

# aaina

a mental health advocacy newsletter

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## Editorial

Another Erwadi day slipped by this year, unnoticed and forgotten.

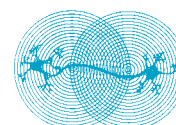
The WHO inspired World Mental Health Day on the 10<sup>th</sup> of October elicited enthusiastic response from many regions. On this day, the State Human Rights Commission of Maharashtra organised an event on Mental health and Human Rights, covering some human rights issues relevant to childhood and adolescent mental health. The Maharashtra Government gave away a coveted award to Shanti Nursing Home, in Aurangabad, for maintaining standards and outreach in providing mental health care. Shanti Nursing Home, a psychiatric facility, incidentally, has clearly articulated standards as well as infra-structural facilities for giving modified ECT. However, the event was funded by SEVAC, an organisation of psychiatrists, which clearly and unambiguously promotes the idea of “pills for pain” ideology in mental health. For some sceptics and those with strong sentiments about local participation, there was also the question of why SEVAC had to bring their “expertise” (and their drug basket), all the way from Calcutta to celebrate a local event: Is Maharashtra so short on local resources? The SHRC has offered to make a plan of action for submission to the Maharashtra government. Organisations and individuals in Maharashtra could follow up with the local authorities for the follow up on this program, where several health and mental health dignitaries from the government offices were present.

The Government of Gujarat has recently released a 200 odd page comprehensive report on the “Mental Health Mission”, under the aegis of the Department of Health. The analysis report is the result of 8 months of local research, aiming towards collecting local data, which will inform policy on the mental health needs and interventions for the State of Gujarat. Outside of service and finance issues, the Report covers various topics, usually not found in Indian policy documents on mental health, such as stigma, communication strategies, women’s issues, consumer and carer perspectives, ethics and law. The report recommends the strengthening of legal, ethical, regulatory aspects of mental health as well as consumer advocacy and self-help work in mental health in Gujarat. The document is likely to be useful in policy making circles, and the participatory process

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**bapu**

Trust  
for  
Research  
on  
Mind  
and  
Discourse

## The Need for Legal Vigilance in the Treatment of Mentally Ill Prisoners

Bibhas Damodar Vaze

Earlier this year I was part of a team investigating the law, treatment, and conditions affecting mentally ill (“MI”) prisoners in Maharashtra state. Recent years have seen increasingly sensational and brutal accounts of prisoner torture, including the acidic blinding of people in Bihar. And few need to be reminded of the burning beds in a Chennai mental health facility, so one might guess a combination of incarceration and treatment would not be very healthy. Indeed, the conditions and law relating to such prisoners have far to go, but at the same time there was little in our preliminary investigation that caused profound shock (though I allow that time can desensitize us all). What this indicates is that we are not at ground zero in ensuring that the MI within the criminal justice system receive both rights and treatment. Some awareness does exist and there are institutions upon which mental health advocates can and should build.

With a view to determining what protection there is for the MI who find themselves before the criminal justice system, our team looked through both the criminal and administrative laws at federal and state levels, and then conducted preliminary fieldwork in two prisons, these being the Pune Yeravda jail and the Ratnagiri Special Prison. We also visited the mental hospitals and judicial institutions in each area. Our objectives were threefold. For one, we

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*aaina* is a mental health advocacy newsletter. Advocacy demands critical, creative and transformative engagement with the state, policy makers, professionals, law, family and society at large. *aaina* will thematically cover issues in community and mental health, NGOs in mental health, self-help and healing, non-medical alternatives in mental health, rights, ethics, policy and needs of special groups. *aaina* provides a forum for user expression of their experiences with mental health services and debates issues concerning rights of persons with psychiatric disabilities. We look forward to meaningful dialogue with individuals and groups alert about these issues.

Those interested in receiving copies of *aaina* may contact us at [wamhc@vsnl.net](mailto:wamhc@vsnl.net). Write to us with all your suggestions, criticism and viewpoints on the issues covered.

This issue of ‘*aaina*’ was edited by **Bhargavi Davar**.

wished to see what special administrative procedures existed in the state and within each prison to deal with the MI *outside* of the legislated law, and whether such procedures were being implemented. Secondly, keeping in mind that official power ultimately determines treatment, we were concerned with the attitudes held by officials who deal directly with the MI, and the level of awareness they had both about the law and of the idea that mental illness is an illness. And finally, we wished to directly see the living and treatment conditions for MI prisoners. At the outset and at the end, the scenario we put before both ourselves and officials was the most basic: what happens –and what do you believe should happen– at all stages of the process following the arrest and incarceration of an MI individual.

A synopsis of some of the chief findings follows. My ultimate conclusion is quite banal; the submission is that extra vigilance is needed to ensure that the rights of the MI prisoners are respected. To understand this, we must understand the theoretical premise which allows us to reach such a conclusion.

### **Collective vs. Individual Rights**

There has been a persistent conflict between the ideas of collective and individual rights. At the extreme, the former believes that some individual freedoms must be sacrificed (by way of state action) in order to ensure the collective “right” of overall social welfare. The individualist paradigm essentially posits unlimited freedom without responsibility to the extent that such freedom does not interfere with the voluntarily-exercised freedom of others. Its extension is civil libertarianism, which includes the view that officials should never be permitted to sacrifice rights in favour of collective welfare, as giving power to them to decide on the best social outcome would allow for the arbitrary victimization of individuals. In today’s context of liberalization this debate has taken on a different turn; in India we ask ourselves whether indigenous collective structures are what we need, whether they be the family, the panchayat, or the state, or if, in line with democracy, we must adopt the individualist ethic which includes the denial of social responsibility on the part of both the state and individuals.

As always, the answer is about balance, but sometimes this is not so easy because if one leans in any direction there is always the possibility of toppling to the opposite extreme. And so in a country of India’s size, with limitations on oversight and riven by unobjective or illiberal tendencies including religion, caste, and language, one may inevitably favour civil libertarianism, of absolute protection for the individual rights of those who come before the state, whether as MI, criminally accused, or both. The idea is not to place a complete objection to family involvement or social protection as a whole, but that with so many interests at play, and the potential for abuse being what it is, only in very few circumstances should the interests of others hold primacy over that of individuals. Therefore, in order to ensure that there is no outside interference or ulterior motive in official action taken by officials in reference to MI persons, we must have due process scrutiny.

As we see, nonetheless, the long-held western belief that judicially-enforced liberties was all that was required to protect people had the fatal flaw of assuming that self-enforcing systems did not require strong social involvement in order to be successful.

### **The Law**

For the most part the penal and administrative law (such as the *Mental Health Act*) does have a myriad of provisions protecting MI rights. There are strong foundations, and an overall structure with which to work, but also dangerous gaping holes. For example, in the event that an accused is insane at the time of trial, the presiding judge will indefinitely postpone the proceedings until such time as the accused is either well or competent enough to instruct counsel. But there is no provision relating as to how proceedings should ultimately be disposed of should the individual never recover or fail to recover within a specified time. It could result in the horrific event (which has occurred in documented cases) that, due to oversight, a person could spend years or decades in jail for a minor crime that was never even tried. Of course, officials state that prosecutors, presiding magistrates and judges, jailors, and mental health workers pay constant attention to cases. But unfortunately one

cannot depend on the goodwill or vigilance of those who are often overworked, overstressed, underpaid and who may otherwise have an adverse interest. Similarly, in the view of some mental health professionals we interviewed, the penal law has completely failed to adequately define ‘mental illness’ or ‘mentally ill’, thus paving the way for arbitrary action to be taken (or *not* taken) against individuals.

