Report

National Seminar

on

‘Perspectives on Mental Illness in India’

1 – 3 July 2010

Venue: Institute of Financial Management and Research (IFMR)

Supported by:

Navajbai Ratan Tata Trust

1st July 2010

Theme : Access to localised care for persons with mental illness from low socio-economic groups

Session 1

Mirjam Dijkxhoorn, Deputy Director, The Banyan Academy of Leadership in Mental Health (BALM) welcomed all the participants of the seminar by elucidating the thought behind getting people together from different sections of mental health sector to present and discuss their views and the themes for each of the three days of the seminar.

The Institute of Financial Management and Research were thanked for providing the venue, Oriental Cuisines and Sangeetha Business Hotel were thanked for providing accommodation for speakers and the key partner of BALM, the Navajbai Ratan Tata Trust were thanked for their ongoing support.

Prof. Mohan Isaac University of Western Australia/NIMHANS
Presentation: Genesis, structure and desired impact of the DMHP

The history & genesis of the DMHP was explained. The 'Bellary experiment' is the root of the national health programmes. The evolutionary history of DMHP is divided into three phases:

Phase I	**Phase II**	**Phase III**
Mid 1975 – mid 1985	Mid 1985 – 1990	1995-96
Early age of experiments and innovations	Pilot programme through PHCs and CHCs	Budget created
From asylum to the community	Bellary experiment 1985 to 1990	Steady increase in plan allocation 9th, 10th, 11th
	NMHP approved by central council of Health and Family Welfare.	
	No funds	
		DMHP is now operational in 127 out of 625 districts of India

The start of the DMHP collided with recommendations of a WHO expert committee to extend mental health services to community and general health and train human

resources for mental health care. Based on this recommendation, a rural mental health center was started in Bangalore in 1975-77 as a pilot, to train human resources to identify, diagnose and manage mental health care as a community awareness initiative. Another international push factor was the Alma Ata declaration of 1978 which had 'Health for All' as its motto, which recommended comprehensive and universal primary health care, including Mental Health Care. Many changes took place thereafter which lead to an attempt at universalisation of health care. As a result of the above factors a pilot District Mental Health Programme (DMHP) came into existence. Later, the Millennium Development Goals also covered Mental Health as a part of general health care.

The DMHP has five components – sensitization and training of all human resources in primary health care facilities; managing typical problems, treatment, reference and follow-up from tertiary health facilities; making psychotropic drugs available at the primary level; supporting through monitoring and evaluation; providing treatment by a multi-disciplinary team at the primary level and providinge inpatient care at the tertiary level and finally, community participation. A pilot programme was developed in Bellary, which has now been expanded to 127 districts. Very recently, the 11th planning commission conducted a review of the programme through a private body, the Indian Council for Market Research (ICMR), in 20 districts from five zones in India. Satisfaction of the services by users was included in the review. It was found that the DMHP is being implemented commendably in Tamil Nadu and it was observed that best practices have evolved in Madurai District, which scored 9 on a scale of 10. It is important that the DMHP delivers effectively, to ensure mental health care to a predominantly rural India, which will lead to a decreased number of homeless persons with mental illness as well as a decreased number of emergency admissions in hospitals. However, given the population size of India and the fact that even the most resourceful countries have not been able to achieve mental health care for all, this is an uphill task.

Prof. M. Thirunavukarasu, President Elect, Indian Psychiatric Society, Chennai.
Discourse: Concept of mental health in a community mental health programme.

The DMHP has been planned well, but continued evaluation is of pertinent importance, including baseline and endline studies. The programme can be implemented extensively, with special focus on a few blocks in each district, which will act as study sites to check the effectiveness. Two terms used with reference to mental health in India, namely 'rehabilitation' and 'mental health programme' are generally confusing. The word 'rehabilitation' is often misinterpreted as only involving going back to the community from an institution and being retained there. The treatment is supposed to continue from home, however this has proven to be unpractical in the real world. Secondly, in the community treatment doctors have a role to play in the rehabilitation, together with rehabilitation professionals. There should be clarity about community treatment and rehabilitation as two different concepts and a separate set of roles for the respective professionals. While DMHP is a mental **health** programme, most of the time and resources are spent in identifying

and treating people with mental illness. There is not enough focus on promoting positive mental health through community awareness programmes. The idea about mental health is generally not clear within the community, which leads to stigmatization. The presentation was concluded with a suggestion to establis five regional mental health hospitals in the State with 300- 500 beds capacity each.

Dr. Poonguthai Aladi, Minister of Information Technology, Government of Tamil Nadu.

The WHO definition of health gives equal importance to physical and mental health. Mental health is a complex issue, since it involves medical and psycho-social aspects. But what is needed is a change in the face of mental health considering the increasing population of people with mental illness and pressure on the human resource available. The Erawadi accident urged us all, especially the policy makers, to see mental illness in a different way than from before. Following the incident, the Government of Tamil Nadu constituted a Mental Health State Authority chaired by the Health Secretary. There is a need for NGOs to be involved in the sector, since mental health has a unique socio-cultural aspect to it. The use of telemedicine is a good tool to counter the problem of limited human resources in the mental health sector. Interestingly, in an internal study at Apollo hospitals, it was found that of all the doctors, psychiatrists used telemedicine the most. The Government of India is now introducing the use of telemedicine in major cities of India. The ministry of IT along with the Ministry of Health can together envisage telemedicine for mental health services. Mental health is a complex issue and it would take a multi sectoral approach involving the departments of health, the police and the judiciary, to address the issue.

Vandana Gopikumar, Founder, The Banyan and Director, BALM, Chennai.
Presentation: Access to care – clients and caregivers perspectives

The presentation started by with stating the number of people and their families The Banyan had reached, in providing services for treatment, inpatient care, rehabilitation and reintegration through the transit care facility through community outreach services in both urban and rural areas, and a day care center, primarily serving people from low socio-economic groups. A geographical spread of the clients of The Banyan transit care center shown on a map indicated that the population of people who have been treated at The Banyan are distributed across not just the nation, but also the neighboring countries of Sri Lanka and Nepal. It also indicated a pervasive lack of access to services nationwide. The presentation brought forth the co-relation between poverty, place of stay, higher disease and family burden. In rural areas, the distance from the care center is the primary cause of burden on family, while in an urban setting, it is the lack of proper housing and the stigma attached to a mental health issue; possibly rendering people homeless in both cases. The role of

economic circumstances is pertinent in the extent of care by family members and related quality of life they experience. The care system usually concentrates on people who are productive. The family burden is accentuated by out of pocket expenditure - loss of wage and travel especially for the low socio-economic groups. The profile of a caregiver is determinant in the process and delivery of care.
The presentation also talked about the various forms of care - traditional, modern, state provisioned and private, where acessibility to these services varies across different strata of society. The presentation provided the perspective of the clients in terms of the stigma and discrimination faced by them owing to the attitude of different sections of the society. This proved to be on eof the key barriers in accessing care. Vandana urged to expand the concept of care beyond medication to peer counseling, psycho-social intervention, housing provisions, legal services, social entitlements and better follow up and aftercare provisions. Employment was cited as another major concern of the clients and caregivers. Another distressing concern is the question of 'What after the caregiver is gone?'. PHC and DMHP, which are meant to provide care at the community level, are in a dismal state and there is an urgent need to take a second look at the efficacy of the programme and what modification can be made to finetune it. The National Health Bill regards health care as a human right; it is hoped that once the National Health Bill it is enforced, the attitude of the care facilities will change. The various Acts and legislation should work hand in hand and there is a need for convergence. Vandana appealed to different stakeholders of the sector, with differing viewpoints, to come together as one lobby on certain issues, for example access to care, and make it a reality to change the lives of the people. Public private partnerships (PPP) are important to promote transparency in the mental health sector and services, which are predominantly provided by the State, which can lead to the promotion of Human Rights.

