



Editorial

This issue of *aaina* prominently features the politics, world views and experiences of user / survivors of psychiatry, particularly in the context of the use of force in treatment. If mental health is about giving nurturance to those who need it, where is the question of force? The Machiavellian practices which pervade the Indian mental health sector must leave, making way for freedom and liberty, values that were originally envisioned to characterize modernity. Enlightened by the powerful intellectual challenges posed by leading philosophers of psychiatry, Tristano Ajmone from Italy makes a firm statement for freedom and against psychiatric coercion. He questions the pragmatic logic of modernity, of “maximum good for all”, as this materialistic logic marginalizes some people as insane.

In August, this year, finally, the draft UN Convention document was accepted by the AHC. The UN Convention will burst open the controversies fermenting in the mental health sector in India, particularly those related to the use of force in treatment and institutionalisation. This issue of *aaina* carries Dr Amita Dhanda’s comprehensive summary of the gains of the Convention for user / survivors.

In October, at the Annual conference of the World Association of Psychosocial Rehabilitation, a major shift was perceived from “rehabilitation” to “recovery”. Several theme panels also featured experiences as well as alternatives developed by user / survivor groups. Some key note presentations are featured in this *aaina*, with a view to address the question of force, and how the user / survivor movement has experienced it. The shift in vision from “rehabilitation” to “recovery” is a welcome one. There is a need in India to gauge the benefits of this shift and to effect this shift programmatically in all healing environments. *Aaina* presents an argument that faith healing systems, widely prevalent in India, offer profound insights to modernity on mental health care.

The review of Ken Steele’s memoirs, presented herein, once again provides hard hitting evidence of the full capacity of persons diagnosed with a severe mental illness. Not only are user / survivors able to match up with others, but are able to set a vision for a sensitive and caring world.

Contents

Arts-Based Therapist (ABT)
Certification Course 2007 **p2**

Reflections: A Call to Heresy
in the Age of Madness **p3**

Empowerment approach to
Recovery **p8**

On voluntarism: learning
from pre-modern institutions
of care **p10**

Speaking our minds: The
Day the Voices Stopped : A
memoir of madness and
hope **p14**

How to tell your lover you
have schizophrenia **p16**

Advocacy News: What does
the Convention on Rights of
Persons with Disabilities
Promise to Persons with
Psychosocial Disability? **p17**

On user / survivor leadership
p20

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Aaina is a mental health advocacy newsletter.

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

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

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

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

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

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A Call to Heresy in the Age of Madnessⁱ

Psychosocial rehabilitation coming of age in a globalised world

■ **By Tristano Ajmone**

One of the greatest opportunities in the field of solidarity is indeed freedom of speech and the will to share ideas and engage in an open and constructive confrontation. Since ideas have consequences, and we are doomed to be both beneficiaries and victims of past, present and future ideas, I hope my dissenting thoughts might stir the stagnant waters of the mental health system toward a radical change.

My name is Tristano Ajmone², I'm an Italian psychiatric survivor and President of OISM - the Italian Observatory on Mental Health³, a non lucrative association founded in 2001 by my father, Dr. Claudio Ajmone. At that time, I was held hostage in psychiatric institutions, and since I've regained freedom, I've taken on the mission of the association and the task to diffuse its vision. I've come here to bring my perspective, as a user/survivor, on the issue of mental health and psychosocial rehabilitation.

From my perspective, this opportunity of free speech should be employed to remind that the mental health system rests on coercion. The intellectual currency we employ in the free market of ideas carries on its reverse, the anathema of diagnostic social exclusion. Bluntly said: we can no

longer pretend that we fail to notice that the psychiatric enterprise engages in the task of social control, by discrediting and depriving freedom (among) people whose ideas and behaviours violate the hidden moral paradigm of sanity, which is nothing else than conformism to mainstream social consensus. Freedom of speech loses its meaning if dissenting ideas are banned by the medical dismissal of those who speak them out.

The WAPR Conference Program

While preparing this speech, I've sifted the scientific program of this international event, and tried to work out how I could contribute to it with a user's perspective. To say the truth, I was disappointed to see the many proposals to adjust methods of intervention by which the mental health system should carry out its work, yet no one brings up the issue of the legitimacy of psychiatric interventions and whether the mental health system ought to carry on intervening in people's life or not. As a matter of fact, psychiatric users and survivors have since long challenged psychiatry on the grounds of its very foundations. I'd therefore like to recall a number of significant dissenting events organized by the various psychiatric survivors' movements.

Psychiatric Survivors' Movements

The Foucault Tribunal

In 1998, the "Irren-Offensive" (Lunatics Offensive) -a survivors group- together with the "Free University of Berlin" organized in Berlin an international Tribunal on the state of Psychiatry, *The Foucault Tribunal*,⁴ where the defence and the accused were academics and professionals, and the jury was a "box of nuts". The whole history of the survivors' resistance against coercive psychiatry is a history powered by the clarity of insight on what psychiatry *really* is, and what it *really* does, which comes from first- person experience of its interventions. The force of our arguments ... grounds on common sense, first person experiences and the legacy of memory (both personal and historical).

I want to express my deepest gratitude to the survivors who struggled to set up the Foucault Tribunal, which is a historical symbol of the civilizing force of the users/survivors movement, because it denounces crimes against humanity, and bridges the media's gap of silence that covers up the links between Nazi eugenics and present day psychiatry. I thank those courageous academics who

¹ This is an edited version of Tristano Ajmone's speech at the World Association of Psychosocial Rehabilitation meeting at Athens, October, 2006.

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³ www.oism.info

⁴ video of this event is freely downloadable online at www.foucault.de

⁵ See: www.mindfreedom.org

⁵ <http://www.mindfreedom.org/mindfreedom/hungerstrike21.shtml>

sustained them out of intellectual honesty and sense of duty — like Professor Szasz, Dr. Ron Leifer, Prof. Narr, and so on.



Mind Freedom's Fast for Freedom in Mental Health

In the year 2003, MindFreedom⁵, an international psychiatric survivors' organization that fights for human rights of people diagnosed with psychiatric disabilities, initiated the *Fast for Freedom in Mental Health*; a hunger strike "to Challenge International Domination by Biopsychiatry". By exerting pressure on the APA, they started a debate that questioned the legitimacy of psychiatry, its theories and its methods.

A conspicuous body of outstanding personalities of the mental health profession — such as Peter Breggin, Fred Baughman, Loren Mosher, David Cohen, and many others — took side with the protesters; examining and refuting the responses provided by APA to defend its scientific claims. The event attracted so much media attention that it jeopardised the APA intention of ignoring the survivors or dismissing them as "crazy fools". Dr. James H. Scully, Jr., MD, then APA Medical Director, refused confrontation with the strikers, saying that he "only talks to serious people".

Today many people in the mental health profession quote Prof. Loren Mosher, one of those 14 prominent scientists who unanimously agreed that the APA did not provide any scientific evidence for its claims. The response letter of the scientific panel, in support of MindFreedom's hunger strike, ended with a serious admonition to the APA:

"The panel members could not help but notice the contrast between the hunger strikers, who ask clear questions about the science of psychiatry and consciously take risks in the name of protecting the well-being of users of psychiatry, and the American Psychiatric Association, which evades revealing what actual scientific evidence justifies its authority. By not giving specific answers to the questions posed by the hunger strikers, you appear to be affirming the very reason for the hunger strike."

— *Fast For Freedom Scientific Panel Reply To The American Psychiatric Association*⁶

I'm proud of having had the honour of translating into Italian Loren Mosher's *Letter of Resignation from the American Psychiatric Association*⁷. I translated it night-time, while I was locked in my cell in the psychiatric prison facility of the OPG Montelupo Fiorentino.

We survivors are quite different from the diagnostic picture portrayed in our clinical charts, which depict us unfit, insane, unpredictable and dangerous. The truth is that we are the eyewitnesses to the crimes against humanity of our age! Therefore, we pose a threat to the ruling elite.

...Thanks to courageous and honest scientists like Mosher that survivors of psychiatry keep alive the hope that things will change in the mental health system through an open and sincere confrontation with its professionals. Meeting each other, is the only way to realize that behind academic

divergences lie strong human factors and sincere convictions. I wish that this point gets through very clear, because the survivors' movement never denied that even mainstream psychiatrists have sometimes proven to be supportive to some of us. Regardless of how rotten psychiatry is, we must not forget that those wearing the white coat are ordinary men and women whose qualities and shortcomings transcend their clinical roles and specializations. I therefore see no point in demonizing psychiatrists as whole, just as I see no sense in glorifying them either.

