

Editorial

If we search for Indian mental health service information, we usually find that the first (and sometimes the last) data presented are the number of beds in mental hospitals vis a vis the total population of the country. This data is updated religiously with each passing inquiry committee or service monitoring report. Every PIL results in more beds, cleaning up existing beds, changing bed sheets, stitching coir mattresses, etc.

When human rights activists or development / policy agents start the search for mental health sector reform, they first ask: "How many beds are there in mental hospitals?" The search for affordable, accessible and good quality *beds* has been a never ending voyage in the mental health reform movement. It hasn't yielded much change in the last four or five decades of mental health service delivery in India. Maybe we should stop asking this question and start afresh with some new questions?

- Can we invent a new institutional design and framework, instead of locks, bars, high walls, barbed wires and iron grills? The traditional healing system in India has much to offer in this regard.
- What are the *police* doing within the mental health system?
- What are the experiences, the lives and times of van drivers who are paid to abduct mentally ill patients from their homes without their knowledge and transport them to far away custodial places? This will make an interesting anthropological study.
- Using all the loopholes of the mental health act, how much money is being spun by private mental hospitals?
- Do we have suitable community treatment programs for battered women? Or the myriad other socially vulnerable groups?
- Why are homosexuals being given aversion therapy still?
- If mental health is about experiencing oneself in a loving way, where is the love in the mental health system? Can there be love inside, if there is no love outside?
- What, and how long, will it take to finally convince medical professionals that there is such a thing called "side effects of medicines", which destroys your body, brain and soul?
- What kind of clinical assessment schedules can we invent, which will not take away people's right to practice their own kind of spirituality? Etc.

This issue of *aaina* covers some of these concerns. The first user survivor consultation was held in Pune in September. Campaigns around the Erwadi Memorial Day highlight the need for a more encompassing human rights language within the mental health system, including a debate on traditional healing. The Biwako Millennium Five Plus was up for review by the UNESCAP this last quarter, giving the opportunity for WNUSP to intervene on behalf of persons with psychosocial disabilities. An incredibly useful modern classic on healing alternatives from around the world was released by Peter Lehmann from Germany.

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Aaina is a mental health advocacy newsletter.

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

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

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

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

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Reflections

Returning The Soul To The Mental Health System

✉ **Dan L. Edmunds, Ed. D.**
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For mental distress to be alleviated, it is often very important to understand how individuals construct meaning. For some this sense of meaning comes from spirituality and religion. Modern psychiatric practice has become medicalized to the point where it has significantly ignored the human experience and sought to understand human experience only in terms of chemical accidents.

Fox News in the United States reported psychiatrists to be the least religious of those within the medical profession, and thus it is obvious that psychiatry has become largely antagonistic towards spirituality and/

or religious expression. Psychiatry can be said to be a religion in itself. If we examine the term 'psychotherapy' we will see that it literally means the 'healing of the soul'. Much of emotional distress is actually a spiritual problem, where an individual has lost meaning and hope. In today's society, we have lost sight of spiritual values and many have in turn decided to turn to the religion of bio-psychiatry.

Bio-psychiatry has a creed; the creed is that all problems of life are the result of so-called chemical imbalances. Any professional or individual challenging such conception is branded a heretic and subject to sanction. The psychiatrist is the priest, and in some cases is also looked upon as a messianic figure. As the

priest, the psychiatrist defines the Social Law and the infractions thereof. The religion of bio-psychiatry has its 'sacraments.' The sacrament of initiation occurs at intake, and confirmation occurs when the individual is indoctrinated into the credo of bio-psychiatry and led to believe that their problems lie in 'wiring' problems in their brains. The religion of psychiatry has absolution. Through their ritual, adults and institutions are able to be completely absolved from taking any responsibility for meeting the real emotional needs of a person or examining how their own actions and choices could have impacted the challenges faced by the individual. Ordination occurs at the conferring of the Medical Degree and the completion of a residency in

psychiatry. The religion of bio-psychiatry has the 'sacrament' of Matrimony. Bio-Psychiatry is wedded to the pharmaceutical industry, and what a generous dowry the pharmaceutical industry has provided! The Psychiatric Associations serves as the "Ecumenical Council" to promulgate the creed of bio-psychiatry and to institute the definitions of the Social Law and the infractions thereof. The scripture of bio-psychiatry is the DSM-IV. The Deity is the enormous ego of the bio-psychiatrists themselves.

As a result of the current bio-psychiatric paradigm, oppressive treatments continue to arise. Each generation of psychiatric practice has been oppressive, from the invention of the swivel chair to insulin coma, shock, and lobotomy.

Physical interventions, such as psychotropic drugs, restraints, and enforced confinement to mental hospitals or residential treatment facilities are a part of this desire to control rather than truly aid and come to an understanding of the distress the person is experiencing (Breggin and Breggin, 1994). Psychotropic medications with seriously distressed individuals only deal with symptoms; they blunt certain functions to make the person more tolerable and amenable to societal expectations. Psychotherapy, on the other hand, focuses on the subjective changes in patient's feelings and on actual changes in lifestyle or conduct of life (Fisher & Greenberg, 1989). Based on the viewpoints of biopsychiatry, persons who are medicated and placed in mental hospitals are labeled as improved when they conform to hospital demands or receive discharge. However, what is not examined is, how do the patients themselves actually feel? An estimated 180,000 to 300,000 young people a year are placed in private psychiatric facilities in the US. These children and adolescents often feel powerless in these placements. But as mentioned above, it is the need for feelings of empowerment and hope

that will lead to a genuine recovery from distress. Psychologist D.L. Rosenhan led a study where 'pseudopatients' had themselves admitted to psychiatric hospitals to experience them first hand and report on this experience. Rosenhan reported in an article appearing in the January 19, 1973 issue of Science, "Powerlessness was evident everywhere...He is shorn of credibility by virtue of his psychiatric label. His freedom of movement is restricted. He cannot initiate contact with staff, but may only respond to overtures as they make. Personal privacy is minimal..." With children and adolescents it is easier to rationalize away their rights and control becomes more arbitrary and complete (Breggin, 1994).

Anti-psychotic medications are reported to cause lack of energy, painful emotions, motor impairment, cognitive dysfunction and tend to blunt; the personality of the treated patients as well as having a risk for the development of tardive dyskinesia, a permanent and debilitating neurological problem (Gualteri and Barnhill, 1988). These drugs subdue the person into conformity by blunting the brain, but never do they teach the person how to develop meaning, how to cope, nor do they allow the person to express his or her pain and emotional distress that is within. The person is merely sedated to make his behaviors more manageable to adults. The person learns nothing. The persons who are suffering from severe emotional distress are in conflict. They have internalized feelings of guilt, shame, anger, anxiety, and numbing. These persons need instead of coercive and intrusive 'treatments', the ability to find a safe place where coercive power is replaced by reason, love, and mutual attempts to satisfy their basic needs. These persons because of their distress have broken away from the accepted realities, they have sought to recreate their existence. The feelings of anxiety the person may experience are linked to a fear of being and belonging. Depression, mania, and anxiety are

all linked together and are indicative of trauma. The person being a shattered person seeks an escape by altered perception. We must begin to realize that all behaviors and experiences have meaning, even those things that may appear the most 'odd' to us. The symptoms labeled to be schizophrenic exhibited by certain persons in distress 'may be understood as manifestations of chronic terror or defense against the terror (Karon, 1996). This is often expressed as anger, loneliness, and humiliation. The therapist and others must convey to the person that he wants to understand, that the client is helpable, but it will take hard work (Karon, 1996). The therapist must forge an alliance with the person, aiding them to understand the real dangers and to be able to develop appropriate coping mechanisms. These persons are often viewed as dangerous themselves but the majority are not. They need to be heard, and forging this alliance will give them the needed voice leading to their recovery. Hallucinations that are experienced by the seriously distressed person are actually repressed thoughts and feelings coming outward, the unconscious into the conscious. Delusions are the adolescent transferring experiences from their past without having the awareness that it is past (Karon, 1996, pg. 36). The therapist can guide in interpreting the meaning of these hallucinations and delusions and once the person is gently approached with their underlying meaning, these events can dissipate. Delusions are also connected with an attempt to find a systematic explanation of our world, to find meaning. A person who has experienced severe distress has lost this meaning and thus develops unusual ways of seeking to make sense of their experiences and the world around them (Karon, 1996, pg. 38). The therapist can gently call the person's attention to inconsistencies but at the same time respect their vision. The results of a psychosocial approach to those with severe emotional distress has been proven

to be more effective than the current biopsychiatric methods as evidenced by a study by Mosher where he took schizophrenic adults who were on either very low doses or no medication, and offered them a 'safe place' with non professional staff residing with them and sharing in their daily experiences. A 2 year follow up of these patients noted higher levels of success and progress than their counterparts who were subjected to neuroleptics and psychiatric hospitalization (Mosher, 1996, pg. 53). The model known as the Soteria project was based on principles of growth, development, and learning. All facets of the distressed person's experience were treated by the staff as 'real' (Mosher, 1996, pg. 49). Limits were set and mutual agreements made with the patients if they presented as a danger to themselves or others. Such a model could be adapted to use with adolescents, offering them the need for compassion, empathy, and finding that 'safe' place, restoring within themselves a feeling of worth and dignity that will lead to their ability to address the issues of their distress and traverse towards recovery. It should be understood that recovery means being able to overcome distress, not being a lifelong consumer of toxic drugs.

What can we do to recreate a mental health system which is humane? First, we must stop looking through the eyes of a medical model, where we see people as broken and disordered and attempts are made to attributing their behaviors and emotions solely to a malfunctioning brain. There is no evidence supporting the psychopathology of a number of disorders. The linkage between the

pharmaceutical companies and psychiatry needs to be evaluated as well as the information that is disseminated via the research and materials provided by pharmaceutical company money. The goal should be to examine the underlying factors of a person's behavior, looking at the person with dignity and respect, and seeing the person as one in conflict rather than a person who is disordered. Such stigmatization remains indefinitely, and labels can often become a self fulfilling prophecy and will follow for years to come and shape the way that one views themselves and also the way others view them. We cannot look to solely the most cost effective solution when people's lives are at stake. Indeed, providing a prescription may control aspects of behavior and be thought to have a 'therapeutic effect' but never gets to the root cause. Second, the realm of psychotherapy must return to its original roots. The word psychotherapy literally means the healing of the soul. We must return the soul to therapy, encouraging therapists to instill within themselves the principles of compassion and empathy that are crucial for any therapeutic relationship to blossom forth. Therapists need to be compassionate and creative, and willing to give additional time and effort to see that a person's needs are met and to also provide community linkages and ongoing support within their environment and to encourage the least restrictive setting. The coercion into forced 'treatments' needs to be eliminated. Third, our society must change in its attitudes. We are a society where we try to find our answers to ailments within a simple pill. We are a society that has unfortunately lost sight of the welfare

of those vulnerable and in need. We are a society where we are prosperous, yet greed often blinds us. Somewhere along the line we have failed our fellow human beings. We need to rely less on psychiatry and its devices to solve our problems and more on what we can do within ourselves- to take a holistic approach, to understand the person as a whole person- physical, emotional, and spiritual, and to examine in each of these areas where there may be difficulties that can be alleviated. We need to rely less on others dictating the course of our own lives and develop workable plans within our own family structure. Nothing will ever be perfect, but even in the most serious disturbances, love and compassion can heal much.

