

Editorial

There is little data and information on “mental health economics”, even as the XIth Five Year Plan is being discussed. A lot of money is allocated under this Plan, according to all sources, reliable and unreliable. Mental health people influencing the XIth Five Year Plan have been advocating for budgets to be provided for across sectors, including education, disability, etc. with the argument that mental health is not just a health subject. The Center / State debate also is ongoing. Sector wise studies on cost effectiveness have been undertaken, e.g. in Gujarat. Sooner or later, we will develop a management perspective to organizing and distributing the increasing money flow into the sector.

Will the following topics be included in “mental health economics”, which are the hidden costs of using services in mental health:

- private money being spent on irrational, unwanted, dangerous and hazardous treatments;
- the cost of psychiatric diagnosis and innumerable “wrongful confinements”;
- the cost of creativity, learning and productivity lost to people due to long term or repeated institutionalization;
- the cost of receiving a false diagnosis and wrong treatments based on substandard and life destroying stereotypes about being a woman, being a disabled person, being a homosexual...;
- the costs of receiving false certifications of “mental illness”;
- the social and economic cost of carrying the label of a “chronic”, “difficult” or “irrecoverable” patient;
- the costs of “drug resistant treatments”;
- the cost of “managing” a “violent” patient; the cost of the tremendous loss of life energy in solitary confinement cells;
- the cumulative loss of self worth of users / survivors by being consistently called “incapable” in various contexts;
- the cost of the loss of abilities caused by deskilling within the mental health system, particularly institutions;
- and the cost of disability caused by poor quality treatments, particularly ECT.

In such economics studies, how about also including the cost of injury and harm caused by unethical research practices? And unethical clinical practices, such as the cost of being given 208 ECTs?

Mental health treatments come with various “hidden” costs if looked at from a management perspective. These costs are life costs for users and survivors of psychiatry.

Welcome to another issue of aaina.

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Aaina is a mental health advocacy newsletter.

Aaina is an opinion-making and opinion-leading newsletter, with a consistent message of user empowerment, good practice, policy, legal and social reform in the mental health care sector in India.

Aaina covers issues in community mental health, the role of NGOs in mental health, self-help and healing, the use of non-medical alternatives in mental health, human rights issues in mental health, institutional reform, ethical dilemmas, policy discussions, and the mental health needs of special groups (young people, women, the poor, sexual minorities, persons with a disability, etc.).

Aaina covers themes related to disability caused by psychiatric drug use, and long term institutionalization. It has a great interest in how much money pharma companies are making by pushing hazardous drugs onto poorly informed communities.

Aaina provides a forum for users to express their problems and dialogues with the mental health service system, and their demands for change. It also addresses issues of social living for persons with a psychiatric disability, stigma, discrimination and deprivation of the right to life and liberty, especially of the poor and the homeless.

If you wish to make a donation to *aaina*, please make a DD or a cheque in favour of "Bapu Trust for Research on Mind & Discourse, Pune" and post it to our mailing address.

Reflections

Inaugurating the post-CRPD era: Promises and pitfalls for the mental health sector

An interview with Dr Amita Dhanda¹, Hyderabad

This aaina interview was done just after the Convention on the Rights of Persons with Disabilities was accepted at the Eighth Ad Hoc Committee Meeting, in New York. The CRPD was adopted by the UN on December 13th 2006. At the time of bringing out this issue of aaina, India has signed the Convention on March 30th, taking pride in being one of the early signatories. The Cabinet has approved the ratification of the Convention.



Dr. Amita Danda

1. What were your immediate thoughts and feelings at the UN when the convention was finalised at the 8th AHC?

Dr Amita: As a teacher of law, I have often made the statement that there is an intimate relationship between international law and international politics. However, I did not really understand the truth of this statement till I was witness to the process by which international law is made. In the final stages, political considerations and country alignments dictated the

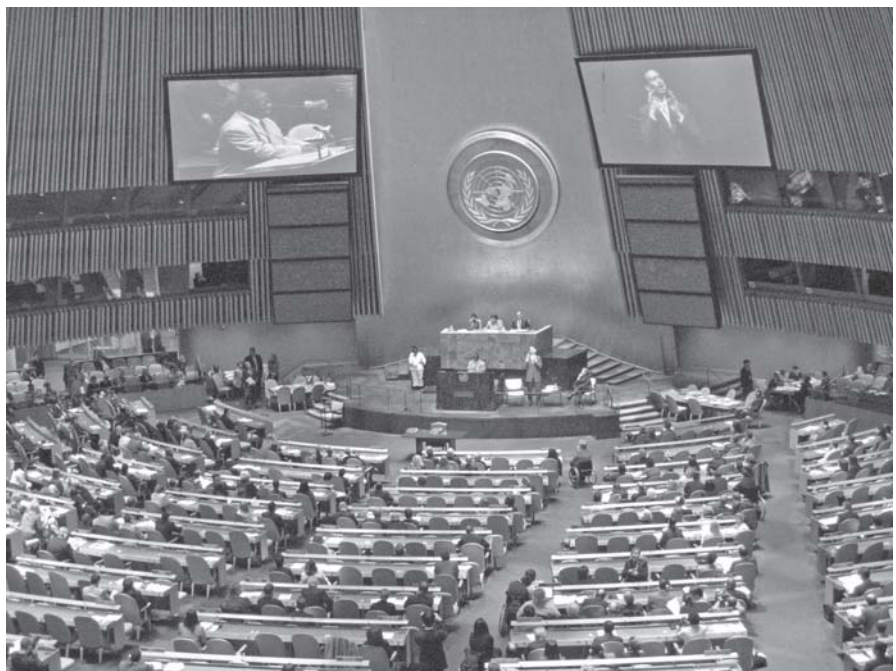
consensus which is so necessary for the making of international law.

However, this Convention was not just an agreement between State Parties. Civil society was a significant third player and it was the emotions and excitement of this third player, which was the mood definer. This third player had a role in not just according approval, but also voicing disapproval. Thus, when a footnote attempting to dilute the substantive content of Article 12² was included, not only did the International Disability Caucus (IDC) voice its own discontent, it also persuaded a number of State Parties to question this inclusion and to keep the matter of the footnote open. It is this unrelenting attitude of the IDC which has got the Convention text to be now finalized without the footnote.

2. What was the mahoul there like when the draft was finalised?

A: It was a festive atmosphere with unceasing cheering and felicitations and hugs were being exchanged between people who both knew and did not know each other. The footnote in article 12 was a bit of dampener but the unity and solidarity of the IDC did not fracture at that crucial moment. Hence, statements were made to both condemn the footnote and celebrate the Convention.

3. What are the implications of having a disabled people's convention for India? There is the view that the UN convention is very far away, and this cannot change anything at the ground level. Even responsible social change agents are saying this.



A: The gap between the law and its implementation is not unique to international law. Such a gap may also be found in national legislation, but that does not cause us to say that let us not change the law to reflect what we require and demand from the State. It is recognised that just the incorporation of appropriate norms in the law do not change the ground level situation, but the incorporation provides leverage to civil society to seek change.

Similarly, international law provides a normative leverage for nation level change. It is a change which has to be wrought by the persons on the ground, but the Convention is a useful aid in the struggle. The Convention is not just a normative assistance but also will help in obtaining implementation. This assistance would be provided both at the national and international level. And persons with disabilities have been accorded an integral role in both processes.

Disabled Peoples' Organisations [DPOs] can obtain international support in the struggle for their rights as States would be required to report to the Treaty Monitoring Body. In substance every mechanism is as powerful or weak as we make it. Just the adoption of the Convention will not change ground-level situations, but the Convention will provide a fillip to the process of change.

4. What are the next steps for India, as well as for civil society organisations, to take, now that the convention will soon be adopted?

A: The first steps are for us to start lobbying for the early signing and ratification of the Convention by India. This is because till India signs and ratifies it is not bound by the Convention. And till we are bound by the Convention, we cannot use the Convention to alter the situation on the ground.

¹Dr Amita Dhanda [Bapu Trust / NALSAR, Hyderabad] actively participated in the AHC meetings on the CRPD, through the WNUSP (www.wnusp.net). Other than overall advocacy on the CRPD, she specialized on Article 12, 'Right to Legal Capacity'.

²Article 12 on 'Right to Legal Capacity': On the last day, in the last hour of the 8th AHC, the chairperson, Mr MacKay (NZ) allowed a controversial footnote to come into the CRPD. The footnote amplified on the meaning of legal capacity as not inclusive of the 'right to act' in Chinese, Russian and Arabic. The IDC strongly advocated against this footnote and it was eventually removed.

We will need to equip ourselves in two ways to undertake this lobbying effort. Firstly, we will need to acquire a basic familiarity with the Convention and secondly, we would need to demonstrate that national disability law will be more firmly grounded in a rights based jurisprudence once India becomes a signatory to the Convention.

5. How does the convention influence the mental health sector? What kind of changes will you work towards, both immediate and long term?

A: What I will like to state here is that the Convention makes a paradigm shift and possibly this shift could only have first occurred in International law. This is because in the making of international law, there was a documentation of the discrimination faced by persons with disability across nations. The physical presence of a community of persons with disability across countries effectively challenged social stereotypes on disability. To

explain further, ordinarily the crusade to obtain a rights consonant construction of legal capacity may have been seen as the concern of persons with psychosocial and intellectual disabilities. However, in the making of the Convention all persons with disabilities interacted with each other and consequently understood how all persons with disabilities were denied legal capacity: If the Convention did not recognise the full legal capacity of all persons with disabilities, then the denial will also extend to all and will not stay confined to any one individual or group. The negotiation for the Convention and the resultant text has integrated persons with intellectual and psychosocial disabilities with the disability community and this foregrounding of the social determinants of identification in preference to the medical identifiers is the most major change the Convention has wrought in the mental health sector.

