SIR RATAN TATA TRUST

National Workshop

On

Human Rights and Mental Health Institutions: Re-thinking Systems of Treatment, Care and Wellbeing.

February: 26—28, 2009

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Introduction:

In India, the history of institutionalised mental health care has been fraught with the issue of human rights violations of persons with mental illness. Despite the fact that the country has legislations in the area of mental health, several deficiencies persist in majority of state run mental institutions. These issues drew attention of the judiciary, which resulted in a comprehensive review of all the state run institutions by the National Human Rights Commission (NHRC) and National Institute of Mental Health and Neuro Sciences (NIMHANS). To a certain extent, NHRC monitoring has made a difference—infrastructural deificiency is one aspect that most hospitals have tried to address, although several grey areas persist. Intervention by non-governmental organisations (NGOs) have been successful in provision of services that encompass medical, psychological and social aspects of care and wellbeing, which contribute to reintegration of the person with the community. However, given the magnitude of the problem—650 lakh people suffer from some form of mental illness in India—it is imperative that health care is taken to the community, rather than continuing with the traditional model of centralised service provision.

The District Mental Health Programme is a step in the right direction towards provision of mental health care at primary health centres. Public private partnership (PPP) offers a sustainable model in community based care. In this context, The Banyan and Banyan Academy of Leadership in Mental Health organised a three day national level workshop on **"Human Rights and Mental Health Institutions: Rethinking Systems of Treatment, Care and Wellbeing".**

1. Inaugural Session on Human Rights and Mental Health Care

The speakers at the **Inaugural Session on Human Rights and Mental Health Care** were:

1. Mr MA Vellodi, Chairperson of The Banyan
2. Dr Sarada Menon, former Superintendent of the Institute of Mental Health, Chennai
3. Ms Vandana Gopikumar, Founder, The Banyan
4. Mr Vidyakar, Founder, Udavum Karangal
5. Ms Meenakshi Rajagopal, IAS, Commissioner of Disabilities, Government of Tamil Nadu
6. Mr Harsh Mander, Writer and Human Rights Worker

The Welcome Address by Ms Madhu Sharan, Executive Director of the Banyan Academy of Leadership in Mental Health (BALM) dealt with the objectives of the workshop—to bring together non-governmental organisations (NGOs), government, funding agencies, mental health professionals,clients and caregivers on one platform to discuss the issue of human rights in mental health institutions and come out with

workable agendas that ensure restoration of human rights and optimum level of well being of clients. She discussed the concept of "Equity in Mental Health" which is the restoration of Human Rights and the implementation of the District Mental Health Programme and National Mental HealthProgramme. Mental health being the fundamental right of people, is largely ignored today with the Government being indifferent towards this sector. However, she mentioned that there is some progress with the 11th five year plan having a budget of Rs. 500 crores for the mental health sector.

The aim of the workshop was discussed as

To examine the progress of the Mental Health Institutions.
Discuss the success and learnings from the Mental health institutions from the state and non-state actors..
To arrive at action points and workable solutions in the area of improvement of the Mental Health Care Institutions.

1) The Inaugural Session was chaired by **Mr. M. A Vellodi**, Chairperson of the Banyan. Mr MA Vellodi stressed on the outdated Indian Mental Health Act and the need for amendments. During his address the following was discussed

- The legislation in the Mental health sector is outdated today with the Indian Mental Health (IMH) Act being over 20 years old.
- The issue has gathered momentum over the last two years.
- The UN convention on Rights of People with Disabilities (CRPD) is now in force with the Government of India being a signatory and has ratified it in July 2008.
- During this convention the signatories decided that the IMH Act of various countries needs to be looked at.
- Several amendments to the IMH act have been recommended and there is a need for advocacy for the changes in the IMH act.

2) Dr Sarada Menon, former Superintendent of the Institute of Mental Health (IMH,) Chennai stressed the need for rehabilitation of the mentally ill spoke about the lack of dedicated social workers in the system. She gave a brief history on the evolution of mental health care in India and work done by SCARF. Dr Sarada has been in this field from 1957 and had briefly discussed the history of Mental Health Care in India.

- **Lack of Proper Medication:** To begin with, there were no anti-depressants for the mentally ill and the doctors used to just hold the hands of the patients to comfort them.
- **No Human Rights Commission:** When she started her career there was no Human Rights Convention.
- **No impact of Media Advocacy:** She tried the concept of advocacy through the media which did not prove to be very useful at one time. Although she drew attention to the plight of mentally ill patients who were chained at various faith healing centres, government authorities were reluctant to take action and the media ignored it.

- **No Social Workers:** When she joined IMH, there were no social workers during that period. The Red Cross was providing a nine-month training for social workers. She had employed these social workers and found them to be of great help. In her words "I FEEL LOST WITHOUT a SOCIAL WORKER"

She discussed the important considerations to be made in the mental health sector.

- **Need for more Social Workers:** As they are a link between the hospital and the patient's home and also between the doctor and the patient.

- **Need for commitment:** As a social worker commitment to improve is more important than the qualification, with not many agreeing to work at the field level.

- **Need for change:** There is a need for social change, legal change and attitude change towards the mentally ill.

- **Need for Advocacy:** The worst hurdle in treatment of mental illness was the "STIGMA" associated with it. There is a need for advocacy to remove the STIGMA associated with mental illness and generate awareness on the same. She discussed this in context of the Mission of the BALM. The solution was for people to come together and discuss and provide solutions. **There is a need to create awareness amongst " Bureaucrats and technocrats"**

- **Need for Communication:** "TALK THERAPY" is important for the mentally ill.

- **Need for Training:** There is a need to train and nurture human resources in this sector.