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Dr. Dan L. Edmunds is a noted therapist and a leading critic of the psychiatric establishment. Dr. Edmunds has sought for a mental health system that does not seek to medicalize and suppress behaviors, but seeks to understand the experience of individuals and regards them with dignity, compassion, and respect. His writings and therapeutic work detail this humanistic approach and helping seriously distressed individuals be able to find the support and empowerment to overcome confusion, trauma, and obstacles in their lives and reestablish a sense of meaning. Dr. Edmunds has worked with a diverse population of children, teens, and adults. He has found that even the experience of those in extreme states of mind is important and can be understood. He can be contacted at voiceforkids@msn.com

Report on ESCAP High Level Governmental Meeting on Midterm Review of Biwako Millennium Framework at Bangkok, Thailand from 19th to 21st Sept 2007

Amrita Dhanda

This was the first major UN meeting in the region subsequent to the adoption of the Convention on Rights of Persons with Disabilities (CRPD). It was therefore of interest to observe whether and if there was a change in the disability discourse post the Convention. The Meeting was primarily concerned with the Biwako Millennium Framework (BMF) though the CRPD was a looming presence. A major learning of the meeting was the need to construct a matrix of convergence between the CRPD and the other developmental documents such as the BMF and the Millennium Development Goals (MDGs).

Statements from State Parties

As a part of the proceedings of the meeting, all attending State Parties made statements on how they have fulfilled their commitments under the BMF. In the main these statements sounded like report cards where States tried to fit in their various disability initiatives under the Biwako goals. A notable exception was the report which was filed by Sri Lanka. In this report the state outlined each of their disability initiatives under the BMF and did not just report what they could do but also admitted what they could not do. It may be of interest to mention that the Sri Lankan delegate was a person with disability.

Whilst it is not possible to make a detailed evaluation of the report of each country it can be mentioned that promotion of physical access and encouragement to self help groups did find mention in the reports of several state parties. China made it a point to mention that they were organizing a special event for persons with intellectual disabilities

to coincide with the Special Olympics. It needs to be noted that there was little or no effort to examine the BMF goals in the light of the CRPD even though the States demonstrated major interest in seeking understanding on their obligations under the CRPD during the special presentation on the CRPD.

Participation by DPOs and Civil Society

The ESCAP was receptive to inputs from DPOs and civil society was demonstrated by a number of initiatives at the meeting. One, ESCAP invited a number of representatives from civil society to make key presentations on the thematic concerns of the meeting. It is as a part of this initiative that Amrita Dhanda was asked to make a presentation on Self Advocacy by Persons with Psychosocial Disabilities [Cf. below]. The keynote address for the meeting was delivered by Monthian Buntan and Andrew Byrnes made the presentation on the CRPD. And Sae Kani spoke on Inclusive Disaster Management.

Along with the Plenary presentations ESCAP organized two side events. Whilst one highlighted good practices initiatives in access promotion to Built Environments and Public Transport the other narrated the growth and development of self help organizations. Insofar as these meetings were chaired by officials of the ESCAP Secretariat they invited substantial attendance and attention from the participating delegations.

ESCAP also invited civil society representatives to make statements under the various themes of the

meeting and as a part of this initiative Bhargavi Davar made a statement on behalf of WNUSP [Cf. below].

However what is significant to note that whilst the invited presentations made in the plenary found mention in the Report of the meeting, the civil society statements were heard but not recorded. Civil Society members were also not allowed to query any decision made by the states parties and a persistent effort by a representative of the World Federation for the Deaf was not entertained on the reasoning that this was an inter-governmental meeting hence intervention by DPO's in the deliberations were not permissible. Even as a number of officials from the ESCAP Secretariat spent time trying to assuage the outraged sentiments of the DPO representative.

The meeting did show that whilst the ESCAP officials were receptive to according full participation rights to DPO's the States had still a long road to travel before such participation gets incorporated in the procedures of UNESCAP.

Goals for BMF+5

The States used this meeting as an opportunity to revisit the BMF goals and here it is of significance that amongst the constituencies meriting special attention the +5 document referred to persons with psychosocial disabilities. The need to address the concerns of persons with psychosocial disabilities also came to the fore in the informal deliberations that we had with the members of the ESCAP Secretariat and some States like India, Pakistan, Sri Lanka, Bangladesh and China.

1 Self Advocacy by Persons with Psychosocial Disabilities¹

✍ *Amita Dhanda*, World Network of Users and Survivors of Psychiatry

Promotion of Self Advocacy by Persons with Disabilities has been detailed as one of the goals of the Biwako Millennium Framework. Presumably this goal was included to accord visibility to disability and to ensure primacy to the vision of persons with disabilities. The slogan “Nothing about us without us” encapsulates the self advocacy agenda of persons with disabilities.

However just the acceptance of the need for self advocacy does not create the environment which allows it to be practiced. For that to happen it is important to lift the barriers to self advocacy. These impediments present themselves in variant forms at different sites. Some of these barriers could be listed as: the absence of access to information; the non availability of appropriate means of communication; inaccessible physical environment and the absence of suitable transportation. The detailing of these factors shows that the creation of a world oblivious of the existence of disability is the greatest impediment to the participation by persons with disabilities, in the creation of a more inclusive world.

Without in any way denying the far reaching effects of these physical barriers, I am in this morning’s presentation drawing your attention to the normative barriers to self advocacy. By normative barriers I refer to legislations, rules, and judicial decisions which deny identity and agency to persons with disabilities. They do so by not recognizing persons with psychosocial disabilities as

persons before the law and disqualifying them from managing their own affairs. Whilst in practice this manner of deprivation may also be inflicted on persons with physical and sensory disabilities, in the text of law this denial of personhood and capacity to act is almost universally limited to persons living with psychosocial and intellectual disabilities. It is this legal disqualification which is the greatest impediment to self advocacy by persons with psychosocial disabilities.

Before proceeding to describe the substantive content and operation of these normative barriers I wish to briefly dwell on the use of the term psychosocial disabilities. We speak of psychosocial disabilities because the differences in our ways of thinking, feeling, expressing, and deciding are socially stigmatized, discriminated and excluded. To explain further, there are amongst us, as in the general populace, persons who have a greater inclination to risk taking behavior; only in our case these individual predilections are mechanically extended to the whole group. These imputations of dangerousness set up a vicious circle between the imputation and the social belief whereby one reinforces the other. It is from these unexamined social beliefs that the social stereotype of the “dangerous lunatic” is born. If the label of dangerousness is one pathway to our social ouster then the attribution of incompetence is the other. Here we are faced with the situation whereby accepted human freedoms of security of person and liberty of movement are

routinely denied to us by alleging incompetence. It is significant to note that these findings of lack of insight and incompetence are always reached when we challenge social expectations and not when we conform to them. It is this lack of social accommodation to our way of being in the world which makes us persons with psychosocial disabilities.

This lack of social accommodation is demonstrated in several ways — the most significant one being by the denial of legal capacity, which in effect means the silencing of our voices and thereby ousting of our choices. Once the law recognizes that a person possesses capacity, then the law deals with that individual directly and not through a substitute such as a guardian or a manager. It accords to this individual the freedom to make her own mistakes and to learn or not learn from them. Whereas for persons with psychosocial disabilities once the label, diagnosis, or finding of psychological difference is reached, be it socially, medically, or judicially, the person who is so labeled is put out of the pale of personhood and presumed to lack the capacity to conduct his or her own life. There is therefore no dialogue with the individual and no effort to understand her perspective towards her life. Instead conversations happen over the head of this individual with the carer be it friend or family or the professional in charge be it doctor or lawyer.

It is true that all legal texts do not attribute incapacity just with the

¹ Statement made by the WNUSP on the occasion of the High level Intergovernmental meeting on the Biwako Five Plus, UNESCAP, Bangkok, September 19-21, 2007.

finding of “unsoundness of mind” or “mental illness” or “insanity” the not so complimentary terms used in legislations to refer to psychosocial disabilities. Many laws require that a finding of lack of capacity should be reached only if the psychological condition results in the afflicted person to not understand the nature of the act, or the effect of the agreement on his interests, or the nature of the ceremony she is performing. Research studies on the operation of these incapacity laws have shown that these functional requirements are often not observed. Thus in practice just the finding of psychological difference results in determinations of incapacity. Further legislative texts accord an unrepresentative preference to cognitive faculties in arriving at findings of capacity. This is so even when all persons do not rely on these faculties, or on not solely on these faculties, to make their choices or reach their decisions. By this exclusive reliance on cognitive faculties many persons lose the capacity to decide for themselves; not because they lack the capacity but because they do not fulfill the requirements of the law. The artificial nature of the legal requirement is not questioned. Consequently all persons who do not make the legal cut off are prevented from advocating their own cause. For the Biwako mandate of self advocacy to be realized, it is imperative that these disqualifying legal regimes be foundationally questioned and dismantled.

Such an opportunity has been provided by the recently adopted Convention on the Rights of Persons with Disabilities which as of now 102 countries have signed and 5 have ratified. This Convention recognizes the human rights of all persons with disabilities on an equal basis with others. In furtherance of this

mandate of equality and non discrimination the Convention reaffirms that persons with disabilities have the right to recognition everywhere as persons before the law. This proposition accords identity to all persons with disability and makes them the bearers of rights on an equal basis with others. Article 12 (2) then recognizes that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life. With this paragraph the Convention recognizes that the capacity to act is an integral component of legal capacity. This recognition of legal capacity is not premised on a mythical belief in human independence. Instead in a realistic acceptance of human interdependence paragraph (3) to article 12 requires States Parties to “take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity”. The crucial point is that this support is to supplement and not supplant the person with disabilities. This requirement is further reinforced by paragraph (4) which requires the support be proportional and tailored to the person’s circumstances, respect the preferences of the person with disabilities and be without conflict of interest and undue influence.

This article along with article 4(1) (b) which requires States to modify or abolish existing discriminatory laws should help in removing significant normative obstacles to self advocacy by persons living with psychosocial or intellectual disabilities. With the lowering of these legal barriers the passage to social participation and inclusion should be opened for all persons with disabilities.

We are certain that the first human rights Convention of this millennium with a non discrim-

inatory formulation on legal capacity will usher the era of full citizenship for persons with disabilities. We are especially excited about this prospect because article 12 cannot be the subject of reservations. This is because any reservations on this article would be incompatible with the object and purpose of the Convention; and article 46 only allows reservations if they are compatible with the object and purpose of the Convention. We eagerly await the fulfillment of the mandated quota of 20 ratifications which will bring the Convention into force and do hope that several of these first ratifications come from this region.

May I end by thanking UNESCAP on behalf of the World Network of Users and Survivors of Psychiatry for inviting my colleague Dr Bhargavi Davar and myself to participate in this High Level meeting and for giving me this opportunity to present the concerns, hopes and aspirations of persons with psychosocial disabilities as we seek the universal application of the Biwako mandate of self advocacy.



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2 Barrier free environment for persons with psycho-social disabilities¹

 V Bhargavi, WNUSP

The World Network of Users and Survivors of Psychiatry [WNUSP] appreciates the fact that, in both the Disability Rights Convention as well as the BMF Five Plus, there is much scope to strengthen the regime of rights of persons with psychosocial disabilities. The BMF places much emphasis on the right to a barrier free environment.

In the disability field, we generally understand barriers in physical terms. It has helped us to develop practical solutions for persons with disabilities and provide many opportunities to more fully utilize their abilities and enhance their mobility. The notion of a barrier is not only something external, but it is also internal. We have to think of the psychosocial dimension as a different sort of environment which must also remain barrier free.

As human beings, we are naturally gifted with the ability to excel ourselves by feeling new emotions, thinking new thoughts, having

aspirations, making new decisions, learning new mental skills, understanding our past and planning our future, expanding our behaviours and skills, etc. We have many non-rational psychological skills also, including intuition, imagination, visioning, dreaming. These, and more, constitute our inner environment.

Instead of seeing this as the gift of being human, sometimes, in our human society, we make judgments such as “Don’t think this thought”, “Don’t feel this emotion”, “Don’t have this dream”, etc. We frown upon some emotions, thoughts and behaviours and call them mental disease, even classifying them through medical terms and providing medical treatments. In this way, we create barriers in our inner world. We do not allow the exercise of full access to our own inner spaces and our right to human insight. We restrict the ability to excel ourselves and expand our inner strengths. We set up barriers in our inner psychological environments.

