

aaina

a mental health advocacy newsletter

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Editorial

The new economic policies in health care world over have propelled a major withdrawal of any active welfare role by the state. In the west, private interest in health care has been controlled to an extent by active state regulation of trade practices as well as a vigilant and demanding user voice. Management philosophy in health care has somewhere also entailed that such care is “quality controlled” and health care providers often mandatorily dialogue with users. Any trade has some kind of regulation of its conduct vis a vis the consumers. However, mental health services in India have been reluctant to dialogue with their consumers about their code of conduct.

Having a code of ethics is about having a common minimum set of principles or values, which are arrived at by professional consensus. It is a *minimalist* standard of practice. It will not resolve all moral dilemmas for the care provider nor will it always be in the user’s best interest. But it will at least ensure that certain minimum standards of quality are met when a user accesses care.

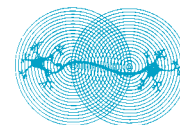
Mental health care sciences have grown within the political economy of capitalism. With every discovery of drug or therapy having strong commercial import, ethics became an important dimension. In an aggressive and highly competitive market, some civil society denominators, such as ethical codes, had to be brought in to maintain a semblance of order. In the present context of liberalizing free markets in health care, concerns about ethics and the creation of assertive consumers who will insist on quality care is of paramount importance. Already as users of psychiatric services, we are experiencing the pain of exclusion in the phenomenally growing private medical insurance sector.

This issue of *aaina* is devoted to ethical considerations in mental health research and practice. We invite our readers to think with us on the many sided dilemmas and questions faced by those offering mental health care services and by users.

Ethics in Practice

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Trust
for
Research
on
Mind
and
Discourse

Mental health service users are people experiencing some kind of mental distress. Typically in medical settings mental health professionals (MHPs) refer to users as “patients” and in Counselling Centres or Psychological Services Centres, psychologists, psychotherapists, psychoanalysts, psychiatric social workers and counsellors use the term “client”.

Counsellors are psychology treatment providers, either in the earlier stages of their mental health careers, i.e., they have a Masters in Psychology or related field and are on their way to getting a higher degree (post-graduate), or they have specialised in a certain area of mental health such as family counselling.

Psychoanalysts are professionals who have trained in a Freudian or neo-Freudian school of thought

and they use this framework to help clients gain insight into their problems.

In medical settings in India, MHP teams are headed by **psychiatrists**— medical doctors who have specialised in the field of mental health. **Clinical psychologists** and **psychiatric social workers** are other kinds of MHPs on this team. Clinical psychologists are human behaviour scientists who specialise in the field of mental health and have a clinically based doctorate degree in mental health. Psychiatric social workers are social scientists trained similarly. When we go to a mental hospital, typically, the MHP team decides the main thrust of the treatment: biological or psychological, or both.

(continued on page 3..)

Editorial Team

Bhargavi Davar
Sadhana Natu
Radhika Kulkarni
V. Radhika
Soumitra Pathare

Design and Layout

Anand Pawar

Printing

Anita Printers, Pune

Contact Address

7, Krishna House
Fatima nagar
Pune- 411 013
Tel. 6872672
Email: wamhc@vsnl.net

aaina

a mental health advocacy newsletter

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. Write to us with all your suggestions, criticism and viewpoints on the issues covered.

We appreciate and thank Jayasree Kalathil for giving shape to *aaina* and wish her the very best with life and opportunities.

The biological aspect requires that all possible medical reasons for our psychological distress be checked out. For instance, thyroid malfunctioning can cause a depression-like disorder, which clears up once correct medication for the thyroid problem is taken. It is the psychiatrist's responsibility to examine us for physiological problems that may produce or add to our distress.

However mental distress is usually not related to a discernible physical problem. There was a time when MHPs were engaged in an intense debate about the cause of mental distress. Biological theorists argued that all such distress occurs because of a biochemical disorder and can be treated effectively with medication alone. Environmental theorists argued that it occurs because of problems in our life situations and should be treated psychologically. Added to this was the evidence from the psychoanalytic theorists that human beings operate from different levels of consciousness and our unconscious part and dream states are also implicated in our mental health. Because psychiatrists are medical doctors they tended to be adherents of the biological theories and the others, because they are trained in the study of human behaviour and ways of bringing changes in it, tended to support the environmental position.

Currently, most MHPs do not engage in this debate because they see it as a 'chicken and egg' problem. Most agree that humans are born with certain pre-dispositions. Environmental factors interact with these dispositions to blend into our mental health. Human mind and body are practically indivisible. Sometimes the pre-dispositions make a stronger impact, at other times the environment is more strongly implicated.

The first thing for individuals seeking alleviation from mental distress is to determine what specific course of treatment is best suited for them. This decision can be made by consulting any well-trained MHP who would be able to offer specific advice and recommendation.

Broadly, mental distress can be divided into two categories:

1. Distress that allows us to function within our world, where even if we are not satisfied with the quality of our life and the repeating unhappiness causing patterns we are caught up in, we *are* functioning. We are able to live in a way that people around us do not immediately perceive us as actively suffering. We might be recipients of lots of well-meaning advice and we might be highly emotionally dependent on some of the people around us, but we *are* able to function.

2. The second category is when distress is of such a degree that we are unable to function adequately. The distress actively obstructs activities and we cannot do the things people around us consider normal for them to do.

The degrees of dysfunction in the second category, where we refer to mental distress as an 'illness', become clearer as we move away from the starting point. People in the second category may require hospitalisation—sometimes involuntary because they are assessed as dangerous to themselves or others.

In India, issues on involuntary admissions are somewhat murky. Our system is still struggling to incorporate human rights respecting practices. Sometimes, people who have had a mental illness that has put them in the second group feel stigmatised. But that comes from a poor and stereotyped understanding. The reality is that some times when we are emotionally distressed this distress can be of such severity that we are unable to make sense of the world around us and that becomes terrifying. We then need an understanding, safe environment and adequate resources to help us get through that period

There was a time when mental illness was even less adequately understood and lobotomies, electro-shock therapies were routinely prescribed. Now extreme moods, hallucinations, delusions and other thought disorders are usually effectively controlled by medication. For this treatment we go to a psychiatrist. Proper medical treatment provides quick relief from highly distressing, confusing and incomprehensible experiences.

Psychological treatment here helps us learn to manage and understand our illness so that we are not overwhelmed by it.