Mr. V K Subburaj, Principal Secretary Health, Government of Tamil Nadu
Address: Status of mental health services in Tamil Nadu

The nature of the issue of mental health is such that it needs sustained efforts of all people involved. All over the world a high number of people suffer from mental health issues at one time or the other. Manifestations of anger and violence could be viewed as some form of mental health issue. Similarly, increased cases of suicide are indicative of the increase in people with MH issue. Conflicts between traditional and modern lives and breakdown or absence of support systems lead to its increase. He also expressed concern over the plight of the people living in Mental Institutions, as once they enter, they usually never return to their families since institutional set ups today are not equipped to rehabilitate. Sadly, a direct proportional relation between the number of years in a mental institution and a poor prognosis of illness is a disturbing reality. Emphasis should be on community awareness as a panacea for Mental Health, as it is preventive in nature and can curb the extent of stigma, enabling people to access mental health care in good numbers. Tamil Nadu has a better psychiatrist to population ratio than other States, but it is still not sufficient, as more qualified people are required. However, it will take a long time to fill up the posts created, as the number of human resources is low. In TN, Panchayat groups

have also been trained on the matters of mental health. He emphasized the role of counseling for interpersonal relations, which are becoming fragile. Mr. Subburaj indicated that there is a need to make the Institute of Mental Health in Chennai an autonomous institution just like NIMHANS, so that delays in carrying out government orders for useful changes could be avoided. Steps have been taken by the Government of Tamil Nadu to improve the lives of homeless persons, by initiating the process of setting up ten shelter homes through Public Private Partnerships with NGOs.

Dr. Sathianathan, Director, Institute of Mental Health, Chennai.
Presentation: Role of the State Mental Health Authority

There is a need for continued training programmes in mental health, as well a need for a multi-disciplinary team to deal with persons with mental illness. Statistics on broad categories of Mental illness that come to IMH, show that people do not access mental health services until the illness becomes uncontrollable, because the real cost of services is high. Societal repression makes women more prone to mental illness. A combination of societal pressure on children and high expectations result in a high incidence of suicides in the state. Slides showing the infrastructure, services and facilities at IMH were presented. IMH is committed to provide an environment as humane as possible for people with mental illness.

Mr. Akhileshwar Sahay, Management consultant and User Survivor
Presentation: Perspective of a user survivor living with bipolar

Mr. Sahay shared his personal experience of being a user- survivor of Bipolar disorder and called it a 'life sentence'. India as a nation lives in denial of mental illness. The low number of mental health human resources has prevented mental health services from being available to all. The presentation raised pertinent questions on why people land up in places like Erawadi, who sends them there and what happens thereafter. The presentation also pointed out the paucity of surveyed data available on different aspects of mental health. He shared his personal journey of living with bipolar disorder and the difficulties that the illness posed in his life. Basing his experience on the Nature-Nurture paradigm, he shared how different socio-cultural experiences could possibly have attributed to his mental illness. He shared the changes that occurred in his life once he started medication. He traced the history of the word insane and pointed out that the word in use, even today, symbolised the insensitivity of the State towards the issue. Highlighting the harsh perceptions of Indian politics and the public life of people with mental illness, he said that people of 'unsound mind' cannot cast their vote. People living with mental health issues face many difficulties, such as the inability to have a membership to a company or a trust, are not eligible for medical insurance etc. These become even more severe if an individual belongs to the low-socio economic strata. Pointing out on the need of community awareness on the issue, he said that the amendments in the Act by itself cannot bring about a change, because it is not the state or government that sends people to Erawadi. Government agencies and communities need to change their attitude in caring for people with mental illness.

Dr. Lavanya Seshashayee, Bapu Trust, Bangalore.
Narrative

The presenter advocated promotion of Self Advocacy for Mental Health. She shared her personal journey, starting from family's apathy, maltreatment, faulty parenting, and a gendered and patriarchal social environment that caused her pathology. She feels the incompetence of the mental health practitioners aggravated her situation. She largely shared her concerns on the mental health practice in India, of holding biology as the determinant of mental illness. In her view, the focus must shift to the newer and more reliable sources of diagnosis. She emphasized the role of family and society in causing mental illness. She expressed that the causative factors should be holistically addressed in clinical practice. If not attended to actively, an individual might return to the same family environment that was not conducive for his or her mental health.

Day 1
Session 2

Panel Discussion

A recap of the preceding session was done, in which participants placed the following concerns

- What are the solutions to strengthen DMHP to serve the vision of the NMHP?
- How can we create spaces for user-survivors to voice their concerns?
- How do we ensure rights of the poor? What about the issue of rightlessness / personlessness due to other laws?
- There is a need to look at the National Health bill and there is a need to look at how discrimination against the marginalized gets legalized through the other Acts.
- Will the 11th 5 year plan make sure that the MH Act is enforced and not remains a paper tiger?
- There is need for a comprehensive mental health policy in addition to the law.
- Why has NMHP not come into force as it was planned until now?
- The provisions of the government such increased allocation of funds and amendments in laws are just cosmetic. The spirit of putting these into action is missing.
- Are we prepared to dismantle hospitals and base care in the community? Would it not mean shifting the burden to the women who are largely the caregivers? Is it also not taking away the only option of institutionalized care for persons with mental illness today?
- The morning session presented two broad perspectives, that of the State and that of the users.

- The MH Act and MH policy should not be confused: Mental health laws are limited to laying down procedures to manage and serve a mentally ill person in the best way possible. It has no say on implementation of services.
- It is heartening to know that Tamil Nadu State's stand on mental health is very positive, however, there is indeed a lack of statistics on varied aspects of mental health that could help in better policy and services.
- Governments at the Center and State levels delay the allocation of the funds to the implementation agencies, which sometime leads to underutilization of funds because the period for utilising the funds would have lapsed.
- There is numerical as well as quality deficit in Mental Health professionals.
- There is a need to have a debate on the legal capacity and rights of people living with mental illness.
- The mental health sector faces an identity crisis. There is a need to have clarity amongst all stakeholders about what needs to be done urgently and on which issues concensus can be reached.
- The Additional Health Secretary, Government of India in a recent regional consultation on revision of the MH Act said: "Mental health care should be a basic right and should be spelt out in the Act to make the provision of services by the Government binding."
- A law gives a definite frame for implementation and both policy and law are closely related. A shift to mental care being a right envisaged in a policy has to be done with the tool of law. Shifting from the lens of the illness to the lens of rights prerequisites a law.
- A few of the participants were of the opinion that if a rights based approach is being achieved through an amendment in the MH Act, then this might have serious repercussions. Ideally mental health and human rights issues should be addressed through a comprehensive rights law, though most of the panelists and participants were in favour of uninterrupted yet in-depth work on the current process of amendments and the mental health act.
- Merely having a right to mental health services is of no use if there are no proper services.
- The session asserted the mental health issues from the perspectives of the LSE group. However, most of the advocacy is led by a group of people from a middle or upper middle class background. Therefore it is pertinent to have an understanding of the needs and suffering of people from low socio-economic groups.
- It is important to define what care means. Care is to be advocated beyond medication as an all compassing gamut of psychological services, community awareness, de-stigmatization, entitlements and legislation.
- Although there have been discussions on access to care for a long time, there is still a huge debate around access to care, in terms of institutionalization versus community based care. Likewise, rights have to be seen from both the user-survivor as well as the care givers' perspective.

