empowerment of different stakeholders within social units such as families, neighbourhoods, community groups, so that everyone can experience their equality and freedoms, and are able to exercise choices within their local context.

- Coping with stress factors through multiple strategies of empowerment, including community based, social and psychological empowerment. Community mental health programs must build on the existing strengths and networks, support systems, local support systems, available, in order to provide a sustainable pathway to mental health.
- Create adequate funding for R&D, infrastructure and human resources for establishing prevention programs in the community.
- The policy must recognize and support various kinds of alternatives practitioners who are already doing excellent prevention work in the community. Arts Based Therapies, Yoga, Meditation, Somatic Healing techniques, various cognitive, behavioural techniques, neuro-biofeedback, and other emerging methods must be promoted. Training spaces must be supported by the government, and cadres of skilled people in these techniques must be encouraged as doing very important community mental health work.
- AYUSH system is there already. But Health Department can create linkages with AYUSH and share responsibility in producing prevention programs as part of mental health planning.
- Enhance the public health service delivery system so that medical problems with psychological consequences can be addressed in a proper way (e.g. severe anaemia, fits, malnutrition, etc.)
- Particularly the psychological sequelae of malnutrition must be thoroughly studied giving sufficient attention to gender, age and other social disadvantage. Appropriate interventions for malnutrition available already as central and state policies must be examined and implementation gaps filled.

- Appropriate nutritional inputs (relating to use of proteins, balanced meal, use of Omega 3 oils, iron and folic acid, etc.) must be provided to all so that mental health is enhanced. Information must be provided by health as well as mental health service providers on nutritional support for overall health and brain / CNS / neuro-endocrine resilience. The media is tweaked towards 'heart health' but 'brain health' is vital too.
- The linkages between chronic illness (e.g. metabolic or cardiovascular diseases) and mental health must be treated in an integrated manner. For example, diabetics are rarely given inputs on the mental health consequences of their health condition; nor provided complete information about how to deal with sugar related mood changes.
- The use of anti psychotic medication and all psychoactive medication during pregnancy and
- Include Mental Health prevention and promotion in the syllabus at an appropriate level in schools.
- Use Mass Media creatively for developing a sensitive and humane approach to wards mental health and towards MI people.
- Empower high risk groups and people living with a mental illness through social development efforts, creative activities, recreation, leisure, and sports.
- Develop more open door, airy, aesthetic and accessible rehabilitation centres with various alternative therapies.



- Make local government responsible for such local centers, providing necessary infrastructure and basic facilities for addressing needs of community needs<sup>8</sup>.

### Ensuring childhood

- Implement a Comprehensive "HEALTH" Programme in schools, colleges, workplaces and other public utilities and services. Mental health is founded on basic health status.
- "Ensuring Childhood" was stressed by the group, including strengthening family, reducing family conflict, 'letting go', and growth conducive parenting styles.
- The mental health policy must provide for trainings on parenting, especially for children who are born with any kind of disadvantage or disability; or who develop such later on through young infancy or adolescence.
- As families become more livelihood oriented, young children are left to fend for themselves at home, and remain in isolation, often for 8-10 hours. This can cause mental disturbance and disability later at college going age, when stresses trigger off early childhood traumas. Parenting programs must aim at addressing this specific need, as psychosis can be averted by acting at the developmental stage itself. This must be a priority area of prevention work.

### Prevention for people living with mental illness

- Sometimes, there is an assumption that 'mentally ill' people, particularly those seen as 'chronic' do not need 'prevention' or 'promotion'. They do, as much as, if not more than, those who are at

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<sup>8</sup>Anjali's scheme of Jan Maanas can be adopted as a useful scalable model of how local government can contribute to enhancing mental health of populations.

risk. Having fallen into a cycle of treatment, recovery, relapse... there is a need for new knowledge, insights and skills to come out of this cycle.