Psychiatrists need to answer our questions about side effects of medication and also inform us adequately about diet and other physiological issues relating to our disorder. We particularly need our psychiatrist to make time for our concerns. If you find that your psychiatrist is too busy or intimidating, get yourself a better psychiatrist. This is your life. Ask questions. Read up. Talk to other people who have similar difficulties—check out what is helpful for them so that you are actively engaged in helping yourself feel better.

If you have chosen psychological treatment then you will need to find someone who is well trained to provide it. Usually, in India, clinical psychologists, psychiatric social workers, psychotherapists, psychoanalysts and counsellors undertake this treatment because this is their area of expertise. However, some psychiatrists also specialise in this area. But beware of untrained psychological treatment providers!

The goal of any kind of psychological treatment is to help clients learn how to help themselves, to feel more in-charge of their lives and to move towards greater mental health. It is always a good idea to be clear about the kind of psychological treatment you are going for. Again, ask questions.

Psychotherapy is a popular form of psychological treatment. Training here requires that the MHP is intensively supervised in providing psychotherapy for at least two years. Please ask questions about your psychotherapist's training, orientation, years of experience. Do ask other clients about their experiences with that psychotherapist.

Psychotherapy is a relationship based psychological treatment where clear rules for relating allow for a professional, safe and non-exploitative relationship, where clients can explore their lives and the elements they wish to change within it. Committing yourself to psychotherapy is an important step because this is a slow laborious process. Particularly, because psychotherapy involves an intensive, emotionally charged relationship, it is important that we engage the services of a MHP we can trust and with whom we have established a good rapport. An effective therapeutic relationship provides the opportunity for honest processing. Do make sure that your MHP understands and respects confidentiality.

Unfortunately, psychotherapy is often confused with giving common sense advice. This is particularly incorrect. Psychotherapy involves a personal exploration of self and the psychotherapist walks with us, never leading the way. Intrinsic to good mental health is the capacity to make one's own decisions as well as the maturity to live with the consequences of those decisions. Even with individuals who have had a serious mental illness, we find that the more we encourage them to take responsibility for themselves the better they do. The goal in any kind of mental health treatment is to help people improve the quality of their life and to work towards their doing so in the most efficient way possible.

Dr Sadhana Vohra is a clinical psychologist in private practise in New Delhi and is editor of 'The Journal' of Psychological Foundations, New Delhi. She can be contacted at sadhanavohra@vsnl.com

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Shock Free Zone

CREATE SHOCK FREE ZONES
Campaign against forced ECT

Persuade, confront or blacklist
doctors in your area
who force ECT treatment.

The Workman and Mental Illness

Maharukh Adenwalla

The Persons with Disabilities Act, 1995 promises equal opportunities and non-discrimination for persons with a psychiatric disability. The case presented here, even though not won through the PWDA, is an important citation for restoring work rights of Class IV employees with such disability.

The Bombay High Court upheld an order passed by the Central Government Industrial Tribunal [CGIT] reinstating a workman who was unable to attend work due to depression.

The workman had been working as a peon with a well-known private bank since 12th August 1986. The workman did not attend work from 3rd March 1992 to 11th May 1993 as he was suffering from depression and required treatment. The workman underwent treatment in Sindhudurg where his family resided. The workman produced a medical certificate dated 20th May 1993 indicating his fitness to resume duties, but the said Bank refused to take him back. The workman pleaded reasonable justification for his absence but to no avail.

This column posts recent cases and judgments in the area of mental health. Both class action cases as well as individual cases may be cited. The civil liberties area as well as care and treatment law is of relevance to our readers. Do bring news of your advocacy efforts by writing for this column.

Due to the inconsiderate attitude of the Bank, the workman was compelled to take recourse to legal proceedings. CGIT held the termination of the services of the workman as not legal and justified. It was further held that the workman was not suffering from any recurring illness and the earlier ailment of

mental stress from which he was suffering has been cured. The Bank carried the matter to the High Court by filing Writ Petition No. 1068 of 1997. The High Court directed that the workman “be examined by psychiatrist – doctor of the choice of the Petitioner to find out about his mental condition.” The workman was accordingly medically examined by a psychiatrist and the result of the medical examination denotes that “the employee was administered selected psychological tests and it was found that employee was not suffering from any mental disorder at present, and he was provisionally fit to resume duties as a peon.”

The workman’s services were terminated on 25th August 1993, and the Order of reinstatement was passed by CGIT on 25th March 1997. The High Court confirmed the Order of CGIT on 12th August 1997. Four years of the workman’s life were wasted. Fortunately, the CGIT directed the Bank to pay the workman his wages from date of termination till reinstatement with other consequential benefits.

“Ill-health” as used in the Industrial Disputes Act is dealt with by the Supreme Court in *Anand Bihari & Ors. vs. Rajasthan State Road Transport Corporation & Anr.* [1991 1 CLR SC 525]. The law on this point is that the workman should be able to efficiently perform the work entrusted to him. An employee cannot be removed from his job because of an illness, it should be proved that the illness interferes with his job performance.

Maharukh Adenwalla is a human rights lawyer working with the India Center for Human Rights, Mumbai. She is a part of the Human Rights Law Network and can be contacted at maharukhaden@yahoo.com

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'Hai koi pagal?' - Disabled Census 2001

Shefalee Vasudev

Nayantara Makhija, a vastu consultant in Delhi, had family friends visiting her on a cold Saturday evening in February when the doorbell rang insistently. It was an impatient enumerator, knocking for statistics for the Census of India 2001.

Tick, tick, tick, no tick, applicable, not applicable... so on and so forth went the enumerator, brisk and distant in his approach. Ever since he had stepped into that crowded drawing room, he had been staring at one of Nayantara's guests, a young man, who looked "strangely lost" and was "behaving funnily", with jerky movements. Halfway through, the enumerator looked up and pointing to the "differently behaved" youth, asked, "*Iske alawa, koi aur pagal hai aapke ghar mein?*" ("Is anybody else mad in your house, besides him?").

"Multiple blows of shame and embarrassment rained on me," recalls Nayantara. Jayant, the 26-year-old boy in question had developed mental impairment and subsequent retarded intellectual functioning. At age 4, when he was suffering from severe typhoid, he had sustained brain injury falling off his cot.