The session concluded on three major themes emerging from the discussions put forward by the moderator:

- The specific roles and differences between mental health policy and mental health legislation.
- The issue of conceptualizing and monitoring mental health systems.
- The need for mental health care for disadvantaged sections of the society and the need for a multi- sectoral response to mental health care.

Presentations continued

Ms. Thiruselvi, user survivor, Nilgiris (Tamil Nadu)

The problems of mental illness are directly emerging from two factors – availability of medicines and the attitude of care givers. If there is a problem with either of these factors, homelessness can be the result. The mental health act is cumbersome and mental health care is not within reach of most. However, it is heartening to see a space for homeless people with mental illness in the new Act. In the Nilgiris, Tamil Nadu, the general practitioners at a general health facility are managing mental health care, which could be practiced everywhere. Mental Health issues have not been publicized in the same way as HIV/AIDS. People visit exorcists, quacks and faith healers for treatment due to lack of awareness. Since families do not know how to handle a person with mental illness, he or she generally ends up locked in chains or behind doors. This is done more for practical reasons and out of desperation, rather than out of apathy towards the well-being of a family member. People with mental illness are often separated from their children, they lose their jobs and social contact. Their capability of holding an opinion or decision making is always doubted. Replacement of all of these losses is very difficult.
The 40% disability criterion for a disability certificate is not effective in the case of mental illness where the condition is not stable. People with mental illness have no share or claim on property and face stigma at the work place as well. It is difficult to travel long distances for people with mental illness due to the nature of their illness and it is mostly imperative for the caregivers to accompany them which means higher travel costs, loss of wages and time spent. The most pinching question is what happens to people once the caregiver is gone? In many cases, the answer is that they wander and become homeless.

Dr. Padmavati, SCARF, Chennai.
Presentation (on behalf of Dr. R Thara): Access to care & untreated psychoses- evidence base.

"We see too much of the end stage of schizophrenia and not enough of the first episode"1. Large volumes of research on the duration of untreated psychosis (DUP) and duration of untreated illness (DUI) by various researchers at different times have shown the DUI is always greater than DUP. Community studies conducted by SCARF showed a large number of people suffering from untreated functional psychoses.

Harry Stack Sullivan, circa 1927 (paraphrased)

Reasons are gradual onset, lack of insight, lack of awareness of the illness and treatment and inadequate care services. People suffering from psychoses often do not work, are dependent, low in hygiene and only a few participate in domestic activities. Health seeking behavior shows a large number of people accessing faith healing and traditional methods. Women, rural and poor people took longer to reach services. Delayed treatment resulted in suicides, longer recovery period, breakdown of support system and more disease burden. Fear of disruption of academics and employment also acted as barriers for early access along with a 'wait and watch' attitude, fear of admission etc. A predictor for a better prognosis would be early identification.

Day 1
Session 2

Prof Mohan Isaac, University of Western Australia / NIMHANS
Presentation: Current status, impact and future recommendations for the District Mental Health Programme

The presentation was based on the impact study done by Indian Council for Market Research on the DMHP. It involved collection of primary data through interviewing three groups of people to understand their perception on DMHP; the professionals, the end users and the community. It studied the sanctioning process, the utilization of funds, procedural problems with the Government, recruitment and retention of human resource, quality and effects of training, availability of drugs, nature and activities of IEC, satisfaction with services, community awareness etc. One of the important recommendations was: "It was observed that the DMHP has resulted in availability of services at the district level, as such it should be expanded to other districts of the country". Limitations observed by the study were low utilization of funds for training, low retention of staff, most beneficiaries still contact district hospitals as first point of contact instead of PHC and CHC, and therefore care is not available at the community level. An improved DMHP should reflect in the admissions in local hospitals, referrals to the tertiary level and increase in follow ups. In a mental hospital in Kerala, a substantial decrease in admissions, increased OP registrations and follow up is indicative of impact. Complete integration of mental health services into PHCs takes time, considering the delivery of multiple services. When people with visible severe mental disorders report to the PHC, doctors are better equipped to refer to a district hospital. However, the majority of people report somatic symptoms for common mental disorder, which are more difficult to identify for a general doctor. Therefore, training of PHC doctors should continue. At the end the presenter asked the question: If after the findings of the evaluation, DMHP is not the right program then what could be? Is not being "ideal" a failure? He added to say that other countries have adopted the Bellary model. Another WHO commissioned report emphasizes integration and training of PHC Human Resources. He cited many other sources internationally where integration is recommended, particularly for low

and middle income countries. Would it be right to call DMHP a failure? Even if it has failed, is there any change in the level of awareness in the community?

Dr. K.S. Jacob, Psychiatrist, Christian Medical College, Vellore.
Presentation: Public mental health policies in India

The presentation pointed out that the mental health budget, infrastructure, policy initiatives, and human resources are very low. The psychiatric practice is limited to specialty settings in urban areas; with limited psychological and social support. India has an almost absent social security net. Health is a low priority in India and within health, physical diseases have a higher priority than mental illnesses. Misutilisation and inefficiency of services occur. Training of general practitioners in psychiatry happens predominantly in a tertiary care setting, which leads to general practitioners with brief training in a tertiary care setting, where only severe cases are seen. This leads to general practicioners being unable to identify milder cases of mental illness in a general health setting. Advocacy is fragmented; evidence based interventions are not being used to argue; integration of general medicine with psychiatry has not happened. He suggested revamping the basic training and integrating mental health with general health care; psychiatry should be taught more extensively in general medicine, with practical training at the primary level instead of only in tertiary facilities. There should be inter-sectoral collaboration among the Departments of Health, Social Justice and Empowerment and NGOs to find solutions to mental health education. Mental health education is a major force, to challenge and to change the attitude towards mental health.