6. What kind of challenges do you expect to face in the mental health sector to the UN convention work?

A: The Convention has foundationally challenged the “incompetent dangerous” stereotype which subsists across countries and cultures for persons with psychosocial disability. It has put in place an empowering, socially integrated image. For me, the challenge is to work at reformulating these national policies and laws in accord with this new paradigm. This would require not just that the dismantling of the discriminatory disqualifying regime which subsists against persons with psychosocial disability, but also the creation of appropriate support networks for those who wish to use them.

Dr Amita Dhanda may be contacted at amitadhanda@gmail.com



Speaking our minds »

Ass and Saints

P.Y. Balan

They said I was mad
I said they were mad
Damn them
They outnumbered me

- Nathaniel Lee (1655 – 1692)

January 15th or 16th of 1986 – The first time they took me to the doctor. I had not slept at all the night before, or for almost a week before that. I was getting scared of all kinds of sights and sounds. As I lay on the bed, Amma came and touched my forehead and remarked how cold it was.

On the way to the doctor, I saw that the shops and houses on both sides of the road had been

decorated with palm fronts. My fear increased. I remembered speaking out against the RSS. I was sure they were coming to get me. When we passed the house where Shivakumar Sir lived, I asked them to stop. When I saw Sir, I started crying. He tried to console me. My family asked him if he knew any good psychiatrists. He mentioned a psychiatrist Ramachandran in Vellayambalam.

Shivakumar Sir and I had not been getting along very well. After we left his house, I started feeling dizzy with anxiety. I was sure that he would call the psychiatrist and say horrid things about me.

When we reached the psychiatrist's house, I got out and sat on a chair on the veranda. A woman came out and said that the doctor would come in an hour. I peeped inside the house through the window. Pictures of Hindu gods were on the walls. This made me think that the doctor was a RSS member and I tried to persuade my family to take me away. They didn't relent.

I started hearing sounds of drums. People were communicating the message of my capture. Slowly the drums faded and there were sounds of people washing clothes. Were we near an area where Dhobis washed clothes? The feeling of being controlled by

other people was increasing. After a while, the doctor came. He led me inside and examined me, checked my blood pressure. I looked at his eyes; they blinked relentlessly. I was convinced that I was now fully under the control of this RSS doctor. He asked me some questions and prescribed some medicines.

We got back home. I didn't take the medicines. I said to my mother that those medicines would kill me. She tried to convince me that they would make me alright. Later, I took them and lay there, waiting to be dead. After a few hours, I was neither dead nor asleep.

In 1981, I registered for B.A. at an evening college in Thiruvananthapuram. I became actively involved with the SFI, and made lots of friends. Two years later, Narendra Prasad Sir, a well-known literary critic, came to teach us. I was very interested in theatre and attended the rehearsal camps that he organised through his drama troupe, Natyagraham. I was an Eezhava, born in a seaside village, a Latin Catholic by religion. Ideologically I was a communist. Prasad Sir was an existentialist and a researcher into traditions. His effort was to combine ritualistic arts with elite art forms like Kathakali and Koodiyattam in order to develop a new performance language. I found it difficult to agree with his particular mode of reconciling existentialism with an ideology of upper caste Hinduism. Slowly, I started pulling away from him.

I got a third class degree in Malayalam, after which I started teaching in tutorial colleges. A year later, I found a job with an organisation working among fishing communities. The salary was minimal – it was the work itself that was more fulfilling. Prasad Sir and his disciples had

started noticing my dissent. I was in a vulnerable position after a failed love affair and dilemmas of a sexual nature. They used this vulnerability to get back at me. I found myself losing my composure.

After the treatment, I found it difficult to get back into my writing. At this time my friend Manoj said to me: "You should start keeping a diary. It will help if you write down your feelings of sadness, anxiety and fear." The following are some entries from the diary I kept during that period.

There was a property dispute in the family. Police stations, courts, arguments, confrontations... Even under the protection of our stepfather, there wasn't enough to eat or to wear. Meanwhile China and India were at war. The elders sat on the veranda, enjoying stories of India's advances. Amma narrated stories about nights when the oil lamps were not lit, about the courage of soldiers back from battle fields. In the morning, newspapers reported that someone called E.M.S was arrested and put in jail. At school, teachers talked excitedly about patriotism. My friend Chandrababu sang a song urging us to "wield our guns and go to Ladak." There was an added fervour in our rendition of the national anthem before we dispersed for the day.

For a whole month, I swallowed pills morning, noon and night. No thoughts, no dreams, no sightings of sun or moon. Only drowsiness and sleep. Friends came to visit. I remember Manoj, Sam, Rajan, and Aji. In my leftover memories, I was sitting up on my bed in the children's ward of the Thiruvananthapuram General Hospital. Eating milk and bread after a bout of

serious illness. The child on the next bed was dead. I watched in a daze as they took him away, wrapped in cloth. I couldn't lie on the bed after that. Amma took me home as soon as she could.

The annual meeting of the rationalist society. We made a small collection and organised a dinner with chicken curry for the invited speakers. I was the president of the local rationalist group. A party was organised in the house of an old rationalist. My colleagues and I were not invited.

It was a Good Friday in 1978. There would be a procession carrying the holy body of Christ on Good Fridays. An elegiac procession with the disturbing smell of frankincense. After the procession, the body of Christ would be laid in the church for public viewing. People kneeled and prayed, touching His feet. Forgetting that I was the president of the rationalist group, I also bowed at the feet. And when I came out of the church, there was a line of friends, waiting to make fun of me. Need there be any more proof of my idiocy? Another item on the long list of my blunders...

One of the old buildings of my school, Leo XIII, was being demolished, to be replaced by a new one. Some of the classes were provisionally moved to the big church. I was in Class Four then. I was afraid to look at the Altar with its wondrous decorative pictures. In the evening, dead bodies were brought to be buried in the cemetery next door. A procession of dead bodies. Thoughts of death and dying were abundant in those days. Even a pinprick generated thoughts of death – was it really a pinprick... or a snake bite?

I chose Malayalam as my main subject for B.A. at the evening college. During the day I worked at the *Theerasabdam* magazine, and used the salary of Rs 200 for college expenses. In the second year, I joined the day college. I did not do well in the first year exams – exams were always a big hurdle. It was around this time that dilemmas about sex started surfacing. I had never had a sexual encounter. Would I be able to have sexual relations with a woman? Anxiety about sex started gripping me. I could not concentrate on my studies and started getting forgetful.

In the second year of B.A. I started a friendship with the poet Ayyappan. I had started drinking soon after my Pre-Degree days. Now with Ayyappan, evenings were festivals of drunkenness. A certain sadness was also growing – almost like a disease.

The third year of B.A. My drinking had reached its zenith. I was even borrowing money in order to get drunk. Literary discussions, critical arguments – all in an alcoholic stupor. I was developing into a Bohemian character. Around this time, I expressed my romantic interest to one of my classmates, a Christian girl. She asked me why I had waited until the end of the final year of college to show any interest. I tried to make her understand that I had always liked her but felt I could express it only now. Actually I didn't even approach her directly – another friend acted as a faithful messenger, delivering my letters to her. Anyway, the girl of my dreams declined my advances.

It was difficult to find the words to continue writing about it.

Suddenly I was ascending a mountain of anger. When I looked down from its peak, nothing was visible. I felt trapped. Then I saw a few moths flying around in the room.

The descent from anger.

I lashed out at a moth. The exhilaration of its destruction was electric. Arms throbbed with a new strength of courage. One by one, I killed those moths, and lay down, steeped in blissfulness.

Now the room was empty of insects. Not even a chattering lizard.

I got tired searching for insects to kill. If I had a microscope I could start destroying bacteria and virus, I thought. The realisation that my own body housed thousands of bacteria and virus made me happy. I could destroy them and keep this loneliness at bay. But I realised that killing them all, one by one, would be difficult. There was only one way out – killing myself.

In the height of my drunkenness, I declared to my friends that I would commit suicide if the girl I loved wouldn't have me. I'm not sure if she heard this – if she did, it must have scared her! I tried talking to her again. She said that she was a Syrian Catholic and religion would be an issue between us.

She saw me as a Hindu. I explained that although I was born in the Eezhava caste, I was a Latin Catholic by conversion. I said I would have no problems in being a Syrian Catholic. I could see her wavering. After a while she said – no, but you'll always have a special place in my heart.

The fear of losing her haunted me everywhere. Then it was summer

and almost the end of college. Mahogany trees were shedding leaves. We went on a trip to Ponnudi. Most of our classmates knew about our little love story. People started noticing my alternating silences and garrulity on the trip. I had bought a parry sweet for her. I gave it to her and she refused it in front of all the girls. I was embarrassed. By evening I was immersed in a deep depression – even the soft warmth of the setting sun was unbearable. Sitting at the back of the bus, she didn't seem concerned at all.

After everyone left, I went to the arrack shop. Waded through the darkness with the aid of alcohol. I was beginning to enjoy crawling through deserted roads, where no one could hear me. There was no compulsion to make meaning.

P. Y. Balan is a teacher and a poet. He has published an anthology of poems titled Ass and Saints. These diary excerpts were first published in their original Malayalam version in the magazine Pachakuthira. Translated into English by Jayasree Kalathil.



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'Jan Manasik Arogya Abhiyan' is a one year old people's mental health campaign, working for human rights in the state of Maharashtra. The purpose of the campaign is to mobilize development and human rights activists to bring about changes in the mental health sector in Maharashtra, and to act as a pressure group upon local authorities organizing mental health care. In the last year, many meetings and discussion forums were conducted, culminating in the preparation of a Charter of Demands for Maharashtra. This was widely circulated and discussed, before being presented to the state Health Department, at the State Jan Swasthya Abhiyan Assembly meeting, held in February in Mumbai.

Charter of Demands

WHO defines mental health as, "the capacity of the individual, group and the environment to interact with one another in ways that promote subjective well being, the optimal development and the use of mental abilities (cognitive, affective and relational), the achievement of individual and collective goals consistent with justice and the attainment and preservation of conditions of fundamental equality". This definition is all encompassing, putting mental health at the basis of all social, political and economic dimensions of life.