What should one say about the enumerator's insensitivity? Should he be reprimanded for his callous questioning, or, should he be praised for making enquiries about a disabled person, since many enumerators were not even bothering to find out whether a family had a disabled member or not? In a country where such gigantic demographic exercises raise heat and dust only in debates, even the impact of these debates has become debatable.

In the very first Census of 1871, the physically and mentally disabled had been considered as a separate category, even though in those days, they were either confined to asylums or exiled out of society. Later on, when the British government trashed this disability clause

after the 1931 Census, there was a huge void, which placed an entire population, their rehabilitation, education and employment, in suspense. These remained theoretical issues, since no one knew what to do for people who lacked definition because of their special needs.

Mental disability found a place in the enumeration after decades of psychosocial neglect by omission on the part of the Indian government. The print media did its bit before the decennial exercise kicked off. There were extensive reports, on the inclusion of Disability as a demographic category for the Census 2001. Garimella Subramaniam's article *Don't The Disabled Count?* (*The Hindu*, November 12, 2000) was a sensitively reported piece talking about the approach and questionnaire that would include the enumeration of the disabled under the five umbrella categories.

After the Census, the articles, posers and debates started abating. That the enumeration of the disabled was dissatisfactory was talked about. But it was not emphasized half as much as the inclusion of disability had been. Kanak Hirani's report (*The Times of India*, 29th March 2001, Bangalore Edn.) even gave names of the homes for the mentally challenged, which were never visited by the enumerators. Imagine the reports that were never filed about the exclusion. Imagine the numbers of families and individuals who never went up to well-meaning NGOs or government bodies nor admit to "brisk but impatient" enumerators to say that yes, there is a disabled person amongst us.

We live in unsure suspension thanks to pseudo-education. Where are the sections of the print media exclusively devoted to sensitisation about mental disability? Till today, most of the work done in the name of the "cause of the disabled" sees mental illness as a health issue (if at all). Not as a human rights issue.

How many of us who don't work within the mental health sector know the difference between cerebral palsy and schizophrenia? Our automatic social reactions to the mentally challenged are defensive. We defend *ourselves*, not them. We either panic, or sympathize, or stare, or immediately start counting our blessings. The very fact that we react strongly, almost every time we interact with a mentally challenged person is proof enough that our education and empathy for the mentally disabled is not half as that for the physically disabled.

Psychiatric disorders maybe genetic, accidental or trauma-inflicted but psychological 'dis-ease', is oh, so common. The media, instead of teaching us interacting techniques with the psychologically upset or the mentally challenged, keeps harping on either "candle making and block printing" endeavours of the mentally challenged in special schools. Or, at the other end of the spectrum, quotes therapist so and so, psychologist so and so, counselor, and psychiatrist so and so to explain every mood swing of person, place or situation. Mental disability is either a "technical matter to be defined" or "a too sensitive subject". Handle with care.

In between oscillates a real world- a world where a portion of the population need commendable responses, rehabilitation, rights and rethinking. Had the lobbying for the rights of the mentally challenged been stronger, the pre-Census preparation of the enumerators would have addressed the ethical concerns involved in information gathering. And the post-Census debates on the enumeration of disability wouldn't have been so damp.

Conspicuous by its near-total absence in the campaign for helping count the disabled, during the Census 2001, was the Union Ministry of Family Welfare and Social Empowerment and its counterparts in the States. Having to contend with inaccurate data for many decades and having been in some ways instrumental in the inclusion of disabilities in the 2001 Census, the Ministry should have been at the forefront to raise public awareness on the need to disclose disability-related information. It wasn't.

Mental disability with all its attendant stigmatization and complicating ethical issues led to at least one casualty. It made the Census 2001 disabled.

Shefalee Vasudev is a television producer, scriptwriter and anchor, with 10 years of background in print journalism.

Email- shefaleevasudev@yahoo.com



***aaina* forthcoming issues**

We have had a wonderful response to the first issue of *aaina*, thank you all!!

We have had many queries regarding subscriptions. Our honest answer to this is that we are trying out *aaina* experimentally for a year (3 Issues) to see if it is viable as an idea. Until the next issue, then, we are circulating it on our own initiative and using our own resources. Of course its viability depends on your interest and enthusiasm.

We are still awaiting news, views, opinions and articles on '*Mental Health or Psychiatric Disability*', an issue that we hope will throw light on treating mental health difficulties in disability terms. We know that many of you out there are actively linking up with the disability movement, so do write right away.

As forthcoming themes, we offer the following and invite contributions:

- *Money Matters in Mental Health Care*
- *Social Attitudes to Psychiatric Disability*
- *Self-Help and Emotional Healing*
- *Carer's Concerns in Mental Health*

Other than the theme articles we do offer regular columns- speaking our minds, images, media desk, reviews and reports, spotlight, post-it, reflections, judgment watch and advocacy news. We have a lasting interest of course in polling opinions and propagating activism around institutional reform, ECT and psychopharmacy.

I am a ‘cured schizophrenic’ whatever it may mean. My history of involuntary hospitalizations started in 1995. Back then I suffered aberration of thought, punctuated by prolonged periods of ‘normal’ thought process. Often both the phases went hand in hand. I would fight my psychosis and be normal like million others.

Once I imagined I was the most powerful man, commanding the entire global politics. I was the President of America, the Pope and President Boris Yeltsin on different days. I imagined that the world was out to knock me off, my parents had initiated a global conspiracy against me, the CID was out to dispose me off, and that my mother was poisoning my food. This psychotic phase lasted over four years.

Initially, my parents consulted a renowned psychologist. I refused to talk to him. Now I realize what a big mistake it was. Had I agreed I would have been left off after a few sessions of psychoanalysis, possibly with a label of ‘mentally ill’ but without lifelong drug treatment. My psychosis continued punctuated with normal thought process. I was forcibly taken to a well-known senior psychiatrist who retired as the head of a prestigious medical research institute near Delhi. His diagnosis: CLINICAL DEPRESSION. I was prescribed PROZAC. I refused.

I believe that through introspection and analysis, one can overcome this aberrant thought process. Medicines can never be the answer. Give a thought to whether what is happening is true. For example: How is it possible that if you are President Clinton, you are still in India? I did just that. I told myself, if I

am in India and jobless and struggling, I couldn’t be President Clinton.

In 1997, it happened. I was pleading with my mother to let me go to Delhi. At that time I was 32, still jobless, though writing as a freelance journalist. The travel money had to come from my mother. She told me that we would talk about it in the morning. I went to my room and started reading Lu Hsun’s short stories.