But, we do attack the ideological foundations of psychiatry.

I've mentioned two major campaigns conducted by the users/survivors against psychiatry, I want to make it clear that there have been many other such campaigns. Just to mention a few more:

*The Great Escape Bed Push*⁸ that took place in London (UK), where a psychiatric bed was pushed 60 miles- from Mill View Psychiatric Hospital, in Brighton, to the original site of the "Bedlam" asylum in London, to protest against "the poor level of choice of treatments and the widespread use of force used in the psychiatric hospitals". The protest organized by the International Association Against Psychiatric Assault⁹ (IAAPA) at the "Deadly Medicine" Exhibition at the "Hygiene Museum" in Dresden; a protest against the falsification of history because the museum denies the over 20,000 murders by starvation carried out in psychiatric institutes from 1945 to 1949.

(Also) the great work carried out on the issue of legal capacity, by the International Disability

⁵<http://www.moshersoteria.com/resig.htm>

⁷<http://www.bedpush.com>

⁸<http://www.iaapa.de>

⁹<http://www.un.org/esa/socdev/enable/rights/idc05.htm>

Caucus¹⁰ for the UN Convention on the Rights of Persons with Disabilities. I'll also mention that the World Network of Users and Survivors of Psychiatry¹¹ (WNUSP) together with the Bapu Trust¹² of India published this summer a booklet entitled *First Person Stories on Forced Interventions And Being Deprived of Legal Capacity*, which gathers survivors testimonials from all over the world, included my personal story.

Wherever you turn you'll find users and survivors of psychiatry engaged in the struggle for the abolition of coercive psychiatry. For this reason I'm rather disappointed that coercion was not a key topic of discussion in this congress.

I want to stress that the issue of psychiatric coercion goes hand in hand with the paternalistic belief that some people are entitled to know what's best for others, and feel entitled to impose their expertise with force or deception. This idea carries the weight of Plato's views on the role of medicine, which promoted both paternalism and eugenics. This is the root of psychiatric evil, but is also a general problem in medicine, so I won't plunge into it any further.

Contradictions Within the Psychosocial Approach

Some of the most relevant discrepancies that underlie the idea of psychosocial interventions:



Crushing Psyche between Philosophy and Medicine

To understand what psychosocial rehabilitation is, we should first understand what the *psyche* is. Most people claim that psyche

nowadays is equivalent to mind. We can't fail to realize the relational gap between mind and brain: mind is a concept, like soul; brain is an organ, like the heart. Psychologists should handle mind and neurologists brains. Psychiatrists claim to manage to handle both in the name of one science – the model of bio-psychiatry. No scientific discovery will ever fill the gap between the physical (i.e., bodily) and that which is conceptual (i.e., existential). Anyone who places his profession in this gap is destined to be a social controller.

The gap between the physically measurable world and our dynamic experience of its reality is irreducible, the reductionist model attempts to fill it by shrinking Man's psyche by denying free will, by reducing individual life to the result of interplay of genetic and biochemical circumstances, thus dehumanizing man and magnifying science to a religious status.

Psychologists have since long given up their art, by accepting a medical model of the mind that denies free will and traces all problems to biological and genetic causes, by accepting the cures of "miraculous pills", before which we are all the same: both patient and healer. The function of psychology has exhausted itself in this system that focuses on the biological sphere.

Most of them (new trends surfacing in mental health) are nothing less than paradigmatic sleights-of-hand to break the frustrating routines of endless therapeutic failures, and keep the illusion of functional services alive. Others are dangerous revivals of paradigms of the past, like the bio-psycho-social approach to mental

health. During the Nazi period, Jews, homosexuals, and all sort of socially unwanted, were diagnosed by psychiatrists as biologically corrupt, psychologically unfit, and socially dangerous. Call it *mental hygiene* or *racial hygiene*; it's the same thing today, because we're witnessing a fusion of the medical, psychological, and social sciences under the umbrella of mental health's bio-psychiatry. As Albert Einstein wisely warned: "Two things are infinite: the universe and human stupidity; and I'm not sure about the universe." How come we are so gullible as to blindly swallow all this scientific nonsense?



The Quest for Moral Justifications

Thomas Szasz marvellously puts it, in his book *The Theology of Medicine*: "In everyday life, the distinction between explanation and justification is often blurred... It is often difficult to know what one should do, what is a valid justification for engaging in a particular action. One of the best ways of resolving such uncertainty is to justify a particular course of action by claiming to explain it."

A bare description of mental health interventions does not sound very appealing, (hence) the mental health profession seeks new names and theories to describe the same cruel interventions. It's not dignified to admit to restraining a young, defenceless woman, and then electrocuting her brain. It is easier to boast of carrying out a medical therapeutic intervention on her sick mind. Yet, crude facts are not altered by the justifications we find for them, especially from the victims' perspective. (However) from the executioner's perspective

¹⁰<http://www.wnusp.org>

¹¹<http://www.camhindia.org>

¹²Tristano recommends - If you want to dig this issue of the mind scientifically- then you should read *The Meaning of Mind*, by Prof. Thomas Szasz, a book that, I warn you, will radically change your vision of mental health!

the linguistic manoeuvre provides a solid moral alibi for justifying what is otherwise plainly a cruel act.

The Catholic Church used to burn people at the stake with the justification of salvation of the soul of people who went astray, heretics. (This) religious blind faith allows a fantastic explanation to blind someone to what the Inquisition was doing to people. Similarly, blind faith in mystical medicine blinds you to what most psychiatric interventions are — cruel measures of physical, chemical and environmental control of today's heretics - homosexuals, drug consumers, etc.

There is no equivalence between mind and brain, or soul and heart. Those who think that they can pinpoint the mind by medicine are fooling themselves; there is no mind, only the person¹³. What you claim to do in the name of medicine to patients' minds, can't justify your failure to see what you are doing *as individuals* to other *individuals*. Doctors curing patients is just a jargon translation — a manoeuvre — of the fact that you are *people* depriving liberty of other *people* who have not committed crimes. End of story!

The first person experience of their actions is not affected by theoretical paradigmatic shifts. Being imprisoned and restrained in a psychiatric institution today has the same flavour as it had in the first mad asylums in the past. We can't accept any apology claiming that tortures have become less bloody, and asylums more habitable (which is, by the way, false). It's not a matter of quantity or quality, it's a matter of principle, just like the Holocaust is not merely a matter of numbers. Being electro-shocked or stunned by drugs in the name of bio-psychiatry, the Sacred Roman Inquisition, or whatever, is after all

one and the same experience all along history....



Mental Illness: A Myth Without a Sanity Model

Mental illness does not exist! While psychiatric diagnosis are growing in an exponential fashion, no reference is made to any model of sanity against which mental "diseases" can be measured, other than the whims of task forces who *vote* on the diagnostic criteria. There are no biological tests to diagnose mental illness, it's all based on interviews or third party accounts.

What is the model of mental sanity today? Is it still, like in the Nazi period, being heterosexual, white, Aryan, productive, and devoted to the regime? Or has it changed? Sincerely, I'm asking you. At this moment thousands of political dissidents are locked up in psychiatric institutions in China and many others all over the world. Nuremberg trials failed to discontinue the psychiatric practice of labelling dissident thinkers as sick, deporting them into institutions, and forcibly treating them.



Heresy: Choosing For Ourselves

The diagnostic labels might have changed, yet the underlying paradigm remains the same: if you don't comply with the system you are guilty of heresy.

I think the intimate relations that interweave the underlying concepts of heresy and mental illness can hardly be overstressed —if heresy implies choice, and the inquisition was denial of that choice, then psychiatry stands to mental illness as the inquisition stood to heresy. Psychiatric labels are *ipso facto* stigmatizing procedures, they are intentionally meaningless

misnomers, not intended to *communicate* anything, and their only scope is to *excommunicate* unwanted people.

Our society seems unwilling to take the responsibilities that ensue from freedom. It's easier to wash our hands of all responsibility and handle embarrassing choices by removing the arena of confrontation and calling into account mysterious diseases that require holy psychiatric interventions. So, whenever in the USA a white American citizen shoots Mr. President, it has to be a madman. It is unacceptable to public opinion that the American society can fail to instil patriotic values into its children. But if an Arab shoots Mr. President, things are quite easier to handle, there is no need of psychiatric jargon to handle the situation: the jargon of the war against 'religious fanatics' is well established.