- For those who have had first episode psychosis also, prevention is most needed. There is growing evidence of the role of social determinants in the case of psychosis<sup>9</sup>.
- Early identification of stress, tension, sub-threshold mental health problems and mental disability, and a range of innovative and integrated programs specifically addressing the 'first episode' of mental illness.
- First episode mental illness is often confounded by fears, panic, and a loss of control in the family, which must be addressed in non-violent and sensitive ways through training and awareness programs.
- Awareness must be given to families who are experiencing mental health crisis situations for the first time, so that they are made available of a range of options and alternatives, and they can make an informed choice.
- Destructive and disabling family interactional patterns must be addressed from the beginning. The government must support trainings and curricula in family development, family counseling and therapies.
- First episode psychosis must not be treated as another routine crisis event, but rather as a separate kind of intervention in itself. The government must support R&D on first episode psychosis so that a robust model of 'early intervention' including psychosocial

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<sup>9</sup> Craig Morgan, Kwame McKenzie, Paul Fearon (Eds.) (2008) *Society and Psychosis*. Cambridge University Press, Cambridge.

components can be provided in a studied manner right from the beginning of the crisis.

- State responses to MH issues: State institutions can also create stress, the state must be sensitive to its role in the creation of stress in its citizens and take steps to create humane systems. Enhancing mental health within mental health systems is a priority area of work.
- We can also talk about specific programs for the 'prevention of relapse'.

#### Promotion of mental health for all people - Recommendations

- Shift policy towards mental health enhancements of all people – The policy must define promotion of mental health, and give clear cut strategies.
- Create more choices of integrated health promotional and stress reduction services to reach those who are not receiving – increase access and affordability. Now only rich people can pay for well being and health support services.
- Constantly update and upgrade mental health promotion services, including information services.
- Integrated mental health knowledge, though available in research circles, is not accessible for most people using mental health system.
- Promotion of well being is the main duty of the government, and not a private pursuit, so this must be found in the policy.
- People living with mental illness or other disabilities should be fully entitled to mental health promotion.
- Increase the standard of mental health and well being services for those who are already the recipients of various kinds of social, development and health services.

### Inter-sectoral issues on mental health prevention and promotion

- Many ministries are involved in MH prevention and promotion including MOSJE, HRD, education, agriculture, urban and rural development, WCD' and intersectoral collaboration is a must.
- Civic amenities, water, environmental health in urban spaces must be upto standard, particularly in slum areas. Over 40% of urban populations live in slum areas.
- Enhance socio economic services such as educational, vocational, recreational, sporting, etc.
- Provide awareness in the community at large about various schemes of the government. Often NGOs spend a lot of time and energy trying to find out what the schemes are.
- Create urban public spaces, particularly for women like speak-out spaces such as women sabhagruhas, create public libraries, spaces for elderly, and disabled and play spaces for children,
- Encourage traditional sports.
- School grounds, aganwadis, and such spaces allocated under Urban and rural development etc. can double-up for such mental health promoting activities.
- Universal design should be implemented, because not having access produces enormous psychosocial stress for all people with disabilities.
- Price control on well being produce including agricultural goods.
- Encouragement through subsidies and incentives must be given for farmers to grow crops such as flax seed, which have a rich nutritional content for enhancing brain health.

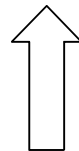
### Direct mental health promotional services by MoHFW

1. Actively implement trainings, Pranayam, Yoga, meditation techniques in community mental health.
2. Encourage local cultural practices in mental health programs such as story telling, song making, and using local musical instruments.
3. Compile and display essential nutritional information on good mental health, such as eating proteins, amino acids and essential fatty acids.
4. Ensure responsible media coverage on wellbeing, diet and mental health issues, and products.
5. Traditional indigenous medicines should be encouraged. The role of homeopathy and ayurveda in addressing neuro-endocrine stress must be recognized.
6. Government should appoint one promotional counsellor for stress management, health, diet and mental health like ASHA workers.
7. Teach grassroots village mental health workers Yoga, meditation, diet therapies and other therapies.
8. In every school and college there should at least 6-7 lectures on diet, mental health and well-being in every class.
9. IEC should produce material on strategies for promotion of good mental health.
10. Promote peace building activities in schools and colleges, peace campaigns in neighbourhoods and in families.
11. Conduct research on mental well-being, empowerment and resilience.
12. Community participants and mobilisation of the community for its development to provide inclusive mental health care should be an integral part of the development plan.
13. Providing appropriate promotional interventions to the 'displaced' and to the 'disaster' struck; also for other groups such as pregnant women, menopausal women, etc.