Mental health is a cross cutting theme. Mental health influences all the areas of life, including one's state of health. The Right to Mental Health is at the core of the right to health. The well being of people includes overall spiritual, emotional as well as physical health. Wherever there is a health problem, we are equally likely to find a mental health program. For example, malnutrition, especially anaemia, leads to chronic psychological problems. Also, a mental health problem can cause further physical ill health.

Mental health of people is determined by social determinants. People living in vulnerable or traumatic situations are more likely to face mental health problems, particularly women and the poor. Violence, conflict, discrimination, displacement, disasters, social inequality and

other such environmental and structural conditions can cause mental health problems. Poor, neglectful and abusive health care environments, particularly in the context of women's health care, reproductive and maternal health care, and children's health care, breeds poor mental health. Other causal factors for poor mental health are: governance sanctioning communal violence, setting up inequitable development processes, gross insensitivity to the human consequences of technological and commercial invasions into the livelihoods and habitats of indigenous peoples and local populations, bio-medical dominance, and man made disasters. The solution to such structural and political problems is not a psychiatric pill. The root cause of social inequality, and the systems that uphold it, must be challenged by providing social justice. Providing social justice is integral to mental health. Mental health advocacy has to address social justice aspects also.

It is usual to include "mental health" as one special type of health issue. Yet, mental health is a separate agenda by itself. Just as health covers umpteen problems, mental health also is a vast area covering many kinds of issues, preventive, promotional as well as curative. Mental health however has received very little attention in programs, policy or in health advocacy. However, this area needs to be also seen as an independent area for advocacy and political action.

There are differences between the health sector and the mental health sector. Advocacy must take note of these differences.

Stigma against people who have been diagnosed with a mental illness is not found among the other health patients. People who have been diagnosed with a mental illness also run the high risk of being deprived of all their constitutional and citizenship rights (e.g. right to vote, right to hold political office, form associations, contract, etc.) All civil, political and social, economic rights are also taken away (e.g. right to free movement, right to consent, right to marry, etc.) Only in mental health can a patient be forcibly treated against her will, by the use of law. These consequences are not there for health patients, who continue to be recognized as full citizens of the state and whose civil political rights are not taken away.

Further, there are problems about how a mental health diagnosis is made: There are no conclusive biological "tests" for a diagnosis of mental illness, for example, a blood sample or a urine analysis. This results in a lot of subjectivity when someone is diagnosed "mentally ill". Once a diagnosis is given, social and political exclusion are major consequences. While we recognize that mental health does have linkages with health, mental health also brings in a lot of issues, which cannot be seen in terms of health.

Mental health as a basic human right of all:

Mental health is related to a just and equal society, where there is no discrimination or violence of any sort. The mental health status of an individual or a group sets the standard whether a state is equitable or not. Where the mental health of people is poor, we can take it that the society needs structural and political reform. A key index of a society's inclusion of its people is the mental health status of its vulnerable and marginalized people, viz. women, the poor, elderly, children, dalits, tribals, religious minorities and sexual minorities. The state has a central responsibility in creating the political and structural environment, and therefore, towards enhancing people's mental health. Mental health therefore lies at the basis of life in all its dimensions and is a basic right of all.

To fulfill the state obligations on the Right to Mental Health, we demand:

- ▶ Protect the basic survival needs of people, including housing, shelter, clean water, nutritious food, work, education, good quality health and mental health care
- ▶ Equal opportunities for all sections of society to find satisfying work and livelihoods; protection of employment of people with mental health problems
- ▶ Programs where there is scope to develop people's potentials, aspirations and achievements; promotion of mental health for people with diverse groups of people with special needs; prevention of mental health problems among vulnerable groups
- ▶ A social, economic and political equity for all sections of society by which they can experience a sense of well being

- ▶ Immediate redressal in situations of violence and conflict, social justice and restoration of peace to people and progress towards a violence free society

- ▶ Good governance which upholds human rights and is inclusive of all people in the process of governing
- ▶ Policies and laws promoting people's mental health and are based on a human rights framework
- ▶ Integration of mental health into other policies and programs related to social justice and empowerment, poverty alleviation, health, disability, food, housing, employment, education, rural health, etc.
- ▶ Special recognition of the needs, protections and rights of people with mental illness
- ▶ The state should remove all barriers in law which prevent people with mental illness to enjoy civil, political, social and economic rights.

Demands for quality mental health care:

- ▶ Specific and greater budgetary allocation be made for mental health at the state, municipal, taluka and Zilla Parishad level; budgetary provisions should be made for community mental health services and not only for institutional services
- ▶ The government should make policy decisions about large, centralized, overcrowded, unhygienic and custodial mental hospitals; creating more homely retreats or rehabilitation homes at the community level should be considered
- ▶ A comprehensive national and state level mental health policy should be developed using an inclusive process of all stakeholders in the sector
- ▶ Increase in the number of professionals and officials working on mental health within the State Health Department to ensure greater ongoing commitment to

formulation, implementation and supervision of mental health policies

- ▶ Community based mental health care should be developed:

- Immediate review and evaluation of the National and District Mental Health Program
- Development of a good database on mental health and distress in the population based on expressed and experienced needs of people and local variations of populations; such mental health surveys should form a part of the routine government records on health status; survey should also map available resources in the area providing mental health care
- Tailor-made community care programs for each community including holistic approaches and social support and not limited to drug therapies
- Identify good community models practiced by NGOs and individuals and document for purposes of up scaling; create funds for supporting the same
- Initiation of promotional and preventive programs at the community level, such as starting counseling facilities, barefoot counselors, etc
- ▶ Development of community mental health programs for substance abuse, domestic violence, suicide and depression and so on
- ▶ Involvement of communities and the users of mental health care in planning and review of services and programs
- ▶ Provision of residential and non-residential rehabilitation facilities, retreats and shelters, day care, and other such facilities
- ▶ Review and revision of all laws relating to the mentally ill and make them human rights sensitive (Mental Health Act, Marriage and Contract Act, etc.)
- ▶ Creation of new policy and legal

frameworks for starting non-medical and rehabilitation / recovery based mental health centers

- ▶ Recognition and support of advocacy work of users and carers for improvement of mental health services through creating policies and other activities

- ▶ Related to children and adolescents, creation of quality psycho-social intervention and prevention programs in all health services, including school mental health programs, child and adolescent guidance services, etc.

- ▶ Provision of psychosocial interventions, promotional and preventive mental health services in women's health, reproductive health, maternal and child health, micro credit, literacy and other empowerment programs

- ▶ Provision and promotion of holistic mental health care including a range of skilled psychotherapies, counseling, home visits, etc.; Non drug approaches such as art based therapies, yoga, meditations, etc. should be a part of such holistic care

- ▶ Affordable, accessible / available and equitable mental health care

- ▶ Rational drug treatment at all levels of mental health care

- ▶ Maintenance of records / documentation of prescriptions, use of ECT, solitary confinement, restraint, etc. in all places where mental health care is provided

- ▶ Respecting rights and choice of people with mental illness regarding admission, treatment and discharge

- ▶ The state must provide violence free and consent-based management of patient care. Where forced treatment is resorted to, restrictions must be placed on this - the State must develop proper guidelines and procedures for assessment, risk, monitoring as well as review and legal representation / aid.

- ▶ Guidelines and good practice standards must be developed for mental health treatments, including:

1. Information to be given to users and carers about available treatment options, which will result in them, choosing the mode of treatment. They also need to be given information about diagnosis, prescriptions, treatment and side effects of psychotropic drugs

2. Standardized, comprehensive diagnostic procedures, which takes into account a person's social history, childhood history, medical, reproductive health and sexual history, history of trauma, violence and abuse, as well as socio-economic history

3. Service from mental health professional that ensures quality time, privacy, confidentiality, dignity, non hierarchical and non abusive forms of care and treatment

4. A charter of rights must be put up prominently in every place where mental health services are provided. Access to redressal mechanisms as well as provision of full information on how to access rights within institutions in event of violations

- ▶ A need-based mental health care model and not one model for all. Women, children, adolescents, vulnerable groups such as street children, women in sex work, people in conflict situations, individuals affected by natural or human made disasters require services that are tailored according to their needs

- ▶ Development of promotive, preventive and curative programs and services

- ▶ Ongoing mental health training for government functionaries with the objective of introducing a mental health perspective across officials of different departments (police, judiciary, social welfare, disability, etc.)