Choice and heresy are intimately connected to present-day mental health system. People like me have made the choice of being heretics and dissidents all the way. I owe to Thomas Szasz the great pleasure of having discovered the true meaning of freedom: through his writings, I discovered inner freedom while I was a psychiatric prisoner. No matter how unpleasant my journey into madness and psychiatry has been, I can proudly say to have discovered the true force of heresy: that unrestrained force of change that challenges the commonplace in the name of Man and freedom.

I want to thank with all my heart Dr. Giorgio Antonucci, one of the greatest heretics of our times: a physician and psychoanalyst who challenged psychiatric slavery at its roots. Giorgio has dismantled several Italian asylums, setting free people who were restrained to beds since 20 years! People who had their front teeth removed

because they refused to eat, in order to die, and were fed forcibly, people on whom psychiatrists applied a muzzle to their mouth so that they won't spit on their jailers. (He is) also an Honorary Member of OISM and both a frontline activist and intellectual dissident. He's been persecuted by Italian psychiatry and institutions; they slandered him and even took him to court. But he never gave up. He's a living example to the Italian survivors, and he never denied us support. His heart is as noble and courageous as that of a lion, and he's a very sweet man too. I thank him for all the support he gives me and for the patience he bears with me, for I acknowledge that I've a rather bad temper.

Many survivors and dissident thinkers unite under the umbrella of heresy. Ours is not an elite club based on accumulation of credits for what you do. It's about *being* what one believes one ought to be. I'm not here to get a certificate of attendance. I'm here because I am what I am, and I want to share it with you. We heretics don't think in terms of social status or academic credentials, we value human qualities most of all. And most of us are economically poor people, and we feel really bad when we're censored and set aside, because we don't have equal opportunities, many of us have been rendered destitute by psychiatric interventions and stigma!

I hope this digression helps you grasp the spirit that animates many survivors who attack psychiatry. Understanding others is a great accomplishment, and psychiatric survivors are mainly people who are very rich inside, and they represent the civilizing force of present day heresy.

Let's go back to the issue of diagnoses being a paternalistic counteroffensive to freedom of choice.

❖
**Choice and
 Psychorehabilitation**

Choice was a central pivot of psychological interventions: the therapist sought means of expanding clients' choices, to overcome the conditions that caused suffering, or what the *client* defined as 'cause of suffering.' Now, psychologists have compromised with the medical model. They accept forcibly hospitalized patients who are denied the basic choice of therapeutic contract: i.e., consent to enter therapy. The general attitude in psycho rehab programs is that if the patient is consentient that is better, if not ... well, never mind. Psychiatric drugs are given for granted as part of the therapy. There is no longer enthusiasm in the psychological profession, there is no more life to it.

Coercion is the denial of individual choice. Freedom isn't really freedom if the individual doesn't own himself and doesn't enjoy the right to choose, *by himself for himself*. Freedom of choice implies that some people might make choices we might disapprove of, like suicide or drugs consumption, and so on. I understand the urge people feel to intervene in such choices, especially when they are carried out by beloved ones, but we need to understand that our duty and responsibility to help others exhausts itself with the simple act of offering and rendering available this help, or else we'll keep falling in the paternalistic trap of justifying coercion and stigma.

Beware- I'm not saying this out of theoretical conjectures! My mother took the emergency exit of fatal freedom, after a lifetime of psychiatric tortures. Of course I miss her very much, and I wish she was here. But I can't condemn her choice. This world is going nuts; violence, racism and social indifference are the norm. How can

we blame intelligent people who decide that living is not worth the pain it demands?

❖
**The foundation of our
 arguments is the issue of
 freedom**

Any "scientific" discussion that does not drag into the discussion arena the underlying ideological and operative paradigm, is nothing less than an escape from responsibility.

I'm sure my intervention can be easily dismissed since freedom and politics should not be part of a medical congress agenda, unless it's a conference on ethics. The point is that when medicine (or psychology) deprive people of freedom and consent to treatment, liberty becomes an issue to be faced.

I can't think of any genuine way of dealing with it other than taking it as a political issue. If you recognize us as human being, and not patients, then you'll have to recognize that we should enjoy inalienable human rights. Yet, psychiatric alienation disrupts these rights and calls for a mandate that overlooks them. This is precisely what makes psychiatrists alienists and us aliens.

The global effort to establish special rights for the 'mentally ill' is an attempt to officialize deprivation of human rights for a subclass of outcasts. The IAAPA has launched a campaign entitled *because human rights are indivisible*. There is no medical condition - true or false - that can justify the implementation of different criteria in human rights for any individual.

Conclusion

To conclude, I invite you to consider that the urge, which many people feel, to treat the alleged mentally sick is not really a primary question in this world, as it is claimed. I'm

not saying that helping suffering people is not an issue. Of course it is! What I'm saying is that I firmly believe that 'hearing inexistent voices' or 'seeing inexistent things' is not as grave as not being able to see what is in front of our eyes, or not being honest enough to listen full length to the voice of those who suffered under psychiatry.

If our intellectuals and scientists fail to see this, we'll be doomed to witness once more the historical horrors of the holocaust, mass sterilizations, and silent genocides in the name of medicine.

Please take in serious consideration this appeal of mine to stop and rethink over your mission of psychosocial rehabilitation. Don't value medicine above freedom, don't value your profession above your humanity.

I'd like to finish my discourse by wholeheartedly thanking Dr. Tibaldi, my psychiatrist, who never ceased supporting me, despite my terrible character and bad temper, and believed in me as a *person* when even my closest friends abandoned me to my psychiatric destiny.

As a closing statement, I'll offer you a quotation from Yevgeny Zamyatin:

"The world is kept alive only by heretics ... Our symbol of faith is heresy: tomorrow is inevitably heresy to today ... Yesterday, there was a tsar, and there were slaves; today there is no tsar, but the slaves remain; tomorrow there will be only tsars. We march in the name of tomorrow's free man — the royal man. We have lived through the epoch of suppression of the masses; we are living in an epoch of suppression of the individual in the name of the masses; tomorrow will bring the liberation of the individual — in the name of man. ... The only weapon worthy of man — of tomorrow's man — is the word.



Empowerment approach to Recovery

By Judi Chamberlin¹

Judi Chamberlin talked about the user / survivor movement's profound belief that mental illness is a social, economic and political problem. She contrasted the "recovery" model, which evolved out of user / survivor thinking, with the "rehabilitation" model. "Rehabilitation" originated within a professional context. It is seen as a different form of treatment model, but a treatment model, nonetheless. In this model, and what it has become the world over, there is little questioning of the existing power relationships.

Recovery models on the other hand give the users choice, and support those choices. These models tend to be in alignment with the user's social and cultural context. This model clearly exhibits a move from a top down approach to a non-hierarchical approach. The rehabilitation language must be recast in the language of "recovery".

The user / survivor movement is skeptical of the concept of "rehabilitation". What do we need to be rehabilitated from? Who decides that a person needs rehabilitation? There is a missionary flavour to rehabilitation, which is being contested by the user / survivors.

The rehabilitation language is said to bring within its purview, all the "stakeholders"- service providers, families, other statutory systems *as well as* the users. However, users are not just "one of the stakeholders", but rather the focus of the mental health system. All others play a third party role with respect to the mental health system. If we forget who the system was created for, or the fact that the total impact of the system

falls squarely upon the user / survivors, we will also forget the necessity for individual choice in recovery.

"Recovery" is not "treatment", or coming out of the "illness", but rather the redefinition of social relationships and roles, the rebuilding of lives. Recovery is about "life". This perspective calls for a fundamental shift in values and practices. It must be emphasized that "recovery" originated from within the user / survivor movement. "Recovery" is not a practice, rather it is a philosophy and an orientation.

The "recovery" model challenges established ways of doing things. In planning "recovery", the person plays the central and directional role. Recovery is self defined and self directed. Recovery connects people back to their dreams again. The role of the professionals is only to facilitate this journey of the self. The 1st step the professional will take is to connect people back to their dreams. Instead of being focused on "activity" and "production", the recovery model builds the spiritual core of the people, bringing about possibilities of hope, happiness and thoughts about the future. Being self directed also involves having the necessary information on hand to make reasonable choices.