Community Care: Recommendations

The group on Community care provided the following schemata as their recommendations on community care:

Services	Stakeholders	Trainings
<ul style="list-style-type: none"> <li>• Local rehabilitation Centres</li> <li>• MH Care Centres linked to public health system</li> <li>• CounsellingCentres</li> <li>• Spaces for support Groups like care givers groups and Self Help Groups</li> <li>• Home Based care</li> </ul>	<ul style="list-style-type: none"> <li>• Existing Self Help Groups</li> <li>• User survivor groups or disabled people’s support groups</li> <li>• Family Members</li> <li>• Care Givers</li> <li>• Parents' Associations</li> </ul>	<ul style="list-style-type: none"> <li>• R &amp; D for robust assessments</li> <li>• Mental Health Inputs</li> <li>• Counselling, psychotherapies, arts based therapies, other</li> <li>• Empowerment Organisations</li> <li>• Advocacy, Networking &amp; Alliance Building</li> </ul>



<u>Services</u>	<u>Stakeholders</u>	<u>Trainings</u>
<ul style="list-style-type: none"> <li>• Community Centres</li> </ul>	<ul style="list-style-type: none"> <li>• PRIs/Community Leaders and</li> </ul>	<ul style="list-style-type: none"> <li>• Individual/Group Need Based</li> </ul>

<ul style="list-style-type: none"> <li>• Day Care Centres</li> <li>• Drop-in-centres</li> <li>• CSR Initiatives</li> <li>• Livelihood Skills Enhancement Centres</li> <li>• Healing Practices/Wellness centers</li> <li>• Community Resilience Building</li> </ul>	<p>community mental health workers</p> <ul style="list-style-type: none"> <li>• MH Professionals</li> <li>• Educators</li> </ul>	<p>Trainings</p> <ul style="list-style-type: none"> <li>• Diversity of healing and peer support skills</li> </ul>
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<p><u>Life Domains</u></p> <ul style="list-style-type: none"> <li>• Education</li> <li>• Work/Livelihood</li> <li>• Daily Living Skills</li> <li>• Social</li> </ul>	<p><u>Stakeholders</u></p> <ul style="list-style-type: none"> <li>• Family members/caregivers</li> <li>• Peers</li> <li>• Community Leaders</li> </ul>	<p><u>Training Contents</u></p> <ul style="list-style-type: none"> <li>• Sensitisation Awareness</li> <li>• Ability to identify MH</li> </ul>
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<p>Relationships</p> <ul style="list-style-type: none"> <li>• Recreation</li> <li>• Health</li> <li>• Civic, political life</li> <li>• Home life</li> </ul>	<ul style="list-style-type: none"> <li>• Community Volunteers</li> <li>• Members of Local Bodies</li> <li>• Faith/ Spiritual Healers</li> <li>• Teachers/Educators</li> <li>• Health &amp; Para Professionals</li> <li>• Transport Service Providers</li> <li>• Be-frienders</li> <li>• Representatives of Corporates</li> <li>• Lawyers</li> <li>• CBOs/ NGOs/DPOs/GOs</li> <li>• Lion &amp; Rotary Clubs</li> </ul> <p>Caste/Identity Groups/Human Rights Groups</p>	<p>needs in full spectrum- curative, preventive, promotional</p> <ul style="list-style-type: none"> <li>• Advocates for MH issues</li> <li>• MH module in other trainings e.g. PRIs, Admin Trainings, Educational Curriculum, CSR</li> <li>• Age &amp; Gender Specific MH Needs</li> <li>• Psycho-Socio Support</li> <li>• Linkages &amp; Referrals</li> <li>• Schemes &amp; Services</li> <li>• Laws &amp; Policies</li> </ul>
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- The above table suggests that Community Mental Health is doing mental health work in the community, and not mental illness work alone. A CMH program will involve the entire community, its social networks, existing support programs, development programs, etc. as collaborators.
- DMHPs should have a 'community approach' to mental health, with a vision of enhancing well being of communities at large, instead of being just drug dispensing centers.
- A broad range of mental health issues should be identified in the community and addressed through multiple strategies.
- Community characteristics, the local mental health needs of vulnerable groups, support systems available locally in the community, the cultural understanding of mental health and illness, the social determinants locally applicable, causing mental stress, etc. needs to be documented.
- Community cadres like the ASHA workers should be trained in giving support and care at the community level, such as barefoot counselors, community mental health anchors, mental health communicators, peer supporters, etc.
- Mental health should be included in other development linked training programmes, which will help to sensitise people in all domains of life.
- We must address the 'stigma' prevalent among mental health professionals that community cadres of people cannot be trained in psychotherapies and providing advanced support techniques.
- For psycho-social interventions at the community level, we need special tools to develop the psycho social clinical content. Every vulnerable group would have its own psychosocial needs. Using psychiatric scales for doing psychosocial work is not appropriate. Other community based tools using