- ▶ Increase in the number of professionals by providing for mental health training facilities in medical, social work and psychology programs to ensure training with regard to psychosocial management of mental distress

- ▶ Incorporation of mental health training in medical syllabi and refresher courses for medical professionals of all specializations, to incorporate a mental health perspective in their practices

- ▶ Periodic social audit of the mental health care systems with regard to equity, technical and ethical issues

- ▶ Integration of justice and legal aid services with the mental health care system at all levels; guaranteeing access to legal aid program for inmates in mental hospitals and judicial and legal custody

- ▶ Addressing mental health care across institutions (beggars' homes, state homes for women, remand homes for children, prisons and other custodial homes) in a human rights sensitive approach. Creating laws which are people friendly to address this issue

- ▶ The special needs of homeless mentally ill persons must be addressed with a human rights approach

- ▶ Ensuring that informed consent is sought in medical and non medical research related to mental health

Special demands with respect to Disability:

- ▶ Mental illness is the seventh category in the Persons with Disabilities Act. However, even the few benefits available to persons with disabilities are not made available to persons diagnosed with a mental illness. From the State we demand:

- Promotion and support of research and actions on

psychiatric and psychosocial disability

- Implementation of The Persons With Disabilities Act for persons diagnosed with a mental illness also
- Representation of psychiatric disability through recognized civil society bodies in State level and National level disability committees
- Better co-ordination between the Mental Health and the Disability Departments and functionaries, from laws to policies to implementation
- Availability of programs for disabilities (psychosocial rehabilitation, self employment, protection of employment, etc.) for people with psychiatric / psychosocial disability
- Availability and access of benefits for persons and families with disabilities and simplification of the procedures
- Creation of vocational training and other appropriate livelihood programs for persons with psychiatric / psychosocial disabilities
- Inclusion and integration of persons labeled with a mental illness into other disability programs
- Provision of disability certificates and also facilitation of the process of securing disability benefits based on the same by more number of institutions
- Removal of the barriers and contradictions in setting up rehabilitation and retreat facilities for psychiatric / psychosocial disability in the existing laws and rules (Mental Health Act)
- A genuine inclusion of mental health in all national as well as state level laws, policies and programs related to disability

Special Demands with respect to Institutional care:

- ▶ Strict adherence to the various judicial pronouncements from the Supreme Court and the state High Court (e.g. Mahajan Committee Recommendations). Implementation of the recommendations of the NHRC in the 'Quality Assurance Report'
- ▶ Provision of more holistic mental health care rather than an exclusive reliance on biochemical modes of treatment as well as a more effective management of debilitating side effects
- ▶ Improvement in the patient - service provider ratio (For example in one of the state mental hospital, the ratio is 3 psychiatrists and 6 social workers to the population of about 1900 clients; Many hospitals do not even have a clinical psychologist. Psychiatric nurses, counselors and occupational therapists are also very few.) Recruitment of staff for vacant posts. Posts of clinical psychologists have lapsed due to non-recruitment. Re-advertising for the same.
- ▶ Creation of new posts for rehabilitation and community mental health professionals
- ▶ Improvement in the patient-attendant ratio, which at present almost amounts to 1:80
- ▶ Judicious use of ECT following the international guidelines. Ban of the use of direct, unmodified ECT which is still practiced at some mental hospitals and government and municipal hospitals
- ▶ Effective strategies to reduce huge number of long stay patients. Development of more community linkages
- ▶ Abolishment of solitary confinement cells. Crisis intervention units must be humane and based on clinical goals. Staffs who are working in these units must be skilled in clinical work. Non-violence should be a value in

institutions and should be realized in practice.

- ▶ Creation of programs on mental health awareness and reducing stigma associated with mental health
- ▶ Ensuring continuity of medicines' supply taking into account the quality of medicines
- ▶ Hygienic conditions at the hospitals. Families must be freely allowed access to their relatives.
- ▶ Self-grooming is an important aspect of personal well-being. Institutions should pay greater attention to this. Residents should be provided soap, oil, and other toiletries required. Hospitals should provide mirrors. (If glass mirrors are a problem, plastic mirrors can be provided). All the residents should be provided with undergarments. Women should be provided with sanitary napkins. Hospital must ensure adequate supply of the same. Routine shaving of head should not be done for women. Baths should be provided for every day. Residents should be provided washed clothes every day. Clothes worn by residents must be comfortable and appealing to the people wearing them. Casual dressing should be allowed instead of uniforms. Clients should be provided with individual storage space to keep their belongings. There should be some private space for prayer, reading, etc. Letter writing, making phone calls, etc. should be freely available. Clean, drinking water facilities must be freely available to all patients.
- ▶ Utilization of large amounts of land owned by old institutions for vegetation and gardening
- ▶ Better ventilation, lights and cleanliness of wards, renewal and repair of old infrastructure, provision of more comfortable bedding for sleeping as the current bed-patient ratio is poor
- ▶ Improvement of dining facilities
- ▶ Installation of intercom facilities

between wards and doctors / nurses' station as the wards are at a distance from each other.

- ▶ Greater emphasis on play, reading, recreation and leisure activities

- ▶ Presence of a diagnosis does not automatically make a person incapable of taking decisions about his / her life. Currently many decision such as, which treatment to carry out, regarding adoption of the child, if the mother is labeled with a diagnosis of mental illness, the child is taken by relatives or most of the times by hospital authorities. We demand that there should be standardized ways of assessing capacity to decide before such decisions are made on behalf of the client

- ▶ Better linkages with community NGOs, civil societies and other resources for eliciting community participation in mental health care

- ▶ Greater financial and material resources and re-allocation of current human resources for strengthening occupational therapy activities and also developing effective marketing strategies

- ▶ Increased range of occupational activities those match and enhance residents' experience, interest and skills and that facilitate their reintegration in the society

- ▶ Patients should not be used as manual labour. If their work is said to be therapeutic, objectives should be set for the therapy and work should be limited by those objectives. General maintenance of the institution cannot be considered as "therapy"

- ▶ Effective and sensitive Information – Education – Communication strategies

- ▶ Involvement of families as active partners in mental health care through increased efforts and effective strategies

- ▶ Privacy in visitors' rooms, space for families to visit and stay, more community friendly ward spaces,

as it is available in other public hospitals

- ▶ Increased participation of residents in planning vocational activities, daily activities, food and any other decisions, which concerns them. Overall there should be a spirit of voluntarism. The system must work towards upholding confidentiality, autonomy and dignity of patients.

- ▶ User fees (daily charges of Rs. 22, certification charges, medical investigation charges, charges for medicines during the Leave of Absence, etc) need to be reduced and if possible eliminated

- ▶ Aftercare plans for those patients who have been discharged. Also facilities like day care centre within the hospital

- ▶ Initiation of support groups for recovered clients as well as for carers

- ▶ Transparency of the workings of the state mental health authority which should be open to review by civil society

- ▶ Implementation of the Legal Services Authorities Act in the case of institutionalized patients. All patients should have a free access to legal representation and legal aid

We assert the civil, political and legal rights of people labeled with the diagnosis of mental illness and we demand:

- ▶ Demand socio economic security with respect to housing, property, food and insurance

- ▶ Recognition of equality before the law

- ▶ Non discrimination in across all settings. Provision of an environment in which positive identity construction is possible for people labeled with the diagnosis of mental illness.

- ▶ Freedom from violence and provision of a safe environment

- ▶ Guaranteeing a right to bodily integrity

- ▶ Right to vote, contest elections, hold public offices and be a member of statutory bodies for people with mental illness

- ▶ Freedom to move freely and no deprivation of liberty because of a diagnosis of mental illness

- ▶ Specific inclusion in poverty alleviation, self-employment programs, free vocational and skills training programs, equal wages

- ▶ Respect of right to love, to marry, to raise a family

- ▶ Legal aid and free and easy access to grievance redressal

- ▶ Participation in formation and review of laws, rules, programs and policies related to mental health

- ▶ Fulfillment of stipulations in the PWDA and UN Disability Convention

The Erwadi accident killing over 25 mentally ill people happened in the year 2001. Since then, very little has changed at the ground level, despite the momentum kept up by the Supreme Court of India as well as the National Human Rights Commission. The Central Government has been releasing large sums of money into the mental health sector (190 crores in the X Plan) but there is very little transparency with respect to how this money has been spent. There is a provision in the XI plan of nearly 500 crores on mental health. The allocations in the X Plan were mostly for mental hospitals. Community mental health is a highly neglected area in India. The government has to engage civil society in the service delivery as well as the human rights reform of the mental health sector.

For further information on JMAA, contact Sadhana Khati / Chandra Karhadkar at info@camhindia.org



About four years ago, there was this young girl of 22 years of age who smoked a lot, wandered on the street outside her college, drank a lot of alcohol, and did many more dangerous and embarrassing things, that didn't embarrass her at that time. This girl had many friends - real and unreal. But she was caught. Not just in the bad habits that many youngsters like her get caught in, but she was caught in her own mind! The most dangerous obsession started pouring in...into her life. It ruled her. It ruled everything she did, everything she said, everything she heard-smelled-touched-tasted, and everything she thought! More so, it was no more her thoughts, as she knew others could hear her thoughts. So she stopped thinking! She stopped talking. She stopped going out of her house, her room. All she did was sit idle and talk to herself. She painted once in a while, but smoking filled her daily schedule and she slept most of the time. Eating was a very big decision she had to make, as her parents were apparently poisoning her meals. She trusted no one. She was imprisoned in her own mind! Nothing could save her now. Nothing imaginable. Her parents thoughts this was the end and also a beginning of a very sad future they all will have to live with and help her understand. Hope was gone. In fact, her father threw that word out of his dictionary. As for her mother, she hardly even knew that word existed. And her younger sister only lived in confusion. This dangerous obsession crept in and grew deeper and stronger over time. Everyone knew something was wrong with her but didn't have the courage to do anything about it.

A couple of weeks had passed with a lot of arguments at home about her behavior. It went unnoticed most of the time as her parents were trying not to notice it. They assumed it was just a phase and one of her rebellious side taking over again. Then, a day came when she stormed into her lecturer's cabin at college and said that she is going to kill every

student outside the cabin. Obviously, her lecturer thought she was joking, only until she pulled out a knife from her pocket and started talking to her herself while walking back and forth. The only thing that could be done was for her lecturer to close the door and leave her there while she called another colleague for help.

What happened after that incident was a one-way roller coaster. It only went downwards. Arguments took place at home. Fights took place within her. The walls at home were not mere walls, but prison bars. This girl was suffering. From the inside and the outside. She looked sick. She had dark circles, unwashed hair, dirty fingernails, and wore the same set of pants and t-shirt. She smelled of smoke. She withdrew from people, her friends, her family, her pet, herself! Days were filled watching TV and interpreting messages from the radio and television. She astral traveled and went to the same place over and over again. Sleeping was no more an easy thing for her. When she bathed, her mom would be around the bathroom, hoping she wouldn't hurt herself. When she wanted cigarettes, her father would walk with her to the shop hoping that she wouldn't run some place else. When she sat in her room doing nothing, her sister would be made to sit in the room just to make sure she didn't lock the door from inside. This took away all her privacy. But did that make a difference to her? No. At that point it didn't. Because she didn't know what that word meant anymore. Her life was in danger. People were trying to kill her. Men were tormenting her by calling her names and making her do things she didn't want to do. She knew she was meant for something higher, a great mission she had to accomplish, where the whole world depended upon her. This dangerous obsession took her many places she had never been before. Places no one else have even dreamt or imagine could exist. A place that would lead her to secrets and great power. This is the place, which she calls 'the

undiscovered mind'. And this girl in none other than me.