Dr. C R Subramanian, State Nodal Officer DMHP
Presentation: Status of DMHP in Tamil Nadu

This presentation explained the DMHP in Tamil Nadu, its outreach and plan of expansion. It presented the aim of the program, to bridge the gap between a mental health program, and the need for basic mental health care. Important components are integration at the primary level with general health, community sensitization and removal of stigma. It also talked about the structure of the programme in Tamil Nadu. The coordination between three directorates, namely education, medical services and primary health is needed for training, treatment and outreach respectively. It presented the activities of the state nodal office like involvement of SHG in rehabilitation work, achievements through tying up with other development agencies, suicide prevention centers at the district level, adoption of schools for early counseling. The programme emphasizes on identification of illness at the PHC level for decentralization, including infrastructural facilities to treat at the PHC level and provisions for community rehabilitation and community participation. District data of people treated at PHC level was presented. A major challenge is recruitment and retention of Human Resources due to the current meager pay scales.

Dr. Mani Kalliath, Basic Needs India, Bangalore
Presentation: Bridging gaps in the provision of services, the non-governmental initiative

Summary: Basic Needs India (BNI) approaches mental health as a development issue and not only as a medical issue. An overview of BNI as an organization throws light on the methodology of MH intervention, which was developed after stakeholder (survivors and caregivers) consultations, seeing it as a community health need. Since BNI was not an expert in psychiatry, treatment was left to the Government resources. It is a grassroots stakeholder approach based on the felt needs of access to health care, sustainable livelihoods, capacity building of the external environment, evidence based advocacy and management of the partnerships. BNI forms partnership for community disability programmes and thereby scales up its outreach. This way 17,000 people and their families have been covered. BNI partners with NGOs with years of credible work in communities where mental health programmes are integrated. The strategies and modules involve identification and documentation, rapport building with the family, organization of referral, follow-up visits and education, capacity building (public events for caregivers where the needs are addressed and roles are spelt out through participatory discussions) and caregiver follow-up. Working directly with people at the grassroots promotes responsibility. People are integrated into various livelihood programmes, including support for entrepreneurship. Research involves gathering information to evaluate the effectiveness of programmes and interventions. BNI partners with NGOs that have an interest in mental health beyond availability of funds in the sector. After 8 years of increasing the workscope, the programme consolidated and evaluated the impact. The outcomes were that pressure from the ground does speed up changes; there was a decrease in human rights violation; and barefoot workers were trained successfully. Its strengths lie in being client friendly, with a focus on individual needs and converting individual needs into sectoral needs; formation and strengthening of solidarity groups (an important part of BNI's work) and federating leadership in disability. The work is not anti-psychiatry, but BNI feels that medicines are only a part of the need. Main issues and challenges faced are confined to a small population; CBOs that are yet to integrate and decentralise mental health into their work; dealing with destitute people with mental illness; initiating a dialogue between public health and psychiatry and building national alliance. In the future, BNI looks at influencing DMHP towards Community Mental health development approach and increasing the role of clients in planning and monitoring.
The session concluded with two presentations on community initiatives, carried over to day two of the seminar.

2nd July 2010

Theme: Need for a multi-faceted approach to the needs of homeless persons with mental illness

Session 1

Dr. Gayathri Balagopal, Director Research, BALM started the session by summarizing the important points raised on the 1st day and giving a brief introduction to the sessions of the second day. The session started with discussion on the need for a multi faceted approach to the needs of the homeless persons with mental illness; status of the responses to homeless persons with mental illness; role of the civil society, the police and the judicial system.

Dr. Nimesh Desai, Director, IHBAS
Presentation: The IHBAS experience in working with homeless persons with mental illness

Dr. Desai talked about how a transition from treatment only in a mental hospital to treatment on an outpatient basis is possible for homeless persons with mental illness. IHBAS investigated the possibilities of doing so and putting it into practice. IHBAS offers a community outreach program where hospital staff go out to the population, to help mentally ill people. According to Dr. Desai it is possible to treat over 99% of the patients on an outpatient basis. This is preferable, because the conditions in a mental hospital are often abominable. Much debate has focused on the question of whether we should deinstitutionalize patients. However, Dr. Desai asserted that it is even more crucial to focus on prevention of institutionalization in the first place. IHBAS has had very positive results with re-integrating homeless patients back into the community. For those who did stay in the hospital, the stay period was reduced. The discharge rate for court referral cases is also high. This is attained by using an adaptation of the Bellary model for community based services. The model had to be adapted because it was originally developed for a rural setting, and IHBAS works in an urban area. An attempt has also been made to integrate hospital and community based services. Dr. Desai pointed out that a striking 4% of the Indian population lives in an institution (according to the census) and other studies show that 55% of the homeless women have a mental disorder.
Many people are not aware of mental illness in general, therefore awareness programs should be carried out. Especially in clinics at the primary level, awareness should be raised, as common mental disorders often go unrecognized and untreated. A project has been started to improve this.

R. Nataraj, IPS, DGP Fire and Rescue and Rehabilitation Tamil Nadu
Address: Role of the police in responding to the needs of homeless persons with mental illness

It is often thought that mental illness leads to homelessness, but it is important to realize that homelessness can also be the *cause* of mental illness. A growing concern in general, especially for homeless women, is human trafficking. Also the number of illegal immigrants is likely to increase in the future. Another big problem among the homeless is drug abuse. The police are now working together with The Banyan in several ways, especially in the earlier Dial 100 scheme. An important issue is that police men have to be sensitized to understand and deal with mental illness. The police now redirects mentally ill women that are picked up on the street to the Institute of Mental Health and occasionally to The Banyan. Instead of just arresting mentally ill people, they are now released on bail, as it is not productive to keep them locked up without treatment.

Vandana Gopikumar, Founder The Banyan & Director BALM
Presentation: A holistic rescue and response system for homeless people with mental illness

Vandana Gopikumar spoke about the various factors that can lead to homelessness in persons with mental illness. The main reasons are: poverty, lack of access to services, wandering, housing, stigma, being elderly without caregivers, and abandonment. With regard to wandering, Vandana argued that we have to scrutinize each case before condemning restraining and tying up, since they are often the result of desperation experienced by the family in dealing with a person with mental illness, instead of the oft referred to acts of cruelty by the family. These are difficult questions arising from complex situations with no clear visible answers. An interesting observation that Vandana put forward is that stigma about mental health seems to be worse in urban areas and less in rural areas. Vandana also critically reviewed the work of The Banyan: Many people have been reintegrated (900/1500), but it turns out that only 50% of the reintegrated women stay well. A much needed facility in Chennai is open shelters. In Delhi, this has been a successful approach. Vandana stressed that it is important to keep asking critical questions. Should the police be involved? Can people discharge themselves? How often are people forgotten in an institution? Suggestions for the future include formulating a holistic approach in treatment, the establishment of a certified training program for social workers, open shelters and public service announcements to raise awareness.

Justice Prabha Sridevan, High Court of Tamil Nadu
Address Responses of the judicial system to homeless persons with mental illness

Justice Sridevan argued that we should get rid of our paternalistic attitude towards patients. For instance, should we always cut their hair? This is a decision they should, in most cases, be able to make for themselves. Another main point of the presentation was that the police should work on a case-basis and not conduct random round-ups, whereby many people are arrested at once. This approach leads to terrible

mistakes. She also expressed concern against the forced relocation of slum-dwellers. The removal out of their social environment and work environment leads to dire problems, e.g. the difficulty of commuting to work.