participatory research methods, FGDs, etc. must be used to develop such locally applicable tools.

- Training curricula with psychosocial content are a must. Such curricula must be piloted and finalized so that they result in effective interventions at the level of community.
- Government should involve self help groups of women and various other support groups for psychological empowerment. Self Help groups, mandals, etc. can be designed with more explicit mental health materials. Such pilots must be supported by the government.
- Home based care (home visits, door step counseling, etc.) should also be included and training modules created to cater to this need<sup>10</sup>.
- In slum areas, especially in BPL families, whole families become disabled or struggle with many disabled members. Government should support such families with 'Adopt or Support a family scheme'. Such schemes will help field level workers to link up the family with various resources, other than providing high level of mental health support to reduce disability in the family members.
- Community mental health program must build strong linkages with public health system on one hand, and social development sector on the other hand.
- We have to think of the transport sector too for trainings as they are generally extremely insensitive to disability issues.

### Advocacy and Empowerment: Recommendations

Studies on social determinants suggest that iniquitous and deprivatory social and interactional environments cause mental distress and disability. Therefore,

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<sup>10</sup>Seher programs is experimenting with some of these ideas.

human rights thinking and practice is an independent mental health strategy; further, those living with a mental illness face special human rights challenges, abuse, exploitation and violence<sup>11</sup>.

Stigma reduction using awareness building on rights issues with

- The government must support a range of awareness activities relating to human rights and stigma reduction with all stakeholders and society at large, including professionals, persons with disabilities, educators, families, NGOs, disabled people's organizations, womens' and other empowerment organizations, etc.
- Government should take up awareness through mass communication methods as they have done in case of polio, etc.
- Government should make it mandatory for all government officials to attend courses on mental health, and human rights, particularly those serving presently within various mental institutions. Such trainings should also be available for district and block level officers.

Forming groups or associations of mental health activists

- The laws presently do not permit the formation of groups and associations of people seen as being of 'unsound mind'. The UNCRPD and other related laws need to be immediately addressed.
- Government should provide trainings and empower psychiatrists so that they respect human rights of their clients particularly in treatment contexts.
- Advocacy has to be done on the issue of 'full legal capacity' and advocacy training content should also be spelt out. Government should take active measures to familiarize itself with the UNCRPD and

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<sup>11</sup>NAAJMI's report on the 'Bill of Rights' covers human rights of people with psychosocial disabilities.

align its present service provision mechanisms in line with the UNCRPD.

- The government must recognize and promote self advocates and involve experiential experts in all its activities.
- All elected persons should be included in the target group for mental health advocacy. Constitutional hindrances to the enjoyment of all rights of people with psychosocial and mental disabilities must be addressed.
- Legal professionals in private as well as in the judiciary must be trained in the concept of full legal capacity, so that they are able to address the needs of people living with psychosocial and mental disabilities.
- The government must support new service programs and experiments that will be in compliance with UNCRPD.

