

aaina

a mental health advocacy newsletter

Vol. 4 No. 2

July 2004

Editorial

Another Erwadi year will pass us by, this August. This year, the Central Government has prepared a budget allocation of Rs 150 Crores. Mental Hospitals are still waiting for the finance to arrive at their institution. The Supreme Court case started *suo moto* in 1999, following Erwadi, is at a total stand still. No hearings this year.

In July, the South Asian Medical Ethics forum circulated news about a “scoop” by *Tehelka*. *Tehelka* exposed Dr. SK Gupta, a “greedy and corrupt psychiatrist” of the Agra mental hospital, who took five thousand rupees to help husbands “dump” their wives. He absconded after that, returning later to surrender to the chief judicial magistrate Sarvesh Kumar’s court in Agra. The doctor was caught in camera stamping a false certificate of mental illness, and accepting money. This made headline news in *Tehelka.com* and regular updates and postings are made at the website, along with case studies.

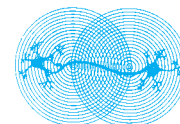
Readers of *Aaina* may be aware that one of the easiest ways to obtain a divorce, under the Marriage and Divorce Act, is to claim that the spouse - (usually a wife who has become a nuisance or a burden) - is “mentally ill”.

The Indian Psychiatric Society is yet to establish any basic ethical principles for giving forensic or civil evidence in court. The “incompetency” provision (“unfit for trial” or “unfit” for any civil function) rules many civil and treatment statutes in India. Doctors who decide incompetency have to be specially trained in forensic medicine and law. Professional bodies in psychiatry have to stipulate clear guidelines for certification of mental illness, as well as for the “incompetency” clause. The statutes give superlative powers in this regard to doctors (even non-psychiatrists), without laying out any framework or safeguards. Indian doctors usually establish a diagnosis as a proof of incompetency. This is against all professional ethics. Improving assessments (clinical or legal) have definitely been a strong point for debate or discussion in the IPS.

Then, there is news about the UN Convention meeting in New York, this June, and the WNUSP General Assembly meeting, this July. We have posted news about these in this issue of *Aaina*.

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Trust
for
Research
on
Mind
and
Discourse

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

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

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

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

Aaina is circulated free to people concerned about these topics. It reaches out to over 300 people and organizations, and also to various policy makers and human rights watchdog agencies.

If you are interested in writing for *aaina*, or in receiving print copies, write to us at: aaina@camhindia.org You may also contact the editors at: davar@pn2.vsnl.net.in or satish.sadhana@vsnl.com If you wish to make a donation to *aaina*, please make a DD or a cheque in favour of "Bapu Trust for Research on Mind & Discourse, Pune" and post it to our mailing address.

Everyone experiences different phases of life—good or bad. However, suddenly when we face a calamity, we are nowhere! We are thrown in a deep valley of sorrow. Ours was a small family. Our only child, our son, who successfully became a Doctor (M.B.B.S.), was preparing for his P.G. in Surgery, when he suddenly passed away. This was the end of our life. Our existence became totally meaningless. Relatives and friends were with us at the time of crisis. Yet, no helping hand was able to bring us out of acute grief. We were in this world, but were not a part of the world. Why we should continue our existence, was a question before us.

Today, everybody's life is full of stress. This affects the young professionals, and in particular, the medicos. There is a need to reduce this stress among medical students and young doctors. We felt that the deep sorrow we experienced should not come to others and they should be saved from such calamities.

With this intention in mind, we approached a noted psychiatrist in Pune city, who is the director of a hospital psychiatric unit. He gave us audience immediately. He understood our feelings. He advised us to have a dialogue with his colleagues. His colleagues were attentive and responded appropriately to the delicate state of our mind. We met them every week for one hour and had very kind, helpful exchanges with them. Each meeting was a further stage of improvement. We got meaningful directions from them. We were earlier completely broken. But psychotherapy helped us to recover and enabled us to stand on our own legs. With continuous monitoring of our problems, counselling, along with some medication, there was definite improvement in our mindset.

It must be said that we will never be out of sorrow. But the psychotherapy has helped us and made us want to devote more time towards prevention of such problems for medicos.

During this time, we were able to study microscopically, the mindset (“mental synthesis”) of our various actions. In everyday life, we do not give much attention to ourselves, or to our minds. When we come across somebody in sorrow, we extend our help, express grief. We utter consoling words. But it is beyond our imagination, how much that person is literally bleeding internally and is mentally fractured. We advise them to come out of sorrow and start a normal life. The sufferer needs something more than this! While giving consolation, her / his wounds may get opened up once again.

When we are physically not well, we take some medicines or visit a Doctor. But when our mind is disturbed, we do not take any action. Some times we are sad, angry, humiliated or frustrated. We ignore all these feelings. In addition to this, we also face stress and professional competition. During such times, we do not get ourselves treated for our disturbing minds. The fact that counselling is available is not even known to most people. It is very essential to have this known to each and everyone in the society. Our experience has convinced us about the importance of counselling. Whosoever is in distress, if somebody could talk to such a person, understand his / her feelings and problems, then he / she will get some sort of solace and feel re-assured.

Everybody's mind is full of different, mixed-up thoughts about himself and about others. Some people are able to control these feelings and distress. However, sometimes this turns out to be a problem. Then, no advice or common sense is sufficient to satisfy the individual. Such a person suffers severe mental tension, and is thrown into depression.

Today we find stress in all spheres of life, especially being faced by young professionals. Particularly medical students are experiencing depression during 6 ½ years of their degree course, internship and rural service. The medical education

course is longer and heavier compared to other branches. The medicos do not realize that they are under constant stress due to studies, competitions, examinations, hospital duties, and being in constant contact with all kinds of patients. Also, they get lonely being away from home. After college, they are immediately thrown into an atmosphere, which demands heavy and continuous duty, odd duty hours, and emergencies. In addition, sometimes they have to face the management's demands, rough handling, insults, etc. Research studies have shown that an experience of humiliation and entrapment may provoke a depression. There is always a constant urge, being an intelligent lot, for performing well and doing better in professional competitions. They neglect to take adequate rest, good food, regular exercise and other enjoyment of life. They have no time to think of all this. Research reveals that stress results from a relentless cycle between work, family and life style, which in turn has a direct biological effect on health and illness. The more sensitive ones become victims of anxiety, worries, dejection, agony, anguish, remorse and dismay. These medicos become victims of anger, rage, resentment, helplessness, frustration etc. They declare themselves unfortunate. This distress feeling sometimes takes a dreadful turn, as happened in the case of our son. Recently, there is increase in the number of medical students attempting suicide.