Harsh Mander, Special Commissioner to Supreme Court and member of the National Advisory Committee
Address : Current status, responses and services for homeless persons: A status report

Harsh Mander started with a story of a homeless woman in Delhi who got very attached to a street boy and they continued to support each other. The biggest tool at our disposal when working with disadvantaged people is compassion. When he started working, he found that hardly anything was really known about the life of homeless people. Therefore a study was initiated, in which many in-depth interviews were conducted with homeless people. The study yielded some interesting results. We always assume that homelessness is somewhat of a transient phenomenon, while in fact, it is a permanent state of living for many. Begging is also less common than one would think, for many people feel this is below their dignity. Loneliness increases tremendously during periods of homelessness. Being homeless is also surprisingly expensive. Everything has to be paid for- toilets, baths, cooked food etc. In Delhi homeless people are overcharged for renting blankets in the colder periods. In Chennai, whole families live on the street, sometimes for generations. The proportion of homeless women is high, often due to violence and/or abuse at home. Likewise, violence at home renders children homeless as they choose to leave home. Old age, destitution, chronic starvation and living on the street without official records all lead to distress in homeless people. The following actions are proposed: community outreach work, establishing open and recovery shelters, establishing options for people to have an address and building community kitchens. Another study showed that mortality rates amongst homeless people are probably at least five times higher than among the general population. For the needs of people living with a severe mental disorder who need long term support, it is harder to find solutions. Protected communities are one of the options, but there is the problem of the funding and finding space for these communities.

Reflections on session one

- Where is the room to have shelters that give food, livelihood, social security, love and compassion for people living on streets, let alone for homeless persons with mental illness?
- What choices are we making as a society: do we choose custodial care or human rights, or a balance between the two based on the experienced needs?
- It would be a crucial learning emerging from the study that homelessness could be contributory to mental illness. This point was reiterated and reaffirmed by many members during the discussions.
- Every homeless person has a journey which is different with respect to their gender, age, place of origin etc. The more we adjust policies according to these

heterogeneous journeys and the real life experiences of people with mental illness, the more accurate we would be in addressing individual needs.

- Nobody can deny the importance of institutions like the family, home and the State as they cannot be replaced by other entities.
- Even a lot of effort by different civil society organisations has only resulted in reaching a fraction of the total population that needs care. How do we address the rest? Therefore, it is important to think of mental health as a developmental issue and not just a health issue, which should be taken up seriously by the government.
- The right to non discrimination would remove many inequalities meted out to people with mental illness.
- Care is often defined differently by the patient and the caregiver.
- Many psychiatrists are unable engage in appropriate follow up, for which other mental health professionals (such as psychiatric social workers) are needed.
- In terms of awareness, it was stressed that the youth should be made more aware of the existence of mental health problems in society.
- Develop a curriculum for mental health students to include lay and peer counsellors in their work as additional resources.
- A lot of trained human resource is lost because we are unable to provide them good employment options in the public and private mental health sector in India. Students also lack in exposure to reality during their course of study.
- While addressing mental health issues one needs to refer to a spectrum of services ranging from medicines to alternative methods, whereas till date referral is made to either one or the other.
- A small group with different perspectives can have a dialogue internally and with the government, on the number of issues that emerge from this seminar.

NGO responses to homeless persons with mental illness

Premavathi Ramesh, Udhavum Ullangal, Vellore.

Premavathi spoke on the home for psychosocial rehabilitation of homeless mentally ill men, that Udhavum Ullangal runs. Homeless men with mental illness are rescued from the streets with the help of the police. They are treated with their personal characteristics and needs in mind. An important realization of the organization was that residents want their families to take care of them and show initial resistance to the care at the home. Sadly, the families in some cases do not accept them. The aim of the project is to discharge people again in good condition, as it is not meant as a long term stay facility.

Prof. Anna Tharyan, Christian Medical College, Vellore

Dr. Tharyan's presentation was again on Udhavum Ullangal. The unique feature of this organization is that it is set up entirely by lay-people, who feel compassion for homeless people. Dr. Tharyan argued that many mental health professionals are too far removed from the needs of the people on the streets. It is very refreshing to work with people that have no training in mental health, because they keep an open mind. Areas of work of Udhavum Ullangal are medical care and hygiene, tracing of origins, escorting people home, advocacy and capacity building. The organization also works on prevention, by trying to keep people mentally healthy. One of the activities organised is a laughter club.

Dr. Debashish Chaterjee, Ishwar Sankalp, Kolkata.

This organization works with homeless mentally ill people on the streets, instead of in an institution. They work together with the police to take care of emergency cases. They also run drop in centres, one of them being located in a police station. One disturbing paradox is that when homeless people start looking better because they receive care, the occurrence of rape increases. Night shelters are also offered by this organization. Dr. Debashish asked questions about the effectiveness of community psychiatry. Would it not be better to have the family take care of the patients instead of admitting them in institutions? These are questions without simple answers and it is hard to establish who is really correct.

Mukul Goswami, Ashadeep, Guwahati

Ashadeep works with homeless women with mental illness, with rehabilitation being an important focus. Rehabilitation is started after the acute symptoms are controlled. Goswami argued that it is crucial to empower the families as well, so that they are better equipped to handle caring for the patient. An outreach program has been started for psychiatric care. It was then discovered that there was a large population that doesn't have access to any care at all, whether it be psychiatric or medical, namely the homeless. In the initial phase, Ashadeep requested The Banyan for technical advice to start a transit care facility. It was found that not all ideas could be transferred from Tamil Nadu to Assam, because of the different context. Goswami maintained that the family is the ultimate resort for patients.

Shampa Sengupta, Sruti, Kolkata
Address: NGO response to homeless people with Mental illness

Sengupta made it clear that this presentation was not about telling success stories, but about raising questions. The organization focuses on the rights of people with disabilities. Disabled people often face abuse, both physical and sexual. Sometimes institutionalisation is the only option left. One of the questions raised was whether living with the family is really the answer, because in many cases the situation in the family is not conducive for healing and well-being. The organization has started a

helpline that people can call when they are in distress. They also help to arrange disability cards for homeless people, which is really hard, because they do not have an address. They are trying to start a dialogue with the government, because there are many laws that are discriminating against the persons with a mental illness.

Session 2

Presentations from day one

Dr. Shyalaja Devi, Ashwini, Nilgiris.
Presentation: Learnings from Ashwini- hidden burden of mental illness in rural community.

Dr. Shylaja presented on a rural mental health program in Gudulur Valley where about 20,000 tribal people live in poverty. Knowledge on mental health is very limited in the Valley. An increase in the number of suicides in this region in the 1990s made people aware of the issue of mental health. The organization noticed that a lot of patients that reported at the general hospital had a mental health problem and the lack of understanding of how to deal with mental illness was the main problem for the staff. This led them to develop a training program for the staff at the general hospital. 40 volunteers are trained every year on mental health and related issues. As a gynaecologist, Dr. Shylaja is now providing psychiatric treatment as well. The volunteers work with families and sensitize them towards mental health and mental illness. Early interventions with mental health issues among this target group showed good compliance and alleviation of symptoms. She pointed out two advantages of this community mental health program: A decentralized approach where people are trained by people on their own level and from their own community and 2. Access to mental health care in the community prevents mental health issues from increasing in intensity at a later stage. She ended the presentation with the statement: "If we are able to provide mental health care, anybody can do it."