I couldn't complete my education and had to take a break from everything I once did. It was no more just giving it a go or trying or even struggling. I needed help. I needed someone else to help me and not myself! The help came in. Family, doctors, counselors, support groups started making a difference. But somehow with every step forward a relapse set in and I only fell ten steps behind. Re-starting once again was too much of an effort. Brushing my teeth, taking a bath, grooming myself well, eating and drinking right, I still felt helpless and hopeless. I woke up each morning with suicidal thoughts and slept each night wishing that I will sleep forever because I was useless! I was just a pain to everyone who tried to help me.

As months passed, relapses and recoveries were the only activities in my life. I somehow managed to complete my bachelors degree and move on to masters. This has also become another struggle for me as this illness doesn't seem to leave me! No matter what I do, it keeps showing up in a different mask and I have to change the way I look at it. Every time I understand it, there is just more of it to understand! I sometimes feel that I shouldn't have the insight that I have! I should just have remained under the care of the medications and let them rule my symptoms for me. I do feel sick of it. Sick of the fact that no matter what I do, it is always caused by my symptoms. I feel there is no me. Who am I? Am I just a combination of all my symptoms? Are they always going to rule what I do and think? So then I began believing that when I have such an illness, why do I need others to talk to? Doesn't it make sense? I have all those wackos in my head that keep talking to me all the time. They are as real as everyone else. I can touch and feel them too. So why do I need others????? Do the real people really matter to me? The answer I gave myself was NO. There was too much of heartache talking to real people.

Too much of hypocrisy in their words and deeds. Too much of politics and lies. Nothing about these real people and this real world seemed exciting and true. My world was a much safer and nicer place. I didn't have to answer anyone nor hate anyone. The love among the fellowmen in my mind grew. Though I knew I was depending on them I liked it. I felt comfortable. No one would ever be able to take them away from me. BUT I was not free! I still felt tied down.

It took me a lot of time, and effort of my own to realize this and do something about it. No doctor, medicine, counselor, friend or family could help me now. I was stuck in my world that I couldn't live without. I felt miserable when the real people were there and miserable when the unreal people were not there. I started living each day with confusion and frustration. I couldn't do anything. How could I chase away the real and call the unreal whenever I wanted to?

A day then came when I realized that if I had to live in both these worlds and survive them simultaneously, I had to do something about myself! I obviously couldn't change any of them though the unreal world was actually a part of me. But, I had to look at it as something that was not a part of me to deal with it. Cause if I did the opposite I would end up living in this unreal world forever and never quite reach anywhere in life. Hence, I decided to speak! Speak to people. The real people. People around me. My mom, sister, friend, everyone. I decided that I had to make the difference in others lives and not them in mine. I had to move to move others. I had to change for others to change.

As Kahlil Gibran quotes: 'And when you have reached the mountain top, then you shall begin to climb'. I have always lived by this quote throughout my recovery. I am still recovering and always will be.

Reshma Val

SIMPLY CHANGED

The love I once knew has taken a new turn...
Not disappeared but simply changed.

The feelings in my heart don't now burn
They have simply changed.

My hallucinations haven't gone away
They are present always, only now changed.

I have better control over them
Because my reactions have simply changed!

The illness that once troubled me, don't anymore
And my perspective simply changed...

This illness that once confused me, don't anymore
As my thinking simply changed.

My cravings don't control me
As my strengths simply changed.

Drugs, alcohol and cigarettes don't exist
As my philosophy simply changed!

My life once confused and nothing that I could do
Because my insight simply changed.

My life I now realize hasn't fallen apart
BUT I have simply changed!

'Change is the only permanent thing in this universe' – Buddhism

Reshma Val
26th June 2005

Disturbing News for Patients and Shock Doctors Alike

by Peter Breggin

Something most remarkable and unexpected has occurred in the field of psychiatry. Led by a lifelong defender and promoter of shock treatment, Harold Sackeim¹, a team of investigators has recently published (2007) a follow up study of 347 patients given the currently available methods of electroshock, including the supposedly most benign forms-- and confirmed that electroshock causes permanent brain damage and dysfunction.

Based on numerous standardized psychological tests, six months after the last ECT every form of the treatment was found to cause lasting memory and mental dysfunction. In the summary words of the investigators, "Thus, adverse cognitive effects were detected six months following the acute treatment course." They concluded, "this study provides the first evidence in a large, prospective sample that adverse cognitive effects can persist for an extended period, and that they characterize routine treatment with ECT in community settings." After traumatic brain damage has persisted for six months, it is likely to remain stable or even to grow worse. Therefore, the study confirms that routine clinical use of ECT causes permanent damage to the brain and its mental faculties. The term cognitive dysfunction covers the entire range of mental faculties from memory to abstract thinking and judgment. The ECT-induced persistent brain dysfunction was global. In addition to the loss of autobiographical memories, the most marked cognitive injury occurred in "retention of newly learned

information," "simple reaction time," and most tragically "global cognitive status" or overall mental function. In other words, the patients continued to have trouble learning and remembering new things, they were slower in their mental reaction times, and they were mentally impaired across a broad range of faculties. The statistical data indicates that a large percentage of patients were significantly impaired.

Many patients also had persistent abnormalities on the EEGs (brain wave studies) six months after treatment, indicating even more gross underlying brain damage and dysfunction. The results confirm that the post-ECT patients, as I have described in numerous publications, were grossly brain-injured with a generalized loss of mental functions.

Some of the older forms of shock—and still the most commonly used—produced the most severe damage; but all of the treatment types caused persistent brain dysfunction. The greater the number of treatments given to patients, the greater was the loss of biographical memories. Elderly women are particularly likely to get shocked--probably because there is no one to defend them--and the study found that the elderly and females were the most susceptible to severe memory loss.

❖ *Destroying Lives*

The study does not address the actual impact of these losses on the lives of individual patients. Like most such reports, it's all a matter of statistics. In human reality the

loss of autobiographical memories indicates that patients could no longer recall important life experiences, such as their wedding, family celebrations, graduations, vacation trips, and births and deaths. In my experience, it also includes the wiping out of significant professional experiences. I have evaluated dozens of patients whose professional and family lives have been wrecked, including a nurse who lost her career but who recently won malpractice suit against the doctor who referred her for shock. Her story is told on my website, www.breggin.com.

Even when these injured people can continue to function on a superficial social basis, they nonetheless suffer devastation of their identities due to the obliteration of key aspects of their personal lives. The loss of the ability to retain and learn new material is not only humiliating and depressing but also disabling. The slowing of mental reaction time is frustrating and disabling. Even when relatively subtle, these disabilities can disrupt routine activities of living. Individuals can no longer safely drive a car for fear of losing their concentration or becoming hopelessly lost. Others can no longer find their way around their own kitchen or remember to turn off the burner on the stove. Still others cannot retain what they have just read in a newspaper or seen on television. They commonly meet old friends and new acquaintances without having any idea who they are. Ultimately, the experience of "global" cognitive dysfunction impairs the victim's identify and sense of self, as well

¹ Sackeim, H., Prudic, J., Fuller, R., Keilp, J., Lavori, P. and Olfson, M. (2007). The cognitive effects of electroconvulsive therapy in community settings. *Neuropsychopharmacology*, 32, 244-254.

as ruining the overall quality of life. Although unmentioned in the Sackeim article, in addition to cognitive dysfunction, shock treatment causes severe affective or emotional disorders. Much like other victims of severe head injury, many post-shock patients become emotionally shallow and unable to relate on an intimate or spiritual level. They often become impulsive and irritable. Commonly they become chronically depressed. Having been injured by previously trusted doctors, they almost always become distrustful of all doctors and avoid even necessary medical care.

❖ **Decades of Opposition to Shock Treatment**

This breaking scientific research has confirmed what I've been saying about shock treatment for thirty years. In 1979 I published "Electroshock: Its Brain-Disabling Effects", the first medical book to evaluate the brain damaging and memory wrecking effects of this "treatment" for depression that requires inflicting a series of massive convulsions on the brain by means of passing a traumatic electric current through it. After many rejections, the courageous president of Springer Publishing Company, Ursula Springer, decided to publish this then controversial book. Dr. Springer told me about venomous attacks aimed at her at medical meetings as a result of her brave act in publishing my work. She never regretted it.

Over the years, I have continued to write, lecture, testify in court and speak to the media about brain damage and memory loss caused by electroshock (e.g., Breggin 1991, 1992, 1997, and 1998). At times my persistence has resulted in condemnation from shock advocates whom I have criticized for systematically covering up damage done to millions of patients throughout the world. It

would require too much autobiographical detail to communicate the severity of the attacks on me surrounding my criticism of ECT. It was second only to the attack on me from the drug companies for claiming that antidepressants cause violence and suicide.

Will the latest confirmation of ECT-induced brain damage cause shock doctors to cut back on their use of the treatment? Not likely. Psychiatrist and their affiliated neurosurgeons always knew that lobotomy was destroying the brains and mental life of their patients and that knowledge did not daunt them one bit. It required an organized international campaign to discredit, to slow down and to almost eliminate the surgical practice of psychiatric brain mutilation in the early 1970s (Breggin and Breggin 1994). The ECT lobby is much larger and stronger than the lobotomy lobby, and much better organized, with its own journal and shock advocates positioned in high places in medicine and psychiatry. Stopping shock treatment will require public outrage, organized resistance from survivor groups and psychiatric reformers, lawsuits, and state legislation.