For the medical course, students are selected on merit. The students from the top cream are generally selected for the course. But, if these boys meet this sort of fate and despair, at least some students and parents are likely to think otherwise.

'De-addiction' has got a lot of importance and that is good also for social health. One reason for a person to become addicted to drugs and alcohol is stress, dejection. Hence, to free alcoholics from the addiction, special efforts are being made. (E.g. MUKTANGAN Project, clinics held by many corporate organizations etc.) We feel that similar efforts should be made for medicos too. Here, we would like to emphasize that doctors, who are supposed to take care of society's health, should be first looked

after, especially for their psyche, spirit, frame of mind and total well - being.

Young medicos are to be guided towards true, real, positive, constructive options available to them. They need to be persuaded against taking control over the things beyond ones' control. They should be helped to transform themselves into the creative mode by avoiding disturbing thoughts. They have to be guided in taking regular nutritious food, sound sleep and leisure. This will lead to an ideal, healthy lifestyle for them while pursuing a very arduous profession. Stress management interventions will include activities which minimize the negative outcomes of stress exposure.

From our own experience, we have learned that medical students are not different from other students. They spent their childhood in a similar fashion like other children. They come to this medical field with eagerness, passion, and enthusiasm. Apart from studies, they are equally interested in all sorts of games, arts, drama, music, reading etc. Also, they wholeheartedly participate in cultural programs and functions. They show their caliber in studies, while attending to other extra curricular activities and are liked and appreciated by all and one. Then, why do they suddenly take such a drastic step?

We have been thinking, what could be done about all this? To help persons already suffering from depression, it is essential to show love and concern. Therefore, developing a good relationship within the community becomes important. It is necessary to create new strategies for reaching out to the people.

1. The first thing to accept is that people may need counselling during the course of his/ his life. Also, the taboo should be removed, that to take help of these experts' means one is 'mental'.
2. Professional bodies and NGOs should expand their activities and give counselling at an individual level.
3. Counselling is most required for the medicos, because there is always an emergency situation in the hospitals. They are always witness to life and death situations. Medical colleges, hospitals, and

(...continued from page 9)

Dr. R. Thara

The word “disability” more often brings to mind a person in a wheel chair or a visually impaired person. Even within the realm of mental disability, it is synonymous with mental retardation. Disorders of the mind, amenable as they are to medical treatment and equally, if not more disabling than many other conditions have stood by the way side for a long, long time – waiting for some kind of recognition.

This is despite the fact that

- ◆ In western countries, those disabled by mental illness form a large part of the beneficiaries of the social security system.
- ◆ Nearly 5-6 million in our country are disabled by various forms of disorders of the mind.
- ◆ Research done, including that in India has in no uncertain terms demonstrated the nature and impact of disability on the course of illness and more importantly the functioning of the individuals. There is data to show that depending on the definition, 50-70% of people with mental disorders have disabilities. For specific disabilities, 0.2-0.6% of the population is disabled by mental disorders.

There are several factors that have accounted for the non-recognition or delayed recognition of mental disability. Some of these are the poor visibility accorded to this disability, its rather subtle and hidden nature, and the lack of awareness and sensitivity to this even amongst mental health professionals. Mental illness, unlike other disabling conditions, on account of the social stigma has been swept under the carpet for centuries. Speaking about it was taboo. It is only in the last decade that family members, consumers and professionals have been more forthcoming about discussing this in the open.

The Persons with Disabilities Act passed by the Indian Parliament in 1996 provided impetus by including this disability on par with others. However a lot of questions were left unanswered and the subsequently formed Amendment Committee addressed some of these issues.

International Developments:

Internationally, the revision of the classificatory tool, the ICIDH brought into sharp focus the importance of classifying and measuring disabilities. A major international project was launched jointly by WHO and the National Institute of Health, USA to field test some of these concepts and permit for cultural and regional diversities. The underlying principle was that disability was an universal phenomenon. ICIDH-2 later renamed as ICF (International Classification of Functioning) envisaged a shift from a purely medical model of disablement to a biopsychosocial model- from a minority model of disablement to an universal model. Due weightage was accorded to the recognition of environmental and social factors in the process of disablement.

The subjective components of any illness or health experience are also being increasingly taken note of and measures and even correlated with the functioning status. Health is no longer viewed in isolation, but closely linked to environmental and personal factors.

The multi-country, international project also recognized that planning of health care services did not depend on diagnosis alone, but on the dimensions of functioning and disability as well.

The Indian scene:

The National Mental Health Programme made only a passing mention of rehabilitation and practically nothing on disability. This issue was also contentious in the sense that the Ministries of Health and Social Welfare (now renamed as Social Justice & Empowerment) were debating amongst themselves as to who should handle this. This was largely because of the fact that although the disabilities of mental disorders are as real and prevalent as other disabilities hitherto recognized, the nature of interventions are different. Both medical treatment and rehabilitation have to be provided simultaneously. To some hard-core rehabilitation professionals, this seemed to negate the basic tenets of rehabilitation since it was

popularly held that rehabilitation could begin only after all medical treatment ceased.

This self-imposed, traditionally held maxim is certainly not applicable while dealing with those with a mental disability. One cannot envisage a situation when medical treatment can be totally stopped and the person exposed only to rehabilitation programmes, except in a handful of instances. This is because every episode of illness can increase the disability and lead to chronicity. This truth has to be well recognized by all those interested in the welfare of this group of persons. I am certainly unaware of any globally accepted definition of rehabilitation that denounces the use of other supportive measures.

Implications for rehabilitation:

The understanding of disability has implications for rehabilitation. Rehabilitation needs of persons disabled by mental disorders differ from others. Planning for such persons differs by age and gender. The needs differ by domain of disability.