### **Administrative Procedures**

The state of Maharashtra and individual prisons have extensive provisions –some legislated and some *ad hoc*-relating to the processing of MI prisoners. Once again, however, they give way to potentially uncontrolled action. In terms of deciding when an individual is sick and requires special attention or treatment outside the prison, for example, the decision is in the jail superintendent’s hands, based on the recommendation of a physician. However, there are only two prison psychiatrists in Maharashtra (in Pune and Nagpur) and in other cases the prison doctor assesses who is MI. There are some problems with this; firstly, the doctor may be employing a restrictive definition of mental illness (which we shall address next) and he or she may not even be qualified to make such a determination (which raises other systemic issues). Generally speaking, the procedures appear to put strong power in the hands of a superintendent, and overall, administrative procedures appeared to be informal, ethereal, and *ad hoc*. Whether they really existed in practise or were made up was a question, and it raises concerns about consistency in the treatment of prisoners.

### **The Definition of ‘Mental Illness’**

If we were to assume for the moment that the prisons were, indeed, doing their best to determine who is MI and treating all those who are ill, there would still be the problem of which definition is employed. There appeared to be the common conception that people were MI if they refused to eat, if they were ranting and raving, talking nonsense, or otherwise violent. But as we know, mental illness can extend across much wider boundaries; a person may suffer from severe depression and would otherwise not be a threat to others, but that does not make the illness any less severe or the need for treatment less acute. Furthermore, we saw a few people in the prisons who were clearly afflicted (one woman had killed her children

and had all the indications of illness) yet not defined as MI or given extensive treatment. A further wrinkle is that when some others were recognized as MI and expressed violent thoughts, they continued to be placed within the general prison population. The outcome, of course, is that it leads us to question how many people are suffering without being treated.

### **Awareness**

For the most part, prison, judicial, and law enforcement officials had a knowledge of the fact that mental illness was an illness and that MI individuals required special treatment. No one, for example, expressed the view that it was proper to beat or mistreat the MI, and both high- and low-level prison officials said that it was their duty to help those who suffered. How much knowledge they had of relevant ‘laws’ or procedures was difficult to determine. Once again, the MI must depend not on the protection of the law but on the extent of the general background officials have in recognizing mental illness *as* illness.

### **Special Cases**

We encountered a number of special cases, which, if investigated further, would provide excellent examples of how the law works –or does *not* work- in relation to the MI. There was the case that everyone was talking about in Ratnagiri, of a brilliant young man, educated in English, Marathi, and Gujarati, who misrepresented himself as a Supreme Court Justice; moved from place to place, from hospital to Court to prison, all the mechanisms of the law had come into play. Then there was the instance of a MI woman who committed a crime while in hospital and was *then* put into prison with no one paying attention until she became violent with a courtroom clerk. And sadly, we had the experience of meeting a young woman who, it seemed, was suffering from illness and wanted to bring it to the Court’s attention, but where was the lawyer to do so?

### **Conclusion: Legal Aid and the need for Vigilance**

There has been little doubt that India’s legal aid system needs to be reformed so that low-income and otherwise marginalized people can truly have access to proper legal representation. This issue becomes starker in relation to the mentally ill. It furthers the idea that

there must be action –whether from civil society, the private sector, or government- to provide a legal aid program to the MI within the justice system.

I began by commenting on the difference between the collective and individual approaches to rights, indicating that many believed an industrial or post-industrial society of India's size required the latter to ensure that criminally accused would be protected. I did so to highlight a major theoretical flaw, which is raised by our project. No system, regardless of how many checks and balances it has to protect people from state power, can survive without those who are vigilant enough to speak out and act in a manner that makes the checks and balances work. It may be lawyers, judges, physicians, civil society, or individual police officers. But somebody has to ensure protection of those who are before the system and cannot speak for themselves. The MI do have voices of their own which must be heard, and they need advocates on their behalf. For all the gaping holes in the law relating to the MI in the criminal justice system, there is a solid foundation. But it will require vigilance to make it work both socially and individually. In my view, a good first step in this process would be in instituting a legal aid system that can ensure there will always be advocates protecting MI prisoners at every stage of their struggle.

(Acknowledgement: In undertaking the study described, the author acknowledges the extensive assistance of Darshana Bansode and law students Varsha Wankhade and Ayesha Sen Choudhary, and the project guidance of Prof. Amita Dhanda. As always, this project and my participation would not have been possible without the initiative, hard work, and patience of Dr. Bhargavi Davar and the entire BAPU staff.)

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## **Editorial** (...continued from page 1)

that the Government of Gujarat set up in bringing out the report, may pave the way for other state initiatives in mental health. Organisations and individuals interested in taking a *dekho* at this document could write to and ask the state health authorities for more information.

Meanwhile, various consumer organisations and mental health support groups around the world are preparing to influence the proposed UN Convention of Rights for persons with disabilities. One round of Ad Hoc Committee meetings were over, and preparations are on for the next one. This is certainly an initiative that requires advocacy from the point of view of psychiatric disability. We need to be more closely in touch with the India office making representation at these eminent gatherings.

The WHO initiatives in mental health of “developing nations” has been gaining ground, with many policy documents, training programs and resource materials and manuals being prepared. Critics of the WHO initiative in mental health argue that the organisation is working too closely for comfort with drug companies and with medical professionals, to the exclusion of consumer or consumer support groups. The rationality of stamping a western model of care in culturally different zones is being questioned.

Several workshops and programs have been held in different regions this quarter. A workshop in Chennai was organised by Action Aid, India, at The Banyan, to facilitate the formation of a national level movement to address the overwhelming care needs of wandering mentally ill persons. Every bit of help or local initiative will be appreciated and interested people could get in touch with the Action Aid India, New Delhi office, for news on this. Anveshi, Hyderabad, organised a meeting on “Family and mental health”, a brief report of which is given here. The Center for Advocacy in Mental Health, Pune, organised a program on ‘Alternative mental health’ which promoted non-drug alternatives to mental illness. Topics covered were homeopathy, nutrition, hormonal treatments, play therapy, drum circle, music therapy, dance therapy, neurolinguistic programming, self help, story telling, etc. A full report is available in print form from the CAMH office.

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The last category of disability on the Persons with Disability Act, 1995, is the one concerning disability due to mental illness. There have been many consultations and meetings set up by the UN towards developing a Convention of rights for persons with disabilities. Consumers of all disability services, including psychiatric and rehab services, all over the world are participating in these consultations. Here, we present the text of the statement presented by Mr. A. Gopinathan, Deputy Permanent Representative of India to the United Nations, for second session of the Ad Hoc Committee meeting, held in New York on the 19<sup>th</sup> of June, 2003.