A consensus statement on the "Recovery" model has been recently adopted in the US by the statutory authorities, showing the influence of the user movement on policy making. The basic principles enlisted herein are as follows, providing the guidelines for interventions:

1) Self-directed

- ◆ Client sets the goals
- ◆ Responsibility to provide full information
- ◆ Connecting people to their own lives and dreams

2) Person – centered or individualized

- ◆ Appreciative of self responsibility
- ◆ Building on hope
- ◆ Innovation and creativity in program development

3. Empowerment based

- ◆ Working towards systemic change
- ◆ Enabling the client to be at the center of her own life and choices

4. Holistic

- ◆ Addressing the whole person
- ◆ Addressing real life needs

5. Non-linear

- ◆ Pacing with the individual through recovery (temporality)
- ◆ Enabling client to define her own “progress”

6. Strengths based

- ◆ Based on what the person can do rather than on what she cannot

7. Peer support

- ◆ Seeing the user as not just needing help, but also able to share experiences and learnings
- ◆ the value of lived experience in program development and clinical thinking

8. Respect

- ◆ Users as citizens
- ◆ Recognition and making pathways to ensure and protect human rights

- ◆ Individuals as agentive in their own lives and choices
- ◆ Addressing issues of stigma and discrimination

A recovery program would appreciate the fact that people are responsible for their own lives, decisions and risk taking². Professionals must take a supportive and facilitatory role in assisting the individual to make choices. The recovery model shifts power relationships, from one of control to one of collaboration. People may need necessary assistance in even learning how to make decisions. “Learned helplessness” is a real and debilitating problem. The response to this disability is to not make those decisions oneself, but rather to have a keen and tight practical definition of “*necessary assistance*”. Knowing when to step in and when to step out is always a difficult process. There are everyday learnings here for the caring professional from every user. The professional must work on the basis of the belief that tomorrow will be different from today, or the same, for this user, depending on her choice for that day. Users are always highly appreciative of that “someone who believed in me, even when I did not believe in myself”. The peer support model, developed by user / survivors in many parts of the world, is a useful model to demonstrate the validity and usefulness of these recovery principles.

To sum up, “recovery” is more than just a new word or a new paradigm shift. The notion conveys the collective power of the user / survivor movement. The recovery philosophy shows that users are active agents of change, rather than passive recipients of services. Not only their change process is effective internally, but also at the systemic level. Therefore recovery is charged with political content for

the user / survivor movement around the world. The user / survivors are in a position to give to the world, and to healing systems, from their visions, insights and experiences. This view of political action, community, self and the world, does not allow for any coercion whatsoever. She was not against anyone choosing the medical model, but would be concerned about the quality of “choice” involved in many conventional treatments.

Judi Chamberlin finished with the user / survivor slogan of “Nothing about us without us!!”

¹Judi Chamberlin, a user / survivor leader with many years of dogged work against psychiatric abuse, is presently Director, National Empowerment Center, a user led mental health service, based on empowerment principles (www.power2u.org) This is an abstract of her key note address at the WAPR, 2006, developed by Bhargavi Davar.

²An interesting discussion ensued on responsibility with an intervention by Tristano Ajmone (cf. this aaina issue), who believes strongly in the freedom to choose death. Judi, in sharing her own experiences, talked about being intuitively tuned to what your friend (who is at the point of choosing death) is about, and whether this is a real choice. She was of the belief that it is possible to accept the choice of death, but we must also be mindful when other kinds of expressions of a person may be misconstrued as choice. We live in an interdependent world, and constantly influence and impact each others’ choices. To treat this interdependence in the context of the choice to die in a responsible manner is the challenge.



On voluntarism: learning from pre-modern institutions of care¹

■ **By Bhargavi Davar**

I want to describe to you a healing experience my research team witnessed during one of our studies in Maharashtra, conducted at a traditional healing center (a dargah).

“On day 1, we heard a girl screaming at the top of her voice. She was sitting outside a hut built on the edge of the hill. She had wild open hair. She seemed to be around 16 years of age. From what we could make out, she looked extremely excitable, violent and uncontrollable, an “unmanageable patient” in modern psychiatric description. This would be considered as a psychiatric emergency.

“On the next day’s visit, we encountered her on our way down from the hill. She was sitting outside the hut, tied to a huge boulder. She was dressed in rags and her hair was loose. She was in a completely manic condition. She was singing and shouting. She asked us to remove her chains and in the same breath turned loose a volley of abuses on us, most of which we thankfully did not understand. She was extremely furious: we thought.

“The next day, she was lying on the floor of shrine, her foot chained to the railing. She was shouting and singing loudly again. As soon as she saw us, she became excited and started screaming out abuses at us all over again.

“The next day, we saw her mother bring her to the shrine holding her chain tightly. She was walking around the shrine touching its outside walls. She looked better. Her hair was combed and tied. She had stopped shouting and singing. However, she was still excited, talking and laughing to herself. In the



afternoon we saw her sitting quietly in a corner eating her food.

“When we went the next time (some 4 or 5 days later), she was unrecognizable. She was carrying something in her hands to the main shrine. Her hair was combed neatly, her face was clean, her expression serious, her clothes clean and neatly worn, her feet in slippers. We came face to face with her but there was no recognition in her eyes.”

Had she been “cured” of whatever she was afflicted with? We had no answer, but she did not seem anymore like a “violent, unmanageable patient”.

I propose that the cultural healing places, such as the one I have just described, are “therapeutic communities”. These places nurture people in their existential quest for emotional and spiritual growth. The Indian law (The Mental Health Act of 1987) allows only mental hospitals to be const-ructed. Recent judgements by the Supreme Court

also order the construction of more mental hospitals. The mental health professionals, policy makers and legal officers are presently debating whether the traditional healing centers, which are non-medical and recovery oriented, should be shut down, and the persons who are suffering from psycho-social disabilities, such as the girl above, should be sent to the mental hospitals.

Why do we want to shut down the traditional healing centers and start more mental hospitals? Is there any benefit of doing this for persons with psychosocial disabilities? Mental hospitals in India, which are seen as “modern”, reduce people to a vegetative state, keeping them over drugged, cutting them off from family and society, and killing all their natural creativity and will for life. “Stigma” of “mentally ill patients” is created by these institutions. People shut away in these institutions are seen as “incapable”, soon becoming deskilled and dropping out of life, all their civil, political and socio-economic rights being taken away from them.

Whereas a rather large class of pre-modern institutions exist, which address the health and well being needs of the people that they are serving. These institutions have their spaces and philosophies organized around *experiences* of illness, recovery and personal growth, and not “mental illness”. People who come there are not labeled with “mental illness”, though many bring emotional and other difficulties. Inbuilt into the value system of such centers is a respect for each person’s capacity, as a person is fully involved in their own recovery process in many ways, importantly through the performance of ritual.

Most important of all, the centers value voluntarism and choice, unlike what is permissible under the Mental Health Act.

Each center has its own philosophy, but some common themes related to personal recovery are: linkage to life, community, nature, to other human beings, to their own self expression and to the cosmos / some transcendental dimension. In these institutions, health is spirituality, and spirituality, health. Health is mind / spirit / body, altogether. There is no “mental” separately from the bodily and the cosmological.

It was amazing for us to see the number of institutions and the number of people who exist, who are struggling with the personal, and inter-personal, philosophical and existential questions of life and are seeking, if not finding, answers through these centers. They are not seen as “incapable” people. The center acts as a “retreat” for these people to find themselves and move on in their lives.

Compared to the mental hospitals, cultural healing centers are very accessible in all parts of the State to all kinds of people. Further, these are not “paid” services in the sense of the free market. Here, pre-capitalistic economies work, leaving much economic decision on the individuals using the centers. Each center is known for its powers to cure something specific: e.g. distress caused by infertility or alcohol addiction.

The principles of architecture of most of these local healing centers deserve to be copied by the “modern” mental health care system. The mental hospitals, being an involuntary system, typically have barracks, with closed wards. A very small area remains open or accessed by the clients. Family members are not allowed to visit the closed wards or the inner wards, being limited to certain

specified visiting areas. What Michel Foucault had described as the “panoptican” remains in most of the colonial, custodial, penal institutions, including the mental hospitals. This type of architecture is built on a vigilance and policing model of care, whereby the wards, the barracks and the spaces of the institution are organized around a central authority. There would typically be a large building with wards extending from the center outwards, as wings, with security systems to be managed from the center. Peripheral grounds would house the less core facilities, such as the rehabilitation ward or the recreation room. Common areas would be restricted to inmates and the time of lock up would rarely allow for free movement. High walls, gates and other security measures such as steel grids, locks, wires other than measures for personal restraint, such as cage like cells for seclusion / solitary confinement, are commonly found. Restricted flow of air and ventilation would be ensured by the small or highly secure windows, making the rooms dinghy and damp. Spaces are not personalized, as everyone is herded together from one ward to another for pre-defined purposes (e.g. dining). Spaces are defined functionally with respect to what activity or treatment will happen where, rather than around the lives and routines of clients. Due to this, personal lives are not individualized but rather regimented. There are often no redeeming sensory features in these institutions, and clients are routinely exposed to bare walls, iron grills, and a colourless life within the wards. To go and visit the garden, see the sky or experience the sunlight is an “outing” for the clients- a part of the structure of daily or weekly activities, if at all, and not a part of life. The doctor’s / service providers’ areas and the client areas are highly bounded and separated. Spaces are organized in such a way to reflect the hierarchy between doctors and clients.