Even though a metaphor, we should also talk about mobility in the

psychosocial / spiritual realm of human existence. A part of our being human is our sense of freedom, coming from using as well as taking our psychological potential to higher and higher goals. That pursuing inner goals is a natural human pursuit is evidenced by our everyday sense of growing more insightful, evolving into a “better” person, etc. We should insist upon freeing our inner worlds and using the right to the opportunity of experiencing a full range of psychological possibilities. The exercise of this right can only lead to more imagination, higher level of creativity and profound insight about psychological wellbeing. Persons with psychosocial disabilities will be able to contribute positively and fully to a better vision for the world, and for human well being, if such barriers are removed.

We at the WNUSP would be happy to offer our experience and expertise in seeing this happen.

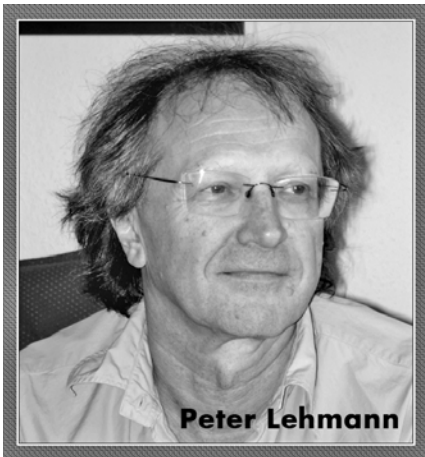


¹ Intervention made by the WNUSP on the occasion of the High level Intergovernmental meeting on the Biwako Five Plus, UNESCAP, Bangkok, September 19-21, 2007.

*'Tis the Majority
In this, as All, prevail—
Assent — and you are sane —
Demur — you're straightway dangerous —
And handled with a Chain*

Emily Dickinson

From the Madhouse to the Warmth of Others



Peter Lehmann

Madhouse

In 1977, I went crazy for the first time, as I tried to manoeuvre myself through an increasingly stressful situation. My marriage had just fallen apart; I was under pressure to finish my thesis, which was an arduous labour. I struggled with anxiety over my exams, I argued with some of my roommates. I was in love with my new girlfriend and simultaneously having disagreements with her because she feared that she was pregnant and would need to get an abortion, leave the apartment or leave me altogether. Now all of this, which for 26 years, more or less out of my own free will, I had silently swallowed but apparently not digested, was breaking out of me.

The parties involved reacted all negatively, towards my—harmless—fantasies, my exuberant speaking, and my fear that I was being monitored, remotely controlled, persecuted, poisoned and brought to a madhouse to be de-brained and killed. The relatives to whom I went in order to type my thesis on their electric typewriter were extremely scared, and the doctor they called resented me for not wanting to play the customary patient role. The fellow students in Berlin and the girlfriend,

who followed me to my relatives, reacted with silent shock. Unclenched by my crazy new perceptions, detached from all binds, I was finally profoundly unsettled.

To some extent my fantasies turned into bitter reality: I was carried off to the institution and locked up there for weeks on high doses of neuroleptics that more or less poisoned me and induced a coma-like state which temporarily brought me to near death. Eventually my liver was permanently damaged, I developed a tardive dyskinesia in the form of a rabbit syndrome (compulsive nibbling). Afterwards I became totally apathetic and finally had to be thrown out of the madhouse. To top it off, I was forced to submit to a community psychiatrist who dispensed depot neuroleptics.

Distraught over my misery and convinced that no positive readjustment of my life could ever happen, I decided to withdraw from treatment and to secretly discontinue my prescribed neuroleptics. After some time I recovered, and founded a self-help group in which I could gather together with other (ex-) users and survivors and also consider my diverse diagnoses. Quickly, I lost the belief in being a mentally ill schizophrenic. Through occupying myself intensely with my earlier crazy utterances and perceptions, I came to understand much of the content, shape and cause of my “endogenic psychosis;” I gained new self confidence, became more open and began to “expose” my feelings as well as I could.

Self-help

I am born in 1950 in Calw, Black Forest (Germany) and have an education as a social-pedagogist. Beside my studies, I owned together with my former wife two book-shops

in Berlin, where I planned to go on working after finishing my studies. But my madness changed my life. Coming back from Hades—in a sense I had shut off my life in the madhouse—I finished my studies, and the professors asked me to become teacher at university and to pursue my PhD. But university was boring, students were not interested in the topic, so I decided to get active more and more in the self-help field. Finally our group was funded by the local administration, I had a paid half-day job, our group had a little bus, so we could travel through Europe, and I could work on my Ph.D. One main question was, what could we learn from the effects of neuroleptics on the nature of madness? Realizing, that most of the so-called side effects are the defined main effects, and that successful neuroleptic treatment suppresses the power of life, everything changed. I wrote a book about this, *The Chemical Gag*, and when normal publishers rejected to publish my book, I got myself another publisher. This book meanwhile is in its 5th edition, and other books, for example *Coming off Psychiatric Drugs* or *Alternatives Beyond Psychiatry*, followed. Meanwhile, since 1986, I wrote, published or edited about 25 books. As I saw so many people dying or getting disabled by psychiatric treatment, I simply feel committed to make these issues public, to distribute counter information and knowledge about alternatives. And together with my fellow colleagues, I founded with the years other organisations, for example the Berlin Runaway-house group, which finally after a one-million Deutschmark gift from a relative could buy a house as asylum for people who flee from psychiatric treatment, or the European Network of (ex-) Users and Survivors of Psychiatry. (www.enusp.org)

Humanistic Antipsychiatry

My philosophy I decided to call humanistic antipsychiatry. To say, abolish psychiatry and emotional distress will disappear, is rather primitive. Academic and patriarchal antipsychiatry played a role, but in the past. Now it should be up to the users and survivors of psychiatry to define their needs and problems themselves. My Publishing House, which is I as a one-person service, but with many supporters, is orientated toward the interests of (ex-) users and survivors of psychiatry whose main concerns are self-determination and freedom from bodily harm. Meanwhile I went on to create branch offices in Great Britain in 2003, and in the USA in 2004. Of course I have no connection to the pharmaceutical industry and to organizations that are dependent on them, nor to Scientology or other sects and dogmatists of whatever colour. Beyond health, nothing is more valuable than freedom and independence. The literature I publish is filled with a contrarian spirit and the fundamental conviction that (1) psychiatry as a scientific discipline cannot do justice to the expectation of solving mental problems that are largely of a social nature, (2) its propensity and practice to use force constitutes a threat, and (3) its diagnostic methods obstruct the view of the real problems of individuals. For these reasons, I plead for (1) developing adequate and effective assistance for people in emotional difficulties, (2) safeguarding civil rights in treatment on a par with 'normal' patients, (3) joining forces in cooperation with other human rights and self-help groups, (4) support in withdrawing from psychiatric drugs, use of alternative and less toxic psychotropic substances and a ban of electroshock, (5) new ways of living with madness and being different—with as much independence from institutions as possible, and (6) tolerance, respect and appreciation of diversity at all levels of life.

Bestsellers

The books, which I sell most, are those ones, which I published in German and in an English translation. *Coming off Psychiatric Drugs: Successful Withdrawal from Neuroleptics, Antidepressants, Lithium, Carbamazepine and Tranquillisers* will have its 3rd German edition, was published in English and will be published in summer 2008 in a Greek and Italian translation, which is like a fairy tale. My latest book (September 2007) is *Alternatives Beyond Psychiatry*, a book of alternatives to psychiatry around the world, which I edited together with Peter Stastny. He is Associate Professor of Psychiatry at the Albert Einstein College of Medicine in the Bronx in New York and has conducted several publicly funded research projects in the area of vocational rehabilitation, social support and self-help, in collaboration with individuals who had survived personal crises and psychiatric interventions.

Alternatives Beyond Psychiatry reflects current approaches to self-help and non-psychiatric alternatives in cases of acute emotional problems, as well as pathways to treatment that respect human rights. Ex-patients/survivors, therapists, lawyers, social scientists, psychiatrists and relatives from all continents report about their work outside the mainstream, their aims, experiences and successes while addressing the following questions: What helps me if I go mad? How can I find trustworthy help for a relative or a friend in need? How can I protect myself from coercive treatment? As a family member or friend, how can I help? What should I do if I can no longer bear to work in the mental health field? What are the alternatives to psychiatry, how can I get involved in creating alternatives? Assuming psychiatry would be abolished, what do you propose instead?

In the chapter "What helps me if I go mad?" for example, 14 former psychiatric patients describe how

they manage their acute emotional crises without entering the psychiatric system. This section also includes contributions about holistic natural healing methods for depression, self-help groups for people with unusual beliefs, and new approaches to voice hearing, which allow people to appreciate their voices and to address them in meaningful ways. In the section on "Models of Professional Support," a number of functioning alternatives are introduced, ranging from the Soteria model, the Windhorse project and the Berlin Runaway House, to non- or anti-psychiatric projects in Alaska and Sicily, and Jaakko Seikkula's "Open Dialogue" in Finland. All of these approaches lead to a substantial reduction in coercive measures and drug prescriptions. Karyn Baker reports how families affected by psychiatry are being trained in Toronto to support their relatives in the recovery process, instead of, as usual, pushing them to take psychotropic drugs, resulting in their becoming "career mental patients." Specific forms of support for migrants, children and youth, confused elderly individuals and men experiencing emotional crises are further areas of interest. In "Strategies Realizing Alternatives and Humane Treatment," Maths Jespersen introduces the reader to a personal ombuds service in Skåne, Sweden, and Jim Gottstein details the success of the Alaskan association PsychRights in getting millions in public funds reallocated to the development of non-psychiatric alternatives. Laura Ziegler and Miriam Krücke elucidate the legal and self-help aspects of advance directives, David Oaks introduces the organization MindFreedom International, which is accredited as an NGO at the United Nations and advocates for human rights as a basis for a non-violent revolution in mental health. Dan Taylor describes the struggle of this organization in the African nation of Ghana, Jan Wallcraft (UK) extols the usefulness of user-controlled research as an

underpinning for alternative approaches, and her colleague Andrew Hughes emphasizes the extent to which his association trains former psychiatric patients for user/survivor involvement work in mental health and social care. In the final section, the Irish psychiatrist Pat Bracken affirms the necessity for a radical paradigm change, away from the tendency to understand human difficulties as technical problems and towards a non-psychiatric approach that gives primacy to relationships, contexts, meanings, values and power-relations within a thoroughly reformed psychosocial system. Therapy, services and even psychotropics are not fundamentally rejected, but seen as secondary to those other elements. Peter Stastny and I hold the century of psychiatric reforms responsible for the spread of forced treatment into community programs, the increase of electro-shock, the rampant psychiatrisation of children and the elderly, and the massive extent of damage caused by psychotropic drugs. We demand the

long overdue creation of alternatives and choices, based on the many successful programs featured here and elsewhere, which should be a matter of course in a society that considers itself democratic. Robert Whitaker, author of *Mad In America*, says in his preface of *Alternatives Beyond Psychiatry*, "There are proven alternatives to psychiatry, programs that have a track record of helping people get better. And there are reports of ways of coping with madness on an individual level. This book hopefully will encourage many, many other such efforts to take root and flourish."

Conclusion

To be true, I do not understand really, how all these things could happen. Surely I had several angels who took care for me. Originally I was ready to become a long-term outpatient to receive my depot neuroleptics for the rest of my life. Beside guardian angels, family and friends supported me, as I am supporting them now

also. In the self-help movement I met many wonderful people from all parts in the world, my love Kerstin included.

My friend Zoran Solomun ends his contribution in the chapter "What helps me if I go mad" with these words: "We listen to one another, speak, and then listen again. We tell our truth, convinced of its existence, and we actually consider these perspectives to be truthful. And in this way we open the gateway to personal and encounter the warmth of others. This is the most normal thing that I expect from life." I have nothing to add.

www.peter-lehmann.de

Peter Lehmann's classic books, "Coming off Psychiatric Drugs" and his recently released classic, "Alternatives beyond Psychiatry" are available at the Center for Advocacy in Mental Health, Pune [www.camhindia.org]. We welcome offers to translate one or both books into local languages, particularly Hindi.