Nimita Bhatt, Trust for Reaching the Unreached(TRU), Gujarat
Presentation : An endeavor to reach out to rural poor and unreached people in need by health care programs

TRU started in 2002 when the founders recognized the high rates of suicides in Panch Mahals (Gujarat). TRU's main motto is to create an affordable, rational and culturally suitable service for disadvantaged people. To achieve this goal the program consists of identification, referral, follow-up, family counseling and community based rehabilitation for people with mental illness. The main aims of TRU are to reach people who are normally not able to access treatment, to reduce the stigma of mental illness and increase awareness of this topic through campaigns, posters, booklets, plays, songs, discussions, as well as training of doctors and paramedics. Ms. Bhatt also reported that people in the area perceive their families as the source of help when facing difficult situations or mental health problems. TRU works closely with the District Mental Health Programme and certain components of the work are funded by the DMHP.

Dr. S Kamath, SCARF, Chennai.

Presentation: Long term needs of persons with mental illness

Dr. Kamath defined long term mental illness as a severe and persistent disability and also pointed out the influence of age, gender, social class etc. on severity of illness. The needs of patients are individually very different. She reinforced the importance of early identification & treatment and support and easy access to services. Besides the needs of the clients, she also talked about the family needs. Group homes can be one possible answer to meet those needs, as there is a demand for residential opportunities.

Harsh Mander, Special Commissioner to Supreme Court and member National Advisory Committee
Address: The Ashagram experience

Harsh Mander shared his personal experiences with homeless people exiled from society but not from hope. As a civil servant he was once surrounded by people with leprosy who were exiled from the society. The message from a homeless person in the gathering was: "I do not want your charity, I only want a chance". This gave Ashagram its foundation with the aim of creating a space where people can get a chance. Mander mentioned that there are several other possible formations of people living together other than families ("units"), referring to a post tsunami village. In the community, people without families had the chance to live together in units and get social support from each other. He strongly believes that humans can heal each other. He urged to create spaces for alternative institutions that are based on the ideas of compassion and love for community living- ensuring protection of unique choices without too many restrictions.

Discussions

- While discussing the possibility of returning an individual back into a dysfunctional environment when re-integrating with the family, it was suggested that the freedom of choice should rest with the people with mental illness. Reintegration is determined by the person and is one of the options instead of a compulsion.

- It was mentioned that 80% of the children, who ran away from their families and were brought back to the families, do not stay at home for long. A solution to this tried out in Delhi was to offer multiple options to a family. Many opined that community living is better because when the person goes back to his/her family, the family suffers. There is no easy solution to this problem.

- Medical care only heals the body; while in addition it is also important to generate an environment where a person can develop his/her own strength to live on his/her own.

- About deciding on behalf of the person with a mental illness, it was suggested that it is the last resort in an acute phase of crisis. It is always important to empower a person after treatment. Decision-making is only taken away for decisions regarding the therapy. It is important to show love and care to a patient and not only medication. Force should be avoided, not only regarding medicine-intake but also with regard to options for rehabilitation. The dilemma between helping and forcing remains. One conclusion could be that every person is different and so every person has to be treated different. Another person pointed out that we should learn from the patients.

- Commenting on the relationship between patients and psychiatrists, some members of the group opined that very often a psychiatrist decides what happens and not the patient. Some psychiatrists have stereotypes such as "the best place for a woman is with her husband", which can be harmful. Often there is no attention for the causes of illness, but only for the symptoms.

- The speaker began with the metaphor of several blind people who all feel a different part of an elephant and therefore would describe it as completely different thing. The metaphor was compared to the different stakeholders in the mental health sector who see only details of the 'elephant'- mental health. An important point was that a change in the system could be reached by bringing violations of human rights to the attention of High and Supreme courts. One critical point is: who makes decisions? It is important to work on the biases and stereotypes that prevail in dealing with people with mental illness. Earlier there were no major concerns about the autonomy of people with mental illness, but now this attitude is changing and there is a shift towards autonomy and empowerment of a person with mental illness.

Dr. Alok Sarin, Sitaram Bhartia Institute of mental health, New Delhi.
Presentation: The need for a person centric approach in institutionalized care

Summary: The presentation started with the de-institutionalisation movement in the USA, where mental hospitals were left abandoned. In India there have been similar positive ideas on treatment early on (e.g. in 1934, where a patient-centric approach was advocated by some). However, at present, there is not much left of this approach in current mental hospitals, which are often disgraceful places where patients are locked up and some staff violate human rights. Social workers and psychologists are not part of the treatment team very often. This attitude is in need of a drastic change. The following questions were raised: Where did the individual get lost? What are the alternatives? Community treatment could be one alternative.

Suzette Titus, Bapu Trust, Mumbai.
Address: User- survivor's perspective

Suzette Titus shared her experience of violations by mental health professionals, where injections were forcibly given to her, after which she was brought unconscious to the hospital. She felt completely isolated in the hospital and was not allowed to call anyone. After returning to her family, her husband told the doctor she was hallucinating, which in her opinion was not true. Her view is that psychiatrists should consider what side effects feel like. She questioned psychological tests, because there is no proper introduction to the tests. She also questioned the practice of her psychiatrist, who only spoke to her husband, instead of to her directly. She stressed on the importance of realising how people are treated and considering the consequences of forced treatment, which should never occur in her opinion.

3rd July 2010

Theme: Need for a multi-faceted approach to the needs of homeless persons with mental illness (Continued)

Prof. Dr. S. Chaudhary, RINPAS, Ranchi
Presentation: Working with homeless persons with mental illness - the RINPAS experience

The Government-run Ranchi Institute of Neuro-Psychiatry and Allied Sciences provides in-patient facilities, but also focuses on outreach to villages and prisoners. Apart from homeless people directed by Police and Judiciary, NGOs and individuals are also involved. The primary objectives are to restore patients to their home on a priority basis and to provide rehabilitation/occupational therapy. Visits to jails, destitute and old age homes to provide psychiatric care are part of the outreach program. Currently, RINPAS is working on enhancing the follow-up for patients who are re-integrated with families.

Dr. Lata Jacob, Medico-Pastoral Association, Bangalore
Presentation: Therapeutic communities for persons with mental illness

A paid therapeutic community was started as an outreach program organized by a church with non-professionals. Participatory approach was implemented in the method involving active participation from clients and the community. In a study done by the NGO, the majority of the clients were men, 49% were in 20-30 years age group, largely Kannada speaking, mostly Hindus, more than 50% with schizophrenia. Outcomes from the therapy were successful interventions – 53% were reintegrated with their families, others were living independently or have been shifted to other mental health hospitals, 12% returned. The methods of the therapeutic community can be applied in half –way homes, families, day care centers, long term stay homes etc. Some of the residents came back because they faced difficulties of a socio-cultural nature, adjusting into society, lack of job opportunities and isolation. In terms of methods of therapy, the organization focuses on communication in individual, group, and family settings; art therapy, sports and productive therapy such as job training. The process of the therapy, personal information and individual interest are weighted to know what the patients really want to achieve in life.