In the morning it happened. I had a premonition when I heard a sharp rap on my door at 7’o clock. I

opened the door. Immediately, two burly men dressed in police uniforms overpowered me. The MSW whispered in a voice palpably radiating joy: ‘So, you think you are Mr. Know All.’ I was bundled into the car and driven off to a government psychiatric facility. A long and unending night of torture in the name of treatment awaited me.”

opened the door. Immediately, two burly men dressed in police uniforms overpowered me. The third (a medical social worker) whispered to me in a voice palpably radiating joy: “So, you think you are Mr. Know all.” I was not allowed to go to either the WC or dress up but immediately bundled into the car and driven off to a government psychiatric facility. A long and unending night of torture in the name of treatment awaited me.

I had read what Stalin did to political dissidents in former Soviet Union and what Hitler did to Jews and Gypsies. Most were shot. Many were incarcerated in psychiatric lockups and injected with crippling anti-psychotic drugs until they could take no more. I already knew about the inglorious history of psychiatry.

The story I was forced to tell these psychiatrists was the same that I had earlier told. But strangely, these psychiatrists gave me a diagnosis of SCHIZOPHRENIA. I repeatedly told them that though I might be under an episode of psychosis I am not in need of either medicines or involuntary hospitalization. No one listened to me.

I was in the psychiatric ward for 13 days and put on 5mg Espazine, 2mg Larpose and 2mg Pacitane. I was discharged after being told to continue medication for 4 months. I suffered such horrendous side effects that I discontinued the medicines as well as OPD.

Subsequently I received letters from the hospital MSW to the effect that if I discontinue my treatment for SCHIZOPHRENIA I would end up worse than before. Fortunately, my mother didn't force me to visit the psychiatrists. Instead, I was told to see the psychologist who concluded that I was suffering from PSYCHOTIC NEUROSES!! The psychologist told me that I would be all right in a few sessions but I refused counselling.

My psychotic phase continued, and with that, the fights with my parents. In 1998, I was institutionalized for a fortnight and put on 2mg of RISPERIDONE. I discontinued the medication after 3 months. I was staying in Delhi on my own and managing my affairs quite well. I also traveled in the US and was doing fine. In 1999, my parents discovered that I was not taking medicines. My father came over to Delhi with the hospital police and forcibly re-admitted me. I was forced to continue with RISPERIDONE in the hospital. I discontinued after a month.

This column is about personal accounts of interactions with the mental health systems or about living with mental distress. The writers can remain anonymous if they so desire, in which case all personal correspondence and information relating to their write up will be kept confidential.

After the first hospitalization, the subsequent ones have all been on ground of non-compliance. The issue was not whether I was psychotic or not but that I had stopped taking the medicine. I have stopped medication for two reasons. Firstly, I believe that even if one is suffering from a mental ailment as serious as 'schizophrenia', medicines

are not the cure. Secondly, I have discontinued the medicines because these have severe and highly discomforting side effects. I suffered from slurred speech, prolonged constipation, tardive dyskinesia, akinesia (slowness of movement of limbs and hands), salivation, difficulty in passing urine and a dozen other grave side effects.

In August 2000 I was again forcibly readmitted and discharged after 2-1/2 months. I had been staying in Delhi alone, cooking, washing my clothes, going to the library for reading, interacting with people and doing activities, which a 'schizophrenic' is supposed to find difficult to do. My medicine was changed to 20mg OLANZAPINE. In addition, I was given 50mg of Haloperidol I/M for four months continuously before it was discontinued. If earlier I had the responsibility of taking the medicine, this time that option has been withdrawn from me. My parents are giving me medicine under the strictest supervision. I am not allowed to travel outside my city. I was not able to go for my honeymoon when I got married. My freedom is compromised in addition to suffering from untold misery because of the anti-psychotic medicines.

The identity of the writer and other personal details pointing to hospitalization and treatment have been masked at the request of the writer.

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Picture by Shilpa

Good Practice in Child Sexual Abuse (CSA) Interventions

Dr Shekhar Seshadri

There is an extensive list of ‘good practice’ parameters in CSA interventions. The sequence of issues that need to be attended to include-

- ♦ Establishing that abuse has occurred (What is the context of intervention? Is abuse the direct context because of disclosure / discovery or is the presenting context some behavioural, emotional or academic problem?)
- ♦ Establishing the nature and extent of abuse
- ♦ Establishing medical issues
- ♦ Establishing psychological issues
- ♦ Establishing family, social, safety issues
- ♦ Establishing legal issues
- ♦ Carrying out medical interventions
- ♦ Carrying out psychological interventions
- ♦ Carrying out family and social interventions
- ♦ Carrying out legal interventions where indicated
- ♦ And PREPARING THE CHILD FOR EACH OF THESE PHASES.

In a scenario where sexuality is relegated out of mainstream discourse in communities, what language does a confused child have to disclose abuse? Does good practice therefore start at creating a culture of discourse and disclosure with children? It is important to have a comprehensive list of good practice parameters across all phases of interventions. For example there is an entire list of recommended parameters for legal interventions including in-camera trials, special interview techniques for younger kids, issues of legal reform and so on. How can you expect a child to depose in great detail, in exact sequence, all the experiences gone through without losing equanimity in the presence of the perpetrator and aggressive questioning to undermine the child’s testimony? That too in a court atmosphere that is not exactly child friendly! Even adults cannot manage this well. Hence activists are talking about child protective trial atmosphere and procedures. These procedures by themselves are extensively documented.