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Chaitanya Mental Health Care Centre, Pune, had organised an interactive session on 1st of April 2007 at Fergusson College, Pune, to encourage the use of ECT. The topic of discussion was "Myths and facts of Electro Convulsive Therapy (ECT) or shock treatment in psychiatric care". Dr. Yusuf Macheswalla, president of the Mumbai Psychiatrist association, and Dr. Vidyadhar Watve, senior private psychiatrist from Pune, were the resource persons for the programme.

On *All fools day*, the program aimed to "eradicate myths" and bring back rationalism. The invitation letter to the program was appealing to the public: "To eradicate foolish myths and phobias on ECT". A large poster with a message "Nothing Shocking about Shock" was also distributed widely.

Bapu trust, an advocacy organisation in mental health, Pune, organised a peaceful protest at the venue. They distributed data and information countering the rosy and romantic picture painted of shock treatment. Questions were raised at the meeting, showing how controversial the treatment is. The organisation has condemned in no uncertain terms, such misleading public presentations, made by responsible senior members of the IPS (Indian Psychiatric Society) and is preparing a full fledged campaign against ECT.

A brief note on Dr Yusuf Macheswalla's presentation

The doctor started by talking about the need to talk about ECT. He stoutly stated that ECT was very safe and if asked, he would say that "it was the only weapon" that he had to treat mentally ill

patients. His reporting on the near magical qualities of ECT included: immediate clinical improvement, rapid recovery, easy management, no side effects, reduction in hospitalisation, and no potential of abuse or dependence.

Reiterating the medical view about the treatment, he advised that ECT may be used as the 1st line of treatment in the management of schizophrenia and related mood disorders. ECT, according to him, may be used as a life saving measure in cases of Neuroleptic Malignant Syndrome, (which is a serious and fatal side effect of anti-psychotic medication). He noted, remarkably, that death due to ECT is extremely rare. Among those eligible for ECT, he was far more inclusive than standard clinical practice. Other than all mental illness, he included neurological conditions such as Resistant Seizure disorder, Parkinsonism, Chronic or extended delirium, intractable epilepsy with psychopathology and Psychosis or depression associated with neurological disorders such as Wilson's disease. He advised the other psychiatrists present in the room that ECT can be safely used in young children, pregnant women, diabetic patients, senior citizens and medically, even orthopedically, compromised patients. In his practice, ECT has reportedly worked with autism, and childhood depression. He noted that the treatment works wonders with "young people who seem aimless and are drifting". His presentation repeatedly emphasised that there were no side effects. With respect to how ECT works, he gave the standard medical view that "it normalises brain chemical imbalance" without citing any evidence. Under

anaesthesia or without anaesthesia does not make any difference, according to him. Both were pronounced equally safe, except that anaesthesia helped in avoiding the patient's fright of the procedure. In his practice, 14-16 ECTs were commonly given. He noted that there was no upper limit to ECT, citing the case of one patient who was given 208 ECTs!

Success stories narrated by Dr. Macheswalla

- ✎ Patient with schizophrenia who developed fracture of spine after an unmodified ECT was safely given modified ECT
- ✎ Cervical spine fracture person was given ECT
- ✎ Eighty two year old person showed rapid improvement after ECT
- ✎ A middle class clerk, schizophrenic patient with strong delusions was treated with 44 sessions of ECT
- ✎ A fourteen-year-old child started going to school after ECT
- ✎ Four-year-old infantile autism has been treated with ECT

In response to consumer interests, he noted that his service facility charges between Rs. 1000 to 5000 per ECT. Taking the consumer culture one step forward, he noted that if a person takes "in bulk" (30-40 ECTs), they may receive one or two ECTs free of charge! The audience were informed that it is easy to subsidize ECT, compared to psychotherapy because it happens in bulk whereas, psychotherapy is time consuming where doctors may not like to subsidize.

In response to the question why ECTs are repeatedly given, he remarked that the nature of the illness is such where people keep

relapsing and keep asking for ECT. He observed that no regulation of the procedure was necessary, as lawyers or judges were in no position to decide whether a patient should be given ECT or not. While casually remarking on the possibility of death, he noted that there are hardly any chances of medical emergencies.

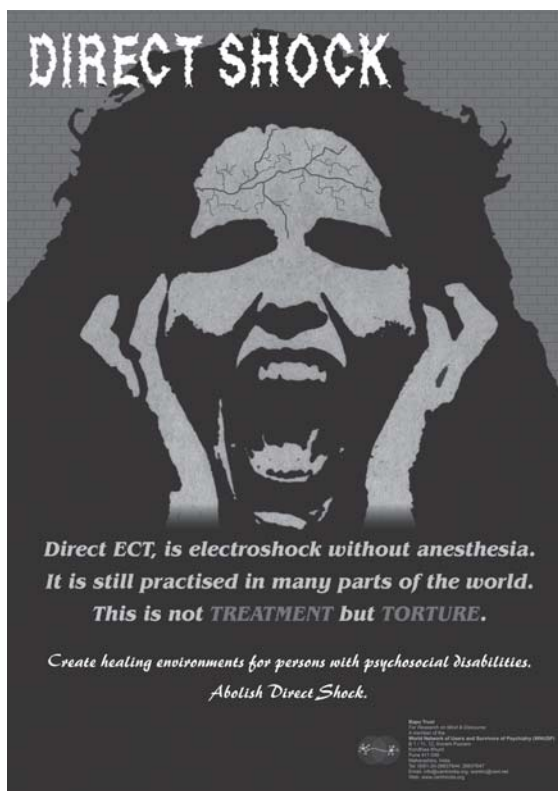
With respect to a question why a person with a mental illness is not given any choice and her consent is not taken, he pointed out that the nature of mental illness is different from the nature of physical disease: Anyone suffering from the former has no insight!!

Statement from Bapu Trust

We are shocked at the very false, rosy, romantic, one sided picture of ECT, portrayed by the program and the senior IPS official, misleading the public. All our fears have been proved true in the IPS officer's admissions at the event. ECT is used for anything and everything; there is no 'upper limit' and people routinely receive 30-40 ECTs; medical emergency precautions are not considered as a vital part of procedure; risks are not explained or are glossed over ("Even if you are walking on the street, you are at risk of death"). It is shocking that 4 year olds are being given ECT. Nobody should ever receive 208 ECTs. The senior resource person was evidently abusing the practice. Even in sheer economic terms, this would have cost the patient a minimum of 2 lac rupees. The commercial and industry interests of doctors giving ECT should be examined. Most controversial of all, according to the Bapu Trust, is the practice of an ECT mobile van being provided by the said doctor: This was promoted as a community service, wherein the van picks up "unmanageable" patients at the doorstep and delivers shock in the van.

When a senior IPS officer makes such presentations, the IPS, which claims on its website that encouraging ethical practice is among its objectives, must be held responsible. The Indian Association of Private Psychiatrists, a 7 year old organisation, claiming to be committed to ethical practice, is equally accountable. These professional organisations have made no attempts to control or regulate ECT practice, or to establish some protocols and standards. It is another matter that none of these organisations have even a shadow of involving users in establishing standards for their practice. Where fear and terror of the procedure is treated as an irrational symptom of mental illness, and sedation or anaesthesia is used to remove this particular symptom, there are serious attitudinal questions within these organisations which must be addressed. Some senior medical professionals in India even want direct ECT restored, with the argument that "India is a poor country and all Indians are poor". ECT facilities must be licensed and regulated. There must be records of ECT practice: We have no idea how much injury and death is caused by shock treatment. In a world where litigations against ECT are the norm, there is a supreme court case against ECT, where the European Convention on Torture has referred to direct ECT as a form of torture, the serious misinformation about psychiatry and promotion of ECT presented herein is absurd and regressive. Doctors should read more about mental health and well being, and keep themselves updated on alternatives to shock and medical treatments. Shock treatment is not a subject for creating "awareness" among the public; it is a matter to be placed before the consumer courts and human rights commissions / courts.

Visit www.camhindia.org for more on ECT.



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Student killings at Virginia Tech: A perspective

Gitika Talwar

I never thought that the assumption of “incapacity” in people with psychosocial disability could have such severe repercussions for students on the Virginia Tech Campus. We have an inherent prejudice against understanding the decisions and wishes of people with disability, with the same equanimity as we would for a person without disability. Our knowledge of the disability seems to colour our perceptions and just as we are unable to understand their decisions of growth, we are unable to understand their decisions of self harm and harm to others. As a result, we are unable to respond to them in the manner that is most human and most appropriate. When Cho’s past history reflected harm towards others, his psychiatric diagnosis pushed him into a mental health system that was unable to respond to the fact that he was capable of harming others, regardless of what his diagnosis was. In an ironic way, his diagnosis appeared to protect him from the police that would have swung into action had the crime been committed by ‘another kind’ of person.

Peter Breggin¹ talks about the importance of police intervention in the case of a person like Cho.

“Almost certainly, the police were hampered in taking appropriate actions by being encouraged to view Cho as a potential psychiatric patient, rather than as a perpetrator. It’s not

politically correct to bring criminal charges against someone who is “mentally ill” and it’s not politically correct to prosecute him or to remove him from the campus. Yet that’s what was needed to protect the students. Two known episodes of stalking, setting a fire, and his threatening behavior in class should have been more than enough for the university administration to bring charges against him and to send him off campus.

How would a police action have affected Cho? Would it have humiliated him and made him more violent? There’s no way to have certainty about this, but anyone with experience dealing with threatening people knows that a good dose of “reality,” a confrontation with the law, is much more of a wake up call and a deterrent than therapeutic coddling. Furthermore, involuntary psychiatric treatment is one of the more humiliating experiences in American society, and tends to make people more angry, not less.”

Just as people of Korean nationality worry about a backlash, so do people with psychosocial disability. I write this article to extend my support to all those of us who live with a psychosocial disability and know that violence is not a necessary consequence of our disabilities, and that violence can be an independent entity. Correlation is not causation.