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“India is fully committed to the realisation of social justice and the empowerment of person with disabilities. We recognise the impact of dual disadvantage and multiple discrimination faced by specific groups such as children, women, rural poor, severely and multiply disabled. In India, in the past decade, the very concept of Rehabilitation has been redefined from the perspective of an individual pathology to that of an issue of human rights and its accompanying implications for broader social change.

“Over the past decade, India has had the advantage of implementing three pieces of legislation for the full participation of persons with disabilities. The Rehabilitation Council of India Act was enacted in 1992 for standardising professional courses in rehabilitation and registering qualified professionals. The landmark legislation of Persons with Disabilities (Equal opportunities, Protection of Rights and Full Participation) Act was enacted in 1995 to ensure equal opportunities for persons with disabilities, to prevent discrimination and deprivation, promote participation in education, training, employment, etc., and to provide for affirmative action in creating accessible environments and to redress the grievances of persons with disabilities. The National Trust for the Welfare of persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities Act was passed in 1999, which enables persons with these four disabilities and organisations for/of them to strengthen families in crisis and provide for legal guardianship of persons with disabilities beyond the age of 18 years. This Act also encourages and supports the formation

of Parent’s Associations where persons with intellectual, severe and multiple disabilities are themselves unable or unwilling to engage in self-advocacy.

“The Government is working at present with over 1500 NGOs in the disability sector. Over 20,000 rehabilitation professionals have been trained, registered and are practicing. More than 6000 grievances have been redressed in the last 3 years. There are over 750,000 students with disabilities in the mainstream education system where 1 million teachers in regular schools have had training in inclusive education. Over 12,000 persons with disabilities have been employed in the government sector alone. More than \$ 10 million has been disbursed as soft loans to 14,000 persons with disabilities through the National Handicapped Finance and Development Corporation of the Government to set up self employment ventures. As many as 78,000 persons with disabilities have been included in mainstream poverty alleviation programmes, mainly in rural areas of India. Through the government rehabilitation programme alone, almost 2 million persons with disabilities have been served across the country. ...

“India believes that all disabled persons have a right to opportunities for holistic development. Any infant born with in impairment or at risk of one, must have immediate access to diagnostic services, appropriate medical/surgical intervention, parent counselling, fitment of assistive devices, where necessary, and also access to necessary therapies

aimed at the development of the full potential of the child with regard to activities of daily living, movement, communication and cognitive abilities. They may also need special support in their education and employment for which appropriate services have to be made accessible and available. Even though many children can and are included in regular schools and work places, the education system and the employment market itself needs to be further modified and made more inclusive supported through provision of appropriate teaching/ learning materials resource support, transportation services, etc. Persons who become disabled in later life through accidents, illnesses and degenerative diseases also need access to rehabilitation services. After the initial interventions, support may be required for vocational training, access to higher education and employment/economic opportunities for earning a living.

“The process that is currently underway in India is dual in nature with multipronged strategies in extending the reach of rehabilitation services on one hand as well creating attitudinal changes in civil society which is essential for a multisectoral convergent and inclusive society....

“While India is ready to examine the need for the elaboration of a legal instrument, it is essential that a number of issues be addressed while considering the issue. It will not only be necessary, but will be vital to ensure that adequate resources are available and committed for addressing the critical gaps between the actual needs and available services. In many developing countries, including India the population of disabled persons is large and a majority of them are in their childhood or in their productive period. ...

“Research in this area followed by appropriate counselling can address the prevention of causes of disabilities such as hearing impairment, muscular dystrophy, retinitis pigmentosa, etc. ...

“It is known that disability is over – represented in the population which is at or below the poverty line of the general population. Their inclusion in poverty alleviation programmes and in economic empowerment strategies is vital. ...

“Affirmative action *across the board* in favour of persons with disabilities is strongly supported by India. Steps have been taken to reserve seats in education programmes and in Government employment for persons with disabilities. However, additional support is required particularly towards ensuring barrier free access to public buildings, transport services, etc. Besides, all places of employment education, recreation, entertainment, etc. need to be done to make existing facilities accessible and for ensuring that future buildings, outdoor spaces and transportation reflects the needs of persons with disabilities. This requires financial investments of large magnitudes for a society like ours, and provisions and mechanisms need to be incorporated in the draft convention to provide for resource flows for these purposes.

“Persons with disabilities also need protection from discriminatory practices. The Constitution of India provides this protection. Besides, the persons with Disabilities Act, 1995 prohibits discrimination on account of disability. Any legal instrument needs to have strong and adequate provisions for protection of the disabled persons from any kind of discrimination whatsoever....

“India strongly believes that any international legal instrument should aim to protect and promote the rights of persons with disabilities in all areas of their development as well as protection from discrimination; and is therefore supportive of a ‘hybrid model’ for any Convention.

“Any legal instrument should ultimately promote and protect the full range of rights of persons with disabilities including civil, economic, social, political and cultural. A Convention should set standards, which are not below standards already established and contextual to member countries.

“The draft convention must commit itself to facilitating opportunities that empower and enable persons with disability through training, care, income, and social inclusion, ways and means of strengthening families, environments that are free from physical,

informational and psychological barriers, ideologies and societies that are inclusive in nature and access to programmes that are affordable and available. ...

“India will continue to work towards a progressive realisation of all the fundamental rights of persons with disabilities, reaffirming their personal freedoms and need for autonomy, which will inter alia reflect a paradigm shift from welfare to rights and opportunities for full participation and the creation of a society that is free from barriers of discrimination, violation and denial of equality, dignity and social justice to persons with disabilities and their families.

“In furtherance of this goal, the Government will strive for pervasive social change, which permeates into mainstream activities of community life so that persons with disabilities in India can lead a life of quality, dignity, equality and justice in a society, which is free from bias, prejudice, stigma and discrimination.”

*Information on the convention and present discussions on it can be downloaded from the United Nations website. The topic of “Disability due to chronic mental illness” is not touched upon in the India representation. Do write your concerns about this serious omission to the India Representative or the Disability office in New Delhi.*

*Address: Permanent Mission of India to the United Nations, 235 East 43<sup>rd</sup> Street, New York, NY 10017. Tel: (212) 490-9660. Fax: (212) 490-9656 E-Mail: [India@un.int](mailto:India@un.int)*



## “Sorry...

... we made an error in our November 2002 issue, on the SC stand on ECT. The SC has so far not commented on the use of ECT. However, the GOI issued an affidavit to the SC, upon advise from the AIIMS professionals, noting the safety of direct ECT.”

## Moving Towards Sex Positivity

A review by Pooja K. Khialani

*“Wickedness is a myth invented by good people to account for the curious attractiveness of others.”*

*–Oscar Wilde*

Sex is commonly viewed as being wicked, sinful and dirty. Nearly all of us learn from a very early age that we need protection from our sexuality. Instead of accepting sex as being an integral part of our lives, we cultivate the belief that sex is inherently bad.

In his article, “*The language of sex-positivity*”, Charlie Glickman, a sex educator, focuses on how to break down negative views about sex or, “*sex negativity*”. Glickman rightly explains how the first step to changing negative attitudes regarding sex is to create a new language to discuss sex. Glickman in comparing sex and food, uses an interesting and highly effective analogy to demonstrate how viewing sex as being a normal and integral part of life, would aid in moving towards a sex positive world. Even those who maybe highly uncomfortable with discussing issues regarding sex, are bound to find this analogy quite convincing.