- **Need to Create Leadership:** Create next level of leadership in this field.

- We have come from the time of symptom management and recovery to rehabilitation or restoration. But there is still a big gap here.

- The Outcome measure of treatment is whether the patient is successful in his or her day-to-day tasks.

- **Need for "Group Therapy":** Communication is lacking in "Occupational Therapy" which leads to the need for group therapy.

- **Need for Recreational Therapy**

- **Need for Volunteerism:** The most important aspect is to encourage volunteerism and enlighten people.

The issues with the Mental Health Institutions were discussed as:

- **Lack of communication:** The staff in Mental Hospitals lacks the ability to communicate. There is lack of Group Therapy or Recreational therapy sessions for the mentally ill.

- **Shortage of staff:** It leads to lesser supervision which leads to lesser communication and ineffective treatment.

- **Lack of rehabilitation:** The IMH does not have funds to take the people back home and hence civil society should help here.

3) Vandana Gopikumar, Founder of The Banyan addressed the need for freedom, choice and dignity for the mentally ill. She shared some successful ideas implemented in the Banyan such as the concept of Protected Communities and Grievance Cells to help in rehabilitation and stressed on the Idea of "Openness to Review" in Mental Health Institutions.

- She appealed to the IMH to allow the Banyan to restart the rehabilitation process.
- Need to recruit social workers—currently the IMH had only two social workers and there were 12 vacant posts to be filled up.
- Need to empower the non-state actors—to work effectively with the institutions.
- Need to reintegrate people
- There is a lot of synergy between SCARF and The Banyan

She discussed the definition of Human Rights to a mentally ill person

- As the sense of freedom
- **Right to access to mental health care:** She mentioned that the mentally ill belong to two sections of society. One section were the privileged that have access to resources for mental health care and the other "Rural and Urban Poor" who form 60–70% of the total population with mental illness. As per the reports, in India only 250 of the 612 districts requiring mental health care have access to the same.
- **Life of dignity:** Dignity begins at the entry point to Mental Health Institutions and there is a need to communicate at that point
- **Life of productivity:** with no workplace bias
- **Right to choice:** Most of the time, institutions feel they have the right to choose what is good or bad for the mentally ill person, for e.g. in their clothing or food habits. The choice of the mentally ill should be considered and they should feel comfortable in the environment where they are in.
- **Access to Privacy:** For e.g. closed toilets, different toilets for men and women.

She discussed the need for institutions to be 'Open for Review" and "Open for Change". There is a lack of intent and leadership within institutions and though non-state actors are ready to help the state actors, they are prevented from doing so. There needs to be the intent to partner with the civil society in order to be successful in rehabilitation of the mentally ill. Most of the time NGOs are boggled down by the nitty-gritty of running the

organisation, such as focus on fund raising and medicines availability etc, and hence they are unable to dedicate sufficient time to the main objectives for which they were established.

She addressed the needs of people with chronic illness and long term care residents.

- Single largest threat to successful mental health care is to take care of the needs of long term residents.
- **Need to create a Protected Community:** There is a need to create a protected community for the chronically ill residents to be as free as possible. Institutions across the country should adopt this model. Currently 500 of 1300 people in IMH need long term care.
- **Need to create a source of recreation and freedom**.
- **Delicate need of sexuality** for the long term residents
- **Need for Self Help Groups:** These rehabilitated groups work amongst themselves for a living and are mostly financially independent of the state and non-state actors.

4) Mr. Vidyakar, founder of "Udavum Karangal" which helps homeless people with mental health issues discussed the problems that his organisation has been facing about renewal of license. He mentioned that non-state actors are under constant fear of being reprimanded in the event of residents committing suicide or leave the institution, rather than focus on helping the mentally ill. He also stressed on the need to relook the rules and revise the same for mental health institutions (e.g. no of beds/toilets etc).

5) Ms. Meenakshi Rajagopal, IAS, Commissioner of Disabilities, Government of Tamil Nadu, stressed on the role of Public Private Partnership(PPP) in providing Mental Health Care and the importance of getting identity cards (ID) for the mentally ill to be able to claim allowances.

Ms Rajagopal discussed the following issues:

- Need for PPP (Public Private Partnership): The need of the hour is to have the civil society work closely with the state to achieve success in providing sufficient mental health care. The NGOs need to understand the limitations under which institutions function; and the fact that they are bound by rules give them lesser flexibility at times.
- Changes for amendment of the Mental Health Act have been proposed.
- Need of rehabilitation of the mentally ill.
- Need for advocacy to remove the STIGMA associated with mental illness and bring about a change in attitude towards the mentally ill.
- Provided clarification that the Disability Commissioners' office deals with people with mental retardation and mental illness, although it is believed otherwise.
- **Provided clarification that the identity cards for the mentally ill can be got by either applying to the Disability Commissioners' office or to the Mental Health Authority.**
- Rs 500 per month were being given to mentally retarded people along with free bus passes.

- The process of certifying eligibility for ID cards is:

i) Government Psychiatrist certification
ii) In cases of districts where the Government Psychiatrist is not available, Collector's permission is required to consult the Private psychiatrists for certification

Issues that arose for discussion with Ms **Meenakshi Rajagopal:**

- Why does The Banyan have to pay Disability Allowance when the Government has to take care of the same for the 250 residents? These residents hold ID cards, but have not yet received their disability allowance.
- Why, as seen in Gujarat, there is no board or representative that functions as a monitoring committee. This board could look into various issues, for e.g. check cases where the ID cards were not given to the inmates of mental health institutions. The Ministry of Social Justice and Empowerment had even mentioned that not enough cards are being issued.