What can we say about good practice in CSA interventions-

- THAT all people in sectors that deal with kids (teachers, families, doctors, paediatricians, gynaecologists, mental health professionals, police and judiciary, media) should first of all believe that CSA exists. If one disbelieves, is uncomfortable, or thinks ‘this is a western phenomenon’, then the child will not be believed.
- THAT the dividing line between sexual misbehaviour, sexual harassment, sexual abuse and sexual violence is not all that sharply defined. Hence it is bad practice to say, ‘After all he did not rape you...’.
- THAT all interventionists must make a habit of CSA enquiry and skill themselves in sensitive questioning as indeed in fighting all aspects of social conditioning that compel people to interpret their abuse in self damaging ways

- THAT the child's abuse must not be constructed as THE SINGLE MOST IMPORTANT EVENT in his or her life that he or she has to live with for the rest of life.
- THAT the interventions must not be experienced in a fragmented way by the child. A primary caseworker should accompany the child in all referrals, procedures and enquiries and be a familiar, consistent figure in the process.
- THAT CSA interventions, if handled poorly, can be as traumatic and as sexualizing as the primary abuse itself and a relatively untraumatized child could be made to feel traumatized because of the intervention.
- THAT people's outrage and activism may not always compensate for the child's pain so an individual child's case should not be used to fight larger ideological battles

Child Sexual Abuse is a child issue, a sexuality issue, an abuse issue, a gender issue, a patriarchy issue and a power and domination issue. And good practice means one should be aware of all these dimensions and develop skills to intervene across these issues. What is in the BEST INTEREST of the child over short term and long term? Perhaps interventionists can keep reminding themselves of this question through this poem of a young girl written to her social worker (Sourced from Adler R, 'To tell or not to tell: The psychiatrist and child abuse'. Australian and New Zealand Journal of Psychiatry, 1984, 29, p. 190).

"I asked you for help, and you told me you would
 If I told you the things my Dad did to me.
 You asked me to trust you, and you made me
 Repeat them to fourteen different strangers.
 I asked you for privacy.
 You sent two policemen to my school
 Like I was the one who was being busted.
 I asked you for help and you gave me a doctor with cold hands
 Who spread my legs and stared at me, just like my father.
 I asked you for confidentiality and
 You let the newspapers get my story.
 I asked you for protection and you gave me a social worker.
 Do you know what it is like to have more social workers than friends?
 I asked you for help and,
 You forced my Mom to choose between us.
 She chose him of course.
 She was scared and she had a lot to lose.
 I had a lot to lose too.
 The difference is you never told me how much.
 I asked you to put an end to my abuse.
 You put an end to my whole family.
 You took away my nights of hell.
 And gave me days of hell instead.
 You have changed my private nightmare for a very public one.

*Dr Shekhar Seshadri is a
 child psychiatrist working in
 NIMHANS, Bangalore,
 India, with interest in gender
 issues, sexuality and
 violence. He can be
 contacted at
shekhar@nimhans.kar.nic.in*

Malathi Ranade

This is yet another story of how judicial victories for hospital reform and patient's rights are rendered a mere paper exercise by the state health administrators.

An opportunity to improve hospital conditions in Maharashtra came in 1989 when the Bombay High Court appointed the Mahajan Committee to look into the affairs of the Mental Hospital, Yerawada, Pune. I was invited to become a member of this committee. I was the only member who was connected very closely with patients in the hospital. Even though the committee was doing an excellent job about gathering facts of the facilities it was not inquiring into the quality of services. The fact of patients as human beings was left out. Their psychosocial needs of freedom, recreation, occupation, contact with dear and near ones, and cordial relations with the staff were neglected. The committee submitted its report to the High Court in August 1989, giving 68 recommendations. My separate report, highlighting patients' needs as well as the failure of the social service department, was not included on grounds that it was submitted 'late'! The High court in its judgment No. 1989 directed the Government to implement the same.

An analysis of the 68 recommendations shows that in fact there are only 52. 16 were repeated and 4 were regarding an NGO. Of the remaining, 2 are about building repairs, 4 about new constructions and creation of new posts. 10 are about training programs for staff. About 20 lay down procedures for doctors and hospital authorities. The remaining are about the physical well being of patients, written in an impersonal way.

Recommendations 1 and 35 refer to the improvement of the environmental conditions. The recommendation states "the patients should be kept in more humane and pleasing environment, wherein they

can live with dignity as human beings". Since no explicit parameters were used to define the term "humane environment" its interpretation was left to authorities. The authorities interpreted it in the physical sense leading to repairs and maintenance of roads, cleaning and refurbishing the open spaces in front of the wards, external painting and planting and maintenance of gardens. The insides of the wards where patients spend all their waking and sleeping hours remained as neglected as ever.

The remaining recommendations, which deal with provision of essential amenities to the patients and make no reference to their psychosocial needs, are as follows:

- ♦ Drinking water and toilet facilities inside the wards
- ♦ Keeping the bathrooms and lavatories free of odour
- ♦ Provision of cots, mattresses and linen to patients
- ♦ Clean clothing for patients
- ♦ Providing soap and towels and ensuring daily bath of patients
- ♦ Hygiene and cleanliness within the wards, including pest control
- ♦ Providing mugs to patients for taking milk or other liquid food
- ♦ Improving the quality and quantity of food
- ♦ No patient should be asked to do menial work
- ♦ No patient should be subjected to cruelty
- ♦ Modified ECT should be used.

The High Court on 10th November 1989 desired the Board of Visitors at the Mental hospital to "monitor" the implementation of the r e c o m m e n d a t i o n s .

This column will report on model campaigns, research studies, workshops, mobilisation or interventions undertaken by various individuals, groups or institutions on advocacy in mental health.

Curiously enough the Board of Visitors was kept completely in the dark about the charge upon them. There is no reference to the “monitoring” of implementation of recommendations in the Visitor’s Book right from 1989 to 1993. A Standing Committee headed by a State Program Officer had been constituted to monitor the implementation of our recommendations (*Indian Express Report, Bombay, 7th May, 1990*). The superintendents of all 4 mental hospitals in Maharashtra were its members. Upon inquiry I learnt this committee was a non-starter. On 13th September 1993 a special committee was appointed by the Government to “evaluate” the implementation. The Committee visited the mental hospital on January 4th 1994 and reported that most of the recommendations were implemented! The report of the District Judge following a writ petition in 1995 however depicted a different picture.

The long and short of it is that nothing was gained by the High Court’s appointing a committee so far as the welfare of the mental patients is concerned. We are back to square one. Serious and concerted efforts must be made to bring relief to the suffering humanity within the mental hospital. This is true not just with regard to the mental hospital at Yerawada but of the 50 mental hospitals around the country.

Ms Malathi Ranade, retired, was the first Psychiatric Social Worker to be appointed at Yerawada mental hospital, Pune. She filed writs demanding implementation of the MC report. In 1998 the file was disposed off. Thank you, Dr. Amita Dhanda, for putting us in touch with her. And thank you, Maharukh Adenwalla for news about the Committee.



dear aaina

Very many thanks for sending the first copy of *aaina* to our organization ‘Kiranh’. Many self help groups of care givers who recently assembled at Chennai welcomed the issue and praised it. The article “Mediating mental health” is well thought out, a lesson for reporters. If any such reporting is there, we should immediately react through letters to the Editor so people at large come to know the real facts. The use of mental illness in film was an equally good article. Shri Anil Vartak’s poem is indeed heart warming and I wish that our brothers and sisters be bestowed with such wonderful insight.