Tarique Mohd, Koshish, Mumbai / New Delhi

Presentation: Homeless mentally ill in Beggars home in Mumbai

Koshish was a response to the needs of people locked up in beggars homes under the Beggary Prevention Act. According to the law, beggars are defined as those people wandering in public spaces, leading to sentences of 1-10 years. It completely ignored that some people might be disabled or mentally challenged. Thus, harassment by police often happens. Mentally ill homeless people are often categorized as beggars in order for the police to arrest them. The conditions in which mentally ill women in the 'mental barracks' live are pathetic. The organization has been working with those beggars who are mentally ill by cooperating with the government and striving to bring mental health care into the beggar's homes. To curb violence against people in jails, Koshish organized socializing activities like sports jointly for inmates and jailors, which was a successful programme. Koshish has strived to provide people with severe mental illness with mental health care, by either moving them to hospitals, providing medical care in the beggar's home, or providing a non-regimental space within the beggar's home. It is important to work together with the Government, because the possibility of reaching large numbers is unparalled.

Dr. K. Seker, Department of Social Work, NIMHANS, Bangalore.
Address: Rehabilitation work done by NIMHANS for homeless mentally ill

The plight of men in relief and rehabilitation center needs attention, similar to that of women and children living in social welfare institutions. In a study, 40-45% of the men in an institution in a sample have mental illness. They are rounded up and thrown into jails during inspections and visits by dignitaries. Dr. Seker has experienced how women and children living in a shelter are subjected to sexual abuse from residents of another center. A scientific study revealed that most showed signs of suicidal tendencies and self-harm and persistent depression. NIMHANS provides psycho–social interventions with a focus on follow up and continuation of treatment. He presented different forms of therapies, and strategies to treat and support the clients and families. The major questions faced in the program are the management of crisis situations, particularly in suicide attempts by people living at the margins.

Ratnaboli Ray, Anjali, Kolkata.
Presentation: Mental Health Rights-Experiences of working in a mental hospital in Kolkata

There is a need to be conscious about the use of words and about the politics of language for mental health and illness. Another observation is that there has been no discourse on providing psycho – social interventions to women. In this, issues of sexuality should also be addressed. A question arises whether users and caregivers can be seen as homogeneous entities respectively, since the circumstances within those groups can vary widely.

We heard individual voices, but what about the collective voices of the people living in institutions? The organization Anjali is a rights-based organization that brought up questions of forcible medication for mentally ill patients even if they refused to take them. A documentary film showcased the plight of the forgotten women in mental health institutions. Ratnaboli Ray then presented the community project 'Jan Manash' on livelihood issues, working with the municipality and 'Lattu' on leadership in Mental health amongst young people. Another docu-drama showed the life of a homeless mentally ill woman transformed after a positive take from a community.

Dr, Gayathri Balagopal, BALM, Chennai.
Presentation: long term needs of the people with mental illness

Dr. Gayathri Balagopal presented the experience of The Banyan in dealing with people who need long term care. Gayathri presented the diagnostic categories of the residents, age groups, geographical origin of the clients, annual admission and discharge, reasons for readmission. A study of 30 reintegrated clients was conducted to assess the socio-demographic profile, level of disability and health seeking behaviour. The study suggested that since the largest age group is those between 30-59 years old, it is likely that their caregivers are aged. 70% of clients are single women, are dependent on their families, functionally illiterate and not skilled. Deprivation may lead these women into more vulnerable life situations. 60 % have reported a relapse and 25% showed severe disability. Follow up treatment was accessed by around 30%, mostly at government services. Carers are generally women, andthey face challenges with regard to allocation of family resource; they lose their wages and employment and have to distribute their time amongst other family members. The population is ageing in TN which means that a lot of carers have diminished resources and might have health problems themselves. Poor entitlements lead to low levels of follow up, disruption in family relations, higher disabling factors, and increased vulnerability to homelessness. These issues raise more questions to which we have to find solutions.

Joseph Lukose, The Banyan, Chennai
Case presentation
Joseph presented the case of a resident of The Banyan who came to The Banyan because she was homeless. After treatment, she was highly functional for a few years, after which re-integration with the family was tried. However, the family rejected her and she relapsed. She now has to find a meaningful fullfillment of her life, either living independently or in a group home.

Porkodi PL, The Banyan, Chennai
Presentation: The Banyan's community living project
Community living is a non-restrictive, long term facility for women who were homeless and are either chronically ill or have a low chance of reintegration with their families. The environment is non- inhibiting, creating livelihood options and equipping the residents towards self reliance as a group and asindividuals (in many

cases). Community living was modelled as a long term facility, where the women can make their home, while The Banyan provides a safe environment. The larger aim is to integrate as many women as possible into the larger community of Kovalam where 2 groups of women have already rented group homes and live independently.

Summary by Dr. Alok Sarin
This presentation highlighted the necessity of verbal communication and relationships within communities, while questioning the numbers of people within the community actively working for people with mental illness. The main challenges are cultural contexts, since many clients hail from various parts of the country. It is important to understand family dynamics and backgrounds of clients. Language barriers are an equally complicated issue, especially since many interventions are based on the ability of the client and the therapist to communicate in a common language.

Session 2
Theme: Mental Health Act, Persons with Disabilities Act & National Trust Act

Dr. Anirudh Kala, North India Psychiatry Center, Ludhiana
Presentation: Mental Health legislations and Policies

The presentation tracked the history of the Mental Health Act in India and the sub continent from the colonial era in 1912 when the Indian Lunacy Act was instituted. Independent India formulated a MH Act forty year later. Law can encourage policy but it scope is limited. One of the objectives of the law is to function as a mandating document for mental health, yet there should realistically be a small gap between the law and the actual possibility of providing services on the ground. This is especially important considering the current situation of lack of resources, facilities and human resources in mental health care in India. The presentation highlighted a primary need: involuntary admission has to be rights-based for unprotected and protected patients; yet, a question of how patients with severe mental illness should be treated in a rights-based approach with regard to involuntary admission was brought up. Another point which was emphasized was the importance of a community-based approach. However, a question in the process of reviewing the laws regarding resources is: Do we have resources to implement the laws? In India, social assets - such as family and community - are strong assets, which should be taken into account and used in a positive context.

Dr. Nirmala Srinivasan, ACMI (Presented by Dr. Anirudh Kala)
Presentation: Challenges in identifying "safeguards" in Article 12 of UNCRPD

Summary: 10 out of 29 Articles of the UNCRPD discuss hospitalization, custody and other miscellaneous items. Human rights were briefly mentioned; yet it was not focused upon. Necessary features of the UNCRPD: 1) to be community and socially

based 2) to establish clear differences between mental disability and illness 3) to have clarity on the roles and relationships between psychiatrists and patients 4) to be clear on licensing and registration of clinical establishments and rehab centers 5) to emphasise on women's disability 6) to ensure that children below the age of 12 years are not sent to mental hospitals 7) to ensure that female attendants are available if mentally ill children are admitted.