In addition, while addressing the issues, Dr Sarada Menon suggested that every district should have mental health homes run by NGOs, with technical expertise from the government. The National and District Administration should take forward the concept of long term care. Self Help Groups (SHGs) should be formed. The issue of licensing should be looked into by the authorities. She mentioned that the resource crunch excuse does not hold true as the replacement of retired staff in institutions is still not complete. She also felt that mental health professionals do not get any credit for their services and there is a need for recognition.

6) Mr. Harsh Mander, Writer and Human Rights Worker, discussed the various issues with mental health institutions and the significance of protected communities for the rehabilitated, as a transition home from closed institutions to open communities.

State's response is a question of "Attitude". The state responds in overlapping ways to the issue of mental health care. He touched upon three keys issues within the context of human rights in mental health care.

- **Invisibilisation**: Here the state's response is that the mentally ill do not exist. This stems from the fact that there are no figures on the homeless people with mental illness. He argued that **"Mentally ill people are not seen as people who have full and equal human rights".**

- **Illegalisation**: The State sees the mentally ill as in conflict with law. The mentally ill people were covered under the criminal justice law.

- **Custodialisation**: The primary response of the state to mental illness is to lock up patients.

The solution proposed was the "Right to Kindness": A question was raised as to how the state creates a system to give the mentally ill the Right to Kindness.

- The need for recognition that mentally ill people are productive was highlighted: We value people who are not productive as worthy of charity and not as humans.

- "Human Rights approach is the Right to Recognition as a human being, irrespective of whether they are productive or not".

- He discussed that the focus should be elsewhere and not on the institutions where only one per cent of persons with mental illness are present.

- Various problems with the mental health institutions (MHI) were untrained staff, brutal treatment of inmates, usage of ECT without anaesthesia, denial of basic rights like food, water, beds, prison like atmosphere, denial of access to facilities, lack of communication.

Solutions for the problems were discussed:
- MHI should be treated as a temporary stay. There should be a timeframe and this should be treated as a transit care.
- Complete ban on any more new traditional Mental Health Hospitals.
- Professional psychiatry helps at the district level. NIMHANS gives trained doctors to districts.
- Closing of mental health institutions is not a good idea as it is a last resort for people abandoned by their families. Solution is to have Protected Communities such as the BAPU Trust in Pune.
- The possibility of creating their own kind of family for the mentally ill. Provide social audit of these communities.
- The need for rehabilitation and the understanding that the return to families need not be necessarily biological.

2. SESSION on Institutional care: Genesis and direction

Resource persons for the session on **Human Rights and Mental Health Care** were:
1. Dr Srinivasa Murthy, Professor of Psychiatry (Retd), NIMHANS
2. Dr Pratima Murthy, Professor of Psychiatry, NIMHANS
3. Dr KV Kishore, Professor of Psychiatry, NIMHANS

Moderator: Dr Lakshmi Sunder

1) Dr Srinivasa Murthy's paper on Genesis of Institutional Care since the 19th Century was presented by Dr. Pratima Murthy. This presentation dealt with development of institutional care over the past century; the transition from the protection of society from the 'insane' to protection of the rights of the mentally ill.

The two key questions to answer from this history and development are:

- Can we make institutions a real part of mental health care?
- How can we network them with the whole spectrum of mental health care facilities?

Interventions are needed at many levels:
- Right to treatment: Availability and access to treatments is essential
- Support for families
- Human rights need to be made known to patients
- Monitoring

Dr Murthy argued for coordinated groups of people to make a change in the areas of:
- Specialised facilities
- Community care
- MH through PHC
- Informal Community Care
- Mechanisms of self care

To plan these services
- Look at demand
- Government support
- Technical support

2) Dr. Pratima Murthy spoke on "Institutional Care: Comparison between 1999 and 2008" and asked why there should be a focus on institutions. The reason is because they mirror communities and the attitudes pervasive within them.

The transition made in the past:
- Custodial to care
- Involuntary to voluntary admission
- Away from jail like atmosphere to therapeutic atmosphere

The presentation detailed the changes that have been made between 1999 and 2008, and then asked how can care be taken forward after this time? In 1999, the NHRC/NIMHANS Report painted a grim picture of the conditions at mental hospitals—of the institutions visited 63 per cent had prison like structure, 75 per cent were closed wards, 69 per cent were involuntary admissions, many individuals had recovered but this was not recognised and they remained in care. The NHRC/NIMHANS Report in 2008 found that efforts had been made to address some of the infrastructural deficiencies, nature of admission (voluntary/involuntary) and dietary requirements of the patients. Yet, there were persistent problems like cell like conditions, mandatory wearing of uniforms and inconsistency of improvements across all institutions. Dr Pratima Murthy argued that while institutional changes like human resource gaps need to be addressed, equal importance should be given to educating all the stakeholders, considering that a large part of the care occurs outside the institutions. She recommended downsizing of institutions, improvements in database, focus on rehabilitation programmes, insurance coverage of

mental illness, increase awareness about mental illness and the need to work with other sectors to reduce the burden of mental illness.

3) Dr KV Kishore, presented information on global and national scenarios on mental health. According to him, mental disorders are universal, burdensome, disabling and lower the quality of life. Globally, as mental health is accorded low priority, investment in mental health is low. While the legacy of mental health lies in institutions, it is important to note that a majority of those with mental illness do not get treatment. As institutions by their very nature violates human rights, an approach that protects rights of the person—community based care—has to be adopted. In India, the acceptance of community based care approach has found resonance in the District Mental Health Programme.

The discussion was moderated by Dr Lakshmi Sunder. Some of the issues that came up during the discussion were:

- The reliability of the Report was questioned. Dr Murthy emphasised that infrastructural changes are visible, although the crucial point is whether these changes have translated into better care for the patients.