After Ervadi: Faith Healing and Human Rights

On August 6, 2001, twenty eight people labelled "mentally ill" died in a fire that burned down the makeshift hut in which they were kept chained in Ervadi, Tamil Nadu. The incident caused widespread public outrage and invoked pleas for preserving the human rights of mentally distressed people from the media, mental health and human rights activists, legal experts, professionals, NGOs and the general public.

Since 2001, it has become an annual media ritual to expose the government's failure to regulate mental health care and highlight "the plight of the mentally ill," by carrying stories on faith healing places. This year NDTV carried a report on the Langar House Darga in Hyderabad¹, alleging that "the mentally ill still

continue to be chained in gross violation of human rights." "With limited room in mainstream institutions of mental care, many who need attention get pushed to where either hope or desperation takes them," the report concluded.

The NDTV report instigated discussions among some mental health and human rights activists, members of the Jan Mansik Arogya Abhiyan, and other interested parties. An immediate suggestion was to file a public interest litigation against the Darga, and using the law to shut it down. Others felt that legal intervention, while putting an end to inhuman practices like chaining, will also take away important community support systems that these places provide for people experiencing mental distress. This article

presents some thoughts arising from these discussions.²



The Langar House Darga

The Darga of Syed Meeran Hussaini Quadri Bogdad at Langar Houz has long been a location of faith healing for people from all religions in Andhra Pradesh. Apart from a large number of people who come here seeking healing and cure, people also come to visit the tombs of saints and the mosque. The Centre for Advocacy on Mental Health, the convenor of the Jan Mansik Arogya Abhiyan, proposed its own investigation and organised a fact-finding visit to the Darga.

M.A. Moid and Mohammed Afzal undertook the visit and submitted a

report. At the time of their visit, they found one person chained to a gravestone. Having talked to the people visiting the Darga, they found that there is a strong faith in the healing power of the Darga among the people and communities who came there. The Darga is seen as offering an alternative to state run mental hospitals which are seen as callous and costly. People come to the Darga on their own accord or are brought there by their families. Some people had already tried allopathic doctors and had come to the Darga as a last option. In one case, an unwell person found on the roadside was brought there by the Police, as it was seen as a safe space within the community.

The Darga is also the location of informal community based care. Local NGOs are involved in distributing free medicines through a doctor who visits weekly. Another NGO provides food to everyone daily in the evening.

After the NDTV report, the Darga officials have stopped allowing people to stay overnight on the premises. This, in effect, has denied access to shelter from rain and sun and also to the healing process. Asked about the practice of keeping people in chains, the Darga officials disowned such practices and left it to the caretakers and families of people visiting the Darga. One official said: "We don't ask anybody to stay or leave. It is a matter of their faith and well being but after the TV news we are asking the people to get a certificate from the police and mental hospital if they want to stay in this Darga."



The Law as Recourse

Following the Ervadi incident the Supreme Court asked all states to submit a report on unregistered bodies detaining persons with mental distress. Several such bodies were shut down. The people

needing treatment found in these places were sent to state mental health facilities. Following the NDTV report, the Andhra Pradesh Human Rights Commission (APHRC) visited the Langar House Darga, and demanded that "those needing hospitalisation be shifted to the government hospital and others moved to government homes if they have nowhere else to go."³

Both the Supreme Court and the APHRC see state run mental hospitals as the "correct" place for people to be. But as any of us who have had the misfortune to spend time in one of these "institutions of care" can testify, they do not stand up to scrutiny. An empirical study of state run mental hospitals in the country by the National Human Rights Commission⁴ classified these institutions of care into two: one, hospitals that were "dumping grounds," where people experiencing mental distress were incarcerated in violation of all human dignity; two, hospitals which provided some basic amenities, but were predominantly custodial, violating people's rights to appropriate treatment and life in the community. The deprivations, control and restraint – both medical by use of drugs and ECT, and physical by strapping to beds, solitary cells and locked wards – within the walls of these hospitals are not considered. Would it constitute less violation of human rights because they are done within legal boundaries in registered institutions, and away from the eyes of cameras?

In the discussions that followed the NDTV report, the voices in favour of invoking the law seemed to stem from a belief that such proactive action would have an impact on other institutions and make them re-examine their inhuman practices. However, as Moid and Afzal's report showed, the increased scrutiny had resulted in the Darga disowning such practices and withdrawing even some of the beneficial services.



The Meaning of Healing

The modernist discourse on health sees mental health provision through regulated medical models as progressive. Other knowledge systems and healing practices are considered reactionary. A good example of this is the WHO discourse on mental health in the so-called developing countries. The 1979 WHO study⁵ reported that people in India (Agra to be specific) did not possess correct knowledge of schizophrenia and that there were superstitious beliefs and misconceptions in how to get treatment. Correct knowledge meant western medical understanding of mental illness and superstitious beliefs referred to as faith and religious healing. Yet, several WHO-sponsored studies in the following decades showed that people diagnosed with schizophrenia and related illnesses in so-called developing countries like India (including people in Agra who were part of the 1979 study) had better outcome measures compared to their counterparts in the so-called developed countries.⁶

Murphy Halliburton, in his study of experiences of people accessing ayurvedic, allopathic and religious healing in Kerala, posits the idea of "psychiatric pluralism" as a possible answer to why India is among the countries with the "wrong" knowledge and "right" outcome measures.⁷ He argues that it is the "fit" that people see between a regime of treatment and their own ideas of illness and wellness, and the access to different kinds of regimes that make people "get better." What is considered "alternative mental health systems" in western countries – ayurveda, faith and religious healing, native medicine – is an integral part of what people access in times of need. While no regime worked for everyone across the board, the people interviewed for this study showed a great deal of initiative in moving from

one system to another until they found what worked for them.

One of the few studies that compared outcomes of healing temples with that of clinical psychiatry was conducted in Tamil Nadu. They found a 20% reduction in the symptoms of schizophrenia, and commented that this “represents a level of clinical improvement that matches that achieved by many psychotropic agents, including the newer atypical agents.”⁸ They found that people saw this temple as providing them a supportive, non-threatening, reassuring setting, an “asylum” in the sense of sanctuary.

The above studies represent a welcome tendency to take community healing spaces and their roles more seriously. An incident like Ervadi creates fear and aversion to these places. But it is true that such spaces come into public attention only in the wake of an Ervadi. Mainstream mental health provision or discussions have nothing to do with them. Liberal secular sections of the society see them as reactionary. Yet a large number of people use them regularly and arguably with less stigma than psychiatric hospitals.

We need to do more work in understanding what “healing” means

to people who access these spaces. An insufficient understanding of these spaces creates confusions about the services that they provide. How can these important community resources be supported to provide their services more efficiently? For example, it is argued that some people need to be chained to keep them and others safe in a public open space like the Langar House Darga. Could it be possible to envisage the provision of safe living spaces close to the Darga for people who visit the Darga for healing?



The Discourse of Human Rights

In the discussions, the concept of “human rights” remained unexamined. Is it a concept that has one universal meaning, despite the Universal Declaration of Human Rights? How do we respond to situations that we see as violations of human rights? In the discussions, an example of a single mother with a young child with autism was presented. Living close to railway tracks, the mother had taken to tying the child up in their home, while she worked in her small shop. The local Red Cross filed a police report against her for violating the child’s human rights. It did not occur to them that what the mother actually needed was

some support to look after her child, day care or babysitting services, while she earned a living. In this case, the child definitely has a right not to be restrained. However, the disproportionate action to punish the already vulnerable mother only makes a vulnerable situation worse.

One of the suggestions that came out of our discussions was that Dargas and other such places should be studied as institutions so that there is a much better understanding of how they respond to people’s problems, their limitations and dynamics. They provide an important social function. It would be more appropriate to strengthen and nurture these spaces through resource allocation, improved management, and support through health and education centres.

Access to appropriate treatment is a human right – who better to decide what is appropriate than the person looking for healing? The right to family and community life is also a human right. Would these rights be granted if healing spaces are closed down and people forcefully taken to mental hospitals? That is all that the law can offer at the moment.

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CAMH resources on Depression

Anant Bontadkar

Awareness, understanding and knowledge are the three main things needed for physical and mental well-being, good relationships, smoother life of the individual, family as well as a society. No doubt, knowledge helps the possessor of it, but it can help others also.

In any interpersonal relationship, knowing each other solves a lot of problems. Also it helps a person to be healthy mentally and physically. Once understanding improves, automatically our responses to things changed and we can induce positiveness. By reading articles like this, one is able to know the nature of mental health problems he or she may be facing in life, consider it and adjust with each other accordingly, helping each other in coping with distresses and in being happy.

Actually, not only in relationships but about anything we come in contact with, knowledge plays an important role in easing up day-to-day life. Outward things we come into contact with are countless. We are in continuous connection with mind also, which experiences happiness and sorrows. One of the things that impairs mental health, is depression.

I would like to say something about the words – disorder, syndrome, abnormality, dysfunction, disease, illness, patient, etc., which are used as medical terms. If you observe yourself, you will find a preconceived notion about each word, attached by your self or infused by society. Whenever we use any word, its related to emotions, and thoughts automatically occupy our mind and we react accordingly. About the words I have listed here, some

negative and harmful emotions, thoughts and behavior patterns are attached to these labels in our society like disregard, phobia, anxiety, disdain, stigma, labeling, marginalization, and denial of rights, which makes the life of a sufferer worse. This is not at all helpful for an individual, a family as well as society also.

If you look at the meanings of the words I have listed before, you will find that it is very difficult and in lot of cases very wrong to label someone with these words. In case of depression, it is absolutely possible to overcome or manage effectively and live a so-called normal life. Actually, perception of normal and abnormal differs from person to person. In such a scenario, labeling someone is very indiscreet, wrong and harmful.

Looking at some of the signs and symptoms of the various disorders, like irritation, sadness, sorrow, forgetfulness, lack of concentration, restlessness, you will find it present in everyone in some amount at some time or other. If someone is approaching a mental health professional for help we think that he is disordered. Someone is suffering but not taking the help of a professional then we do not think that he is disordered. Is this thinking logical? Do think a hundred times before labeling someone with some disorder or a syndrome.

I would like to urge the person suffering, that at least you do not label yourself with disorder, let others say anything. How you see yourself impacts the attitude of society towards you. So, work on your attitude towards yourself.

Yes, you are in distress now, but you need not be in distress all your life. Work on your abilities, your self-worth and condition of mind, but keep away from these harmful labels. Any human being is not restricted to only one aspect of flaws, but consists of other positive aspects also. Think about those positive aspects and you will find peace, energy, and inspiration within.

The words like disorder are names given to identify some symptoms of distress or illness, not worthy of the negative thoughts, emotions and behavior patterns attached to them by people in general. Change is the only constant thing in this world. It is true to characteristics of mind also. With proper efforts and help from others it is definitely possible to subside depression and gain positive mental health.

While reading something, what could one take from the reading is purely subjective, but still I would like to say something about how you could make this article beneficial. By reading signs and symptoms, we can come to know the condition of the person in depression. If any of our close persons is in distress, we will be able to identify his distress from these symptoms. If possible, we can help him/her, directly or indirectly, in reducing his distress. At least, we can take care that our behavior is not increasing his distress. If we are not capable of reducing the burden of depression someone is carrying, we can at least listen to him. Just listening attentively, seriously, without judging, without giving opinion helps a lot. It will improve relationships. Helping someone in

distress gives us contentment and self-worth, which are the most valuable things to be earned in life compared to anything else, I believe.

Mind works on very subtle level, with very fast speed and lot of times subconsciously or unconsciously, storing negative thoughts, feelings and beliefs, which we do not come to know easily most of the times, unless it shows some intense distress. If we find some symptoms in excessive amounts in ourselves, we can work on them well in advance according to the wisdom, 'Prevention is better than cure'. I am not intending to threaten anyone, but just alerting, to reduce possibility and intensity of depression in self. If we can think about the root causes of depression, it will help us in improving our condition of mind. Signs & symptoms tell you who has a depression in *medical* terms.