27<sup>TH</sup> July, 2011

NAAJMI through its earlier consultations in 2010 and other lobbying efforts, seriously challenged the presumption of ‘incapacity’ which is at the core of the Mental Health Care Bill. This presumption led to the twisted logic of the MHC Bill, wherein a right given in a single provision was then taken away through multiple provisions. NAAJMI’s alternative vision for mental health sector<sup>12</sup> had several recommendations for a phasing out of institutional / custodial care and actively creating community based mental health care programs for all people. At the earlier consultations, the roles of the ministries involved were also discussed threadbare. NAAJMI group has proposed that the MOHFW should keep its role only to the provision of high quality, affordable and accessible health care for all; while leaving rights to life, livelihood and various other rights

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<sup>12</sup> Presented by BhargaviDavar

based services to the MOSJE. Further the contradictions between the perspectives, practices and the works of MOHFW and MOSJE should be bridged. Some other points, which emerged during the discussion were:

- Information on finances, expenditure in the mental health sector is not easily available. It is the government's and the NGO sector's joint responsibility to make it available.
- One of the realities with reference to the disabilities and the mental health sectors is that a huge gap exists between the two. We have to say that today there are 2 Ministries, 4 laws, 1 Plan, and 1 policy!!
- How are we going to deal with all the custodial institutions (private and public), which are governed by many laws? Can the new Disability Act address these? Can the Ministry of Health and Social Welfare de-institutionalize these institutions? If not, what is the solution? Who is going to take care of the de-institutionalization process? How much is it going to cost financially and socially, and who will pay?
- One member of the group suggested, why the government should not convert all these institutions into general hospitals, which will put a stop to this 'close door' practice. We have never understood how custody can become care.
- Hence forth, only the term 'psychosocial disability' should be used; not 'mental illness'.
- We need to be moving from the term 'mental illness' to 'good health for all'. The policy is for all people not only people living with mental illness.
- A lot of money is lying unused in the National Disability Fund. We should lobby so that it can be used for mental and psychosocial disabilities also.

- Dealing with the issue of 'limited guardianship', which has come up in the last draft of the New Disability Legislation, echoing the mentality of the MHC Bill, is a difficult challenge before us.

#### Mental Health Care Bill: Expert opinion

After the general discussion, an interactive session with two lawyers of the Human Rights Law Network, GayatriSingh and Kranti, followed.

- At the outset Gayatri expressed her dissatisfaction about the newly drafted Mental Health Care Bill. She felt that there were many problematic areas like the definitions of capacity, limited capacity, and setting up of institutions. She voiced her professional opinion that there is no need for a MH Care Act at all. When we are talking about better health care facilities, services whether better hospitals, well-trained staff etc. then UNCRPD should be our frame of reference. MHC Act is in fact taking away rights of people with disabilities.
- Criminal law exists, and other common laws, so why should we insist on a separate custody law for people with disabilities? There is the larger question about institutions even for crime, so where is the question of custodial institutions for care? Institutions started for care and protection always end up criminalizing their beneficiaries.
- We should be more articulate and forceful in our future Public Interest Litigations. Why should we even allow the concept of Limited Guardianship? Why not set higher standards for people with disabilities?
- Kranti then elaborated on some of the points raised by Gayatri. He gave the recent example of a legislation getting scrapped which treated individuals differently, namely Section 377. Sometimes we have to make the argument that 'we are the same' rather than emphasize difference. Difference in this case has meant discrimination.

- Again Gayatri drew everyone's attention to the difficulties in defining mental illness. How to define it and who defines it? How this concept is used in society? Who gains from the definition?
- Kranti gave his opinion that this draft, in an act of giving something, is actually taking away a lot more of an individual's fundamental rights. All the rights have deprivatory provisions, what is given is then taken away.

After the coffee break many questions were asked to the legal experts. Listening to their opinions based on courtroom practices and what can happen outside courtrooms was indeed a learning experience for all. Some participants were deeply concerned with the lawyers' position that there should be no mental health Act. They felt that will increase the invisibility of people living with psychosocial disabilities. Questions from the floor:

- If one wants to challenge the constitutionality of the Mental Health Act, where should one can go, whether to the High court or the Supreme Court? What is the legal process to contest the Mental Health Act? If we contest the constitutionality of the MHA, 1987, will it automatically take care of the reform process and the new law also? Or will that have to be challenged independently?
- Both ministries are messing with the issue of legal capacities in small and big ways. How to handle the different laws and their disharmony? What is the scope of work given to the lawyers in context of present laws, and the UNCRPD? How and where do we deal with these exclusionary laws??
- Kranti gave his opinion that there are three debatable sections, which are at the core of the MHC draft. One is the definition of mental illness. How do we go about redrafting it? The second one is the definition of legal competency as it is a very subjective term. The Act wants to apply it

universally which is very hazardous for society. And the third is the formation of committees and the question of representation.