- There was a sense of anguish that changes are reflected only in the infrastructure and that there was an absence of strategy that protects the individual. Is there a scope for a report by the civil society rather than one directed by the NHRC? (Sudha Ramalingam).

- There is a need to work with institutions, rather than put them on the defensive (Dr Pratima Murthy).

- As most changes in the sector have been the result of confrontation of civil society with the state, patients and their families should be involved to establish the appropriate levels of care.

- Does the NHRC have a response to issues like migration of trained medical professionals to other countries and the fact that the problem is very often not one of resource deficiency but of apathy?

- The NHRC intends to address these issues, although it must be noted that the problems are not unique to the mental health sector.

- Although there is a lot of concern about institutional reform, we need to understand the fact that solutions have to address fundamental changes in the provision of care.

- Planning has to accommodate the fact that institutions should not be seen as the crux of the problem—they are part of a whole framework of care provision. There are inherent limitations to top down policies; what is required is bottom up investment.

- NGOs should conduct workshops on the issue of families distancing themselves from the patient.

- NGOs face problems while training doctors in the primary health centres on mental health, as doctors are frequently transferred (Mr MA Vellodi).

- Has any NGO worked with the government on DMHP? (Ms Vandana Gopikumar)

- Although there is provision for NGO involvement, so far no NGO has worked on DMHP (Dr KV Kishore).

- A grey area with respect to DMHP is what happens after the programme runs its course? (Mr Mukul Goswami)

- The whole discussion on violation of human rights are institution centric, but what about violations in the community? Besides, the DMHP seems to be very dependent on the goodwill of the officer. Will NGOs function as BPOs of the DMHP? (Dr Amit Basu)

- To what extent do state level organisations engage with the community? Prior to the face off with IMH, it was observed that the IMH staff was reluctant to engage with the community. Also institutions can follow the example of barring doctors from private practice, which is demonstrated by the successful examples of NIMHANS and CMC (Dr Anbudurai).

- In the long run, the state will continue to be the most important actor, as the sustainability of individual and organisation-delivered care is doubtful (Mr Milesh Hamlai).

- What is the degree of involvement of stakeholders in DMHP and what has been the response of service users? (Ms Meenakshi)

3. SESSION ON Mental Health Institutions in India: The beginning of change for treatment, care and well being

Resource persons for the session on **Systems of Treatment and Care in Mental Health Institutions in India** were:

1. Dr Ajay Chauhan, Superintendent, Hospital for Mental Health, Ahmedabad
2. Mr. Milesh Hamlai, Founder, Altruist (NGO)
3. Dr Asha Banu, Assistant Professor, Tata Institute of Social Sciences, Mumbai
4. Mukul Goswami, Founder Ashadeep, Assam
5. Dr. Debashis Chatterjee, Trustee, Anjali
6. Dr. Anubha Sood, Research Fellow at Washington University and former Project Director, Maitri

Moderator for the session: Dr Lakshmi Sunder

1) Dr Ajay Chauhan spoke about the remarkable transformation of the 165 year old hospital, from one that was rated as poor by the NHRC/NIMHANS Report of 1999 to one that is being held up as a beacon of efficient functioning by the NHRC/NIMHANS Report of 2008.

At present the hospital is characterised by:

- No cell-like rooms
- Psychiatrist in charge
- Special clinics
- Facilities on site
- Gradual increase of outpatients and associated facilities
- Infrastructure changes
- Daily monitoring of diet
- Steps taken to reduce number of long stay patients
- Close involvement with NGO in rehabilitation
- Established community services
- Rehabilitation department

2) Mr Milesh Hamlai elaborated on his organisation's work that dealt with implementation of grass roots care in a faith healing environment—Dava & Dua. Three organisations work together—Funding agency (Gujarat Foundation for Mental Health and Allied Sciences), Nodal Agency (Hospital for Mental Health Ahmedabad), Implementation Agency (Altruist) at the Holy Shrine of Mira Data Dargah in Gujarat well known for faith healing of various ailments, possession by spirits, and particularly mental illness. Mr Hamlai described the Dava & Dua Model as an excellent amalgamation of traditional faith healing and modern mental health system for provision of treatment to persons with mental illness. The object was to facilitate the relationship between the government and the shrine, and provide a community-centric and not an institution centric solution to the problem.

3) Dr Asha Banu presented her findings on the issues within the Mental Hospital, Thane, with an emphasis on women patients.

- Staff problems:
    - Understaffing: many vacancies not filled placing a burden on those still working
    - Staff uncared for
    - Vocational training absent
- Women specific issues:
    - Sanitary issues—absence of menstrual hygiene, as the hospital did not provide sanitary napkins.
    - Clothing problems—women were made to wear clothing that they were not used to wearing at home.
    - Self-image was found to be very important to women—they often felt ashamed of the way they looked which perpetuated their illness.

4) Mukul Goswami spoke about his observations on LGB Institute of Mental Health, Assam based on the work that he does with the institution. He stated that he had his own preconceptions of mental institutions based on images he had encountered, which he was forced to challenge upon interaction with institutions. He cited various areas as positive functions within the institution:

- Dresses designed especially for the women.
- Workshops established for staff.
- Bed linen and clothes all made by the residents, which also generates income for the institution.

He also felt that following all recommendations made by the government would cause serious problems at the local level—with staff within the institution, the community and NGOs working in the area.