As a race, we find ourselves uncomfortable with deviance from the norm and the best of us willingly criminalize deviance, without realizing that there are certain deviant acts and not deviance *per se* that cause harm. We need to be able to condemn deviant acts that hurt us, instead of condemning deviance by itself. Cho’s problem was not his illness, it was the acts he committed.

This article is about condemning harmful behavior for what it is, rather than losing perspective over the context in which that harmful behavior emerged. It is human tendency to get embroiled in contexts to the extent that we punish contexts rather than punishing behaviours – in Cho’s case, my fear is that we will condemn the illness rather than the act. It is necessary that they both receive entirely independent responses.

Even as we address the needs of someone with a disability, we need to ensure that they do not cause harm to others, and if we do see patterns of harming behavior, it is necessary that we take appropriate action, even if the action is police intervention. Cho deserved every ounce of psychotherapeutic intervention that anyone with psychosocial disability deserves. And just as we say that a person is

¹ www.peterbreggin.com

more than his disability, we have to understand that Cho too was not just a person with a disability; he was also someone who had committed crimes on a number of occasions.

Advocating for the rights of people with disability and safeguarding against harmful behaviour, are not antithetical to each other. As we speak about capacity among people with psychosocial disability, we also speak about responsibility for actions. Even as we say do not make a syndrome out of a symptom, do not make a person out of a single act, similarly experiencing a psychosocial disability does not condone or forgive a crime. No matter who or what made someone commit a crime, the nature of a crime does not become 'less criminal' if it is committed by someone who had a disability.

I am reminded of the case of a man who killed a couple and then sat beside the dead bodies to eat his dinner. The defending attorney spoke to the jury about his troubled childhood and how he was not responsible for the murder; his history had created him in the manner that made him hurt others. I wonder, are we saying then that past histories can alter the nature and evil of a crime?

I am aware that crimes are also committed in self defense and I leave the discussion of those crimes out of this discussion. Let us not confuse Cho's crime with crimes committed in self defense.

Many people with mental illness are likely to harm themselves and NOT others and this is a fact that is necessary to talk about to protect the already fragile public image of people with psychosocial disability. Hence, it is important that Cho not be seen as representative of people with psychosocial disability. And I also want to emphasize that criminal behavior is criminal behavior, psychiatric angles notwithstanding.

It is possible for a person with a psychosocial disability to commit a crime, and it is completely possible for the disability to have nothing to do with the crime. It is necessary that crimes be seen as crimes and not be seen as part and parcel of the disability.

The complexity of this issue reminds me of the women's movement's reluctance to discuss violence perpetrated by women, or the LGBT movement's hesitation to discuss couple violence within LGBT couples. We refuse to see victims as perpetrators, though it is possible to be both. Similarly, in the process of protecting people with disabilities from stigma and discrimination, we often forget to treat them as people first. This is why it is easy to lose perspective, I realize, of the fact that a crime is a crime is a crime.

To put it in dry and brittle words - limit setting and installing boundaries is an important part of any psychotherapeutic intervention to help the client stay rooted in reality. I am reminded of a client who was often verbally abusive towards her therapist. When the therapist responded sternly, saying "you cannot talk to me like that", the client was surprised and said "But my previous therapist always let me say what I wanted to". To this, the therapist retorted, "That is why you are still in therapy." Even if I may withhold that final retort from my own interaction with a client, I do know that therapy is only prolonged when one pretends to liberate the client from the real and non-negotiable boundaries that exist in the world that lives outside the clinic. People (regardless of their diagnosis) need to understand the nature and implications of their actions, and if police intervention is the only way to do it – then be it.



It could have been me

A woman at Napa
Not 40 miles away
Was killed by a shot of
Prolixin Cause she did not
want to stay.

When a woman cries out angry
They'll drag her to the ground
You can kill a woman,
not a song
When it's sung the whole
world round.

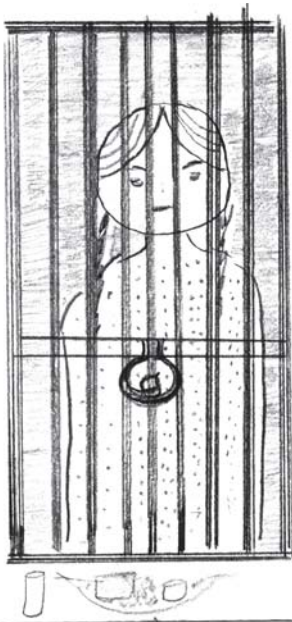
It could have been me, but
instead it was you,
So I'll keep fighting the war
you were fighting as if
I were two,

I'll be a student of life,
a singer of songs,
A farmer of food, and a
righter of wrongs.
It could've been me, but
instead it was you,
So I'll keep fighting the
war you were fighting as
if I were two,

If you can fight for freedom
Freedom, freedom, freedom,
If you can fight for freedom,
I can too!

Anon.
Madness Network News,
Summer 1983, Vol. 7, No. 2

Selection by Saroj Acharya



"How can I eat my food through these bars? Be human enough to atleast serve the food inside the cell."

FREEDOM IS MY BIRTH RIGHT AND I SHALL HAVE IT!!

The above title is taken from the utterances of Lokmanya Tilak, who was an Indian freedom fighter. I am not a freedom fighter, but definitely, I am a fighter, who fights literally when it comes to injustice.

I have suffered for the last 30 years and am still suffering from a severe mental disorder. I have been locked in cells in the state government mental hospital which had only a window with strong iron bars, and no toilet facilities. The door of the cell was also made of iron doors and rods. I had to eat my food by putting my hands in the space in between two rods.

Once when I was angry (angry, NOT violent) in the mental hospital, they anticipated that I would get violent and Sister _____ called another patient named _____ to control me. This patient pounced on me, pushed me down and pierced my eyes with her two fingers.

I agree that I was also a troublesome patient. I used to often undress myself when I was put in a closed cell. I was so angry at the injustice.

But this never happened in _____ (another hospital) because the closed ward there was open to sky. I could see sunlight and the birds. There were toilet facilities there. It was a clean and infection free hospital. In the state government hospital, the patients suffer from scabies and bathrooms are filthy. Sometimes the water is not available throughout the day.

I am writing because I care for the patients. I, being JUSTICE Saroj Acharya, want justice.. I want justice to be given to the patients.

Saroj Acharya

Pune, 18th April, 2007

An Orientation to AMH

By Bhargavi Davar

We welcome all our readers to a new section in Aaina, 'Paryayi'. Paryayi is another step in our journey towards ensuring a safe, mental health friendly environment within the community. Paryayi is an effort towards generating awareness and creating a forum for discussion on all alternative methods of ensuring good mental health.

In India, mental health services are largely identified with psychiatric services. Psychiatry is a very limited discipline, which looks at mental health from a narrow and symptomatic perspective; The mind and body are rarely treated as a whole. Alternative methods of healing use more holistic therapies, which are culturally accepted within the societies that they originate in. They are gentle and non-invasive in nature, having a proven scientific basis to them. However, awareness about these therapies is limited only to a small section of society. Bapu Trust, Pune, organizes regular interactive sessions with alternative therapy practitioners. We also integrate these therapies among other mainstream therapies offered in Seher, a psychotherapy center of Bapu Trust. Evidence base about alternative therapies and their benefits is being assimilated in our library and documentation unit. We invite aaina readers to share their opinions, experiences and knowledge of alternative mental health care within in this section of 'Paryayi'.

My interest in AMH is tied to my work in the traditions of the philosophy of psychiatry, the social scientific, historical, feminist and cultural critiques of psychiatry, and most importantly, the user / survivor movement, which began in the west around the 1960s.

At this time, most of the western economies were reeling under the ravaging after effects of the world war. Mental institutions, which thrived during the imperialist period, were seen as unsustainable for the weak economies. Policy makers, in a vested interest to cut back on government expenditure, harvested human rights arguments about the horrors of institutions. A "de-institutionalisation" process started, wherein lakhs of people interned in these large hospitals were discharged all over Europe and the north Americas. Thousands of people labeled with mental illness, and disabled by long term drugging, shocks and institutionalization, were literally thrown out on the streets. Communities did not want them, and they were outcaste and stigmatized as poverty ridden, welfare mongering and violent.

The first stirrings of the mental patients / user movement started then, right there on the streets, when these people mobilized, exposed horror stories about mental hospitals and psychiatric treatments, and started to imagine creative and humane alternatives to psychiatric / institutional care.

The user/survivor movement was a part of the larger civil liberties movements that had swept North America and Western Europe. Progressive thinkers within the mental health profession, such as RD Laing and David Cooper joined the movement. Existentialist philosophers such as Jean Paul Sartre, Paul Ricoeur and many others were giving a humanistic perspective to psychological well-being. Supported by intellectuals and critical historians such as Thomas Szasz, Andrew Scull, and others, and feminists like Kate Millet and Phyllis Chesler, the movement consisted mainly of ex-users of psychiatry, who were now questioning the very foundation of coercive psychiatry, criticizing the pathologisation and medicalisation of human life entailed within the psychiatric system.

In the post war period, psychiatry was trying to establish its credentials as a scientific discipline. The first version of DSM - Diagnostic and Statistical Manual - was released in the year 1952. First generation psychotropics were introduced by the 1960s. Psychiatrists flung their nets far and wide by aggressively introducing community mental health policies in the western countries. They were followed everywhere by the pharmaceuticals. Schools, work environments, the streets, family spaces, community spaces were all invaded by the new language of psychiatry, and by the technological power of psychiatric drugs. By the 1990s, "prozac nations" were born in much of the developed world. Insurance companies adjusted their policies to the demands of the emerging new medical discipline.

A serious loss of this modernization process in the western world was the loss of cultural memory about traditional or naturally found alternatives for dealing with psychological suffering. It is against this background that concepts of self-determination, self-advocacy and a search for alternatives to psychiatric treatment gradually developed. The thrust was upon users of psychiatry getting

more control over their own treatment, and being able to exercise more agency in their recovery process.