The use of ECT is a controversial issue. The subject is to be seen from both sides. Outright condemnation more so by persons other than the consumers or doctors is not proper. Sometimes it is inevitable but sometimes it is used commercially and put on display as a wonder treatment, whereas it is

only very temporary. The case of Ms. Gita Ramaswamy is very unfortunate. It is the stigma, which makes the case so big. Had it been any other sickness, which was not treated properly, will people shout from rooftops? Let us have an opinion from the consumers. Wishing all success, I remain,

Yours sincerely

PN Krishnan
Secretary, Kiranh
10/1 Greenfields
Ghatla Village Marg
Chembur, Mumbai – 71
India
T: 0091-22-555 6955

Your letters and responses will find a place for our readers in this column. We may not be able to publish all letters nor letters in their entirety.

Researching Mental Illness- Ethical Issues

Tejal Barai

Pharmaceutical giants like Eli Lilly, the makers of PROZAC, are entering the Indian market in a big way. These entries also involve collaborative research with Indian medical professional and research agencies on introducing newer anti-depressants. The totally unregulated Indian medical practice is a very profitable playing field for multinational drug companies. The Mental Health Act, 1987 also liberally allows medical research on those with psychiatric disabilities without taking issues of consent seriously. Ethics in mental health research therefore is an area of utmost importance.

Our society does not have uniform standards to understand or acknowledge needs and rights of individuals. An individual who has suffered physical disability as a result of an accident has ‘legitimate’ reasons to be depressed. But those with no ‘visible’ reasons to be depressed are marginalized, and looked down upon. Such standards not only leave persons with psychiatric disabilities amongst the least understood, but also amongst the most vulnerable, not only as individuals in society, but also, *vis a vis* research. This vulnerability and some of its consequences is something that I attempt to bring out in this brief article.

The primary attributes, that of compassion, concern, responsiveness and sensitivity in various contexts of research take on a different character and meaning in research involving individuals suffering from mental illness. Guidelines and principles of autonomy, competency, informed consent, amongst others, take on a different significance as a result of their greater depth and wider scope. I seek to explain this by means of an illustration of a real participant.

A volunteer for a study, who suffers from chronic anxiety and depression, agreed to participate with the hope of gaining some relief, and thus benefit, from the medication to be tested. (His regular medication had stopped helping him). He was handed over details of the study and the consent form in a casual manner. The participation aggravated his condition and he felt like

committing suicide on two different occasions. Unknown to him, the study in fact involved taking him off medication altogether. The purpose of the study was to observe the progress of illness when patients relapsed. The rationales provided by the researchers was that it would have helped in understanding progress of the illness thereby helping patient needs in terms of future medication, as well as understand mental disorders (*Report, New York Times, May 19, 1998*).

In this example, was the patient – participant in the frame of mind to have ‘voluntarily’ consented to participation in the study? Would he have participated in the study had he known the real objectives of the study? Would he have participated had he been explicitly told that there were no real benefits for him, and on the contrary, his original medication would have to be discontinued, thereby possibly causing him harm? Does not the fact that the researchers only casually handed over information, not clarifying any of the above, amount to deception? Isn’t allowing the participant to assume that there would be immediate benefits an indirect form of inducement? These are all serious lapses in the informed consent procedure.

Considering the fact that the participant was suffering from a mental illness, a lapse such as the above even impinges on his autonomy to decide on participation. It is also necessary to evaluate the competence of the participant (and others) to

comprehend the details of the study and give consent, on the basis of the nature and stage of mental illness, especially since the participant is already biased towards participation.

Moreover, can such a study be permissible even if all the above are considered and addressed? Thus we come to the rationale of the study. Is not the fact that the participant had become suicidal, as a result of the severe relapse, a consequence of participation, too large a cost to pay for studying the progress of the disease? What also might have been the end point of the study- death, by suicide of a participant?

An Institutional Ethics Committee reviewing the above study would have the responsibility of not only addressing the above ethical issues, but also more. The following are the minimum that need to be addressed by not just the ethics committee, but also applied by the researchers, and only when these are satisfactorily answered, should such a study progress:

1. Does the study have justification enough?
2. What information is to be given to the participants? Are they being told about the actual nature of the study? Are they being informed about the fact that they would in fact be taken off medication? Are they being told that there are no real immediate and direct benefits to them?
3. How is information being conveyed to them? Have they been explained fully and patiently, before seeking consent? It is the responsibility of the research team to see to it that the participants comprehend the information given.
4. Have assessments been done of competence to consent to the study?
5. What is the responsibility of the research team and the institution sponsoring such a study in the following two scenarios? One, when the participants turn suicidal, and two, at the end of the study, when the patients are left in a worse condition than they were in at the start of the study?
6. What in fact is the end point of the study? Till what

stage would the participants be denied medication all together?

7. Finally the Ethics Committee would need to see to it that the recommendations that it gives are adhered to. It thus needs to evolve such a process.

To some, especially those cynical about ethics committees and about ethics in general, the last statement above, about monitoring could be read as going a little too far. Well, I agree, it is quite a task for an ethics committee to monitor research. What then is the option? What then remains is to change the perception of the entire concept of the researchers, the ethics committees and the participants being on different sides of fences. Ethics, rights of participants and rights of science and researchers can be best accomplished when they work together as partners, and share the same concerns. The final benefit will come to all those involved in the process.

Resource: “Ethical Guidelines for Social Science Research in Health” (2000) National Committee for Social Science Research in Health, Secretariat- CEHAT, Mumbai.(cehat@vsnl.com)

Tejal and Dr Amar Jesani co-ordinated consultations which led to the evolution of this document. Tejal was until recently working with CEHAT, Mumbai, and can be contacted at tejalb@rediffmail.com

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Picture by Shilpa

Dr Soumitra Pathare

Abstracted from Dr Soumitra Pathare’s contribution to the Panel Discussion on ‘Ethics of Practice’ and the active discussion, which followed.