“*Sex positivity*” is commonly defined as the belief that sex is good. However, Glickman reframes sex positivity as being “working towards a more positive relationship with sex”. This redefinition not only acknowledges that sex is neither good nor bad but also recognizes that each individual has a different relationship with sex as it is a subjective experience. Moreover it also demonstrates that an individual’s relationship with sex always has room for improvement. Glickman also succeeds in demonstrating to the reader that sex is infact no different from any other basic need of human beings. It is just that sex has been overly hyped as being bad; hence leading to a world that is largely sex negative.

Furthermore, sex positivity allows us to stop questioning our own normality. In a sex positive world, one would not have to worry about being “normal” as



comparisons with others would cease to be important and “normal” would be defined as what is normal for ourselves. In addition to this, a sex positive world would be more poly-positive as the number of partners and their genders would no longer be of importance as long as everyone is happy. Glickman demonstrates how becoming sex positive helps bring the world closer. Another advantage of sex positivity as stated by the author is that it helps us get what we want by doing the equivalent of trying new foods. It hence accommodates for the fact that our sexuality changes over time as a result of which our needs change too.

Sex positivity also changes the way we speak in several ways. The author brilliantly describes how language around sex reinforces sex negativity without our realizing it. He explains how while abusing people we use words that are sex related such as asshole, dick etc. as opposed to calling people elbows or ears! This clearly demonstrates that some part of us believes that there is something wrong or bad about these organs. Trying to use other words can thus change how we think about sex words. Another change in language as a result of sex positivity is being able to use accurate words and hence being able to convey what one really wants. Also as Glickman illustrates, since most of our sex negativity comes from our body negativity, overcoming one often involves overcoming the other. In addition to this, Glickman explains how learning to break sex negativity is linked to working to end other prejudices. An example provided by him to illustrate this point is how sex negativity enforces sexism every time a woman is insulted by being called a slut.

The author succeeds in conveying to the readers the importance and need for sex positivity. In today’s so-called liberated culture, it is indeed sad that we are still unable to come to terms with our sexuality and to accept sex for what it is—a basic need for every human being. We still view sex as being an animalistic instinct that is necessarily evil unless it is used for procreation, especially in India. It is necessary for us to break these barriers of sex negativity in order to be able to function at an optimum level in various domains in life. Articles

such as the one by Glickman can go a long way in changing negative attitudes about sex. In addition to being compelling and forceful this article in itself succeeds in breaking the first barrier of sex negativity by openly talking about sex and the need for sex positivity. Moreover, the article helps us understand how many prejudices just creating a more sex positive world can do away with. Just imagine how much more tolerant we would be of the gay and lesbian communities if we were sex positive. And this covers only one domain of discrimination. We can only imagine how many more forms of prejudices a sex positive world can get rid of. Food for thought, isn’t it!

*Readers can find Charlie Glickman’s article in the Electronic Journal of Human Sexuality, Volume 3, July 6, 2000 at [www.ejhs.org](http://www.ejhs.org)*



**Father:** *The shock treatment did not help cure my son’s illness. But it saved me a lot of money otherwise.*

**Friend:** *How?*

**Father:** *I bought only one movie CD for him to watch. He has already watched it 40 times. But everytime he watches it, he thoroughly enjoys it, as if it was the first time he is seeing it. He doesn’t remember anything!*

## ‘The Family and Mental Health’

Jayasree Kalathil

The workshop on “The Family and Mental Health”, organized by Anveshi, Hyderabad in April 2003, was the outcome of the year-long discussions within the Study Group on Mental Health in Anveshi. In the study group, several issues relating to the understanding of and coping with distress were debated in the context of the family. These debates highlighted the fact that what each of us understand as the family was necessarily different – a difference that is not simply in terms of an ahistorical experience of the family, but rooted in the changing modes in which the idea of the family was being articulated. The workshop sought to look closely at the articulations of and negotiations with mental distress in the context of family and addressed concerns in understanding distress, the question of care, issues in working with families and the legal implication for the family as caregiver.

The introduction by Jayasree Kalathil (Anveshi, Hyderabad) laid out how the family features in statist interventions and policies on mental health, the concerns that have come up in discussions within caregivers’ groups and as spoken about in narratives of distress. In statist interventions and policies, the family is mostly seen as an isolated unit, with a natural tendency to nurture. There seems to be little acknowledgement of the conflicts within families and the contradictory desires of individual family members. These are evident in the concerns of caregivers groups and in the way distress is articulated in experiential narratives. The isolation that the family faces in mental health care seems to be the result of a lack of understanding of the family as a complex unit within political processes. The significance of mental distress and the experiences of it need to be placed within institutions, language, interactions and discourse for a more nuanced engagement.

Reviewing the social anthropological engagements with the family, Bindulakshmi (IIT, Mumbai) elaborated on the problems with understanding the family as the ultimate location of care. Despite efforts to universalize and naturalize the heterosexual family, there is more and more evidence of crisis within family. What is required is a re-articulation of individual emotions. We need to consider that emotions are not only the products of socialization but might also break away from given patterns of social mandates, within which they are sought to be authorized and expressed. It is only through a concerted and systematic dismantling of the existing ideas of the family, familialism, family ties and familial emotions that we can arrive at a positive articulation of emotions, thus paving the way for a better and healthy living standard for the individual within this institution.

Is a re-examination of the family as an institution necessary in the context of mental health? Is it not enough to address how each individual member reacts to distress within the family? It was felt that while individual interactions with the distressed person is extremely important– and is the most commonly addressed issue in family therapy– it is the absence of a critical analysis of the idea of the family that creates the current situation in concerns about the family in mental health. In addition, how much can a therapist do to negotiate individual interactions?

Sadhana Vohra (The Psychological Foundation, Delhi) looked at how the therapist negotiates with the family. The issue of “my family” and “what they have done to me” seems one of the main things that many people have had to deal with in their work on their mental health. Very often, a family’s concern is experienced as controlling and leads to many of the tensions in the relationship. The idea of “toxic families,” where the structure works in modes of controlling and containing, is still valid. A therapist’s work is to help identify support and separate it from control and to facilitate the client to work with the support to enhance her mental

health. The need to question assumptions about unconditional love was raised again by Sadhana, even as she spoke of the shifts in the rigidities associated with the Indian family.

Looking at the representations of mental health and the family in Hindi cinema, Madhumeeta Sinha (Anveshi, Hyderabad) spoke of the conspicuous absence of the family in recent films like *Road*, *Deewangi* and *Aankhein*. In a context where the family is often the site of conflict resolution in Hindi cinema, the absence of any discussion of the family in these films lends to the construction of the obsessed individual who pushes his desires to limits without being concerned of the consequences. Another break with the past is the portrayal of the villainous heroes in these films in a way that invokes the sympathy of the audience. The narratives in these films seem to blur the boundaries between sanity and insanity and between being good and being bad. We need to explore the consequences of the absent family in the portrayal of cinematically defined mental illness.