My own Ph.D. was on Disability in Schizophrenia. It revealed that almost all family members were most affected by the loss of functioning of their wards rather than their clinical symptoms. Although they did not use the word disability, they were considerably distressed and concerned by the occupational unproductivity of their family members.

Why should we recognize psychiatric disability?

There are several reasons for this. One is that it is imperative for professionals and public to understand the social sequelae of mental disorders, in that they can be disabling enough to interfere with daily activities, family life and interpersonal relationships.

This certainly helps in health planning, differential allocation of resources, and manpower planning.

The other reason is that this group becomes eligible to receive the benefits accorded to other disability groups. SCARF clients regularly benefit from pension transfers and tax concessions. We hope this gets extended to travel

concessions especially bus passes. Access to loans to the disabled and their families to start some private ventures to generate employment is another avenue.

This also provides a platform for consumers to protect their rights and needs.

Tools to measure disability:

There are several instruments available to measure disability, the WHO-DAS being one of the most used. In India we were in need of a simple, yet comprehensive instrument to measure mental disability, which can be used at the primary care level, by all mental health professionals. It was also necessary that disability scores with corresponding percentages had to be generated by the instrument. With all this in mind, the IDEAS was developed by the Rehabilitation Committee of the Indian Psychiatric Society. The Ministry of Human Resources and Empowerment, Government of India have since gazetted it. IDEAS needs to be tested on the field for a few years in order to be refined. It has however effectively dispelled the notion that measurement of mental disability is not possible or feasible.

Finally, it needs to be stressed that much more work awaits to be done in this field- both in terms of collection of hard data on disability and address its relationship to cost- effectiveness of existing programmes, health service utilisation, changing public attitudes and stigma. All intervention programmes must be sensitive to the recognition of abilities and disabilities and work towards enhancement of functioning rather than amelioration of clinical symptoms alone.

Dr. R. Thara is the Director of Schizophrenia Research Foundation (SCARF) based in Chennai. Dr Thara can be contacted at - scarf@vsnl.com



Why a special service catering to women's needs?

Seher was started in Pune city because, we believe that the subject of *women's* mental health should be viewed separately from a general notion of mental health.

- *Differential social stressors*: Women, as a result of patriarchy and their unequal social status, experience a different social reality, which strongly impacts their emotional health.

- *Differential role constraints*: Due to the way our society, and the social roles within it are structured, women invest more in family, children and other care giving roles. As cultural standards for these roles are near impossible to achieve, women are riddled with guilt, shame and diminished self worth.

- *Differential work satisfaction*: While women may be overburdened with household labour and paid work, such work does not obtain much value or power for them in social or family negotiations. For example, even a highly educated woman may be forced to accept conventional roles driven by stereotypes, such as, "*women are better at being wives or mothers*".

- *Differential socialization*: Women, right through their developmental years, are taught to prioritize others' emotional needs over their own. They are often pushed into care giving roles very early, even before their own developmental needs are met. Their physical development, stamina, capacity to defend themselves or set boundaries in relationships, is not encouraged.

- *Violence against women*: Women are often victims of abuse and violence within their own families. Women are more often victims of hate crimes by men.

- *Differential health needs*: Women's nutritional, health and reproductive health needs are often unmet, causing minor to major mental health problems.

- *Differential mental health needs*: Women's mental health is affected by the cumulative effect of all the above. Common mental health problems (depression, anxiety,

phobias, panic and trauma) are two or three times more frequent in women than among men. Recent data from the World Health Organisation suggest that depressive disorders account for 30% of neuro-psychiatric disability among women in the developing countries, but only 12.6% of that among men. Women are more likely to experience a chronic and longer-term episode of depression, with a higher likelihood of recurrence as compared to men. 10% of women experience post-natal depression in weeks following childbirth.

***Seher* – A woman centered service:**

Seher was created to fill a gap in mental health service provision for addressing this diversity of needs among women. Through *Seher*, we want to create healing alternatives, which anchor a woman's emotional health meaningfully within the context of her lived experiences, rather than on medical diagnosis. We are striving to create a woman centered mental health service, addressing a diversity of women's needs.

Medical diagnosis of mental disorder, while being a useful tool to manage complex psychological realities, tends to be gender biased. The diagnostic categories reflect a bias in the concept of a "mentally healthy person" itself. Masculine attributes (rational, balanced, decision maker, logical thinking, assertion, etc.) describe the desired standard, whereas feminine attributes (emotional, sensitive, dependent, submissive, etc.) describe standards of mental disorder. *Seher* does not place a premium value on psychiatric evaluation and diagnosis, in planning individual interventions.

The social life of the woman and her relationships are not very relevant in a medical model of intervention. Issues concerning inequality in the household or community, domestic violence, sense of powerlessness and lack of hope or joy do not get addressed. At *Seher*, the psycho-therapist will situate the intervention around issues concerning a woman's resistance and struggles for empowerment.

Seher's objectives:

1. To offer a need-based cafeteria of mental health options to women in emotional distress
2. Promotion of emotional well-being of women, users, carers and the community at large
3. Offering holistic, gender sensitive, and user-centric mental health services
4. Raise awareness and enhance capacity on mental health issues, as a way of preventing mental ill health.

Seher's cardinal principles:

1. Women will be index clients.
2. A gender and role analysis will inform and structure intervention.
3. Intervention will be based on an understanding of the structural and social determinants influencing her emotional health.
4. Intervention will be holistic: The program will include nutritional, health, reproductive health status in the planning and treatment through appropriate program protocols / referrals / consultations.
5. The service provider (sp) will establish an equal relationship with the client (a fully informed process with mutual goal setting).
6. The sp will be mindful of the client's present situation and avoid victim blaming and other such misuse of therapist power.
7. The client will be assured of an enabling space where she can explore barriers to her personal growth, her abilities, creativity and resilience.
8. The client will be assured of a respectful space where her experiences and perspectives will be valued, yet allowing for discussion on opportunities for growth and empowerment.
9. The sp will give importance to client self-determination and will facilitate self help.
10. The sp will not withhold treatment options (drugs, alternative treatments) or appropriate referrals if the client expresses a desire to try them.