5) Dr. Debashis Chatterjee presented information about the five government mental hospitals, in West Bengal. Although the hospitals suffer from infrastructural deficiencies,

there have been improvements because of PPPs and intense media scrutiny. He identified a serious lack of capacity within the institutions in the state as follows:

Very busy outpatient services
No medical care facilities in some cases
No ambulances

Overcrowded and understaffed institutions lead to many problems including:

- Old buildings
- Poor sanitary care
- No laundry facilities
- Only involuntary admission

6) Dr. Anubha Sood dealt with Project Maitri, which was an intervention programme (in three state run mental institutions at Agra, Gwalior and Ranchi) of Action Aid to humanise mental health hospitals and develop community based rehabilitation. A key issue was seen to be that care provision was often not good enough to promote recovery. The project is a model building exercise within three institutions to establish a system to replace the custodial system within institutions and combat some of the following problems:

- Human rights violations
- Long-stay patient prevalence
- High levels of disengagement (patients found to have not been spoken to for many years)
- Training of staff deficiencies

The design of the project was as follows:

- Long-stay patients within the institutions studied were categorised as those for whom reintegration was possible, those for whom reintegration was not possible and those who had chronic illness.
- Recruitment of para-workers to support the work of mental health professionals.
- Set up day care centres, halfway homes and protected community in the hospital.

Outcome of the project:

- Para-workers were found to be very successful: lay people can make a real impact if properly trained because of the reduced barriers between them and the patient compared with professionals.
- Volunteers and other 'outsiders' working within the institution has the most impact on resident well-being.
- Hospitals continue to be resistant.
- Partial success in dehumanising but failed in decustodialisation.

The following points emerged from the discussion:

- **Ms Jayshree Nikam, psychiatric social worker at the Regional Mental Hospital, Pune** spoke about the problems that psychiatric social workers face in the hospital. As most of the patients were from villages and belonged to low socioeconomic strata, families very often discontinued treatment because of economic constraints and the long distance of their village from the hospital. She felt that NGOs have an important role to play by filling this gap, besides educating people about mental illness.

- **Mr Nitin Shivade, psychiatric social worker at the Mental Hospital, Thane** highlighted the positive changes that have occurred at the hospital.

- Budgetary allocation needs to be increased for the mental health sector.

- There should be a standard protocol for people with mental illness to access care in the public care domain.

- The concept of mental health services has undergone changes from asylums to an institution—which is the next step, as the term institution itself embodies restrictions.

- Institutions should address issues like inadequate sanitary facilities, access to patient's choice of clothing and right to dignity (the example of the mental hospital at Thane reveals that there are human rights violations of female patients).

- Should institutions focus on long term care, day care, half-way homes, rehabilitation, community based care or should it be all of this?

- How should roles be assigned in the case of PPP—NGOs in rehabilitation, SHG, day care?

- How to handle capacity issues, human resource gaps, which type of human resource is required—medical professional or health care workers (successful examples of Banyan and Maitri)?

- Who will monitor long term patients and what happens in the event of patients who have recovered, but not accepted by their families?

- Which are the human rights interventions that are required?

- If change across the process is to be implemented, there should be coordination among all the players involved.

- Is the interaction between institution and faith healing centre a compatible one?

- Leadership, intent and strategic planning are powerful tools of change in the government mental health sector as demonstrated by the experience of Ahmedabad.

- NHRC monitored institutions performed better than non-monitored institutions.

- A realistic report on the institutions should include appraisals from clients, family caregivers and other caregivers.

- Dava & Dua provides a model that can be replicated in places where cultural traditions are embedded—the example of 'black magicians' who treat mentally ill persons in Kerala also attests to this (Dr Jose Antony).

4. SESSION ON Human Rights and Mental Health: Role of NHRC in Ensuring Protection of Basic Human Rights in Mental Health Institutions

Resource persons for the session on **Human Rights and Mental Health: Role of NHRC in Ensuring Protection of Basic Human Rights in Mental Health Institutions** were:

1. Dr. Lakshmi Dhar Mishra, Special Rapporteur, NHRC, India
2. Dr Suresh Bada Math, Assistant Professor, NIMHANS
3. Mr R Nataraj, IPS, Director General of Prisons, Government of Tamil Nadu

Moderators for the session:

1. Dr KV Kishore, Professor of Psychiatry, NIMHANS
2. Dr Achal Bhagat, Director, Saarthak, New Delhi

1) Dr. Lakshmi Dhar Mishra highlighted the role of the Supreme Court, NHRC and NIMHANS in protection of human rights of persons with mental illness. Mentally ill persons do not cease to be humans because they suffer from illness. Thus the Supreme Court and NHRC are concerned with rights violations within the family—stigmatisation and lack of reintegration, although treatment and recovery is possible. The Supreme Court directed the NHRC to get involved in state run mental hospitals at Agra, Ranchi and Gwalior, as several complaints of rights violations were reported from these institutions. This led to the study undertaken by the NHRC and NIMHANS. The Report is based on visits to government mental health hospitals surveyed across the country. NHRC monitoring accorded greater visibility of human rights dimension of mental

health. It resulted in some improvements in infrastructure and more NGO participation in service provision with the institutions. However, some persistent areas of concern which require attention are human resource gaps, integration between teaching, training and research, inadequacy of day care and short stay facilities, infrastructural problems, the issue of long stay patients and the problems with reintegration, and an alarmingly high death rate of patients at mental hospitals in Thiruvanathapuram and Chennai. Mental health discourse needs to pay attention to issues of accessibility, affordability, adaptability and acceptability.

2) Dr Suresh Bada Math addressed the issues of need for mental health legislation and critically examined the existing Indian legislations. In India, seven crore people require mental health services, although we have abysmally low human resources—just 3000 psychiatrists, 800-900 clinical psychologists and 700-800 psychiatric social workers. Mental health legislation is essential to address human rights violations by state and non-state actors, to eliminate stigma and discrimination, to ensure access to treatment, to uphold the dignity of persons with mental illness and to integrate them into the community. While the Mental Health Act in India provides for protection of human rights, access to health care, legal aid, PPP and policies; there should be a paradigm shift in the law from one that protects society to one that protects the patient, custodial to therapeutic care, medical to sociomedical models, institutions to communities and charity to rights. Immediate attention needs to be paid to identification of barriers to implementation, education of the public, encourage PPP and funding to develop mechanisms to implement the law.