Another context where the family often finds itself in a fraught situation is the legal aspects of mental health. Analyzing the law's interest in mental health, Amita Dhanda (NALSAR, Hyderabad) said that along with its concern of preservation of order, the law is also concerned with protecting people in distress. In almost all instances, the legal provisions are activated not by the people for whose protection the law claims to function but by people who benefit from their property. The legal order battles with the question of the family as protector and as transgressor. As protector, the law designates the family as the surrogate decision-maker for the person with mental illness and empowers it to take all kinds of decisions relating to care and treatment. As in other contexts, in the legal context also, there is an assumption of the innate good intentions of the family towards the person experiencing mental distress. It assumes that relatives cannot or will not treat this person cruelly. But even as these assumptions are made, the law recognizes the family as transgressor. For instance, no legal heir can be appointed as a surrogate decision-maker. This is a major acknowledgement of self-interest or conflict within the family. The law essentializes both the family and the person with mental illness. There is no recognition of the nuances of either the family or of mental illness. While there seems to be some suspicion in matters regarding property, there is no such acknowledgement in matters like personal liberty of the person with mental illness.

The nuances of the negotiations that go on in the situation of family based care were discussed in the panel on "Questions of Care." K. Lalita, Sheela Prasad, Veena Shatrugna and Vasudha N (Anveshi, Hyderabad) spoke on the panel. Based on interviews with two persons diagnosed with schizophrenia and their families, Lalita and Sheela spoke of many issues in care. In general, they found that psychiatrists are more concerned with diagnosis and cure rather than involving the family in care. There is very little help for the family members from any quarter. They have to deal with their sense of guilt, shame and often their own stress and depression on their own. Social ties are slowly lost and they seem to move towards larger isolation. Each family seems to work out their own ways of dealing with everyday life, taking care of the needs and communicating with the person experiencing distress.

Veena's presentation reiterated the social isolation and "shrinking" that the family experiences. She raised the question that perhaps family is not the best place for care. It is the family that is the most involved; it is also the one that is caught in the complicated patterns of communication. We have only frightening histories of mental hospitals. The only available resort for the families are the dargas, babas and so on. It is unfortunate that we did not work with any other system that gave the right amount of care, love and perhaps medication. The family is fairly burdened and the stress placed on it produces all kinds of skewed reactions. We need to do a lot more work in this area in order to find out how to open up new spaces within the structures of these institutions.

Vasudha felt that the idea of care in the context of mental distress is very different from that of physical illness. One has no physical measures to depend on to gauge the reactions of the person one is caring for. Vasudha also pointed out that the kind of care that is required is very specific to the person who is being cared for. For instance, caring for a child who is experiencing distress is very different from caring for an adult. The world of the caregiver is as isolated as that of the person experiencing distress. Rather than posing them as in opposition with each other, we need to understand how they are trying to work out a world together.

The workshop raised several issues about the family in mental health care. On the one hand, it was felt that in the absence of any other unit which is involved in care, the idea of the family needs to be retained unquestioned. Negotiations happen in these spaces and the person's stature in the family changes over time, resulting in changes in the ways in which the family reacts to the person's distress. On the other hand, several people argued that the ahistorical and isolated ways in which the family or members of the family continue to exist in the thinking about mental health care perpetuates the completely individualized understanding of distress itself. Everything becomes a matter of personality, as if personality itself is a natural category. Unless we take into consideration the ideological baggage that overwhelms the disparate ways in which families actually function in society, can there be any way out of the static and individualized idea of the family and of distress, not only in therapeutic situations, but in the larger contexts of mental health debates.

Is the problem, then, with the assumed naturalness of the space of the family as the only space where an individual really belongs? Is "the family" that we are talking about the same as "the family" in social anthropology or in feminist criticism? Or would it be more productive, for mental health debates, to look at the negotiations that happen within spaces of care, and see what idea of the family emerges from these negotiations? The workshop opened up several questions for future work in this area.

Jayasree Kalathil prepared the report for the Study Group on Mental Health, Anveshi Research Center for Women's studies, Hyderabad (hyd1\_anveshi@sancharnet.in). Jayasree started the *aaina* initiative in 1999 for Bapu Trust. She now works with the Mental Health Media, London on an anti-discrimination tool kit project for users of mental health services. She can be contacted at-jayakalathil@yahoo.com



## **Thank you, *aaina* readers, for your feedback...**

Of the 200 letters sent out to readers of *aaina*, we received 26 valuable responses. You have found *aaina* useful. Some feel that clinical aspects of mental disorder should be more comprehensively covered, but others feel that *aaina* is set at the right, if unusual, pitch. You have given a wide range of topics for more comprehensive coverage, including

"Mental health of women, homeless people, people within institutions, positive mental health, prevention, latest drugs, new research, ethical issues in mental health, emerging psychiatric illnesses (ADHD and PTSD), more on Drug Tracks, role of the family, linking with disability rights, suicide prevention, user accounts of drug use, more of advocacy news and speaking our minds, rural outreach, human rights, news about voluntary organisations, use of art forms in overcoming trauma, yoga / meditation in mental health, rehabilitation, stress management and policy.

You have urged that we do less armchair, and more action oriented, writing. This sharing has helped us to imagine an *aaina* community, and we hope to draw from your vision and experience to take *aaina* forward in the coming months. Do write in about concerns, initiatives and campaigns from your own region.

Rose D, Fleischmann P, Wykes T, Leese M, Bindman J. (2003) Patients' perspectives on electro-convulsive therapy: Systematic review. *British Medical Journal*, June 21, Vol 326: p. 1363

The objective of this systematic review was to ascertain patients' views on the benefits of and possible memory loss from electroconvulsive therapy, by looking at data sources from Psycinfo, Medline, Web of Science, Social Science Citation Index databases, and bibliographies. Articles with patients' views after treatment with electroconvulsive therapy were selected. 26 studies carried out by clinicians and nine reports of work undertaken by patients or with the collaboration of patients were identified. 16 studies investigated the perceived benefit of electroconvulsive therapy and seven met criteria for investigating memory loss. The review shows that the methods used by the studies were associated with levels of perceived benefit. At least one third of patients reported persistent memory loss. The study concluded that the current professional claim that over 80% of patients are satisfied with electroconvulsive therapy and that memory loss is not clinically important, is unfounded.

Bolton P, Bass J, Neugebauer R, Verdelli H, Clougherty KF, Wickramaratne P, Speelman L, Ndogoni L, Weissman M. (2003) "Group interpersonal psychotherapy for depression in rural Uganda: a randomized controlled trial" *Journal of the American Medical Association*, June 18, 289(23): pp. 3117-24.

The objective of the study was to test the efficacy of group interpersonal psychotherapy in alleviating depression and dysfunction and to evaluate the feasibility of conducting controlled trials in Africa. For this cluster randomized, controlled clinical trial, 30 villages in the Masaka and Rakai districts of rural Uganda were selected. 15 were then randomly assigned for studying men and 15 for women. In each village, adult men or women believed by themselves and other villagers to have depression-like illness were interviewed using locally

adapted tools. 341 men and women who met Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV) criteria for major depression or subsyndromal depression were interviewed. Of these a total of 108 men and 116 women completed the study. Eight of the 15 male villages and 7 of the 15 female villages were randomly assigned to the intervention arm and the remainder to the control arm. The intervention villages received group interpersonal psychotherapy for depression as weekly 90-minute sessions for 16 weeks. Main outcome indicators were reduction of depression and disability. The study found that group interpersonal psychotherapy was highly efficacious in reducing depression and dysfunction. This is a benchmark study in appropriate cultural psychotherapeutic models for use in depression care in non-western societies.