11. The program advocates against the use of shock therapy in the treatment of mental disorder.

Seher's approach and activities:

Seher approaches women's mental health and in general, common mental ill health, in a holistic manner. *Seher* offers psychotherapies (individual, group, family and CBT). *Seher* believes in the prevention of mental disorder and conducts training and capacity building programs for community case-workers. *Seher* works with a multi-disciplinary team - (user, activist, medical doctor, nutritional therapist, psychologist, psychiatric social worker, psychiatrist) - to give direction to the work, to build capacity of *Seher* staff, peer review and to offer consultations to *Seher* users. *Seher's* referral system, in due course, will include clinical referrals (health, reproductive health, psychiatry, ISM, clinical psychology, nutrition) and social referrals (lawyers, support organisations).

The program invests in sufficient study time and capacity building time for the staff, so that the program remains tied to current knowledge. The program also encourages staff to take steps to enhance their own psychological well-being and prevention of burn out.

Seher's indicators of woman centered psychotherapy:

1. *Seher's* clientele is mostly women.
2. *Seher's* clientele come from diverse backgrounds.
3. Case work data, referral data and peer review evaluation indicates that the sp has considered-
 - a. holistic health assessments (health, nutrition, psychiatry)
 - b. assessment of referral needs (clinical, social)
 - c. clients' gender orientation, social determinants, role analysis and bargaining position
 - d. client's present position in goal setting
 - e. client's agency and resilience
 - f. consistency with client's own interest
 - g. impact of psychological evaluation (diagnosis) on her life.

4. The sp's academic work (seminar presentations, publications) and capacity building (trainings attended, use of trainings in clinical work) indicates updation of concepts and information on gender, psychological ill health and clinical management.
5. Client satisfaction data indicates sp's mindfulness of -
 - a. maintaining quality and consistency of interaction (trust, empathy, warmth, respectfulness, affirmation)
 - b. not forcing either normative or subversive stereotypes on client
 - c. providing necessary and sufficient information for client consent
 - d. addressing requests for referral to other agencies, treatments
 - e. client's full participation in process and goal setting
 - f. client's requests for education / awareness have been addressed

For more information on Seher, contact the co-ordinator of the program, Ketki Ranade at - wamhc@vsnl.net



reflections

The need for psychotherapy

(...continued from page 4)

professional bodies should make efforts to help medicos maintain a balance of mind.

4. It is necessary to survey the problems and life style of medicos.
5. Today, young people working in the IT field or Management/Business areas are provided with various facilities such as food, games, entertainment etc. at the work place itself. This is done to enhance their performances as well as to take care of their health. Proper medical attention, yoga, food and diet, games and entertainment, all this helps them to keep in good spirit. However, medicos are not given these facilities at all. Doctors definitely understand the importance of good diet, sleep, rest and regular exercise. But all

this they tell their patients. They must follow these dictums themselves.

6. A database of institutes, experts, and volunteers working in the field of counselling and psychotherapy must be available to the public. A referral center should also come up with the help of the NGOs in the field. There should be good coordination and networking amongst all the players from the field, a sort of a "virtual NGO". Many IT possibilities can be richly harvested for the working and growth of such a NGO (such as newsgroups, data banks, referral service, etc).
7. There should be training institutes for counsellors / psychotherapists with accreditation of the government.
8. At the same time, management of medical colleges, hospitals, trustees of NGOs and Sr. Hospital staff, where doctors are working must create more mental health friendly work environments for young medicos.

Sensitive, young medicos' psychological, emotional, physical, and social needs, if understood and met by their colleges, seniors and peers, will make them stand in the profession with vigour and strength. It will help develop their mindset for social work, and the society will get creative, performing, skilled specialist doctors. Ultimately, society will gain by having happy, enthusiastic, and energetic doctors.

We wish, the sad, terrible incident, which made us unfortunate parents of a helpless child, who was very honest, sensitive and loving, may not come to others. The pain being experienced by us should not be part of life of parents of other medicos. We would like to do, in this regard, whatever we can do to the best of our abilities and resources.

Mr. and Mrs. SPK, Pune, who have shared their grief with aaina readers, at present wish to remain anonymous. They have gained a lot from the timely help given by Dr. Mohan Agashe and his colleagues at the Maharashtra Institute of Mental Health, Pune.

The Cultural Experience of Health

Deepra Dandekar

Psychiatry developed as a means to study and control those within custodial care. It became a clinical approach for interpreting social deviance. Both psychiatry and psychoanalysis have their inception in ideas of morbidity and illness. Typical behaviours unacceptable to western morality began to be looked upon as illness based. Differences in region, social background and culture were not considered to be important as influence on behaviour.

In contrast, studies in mental *health* have tried to deconstruct this over-pathologised concept of mental illness which lacks any experiential or cultural dimensions to it.

The mental health movement has considered the user's perspective in psychiatry to be an important tool for advocacy. It has always been important to validate the experience of emotional pain, holding responsible the underlying political inequalities, which exacerbate and cause great distress.

Collecting experiences of mental illness have brought to light hitherto overshadowed aspects of creativity, spirituality and thought. Experiences of illness, diagnosis and clinical treatment have demonstrated the short sightedness and inhumanity of clinical work, in treating the mind only as a deficient organ.

An additional effort to define good mental health was made so as to mean much more than the absence of illness. Parallels to understand the experience of happiness, well-being and good mental health were drawn from popular imagery such as a beautiful waterfall, a serene sunset or a placid lake.

This imagery, however, is very limited to a certain class of urban, educated, upper middle class persons who can afford to be tourists with vacations spent in exotic, beautiful and good mental health enabling locales. Persons, being local to those regions, may have to bear terrible economic and other hardships to be able to live their daily lives (never mind the beautiful mountains) over there. The notion of good mental health and the sense of reality in living within those "savesaver" images for them may be entirely different.

For many semi-rural, rural and even urban populations, it is religious activities, which take on the dimension of entertainment. These may variously include going to pilgrimage centers for extended visits, taking part in religious festivals or *Jatras* or participating in the various cultural programs surrounding religious festivals, such as folk dances, folk songs and *bhajan mandalis*. The fusion between religion and entertainment is as culturally accepted as the fusion between information and entertainment seen in many upper middle class urban homes.