Spaces are also organized in such a way that the clients will not Escape, Die or commit Suicide, a typical pattern of behaviour that we have called the “EDS syndrome” in our other work.

In complete contrast to this, we have found the local healing centers to be community spaces, open and airy. Of course we did not see high walls, wires, grills, and locks anywhere!! There were no solitary cells anywhere. Shock treatments and solitary confinement are for me still the most barbaric of all possible treatments that I have seen anywhere, and we have studied at least 20 traditional healing centers in great detail. People come and go as they please, and they choose where they want to go. This in itself is the evidence of the voluntary nature of these institutions.

The entry into a mental hospital, unlike a local healing center, is violative of human dignity. The family often commits fraud and brings the client per force. The admission procedure is corrupt, as the officials can be bribed into making wrongful admissions. The risk of “dangerousness” is usually more imputed than real, as there is naiveté and bias regarding risk assessment.

In the mental hospitals, people can be shut away for days, weeks, even months together, in solitary confinement or kept in physical restraint until they are dubbed “beyond recovery”. They become the invisible population, the people that visitors are not allowed to see, people occupying the darkest parts of even the most sparkling mental hospitals in India. These people are branded “violent” and “dangerous” and run the high risk of repeated punishments for their imputed reactivity by the mental health care system. Other than the label of mental illness, they also have to carry the label of being socio-paths. Staffers shun them, and violate their human rights (e.g. beatings and

withdrawal of benefits). They do not see other people, the sunlight, or the world outside. They have no access to toilets and have to live in their own waste. The staffers very rarely visit these people, and exhibit fear and anxiety, or worse, anger and brutality, in the face of the patient's violence. The staffers are not relaxed people at all. They are taught to protect themselves from the patient's real or imputed violence. They are taught simple tricks to protect themselves from the violence: stay near the door way, do not make eye contact, do not touch, keep your back to the wall, keep distance, etc. etc. Such lessons are indicators of the overall anxiety about violence in institutions, and shows up the staffers as powerless and fearful people. Therefore, the healing model slips into the punishment model, as the problem is seen to be within the patients, and somehow it must be controlled by the weaker staffers. This fearful attitude actually diminishes the patient even further, making him or her feel beastly.

In the local healing sites, people who were seen as violent and dangerous, such as the girl described above, were out there in the open, in front of everybody, posing a moral question to the community all the time. They were tied to a tree or a stairway, but they maintained their interactions with the community. The community was left to deal with the shouts and abuses, the tearing of clothes, etc. The community also had the moral obligation of seeing that such lives are maintained and some personal needs are provided for (including a bit of the sky). They were not forgotten people.

People with a universal human rights perspective may say that tying up the girl with chains around a stair way was a violation. Of course it is. We are not romanticizing the girl's plight at all. I am also aware of the

community dynamics which results in someone being brought to these centers and being tied up.

But if the proposed alternative is that we take her to a mental hospital, that would be a bigger and grosser human rights violation. The local healing centers deal with personal agitation, anger and violence, in gentler and often non-violent ways, finding ways and means of bringing the person back to the community quickly and in a way that does not fully rob the person of dignity, freedom and liberty. Dealing with violence in a ritualized manner, through non-violent and playful means, may be a strategy that mental institutions can learn from these healing centers.

In these centers, violence is dealt with in a ritualized manner, as a part of the Grand Play by the Deity or by Destiny. Ritualised dealing of violence, as happens in these centers, does not objectify the violence as a part of the person. Violence is a part of the overall delusion of existence and attachment to this in a personal way was not necessary. The cosmology of health attributed the people's violence to external causes (e.g. spirit or demon) and so individual labeling or criminalizing did not happen.

The experienced *mujawars* and the healers had sufficient inner stability, skill and confidence in their practice and in their healing traditions, to tame the angry spirits or the demons, and return the person intact and whole to the community. Healers who believe they are protected by the divine are not afraid of human follies. They do not exhibit anger or anxiety or fear when confronted with the violence of the evil spirit.

An angry and evil spirit spelt trouble and destruction for the whole community, not just for the person.

So the community had a stake in the safe return of their relative. They were only too happy to participate in driving out the angry spirit and have their relative back intact. Also, they have faith in the presence of the divine in the *mujawar*. This is evident in the way the *mujawar* reflects off knowledge, confidence and power, instead of fear and anxiety. They remain reassured by the *mujawar's* demeanor. In this sense, any imputed or actual violence happening in the context of suffering is understood as such, as an indicator of external evil forces, and as a community issue, and remedies sought within the healing and ritualized framework, rather than the individualistic punishment framework.

The segregation of users of the services and the families, found in modern institutions, is not found anywhere. People visiting have access to all parts of these centers. There are also no division of spaces between the healers and the users, and their families. Community healing spaces exist where everyone participates equally, although under the directorship of the healer.

There is great attention paid to the celebration of the deity or the saint, which reflects in the architecture. Particularly, the *sufi* shrines are very beautiful structures, full of colour and fine decorative work in vivid and celebratory colours. Visitors are exposed to a variety of sensory inputs in the architecture and in the ritual practices. Spaces are organized in a seamless and negotiable manner, suited to human living, and survival, community negotiations and bonding, and also expression of illness and recovery, rather than being tied to a curative perspective, that in this room or that ward, such and such treatment will happen. The healers do not interfere or intrude upon the non-ritual parts of people's community lives.

One World

"I would rather be tied to a tree, than taken to a mental hospital".

Bhargavi Davar, Survivor, India

"I would rather be physically restrained in a mental hospital, than given anti-psychotic medication".

Mary O'Hagan, Survivor, New Zealand.

WAPR, Athens, October, 2006

The landscape of the place is a part of life and well being for people who are visiting. While an organized "garden" is hard to find in most of these places, nature itself is sanctified and becomes part of ritual life and habitat in many of these centers. The tree is a symbol of stability, hope and vitality in most of these shrines and people connect to this symbol, sometimes, in an intensely personal way. They literally pin their hopes and their pains, sometimes their aggressions, on the trees. The trees have a totem status, physically carrying the dreams and aspirations of thousands of people as well as their suffering. As the tree is witness to the life worlds of millions of people, tens of years before, and will continue to be witness for tens of years after, the tree carries a sense of eternity for the sufferer, beyond individual mortality. These are "healing habitats" for the people residing here, with the intent of recovery and recuperation, and so many natural and other objects in the centers take on the aspect of an icon or an artefact.

The *Balu Mama* sect is an exemplary instance of habitats for healing where nature itself

becomes healing in the forms of the sheep. The highest form of voluntarism for users is found in this sect. The "modern" system restricts the mobility of users, whereas, in this sect, also typical, users' mobility is expanded tremendously. The users, who seek their own recovery, by joining this group of wanderers, wander and journey with sheep, caring for them. It is believed that the sheep have miraculous healing powers. This, to me, is a most beautiful metaphor for personal journeys. "Wandering" is treated derogatorily within the modern psychiatric discourse, even deserving of a label of psycho-pathology (psychosis). This leads to large scale involuntary commitments and forced institutionalizations. However, in this sect, troubled people live in the freedom and space of nature, as wandering pastors, their lives anchored to and their experiences shaped by the lives of the sheep. There is a special value attached to such wandering in this cult, the value of being *free*. Wandering minstrels living on alms alone are found singly or in groups in many of these centers, and the large open spaces available within and surrounding the shrine allow for their stay and transit.

We are not romanticizing poverty or homelessness here, but pointing to the fact that from another kind of imagination, literally, wandering has led to a spiritual re-opening for at least some people.

We also observed that in most of the healing shrines, healing is organized in order to cater to community healing, rather than to individualized healing. Small, clinic type of arrangements is not found. There seems to be an underlying philosophy that "I remain well only if my friends, neighbours and relatives, my ancestors, my extended community, nature, and

god, remains well". Large open spaces were congregations of sufferers and others at the time of the healing sermon or *aarti* and there was space for the expression of appropriate behaviours at this time: celebrations, dancing, trance, drumming, chanting, possession, mediumship, etc. Particularly in Nandre, the healing séance is an intense form of group therapy, even psychodrama, for which space and time have been apportioned and structured in a requisite manner.