Laine, K., Heikkinen, T., Ekblad, U. and Kero, P. (2003) "Effects of exposure to selective serotonin reuptake inhibitors during pregnancy on serotonergic symptoms in newborns and cord blood monoamine and prolactin concentrations" *Archives of General Psychiatry*, July, 60(7): pp. 720-726.

The study investigated the perinatal sequelae of infants exposed to SSRIs during their fetal life and the relationship of these symptoms to the cord blood monoamine and prolactin concentrations. It was a prospective, controlled, follow-up study with 20 mothers taking 20 to 40 mg / d of either citalopram or fluoxetine for depression or panic disorder, and their infants, and 20 matched controls not receiving psychotropic medication for confounding obstetric characteristics. Maternal cord blood and infant drug concentrations were measured. The newborns underwent standard clinical examination and specific assessment of serotonergic symptoms during the first 4 days of life and at the ages of 2 weeks and 2 months. The study found that infants exposed to SSRIs during late pregnancy are at increased risk for adverse effects on the serotonergic central nervous system.

## A view from below

Ram Kakkar

My summer placement as a first year student of NALSAR, University of Law, Hyderabad, was at the Central Institute of Psychiatry (CIP) in Ranchi from the 10<sup>th</sup> of May, 2003 to the 30<sup>th</sup> of May, 2003. As part of my placement, I interacted with the doctors, nurses as well as the patients with a view to gain a first-hand experience of the state of institutionalized care for the psychiatrically challenged and analyze the role of law and its effectiveness in this field. The more time I spent working at the CIP, the more I realized that the need for proper legislation for the protection of the mentally challenged against discrimination and exploitation is immense.

Medical disorder is an illness as well as a disability. Like any other human being, the people with mental disorders too have rights. But because of their disability they are more prone to discrimination and exploitation. That is where law is required to safeguard their interests and rights, and for the welfare of the mentally disabled.

The time at the CIP was well spent, gathering information about the admission procedures, kinds of 'illness', forms of treatment, a study of outpatients vis-à-vis the inpatients, facilities provided in the hospital premises, etc. During my assignment, I realized that there were working problems that created loopholes in the provisions of the Mental Health Act, 1987, to the detriment of the mentally ill patients at large. The ground realities and practicalities (at least with regards to the CIP) make it difficult to implement the provisions in the spirit they were intended to be.

The Central Institute of Psychiatry was established on the 17<sup>th</sup> of May, 1918. Initially, it catered to the needs of European patients only. Eighty five years down the line, it is one of the premiere psychiatric institutes with the best facilities and doctors in the country. It runs under the administrative control of the Directorate General of Health Services under the Ministry of Health and Family Welfare, New Delhi.

The Institute covers a sprawling 400 acres of land with an immense scope for development.

The Outpatient Department (OPD) functions in a separate building outside the main hospital boundaries of the CIP. The number of patients from various parts of East India who are treated at the OPD has been steadily increasing. In 1980, only around two thousand patients came for consultation services and most of them got admitted. Twenty three years later, the OPD of the CIP now gives consultation to more than twenty five thousand patients a year, few of whom are admitted. The OPD also has wards to admit patients temporarily or in cases of emergency, when admission to the in-patient department is not possible. Electro convulsive Therapy (ECT) is available in the OPD. The doctors here examine the patients and determine whether admission in the IPD is necessary. Patients requiring constant supervision of doctors may be given admission to the Inpatient Department (IPD). Admission may be given by any of the following procedures:

1. *Voluntary admission:* In accordance to section 15 of the Mental Health Act, any major who considers himself to be mentally ill and desires admission in a psychiatric hospital may do so by filling up the voluntary admission form.

2. *Involuntary admission:* In accordance to section 19 of the same act, if a person is unwilling or too disabled to give voluntary consent, he may be admitted as an inpatient by filling up the form for admission of patients under special circumstances.

3. *Through a magistrate:* In accordance to sections 23 and 24 of the Mental Health Act, any person who for reasons of mental insanity is detained by a police officer must be produced before a magistrate within 24 hours. The magistrate after the necessary enquiry and examination by a medical officer may pass a reception order authorizing his or her admission as an inpatient in a psychiatric hospital.

The Inpatient Department consists of sixteen wards- separate sections for the male and female patients and a family unit (in case one or more of the family members wish to stay with the patient during most of his/her treatment). The total capacity of the IPD stands at 643 patients though it generally holds about 450-500 patients at any given time. The number is variable because admissions and discharge takes place on an everyday basis. The number of doctors, nurses and ward attendants to supervise the treatment and care of patients varies from one ward to another.

Patients are admitted for two months at a time, and depending on their progress, they may be readmitted or discharged at the end of the said period. The facilities provided to the patients vary and the wards are classified in three types. Admission given for two months at the IPD may amount to Rs. 300, 900 or 1200 per month, depending on what the patient can afford. (The number of patients kept per room in the wards decrease respectively). Consequently, the proportion of the number of patients to doctors, nurses and attendants also goes down. The IPD, amongst other forms of treatment provides for a de-addiction centre and an occupational therapy department.

### **The De-addiction center**

The de-addiction Center, within the main hospital boundaries is for patients whose lives are so terribly affected by habit-forming drugs, that they become incapable of thinking rationally. A considerably large section of the lower strata of society in the region needs an escape route from their depressing, overburdened lives. They find temporarily relief in drugs, which seems like a solution to all their troubles. With passage of time, they get so badly addicted that all other aspects become secondary to the temporary utopia they find in drugs. The addicts become violent, helpless and lose control of their own lives, directly affecting a number of others. This kind of addiction also comes within the ambit and scope of mental health because it is considered to be mental disease that affects clear, unambiguous thinking on the part of the

addict. The de-addiction centre provides treatment to these people by way of medication and counseling.

### **Occupational therapy**

The Occupational Therapy Department (OTD) at the CIP is the oldest of its kind in India, established in 1922. Also within the premises of the IPD, it keeps the patients occupied in a positive, constructive manner. The patients spend their time in activities such as gardening, carpentry, painting, pottery etc. under the supervision of the attendants.

The Occupational Therapy Department plays an important role in the daily routine of the inmates. Patients are generally woken up by six-thirty in the morning. Treatment and check ups follow breakfast and after lunch around noon, when the patients would otherwise have nothing else to do, the OTD keeps them engaged. The inmates learn a lot through such activities that may help them once they are discharged. The creative endeavors of the inmates- paintings, pottery and furniture, the aesthetic appeal of which has to be seen to be believed, are prominently displayed throughout the Institute, haunting reminders of the frustrated minds trapped inside, seeking an outlet.

About two kilometers from the CIP is the Davis Institute of Psychiatry. More than 50 years old, this privately owned well known psychiatric institute also caters to the needs of the mentally disabled from all parts of the country. The working of this institute is very similar to that of the CIP, though on a much smaller scale. My visits to the Davis Institute were primarily regarding the Electro Convulsive Therapy controversy. Both these institutes provide ECT in its direct form, which is criticized by many. However, doctors of both these hospitals strongly refuted these criticisms. Referring to their experience on the subject, the doctors pointed out that the highly publicized cases of direct ECTs creating complications are the exception rather than the rule, and though modified ECT may be preferable, with the limited means and resources in the field, it would be wrong to classify the direct form as inhuman and cruel.