Common imagery for enabling good mental health for these populations may also hinge more closely on religious euphoria and trance. It is common in these areas to see especially women possessed by gods and goddesses significant in their cultural context.

An episode of trance wherein a person is consumed with religious ecstasy, is a popular mental health enabling behaviour, culturally accepted almost in all communities adhering to old-world religions (Christianity included). Trancing activities enable a person to win a position of authority and acceptance within his or her own community. But this, however, is not the only reason for which it is resorted to. The ability to trance becomes a part of one's identity and self-image. It is a culturally sanctioned and socially approved power, for a group to engage in joyful activity.

In cultures, where a woman's joy is viewed with growing doubt and fear of loss of control, and rebellion, engaging in divine trance becomes a way to internal knowledge, healing and joy. A divine trance is indeed like finding one's rightful place, in the order of things.

Opposition to such esoteric practices is vehement, especially in Maharashtra, where modernizing agencies feel the need to “educate” populations in demystifying these experiences within the community. It is their mission to falsify experiences of ecstasy by colouring it as deliberate and deceitful activities, engaged in by a group of individuals in order to gain popularity, and cheat others of money.

One would wonder, however, that if cheating and malpractice was the pivotal issues here, then how did their scrutiny overlook the cheating and fraudulent activities of “science based” disciplines, supposed to render service within the community.

Deepra Dandekar is co-ordinating the field work on a project on “Health and healing in western Maharashtra: The role of traditional healers in mental health service delivery” at Babu. She may be contacted at - wamhc@vsnl.net



Rules for the Gracious acceptance of Lithium into Your Life

1. Clear out the medicine cabinet before guests arrive for dinner or new lovers stay the night.
2. Remember to put the lithium back to the cabinet next day.
3. Don't be too embarrassed by your lack of coordination or your inability to do well the sports you once did with ease.
4. Learn to laugh about spilling coffee, having the palsied signature of an eight-year-old, and being unable to put on cuff links in less than ten minutes.
5. Smile when people joke about how they think they “need to be on lithium”.
6. Nod intelligently, and with conviction, when your physician explains to you the many advantages of lithium in levelling out the chaos in your life.
7. Be patient while waiting for this levelling off. Very patient. Reread the Book of Job. Continue being patient. Contemplate the similarity between the phrases “being patient” and “being a patient”.
8. Try not to let the fact that you can't read without efforts annoy you. Be philosophical. Even if you could read, you probably wouldn't remember most of it anyway.
9. Accommodate to a certain lack of enthusiasm and bounce that you once had. Try not to think about all the wild nights you once had. Probably best not to have had those nights anyway.
10. Always keep in perspective how much better you are. Everyone else certainly points it out often enough, and annoyingly enough, its probably true.
11. Be appreciative. Don't even consider stopping your lithium.
12. When you do stop, get manic, get depressed, expect to hear two basic themes from your family, friends and healers:
 - ◆ But you were doing so much better, I just don't understand it.
 - ◆ I told you this would happen.
13. Restock your medicine cabinet.

Source: An Unquiet Mind
A Memoir of Moods and Madness
By Kay Redfield Jamison

United Nations Disability Convention – A brief report

Aaina readers may be aware of the United Nations efforts at formulating a “Convention for the protection and promotion of the rights and dignity of persons with disabilities”. Groups around the world, working on psychiatric disabilities, are viewing the Convention as a vital instrument in setting stringent human rights standards in civil life, as well as in care and treatment. The Indian Government too, is briskly involved in the negotiations, and holding regional consultations on the Draft. So, what does the Draft Convention offer to persons with psychiatric disabilities? A brief visit to the Draft...

Article 2 on General Principles offers full, effective and equal enjoyment of all human rights and fundamental freedoms to persons with disabilities, including dignity, individual autonomy, non-discrimination, total inclusion, respect for diversity and equal opportunities.

Article 4 enjoins all States to be *obliged* to adopt legislative, administrative and all necessary measures, including amending, repealing or nullifying laws and regulations, as well as discouraging customs or practices, which are inconsistent with this convention. States are also obliged to mainstream disability into all their existing programs.

In India, except for a few southern states, psychiatric disability remains an alien topic in the disability commissions, and remains unintegrated *even* in the *existing* disability programs. Also, if India ratifies this Convention, then large-scale law reform (mental health law; all relevant criminal procedure and custody laws; civil laws such as Contract Act) will be required to ensure that the standards set by the Convention are met.

Article 5 makes the States obliged to promote positive attitudes towards persons with disabilities, as capable people, who can contribute to society.

Article 7 is a non-discrimination provision, making the States obliged to guarantee equal and effective protection against discrimination on any ground, such as race, colour, sex, language, etc. The proviso includes direct, indirect and systemic discrimination.

Article (7.3) has been debated widely among psychiatric user and survivor groups. The Article implies

that, States may take actions (including legal) if they can “objectively and demonstrably” justify them as legitimate aims of governance, and is able to demonstrate the reasonableness of the process. The psychiatric consumer groups are viewing this as a gap, by which States can turn coercive against them.

Article 8 enjoins States to reaffirm the inherent right to life of all persons with disabilities. This provision has many serious implications for states like India, where managers of custodial institutions, known for their gross violation of the right to life clause in the human rights discourse, have to reconsider their approach.

Under *Article 9*, all persons with disabilities will be assured of equal recognition as a person before the law (*9a*). Also, persons with disabilities will have full legal capacity on an equal basis as others, including in financial matters (*9b*). *Article 9* has far reaching implications for persons with psychiatric disabilities in India.

Readers of *aaina* may be aware that the Indian laws and adjudication on mental ill health, regularly uses legal incompetency as a systematic way of social exclusion and disempowerment of persons with a psychiatric disability.

Article (9c) is on “assistance” (relevant for example, in the context of guardianship arrangements in the Indian context). The article enjoins that assistance given should be proportional to the assistance sought and tailored to their situation. Such assistance also must not interfere with the legal capacity, rights and freedoms of the person with a disability.

Further, the provision, meant to prevent abject dependency or legal take over of persons' lives, allows proxy decisions only in accordance with a procedure established by law and through legal safe guards.