3) Mr R Nataraj, articulated the mental health care requirements of prisoners. He felt that prisoners with mental illness need access to psychiatric treatment and counselling. He compared the situation at IMH with that of prisons.

The following issues emerged from the discussion:

- Human rights of persons with mental illness can be classified as negotiable and non-negotiable rights. Can the NHRC address the violations of non-negotiable rights in mental health institutions or should there be civil society intervention? **Dr Achal Bhagat** proposed a parallel civil society report of state of care in mental health institutions. He initiated the idea of a forum of voluntary organisations and individuals in India—Mental Health Alliance—to address the issue of rights violations in mental health institutions.

- In a human rights framework there should be no compromise— but many issues have not been addressed. Maintenance of human rights should be non-negotiable (Dr Vikram Gupta).

- NHRC is not an enforcement agency. How can we take action against violations? (Dr Lakshmi Dhar Mishra)

- There is still no solution to the despicable conditions in IMH, Chennai. While intent was shown, change has not yet taken place. Government partnership with The Banyan has been disbanded. How can the NHRC help? How can NGOs be empowered by NHRC? Why do NGOs continue to be excluded from IMH? (Ms Vandana Gopikumar)

- While the frustrations are understandable, there has been an acknowledgement of mistakes and efforts are being made to make amends. Further investigations required, as IMH is denying many claims. NHRC will take a stand if they are convinced that compliance has not taken place (Dr Lakshmi Dhar Mishra).

- There is no one institution that can solve the problems—the community needs to be strengthened. Man can be as kind as he is destructive.

- Can we have an authority that implements rather than just advises as the NHRC does now? Can there be policy guidelines for legal parameters for NGOs to work?

- Legal space is vital. Giving more teeth to bodies would only cause more problems due to abuse of power. NGOs can cause problems and need regulation.

- Accommodation is too prevalent an attitude towards human rights problems. There must be a pressure lobby to encourage change, as it the only way changes have occurred in India in the past.

- Formulation of an approach paper to design a body which is objective and rational and functions as a social order body. A group that incorporates all areas: social and community (Sumitra).

- We can all end up in an institution. Any reform has to start somewhere and it is important to apply pressure. Where do bodies spring from?

- Why should the public know about what is happening in an institution?

- All live in a democracy, so use the prevailing structure to address issues. Institutions do create problems. Work is being done but there are government restrictions. The main thing is to develop district mental health centres. Strengthening community care is the key—creative solutions are needed.

5. SESSION ON Civil Society Interventions in Rights based Mental Health Care were:

Resource persons for the session **Civil Society Interventions in Rights based Mental Health Care** were:

1. Mr Anil Vartak, Founder, Ekalavya
2. Ms Chitra Khare, Member, Parivartan
3. Debashish Chatterjee, Trustee, Anjali
4. Mr Mukul Goswami, Founder Ashadeep
5. Ms Ratna Chibber, Founder of Aasha
6. Dr John Thomas, Board Member, Maria Sadanam
7. Ms Porkodi, Senior Coordinator, The Banyan

Moderator for the session:

1. Dr Vikram Gupta, Senior Programme Associate-Health, Sir Ratan Tata Trust
2. Dr Asha Banu, Assistant Professor, Tata Institute of Social Sciences, Mumbai

The session on responses of civil society and non-governmental organisations in mental health care was moderated by Dr Vikram Gupta. He spoke on the universality of the human rights framework and the debate about institutionalised versus deinstitutionalised mental health care—emphasising that the functioning of both are of equal importance. Dr Gupta felt that the government, although encouraging of non-governmental organisations (NGOs), have also limited their powers and have even pushed out NGOs that work with state run mental health institutions. It is a moot point whether human rights can be upheld in an institutionalised setting. Dr Gupta called for the initiation of a civil society movement or think thank that will constantly engage with mental health care to ensure larger visibility to the issue. In India the problem is bringing all different approaches together to formulate a common strategy to address mental health. However, for advocacy to impact public policy, NGOs have to incorporate evidence-based research practice and publish in reputed journals.

1) Mr Anil Vartak emphasised protection and promotion of rights of persons with mental illness with the use of self help as a tool of recovery. Ekalavya is a self help group formed by patients and their caregivers wherein self help in recovery and acceptance of responsibility by caregivers are the guiding principles. According to him, the SHG was designed to address:

- Loneliness is a big problem once initial symptoms of the illness have been addressed
- Each client has a stigma of their own and they struggle to accept themselves. They undermine and violate themselves with these opinions.

Mr Vartak calls for support groups that address awareness of human rights and demand better infrastructure for persons with mental illness, rather than advocacy per se, as it is a

fairly complex issue for lay persons to start with. He also deliberated on the allocation of scarce resources among competing uses to ensure an optimal mix of services.

2) Ms Chitra Khare is a member of Parivartan, a non-governmental organisation which works with the Regional Mental Hospital, Pune. In her presentation she spoke about the strategic importance of government mental hospitals, as the government sector is the most important source of mental health care provision and is the largest beneficiary of budgetary allocations for mental health. So Parivartan decided to work with the Regional Mental Hospital, as they felt the hospital represented a powerful conduit for change. Parivartan started the process by establishing a healthy working relationship with the hospital staff. Initially group meetings were started with outpatients and their caregivers to create awareness about the nature of illness and how caregivers can play a vital role in recovery. Subsequently group sessions were extended to ten male inpatients to provide a platform for them to share their thoughts and experiences.