The human is an emotional being. Like day and night, we feel good and bad, high and low alternatively. But if only negative feelings are occupying the mind for a longer period continuously, then it needs to be taken seriously. Everyone feels a bit low sometimes. But for some, it becomes serious enough to bring their lives to a standstill. That is where the problem worsens. For any age and sex, in general, depression can be seen as a state of disability, morbidity, excessive melancholy, mood of hopelessness and feelings of inadequacy, often with physical symptoms, explored later in the article. Some of the following can be seen in various other types of physical illnesses or may be felt by everyone sometimes in life, but it doesn't mean that it is a depression. Three main factors stated in the section 'Major Depression' should always be kept in mind.

Behavioral

- Slowing down in everything
- Ignoring responsibilities
- Ignoring appearance of own body and clothes
- Forgetfulness
- Lack of concentration
- Increased irritation, anger outburst
- Being violent
- Restlessness
- Alcohol, drug abuse
- Dislike socializing
- Singing & listening always to sad songs

Emotional, Mental, Intellectual Symptoms

- Lack of interest in anything including pleasurable activities
- Feeling of despair, sadness
- Decreased sexual desire
- Not feeling affection towards family members and friends
- Extreme guilty feeling
- Self-blaming, worthlessness
- Degradation of self-esteem
- Loss of interest in living
- Thoughts and efforts of suicide
- Self-loathing
- Panic attacks
- Feeling violated
- Feeling like a loser always
- Wrong & distressing perceptions, beliefs, conclusions, for instance, a depressed chef, after receiving compliments for this salad or rolls, may conclude that the soup must have been terrible.

Physical Symptoms

- Problems with sleep
- Feeling weak continuously
- Decrease or increase in appetite
- Decrease or increase in weight
- Headache without reason
- Backache
- Digestive disorders

Unfortunately, resources on depression in general emphasise only the symptom part. References to the following 'types' of depression has been found in our documentation.

1. Major / Clinical / Unipolar depression: Symptoms are greater in number; they persist over longer periods and hamper normal functioning.

2. Dysthymia: Feelings of mild depression continuously, for around last two years. Daily work is done but with some type of continuous burden, affecting work and relationships slowly.

3. Mixed anxiety depression: With depression, symptoms like worry, anxiety, shivering of hands and legs, restlessness etc. are found.

4. Bipolar depression: In bipolar disorders, one swings between highs and lows which can last weeks or even months. During the low phase, the usual feeling is of hopelessness, loss of interest in work and all other symptoms of unipolar depression—this phase can be triggered by a traumatic event or even without any apparent reason. But in bipolar disorder, there's also a manic phase, which usually begins with a sort of all's-well-with-the-world buzz. But as energy revs up, it becomes too much for anyone to handle and may result in aggressive and impulsive behavior like picking fights without reason or impulsive purchases. The person suddenly becomes hilarious and then withdraws again in his own shell.

5. Masked / Smiling depression: The individual neither feels nor appears depressed to others. There are, however, other persisting bodily symptoms of aches and pains, tiredness, reduced appetite and sexual desire that indicates the person is probably suffering from masked depression.

The subject of "Depression" is vital and vast, and can contain other aspects like, depression in different categories (women, youth etc.), causes of depression, positive dimensions of depression and mainly, dealing with / overcoming depression by oneself. Our resource center covers these. Maybe I will have another occasion to write about these. Until then, let us all be in touch with positive, inspiring, motivational, energizing, capacity building things, to the possible extent, to overcome distress and be healthy, mentally and physically.

Newspapers

TH	= The Hindu
TOI	= Times of India
IE	= Indian Express
Lok	= Loksatta (Marathi)
Sakal	= Sakal (Marathi)

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- 8 TOI-22.8.04- The Great Depression



Observance of Erwadi Memorial Day and World Mental Health Day

A report from Jan Manasik Arogya Abhiyan, Maharashtra, a people's campaign in mental health

Erwadi Memorial Day - 6th August 2007

The second half of this year was filled with a lot of activities related to human rights awareness in mental health. It started with the Erwadi Memorial Day. Through JMAA, since last year, we began observing 6th August as the Erwadi Memorial Day. This year, we reached out to different communities to talk about mental health where the focus would be on awareness on human rights in mental health.

A poster exhibition was held at Kamala Nehru Hospital in Pune on 6th August in collaboration with our partners, Susamvad, Schizophrenia Awareness Association (SAA) and Kamala Nehru Hospital. Poster exhibitions were put up in different community spaces as well, in collaboration with some of the JMAA partners like Susamvad, Karve Institute, Vanchit Vikas, and CYDA. A film screening along with a poster exhibition was organized for the psychiatric social work students in Karve Institute, a social work college in Pune. This event also elicited participation of various individuals and NGOs. Prof. Anil Vartak of SAA & Dr. Shirisha Sathe a practicing psychologist, were speakers for the programme. Karve Institute, a teaching college, is also one of the partners in JMAA. JMAA posters were displayed for students and staff. Students, faculty and other administrative staff of institute participated in the programme. The objective of the programme was to create awareness about issues of mental health keeping in mind students across all specializations in the institute. After this, group observed silence for a few minutes to remember the Erwadi victims. Following this, three short films - 'Beyond the

Cuckoo's Nest, 'Two Sisters' and 'The Window' were shown to the group. These films were based on the experiences of Anjali's (An organization working with the Mental Hospital in Kolkatta) interventions in the mental hospitals in West Bengal, which depicted the institutional realities, plight of women in mental hospitals and the necessity of changing attitudes of people and families. Following the screening, Prof. Vartak spoke about the need to be aware about the rights of mentally ill people and the issue of stigma, which is widely prevalent in community. Dr. Shirisha spoke about severe mental illnesses, its causal factors, the relevance of social determinants in the illness and the role of family, society in care and treatment of people. She encouraged students to bridge the gap between 'us' and 'them' while interacting with persons with mental illness. She also emphasized community-based rehabilitation.

JMAA actively tried to collaborate with the media to talk about mental health and introduced a basic language of mental health and human rights in the media as a part of the awareness activities. A radio program organized in All India Radio where one of the JMAA members spoke about the Erwadi incident and about JMAA, its objectives, demands, and the perspective with which it operates. Persons from newspapers having a wide reach were contacted to talk about mental health and human rights.

The JMAA Mumbai group organized films screening along with discussion for students of Mumbai University. The event comprised of a

poster exhibition where the JMAA members put up various posters on the issue and concerns of mental health. Apart from briefing the students about mental health, JMAA as a movement and the Erwadi incident, there was a very engaging discussion about various aspects related to mental health other than what they read in the textbooks. Issues like government's accountability, dearth of mental health professionals, developmental factors and mental health, funds, attitudes towards mental illness, violations as well as contributing in the movement were discussed. This was followed by screening of Anjali's films.

National Appeal for Erwadi Memorial Day

Apart from the local, Mumbai and Pune activities, a national appeal to commemorate the Erwadi Memorial Day was made and e-mails were sent to about 300 individuals and organizations all over the country and to some of our international collaborators as well. Handouts were distributed by Leela Ketkar from Maharishi Karve Institute's management center in Pune, amongst her students on the 6th of August to talk about the incident. Tarique of the Koshish program, TISS, Mumbai, organized a drawing competition at the Beggars' Home (female) in support of the campaign against the violence towards mentally ill patients. 15 women participated in it. Following this, there was discussion about how society treats people with mental illness. Later, they remembered and prayed for the victims of the incident.

Tina Minkowitz (Co-chairperson, World Network of Users and Survivors of Psychiatry, HQ: Denmark) submitted two poems "*Attacked*" and "*Halloween*" for the occasion. She also circulated the campaign news on Erwadi Memorial Day in the global human rights networks.

Ratnaboli Ray (Anjali program, Kolkatta) organized a Memorial evening by the lakeside in Kolkatta, where friends from various movements, especially the women's movement, attended. Candles were lit in memory of the Erwadi victims. J.K. Trivedi from Dept. of Psychiatry of King George Medical University Lucknow and Abdul Mabood of Snehi New Delhi sent commemorative messages.

Following the campaign appeal, which went out, Kamayani Bahi Mahabahl from CEHAT circulated news about an NDTV news item, which projected human rights violations at a famous durgah in Hyderabad. Moid and Mohammad Afzal, two students from the Philosophy department, University of Hyderabad, visited the said Durgah and filed a report and shared their experiences with us. A separate report on this is carried in this issue of aaina.

World Mental Health Day – 10th October 2007

Media Interaction

The week started with a press conference. Some of JMAA partners were present to talk to press reporters and convey the importance of the movement, share various aspects related to mental health and to put forth the violations that take place within mental institutions. The press engaged well with the panel and was curious to know more about the mental hospitals and was interested in being there at the mental hospital meeting with the authorities. The JMAA group felt that it would be worthwhile to have the reporters at the meeting with the mental hospital authorities. The reporters as well as the JMAA group was of the opinion that we should focus on the mental hospital report rather than talk about awareness relating to mental health. The group felt that we should voice our demands relating to the mental

hospital during this week. The JMAA group agreed with that and thus, the focus of the activities for the rest of the week was on the mental hospital, the conditions there, and our demands relating to that.

Human Chain

On 10th October, Mental Health Day, a human chain was planned at a prime location in Pune. All members of JMAA and many other partner organizations as well as the general public were invited to be a part of this. There were several representatives from different organizations as well as some users present to participate in the human chain. Leaflets were distributed to all people passing by and they were urged to join the human chain and write a message for the day. There was a lot of interaction with the public. After the human chain, everyone gathered at a park close by where some of the JMAA members were scheduled to talk. Dr. Yashwant Oak from SAA gave a brief introduction about the event and about JMAA. Dr. Anant Phadke, JSA, talked about the state the health and mental health services are in. He also talked about the political debates and struggles within the health sector that inform the advocacy stands of both JSA and JMAA. Then Sadhana Khati, JMAA coordinator talked about the press conference and mental hospital visit report. She gave a brief background about what the report contains and the conditions in which the mental hospital is functioning. Bhargavi talked about the mental health act and how that law stigmatizes and marginalizes the people affected further. She talked about the rights violations of users, the scarcity of good mental health care systems, ECT, and dire conditions in which people with mental illness live. Prabha Agle, CYDA, has been working with the youth for a long time and she talked about the issues related to the youth. She said that 35% of the population is the youth

and there are so many social factors affecting the lives of the youth. The session ended with a reading of a message that a user had sent for all the people present there, particularly the students. She urged the students to reflect and think about why they are actually here. We always talk about diagnosis and therapies and treatments, but the syllabus never tells us what the user is actually experiencing. She asked them to reflect on that aspect and to understand why they are studying the subject and let it not be just for a degree.

■ **Mental Hospital Visit** ■

JMAA Mumbai and Pune groups had visited the Thane and Yerwada mental hospitals in the year 2006. A report of these visits containing our observations and recommendations was submitted to the Directorate of

Health Services (DHS) but there has been no reply or response till now. The JMAA group felt that the world mental health week would be a good time to interact with the mental hospital authorities regarding this report. There was a meeting organized with the Superintendent of the Yerwada mental hospital in Pune. The group and press interacted with a senior psychiatrist as well as another psychiatrist from the mental hospital. At the end of the last visit of the JMAA group, we had interacted with the superintendent of the mental hospital. We had talked about issues like the care and treatment procedures, after care plans (rehabilitation and family reintegration), cleanliness and hygiene, resources, human rights issues, and other health facilities. This time, the authorities were asked questions on similar lines but the responses were similar. Though

there was a gap of one year between the interactions, there was not much change in the responses. Also, the authorities were asked about the NHRC report and they gave very vague responses saying that government procedures take time. When asked about ECT, they justified it completely saying that the west talks about the efficacy of the procedure.

There has been a lot of media interaction over these past few months, which has helped us, reach out to more people and introduce a mental health vocabulary in the everyday parlance of the newspapers. Through the awareness activities, we have been able to bring some visibility to the work of JMAA as well as the issue of human rights in mental health.