Further, under this Article, there may be a context for speaking about a "right" to necessary assistance, wherein assistance may be assured in understanding information, expression of decisions and choices, expression of preferences, assistance in contracting, signing documents or acting as witnesses.

This Article also enshrines the right to own or inherit property, to control their own financial affairs, equal access to bank loans, mortgage and other forms of financial credit, and protection against arbitrary deprivation of property.

Article 10, on the right to liberty and security, enshrines the right, not to be arbitrarily or unlawfully deprived of liberty. If so deprived (by law) such persons should be treated respectfully, given all information, offered legal aid, and regular review must be done, of the deprivation.

In the Indian context, it is predictable that this Article will be liberally used to indefinitely deprive someone of the right to liberty. Even something as serious as civil commitment to a custodial house, rarely comes under review or reconsideration. Relevant papers are nominally signed and pushed by the institution managers and the courts, prolonging incarceration indefinitely.

Article 11 prohibits torture and cruel treatment, as well as research without informed consent. *Article 12* places restrictions on forced treatment and forced institutionalization. It also places responsibility for violence within institutions (among residents, for example) on the institution managers.

Advocacy groups have been pressing for a more unconditional statement prohibiting forced treatment.

Article 14 enshrines the right to privacy within institutions, as well as a right to sexual and family relationships. Under this provision, there are restrictions on separating child from parent.

Article 15 grants the right to independent living, and prohibits forced stay within an institution. In the Indian context, one can think about the many unfortunate persons with psychiatric disabilities, living hopelessly within such institutions because "they have nowhere else to go". It would now become the Indian State's responsibility to organize independent living and other proactive measures to facilitate re-entry of such persons into the community.

Other rights enshrined in the Convention are right to education, right to political participation, mobility and access, right to work, right to health and rehabilitation and right to cultural life, sports and recreation.

If implemented in letter and spirit, the Convention would normalize psychiatric disability among the range of disabilities, and grant the *same* rights to those with psychiatric disabilities. The two significant gains of this Convention, for persons with psychiatric disabilities, are the right to be recognized as equal and competent before law; and secondly, the prohibitions on forced treatments.

This report was prepared by Bhargavi Davar at Babu Trust. Bhargavi is profoundly grateful to Tina Minkowitz, who is a key spokesperson for persons with psychiatric disabilities at the UN Convention, for sharing news and her work at the recent WNUSP General Assembly. Users, ex-users or survivors of psychiatry wishing to connect with the discussions around the Convention may write to Tina Minkowitz at - tminkowitz@earthlink.net. The full Draft of the Convention may be downloaded from the United Nations website, including various reports of the Ad Hoc Committee meetings, NGO reports, experts consultations, and information about the UN consultative processes.



Resolutions of the workshop on the United Nations Convention on human rights and disability, adopted by the WNUSP General Assembly, Vejle, Denmark, 20th July 2004.

The *World Network of Users and Survivors of Psychiatry* [WNUSP] is an international NGO of user and ex-user / psychiatric survivor organizations, having representation at the UN Disability Convention Ad Hoc Committee meetings to discuss the widely disseminated Draft Convention. Leading the INGO on this advocacy initiative is Tina Minkowitz [tminkowitz@earthlink.net]. One of the key agendas at the recent WNUSP General Assembly Meeting was to create awareness about this important activity, and also arrive at some agreements about the Draft Convention. Here are the "Resolutions" made at the General Assembly. Read on...

Resolutions

1. The conference calls for the Disability Convention to fully incorporate users / survivors concerns, including self-determination and the right to make our own decisions.
2. The conference calls for the adoption of articles 9(b), (c)(i) and (d), article 10 (1)(b), article 11, article 12 (2) and article 15 of the present draft.

In summary, 9(b) guarantees full legal capacity; 9(c) gives surety about giving required assistance without taking over social or legal lives; 9(d) gives rights to persons with psychiatric disabilities to have the required assistance to information, contracting, expressing decisions, etc. Article 10(1)(b) guarantees that no one will be arbitrarily deprived of their liberty. Under Article 11, States will take all measures to prevent torture and cruelty, inhuman or punishing treatment for the disability. States shall prohibit research without free and informed consent. Article 12(2) prohibits forced institutionalization or forced intervention. Article 15, among other things, ensures the right of persons with psychiatric disabilities to independent living, choice of residence, and the right *not* to be forced to continue life within an institution.

3. In addition, the conference calls for *leaving out* article 7(3). Article 7(3) proposes that "discrimination" will not include "any provision, criterion or practice that is objectively and demonstrably justified by the State as a legitimate aim and the means of achieving that aim are reasonable and necessary".

The Conference also called upon all members of the WNUSP to lobby their national government and to make alliances with the wider disability movement to pursue their goals. The participants of the Conference supported the view that people with psycho-social disabilities have equal rights and responsibilities with all other people.

The Ad Hoc Committee (a committee of the UN member states looking into the Disability Convention) will come together in August 2004. After that, another 4 meetings are envisioned in 2005 before the draft is finalized. During this process, input is still possible. Contact Tina for any further information or communication on this.

Reporting on the two NGO consultative meetings on the UN Disability Convention, held in India before the Ad Hoc Committee Meeting

Two NGO consultations were held this year, in March and April, at Bangalore and Delhi, to bring grass roots perspectives to the UN Disability work. The report of the consultations can be downloaded directly from the United Nations Website, or can be obtained from Ms. Anuradha Mohit, Special rapporteur on Disability, National Human Rights Commission, Sansad Marg, New Delhi. A wide range of disability organizations participated in these consultations. Among the organizations representing psychiatric disabilities, carer groups (AMEND from Bangalore; NFMI, New Delhi) and service provider groups (IHBAS, New Delhi; The Turning Point, Calcutta) participated.

In general, the recommendations made by the consultants and authorities have been liberal and progressive, and inclusive of the needs of persons with a psychiatric disability. However, some modifications suggested are detrimental to the right to self-determination of psychiatric users.

For example, with respect to Article 9(d) the consultation has asked for the inclusion of the following provision: *“In the event of reduced or temporarily diminished legal capacity, a duly appointed surrogate may exercise the legal capacity in the best interest of such a person with a disability”*.