## **Informed consent**

Section 15 of the Mental Health Act states that any major who considers himself to be mentally ill, and desires to take admission in a psychiatric hospital or nursing home for treatment may request the medical officer in charge for admission as a voluntary patient.

## **Who Should Apply**

This section is specifically for patients who suffer from mental illness' like the *Obsessive Compulsive Disorder* or *severe depression* and are capable of understanding the problem, related issues and the treatment that may be given to them. The question of informed consent is critical here for which knowledge is a pre-requisite. The mentally disabled have a right to know about their illness and the treatment that may be given to them before they give consent. Voluntary admissions are only for these patients who do not suffer from the more acute disorders and are capable of understanding the relevant issues.

## **Who Actually Gets Admitted On Voluntary Basis**

Ranchi, as is the case with other places in the region from where the CIP receives a large number of patients, has a pitiable literacy rate. It is imperative to repeat here that admission on voluntary basis revolves necessarily around the concept of informed consent. Most of the patients are unable to read or understand the contents of the admission form, which I may add is only in English. Often, they are asked to sign or even give thumb impressions on the form without being informed about the illness that they suffer from or the treatment that they are consenting to. The concept of informed consent, for all practical purposes, at least at the time of admission, gets thrown out of the window, even when there are provisions for it.

Also, patients too disabled to give consent may sometimes be admitted on 'voluntary' basis, by merely making them sign the voluntary admission form. These patients should ideally be admitted under section 19 (*i.e. admission under special circumstances*) which is for "any mentally ill person who does not, or is unable to, express his willingness for

*admission as a voluntary patient....* ". Section 19 has certain complications that may be made simpler by giving admission under section 15. The patient, on paper, would have thus given his consent to various forms of treatment even though he was unable to express his willingness as a voluntary patient. A mockery is thus made of the concept of informed consent.

The doctors, however, insist that the patients are informed about the illness that they suffer from at the time of treatment and consent is obtained wherever required. Only in some emergency cases, when there is no way that consent could be obtained, are the patients provide treatments like the ECT without their knowledge.

## **Direct shock**

Electro Convulsive Therapy is used to pass small electrical current (0.5-0.8A) through the brain via electrodes applied to the scalp of a person. The current stimulates the brain and elicits a generalised seizure. Psychiatrists point out that ECT is life saving for patients with suicidal instincts or severe depression, something that cannot be refuted by even its fiercest critics. However, in India, administration of anaesthesia for the treatment is not mandatory and psychiatric institutes across the country, including the CIP and the Davis Institute of Psychiatry, give ECT in its direct or unmodified form (*i.e. without anaesthesia*).

The Delhi based NGO, 'Saarthak', filed a PIL<sup>1</sup> in the Supreme Court in October, 2001, calling for a ban on the practice of physical restraint and administering of unmodified ECT. It is their view that this form of treatment is unsafe as well as cruel given that a common after-effect of the direct form of ECT is weak or broken bones on the part of the patient.

The Indian Psychiatric Society (IPS), an association of over 3,000 psychiatrists, however, strongly opposes this view, insisting that most patients feel no pain during this treatment. This claim is difficult

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<sup>1</sup> *In Re v. Union Of India; (2002)3 SCC 31*



to accept. The actual way in which direct ECT is carried out is nothing short of barbaric, the patient being held by three or four other persons or having his limbs tied. Supporters of the practice, however, are quick to point out that this is only to make sure that the patient does not hurt himself during the process. Psychiatrists, even in light of constant controversy, continue to insist that the direct form of ECT is as safe and successful as the modified form.

Direct ECT is routinely conducted across India because of the unavailability of qualified anaesthetists and due to the fact that modified ECT would increase costs by upto Rs. 1,500 per patient.

There is no doubt that modified ECT would be preferable over the direct form, but time and effort will be needed before this becomes a reality. While 'Saarthak' continues to dub the procedure of direct ECT as "barbaric", the debate still continues. There is little doubt regarding the importance of this therapy. However, if it is as inhuman, cruel and barbaric as it seems, then it must be banned and efforts must be made towards making modified Electro Convulsive Therapy available in all psychiatric institutes.

### **Informed Consent – Food for thought**

No matter how much has been written about the hotly contested issue of informed consent (or rather, the lack of it), as in everything else, my experiences at CIP opened my eyes to the dichotomy that exists between ground reality and the written word. "Concerned" NGOs cry themselves hoarse over patients being admitted without their knowledge or against their will and this apprehension, while by no means overstated, glosses over an important issue. What we often overlook is that mental illness remains a taboo and even those families bold enough to actually bring a member to a 'pagalkhana' hesitate to go the whole distance. During the course of my first day at the 'minor' section of the IPD, I saw a father bring in an obviously disturbed child (who was running around in circles, crying and laughing in equal measure, screaming at the top of his voice, "main jawan hoon, main jawan hoon!"). The doctor who examined him

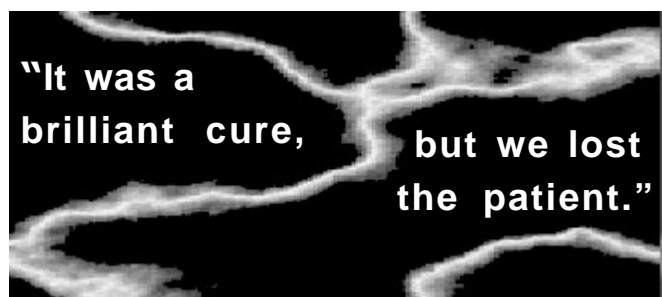
determined that ECT would be the only way out, something he took pain to explain in great detail to the worried father. When it came to actually signing the consent form, however, and following a hushed conversation with accompanying family members, the attitude of the father underwent a sea change. Refusing to accept that anything was wrong with his son, he refused to sign the form and walked out.

This project all throughout has taken a very strong stance on the unacceptable practice of neglecting to take the consent of patients before admission. This brief experience, however, forced me to take another look at the other side. Doctors who are actually motivated by the desire to serve are constrained by the medieval attitude towards issues of mental health of the public at large and forced to take the law into their own hands. While this can under no circumstances be condoned, it would be unfair to present a one-sided view of this contentious issue. To damn doctors and mental institutions without considering these factors would be just as unacceptable.

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*- Ernest Hemingway, after shock treatment*

**An expert view on ECT: Dr Maneesh Gupta, Psychiatrist, New Delhi.**

I read with interest your article in *aaina* March 2003, regarding Direct ECT. I am a psychiatrist having worked at a central government hospital in New Delhi. The department has an indoor ward of 30 male beds and 6 female beds. Often the indoor admissions are of patients who are either unmanageable at home due to their illness or who pose a danger to their life due to suicidal intentions. Some patients are those who have not responded in part to OPD treatment and have been admitted for more intensive treatment. There is a provision of ECT for patients with modified ECT being administered on three days a week only.