There are bystanders, but most if not all, are there with a personal purpose and can feel an engagement with the healing séance. The identities of who is a sufferer and who a family member or care giver, and who is a bystander, becomes merged. The healing spaces are so organized that they do not isolate any person as the "primary client", indexing that person as "mentally ill" and leading to the risks of psychiatric labelling. Everybody involved in the ritual healing assumes a part of the responsibility in the healing. It is allowed in the local healing centers that healing is primarily interactional, (involving the interactions of human and non-human systems), and the working spaces where healing actions take place are organized in congruence with this outlook.

Here, it is necessary to reflect on the ethical principles of "privacy" and "confidentiality" which inspires much healing work. Much of the traditional healing happens in public, before everybody. How to relate to this becomes a dilemma. Is it alright for a healer to ask a woman about her being battered in front of everyone? Does she feel shamed to speak out in public? Does an alcohol addict feel shamed to speak out in public and to be confronted or admonished in public, before strangers, by the healer? We are not clear what the

answers are. We have seen sensitive healers who are careful to address the group as a group, and not let anyone feel threatened, by establishing rapport and a suitably high level of intimacy and safety. There have been others who have been brash with their clients, disturbing *our* comfort levels.

Mental well being is about a person being able to attain complete self

potential through harmony of the mind / body / social environment / spirituality. The values of freedom, liberty and choice are vital for any system of health care to be nourishing. Mental health systems (inclusive of law) should be congruent with these fundamental values. Laws and institutions in India are anti-therapeutic, and are largely based on a penal model of crime and punishment, leading up

to a custodial mentality. The traditional healing centers, what we call “pre-modern” institutions, have much to teach us in this regard, particularly about the type of mental health care programs we want to create in future. Voluntarism, the right of liberty and recognition of the full capacity of persons with psycho-social disabilities, must be at the very basis of such an imagination. 

¹ Key note address, October 13th, World Congress for Psychosocial Rehabilitation, Athens, 12th-15th October, 2006. Bhargavi Davar, Deepra Dandekar, Madhura Lohokare and Deepak Salunke conducted a 3 year research study on “Health and Healing in Western Maharashtra: The role of traditional healing centers in mental health service delivery”, supported by IDPAD / ICSSR, New Delhi. These impressions were shared from the experiences on this project.

 **The Day the Voices Stopped :
A memoir of madness and hope**

By Kenneth Steele and Claire Berman

 **Gitika Talwar**

Ken Steele once said ‘I’m not just managing my illness; I have a real life now’. You can’t help but smile when you read this. Steele’s story is about an elusive concept called recovery. Elusive, not because it is mysterious but because people say they have never seen it; we have images of illness but hardly any of health, and still fewer images of ‘recovery from illness to health.’ We seek to quell symptoms but are blind to the deeper wounds that lie under the surface of illness, taking on a life of their own and preventing people from becoming well enough to lead the lives they choose.

This book is the story of Kenneth Steele’s journey from being a mental health service consumer to becoming a mental health advocate who initiated the Mental Health Voter Empowerment project to register people, who were not registered previously due to their mental illness. His story inspires you and simultaneously makes your eyes well up – with pride, with amazement

and sometimes with sadness over, as he says, “*the opportunities I was robbed of by my voices.*” This book sharpened my awareness of what it means to be wandering, ill, scared and strong all at once. I was most amazed reading about how Kenneth often alternated between being a wandering ill man who used shelters to being an extremely impressive mental health advocate.

This is the first time I read about user-led advocacy, which - to me - is advocacy from the trenches. Kenneth Steele described firsthand not only his descent into madness but also his journey through this darkness, and then his re-entry into the light. The synopsis behind the book says that this story is about ‘...*Steele’s hard-won recovery from schizophrenia and how activism and advocacy helped him regain his sanity.*’ I think this is the most accurate description of the book. As Kenneth learned to fight the voices within, he empowered himself and others to fight the system that left them behind because of their illness. His fight outside fueled the fight within.

This book describes his parallel journeys as a user and a mental health advocate and keeps you in touch with the deeply personal issues and the political issues that make up the mental health system. Kenneth’s story is of a man who endured the kind of mental health system we advocate against, and simultaneously experienced the kind of system we would like to instate. He describes numerous doctors, therapists, nurses who cheered him on as he found himself. He describes tiny ways that he would run into his selfhood, like the time he voluntarily admitted himself into a hospital and was asked to clean himself up. He describes the routine shower and you, as a reader, suddenly realize how he had *exoticised the domestic* (to borrow a phrase from Narrative therapy).

“It felt wonderful to soap myself down, wash my hair by myself, dry myself off...**my self**. Each detail of my grooming – liquid soap, mentholated toothpaste, mint-flavoured mouthwash – was a gift, recognition that I was a human being”.

He describes his warmth towards people who were supportive whenever he needed it. For instance, his last psychiatrist and psychotherapist were people who, according to Kenneth, showed genuine interest in listening to him. When he was given a new drug this time, he was also told (for the first time in his life) – “if you don’t like it, don’t take it.” Kenneth described his amazement and also his willingness to continue the drug when he saw it helping him. His therapy continued alongside and he discussed his advocacy projects with his therapist. This is the period he started the Mental Health Voter Empowerment Project.

He speaks about friends who managed to leave hospitals to live in managed care communities and also spoke of friends who were too afraid to leave the system, because they had grown dependent on the system to monitor their behavior and their needs. Also, they experienced what Kenneth describes as ‘a dread of independence that makes a person return to the perceived safety of the system time and again.’ His experiences with his own voices and how they would jeer him and steadily debilitate his self esteem, alongside his experiences with the mental health system made him more sensitive to what users needed.

He makes it abundantly clear that those involved in mental health work need to take into account that people with illness could understand what was being said about them and that it broke their self esteem when someone declared that they would never get okay. He speaks about himself while saying that he knew he may **never get well**, but he knew he **could get better**. There is a difference between those two levels of being and it meant a lot to him to know that even if he always heard the voices in his head, he could reach the stage of fighting those voices and rebelling against them. His faith in getting better egged him

on, just as it egged on the people who turned to him for advice after reading or hearing his interviews about surviving schizophrenia. Giving interviews was a conscious decision he took in order to provide a face to the work he wanted to do as a mental health advocate.

His political awakening came when he realized that many people were demanding that there needed to be a reduction in the amount of money the government spent on welfare schemes for people with illness. Kenneth felt that the consequences of such cutbacks could include landing many people in jail or on the streets. Then he heard Mario Cuomo, the Senator of New York announce his support for community mental health services and also heard him announce that though this support was the most compassionate thing to do it was not a smart political act because people who supported his act did not vote. When the Senator lost, Kenneth describes his anger at the fact that the group the Senator had supported was not in a position to reward his courage with the votes he deserved. This anger was the genesis for the Mental Health Voter Empowerment Project

Becoming a mental health advocate put him in a position to answer questions of users, carers, service providers and, in some cosmic sense, make up for the answers most people did not have when he was ill. Answering questions was sometimes accompanied by a sense of loss over what he did not get because people did not know what he needed. He mentions this at one point,

“If my parents had stayed by my side from early on, if they’d supported me, who knows what a different course my illness might have taken. I wish someone in authority had given them the advice I now offer to parents of young people with mental illness—parents who are concerned because their sons and daughters are

isolating themselves, behaving erratically, not taking their medication, or are hospitalized. I tell them to continue to offer support, to let their children know they are there for them, but to take care of themselves as well. I also advise them (whenever possible) to share the care, to involve other family members in helping the sick person, so that they don’t burn out”.

As a service provider, I often face dilemmas about the best course of action with clients who ‘resist treatment’, I wonder whether it is ethical to let someone live with hallucinatory voices when I know there is another way of being. Kenneth seemed to speak to me when he responded to a psychiatrist who asked him what to do about patients who denied being ill and refused medication. This is what Kenneth said,

“This is the question I’m asked most often by doctors and it’s the hardest to answer because it deals with relationships and attitudes. Mental health professionals need to view the patient as a part of the treatment process, not the patient as the object of the process. A patient who trusts a doctor, and who is trusted, is more likely to comply with a proposed plan of treatment. But I understand your frustration as a physician. Sometimes the patient has to sink to the bottom before he decides that he does not want to drown and reaches for a lifeline. I hope you’ll be there for him then.”