The issue of ‘informed consent’ with respect to treatment for a diagnosed mental illness is often reduced to a paper exercise. It is simply understood by the professionals in a bureaucratic and impersonal way, as in, ‘I have told the patient that I need his or her consent’. Following this declaration, the patient is supposed to sign on the dotted line. The process of giving correct and full information about the treatment and ensuring that the patient understood are not complied with. Sometimes medical or surgical departments in hospitals refer patients to psychiatry saying that ‘this person has a psychiatric illness, please take his consent’ for a particular medical intervention. It is the mandate of the doctor who does the surgical / medical procedure to do so irrespective of whether the patient has a mental illness or not. This shows the authoritarian and paternalistic model within which our health services work.

Ideally, informed consent involves the process by which different treatment options may be thrown open before the patient so that the patient can exercise her choice. This should be followed irrespective of the kind of mental illness or the kind of treatment involved. If at all anyone is *not* to be given the information (as in involuntary treatment) the professions must specify very clearly under what conditions this can be done. There must be a standardized procedure (clinical and ethical) for assessing the inability to give consent. Not taking consent must be the exception, not the rule.

However, in reality, things work the other way round. The treatment options are never even specified even less clarified. The only model used as the basis of ‘informed consent’ appears to be the ‘whip or carrot’ model, wherein the doctor says, ‘Take what I offer, or else don’t come to me anymore for cure’. Ethically, the psychiatrist does *not* have the option to refuse treatment upon patient refusal of consent to a particular treatment! This makes the whole issue of ‘informed consent’ a mere ritual at best. In residential or outpatient facilities in India, the on-duty psychiatrist is often given the role of a whip master, dishing out consent signatures automatically upon patient admission. Conscientious psychiatrists may and do resist this role, but at the cost of irritating the ‘higher ups’ of service administration and peers.

Economic factors cannot be overlooked in evaluating the question of ‘informed consent’. In private practise, it is often the family who take a relative for treatment and eventually pay the bill. In a ‘pay-as-you-go’ system, where payment for service is made at the point of delivery we cannot fully dismiss the doubt that the doctor will only comply with the ones who will finally pay his / her bill. Also when the doctor has a vested interest in a particular treatment, why would he offer any thing else, like counselling or therapy? ECT is also overused for economic reasons- the doctor stands to gain by this practice. Such economic factors do determine the issue of informed consent in the Indian context.

Bapu has a small resource library on mental health advocacy, including books and documents on services, user movement, activism, self-help, law and policy. Our archives also has a small collection of workshop reports, studies, media clippings, case papers, interview transcripts, etc. on advocacy related themes. This column brings some snippets from the archives to our readers.

The salient points of the panel discussion were:

1. There is a need to actively advocate for informed consent protocols for the mental health professions
2. As a rule, there are few patients who are *not* in a position to give informed consent
3. As a rule, age, relationship to care giver or other personal details has little to do with capacity to consent
4. Criteria must be clearly specified regarding patients who cannot give consent or who will be treated involuntarily. This must be a standardized practice protocol.
5. Even for them conditions must apply which will not rule out professional accountability and giving information after treatment
6. As a rule, the professions must recognize that there is conflict of interest between family and sufferer and build informed consent protocols accordingly.
7. There must be a debate on third party involvement (e.g. friend of mentally ill, patient council, user advocate from the locality / region) in arbitration of every case of compulsory treatment.

(Source: Bapu Workshop on 'Women and Mental Health- Planning gender sensitive community interventions', September 17-18, 1999, YMCA, Pune, India)

Dr Soumitra Pathare is a practicing psychiatrist living in Pune, with interest in social rehabilitation and mental health advocacy. He can be contacted at pathare@pn3.vsnl.net.in

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useful links

Bhargavi Davar

www.MindFreedom.org is a site that I have eagerly browsed in July. This is the site of Support Coalition International (USA), a global coalition that promotes self help and defending rights of people in the psychiatric system.

The site correctly points out that 'In the family of social change movements, the psychiatric survivors liberation movement has been the "aunt in the attic" who is usually ignored'. I appreciated the point that the psychiatric survivor's liberation movement is not just about the problems of a minority with chips on their shoulders. It is about all of us who care about ourselves, our families, communities and about our fellow human beings. Commerce in mental health and the influence on 'mental health' by drug companies has put our health and personal lives in jeopardy. Today, you cannot even go to a GP without the fear of being prescribed anti-depressants.

From SCI and the many links thereon, I learnt many things, e.g., that deaths have been caused in very hot weather by some medication given for schizophrenia. Who among us, visiting psychiatrists, has been given this bit of vital information about medication and hot weather? The latest issue of their journal, *Dendron / Mind Freedom*, voices concern about the psychiatrization of childhood. I was shocked to know that over 6 million children, including infants, in the US are being prescribed psychiatric drugs.

Through the SCI website, I learnt that organizations are celebrating July as the MadPride month, and organizing campaigns and events around the world. In Vancouver, on July 22nd, many are coming together to hold a protest against 'Globalisation of Psychiatric Human Rights Violations'. The protest is being co-ordinated by the World Network of Users and Survivors of Psychiatry, Denmark, which is also organizing its first World Congress in July.

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Newspaper Cures

Sadhana Natu

It has become *de rigueur* these days for newspapers to publish counselling columns. These feature agony aunts and a few uncles as well, dishing out advice on a range of psychological, interpersonal and familial issues. The queries indicate a broad spectrum of individual and social problems. It is interesting to note that people write to these columns rather than seeking help from mental health professionals.

The basis of selection of those who give advice in these columns defies classification, ranging from counsellors, actresses and celebrities to in-house 'experts'. Sometimes the identity of the advisor is not disclosed. The advice often reveals gender, class biases and stereotypes. Since both questions as well as replies appear in their edited version readers do not get a holistic picture about the problem.

The Saturday supplement of *Times of India* (Bombay Edn.) used to carry a column by Tommy and Anna. It was supposed to be a space for adolescents but it never transcended banalities about dating, dancing, love lives etc. It was highly elitist and created a feel-good aura. After reading it, one wondered whether the younger generation eschewed all matters that were cerebral and mature.

Women's magazines (*Femina* and *Women's Era*) devote pages for counselling. In *Femina* the late Pearl Padamsee often gave commonsensical advice. Her intent to help could not be doubted. The same, however, cannot be said about the patriarchal and regressive views expressed in *Women's Era* by their in-house counsellors. The magazine reinforces sexist ideas and promotes the dogma of women's primary role of 'wife, mother and homemaker.'