- We are all for a civil rights approach. We do not want anything that curtails peoples' rights. And these are not issues just related to the Mental Health sector. What we are recommending is a more humane, better way of looking at MH and offering necessary services.
- To this Kranti responded by saying that there is no one law, but many laws. It's not only one legislation, but a series of policies, programs, which are deeply entrenched. Various examples are available of things happening inside and outside of courtrooms. For PWD, a plan has existed for 10 years wherein 3% of the budget is allocated for people with disabilities. This has never been used. We must take up these kinds of issues in the courts. We must ply the courts with human rights concerns.
- Gayatri said that even as a lawyer she had problems with definitions of mental illness, and competence. Is competence linked to capability? Again it is a very subjective area. She agreed with Kranti by saying that a law is supposed to give you certain rights but in this case they are not giving you anything.
- Kranti took the example of the Juvenile Justice law and jurisprudence. Instead of seeing a person living with mental illness as a criminal, the law can provide special status to that person as in the JJ laws by referring to him or her as a 'person in conflict with the law'. A care pathway can be created from thereon.
- Pawan had a question about schemes. He said when there is no legislation in place, what happens to the schemes? His question was answered by Kranti who informed that numerous schemes have existed without the



government legislation. He reminded all that citizens get rights through both the law and the constitution.

- Kranti reminded that this Mental Health Care Act has to go, otherwise you are not going to get in the 33 category which gives you 3% reservation in jobs. An incapacity law like MHCA 2010 will cancel out entitlements given elsewhere in law. And since incapacity is subjective, there is no saying who will be disqualified. Finally he urged all activists to self advocate their own cases. He said one could make a beginning with simple issues like full range of services and facilities not being available in a particular set-up where it is mandatory by the law to make these provisions. This way he felt, many more issues could get tackled and settled.
- Pawan opined that the government is going to come up with this law, no matter what we say. So it is better for all to work at both levels i.e. prepare our alternative policy statement and also give our recommendations to the government on the present draft; at the same time advocate against the law.

The lawyers' final suggestion was to see our rights in the context of the UNCRPD, work directly with UNCRPD, scrap this draft altogether and prepare an alternative policy document stating our views, expectations and recommendations clearly.

Reservations were expressed about 'de-institutionalisation'. Strong dissent was expressed by care givers that we cannot do away with institutions. The organizers clarified that NAAJMI is not against institutions, but is against the penal design of existing institutions. They pleaded that we start on tabula rasa (blank slate) about design of institutions. What is our ideal type institution?

In the post-lunch session, participants divided themselves into three groups to prepare a wish list of their recommendations on the following three themes:

1. Institutional Design
2. Independent Living
3. Social Support Schemes

#### Group on Institutional Design

The ideas for institutional design were presented in terms of ‘assertive community treatment’. Recent research has suggested that the use of ‘social pressure’, which is non-threatening, helps in the rehabilitation of substance users. Peer support models also show the importance of supportive environments where influence, arguments, persuasion, exhortation and other social components of interactions help in building hope, and an environment of care. We use ‘assertive community treatment’ in this sense, and not in the sense used in western context, of forcibly applying relevant sections of the extant mental health legislation in order to bring people into the asylum system.

The institution can be considered as one of the nodal hubs of several activities happening within communities, and having a ‘local’ flavour. It can be seen as a ‘respite service’ or as a community retreat. Other models around the world (Soteria, Runaway House, Geek model, Living Well Clinic in the Netherlands, Anthroposophical models, etc.) do exist to provide precedence to alternative institutional design. In our country context, various traditional healing systems do provide an alternative institutional design. Such systems serve as a center for people to seek healing, are local, voluntary.