When I read this passage, I was moved not only by Kenneth’s empathy for the person who posed the question but also by what he was saying on behalf of many users, that we need to be participants in the process and not passive recipients of it.

This book is filled with many such moments. I hope you will read it and you too will find the answers you are looking for.



How to tell your lover you have schizophrenia

■ **Bonnie Chernin**

Your lover confides in you how much he respects your stability, unlike his mother, his sister, and his sister-in-law, who have a tendency to overreact to the slightest inconvenience. You wonder if your lover is about to do some overreacting himself. Expect it. You think about what words to use. You imagine the direct approach. "Honey, I have schizophrenia." You hear the word. It sounds clinical, and you like the matter-of-factness. But then you remember its misconceptions: split personality, dangerous, chronically dysfunctional. You have a connected self, you wouldn't step on an ant let alone assault someone, and hold down a full-time job, rent your own apartment, and have paid off your car.

You rethink this scene. "Honey, you know, I've been psychotic." You like the truth behind this statement, a state of mind that reflects the confusion you had felt. Like the time you believed the "exit" sign was not a direction showing the way out, but a command for you to leave. Immediately.

You remember the time you said the word "psychotic" to a friend. The friend had looked scared. You decide to find another expression, something less threatening.

"Darling," you picture yourself saying, "I've been sick." You use the term 'sick' when you don't want anyone to know what you are talking about. Like when people ask why it took you eight years to finish college. A euphemism, something to say when you want to hide. But this is your lover. You want to be open. So you search for something else. "Dear," you envision again, "I'm mentally ill." You wonder about that. Because sometimes you are mentally well, like say, for the last six years. Consider qualifying it by

adding, "occasionally I was mentally ill." You realize that this applies to the entire human race.

Immediately dismiss the o-words: psycho, schizo, wacko, loco, that automatically discount you or anyone else human. Wonder about the colloquial idioms: freaked out, over the edge, breaking down. You feel attracted to them because they convey a temporary lapse, something to return from, which is true for you. Come to understand that these are casual blue jean words - washed and worn everyday and applied to anything from a broken fingernail to a drug overdose. Ignore silly slang, bonkers and crackpot, as well as food imagery- crackers, nuts, and bananas.

You consider explaining: "There was a time when I was out of my mind. I sat on the floor of my kitchen for an hour and did not know where I was, did not know who I was, did not feel myself in my body." Recognize that as much as you wanted to be out of your mind, you were hopelessly within it at all times.

Then, you think, "that sounds abstract" and figure he'll want something concrete. So get specific. "Sweetheart, I've been paranoid, grandiose, and deluded sometimes all at once. I believed my father wanted to kill me with his special chicken recipe, special for its secret poison that could murder me only but not the rest of the family who ate it. I thought Reagan was elected in 1980 because I was in the hospital and could not vote against him, and if only I could have cast my ballot, the whole course of American history would have changed. I thought if I read the obituaries at night I would understand what was in store for the new babies born the next day, new

lives to take up where the old ones departed."

Feel surprised by how these beliefs once felt like reality bound around your arms like Teflon, and now seem distant, old dreams that have lost their powerful hold? Despair of the English language, encumbered with history, loaded with preconceptions, to express meaning for you. You try other tongues and discover words like meshugana, loca, folle, sumashedshaya, bezumtsa, wariatka. You like the sound of them, but you know they're lacking too. Make your own words, biotwist, whirrwind. Realize one word cannot say it all. You need to tell your story. However, you want to tell it in pieces, slowly, over time, all at once in a marathon sitting with gaps, with telling by those who cared for you. Discern that your one story is one part. You will need many people telling many stories to banish the myths starting now to fade. Look at your lover. Remember what is between you. Remember who you are, how far you've come to arrive at this moment. Here, out of this place, Speak.

From **NEW YORK CITYVOICES**,
January-March 2001



Please record our change of address:

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Mental Health**

Survey no. 50,
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What does the Convention on Rights of Persons with Disabilities Promise to Persons with Psychosocial Disability?

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Introduction

The progress of deliberations on the United Nations Convention on Rights of Persons with Disabilities (hereinafter CRPD) has been regularly reported in the earlier issues of *Aaina*. In the eighth meeting of the Ad Hoc Committee from 14th to 25th August 2006, the Committee agreed upon the basic text of the Convention, and constituted an open-ended Drafting Committee to undertake a linguistic clean up of the text. The Drafting Committee has completed its task and the draft text along with the six other language versions shall be formally approved by the Ad Hoc Committee in its meeting scheduled for 5th December 2006. The Committee shall then refer the Convention text to the General Assembly for formal adoption. It is reported that the Convention should be considered by the General Assembly in its session scheduled in the middle of December. After its adoption by the General Assembly, the Convention shall be available for signature and ratification. The present Convention shall enter into force on the thirtieth day after the deposit of the twentieth instrument of ratification or accession.

In the wake of these developments, which show that the adoption of the Convention is imminent, it seems appropriate to analyse the text as finally settled. Space constraints may render a comprehensive analysis of the Convention impractical. Therefore this article only assesses what the Convention promises to persons with Psychosocial Disabilities. To that end, this article examines how the Convention addresses the issues of discrimination, legal capacity and deprivation of liberty.

The Issue of Discrimination

Persons with psychosocial disability have an every day experience of discrimination. This discrimination is all pervasive as it finds place in both law and practice. The manner in which the Convention deals with the fact of discrimination is thus of signal importance. Non Discrimination is the overarching motif of the Convention. It finds mention in both the preamble and in substantive articles. And most importantly for persons with psychosocial disability, discriminatory practices against them, can no longer be justified by contending that they are sanctioned by law. Insofar as a General Obligation is placed on States to “take all appropriate measures, including legislation, to modify or abolish existing laws, regulations, customs and practices that constitute discrimination against persons with disabilities”. The duty of ensuring non-discrimination has not been confined to actions undertaken by the State Party itself but it is also required to “take all appropriate measures to eliminate discrimination on the basis of disability by any person, organization or private enterprise”.

That these exclusions stem from prejudicial attitudes is an oft stated proposition for persons with disabilities generally and more particularly for persons with psychosocial disabilities. The attitudinal basis of this exclusion is underscored by the fact that awareness raising has been undertaken as a specific strategy of intervention. In furtherance of this duty, article 8 requires State Parties to adopt a range of awareness raising measures which amongst other things shall “combat stereotypes, prejudices and harmful practices relating to persons with disabilities”.

This commitment to non-discrimination is carried further by article 5 where States recognize that all persons are equal before and under the law and are entitled without any discrimination to the equal protection and equal benefit of the law. This article places a duty on States to both prohibit discrimination on the basis of disability and to provide equal and effective legal protection against discrimination.

In order to ensure that the right to equality does not result in the same being provided, where different is required, Article 5 (3) obligates States to ensure that reasonable accommodation is provided. Reasonable accommodation allows for “necessary and appropriate modification and adjustments where needed in a particular case” to “ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms”. However such modification can be sought provided it does not impose “a disproportionate or undue burden”. The principle of reasonable accommodation has largely been utilized to modify physical infrastructure to make it disability friendly. For persons with psychosocial disability it is important that the concept be used equally effectively to alter normative structures of rules and regulations. The CRPD opens up opportunities to this end insofar as the principle of reasonable accommodation can be used by all persons with disabilities.

Legal Capacity

The right to be recognized as a person before the law, with the capacity to act on the basis of one’s own will and preferences, are integral components of legal capacity. Such

capacity has almost routinely been denied to person with psychosocial disabilities. How a Rights based Convention deals with this issue thus critically determines whether there is real intention to use the rights rhetoric to alter the reality for persons with disabilities.

Beginning from the evocative part of the preamble, it is important to note that paragraph (n) recognises “the importance for persons with disabilities of their individual autonomy and independence, including the freedom to make their own choices”. And the fact that some persons with disabilities may need high support in no way detracts from their human rights claims. In fact paragraph (j) *recognizes* “the need to promote and protect the human rights of all persons with disabilities, including those who require more intensive support”. These commitments of the preamble find reiteration in the General Principles.

It is important that whilst the preamble in clause (f) recognizes the importance of the World Programme of Action concerning Disabled Persons and in the Standard Rules on the Equalization of Opportunities for Persons with Disabilities no mention is made of the Declaration on the Rights of Mentally Retarded Persons; Declaration on the Rights of Disabled Persons and Principles for the Protection of Persons with Mental Illness and Improvement of Mental Health Care. These documents have a strong streak of paternalism in them. Their omission from the text of the Preamble signals that the International Body is not reiterating support for the principles voiced in those documents; an omission which assumes significance in the wake of the fact that some members of civil society trenchantly critiqued some of these texts and strongly opposed any reference to them. This deduction is further strengthened by the fact that in contrast to the CRPD the Convention on the Rights of the Child expressly mentions the Geneva

Declaration of the Rights of the Child 1924 and the Declaration of the Rights of the Child 1959.