Report by Puja Modi

Consultation of Users and Survivors

YMCA, 26th September 2007

A half a day consultation of users and survivors of the mental health system was held in Pune, on 26th September 2007. This was organized as a part of Sanchit, the oral history archive of the Center for Advocacy in Mental Health. In all there were 15 participants, all from Pune.

Background:

Bapu Trust began as a research and documentation center with the objective of working on user advocacy, empowerment and rights and started the Centre for Advocacy in Mental Health (CAMH) in year 2000. Bapu's vision has been to create a more humane and user centered approach in the mental health system. Sanchit, the oral histories Archive of the Bapu Trust was one of the first activities of the organization, which was conceptualized as a user space. But in these years, not many users

survivors have actually used the advocacy center or participated in its programs. It was strongly expressed that there needs to be user spaces within the organization and this should reflect in each of our advocacy programs.

One of the important outcomes of a subsequent review was to brainstorm about how to create user spaces within the organization. A need was felt to understand the ideology of the user / survivor and how to have a deeper user / survivor involvement in our activities. We planned to conduct a user survivor workshop where we wanted to understand the need for such a space and also get feedback from participants regarding our work, and in which direction we want to take it. This was the first time that such a workshop was being planned in the region. For us, it was important to

know whether there is a need for user space in the city; to examine whether the user identity exists and is not an alien concept in the Indian context.

We got in touch with all the users we knew in our circles, either through our work or personally, who have been politically active in this field or have some very intense experiences to share and to give constructive feedback regarding incorporating user spaces in our work. We also invited some individuals from the care giving perspective who could contribute to our user survivor work. We reflected upon the process by which users / survivors could be contacted. We also reflected upon our own identities as users / survivors.

In our work, we have seen that every user does not just have a need to access therapeutic spaces but some

also have a need to access advocacy spaces. They would like to specifically talk about the injustice done to them within the mental health system. Or, they may have tried different therapists and have finally decided to focus upon their self-recovery on their own terms. It was decided to call the activity, a “consultation” as users / survivors were seen as experts of their own experience. Appropriate compensation was devised to cover travel, consultation time, etc., an aspect often disregarded when users are invited to participate in such programs. We wanted to challenge the assumption usually made in India that users only needed to be ‘kept occupied’ and that users’ time need not be monetized.

History of the User / Survivor Movement in the West

The history of the user / survivor movement which began in the West in the late ‘60s and ‘70s was discussed. The user / survivor movement started after the government’s focus shifted from custodial care to community care. Medical power grew during the Second World War leading to the invention of ‘chemical restraint’. During this process, a lot of people were rendered homeless, as there weren’t mechanisms for integration back into the community. Neither the state nor the community was willing to take responsibility of those who were not institutionalized nor create necessary spaces for accommodating their needs. Many experiments, such as with drugs and ECT, also resulted in user ire and mobilization. Many were also vocal about the injustice done to them within the secret wards of the mental hospitals. This facilitated the mobilization of many groups, which was the beginning of the user / survivor movement. A lot of literature was created to talk about the nature of the mental health sector.

Mental health is seen from a very medicalized perspective. The Diagnostic and Statistical Manual

(DSM) released first in 1952 now has several versions. It talks about the various diagnosis in mental health and looks at all the symptoms from a very medical point of view. The subjective experience of an individual is not given any importance. Also, the treatments are very medical. ECT is still rampantly used across the country in spite of it being such a barbaric procedure.

Confidentiality

The group was informed that we would maintain complete confidentiality, as many people would not be comfortable with their identities being disclosed. But one participant felt that there is no need to keep confidentiality, as a lot of people also have similar experiences. Another participant said that maybe this is true for this group but in her experience she has had negative experiences. She said that a lot of things have been taken away from her

We wanted to challenge the assumption usually made in India that users only needed to be ‘kept occupied’ and that users’ time need not be monetized.

just because she has disclosed certain things with regard to her problem. Another participant felt that it’s better to maintain confidentiality so that people can be more open if they are assured of confidentiality. The social aspects can be separated from the personal aspects.

There is a difference within the user groups especially in the Indian context. Some have a political identity and some do not. There is a lot of discrimination of patients. A diagnosis or certificate is a total write-off of the person. To make everyone an advocate for rights is also some kind of coercion. The individual has to determine to what extent they want to disclose and what her / his identity is.

The group felt that precautions need to be taken. Sometimes in our enthusiasm, we may ask the user

what benefit they are getting from a particular thing / activity. But it is important to remember at all points that people come with different intentions and we must respect that. One participant said that sometimes one’s experiences can be very good learnings for others. That’s why keeping the identity confidential, we can still put forth the experiences. There is confidentiality as well as public sharing.

The group reached a consensus that we should keep the experiences but not the identity, though one user felt strongly that he would still like to keep his identity. Also there were questions about how we would be disseminating the report; whether it would be just within the group or will it be open to all. The group felt that this process needs to reach out to everyone. A participant was also of the view that a user has some thing invaluable in the perspective that comes from so called inexperience. He said that the world needs the knowledge of the inexperience and one needs to keep this in mind before one accepts their status quo. Even so-called inexperience has its value. This knowledge must be shared in public forums.

Objectives of the Consultation

The objectives of the meeting were shared. We have not been able to create the necessary user spaces. There are very few users who have a political identity. Communities and families also do not allow users to form friendships or associations. To form a group with a political / public identity was an objective of this group. The group felt that one of the objectives could be to decide what all we want to do as a group as this is the first time a user consultation is being held. Another user pointed out there are clear issues that users have faced, articulated in this group. But we should focus on the objectives of the workshop. She felt that there was a need to nurture the political identity of a user, which this group could do.

While planning this workshop we had decided to invite only users but we have also invited some people from care giving perspectives. It is important to put before others the personal journeys of users / survivors. The anchor point of the workshop was for people who have gone through these experiences to come together as a *community* and put that out to the public at large.

User / Survivor Identity: Is it an alien concept?

The user / survivor identity has always been seen as a very western concept. Thus, not many such movements are there in India. But there is a strong need perceived to have spaces where people can come and share their experiences with the mental health care system. When we talk about the identity of users / survivors, we're talking about different groups:

- a. One is a group which is a user of mental health services of any kind
- b. Those with profound psychological experiences and who have self reflected upon these experiences
- c. Those who are on the chosen path of self recovery, having tried out many services
- d. Those who have been seen as having or have actually been diagnosed with a mental illness and who have suffered social stigma and exclusion
- e. Those who have experienced injustice in society due to a label of mental illness, degrading and inhuman treatments, and who have a political identity as users and survivors

Each participant introduced him / herself addressing the question of identity. One of the participants talked about his background, what his psychosocial experiences were and his relationships within the family. He then talked about the time when he joined an organization and experienced counseling there. He was counseled but his family was not counseled. He felt that maybe he has changed, but his family has not. He

experienced that the environment plays an important part. The goal is to handle stress effectively. He has accepted his illness and has started taking medications. But he has also experienced the side effects. He said that he hasn't read much but has learnt a lot on the streets. Even when he was in a big city, he lived on the streets while going to an organization to work.

One can be both a user and a survivor. But we can in fact talk about a survivor identity due to surviving the experiences of mental illness as well as the effects of the mental health service system.

Another survivor, associated with Bapu Trust right from its inception, said that users and survivors are her community. She has lived with a survivor identity because of her personal experiences and the violence experienced by her family in psychiatry. She herself chose the self-recovery method when she went through severe depression. It has been a spiritual journey for her. There are a lot of self-recovered patients whose spiritual journey needs to be represented before the public. We have gathered today to receive learnings from the users in this consultation and to see if we are capable of establishing a community of users / survivors.

Another user said that what she has experienced would be of help to others. One can be both a user and a survivor. But we can in fact talk about a survivor identity due to surviving the experiences of mental illness as well as the effects of the mental health service system.

Experiences in the Mental Hospital

One user with very intense experiences with the mental hospital and other mental health care systems

suggested that Bapu should be seen as a needed space for users. She said that she was a very troublesome patient and had to be put up in a cell. Very often advocates say that solitary confinement is illegal. But when they are unmanageable and violent it is unfortunate. No one likes it but has to be done. Otherwise what can the carers or the caretakers do? She said that she used to beat up doctors when she got violent and has beaten up doctors even in NIMHANS. But the doctors also go wrong. The patients are not taken care of properly. There is no hygiene and they are not well taken care of. She felt that users should write to WHO and maybe they can do something. There is a lot of corruption and it is there to the roots.

One participant appreciated this user who just shared her experiences. She has known her for a long time and really admires her for being where she is today in spite of everything that she has been through. She felt that she really is a survivor.

She replied that Tilak said that "Freedom is my birthright and I shall have it", but she is not a freedom fighter, but she is a fighter.

Another carer talked about her son and also her experiences with a self-help group for schizophrenia. Initially, she was very gloomy about her son's illness but this group helped her change her perspective. She said that she has applied everything they taught her. She felt a lot of love towards her child when she understood the real suffering. The first thing she learnt was that the person who is affected is not at all at fault. She concluded that love is the most important thing. Now her son is an artist and is pursuing that.

She added that if we all believe in alternative therapy, with our movement, we could gather more people and make it a bigger movement. Nobody is unmanageable if there is love. If a person seeks help in the early stages and if there is a good environment then there maybe

no need for ECT. Many users don't have work. She was not sure about what kind of monetary help we can give, but we can all work towards it and wipe off corruption.

A user stated that there is so much space in the mental hospital and they can beautify the place. But there is absolute filth outside the wards. There can be so many other things done for the entertainment of the residents there. Another user felt that the residents are already troubled and the environment there is also not conducive to recovery. The group questioned why the situation was like that. Sometimes the situation at home is also similar. He shared that he hasn't lived in the mental hospital but his experiences of living at home and with society have also been similar.

A user said that she has been out of the mental hospital for the past 7-8 years. She said that even if she suggests the superintendent of the mental hospital to create a good environment they wouldn't listen. They don't even pay attention to what the patients need.

A user was of the opinion that changes in the mental hospital are needed but it also important that users must learn to forgive. He said that being bitter doesn't get you much. Probably the staff there also has their limitations. To which another user replied that anger is understandable when the system is so poor. If the system shows some signs of changing, maybe the anger will also go away. Only when that happens, will users be in a position to forgive easily.

Self-Recovery



User 1

He said that any illness has stages and that is crucial. There is definitely a need for "user only" spaces. We should be able to create something

Users can be fully involved in advocacy work. For example, the users in the group who have a strong experience with respect to mental hospitals should be included in the state mental health authority

like alcoholics anonymous. If we can provide healing services in the first few years itself that will help in the recovery process. The stories and experiences of users, which we are collecting, must be published highlighting the strengths and coping strategies. There should be a person on call to help users. He talked about someone who was working at a call center who gave a distress call. He was advised some recovery tools. This kind of help should be available. A help-line for peer support should be there. The literature at CAMH is useful and should be made available to

She has also been told that she was getting addicted to depression and that is the most demeaning thing that can be told to anyone.

general public. Users can be fully involved in advocacy work. For example, the users in the group who have a strong experience with respect to mental hospitals should be included in the state mental health authority / committee / panel. Advocacy for support groups is important. If we have a good number of groups, then we will be able to draw quite a few people who are already working. If there is recognition then naturally the stigma will reduce. Creating an environment is important. We will be able to create an environment where people will not mind taking help from support groups. He reiterated that working on existing strengths of people and coping strategies are very important. We have to see and present ourselves on the basis of our strengths and coping strategies.



User 2

He talked about the effectiveness of yoga and meditation. He continued with saying that yoga and meditation has been very useful for him. There is a diversity of practices such as *thratak*, *yoga nidra* and *shavasan*, along with self-hypnosis techniques. But one needs to do it under expert guidance, as there are contra-indications. For example if you're already depressed then you should not be doing certain *asanas* of yoga. It is a rich area of research and advocacy. He has been trained in yoga. One of the things he finds with therapy is that it focuses on personal insight. For some of us, this can almost become an obsession. One turns from a regular neurotic to an enlightened one. It is important to build a coalition amongst users. There is a lack of information regarding thriving at work or how do you deal with certain things within the family, etc. and short-term workshops on these topics could really help. It provides an opportunity to get to know each other and share within the group.