Many of us have tried various non-drug approaches for coping with our emotional ill health and recovery. Some of us may have tried only such approaches, because of our belief that these are more life affirming and holistic than taking a psychiatric pill. An “alternative” is usually seen as a substitute. When the ideal is not available, we go for the second best “alternative”. However AMH is a stand-alone strategy: For many, common mental health difficulties faced in community care, AMH alone may help to cure. AMH is respectful of user’s self-determination: AMH gives a wide range of choice to users and involves them meaningfully in their own healing process.

AMH has a great potential in the prevention and promotion of mental health. Prevention may include the prevention of mental health difficulties in high-risk groups, as well as the prevention of relapse in persons who have already been through a mental health problem. AMH may also help in the promotion of positive mental health and overall well-being.

Using a drug, such as antidepressants, depletes our bodies of essential nutrients and changes its bio-chemical balance. AMH may be used to balance this depletion and enhance the physiological capability of the body, so that the body is able to process the drug in the least harmful way.

In general, by “AMH”, we include non-medical and non-drug alternatives to healing and recovery from mental health problems. There are many other medical systems in the world, beyond the standard Western system. These systems are well developed, with an ancient track record for healing, and many are gaining wide acceptance as alternative or complementary approaches in the West. These include:

- ☛ Body therapies (e.g. nutritional therapy, acupuncture, massage)
- ☛ Art therapies (music, dance, theatre, story telling, visual media, etc.)
- ☛ Breathing based mind-body techniques (yoga, meditations)
- ☛ User-led self help groups, counseling and psychotherapies
- ☛ Alternative forms of medical treatments (e.g. Homeopathy, Naturopathy, Ayurveda)

Along with these, we strongly advocate that basic medical or health problems should be detected (e.g. reproductive problems or hormonal problems) and corrected before planning a psychiatric treatment.



Spanning Continents: My journey as an Art Therapist

Susan Bullough-Khare



Susan with one of her training groups on Art

I began my professional life as a teacher in England. Even before attending college I had experience of the classroom, as my aunt was the principal of a large school, which also had a unit for hearing impaired students. In addition to this, after taking my final school exams I worked as an unqualified teacher for a year in London. It seemed my career path was set!

However, unexpected opportunities often present themselves as hurdles to be overcome. When I was unable to find a teaching job in the area where I wanted to live I took what turned out to be an interesting job as an occupational therapist in a psychiatric hospital. I was the only volunteer to accompany the head psychiatrist to the locked wards to conduct art and drama therapy.

Later I became a house parent in a home for emotionally disturbed children. We had twelve resident children, between the ages of five and sixteen years, all of whom had significant problems, which included being educationally challenged, hearing impaired, epileptic, abused, hyperactive and abandoned. Such problems had to be coped with in order to create a harmonious refuge for the children who demonstrated extreme forms of behaviour.

In 1977 I moved to Southern Ireland where I provided individual tuition for girls with Downs Syndrome and private art classes in local towns. Having grown up in a multi-cultural area of London I gradually became aware of how little Irish children knew about, or came into contact with, people from different countries and cultures. Since so many young Irish people emigrate I felt this was

a serious impairment to their preparation for the big wide world. An idea started to evolve in my mind, which eventually found fruition in my first project - exploring different cultures and life styles through art. I worked in nine local schools and the work culminated in an exhibition of 765 paintings.

As a result of this work I was invited to design an education project for the Dublin Millennium. It was this that first brought me to India in January 1988 and set me down on yet another path. I wanted Indian children to tell their Irish counterparts what it was like to live in India. I was disillusioned by how adults were portraying India and felt that children would give a more open and accessible message to Irish students. The project was a great success and had an influence on me professionally and personally. As I traveled to various schools in India I came into contact with urban and rural life, crafts people, puppeteers and artists. Each year I designed one or two projects, which brought me back to India, initially for one or two months, then gradually evolving into six months of continuous travel into rural heartlands and cityscapes of more than eight different states.

During this time I was invited to set up and run the Intercultural Education Project for the Kerry Education Centre. Through my work in Ireland and my travels in India I produced some education materials that focused on the value of art in an integrated syllabus and the importance of learning about a variety of cultures and lifestyles. Some of the resources I produced included an education pack on the *Banjaras* and another on Indian jewellery. These were launched by the Indian Ambassador at the Indian Embassy in Dublin and my exhibition of photographs and artifacts on the *Banjaras* was also exhibited in Kerry and launched by the then Minister of Foreign Affairs, Dick Spring. My packs used my own photographs as a teaching resource and the ensuing exhibitions and workshops were conducted with children, teachers, parents, gypsies, art students, teacher training students, social workers, women's groups, bereavement groups, minority forums, anti-racist and equality organizations and refugee support groups. A project with children in England and Ireland on the *Banjaras* included work on the effects of environment and social change on nomadic communities.

I became more and more convinced of the value of art as a tool for learning, communication and for healing. Through the artwork they produced with me, children told me about their experiences as refugees, women talked about their adjustment to a loved one dying, individuals shared their experiences of racism, people expressed personal reactions to rejection, disappointment, fear and survival. My workshops began to evolve, in Ireland, England and India, and teachers

working in special schools started to attend and discover how they could adapt the work and my suggestions for the benefit of their students. The secret burdens, guilt and resentment experienced by the mother of a handicapped child or the wife of an alcoholic husband can be debilitating. My workshops may not solve the problems but they help reduce the anxiety and loneliness people feel and provide a safe environment in which to explore, talk, share and support one another.

It is with great personal joy I witness women who are quiet and insecure on the first day, stand up at the end of a workshop and describe the minute details of their art work that illustrates some of their most personal life experiences. It is humbling and enriching for me when people find the courage, with tears in their eyes, to share the pain and burdens they have never before had an opportunity to express.

Now that I am a resident in my adopted country, India, I encounter personal hurdles and challenges on a daily basis. However through the process of communicating and creating art together I have grown closer to and more knowledgeable about many of my neighbors from different states, classes, castes, occupations, religions and environments. Not only from a cultural and historical perspective but also through mutual empathy and understanding.



Music Therapy

The human body is like a musical instrument, expressing numerous frequencies and rhythms in a constantly changing spectrum of life. It responds and resonates in consonance with music, sounds, speech and thought from the environment, and undergoes changes of heart beat, breathing, blood chemistry and circulation of energy in various energy centers of the body.

The idea of music as a healing influence, which could affect health and behaviour, is as old as the writings of the Vedas, or Aristotle and Plato. Modern science and medicine are now rediscovering the healing powers of music. Music therapy is a specialized use of music in treating persons with special needs in mental and physical health, rehabilitation and special education as well as in promoting well being.

The rhythm can guide the body into breathing in slower, deeper patterns that have a calming effect. Music allows us to transcend the everyday states of consciousness and

travel to places that we either have a memory of or create in our imagination. This process of transcending the mundane evokes psycho-physiologic responses when people shift to altered states of consciousness.

While listening to music, there is an increase in the level of endorphins in our bodies, which are natural pain relievers. Music also aids in decreasing stress hormones and helps in improving immune function. It is one of the most effective ways of controlling emotions, blood pressure and restoring the functioning of liver. It is known to be an efficacious and valid treatment for persons who have psychosocial, affective, cognitive and communicative needs.

Music therapy sessions are held with individuals or groups. The flexibility of music allows for very individualized programming. Music therapists use music activities, both instrumental and vocal, which are designed to facilitate changes that are non-musical in nature. Music therapists draw from an extensive array of music activities and interventions. The techniques used to achieve the goals are singing, listening, instrumental music, composition, creative movement, guided imagery etc.

Ideally, an interdisciplinary team works together to assess emotional well being, physical health, social functioning, communication abilities, and cognitive skills through musical responses. Other disciplines can also be integrated – dance, art, psychotherapy, etc, where the primary aim is to improve the client's ability to function.

Effects of Music Therapy:

Music therapy aims to help people develop skills that have to do with overall development and personal growth. It can be effectively used to form a primary relationship or build rapport with the client. Often the goals and objectives chosen are very specific and may include things like attention span, self-esteem, listening skills, turn taking, nonverbal communication, self-expression, etc. Music can convey feelings without the use of words. For a person whose difficulties are mainly emotional, music therapy can provide a safe setting where difficult or repressed feelings may be expressed and contained. By offering support and acceptance the therapist can help the client to work towards emotional release and self-acceptance. It helps to deal with grief, sadness, anger or other feelings. Music as a medium

helps one to come in touch with the deeper feelings within oneself and aids an individual to express those feelings.

Music is essentially a social activity involving communication, listening and sharing. These skills may be developed within the musical relationship with the therapist and, in group therapy, with other members. As a result clients may develop a greater awareness of themselves in relation to others. This can include developing greater confidence in their own ability to make relationships and to find positive ways of making their needs known. It can greatly enhance their self-esteem.

Music therapy also plays a very important role for children with learning disabilities. Sensory stimulation and playful nature of music can help develop a child's ability to express emotion, communicate and develop rhythmic movement, and build self-esteem. It helps to improve interpersonal relationships, motivation, manage pain and stress, encourage socialization, self-expression, communication, motor development, and speech and language skills among children.

Music therapy is a complex task and requires certain special considerations before any individual takes it up. It is imperative that the therapist provides a non-threatening environment to the client. The therapist's perception of the client as an individual with self-determination is vital which is irrespective of the population the therapist works with. Before beginning work with any client, it is essential that the limits and expectations be defined. The therapist at all times has to be aware of individual responses and the significance of interactions in group settings.

It is important to note that noise and disharmonious music are equally responsible for disturbing the space around as well as within us. Healing and relaxing music brings the fields of resonance around and within us back to order and sets into motion a pattern that attunes us to our natural healthy rhythm. Music therapy offers a safe healing environment to get in touch with one's own feelings and emotions. So just sit back, relax and let the music play!

For more information about Alternative Mental Health and Paryayi, contact pujamodi@gmail.com

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