It is in the background of these pre-ambular provisions and the right to equality mentioned above that article 12 dealing with Equal Recognition before the Law needs to be read and understood. Paragraph (1) of the Article reaffirms that persons with disabilities have the right to recognition everywhere, as persons before the law. The second paragraph requires states to recognize that persons with disabilities shall enjoy legal capacity on an equal basis with others in all aspects of life. As has been reported in earlier contributions on the Convention, the fact of seeking support has not been viewed as derogating from legal capacity. Consequently paragraph (3) requires States to take “all appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity”.

One of the major controversies in the Convention has revolved around the nature of support and the safeguards required to prevent its abuse. Whilst the need for safeguards has been more universally accepted, the nature of support has been more contentious. A number of States and members of civil society have insisted that whilst the support should be tailored to the requirements of each person with disability, it should in no case displace the will and preferences of persons with disability. Thus the safeguards against conflict of interest, undue influence and coercion should be observed even when the high support needs of persons with disabilities are being met. As the support is an aid which facilitates the exercise of capacity by persons with disabilities unnecessary formality should not be introduced. In line with this positive perspective, an insistence that the support should continue for the shortest time possible, would not be

appropriate. The proponents of the supported decision-making wanted this model to displace the substituted decision-making or guardianship paradigm. They contended that the supported decision-making model was flexible enough to include within itself the needs of persons with high support needs. Hence substituted decision-making, premised on the incapacity of persons with disabilities, should not be endorsed by the Convention.

Even as the need to change the paradigm of discourse was accepted, a number of States stressed that it would be sometime before guardianship could be phased out. In such a situation it was necessary that the Convention should introduce explicit safeguards against the abuse of guardianship. They were not convinced that article 16 which deals with freedom from exploitation, violence and abuse could sufficiently address the abuse of guardianship power. In the wake of this divided house, a periscope like text was introduced in paragraph (4).

Insofar as the Convention has not expressly prohibited guardianship, and there are a number of phrases which seem to recognise guardianship, it is possible to read article 12 in a conservative or radical manner. If a conservative interpretation is adopted, it could well be said that the Convention would be the victim of the very prejudice it has resolved to combat.

This prejudice has also found voice in article 12 (2) by the incorporation of a footnote which states that in Arabic, Chinese and Russian, the term “legal capacity” refers to “legal capacity for rights”, rather than “legal capacity to act”. The footnote has been strongly criticised and may well be deleted before the Convention is finally adopted. However, even if the footnote were to stay, it cannot alter the substantive recognition of full legal capacity incorporated in the text of the main article. Further human rights being universal and

indivisible, it is not possible for any country or region, to ask for differential standards to be adopted. A country can make a reservation in the application of a specific norm of international law to itself. However this reservation is particular to that country and can be withdrawn by the country, whenever it believes it is ready to adopt the international norm. As the footnote seems to be making a substantive reservation in the guise of making a linguistic point the legal validity of the footnote is highly questionable.

Other than the abovementioned contention of reinforcing stereotypes, the conservative interpretation is also questionable because it undermines a number of other substantive rights guaranteed by the Convention. The recognition of full legal capacity of all persons with disability is thus mandated by the demands of equality and non discrimination. It is also the basis of the right to education, which speaks of “the development by persons with disabilities of their personality, talents and creativity, as well as their mental and physical abilities, to their fullest potential” and thus “participate effectively in a free society”. Without legal capacity, the guarantee of free and informed consent in article 25 gets diminished. The right to marry in article 23 and the right to political participation in article 29 become meaningless. Consequently if the various other rights guaranteed in CRPD are not to be rendered an empty shell, it is important that all persons with disabilities should be a bearer of rights and be able to exercise them.



Right to Liberty and Security of Person

The pattern of speech and silence, which was found in the manner in which the other issues have been dealt with, is also in play in this issue. Article 14, the primary article which guarantees the right to

liberty and security of person has been constructed by drawing upon the twin values of equality and non discrimination. Thus persons with disabilities have been guaranteed the right to liberty and security of person on an equal basis with others. They cannot be deprived of their liberty unlawfully and in no case shall the existence of a disability justify a deprivation of liberty. Thus, persons with disabilities can be deprived of their liberty only on the basis of those grounds which are employed to deprive the liberty of the non disabled. The guarantee of non discrimination is also extended to the procedure by which the deprivation is effected. However in acknowledgement of the fact that for this procedure to be fair, it will need to be tailored to the requirements of persons with disabilities. To this end, the article lays down that reasonable accommodation shall be provided for wherever required.

The question of force and especially, forced treatment was one of the contentious issues deliberated by the Ad Hoc Committee. Whereas members of civil society desired an express embargo to be incorporated; a number of States desired that the use of forced interventions should be permitted in specified circumstances. The Convention text neither expressly prohibits nor permits forced intervention.

However, when read as a whole the Convention seems to be veering towards eliminating forced interventions. Article 1 states that the purpose of the Convention is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity. The need to respect the inherent dignity of persons with disabilities also finds mention in the general principles and article 17 lays down that “every person with disabilities has a right to respect for his or her physical and mental integrity on an equal basis with

others”. Article 12 recognises full legal capacity of all persons with disabilities and article 25 “requires health professionals to provide care of the same quality to persons with disabilities as to others, including on the basis of free and informed consent by, *inter alia*, raising awareness of the human rights, dignity, autonomy and needs of persons with disabilities through training and the promulgation of ethical standards for public and private health care”. And, article 19 whilst guaranteeing to persons with disabilities the right to live independently and being included in the community lays down that “persons with disabilities (shall) have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement”.

Conclusion

The above said descriptive analysis does show that the CRPD does set up a new living paradigm for persons with psychosocial disabilities. These principles have obtained inclusion in the Convention largely because persons with disabilities actively participated in the making of Convention and with their physical and intellectual presence effectively smashed social stereotypes on disability. The active advocacy of persons with disabilities all over the world is necessary, for these norms to be interpreted and implemented in the same spirit with which they were adopted. The Convention text has provided the correct principles, the struggle now is to render them real. And in this struggle, amongst the first initiatives that the Indian disability community would need to take, is to ensure a swift Indian ratification of the Disability Convention.



On user / survivor leadership

Sylvia Caras is the 2006 recipient of the US Mental Health Association Beers Award, their highest honor, "for her work to improve the rights of mental health consumers through outspoken advocacy and by sharing her own experiences. Her pioneering efforts as the founder of People Who and electronic communities have spread the meaning of "Nothing about us, without us" across the movement, and have empowered mental health consumers nationally and internationally." In her award acceptance remarks, she said:

"Awards are about successes and it gives me great pleasure to receive this Beers award tonight, acknowledging my contributions to the reframing of people who experience mood swings, fear, voices and visions.

"You know and I know that no success is solitary, there are many who should share, many in this audience today, many whom you all know. Thank you.

"My goal was and is to use the internet for support and advocacy.

"Along the way that goal has morphed into other involvements and my words have become strong and clear. But in 1987, just released from yet another involuntary hospitalization with no discharge plan, drugged, I was confused, I was frightened, and I felt I had failed, not only in living, but even in trying to die. Failed.

"I think most of you who are Mental Health Association leaders are good people. Think for a moment about how you got that way. To good. The US author William Saroyan said "Good people are good because they've come to wisdom through failure."

"And so I'm going to speak about failure.

"Failure is not the falling down but the staying down. The more failures, the more one has fallen down, and not stayed down. The more failures, the more rebounds.

"Instead of branding my decisions as impaired, my wishes not insightful, protecting me from myself, instead give me space to make mistakes and learn.

"Do not help me to perceive myself as a victim. Do not continue to help me perceive myself as weak, fragile, unstable, unable. Do not aid me to stay mired in the flatness of not trying. Do not deny me dreams.

"My impact that you are recognizing here has been through the internet, access to peers, access to ideas, and access to information. Access which empowers me to make my own life choices, to take pride in the results of the good choices and to learn from the unintended consequences.

"Give that chance of learning from mistakes, that chance for wisdom, to all people who experience mood swings, fear, voices and visions.

Sylvia Caras is the founder of peoplewho.org and may be reached at sylvia@peoplewho.org

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