A hostel system or a retreat center can also be considered as likely institutional designs where the facility is self or peer managed, with necessary case workers, peers, carers and barefoot workers available on site when needed.

Many people do not require residential care, but may require a place to go to everyday for skill building, retreats, have options to express themselves, and making use of recovery and wellness services.

Such care centers could have linkages with recreation spaces or clubhouses for facilitating social interactions and friendships, which people with disabilities sorely miss.

The institution would have certain core services including a suicide hotline, various psychotherapeutic, psychiatric and other treatments. Quality control, registration, ethical codes of conduct and monitoring would define the clinical practices.

The centers would cater to tertiary care, but with linkages to secondary and primary care services at the community level.

The services would address the entire spectrum of mental health from illness, to prevention to wellness and promotion.

We can think of some innovative ways of tracking and supporting people with high support needs, such as 'Silver Alerts for Missing People'.

In any institutional system, there must be access to justice, legal services and legal aid. A 'behavioural health court' was suggested by the group, to address specific problems coming out of health in the context of law.

The institution would encourage and promote supported, buffered or independent living. There would be active services along the pathway towards independent living, such as group housing, home care, doorstep services, daycare centers, drop in centers, employment services, family training centers, peer services, family counseling, group homes, communes, etc. A continuum of care would be provided at such centers, with humane crisis interventions.

A neighbourhood watch system should be established, wherein services will be used by as well as monitored by neighbourhood groups organized specifically to address mental health issues. Such activities will lead to a peer system within the community itself. There would also be contributions from the local community to the development of such centers.

Traditional residential care services provided by private and public agencies would be more open to receiving people living with a mental illness, and appropriate skills would be given to them.

Other than this, the institutions will involve themselves in various research, trainings, upgradation of services, and anti-stigma activities.

Institutions would have children, gender, sexuality, culture as cross cutting themes which will determine experience of stress, disability, treatments, and outcomes.

Voluntary care, with active support in healing, by friends and family, must be provided.

Such local centers would cater to the homeless and resourceless populations in its neighbourhood. Community befriending teams, rescue teams, etc. would be geared towards providing services on the streets, collaborating with the patients to use the institution for their own recovery.

The institution would have referrals of SHGs, vocational activities centers, friendship or support groups, therapeutic groups, etc. in the locality, and actively network with such groups to mainstream people into community life.

Recommendations on Independent Living :

- What is independent living? It does not mean living in isolation, but in an inclusive society. We are not thinking of exclusive or 'special' societies but societies where people with disabilities are mainstreamed.
- Support groups of friends and family is important; equally, support for the suffering person from the family is important because sometimes family itself is a violent institution.
- Peer support groups as also schools, neighbourhood, and work environment support groups.
- Self help support groups.

- Support groups of people with MI. Law should permit the registration of such organisations.
- Support groups for care-givers.
- Should there be an option of Day Care Centres at all? They too become like institutions sooner or later.
- Drop in centres where counselling/daily living skills are taught.
- Community living (various models do exist in the country and can be emulated.)
- Incentives for employers for giving jobs/positive discrimination.
- Self-employment – access to bank loans/insurances.
- All these issues have to be gender specific.
- Options of sexuality, marriage/reproductive rights.
- Develop training models for care givers and people with disabilities.
- Also trainings for community health workers.

After this presentation, there was a brief discussion.

- In the context of Day Care Centres we have to keep in mind the negative impact of family.
- Some felt that it was not possible to have total individuality, choice and freedom with reference to independent living. It has to be interdependent living on equal basis.
- The group envisaged a spacious college campus with dormitories where each person has his/her own little space. There would be a wide range of infrastructural facilities like playground, swimming pool, gym, recreation centres to encourage inmates to express themselves through various mediums like paint, draw, dance, act, sing, write, resource centres and a library. She felt that there would be freedom and yet there would be a structure to the place. Professionals and people from different walks of

life could come in and volunteer their time and expertise. There could be a facility for family members of inmates to live on the same campus, but separately.

Ratna proposed a vote of thanks to all concerned agencies and individuals who made this consultation possible. She expressed satisfaction about the fact that the consultation had been a fruitful one and all participants were leaving with happy memories.