Amrit Bakhshy, Caregiver and member Schizophrenia Awareness Association (SAA), Pune.
Address: Caregivers perspectives on UNCRPD

Amrit Bakhshy added his personal experience to the paper already circulated about the UNCRPD. He started providing support to other caregivers on his own initiative. He later attended workshops and got introduced to UNCRPD. From there he focused on the UNCRPD and summarised its provisions and amendments from the perspective of a care giver and on incorporation of the UNCRPD in Indian laws. If one looks at the Mental Health Act of 1987, 98 sections deal with admission procedures and hospitalisation and there is one section on Human Rights. Certain Indian Psychiatric Society documents demand a new Act with extra emphasis on the role of the community; It is important to have a clear distinction between people with mental illness and people with a learning disability. In all dealings, the client should be informed.

Bhargavi Davar, Bapu Trust, Pune.

Presentation: How to integrate Mental Health Act and Disabilities Act

Bhargavi Davar raised the question of whether a separate mental health act is necessary at all, or whether the Persons with Disabilities Act, a National Trust Act and if needed, other laws can deal with issues related to mental illness and related legalities. She also raised the important issue of self-advocacy by people living with mental illness – 'When will the elephant speak?'. She also pointed out that recovering from mental illness could be possible without resorting to medication, but by other forms of healing.

Vaishnavi Jayakumar, Founder, The Banyan, Chennai

Presentation: Persons with Disabilities Act – How to integrate mental illness

The presentation centered around one question: Is mental illness a disability or disease? One of the answers was that mental illness can be both, since mental illness has biological impacts which can result in reduced capacities/abilities. Due to social and political dynamics, persons with a disability are often defined as being those who cannot be independent and sustainable in terms of their lacking social skills and economic productivity. The presentation exposed structures in laws which would

create stereotypes. The question is important, because being disabled is linked to entitlements from the government. If people with a mental illness are disabled, they are eligible to receive government support or the same support as disabled people are receiving. While people with mental illness are included in the Persons with Disabilities Act, the entitlements for people with a mental illness are not so accepted and hence people do not receive any disability allowance. This grey area has to be addressed in the law and define those people who need to receive essential services.

Poonam Natarajan, Chairperson, National Trust, New Delhi.
Presentation: National Trust Act-how to integrate mental illness?

In 1999, local level committees at the district and panchayat level were taken into account in the National Trust Act.
Regarding the amendments to the 2010 National Trust Act, the followings are important areas to consider:

1. legal capacity of people with a disability

2. Identifying the groups and kinds of disabilities that are in need of support.

One of the challenges is how to develop support networks at a local level. Consultations with people with disabilities at an individual level, with family members and with the community are required. A support network can be built with those whom
somebody trusts the most; yet, the process of structuring network support in the community is a challenging process. Another challenge would be identification of disability verses mental illness: 'Is mental illness a disability?' which was discussed in the previous presentation. If mental illness is considered to be a disability, the advocacy for issues such as the legal capacity of disability support by National Trust Act has to be addressed, to build support networks.

Dr. Achal Bhagat, Saarthak, New Delhi.
Presentation: The use of PILs in mental health advocacy

The presentation started with a question: 'What is the "one thing" that you would go to court for?' The answers ranged from freedom, justice, equality, rights, non-discrimination, exploitation and mal-treatment. The UNCRPD gives people the possibility to contest the infringement of these issues, while the Mental Health Act takes away these human rights from people. PILs exist so laws can be tested, but the Mental Health Act does not include any of these features, so the judiciary has to be the protector of the rights of the people and not the protector of the law. Some change in the MH sector has been brought about through judicial activism. Laws have to be written in the framework of human rights to begin with. Interpretation of laws within in the human rights perspectives is necessary, but not in isolation.

Panel discussion

- In caring for people with mental illness, love and compassion play a major role. It is equally important to consider the opinion of the client in deciding on a certain treatment.

- For those who are willing to return home, family members do not always accept them. So empowering the family is equally important in rehabilitation. However, the question of what a home is, remains.

- Integration of mental health into general health care is one of the biggest challenges.

- A dilemma will remain whether to favour the rights of a person with mental illness to refuse treatment, or to urge for treatment of a person who might not be able to decide for himself or herself at the moment of severe illness. In the case of severe mental illness, medication is often necessary for family integration or to progress towards a state of wellbeing. An ideal balance will be to focus on choice when the person is well enough to make decisions.

- Models of care and approach in hospitals, NGOs, and community settings can showcase cases of abuse. Monitoring and evaluating by third parties would be necessary. Meanwhile public awareness towards mental illness can reduce confusion and stigma toward mental illness. The importance of the role of communities was emphasized; yet, how to restore those whose community does not accept them back could be a major challenge.

- With regards to legal acts, the major challenges are territoriality of laws, power of legal capacity and the words used to describe certain phenomenon (such as mental health). Laws have to empower each stakeholder who is part of the healing and care of mental illness: i.e., psychiatrists, caregivers, clients, etc., in order to work together like an orchestra. Who the conductor will be may be questionable; however, based upon what clients want and need, conductors can be altered: NGOs, psychiatrists, faith healers, caregivers, or the client himself or herself.

- Degrees of support was brought up for discussion. Support might turn into control which causes the loss of decision-making possibilities in people with mental illness. There is a fine line between support and control. Therefore, it is important that one focuses on the paradigm of recovery and wellbeing and is led in all interventions by those goals.

- A complex situation requires complexity in approaches and solutions. Mental illness is so complex that humans have been debating it for a long time. Yet, one of the solutions toward understanding this complexity is to hear the voices of each stakeholder and to be part of the 'orchestra'.

- What happens to people who need acute care if there is no mental hospital?

- Even if laws and policies prescribed NO mental health hospitals, many other kinds of authorities would be created; in fact, they were created in Italy - such as home care transit centers, etc. We need to look at more alternative ways to support people with mental illness, while laws should create an environment where alternative methods of healing are possible. For instance, in the USA, admission in a mental health facility is not always forced. Instead, many NGOs or community-based institutions have been developed. While most advocate for integration into general hospitals, there is a need for emergency services and tertiary care many times. Law and activists should work towards improving those aspects of care and treatment and safeguard the rights of clients when this option is sought.

- Would deinstitutionalization cause mental hospitals to lose assets, such as real estate?

- How can family based organisations be sustainable? When there is sufficient support, people are often able to work and be independent after rehabilitation. However, the challenge is when care givers become old. Who will take care then? What happens if family or care givers become incapable with age? One of the answers given was that friends, relatives, and neighbours might be part of a community to take care the patients. Informal networks might play a role in ensuring sustainability. However, a question arises when decisions have to be made with regard to treatment methods. How much responsibility can friends, relatives and neighbours take then?

- A recommendation was made to institute a mental health commission at the national level.

- What services should be available for care givers of people with severe mental illness, whose communities discriminate against them; who live far away from care facilities; who are so poor that they cannot afford the medicines and who do not receive any support from the government?

- It could be considered that existing insurance schemes of the National Trust include people with mental illness as well.

- There should be a strong focus on prevention of mental illness.

- NGOs have to play the role of being watch dogs both in institutions, as well as in the process of rehabilitation. It is equally important that NGOs are involved in identification of high-risk families and individuals and target those families for interventions.