3) Debashish Chatterjee argued that the state is an agent of society. He spoke about marginalisation being as old as human civilisation. Institutional care in India is premised on the notion that the world of the mentally ill is a cuckoo's nest—it does not exist. Consequently, state run mental hospitals function in a prison like manner and serve as dumping grounds. Anjali has tried to address this issue to ensure that mentally ill persons have a life beyond barbed wires and has many activities like rehabilitation, reintegration with family, engagement with hospital staff, advocacy and awareness creation. The NGO desires to achieve a systemic change in mental health treatment and care; and to increase awareness through partnership with the government, developing a movement around mental health issues and create an environment where socioeconomic rights of mentally ill persons are recognised. Anjali is not just a programme, but a space that participants can call their own—treatment is completely voluntary. In the course of their work with three mental hospitals in West Bengal, while they faced several problems, they have also been able to make a difference in humanising care, improved living conditions and increase in awareness.

4) Mr Mukul Goswami emphasised rehabilitation of persons with mental illness and reintegration of patients with their families. Ashadeep has day rehabilitation centres and a residential rehabilitation facility. Income generating vocational activity is accorded importance. Ashadeep works closely with the LGB Regional Institute of Mental Health.

5) Ms Ratna Chibber an NGO formed by family caregivers, deliberated on the importance of human rights in rehabilitation and residential care of persons with mental illness. She asserted the supremacy of the patients' perspective by saying that the patient is always right. Rehabilitated persons with mental illness who displayed interest in employment were employed in retail shops started by Aasha.

6) Dr John Thomas spoke about the organisation's work in psychosocial rehabilitation of homeless mentally ill persons. The rehabilitation centre has managed to reintegrate a sizeable number of patients with their families, after providing medical attention and rehabilitation. Rehabilitation focuses on providing basic needs, training in self care,

vocational rehabilitation and adaptation to the community. Agrarian based occupational activities are stressed, as most patients relate to it. Maria Sadanam intends to initiate a community mental health literacy programme.

7) Ms Porkodi elaborated on how Banyan has strategised its interventions to address prevention and intervention. Reintegration with families, community based care, formation of SHGs, vocational training and capacity building form important components of rehabilitation at the Banyan. The staff of The Banyan presented an informative and enjoyable skit on its projects and how it seeks to address dignity and human rights of persons with mental illness.

On conclusion of the session, the issues presented were thrown open for discussion. During the discussion, Dr KV Kishore was doubtful about self help as a panacea for recovery, as he felt that the very concept of self help was alien to Indians who prefer to be led by someone. He added that group formation posed practical problems owing to the class, caste and religious differences in India. He also did not favour using patients for psychological work. However, Ms Madhu Sharan articulated the importance of self help groups in the context of those who are not reintegrated, adding that SHGs requires a high level of capacity building. Mr Anil Vartak disagreed with Dr Kishore's views on SHGs and stated that every patient wants to recover from their illness. Dr Jose Antony also did not agree with Dr Kishore and said that SHG was not a foreign concept, although the notion of SHG itself needs to be reformed. Dr Amit Basu wanted to know from Ms Khare whether it is right to use patients as helpers to cover up institutional callousness. Ms Khare responded by saying that patient groups were formed primarily to assist in socialising. Mr Vartak did not see anything wrong in the participation of persons in recovery.

6. Valedictory session on Future Direction for Mental Health Care

The speakers for the valedictory session on **Future Direction for Mental Health Care** were:

1. Justice Prabha Sridevan, Judge of the Madras High Court
2. Ms Supriya Sahu, IAS, Joint Managing Director of Tamil Nadu Water Supply
3. Ms Vandana Gopikumar, Founder, Banyan
4. Dr Poongothai Aladi Aruna, Minister for Information Technology, Tamil Nadu
5. Dr Vikram Gupta, Senior Programme Associate-Health, Sir Ratan Tata Trust

Moderator for this session: Dr KV Kishore, Professor of Psychiatry, NIMHANS

The valedictory session started with a brief introduction by Ms Madhu Sharan on the issues related to mental health care that was discussed in the preceding sessions and she stressed on the need to map workable and practical models of mental health care as a way forward.

1) Justice Prabha Sridevan, Judge of the Madras High Court, in her talk, addressed the following issues:

- The discourse on mental illness was largely silent on the subject of 'what they (patients) want'. On her visit to RINPAS, she observed that all the female patients had short hair, as it was convenient for the hospital staff and not because the patients had a choice.
- Families' assertion that as primary caregivers they need not be sermonised on human rights. At the Agra Mental Hospital there was a scandal of forced hysterectomy of mentally ill patients. When the families were asked why they allowed it, as it violated the patients' rights, they argued that they need not be lectured about human rights, considering that they were responsible for providing care to the patient.
- She emphasised that concern for persons with mental illness cannot be paternalistic; rather there needs to be recognition of all their fundamental rights.
- Constitutional safeguards by themselves do not address the issue of human rights violations of persons with mental illness; the state has to fill the gaps in the legal system.
- The gendered nature of family support was evident at RINPAS, where there were hardly any family visits in the women's wing, but most of the patients in the men's wing had family visits at least once a week.
- According to the National Human Rights Commission, government mental health institutions were primarily custodial in nature and served as dumping grounds.
- Misuse of the law to institutionalise persons without mental illness to settle scores, which has been referred to as psychiatric silencing of differences by Amita Dhanda. She cited the instances of a case in the Madras High Court, in which the husband had got an order declaring his wife as insane and institutionalised her at the mental hospital; and the case of a woman captain in the Indian Army who was certified by psychiatrists as mentally ill, as she had filed a complaint of harassment against some officers.