Users of psychiatric services, and user support organizations, must consider and interrogate this recommendation. This provision will, in India, and in countries like India, allow the continued social and legal oppression of psychiatric users, by surrogate decision-making, proxy consent, involuntary commitment / treatment and forced guardianship arrangements. Bapu Trust, a user support organization, presently aligned with the advocacy position of the WNUSP on the disability convention, supports full legal capacity with the right to different kinds of appropriate “assistance” (as defined elsewhere in this issue of *aaina*).

Another modification suggested has been with respect to Article (11): *“To ensure that the best interest*

of the person is protected in the event the person is passing through a phase in which he or she is unable to communicate free consent, no intervention shall occur unless a form of consent is given on their behalf by a duly appointed nominee by the person concern(ed) or by an impartial authority established under the law”. Users of psychiatric services would be wary of this provision, as once again, there is the underlying threat of forced treatments.

The NGO meet has made a revolutionary note, as an addition to Article 24, which users may support: Special provisions should be made for psychiatric users as they often suffer from *“prolonged intake of medication and their side-effects”*. This point highlights the disability caused by long term drug use, long term institutionalization, as well as disability caused by the indiscriminate and repeated use of shock treatment among the psychiatric patients. The Disability Convention should indeed consider these issues, as it is in a way unique to the context of developing nations, where there is glaring lack of prevention and rehabilitation programs.

In the Indian context, the family remains the predominant support for users of psychiatric services. However, we also need to acknowledge the conflict of interest between carers and users. Law and advocacy should not presume matching interests between these two parties. Families cannot completely take over the decision-making capacity and independence of the end users of psychiatric services, as will continue to happen if these provisions are included.

Along with the main recommendations of the NGO meet, an annexure of recommendations has been appended, made by *“The Turning Point”* (Calcutta) and the *“National Federation for the Mentally Ill”* (New Delhi). These recommendations are pretty regressive from a user point of view and should be rejected. It is noteworthy that many of these recommendations have not found a place in the main recommendations of the NGO meet. The annexure writes against the spirit of Article 9, by suggesting forced treatment, and the *“right*

to treatment of uncooperative mentally ill with full consent of parents or caregivers”. “Special provisions should be kept for necessary interventions of persons with mental illness when and if required with the consent of their caregivers as often in acute phase, mentally ill persons are not able to take decisions for themselves and reject intervention that is detrimental to their health”. These carer groups and NFMI, a coalition of organisations, have repeatedly suggested provisions for forced treatments and the unconditional right of care givers to make treatment as well as life / legal decisions. Some terms used, such as “uncooperative”, etc. smack of paternalism, dependency relationships and lack of respect for the wishes of the individual sufferer.

In this context, it is useful to refer to the WNUSP caution and clarification about “assistance”. This global user coalition notes that “assistance” can be inadvertently turned back to substituted decision-making if the fundamental nature of the freedom to make one’s own decisions is not adequately understood. WNUSP “*would like to see explicit recognition that assistance should never be imposed on a person who objects to it, and that the person who is being assisted retains the ultimate decision-making authority in his or her own life*”.

In some of the recommendations above, we are once again wary of well-meaning carer groups, fostering dependency, infantilism and a life of social deprivation and choicelessness, for persons with a psychiatric disability. There is a need for users to come together on their own, and talk about their issues, without being led by the hand, by one or the other third party.

This report was prepared by Bhargavi Davar. Bhargavi Davar was reappointed as a Board Member of the World Network of Users and Survivors of Psychiatry, an International NGO representing the psychiatric user / survivor community at the UN Disability Convention. Bapu Trust, sponsoring aaina, is a user support organization, involved in various advocacy activities relating to user empowerment in India. Bhargavi can be contacted at - info@camhindia.org or davar@pn2.vsnl.net.in

Priceless quotes from the WNUSP conference, 2004, Vejle, Denmark

“Mental health professionals are very slow learners”

- Mary O’Hagan, New Zealand

“I am a recovering mental health professional”

- Chris Hansen, New Zealand

“Behind every mental health clinic is a mental hospital”

- Akmet Moosa Salie, South Africa

“The world breaks down EVERYONE and afterwards, many are found strong at the broken places” ERNEST HEMINGWAY

shared by Shantanu, the garbage guru, Green Cross Project, Mumbai.

The World Network of Users and Survivors of Psychiatry [WNUSP]

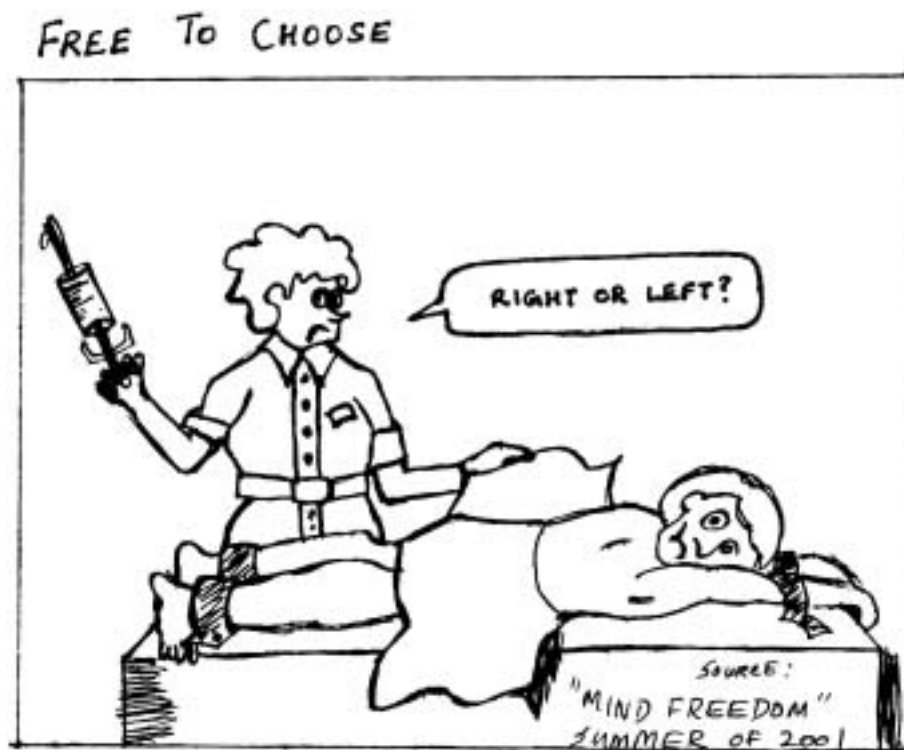
WNUSP is a global forum and voice of users and survivors of psychiatry, to promote their rights and interests. The aims of the organisation are to:

- ♦ advocate for the advancement of human rights of users and survivors of psychiatry;
- ♦ provide international representation and consultation to influence matters that affect users and survivors;
- ♦ encourage the development of national user / survivor organisations in each country;
- ♦ facilitate effective information exchange among user / survivor organisations around the world;
- ♦ develop networking opportunities for individual users and survivors of psychiatry throughout the world and other such activities.

The WNUSP was formed in 1991. Their position papers on Human Rights, the UN Principles for the protection of persons with mental illness and the UN Convention, and an inspired article by Mary O'Hagan of New Zealand ("A call to open the door: A psychiatric disability perspective on rethinking care"), may be found at the website: www.wnusp.org

WNUSP has developed an exhaustive critique and position paper with respect to the widely used 1991 UN Principles, rejecting the dominance of the medical model used everywhere in the instrument. The UN Principles are also seen by the WNUSP to endorse coercive treatment and involuntary detentions.

They are the only International NGO to represent the agendas of users and survivors of psychiatry at the



UN Disability Convention. Their exhaustive study of the Convention, and their positioning with regard to this, are also posted at their website.

ENUSP Press Release, Vejle, Denmark - July 20, 2004

The World Network of Users and Survivors of Psychiatry (WNUSP) and the European Network of (ex-) Users and Survivors of Psychiatry (ENUSP) held their first joined conference with the title “Networking for our Human Rights and Dignity” this week in the small Danish town in South Jutland.

Some 200 users and survivors of psychiatry [1], representing 50 countries around the world, attended the four-day event, held at the Vejle College of Sports.

WNUSP is an international disability organisation that seeks to improve the lives of people facing mental health difficulties by seeking alternative forms of recovery, fighting abuses within the psychiatric system and promoting a dialogue of reform among both health professionals and users and survivors of psychiatry.

ENUSP is an initiative to give (ex-)users and survivors of psychiatric services a means to communicate, to exchange opinions, views and experiences in order to support each other in the personal, political and social

struggle against expulsion, injustice and stigma in our respective countries. ENUSP is the only grassroots umbrella organisation on a European level that unifies (among others) national organisations of (ex-)users and survivors of psychiatry across the continent to provide a direct representation of people who are or have been on the receiving end of psychiatric services.

The conference this weekend endorsed WNUSP’s and ENUSP’s pursuit of the inclusion of a prohibition against forced treatment and a guarantee of legal capacity for people with disabilities in a forthcoming treaty on the human rights of people with disabilities.

The conference also saw the beginning of new networks of users and survivors of psychiatry in Africa and America. ENUSP was glad about the enhanced involvement of (ex-)users and Survivors of Psychiatry of the East European region, financially supported by Hamlet Trust, and the Mediterranean region.

On its web site <http://www.enusp.org> ENUSP informs extensively about the successful conference. URL directly: <http://www.enusp.org/congresses/vejle/index.htm>

On behalf of ENUSP Peter Lehmann, Secretary.

[1] With participants from Argentina, Australia, Austria, Canada, China, Costa Rica, Czech Republic, Denmark, England, Ethiopia, Finland, France, Germany, Ghana, Greece, Guinea, Hungary, Iceland, India, Ireland, Israel, Ivory Coast, Japan, Kenya, Lithuania, Malta, Moldova, Nepal, New Zealand, Nigeria, Northern Ireland, Norway, Pakistan, Philippines, Poland, Portugal, Romania, Russia, Serbia & Montenegro, Slovakia, Slovenia, South Africa, Sweden, Switzerland, Tanzania, The Netherlands, Uganda, USA, Wales & Zambia



Hi Bhargavi!

I am still disappointed with the stand you are taking in *aaina*. I received which I think was the March issue of *aaina*. I will be honest with you. I glanced at the issue at random & I found all most all articles espousing the cause of psychiatry.

It leaves untouched the issues concerning people like me. I still urge you to write more about the devastation caused to people like us by psychiatric abuse.

For recovery from mental ailments, foremost schizophrenia, play of free will of the individual has to be given utmost precedence for self-recovery.

I hope your next issue of *aaina* will blast the guts out of the psychiatry.

Manu

Editor

www.freeindiamedia.com



Kate Thompson, *Women's Press*, July/August 1976

WNUSP / ENUSP Confederal Rap

David Kommar

Wee-Nusp / get together now / you know the drill /
Do not let the doctor make you / take the pill /
We meet and get acquainted / from all over the Earth /
To form an NGO / it is a difficult birth /
Today / they are using torture / It is publicly known /
They tie you to a bed and say / your thoughts are not your own /
We think / they are brutally / denying our rights /
I think that / now its time for me / to choose my sides /
For it or against it / the medieval medication /
So if you are thinking suicide / you should take a vacation.

In Ee-Nusp / we have countries / that can pay the bill /
In Asian lands its terrible / to be mentally ill /
They are kept in locked up places / and are treated like beasts /
The same thing is the case / in all of Middle East /
From Poland, Lithuania / France, Greece, Germany, Spain /
We gather here together / and will ease the pain /
The "Lands-organisation" / are the guardian lights /
Together we shall / work towards our human rights.

David Kommar drafted this song at the "Networking for our Human Rights and Dignity" Conference, organized as a part of the General Assembly of the WNUSP, held at Vejle, in Denmark in July 2004. He may be contacted at - david.kommar@get2net.dk

Aaina, a networking and opinion sharing newsletter in mental health, is for private circulation only. It is sponsored by Bapu Trust for Research on Mind & Discourse, an organisation committed to mental health literacy and advocacy. The views expressed in the newsletter are however not those of the organization.