While the use of ECT has indeed been going down, it is STILL a therapeutic modality, the benefits of which cannot be denied. If as a psychiatric professional, I have to make my services patient centric, then providing the choice of all forms of treatment to all patients is essential. Because of the limitations of medicines, which take some time and have their own side effects, ECT becomes a reasonable therapeutic option for patients who are very violent, aggressive or disruptive. Due to the non-availability of Seclusion rooms, the risk of patients injuring themselves or other family and staff members is very high. It is a priority to calm them down. We have to make a choice, between high doses of antipsychotics that are known to have residual effects, and ECT that is perceived as inhuman and injurious, but which can bring a faster response. The patients' caregivers are told all the pros and cons of the procedure and we have found that the need for a faster response so that the patient can get better speedily, overrides their (caregivers') concerns of ECT.

In many patients who have not responded to medication on an OPD basis, we admit them for either more intensive medication (more number of medicines in higher doses) or by prior consent for a course of ECT (which is known to often turn treatment resistance into treatment response). Apart from this many patients themselves ask for ECT as they find that they feel and remain better for sustained periods of time, after ECT on the same medication which seemingly was not helping them before.

The point is that a complete ban on ECT is not warranted or justifiable. What is required, are safeguards to prevent the use of ECT without justification, without consent or without safeguards. If used properly and judiciously, it is treatment. If used improperly or unscientifically, it is unethical. Let me give you an example. We all know and accept that the police in our country is corrupt and often misuses its powers. But the solution is not a termination of the police and their powers, but rather continuous attempts to safe guard the public from transgressions through awareness, advocacy, and punishment for the guilty. Similarly, we should help psychiatrists understand that ECT is to be used wisely and judiciously. We should enforce proper informed consent at all ECT centers. Perhaps a licensing procedure for centers administering ECT, will help. The mental health authority in each state should be approached for this.

Where ECT is to be given, it should be administered with all due precautions and safety measures, e.g. proper resuscitating equipment. Help should be offered to all psychiatrists who are unable (or unwilling) to offer modified ECT to their patients. The concern of increased costs should be offset against the risk of injury to a patient. If a doctor and his patient still want to go ahead with the procedure, we should monitor and provide feedback to the doctor about the procedure. Just as advocacy for patients is befriending patients, we should also try and gain the confidence of psychiatrists and try and understand their point of view.

Some psychiatrists have repeatedly expressed the inability to judge whether a seizure occurred or not in modified ECT. It is one of the reasons why they shy away from this modification. The valid option is to have an ECT machine that records an EEG of the patient too, so that a clear evidence of the seizure is available. Such machines are very costly. Patient advocacy and patient benefit should set us in the direction of making such machines cheaper rather than trying to ban ECT as such.

Many private psychiatrists, especially those in the rural areas, often use sham ECT with thiopentone injection to mislead patients and their care givers, along with being able to overcharge for treating the patient. Should we not stop this practice which is downright thievery and quackery?

There are a number of patients on whom medicines seem not to have a positive effect till they are given ECT. A substantial number of them return to once again take the ECT procedure every year. It is clear that medicines are not helping them. Should we not review the patient and then perhaps change the diagnosis or change their treatment, even if it is keeping them stable after ECT? I have seen many patients misdiagnosed as schizophrenia, who are given antipsychotics and anti depressants together, to keep them stable for 10 months and then to be given ECT due to an exacerbation. Reviewing carefully such patients led me to change their diagnosis to bipolar disorder, give them mood stabilisers, tapering off the antipsychotic and the antidepressant. The patients live happily ever after without ECT.

The question has been raised of why patients are offered only drugs or ECT. I believe this is because community work has a strong role in primary prevention and tertiary rehabilitation. When a person consults a psychiatrist he or she has already developed an illness, and as such, primary prevention techniques are unlikely to benefit him or her any more. The role of ECT and drugs is in secondary prevention where we aim to treat him and reverse the distress and suffering that is a concurrent part of any illness. I offer patients a role in community psychiatry when it becomes clear that the level of disability that he has, will require rehabilitative efforts. Fortunately, more and more patients are coming to us at a much earlier stage of their illness and as such, primary prevention is working. The holy grail is when we do not need any tertiary prevention efforts because we manage to treat and cure all patients of their illness. Will we ever get there?

I have tried to provide you with my point of view on ECT and hope to hear from you on this issue.

*Dr Gupta can be contacted at maneesh\_psych@hotmail.com*

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**A carer's view: B. Johann Samuhanand, Carer, Bangalore**

Regarding, ECT, your arguments are really interesting and truthful. I am a parent of a girl who got schizophrenia at the age of 12 in 1986. There were no clozapine or any of the new atypical antipsychotics available now, at that time. I was advised to do 10 sittings of ECT as my daughter was not showing any improvement with Serenace, Trinicalm forte, Exazine plus, Orap, etc. During the long years of treatment I found that there is no clear cut scientific treatment for mental illness. When I asked a doctor about ECT he was kind enough to say that once I gave ECT I can forget about medical treatment in later years. So I did not give ECT, repeat, did not give ECT. But later years when we were inpatients in NIMHANS I found some depression patients getting miraculous cure with ECT. I have an open mind on this. You seem to prejudge the issue. Once ECT is banned, what will happen to those people who cannot afford modern medication? What about the old typical medication and modern atypical medication? Are the old medications, which were only tranquilizers, to be banned? The old tranquillisers are still

being prescribed. Along with ECT they also should be banned, as they also do not have any scientific basis. Once ECT is banned, it will only encourage behind the scene ECTs in backward areas. It will only encourage medication and fat profits for multinational pharma companies. I feel that when all medications fails, a care giver can take recourse to ECT as last resort, after taking a physical examination of the patient. Do you agree?

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### **A lawyer's view:** Prof Amita Dhanda, NALSAR, Hyderabad.

The question of ban are being raised by consumer groups with regard to unmodified ECT. The main professional reason given for this line of treatment are not therapeutic, but economic- Because anesthesia cannot be afforded by a large number of people, it is alright to give unmodified ECT. I do not see this as an 'either-or' issue. ECT has to be judged on its own efficacy and pitfalls. It cannot stand in for the inadequacies of the other medicines, meaning that, unless all unsafe medicines are banned we should not touch ECT. Nor can ECT be advocated on the ground that because a number of persons cannot afford more safe and sophisticated medicines they should be allowed to use ECT. The idea is effective treatment, not the semblance of treatment. The way to approach the issue would be that, let ECT be prescribed where it has evident therapeutic benefit. There should be some kind of burden on the doctor to demonstrate the benefit.

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## **"I see Brain Cells"**

by Cal Grandy

"I see brain cells on the rocks  
brain cells in the trees  
brain cells relieved from thinking  
free to ride the breeze  
delivered there by the lightning  
delivered on a rain drop  
delivered from psychiatry  
and from further need for shock"

images

*This poem has been sourced from the MindFreedom Journal: Winter 2003-2004. This special issue on "Electroshock's Secret Comeback" should be a part of any ECT survivor's collection. A wide range of mental health professionals and community workers should also read it. The issue carries research and campaign news, book lists and interviews with stalwart advocates from around the world leading the movement against shock treatment. The issue costs \$4/- and can be sourced at [www.mindfreedom.org](http://www.mindfreedom.org)*

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