User 3

Self Help

She has worked with a self-help group right from its inception and found that groups that are led by experts tend to deteriorate because of the power hierarchy. Here also, we have to consider aspects of force. Sometimes self-help groups become a pathway to a doctor's clinic. She was focusing on depression as she has been through those experiences. She has also been told that she was getting addicted to depression and that is the most demeaning thing that can be told to anyone. They should also not be teaching therapies or counseling skills, etc. She is now withdrawing from both medication and the self-help group. The challenge is how to start a group without getting into these traps.

There is a need for a platform to share without the power struggle and various kinds of games and interests coming in. Also a hotline especially for suicide is needed. Suicide is just a desperate call for help. But after the attempt, everything is forgotten as one is trying to improve and move on from the incident. People who are suicidal need continuous interaction with others who are improving. Depression comes due to:

1. Dependency and lack of decision-making
2. Depression dominates emotions and only brings out negative emotions
3. Disorganization.

One user from his experiences of self-help groups felt that generally in such a group the facilitator should not be commanding. The facilitator should not end up by making *upadesh*. This does not help. Even though there is awareness that one could be wrong, sometimes there is very little one can do about it. This should be kept in mind. The needs of the users are more important.

Another user reiterated this and felt that it was very important to understand this while forming any group. Self-help groups can evolve into different things. Power hierarchies are created when actually need-based user-friendly groups are important. When its too formalized it becomes a different structure altogether. The group should be created taking into account what the needs of the users and survivors are.

All this needs to be addressed on a proper platform through different methods. There is a fine-tuning in the mind of anyone undergoing therapy. Therefore therapy should focus on not blurring the picture while not exaggerating the symptoms. She felt that exaggeration is part of the self-expression and experience of the user. Depression is darkness unfathomable. Exaggeration is inevitable.

Exaggeration is part of the self-expression and experience of the user. Depression is darkness unfathomable. Exaggeration is inevitable.

Non-religious spirituality is essential. The use of ritual must also be considered. We must examine traditional methods to see what helps and what does not. Without having harmful practices and being blindly ritualistic, we can use indigenous methods for recovery. For example, giving is a part of all traditions. Giving in material terms is also giving in mental terms. Families can also be more supportive. The everyday healing touch of the family is important. Such activities create new memories and provide space for creativity, which are

We all settle at our own comfort zones and make these choices from there. This is a journey of discovery and not recovery. There is a need for spaces to pass through these experiences. Recovery is individualized and we must not make generalizations.

important for good mental health. Music, dance, cooking, or celebrating things together can be helpful. Networking of users is important. Isolation and loneliness need to be addressed. With children grown up and work is antagonistic and family keeping away leads to loneliness and isolation and loneliness can be addressed well through these groups.

Another user added that even she feels lonely. Parents are involved in their own work and she said that the void one feels is unexplainable. A person has been aloof for so long from social interactions and there is so much void that one can't engage with larger social groups because emotionally you have

withdrawn from that totally. She felt that sometimes it is not possible to participate in family celebrations or functions.

One user who has been a founder member of a self-help group said that family occasions are opportunities. The support group can provide some time but the family, friends and neighbors are also important. There is bound to be shortage of people who are going to provide help. Family support is more enduring in nature than any group; group meetings have considerable time gap during which it is the family support that will remain with the user.

A carer also explained that the family needs to be aware about all the issues and make it a lifestyle of the family. If you don't know anything about the illness then it becomes difficult to cope. There are very minute things, which the family needs to be aware at an everyday level. She said that she has made a new beginning for her son and she chooses the environment for him. The family should be trained and there should be healing touch within the family.



User 4

She has been living and working in the UK. Recovery is a term that has come from the US. The state policy in the UK is called a Journey to Recovery. The governments have co-opted the concept of recovery into their own agendas and from their own interests. She has recently finished an audit of 9 community mental health services in UK. One of their findings was that black people were given more depot injections than whites. Racism is a big part of how recovery is thought of in the West. Recovery means different things for everyone. There is a capacity building group [Catch-a-Fiya], which is a national network. We started with talking about recovery. One of the group members is there who does not believe that his psychotic episodes

are an illness. For him it is a religious experience. He doesn't have anything to recover from.

We need to understand what recovery means. How do we allow these differences to be incorporated in a group situation? Another woman says that it is discovery and not recovery. She says that even though she still has her ups and downs, she doesn't take medications. We all settle at our own comfort zones and make these choices from there. This is a journey of discovery and not recovery. There is a need for spaces to pass through these experiences. Recovery is individualized and we must not make generalizations. In a group situation, we have to respect diversity and every one's individual experiences. Different users react differently to various diagnosis and prescriptions. For some people, even to be told that there is a "chemical imbalance" does help. This cannot be denied. But we must not hold general theories. We must depend on individual experience and be sensitive to what is helping or working for that person.

For this user, being a part of political movements has helped. This gave visibility to her problems. She could appreciate how giving visibility in public forums to the problem is important for recovery. She said that there are three things that are important:

1. Understanding of what is actually happening to me and acceptance by family and friends and getting visibility for my problems
2. Political work – have started asking questions when applying for work like what facilities are available for someone with emotional problems.
3. Constantly looking at oneself and understanding what is working for oneself and keeping track of all that.

She really sees that this group is clearly expressing a need for a users' space in the region. Whether a formal

organizational structure should be given to it or not could be considered. A participant who has also been an active part of a self-help group for schizophrenia added that that group is purely a peer group and everybody is at the same level including the facilitator. There is no hierarchy. Another important point is that whatever is shared in the group, is always confidential.

It is necessary to have a 360-degree approach, according to one participant. It means that it is not enough to help a struggler to become a survivor. Maybe a person is hesitant to seek help. Helping the family members to be trained is an important activity. There should be *attitudinal healing*. It is important to identify employers who have employed users and highlight that. It is better to have dialogue where there is scope but at the same time the employer may also have reservations and apprehensions. It is important to understand that and then have a dialogue. At least it will lead to a meeting point. It is also important to create a space where experiences of people who have benefited from being a part of a group are shared. Coming out and reaching out can be termed as a day-to-day spiritual act. We can create a forum of inter-disability collaboration.

Another user said that he has never been to a psychiatrist or taken medications. Though he has been to a therapist with whom he can share and also it is someone who understands him. The process is how we cope, accept or deny. He has done self-caring and self-loving. For example when it is his birthday he buys things for himself irrespective of whether someone else gives it or not. If he feels that he has done a good job he appreciates himself. He said that at one point of time he needed someone to share. But now he doesn't feel so. We just need to understand our own pain. If you're getting appreciation and love from others, you can provide that for yourself as well. Here we understand

each other we are in the same pain. But it also important for others to understand this pain. Everyone has different sensitivity levels and this should reach out to people. Each one's sensitivity, creativity, and intellectual levels is different and what we are doing should reach out to everyone.

It is important for this group to be in everyday contact, perhaps on the phone. Coming out and trying to reach out to others also is an important step. The forum could also try to bring some contacts across the disability spectrum. Another user felt that everyone needs to understand that life is beautiful and nobody can destroy it.

Use of Medications

The use of medication was discussed in the context of self-recovery. A user demanded to know whether the doctor himself has taken the medication that he prescribes to his patients? Has the doctor ever taken ECT himself or been in solitary confinement? They should volunteer to do so and then see what happens. Without that experience, they will not have any conception of what actually happens to the patient. Does the doctor know what the medication does?

The group talked briefly about the various side effects of medication and what kinds of problems the medication can lead to. The extensive abuse of Ritalin for a fictitious disease like ADHD was discussed. A user shared her experiences with weight gain, obesity, asthma and diabetes through the use of psychiatric medicines. Obesity causes self and body image related issues. The medical community does not help you to deal with these. Everyone was of the opinion that it was important to understand the medication thoroughly and then take decisions regarding whether to take medication or not. It is also important to know when one can stop medication and how to taper it off.

One user felt that each one is at a different stage and one need not share their spiritual experiences because everyone's experiences are different and we need to keep this in mind when we form a group. There should be space for each one to grow and share at their own time.

One survivor gave her inputs on how do we distinguish between users and survivors. Users use the mental health services. But survivors are those who have used the medication and suffered its side effects, which are physical. She said that when she started taking medication nobody told her about issues related to the medications.

User Litigation

A user questioned the system and asked who was going to pay for all the years that have been taken away due to misdiagnosis. What about the malpractices? Can an organisation provide legal services? One of the participants who comes from a legal background said that when one gets involved in a legal battle, the cases ceases to be about the individual and only becomes another case a legal professional has to win at any cost and the point of the case gets lost. One user felt that one should at least start writing about these issues and said that she would be glad to be part of the legal process for users. Often however people do not choose this recourse to law.

Summary and Conclusion

The consultation concluded with a brief summary about what was discussed throughout the day. There are a few self-help groups already working actively in Pune. Then why should we have another meeting for networking users / survivors? There is also limited talk about users and survivors within the mental health system. Users and survivors are never consulted for anything. We have not spent time or resources in building a support community. This workshop is a result of all these conversations. There is clearly a user / survivor identity and

there is a need for a safe network which is led by user / survivors.

The fact that several senior and experienced user leaders from the city made it a point to attend the consultation was encouraging. It is evident that everyone is feeling a sense of isolation and we are doubtful of some well-meaning efforts taken by

How do we forgive someone who has completely violated us and taken away our lives? We have to see whether we want to use our anger and frustration more constructively, instead of talking about forgiving.

non-users, especially professionals. While not disconnecting from others, users and survivors need to do work on their own behalf by themselves. The need to build a public foundation for a user collective based on experience was repeatedly heard. People did not only want necessary services, but at some point experienced a "help fatigue". They have tried all the available services and have found that teaching themselves through the process of recovery is the most effective one. The concept of "enlightened neurotics" is a very useful one. There are many enlightened neurotics! It should not be a group for purely airing private suffering. These learnings need to be put out in public. We must see ourselves as a capacity group, which can train or give consultations to others.

Action Points

There was a clear need for user survivor spaces in the city. This point was reiterated by most people in the room. For various reasons, advocacy and self help efforts in India have not managed to create such spaces. The users and survivors in this group have articulated many ideas on where all a self help group can go wrong. It was even a

question whether we should call ourselves a self-help group. This group could take this forward through follow up meetings and plan further concrete actions. We need to define for ourselves how we are different from other groups. Naming ourselves is important.

There are advantages and disadvantages of users coming together formally. The stages or the journey is from a struggler to a survivor and finally to a thriver. When survivors form a group would they like to be addressed as such or rather what would they like to be addressed as? Only when you have a formalized group is when you are recognized by government agencies. We can think about registration, etc. in the follow up work.

Peer support / help line is a good idea but we have to see how does it not become just another mental health service. What kind of trainings do we need? Forgiving was talked about. In fact, the mental hospital system has been very punishing. There is no forgiveness in this system. How do we forgive someone who has completely violated us and taken away our lives? We have to see whether we want to use our anger and frustration more constructively, instead of talking about forgiving.

Some ideas had come up in the process of the discussion, including writing a letter to the WHO; writing to the State Mental Health Authority to request them to include user / survivors; and making a representation before the mental hospital so that some of the issues discussed could be taken up.

Report by Puja Modi, CAMH



Narrative Therapy - A therapist's journey of exploration and understanding

▣ **Aparna Sathe**

The issue of power and hierarchy within therapeutic context or for that matter in any context has been of interest to me as a counselor and as a mental health practitioner. Psychotherapy is a special relationship where there is an in-built hierarchy between the one who seeks help (namely client) and the one who offers help (the counselor). The client usually enters the relationship with some amount of vulnerability. The therapist is somewhere, consciously or unconsciously attributed with power and control over client's life. It is extremely important a question to me 'whether the therapist is mindful of this power. It is equally important for me to know what he or she does to empower a client while they both engage in a change process.