In conclusion, Justice Prabha Sridevan argued for the need to be more vigilant as the voices of persons with mental illness are feeble.

2) Ms Supriya Sahu, IAS, Joint Managing Director of Tamil Nadu Water Supply, drew attention to a positive story about a mental health institution at Taiwan, which has transformed from being a symbol of shame to a symbol of what can be achieved. This change was attributed to four basic actions of separating the patients into:

- Long term
- Short term
- Reintegrated
- Day care

The hospital functioned as a residential care unit with a beautiful appearance, privacy for patients and hygienic surroundings. One of the striking features of the hospital was the lack of a boundary between the institution and community—the former merging seamlessly into the latter.

Ms Sahu discussed some important factors that have a bearing on future directions for mental health care.

- The mental health sector needs reform and requires a mission mode. Change should begin at the ground level through the District Mental Health Programme. There should a vertical programme on the lines of blindness control programme for mental health.
- There should be financial devolution for the mental health programme, which can produce better results as demonstrated by the National Rural Health Mission.
- A new service delivery model has to be initiated at the institutional and field level along with a strong Information, Education and Communication (IEC) programme. The IEC programme should have celebrity endorsement similar to that of HIV.
- There should be time lines for institutions to deliver results.

3) Ms Vandana Gopikumar, Founder, Banyan deliberated on Banyan's engagement with multiple stakeholders and listed some important areas that Banyan will address in the future:

- Mental Health Authority in each state needs to be examined.
- Coordination among various civil society organisations.
- Develop workable models of Public Private Partnership with equal participation of both players. The Banyan intends to extend its PPP from Tiruporur to Kanchipuram.
- Focus on destigmatisation by partnering with the Judicial Academy, training of the police force and produce a strong IEC campaign.

Ms Gopikumar made two key points about understanding the best practice among the different models of mental health care with research; and instilling a sense of reliance among persons with mental illness with the help of SHGs, which will aid in positive portrayal. She articulated the need for establishing a post of Director, Psychiatric Social Work in order to strengthen the community that provides tremendous support to persons with mental illness.

4) Dr Poongothai Aladi Aruna, Minister for Information Technology, Tamil Nadu spoke about the vision of Banyan. She lauded the efforts of Banyan in not just providing clinical services to persons with mental illness, but also playing an important role in reintegrating persons who have recovered, with their families. She emphasised that doctors at the primary level should be trained to assess and treat mental illness in order to make mental health services available in rural areas. The importance of including mental health in the medical education syllabus was also stressed.

5) Dr Vikram Gupta, Senior Programme Associate-Health, Sir Ratan Tata Trust discussed the bond that SRTT shares with Banyan. However, he said that although SRTT spends Rs. 50 crores annually on health, most of the programmes do not offer evidence of their impact on society. He urged NGOs to rely on evidence based practice so as to remove individual bias. Government and NGO involvement was critical in ensuring delivery of primary mental health care services.

The questions and points that arose from the panel discussion dealt with the following issues:

- The proportion of SRTT's health budget that was allocated for mental health and the reason for absence of government involvement with SRTT projects (Vandana Gopikumar).

- An encouraging aspect of the workshop was the exposure of the participants to community oriented mental health service providers like Dava & Dua and Maria Sadanam (Mukul Goswami).

- Whether health being treated as a state subject (constitutionally) acts as a barrier or facilitator (Dr KV Kishore)?

- The example of funding for HIV programmes offers an excellent mechanism for replication in the mental health sector. A consortium can be given funds for the mental health sector and based on the application that it receives; it can disburse funds to NGOs. Matching government resources with NGO capability will result in a win-win situation. A brainstorming need to be conducted to analyse why the Banyan model of mental health service delivery has not been replicated (Supriya Sahu).

- There is a need for good leaders in the government and good negotiators in NGOs. In the case of human rights violations does the court give a time line to government institutions to respond? (Madhu Sharan).

- Is there legal recourse to address violation of human rights at IMH, Chennai? (Vandana Gopikumar)

- Justice Prabha Sridevan said that there are time lines for government institutions to respond to court orders regarding violation of human rights. She added that there are legal remedies to address human rights violations at mental health institutions—a PIL can be filed or a case representing a patient whose rights have been violated can also be filed.

- The problem lies not with the system, but with 'I and We'. Despite many success stories like the mental hospital at Ahmedabad, problems persist in many institutions (Asha Banu).

- As the nature of mental health poses difficulties, the approach is not about success or failure. Community care provides answers to many of the ills plaguing the system because only 10 per cent of persons with mental illness require long term care. The least stigmatising method of mental health care provision is to route it through primary health centres. However, it is important to note that the system also fails not

only the people, but also medical professionals with respect to poor work conditions and low salaries (Dr KV Kishore).

- The approach to mental health is of importance because of the complexities of mental health (Vandana Gopikumar).

- The future of psychiatry in India lies in community psychiatry. However, there is a poor understanding of this concept, as institutions do not teach community psychiatry. Medical ethics have to be included in medical educational syllabus (Dr Amit Basu).

- The rights of persons with mental illness are divine rights (Dr Anjaneyulu).

Dr KV Kishore concluded the workshop by saying that **throughout history there are barricades which we have to fight; and we have to find the strength to move forward**.

A report on the workshop on "Human Rights and Mental Health Institutions: Rethinking Systems of Treatment, Care and Wellbeing" at the Institute for Financial Management and Research organised by The Banyan and Banyan Academy of Leadership in Mental Health, with the support of Sir Ratan Tata Trust on 26–28 February 2009.