The column in *Indian Express* is consistently balanced, gender-sensitive and empathetic in its approach. The counsellor, not claiming to be a know-it-all, also advises readers to seek help from other experts when necessary. Also, the column does not shy away from addressing sexuality, sometimes the core issue in

mental health. Other columns either evade this issue or relegate it to the sexology expert, where it gets medicalised. In one of the columns a professional wrote about a case where the problem was related to sexuality, *without* mentioning the word. This kind of evasion strengthens the very attitude that the professional is seeking to correct or change.

In the Marathi newspaper, *Sakal*, an anonymous agony aunt (or *Vahini*- sister-in-law) answers queries every week, tackling familial, marital and social issues. The advice given is liberal but cautious and preservation of institutions of family and marriage is never lost sight of.

Sample this question-answer vignette: the sender narrates that she is a 22 year old girl in love with a boy who belongs to another religion and is not sure whether she should marry him. She is sure of facing opposition from home if she does marry him. The advice given is that she should be cautious and give the relationship some more time to find out about her true feelings (so far so good). She is warned that though inter-religious marriages can succeed, cultural and religious differences can prove difficult to surmount! This is where the counsellor's biases creep in.

Columns on mental health usually seek legitimacy and primacy for the practice of psychiatry. In doing this, they inevitably 'medicalise' the problem instead of giving due importance to psychosocial and economic aspects involved in the problem. As media consumers we read these counselling columns and often they influence our attitudes. We may approach these columns as users too. For both these reasons we need to re-read the counselling columns critically.

Sadhana Natu teaches psychology at Modern College, Pune and is committed to research, teaching and activism in the area of women & psychology.

Email- satish.sadhana@vsnl.com

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Seeing Children, and Not ‘Disorder’

spotlight

Nandita D’Souza

Children are particularly vulnerable to stress as the world becomes a more troubled and violent place. The Sangath Centre for Child Development & Family Guidance was started in Goa in 1997 by a multidisciplinary team of professionals in order to provide a community-based child and adolescent mental health (CAMH) service. Of the 350 or so children assessed and cared for by us every year, less than a third have established psychiatric conditions, but over half are facing abnormal psychosocial situation such as disturbed family relationships, alcoholism, parental mental illness, migration, poverty and stress arising from the child’s disorder or difficulty. In our center, we emphasize the following aspects:

- ♦ In promoting CAMH, the clinic, home and school are all connected. The multidisciplinary team is able to form linkages with the family and the school, thereby ensuring that all aspects of the child’s functioning are addressed.
- ♦ Most problems are everyday concerns of the carers of children such as temper tantrums, disobedience, mischievousness, overactivity, worries about development and difficulties with eating and sleeping. Every professional views the guidance and education of parents, teachers and other carers of children as their vital responsibility. Child mental health services primarily focus on prevention. If, as a CAMH professional, you are encountering children only with established disorders, then you are not seeing enough children!
- ♦ An intimate knowledge of the range of ‘normality’ in a child’s behaviour is paramount in making a correct judgement about whether a symptom is just a temporary problem or a definite disorder. An understanding of where the child is developmentally helps one gain a perspective on how she’s dealing with difficult situations.

- ♦ The “complainant” is often the parent or teacher, not the child who may be brought to the clinic against his or her wishes! Befriending the child facilitates trust and confidence, and building a relationship between the child and the professional. In older children, confidentiality must be mentioned and maintained.
- ♦ As the pressures of the academic curriculum increase and parents become more preoccupied with the competitiveness of the school system, children who lag behind soon become a parental nightmare. Difficulties of scholastic skills may present as somatic symptoms such as headache and vomiting related to school attendance.
- ♦ Be aware of the proxy patient. Quite often a child is brought by the parent with a long list of complaints about his or her behavior at home. On closer questioning, one finds that the child is doing well in school and has many friends. In such families one must look for signs of mental health problems in the parents. Parental depression or stress can sometimes present as “a problem child”.

The stigmatization of psychiatric care often leads to a delay in seeking help and therefore a worsening of the condition. Pediatricians and GPs must be trained to ask parents about childhood emotional and behavioral concerns as they can identify and refer children in difficulties. Child mental health supervision has more to do with promoting good parenting, developmentally appropriate education programs and building personal self-esteem than providing psychiatric care.

Nandita D’ Souza is a Developmental and Behavioural pediatrician working at Sangath Center, Goa and can be contacted at ndesouza@goatelecom.com. The Sangath website address is- www.goacom.com/community/sangath

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Call for papers

2-Day Seminar on **CASTE, COMMUNALISM AND DISCOURSES OF THE MIND**

December 2002, Pune, India.

In India, the knowledge/power dimension to the mental and behavioural sciences is presently under scrutiny. Counter-discourses to mainstream ideologies are gradually being articulated. We plan this seminar in continuity with recent foundational questioning of these sciences where issues of culture have been prominent axes of analyses. The objects of our study are the following: psychology, psychiatry, medical anthropology / sociology, narratology, social work, cultural and feminist studies and *Dalit* scholarship. Through the seminar, we aim to show, yet again, that discourses of mind, those that promise healing and self-realisation, are *political* discourses. We invite a group of inter-disciplinary researchers, scholars and activists to share your research with us on any of the following themes:

- ◆ Looking at *Dalit* literature, autobiographies, narrative writings and making thematic and critical linkages with psychological concepts
- ◆ Is there a *Dalit* psychology? Notions of ‘Stigmatised identities’, vulnerability, resilience and resistance
- ◆ Is caste-ism a cultural or collective mental health pathology?
- ◆ Gender, psychology and caste
- ◆ *Hindutva & Brahmanism* within mental health sciences and professions.
- ◆ Colonialism, cultural revivalism and the discourses of mind
- ◆ History of institutions, the ‘native’ asylums and caste
- ◆ Research and interventions in psychology for ‘scholastic backwardness’
- ◆ Caste as experienced and ‘managed’ within the psychiatric / service regime
- ◆ Psychoanalysis as a location for discussion and critique

For initial enquiries, please contact Dr Sushrut Jadhav, Department of Psychiatry, 48 Riding House Street, University College London W1N 8AA, United Kingdom. Email: s.jadhav@ucl.ac.uk Tel: 00-44-207-679 9292; or Bhargavi Davar, 16/A Shanker Shet Road, 1st floor, Pune 411042, India. Email davar@pn2.vsnl.net.in Tel: 00-91-20-6872672, 6359969.

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