If I try to trace my own journey as a counselor and my own relationship with the issue of power within therapeutic context, I realize that it has changed over a period of time. After my post graduation in psychology, I received training in traditional forms of counseling (and psychotherapy to some extent) which fostered traditional notions of diagnosis, pathology and therapist's expertise over client's life situation and problems. Though we were taught to handle this expert power with great deal of care and in an ethical way, the notion of the therapist being powerful remained at the core of my practice.

After the initial years of my work with mental distress and illness, I was offered an opportunity to coordinate a counseling center for women facing violence. I worked there for 5 years. This experience in particular challenged my notions of armchair counseling and also my own expertise. Along with exploration of clients' inner psychological worlds, I also started exploring the larger context that affects their inner worlds. Introduction to feminist analysis of power made me question many of my own practices and made me mindful of the power I yielded as a therapist, in overt and covert ways. Empowerment, as we all know, is a much revered value in feminist practice. I started looking for therapeutic practices that empower clients within the therapeutic relationship itself.

This experience made me look for and appreciate stories of strength and courage, while women narrated their stories of victimhood. My focus shifted from 'search for pathology', to 'search for strength and resilience'. I gradually started understanding that these stories of struggle, courage, these voices of resistances, these attempts to swim against the tide, were like twinkling and

sparkling moments in a stream of darkness of life. If not caught and held, they may disappear. One may not even know that they existed. Such is the power of the problem story. However once caught and held in hand, they start shining. A new self can develop in this new light; a 'self' of one's own choice.

After the initial discomforts of gradual weaning of power (and let me tell you, it is not easy to give up the expert position), I started experiencing a sense of relief for not having to shoulder responsibility for client's life and for finding solutions for their problems. I started breathing more normally and being more genuine as a therapist. There began my search for non-hierarchical models of counseling.

Against the backdrop of this, last year I had an opportunity to attend a few workshops on narrative therapy organized by the, 'Behavioral Science Foundation', Mumbai. When I had first heard of narrative therapy a few years back, it seemed like a bundle of interesting ideas. However I was not sure how some of these ideas could be used in a therapy situation. The workshop set me reading and practicing some of the ideas and techniques related to narrative therapy.

What excited me the most about narrative therapy is the liberating idea that it does not believe in the notion of one ultimate truth which is decided and discovered by the so called knowledge makers and keepers of a particular time, in a given society. This also includes the therapist, given the therapeutic situation. Narrative therapy believes that realities are multiple and each human being is a maker and interpreter of his or her own reality. It therefore centers people as experts of their own lives, rather than the therapist. It is evident that this has serious implications for the therapist-client hierarchy and power. The therapist is no more supposed to fix people up, but is a co-voyager in people's journey of rewriting their lives.

Narrative Therapy was initially developed during the 1970s and 1980s, largely by Australian Michael White and his friend and colleague, David Epston, of New Zealand.

Let us take a look at some of the key tenets of narrative therapy and what narrative therapists do.

Narrative therapists invite people to tell and re-tell their stories, by engaging in curious conversations. The therapist does not assume a position of, "Knowing the client's reality", But adopts a curious stance of "wanting to know and explore".

Narrative therapy believes that human beings are interpreting beings. The narrative metaphor proposes that everyone tells stories about their lives and experiences. It is through the telling of these stories that meaning is given to life experiences. Let me take a common example

of a student who barely manages to pass in the mathematics exam in 9th standard. The way he interprets this experience is by a story called 'I am poor at mathematics'. Once this experience is storied, he picks up many such incidents where he had difficulty learning mathematics or clearing the exam in the past. This story may become a powerful and the only way of interpreting his past and future experiences with the subject. It may govern the future by reducing amount of efforts he/she puts into studying the subject. Thus this may become a story by which he lives.

We live by many stories at the same time. There is always a context in which the stories of our lives are formed. This context contributes to the interpretations and meanings that we give to events. The context of gender, class, race, culture and sexual preference are powerful contributors to the plot of the stories by which we live. The dominant voices in a given society at a given point of time, define what is good or normal. These stories affect our identities.

Some stories have greater influence on our lives than others. There are some dominant stories which are propagated by societies and cultures that we belong to, e.g. women must live, feel and behave in a certain way, children must respect elders, heterosexual and married relationships is what everyone should aspire for, certain caste and class is superior to others etc. There are certain dominant stories that are specific to the family that we belong to, e.g. we should never trust strangers; someone is a troublesome child, someone is not a good mother because she puts her child in a crèche, one must be successful in life, etc. These stories, over a period of time, get internalized and are treated as truth. They become a part and parcel of an individual's self-concept. They seize to be stories, which are constructed and therefore can be deconstructed; instead they become 'essential' descriptions of self, others and the world around us.

Most of the time when people enter therapy, their lives are governed by problem stories, some of which are in turn governed by the dominant cultural or societal stories, which I mentioned above. Problem stories trick people into believing that they or others are bad, worthless, problematic people. E.g. I am depressed, my wife is too aggressive, I am short-tempered etc. Certain events are privileged and selected over others that support the problem story. There may be other stories or events that do not fit the problem story, however they are filtered out or ignored.

Narrative therapy believes that people are separate from problems. "The person is not the problem, but the problem is the problem." Problems are external to humans. There is more to a person than the problem story, as people's lives are shaped by multiple stories, realities and identities.

Narrative therapists explore the problem stories and their effects on people's lives, self-concept and relationships etc. However, while they do so, they are interested in looking for exceptions to the problem story; moments which have evaded the influence of the problem story. They are looking for what are called "alternative stories-stories of identity that will assist people to break away from the influence of the problems; stories which are preferred because they depict where one wants to go; stories by which people want to live their lives.

The act of living requires that we engage in the mediation between the dominant stories and the alternative stories of our lives. Narrative therapy facilitates a process by which the person can separate him or herself from the problem story and take a position on it. With the help of exploration of the preferred stories, and exploration of dreams, values and commitments that the person adheres to, Narrative Therapy frees the person to rewrite his or her story. Narrative therapy focuses on skills, competencies and resilience that assist people in fighting with problems. As people begin to inhabit and live out the alternative stories, the results are beyond solving problems. Within the new stories, people live out new self images, new possibilities for relationships and new futures. Narrative therapy adopts techniques that help people explore these new territories of preferred stories and also develop landscape of action, which helps translate these preferred stories into a reality.

I personally see a lot of merit in adopting narrative practices. These practices make us mindful of the power we yield as therapists/experts and of centering clients as authors of their own lives. As a logical sequel to the same, Narrative Therapy encourages us to engage in practices that deconstruct these hierarchies.

It is also highly relevant in our context, where many of our identities are relational or cultural projects. Dominant cultural or societal voices play a pivotal role in shaping people's self-identities, leading to subordination or invisibilization of some voices. Work with marginalized populations such as women, street children, sexual minorities, violence victims, migrants, commercial sex workers, slum dwellers, users of psychiatric services etc, adds to our conviction in this belief. Narrative therapy does not believe in hegemony of any one culture or of any one reality / truth over others and respects diversity. Narrative practices provide an opportunity to unpack many of these cultural contexts and explore effects of the dominant voices on people's identities. It provides them with an opportunity to free themselves from these voices and rewrite their own stories.

To summarize I will say that narrative therapy is a respectful, non pathologising approach that assists people

in their struggles against problem stories by focusing on their skills, strengths, resilience and transports them to into territories where they truly want to belong.



Aparna Sathe, a clinical psychologist by training, has been working as a counselor and a psychotherapist for past 10 years. She has worked extensively as a mental health professional on issues of women facing domestic violence. Over the years, she has offered numerous trainings in the area of violence and mental health, gender and mental health, and counseling and psychotherapies with

NGOs, counselors, social workers, and students within and outside Maharashtra. She has been instrumental in creating community literature in mental health and related areas with an objective of demystifying and mainstreaming mental health into other discourses such as development, gender, health etc.

Since past two years, she has been working with Bapu Trust, as a psychotherapist and is also involved in trainings, mental health program development, and the rights based work carried out by the Trust.

Talk Therapy Pivotal for Depressed Youth

▣ **Benedict Carey** ▣ **William Duke**

A talking cure for depression called cognitive behavior therapy appears to cancel the risk of suicidal thinking or behavior associated with taking antidepressant medication, according to the most comprehensive and long-running study to date of depression treatment among adolescents.

The study, which followed for a year more than 600 adolescents being treated for chronic depression, found that four in five recovered entirely, or nearly so, when treated over nine months with medication, talk therapy or a combination of the two. Patients taking medication showed significant signs of improvement up to six weeks earlier than those who received talk therapy alone, but were about twice as likely to report feeling suddenly suicidal. The combination of the two therapies, the authors found, produced the most rapid recovery and protected against sudden suicidal urges.

For several years experts have been debating the risks to children and adolescents who take antidepressants like Prozac and Paxil. In 2004, health regulators required that all labels for antidepressants carry prominent warnings that the drugs were associated with increased risks of suicidal thinking and behavior in young patients, a link that many psychiatrists say has been blown out of proportion, scaring off patients who could benefit from drug treatment.

In this study, antidepressants lowered the risk of suicidal thoughts and actions over all, but significantly less so than talk therapy. “What this study shows, convincingly and for the first time, is that there are very good options for a child who is thought to be at risk for suicidal thinking,” said Kevin Stark, a psychologist at the University of Texas, who was not involved with the research. “Psychosocial therapies do work on their own, with time. But they also help prevent relapse, and this shows that they can help make drug treatment safer.”

In the study, which began in 1999, researchers recruited 654 youths ages 12 to 17 who had been moderately to severely depressed for up to a year or longer. The adolescents were randomly assigned to be treated with Prozac, the antidepressant made by Eli Lilly; cognitive behavioral therapy for a weekly hour-long session; placebo pills; or a combination of Prozac and talk therapy. After 12 weeks, about three in four of the patients receiving both talk therapy and medication were rated as “much better” or “very much better,” and two-thirds taking just the drug fared just as well. Talk therapy by itself was no better than the placebo. After four months, about two-thirds of those receiving any treatment were rated as much or very much improved — significantly better than a typical response to placebo pills. By nine months, 8 in 10 adolescents had shaken off their depression, entirely or almost entirely, no matter the treatment. Talk therapy was a safer alternative. Almost 15 percent of the patients taking just Prozac reported what were described as “suicidal events,” mainly talk and thoughts of suicide so alarming that doctors called in the patients and, often, altered dosages. The rate of such events for those receiving just cognitive behavior therapy was 6 percent. The results for combination therapy were about the same.

“The message is that medication accelerates recovery, but cognitive therapy protects against these bad reactions, and the combination is the best option,” said Dr. John March, chief of child and adolescent psychiatry at the Duke University Medical Center and the principal investigator for the study. The talk therapy promoted changes in behavior like getting patients out of bed and doing something that they enjoy, like playing basketball or going to a party. It also provided cognitive therapy, in which patients are taught to diffuse poisonous assumptions like “I’m a loser” or “I’ll never get a girlfriend.” Experts say it is not easy to find specialists in this therapy outside large cities. The techniques have been widely published in manuals and books, and Dr. March said a good therapist could usually work such techniques into a treatment plan. “The trick,” he said, “is to be an intelligent consumer and find a skilled therapist who’s willing to work with you on these methods.”

Source: The New York Times

In memory of

You, who softly touched my breast
 Before you overdosed and died
 I know you died by choice
 But I miss you.
 You, who filled my head with useless thoughts
 Of love and togetherness for ever,
 Did not survive your last drink
 Did you choose to die?
 I don't know and don't care
 Enough, that you died.
 And then, you,
 Whose mouth said 'No'
 And whose eyes said 'Yes'
 You died willfully, racing
 On a mundane road
 No prizes, even
 I wasn't there when they burnt you
 Sorry! That was an important day for me
 When I looked ahead
 Not behind

 You all crowd me today
 When I ponder
 Once again
 On a choice to die

 Not today, maybe...

Bhargavi V

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